SUBMISSION TO NORTHERN TERRITORY VOLUNTARY ASSISTED DYING CONSULTATION (2025)

We are members of the Australian Centre for Health Law Research (ACHLR), a specialist research centre within the Queensland University of Technology's Faculty of Business and Law. ACHLR undertakes empirical, theoretical and doctrinal research into complex problems and emerging challenges in the field of health law, ethics, technology, governance and public policy.

We have been conducting research into the law, policy and practice of end-of-life decision-making for more than 20 years. We have published over 200 publications on end-of-life decision-making and received over $66 million for our end-of-life research and training programs.

Our research on voluntary assisted dying (VAD) includes a body of work on comparative and legal analysis of the various international assisted dying regimes. We also developed a Model Voluntary Assisted Dying Bill[1] which has been cited widely and was adopted as the basis for law reform by the Queensland parliamentary committee, the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee.

Our current work includes a four-year project 'Optimal Regulation of Voluntary Assisted Dying' which includes research into VAD systems in Australia, Canada and Belgium: https://research.qut.edu.au/voluntary-assisted-dying-regulation/. This project will make recommendations about how best to safely regulate VAD.

We were also commissioned by the state governments of Victoria, Western Australia and Queensland to design and deliver the legislatively-mandated training for practitioners wishing to provide VAD. One of us, Lindy Willmott, is a member of the VAD Review Board in Queensland. (We note, however, that we make this submission only in our capacity as academics.)

In terms of law reform, we have been consulted and participated in various VAD law reform exercises in Australia and overseas. We also edited the book *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021). This is a collection of ten case studies from six jurisdictions (the United Kingdom, the United States, Canada, Australia, Belgium and the Netherlands) analysing different aspects of end-of-life law reform.

More background information is available here:
https://www.qut.edu.au/about/our-people/academic-profiles/bp.white
https://www.qut.edu.au/about/our-people/academic-profiles/l.willmott

[1] White, Ben & Willmott, Lindy, A Model Voluntary Assisted Dying Bill (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

We note that this submission represents our views but does not necessarily represent the views of other members of ACHLR. For this reason, we request that any mention of this submission refers to us as authors and not ACHLR, the Faculty of Business and Law or QUT as entities.

Thank you for the opportunity to contribute to this consultation exercise. We would be pleased to provide any additional information which may assist the committee, including providing further evidence on the below or other matters.

Yours sincerely

Professor Ben White
Professor of End-of-Life Law and Regulation
Australian Centre for Health Law Research
[redacted]

Professor Lindy Willmott
Professor of Law
Australian Centre for Health Law Research
[redacted]

15 July 2025

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Our approach to this submission

We recognise that the Legal and Constitutional Affairs Committee is considering VAD in the context of the previous report produced by the Voluntary Assisted Dying Independent Expert Advisory Panel. As such, we will not repeat matters raised in our earlier submission to that Panel (which we attach as Appendix 1), even if we have expressed a different view to that reached by the Panel in its report. In this submission, we will focus on updating the Committee on key new research findings since that earlier submission.

We do, however, take this opportunity to reiterate our support for safe and accessible VAD to become lawful in the Northern Territory.

People are grateful for the opportunity to choose VAD

We interviewed 32 family caregivers and one patient about the experience of 28 patients seeking VAD in Victoria. One of the key themes that emerged from that research was the gratitude people expressed for VAD. They spoke about gratitude often and with deep emotion.

People were grateful for VAD because it helped avoid a bad death or dying in a "long and protracted and unkind" way. It also enabled a good death. People spoke about how VAD gave "choice", "control" and "empowerment" as well as "peace", "relief" and "comfort".

People expressed gratitude towards health professionals who supported the VAD process. But significantly, there were also expressions of gratitude for "everybody who got the [VAD] legislation through" – people specifically thanked the Victorian Government and "lawmakers", some even personally acknowledging Daniel Andrews, the then Premier of Victoria.

These expressions of gratitude for the choice of VAD support our view that this should be a lawful option for eligible patients.

- This research is reported in: Ben White, Ruthie Jeanneret, Sarah Holland-Batt & Evonne Miller, (2025) 'This is perfect, thank you': Research poetry on gratitude for voluntary assisted dying in Victoria, Australia. *Australasian Journal on Ageing*, 44(2), Article number: e70019.

A short Research Briefing summarising this research is also available here: https://eprints.qut.edu.au/258362/1/Expressions_of_gratitude_for_VAD_-_Research_briefing_with_poetry.pdf.

Evaluations of the Queensland and Western Australian VAD systems

In our earlier submission, we advocated for evidence-based law-making on VAD. We share with the committee some research which has evaluated how the Queensland and Western Australian VAD systems are operating in practice (both geographically large states).

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Research evaluating the Queensland VAD system is reported here:

- Ben White, Amanda Ward, Rachel Feeney, Laura Ley Greaves & Lindy Willmott, (2024) Models of care for voluntary assisted dying: A qualitative study of Queensland's approach in its first year of operation. *Australian Health Review*, 48(6), pp. 693-699.
- Laura Ley Greaves, Rachel Feeney, Lindy Willmott & Ben P. White, (2025) Voluntary assisted dying in Queensland: doctors' perceptions of its first year of operation. *Australian Health Review*, 49(4), Article number: AH25055.

Research evaluating the Western Australian VAD system is reported here (this research report was part of the Government's official review of the VAD system):

- Lindy Willmott, Ben White & Casey Haining, (2025) Review of the Voluntary Assisted Dying Act 2019 (WA): Research Report. *Journal of Law and Medicine*, 32(1), pp. 94-160.

We make two observations from the Queensland research. One is how the government's Health Service Directive, which required each Health and Hospital Service to have a local VAD model, has enhanced access to VAD through its availability in the public health system. A second important finding from this research is that over the course of the first year of VAD, it became "largely accepted as an end-of-life option and there is a collaborative approach with palliative care". We consider this connection with palliative care and the wider health system is important for integrated end-of-life care for patients.

Once VAD is lawful, community education is needed

We conducted a survey of 1000 adults in Queensland about their knowledge of, and perspectives on, VAD 17 months after VAD became legal. Our survey asked: whether people knew VAD was legal in Queensland; whether people knew how to access VAD if they wanted to; and where people would look for information about VAD.

We found awareness that VAD was a lawful end-of-life choice was low with only 33% of people surveyed correctly identifying that VAD is legal. Further, few people (only 26% of people surveyed) knew how to access VAD. If VAD laws are passed, it is important that awareness raising strategies are implemented so members of the community are aware of this new end-of-life choice.

- This research is reported in: Ben White, Rachel Feeney & Lindy Willmott, (2025) Community knowledge of voluntary assisted dying: a cross-sectional survey of the public in Queensland, Australia. *Death Studies*.

A short Research Briefing summarising this research is also available here: https://eprints.qut.edu.au/255020/1/QUT_Policy_Briefing_January_2025_Web.pdf

How best to regulate VAD

This research examines the issue of how best to regulate VAD. We interviewed 92 people about this question – 39 doctors and 55 'regulators' (both groups involved in

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the regulation of VAD) – in Victoria and Western Australia. We asked both doctors and regulators about their thoughts on the best way to regulate doctors who are providing VAD. This research has findings about how to design an overall VAD system, including the role of law and other regulatory tools.

- This research is reported in: Ben White, Casey Haining, & Lindy Willmott, (2025) How best to regulate voluntary assisted dying: a qualitative study of perceptions of Australian doctors and regulators. *Medical Law Review*, 33(1), Article number: fwae045.

A short Research Briefing summarising this research is also available here: https://eprints.qut.edu.au/255408/1/How_VAD_should_be_regulated_Aust_-_Research_briefing.pdf

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APPENDIX 1 – PREVIOUS SUBMISSION TO VOLUNTARY ASSISTED DYING INDEPENDENT EXPERT ADVISORY PANEL

[included as a separate attachment]

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APPENDIX 2 – PUBLISHED RESEARCH REFERRED TO ABOVE

The below list of publications is presented in the order in which they are first cited above.

- Ben White, Ruthie Jeanneret, Sarah Holland-Batt & Evonne Miller, (2025) 'This is perfect, thank you': Research poetry on gratitude for voluntary assisted dying in Victoria, Australia. *Australasian Journal on Ageing*, 44(2), Article number: e70019.
- Ben White, Amanda Ward, Rachel Feeney, Laura Ley Greaves & Lindy Willmott, (2024) Models of care for voluntary assisted dying: A qualitative study of Queensland's approach in its first year of operation. *Australian Health Review*, 48(6), pp. 693-699.
- Laura Ley Greaves, Rachel Feeney, Lindy Willmott & Ben P. White, (2025) Voluntary assisted dying in Queensland: doctors' perceptions of its first year of operation. *Australian Health Review*, 49(4), Article number: AH25055.
- Lindy Willmott, Ben White & Casey Haining, (2025) Review of the Voluntary Assisted Dying Act 2019 (WA): Research Report. *Journal of Law and Medicine*, 32(1), pp. 94-160.
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- Ben White, Casey Haining, & Lindy Willmott, (2025) How best to regulate voluntary assisted dying: a qualitative study of perceptions of Australian doctors and regulators. *Medical Law Review*, 33(1), Article number: fwae045.

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SUBMISSION TO NORTHERN TERRITORY VOLUNTARY ASSISTED DYING CONSULTATION

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We were also commissioned by the state governments of Victoria, Western Australia and Queensland to design and deliver the legislatively-mandated training for practitioners wishing to provide VAD. One of us, Lindy Willmott, is a member of the VAD Review Board in Queensland, while the other, Ben White, is a member of the relevant review tribunal, the Queensland Civil and Administrative Tribunal. (We note, however, that we make this submission only in our capacity as academics.)

In terms of law reform, we have been consulted and participated in various VAD law reform exercises in Australia and overseas. We also edited the book *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021). This is a collection of ten case studies from six jurisdictions (the United Kingdom, the United States, Canada, Australia, Belgium and the Netherlands) analysing different aspects of end-of-life law reform.

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[1] White, Ben & Willmott, Lindy, A Model Voluntary Assisted Dying Bill (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

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Yours sincerely

Professor Ben White
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13 February 2024

BEST VOLUNTARY ASSISTED DYING LEGISLATION FOR THE NORTHERN TERRITORY

It is possible to pass legislation that achieves both safety and access

A primary consideration for the NT is ensuring that its VAD system operates safely but also that it is accessible to patients who are eligible for VAD.

Existing VAD laws contain numerous safeguards.[2] These include:

- *Strict eligibility requirements*. Only adults are permitted to access VAD, and all persons wishing to access VAD must meet specific residency and citizenship requirements. Though there is some variation between states, in most cases, a person must be diagnosed with a disease, illness, or medical condition that is advanced, progressive, and will cause their death. A person must be assessed as having decision-making capacity for VAD, and be acting voluntarily and without coercion.
- *A tightly prescribed request and assessment process.* In all states a person must make three separate and specific requests for VAD, and their eligibility for VAD is assessed by at least two independent medical practitioners.
- *Mandatory VAD training*. All laws require that health practitioners undergo mandatory training before they can provide VAD.
- *Oversight by a specifically constituted review board*. Each jurisdiction has established a body which monitors compliance with the VAD legislation. Health practitioners who provide VAD must submit several forms to the relevant body throughout the VAD process. In four of the six jurisdictions in which VAD is currently operating, a 'pre-authorisation permit' must be issued before VAD can be performed.

The experience of VAD in the Australian states so far is that VAD laws are operating safely. Victoria and Western Australia are where VAD has been operating the longest, and have released several reports outlining the extent to which VAD laws are complied with. In Victoria, the cases of non-compliance that have been described by the VAD Review Board relate to procedural errors which did not result in an ineligible person accessing VAD. To this end, the Victorian VAD Review Board stated in their most recent report that:

> *"the most significant matter to report is that voluntary assisted dying in Victoria continues to operate safely and lawfully. The numerous safeguards in the Act and the integrity of those involved have ensured that those risks that were raised in debates about the Act have been safely avoided."*[3]

[2] Lindy Willmott et al, 'Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study' (2021) 215(3) *Medical Journal of Australia* 125; Marcus Sellars et al, 'Medical Practitioners' Views and Experiences of Being Involved in Assisted Dying in Victoria, Australia: A Qualitative Interview Study among Participating Doctors' (2022) 292 *Social Science & Medicine*.

[3] Voluntary Assisted Dying Review Board 'Report of Operations July 2021 to June 2022' (Report of Operations, Safer Care Victoria, June 2022) 1 <https://www.safercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-report-of-operations-july-2021-to-june-2022>.

In Western Australia, reported cases of non-compliance relate to procedural requirements, such as the timeliness of the submission of forms.[4]

Research with Victorian medical practitioners involved in providing VAD reinforces that this system is operating safely. However, this research indicates that medical practitioners can experience the number and nature of these safeguards as frustrating and overly conservative, reflecting an "excess of caution."[5]

Research with Victorian family caregivers and Victorian health professionals highlight difficulties that patients experience accessing VAD, which can often be attributed to the heavily safeguarded nature of the system.[6] Significant barriers that research has highlighted as making accessing VAD challenging are listed below.

- Difficulties finding willing doctors to assist with access (especially when VAD first becomes legal).[7]
- Delays associated with the process of applying for and accessing VAD. Medical practitioners can be frustrated when they have to wait for a permit to access VAD and when forms submitted to the relevant oversight body are rejected as this causes delays for patients, who have already been assessed as experiencing intolerable suffering.[8]
- Institutions with objections to providing all or some parts of VAD. Research highlights the impact that institutional objection can have on patients wishing to access VAD, which include delays, distress, and being forced to choose between accessing VAD and remaining in an institution which is their home.[9]
- The prohibition on raising VAD with patients contained in the Victorian VAD law. Some medical practitioners have reported feeling "deceitful" or "intellectually dishonest" adhering to this provision, and are concerned that it may be preventing patients from making an informed choice about their treatment options, particularly those from non-English speaking backgrounds or individuals with poor health literacy.[10]

We urge the NT to consider the need to balance safety and access in its VAD legislation, so that VAD is accessible for eligible patients. This point was made in an article reporting a study with Victorian doctors who had participated in VAD in Victoria:

[4] Voluntary Assisted Dying Board Western Australia, 'Annual Report 2021-2022' (Annual Report, 16 November 2022) 35 <https://www.health.wa.gov.au/Reports-and-publications/Voluntary-Assisted-Dying-Board-Annual-Report>; Voluntary Assisted Dying Board Western Australia, 'Annual Report 2022-2023' (Annual Report, 8 November 2023) 50 <https://www.health.wa.gov.au/Reports-and-publications/Voluntary-Assisted-Dying-Board-Annual-Report>.

[5] Sellars et al (n 2); Willmott et al (n 2).

[6] Ben P White et al, 'Access to Voluntary Assisted Dying in Victoria: A Qualitative Study of Family Caregivers' Perceptions of Barriers and Facilitators' (2023) 219(5) *Medical Journal of Australia* 211.

[7] Ibid.

[8] Willmott et al (n 2) 127.

[9] Ben P White et al, 'The Impact on Patients of Objections by Institutions to Assisted Dying: A Qualitative Study of Family Caregivers' Perceptions' (2023) 24(1) *BMC Medical Ethics* 22.

[10] Willmott et al (n 2) 127.

> *"Safety can be achieved with legislative safeguards or by system design. The safeguards embedded in the Victorian system indicate the focus on safety. Some participants commented that the detailed checks and balances provided them with the confidence to participate in the system. However, it is also important to reflect on how the system operates in practice. Making voluntary assisted dying accessible to eligible patients will not be achieved if doctors find the system too onerous to navigate or if some patients die before receiving the medication."*[11]

The NT should not just copy other jurisdictions such as Victoria

The aim of any VAD reform exercise should be to produce the best possible legislation for the NT. As mentioned above, we have developed a Model VAD Bill which has been published in a legal journal.[12] This Bill was developed after articulating the relevant principles that we believe should guide law reform in this area.[13] Importantly, we did not assume that the Victorian law was the best law possible and use it as our starting point. Instead, we began by identifying the principles that should guide reform in this area and developed our approach based on those principles.

This is an important point because arguments can sometimes be advanced that if the NT Bill is different from Victoria (or other states), then this, in and of itself, is cause for alarm. But such claims cannot be sustained. First, the Victorian, Western Australian, Tasmanian, South Australian, Queensland and New South Wales VAD laws are all different from each other. The proposed ACT VAD Bill is different again. It is true that they are all based on the same broad model. But each of the State Parliaments coming after Victoria, have exercised their own judgment about what law should be passed in light of what is best for those states. As a result, there is already variation across the country (and likely to be further variation if and when the ACT passes its Bill), and it is reasonable and appropriate to expect more.

Secondly, the people of the NT should expect that its Parliament pass the best law possible for the territory, even if that means some differences from other Australian states. The fact that Victoria happened to be the first does not make it better. Indeed, we now have experience and evidence about some challenges in the Victorian system that NT has the opportunity to address. We discuss some of these challenges further below but, in short, the Victorian system is working safely but there have been challenges in practice for patients trying to access VAD.

Law-making on voluntary assisted dying must be evidence-based

A further point in relation to developing the best possible VAD legislation for the NT is to repeat our call for evidence-based law-making in this area. There is a large body of reliable evidence about how VAD systems operate internationally. There is

[11] Ibid.

[12] White, Ben & Willmott, Lindy, A Model Voluntary Assisted Dying Bill (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

[13] Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).

also emerging evidence about how the Victorian system is operating in practice, including that which suggests there are challenges with the Victorian model. Our call for evidence-based law-making in relation to VAD laws is set out elsewhere.[14]

Avoid incoherent law by ad hoc addition of safeguards

We urge the NT to avoid the situation that other states have experienced where safeguards are awkwardly added to already sound law in an ad hoc way. This leads to the VAD law being incoherent or inconsistent in important ways.

An example of this is eligibility for VAD depending on a variable time period – 6 or 12 months until expected death – depending on the nature of a patient's illness. This change in timing was a political compromise in Victoria which has since been uncritically adopted and replicated in all other states in Australia except Queensland (and we note ACT's proposal not to have a specified time until death). Yet this was only a last-minute addition to the Victorian Bill as a result of political compromise.

Our research has shown that the Victorian VAD law fails to meet its own stated policy goals in important respects, sometimes because of these later ad hoc additions during the law-making process: Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.

For this reason, we argue that the operation of safeguards must be seen collectively as a whole:

> *'When thinking about the politics of reform, it can be tempting to only consider each safeguard or process individually. Each may have merit and advance a particular policy goal. It may also be difficult politically to argue that a specific safeguard is not needed, particularly if it appears to achieve at least some useful purpose. However, when the safeguards are aggregated, the VAD system as a whole can become very complex and unwieldly, and slowly take the legislation away from its policy goals. This "policy drift by a thousand cuts" – the incremental loss of policy focus through accumulation of individual safeguards without reference to the whole – is a key issue for other states to consider when evaluating their proposed VAD reforms. It is suggested that each part of the law be evaluated both on its own, and also for its impact on the functioning of the overall system. This is needed to enable VAD laws to meet their policy goals, in particular, the two key goals at the core of the design of the VAD Act: safeguarding the vulnerable while respecting the autonomy of eligible persons who wish to access to VAD."*[15]

We have also written on this point in 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks':

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[14] Ben White and Lindy Willmott, 'Evidence-based Law Making on Voluntary Assisted Dying' (2020) 44(4) *Australian Health Review* 544.

[15] Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417, 451.

> *"Taking a holistic view is also an important consideration more generally when designing VAD regulation. While it may be politically attractive to add numerous safeguards to VAD legislation, including in the eligibility criteria, there is a risk of what we have called elsewhere 'policy drift by a thousand cuts' if the cumulative effect of these individual safeguards is not properly considered. For example, it is possible that a series of provisions designed to make VAD legislation safe, when aggregated, can in fact make access to VAD cumbersome or even unworkable:"*[16]

Some of the ways in which the Victorian system has been shown to be cumbersome or very challenging to navigate as a result of the aggregation of safeguards are discussed further below.

A policy briefing

A final matter to mention before turning to some specific considerations for the NT is that to inform the parliamentary debates in Australia, we produced a policy briefing in August 2021 which summarised the key findings from our research about VAD over a period of almost two decades.[17] The briefing is reproduced in full below and may also be accessed at the following link: https://research.qut.edu.au/voluntary-assisteddying-regulation/other-resources/. Also available at that website is the research that underpins the briefing (PDFs available in five volumes).

[16] Ben White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663, 1699.

[17] White, Ben & Willmott, Lindy (2021) Voluntary assisted dying research: a policy briefing. Australian Centre for Health Law Research, Queensland University of Technology.

QUT Australian Centre for Health Law Research

Voluntary assisted dying research: a policy briefing

This briefing summarises research about voluntary assisted dying (VAD) conducted by Professors Ben White and Lindy Willmott (with colleagues).

1 Australia should have VAD laws: they are ethical and VAD can be safely regulated

» There is a strong ethical case for allowing a limited cohort of patients, who are already dying, to choose VAD.

» Reliable evidence about VAD systems internationally and now in Australia shows that VAD can be safely regulated.

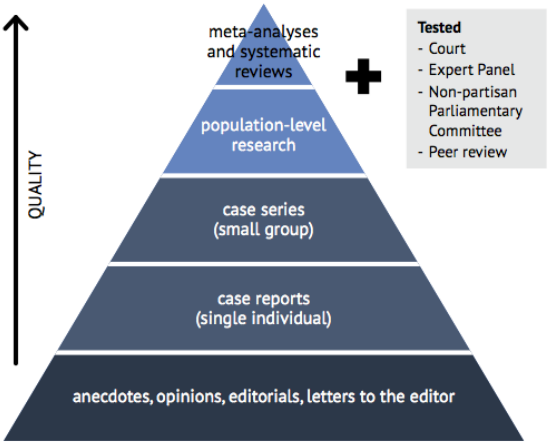
» Politically, legalising VAD has been challenging. Only narrow and conservative VAD models have passed in Australia.

2 VAD laws must be evidence-based and consistent with intended policy goals

» Law reform must be based on reliable evidence (see the "reliability pyramid").

» VAD laws must be designed to meet their intended policy goals.

Higher up pyramid + tested = greater reliability



3 There is now a broad "Australian VAD model" but each jurisdiction should pass a law most appropriate for its circumstances

» Although based on the same model, Victoria, Western Australia, Tasmania and South Australia have all taken slightly different approaches to regulating VAD.

» Jurisdictions should learn from how existing laws work in practice and design a law that is most appropriate for its circumstances (e.g. unique geography and population distribution).

4 Designing VAD laws requires seeing how the entire legal framework operates

» Evaluating a VAD law must be based on how it will work as a whole, and not by considering individual provisions in isolation.

» For example, numerous eligibility criteria for accessing VAD work together in these laws. Concern about one criterion when considered in isolation may resolve if all criteria are considered as a whole.

» The process of designing VAD laws should include testing how eligibility criteria affect who can access VAD and for what medical conditions.

5 "Piling on" ad hoc safeguards to already sound VAD laws does not make laws safer and can make them worse

» Ad hoc safeguards have been added during parliamentary processes to already sound proposals for VAD laws.

» This led to inconsistency and incoherence in those laws without improving patient or community safety.

www.research.qut.edu.au/achlr

6 VAD systems must be workable so eligible patients can access VAD

» The complex Victorian VAD law and system make patient access to VAD challenging.

» Key problems include:

- doctors are not allowed to raise the topic of VAD with patients
- the need to obtain a government permit to access VAD, and
- the complexity of the administrative process when applying for VAD.

7 The Commonwealth Criminal Code must be changed: it is an unjust barrier for patients seeking VAD and their doctors

» The Code makes illegal using a "carriage service" (e.g. email, telephone, fax, telehealth) in relation to "suicide". This creates risk for doctors and others who are otherwise acting legally under State VAD systems.

» This means some steps in the VAD process must be done face-to-face. This is causing hardship and delay for patients and doctors.

» For constitutional law reasons, States cannot resolve this issue.

» The Commonwealth Government should amend this law so it will not apply to lawful VAD systems.

8 Institutions should not have power to prevent their patients or permanent residents from accessing VAD

» There is some limited evidence that institutions are blocking access to VAD in Victoria. Some institutions in other States have also indicated they will block access.

» Legislation should permit an institution to not participate but must ensure eligible patients and permanent residents can still access VAD.

9 Effective implementation of VAD is challenging but very important

» How a VAD system operates depends not only on the law, but also system design, including factors such as IT, navigation and support services.

» Sufficient time and resources are needed to effectively implement VAD laws. And once implemented, VAD systems should be kept under constant review.

» VAD laws are complex so implementation should aim to make the patient, family and doctor experience as smooth and simple as possible.

» Effective training for practitioners involved in VAD (and others) is critical as is a user-friendly IT system.

A compilation of the 37 research papers this policy briefing is based on is available here:
https://research.qut.edu.au/voluntary-assisted-dying-regulation/other-resources

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August 2021

SPECIFIC CONSIDERATIONS FOR THE NORTHERN TERRITORY

We broadly support the approach taken in the VAD legislation in the Australian states (and in the ACT's *Voluntary Assisted Dying Bill 2023*). However, we outline below some specific areas with respect to which we think that an alternative approach is desirable and in relation to which NT should consider taking a different approach.

Eligibility requirements

We broadly support the current narrow framing of the eligibility requirements for VAD contained in the VAD legislation in the Australian states. We consider access to VAD should be permitted for competent adults who have decision-making capacity in relation to VAD; and who are diagnosed with a disease, illness or medical condition that is advanced, progressive and will cause death; and where that condition is causing intolerable and enduring suffering. Eligibility criteria should also include that the person's decision to access VAD is enduring and made voluntarily and without coercion.

We do not support the inclusion of a timeframe to death eligibility requirement

We do not support the inclusion of an eligibility requirement that a person be expected to have a specific amount of time left to live to access VAD. It is sufficient that death is expected. Our Model Bill (referred to above) does not impose this requirement. A timeframe requirement does not make a real difference in practice to who is eligible for VAD when the eligibility criteria are viewed holistically. This was confirmed in our research which analysed eligibility to access VAD in relation to nine medical conditions across a range of legal frameworks. In the paper 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks', we concluded that the absence of a time limit under our Model Bill did not affect the people who could access VAD.[18] In other words, access to VAD was possible for the same medical conditions under the Victorian VAD law (primarily a 6-month time limit) as under our Model Bill (no time limit).

In addition, research confirms that it is difficult for assessing medical practitioners to prognosticate about time until death.[19] An approach which does not include a timeframe as an eligibility requirement therefore removes this difficulty. Further undesirable outcomes of imposing a timeframe to death eligibility requirement are that it forces terminally ill individuals to wait, and continue to ensure considerable suffering until they satisfy this requirement, and that it may deprive an eligible person of access to VAD, if the delay in reaching this timeframe means that they are not able to complete the assessment process.[20]

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[18] Ben White et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401.

[19] Marcus Sellars et al., 'Medical practitioners' views and experiences of being involved in assisted dying in Victoria, Australia: A qualitative interview study among participating doctors' (2022) 292 *Social Science & Medicine* 4.

[20] Ben P White et al, 'Who Is Eligible for Voluntary Assisted Dying?: Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401, 435–6.

Consistent with the above reasoning, the ACT's *Voluntary Assisted Dying Bill 2023* (ACT Bill) does not include a timeframe until death eligibility requirement. While we support this feature of the ACT Bill, it also provides that an individual must have been diagnosed with a condition that is *advanced* as well as progressive and expected to cause death.[21] 'Advanced' is defined in the bill as the individual being in the 'last stages of their life'.[22] We do not support the requirement that a person is in the 'last stages of life' to access VAD for two reasons.

First, it may cause confusion and uncertainty for health practitioners who must assess the person's eligibility. Different practitioners may interpret this phrase differently, for example, to mean that a person must be dying within 6 months or less, alternatively, within weeks or days. It is undesirable for VAD legislation to contain a provision which health practitioners, though attempting to comply with the law, are unable to interpret with certainty.

Second, the inclusion of the requirement that a person must be in the 'last stages of their life' may defeat the potential benefit of removing a timeframe until death eligibility requirement. Including this requirement may result in assessing practitioners introducing their own criteria regarding when the person meets this requirement. This may have the potential for the criteria to be interpreted even more narrowly than the 6 month to death requirement included in the laws of most other states.

While we encourage the NT to omit a timeframe to death eligibility requirement in its VAD legislation, we urge it to avoid defining 'advanced' in such a way as to require that a person be in the last stages of their life to access VAD.

Request and assessment process

We recognise that there is a generally established process for requesting and accessing VAD in Australia. We broadly support this general approach to the request and assessment process.

We do not support a default administration method

We do not support a default method of administration as is present in some states' VAD laws. Rather, we support patient choice with respect to choosing the method by which they will administer the VAD substance. We support the approach taken in the NSW VAD legislation and ACT Bill (which reflects our Model Bill) that permits a person to decide whether they wish to self-administer the VAD substance, or have the substance administered to them by the administering practitioner. Where this choice is made in consultation with their coordinating practitioner, this choice best promotes the person's autonomy.

[21] *Voluntary Assisted Dying Bill 2023* (ACT) cl 11(1).

[22] Ibid cl 11(4)(c).

Role of health professionals

Non-participating health professionals should ensure a person can still access VAD

We support the inclusion in legislation of protections for health professionals who conscientiously object to participating in any or all aspects of VAD. However, any protection in the legislation should be limited to roles associated with the VAD process. Activities distinct from the VAD process, such as caring for a patient (aside from their VAD request) or certifying a patient's death, should not be included in any protection of conscientious objection.

While conscientious objection should be protected by legislation, the law should also include an obligation that a health professional who declines to be involved in VAD must take action to ensure access remains possible for the patient. Our research with family caregivers of patients who sought VAD in Victoria identified this as an issue that impeded patients' ability to access VAD.[23] Given the significant impact that conscientious objection can have on patient access to VAD, these provisions should impose obligations on conscientious objectors who receive a request for information about VAD or a request for VAD access. The obligations should at the very least require the conscientious objector to provide the patient with details of a central VAD agency who can assist the person.

We support the structured approach taken to regulate this issue in the Queensland VAD legislation both in terms of responses to requests but also in its regulation of conscientious objection. There should be a duty to refer the person to another health practitioner who would be willing to help or provide details about the care navigator service would assist patients to access VAD.

We support nurse practitioners' and nurses' ability to have a broader range of roles in the VAD process

We support nurses and nurse practitioners having a broader range of roles in the VAD process. We consider this is an important improvement to the Victorian model (which does not permit nurse practitioners or nurses having a role in the VAD request and assessment process) as it addresses potential barriers to access for patients. It does this by increasing the 'pool' of providers able to assist a patient to access VAD, which may be important in light of the NT's specific health workforce capabilities.

There are two approaches by which nurses and nurse practitioners could have a greater range of roles in the VAD process, both of which should be considered in the NT's VAD legislation to enhance patients' access to VAD.

The first approach is to allow nurse practitioners and nurses to be administering practitioners. This is already a feature of the VAD legislation in some states. The experience in Victoria, which was the first state to legalise VAD in Australia is that it

[23] White, Ben, Jeanneret, Ruthie, Close, Eliana, & Willmott, Lindy, 'Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitators' (2023) 219(5) *Medical Journal of Australia* 211.

has been difficult to find enough practitioners who are willing and trained to assist patients who wish to access VAD.[24] We support the inclusion of nurse practitioners and nurses, at the very least, in the role of administering practitioners.

The second initiative to consider is including suitably qualified and experienced nurse practitioners as assessing practitioners. The ACT Bill contemplates that nurse practitioners with relevant experience and at least one year post-nurse practitioner endorsement may also be eligible to act as either the coordinating or consulting practitioner (where the other role is filled by a medical practitioner). Including appropriately qualified and experienced nurse practitioners as assessing practitioners in the VAD process should not compromise the safety of the VAD process. All practitioners who may have a role in the VAD request and assessment process must be suitably qualified, and legislation would contain a requirement to refer the person for an additional assessment if the assessor is unable to make a determination about a person's eligibility.

Role of health services

Many individuals who seek VAD will be in institutions generally as residents or patients. Some of these institutions may be opposed to VAD for religious or secular reasons. However, institutional views should not adversely affect the ability of an individual seeking to access VAD. Recent research has revealed that institutional objection can cause considerable harms for patients or residents seeking access to VAD, either through their ability to access VAD or adversely affecting their experience. The study's findings were institutional objection:

- causes delays for patients who wish to access VAD,
- reduces patient choice in relation to VAD, and
- causes anger, frustration, and stress for patients who wish to access VAD, as well as their families.[25]

It is important therefore to regulate institutional objection so that such objection does not result in harm to the resident or patient of that institution. In terms of the nature of the regulation, we make two points.

Institutional objection should be regulated by legislation

Firstly, we consider that institutional objection should be regulated by legislation and not by policy. We believe that including obligations in legislation rather than policy provides greater normative force to those obligations, so they are more likely to be complied with by institutions. We have outlined our arguments in support of a legislative response elsewhere.[26]

[24] Ibid.

[25] Ben White et al, 'Harms to patients caused by institutions objecting to voluntary assisted dying', Research Briefing (2023); Ben White et al, 'The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions' (2023) 24 *BMC Medical Ethics*, Article number: 22.

[26] Ben White et al, 'Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia' (2021) *University of New South Wales Law Journal Forum* 1.

We support a reasonable accommodation model

Secondly, while there are a range of potential legislative responses (which we have written about elsewhere),[27] the option that we favour is a reasonable accommodation model. That model aims to respect institutional values while also ensuring patient access. But if both cannot be accommodated in a particular case, then the interests of the individual who is seeking VAD should be prioritised, as it is the individual who is terminally ill and enduring intolerable suffering and who may experience considerable harm as a result of institutional objection (as described above).

We believe a preferable approach for the regulation of institutional objection for all institutions is the legislative framework that applies to permanent residents under the Queensland legislation (which can be found in the *Voluntary Assisted Dying Act 2021* (Qld), Part 6 Division 2).

[27] Ibid.

APPENDIX – PUBLISHED RESEARCH REFERRED TO ABOVE

The below list of publications is presented in the order in which they are first cited above.

- White, Ben & Willmott, Lindy, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.
- Lindy Willmott et al, 'Participating Doctors' Perspectives in the Regulation of VAD in Victoria: A Qualitative Study' (2021) 215(3) *Medical Journal of Australia* 125.
- Marcus Sellars et al, 'Medical Practitioners' Views and Experiences of Being Involved in Assisted Dying in Victoria, Australia: A Qualitative Interview Study among Participating Doctors' (2022) 292 *Social Science & Medicine*
- White, Ben, Jeanneret, Ruthie, Close, Eliana, & Willmott, Lindy, 'Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitators' (2023) 219(5) *Medical Journal of Australia* 211.
- Ben White et al, 'The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions' (2023) 24 *BMC Medical Ethics*, Article number: 22.
- Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).
- Ben White and Lindy Willmott, 'Evidence-based Law Making on Voluntary Assisted Dying' (2020) 44(4) *Australian Health Review* 544-546.
- Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.
- White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663.
- White, Ben & Willmott, Lindy (2021) Voluntary assisted dying research: a policy briefing. Australian Centre for Health Law Research, Queensland University of Technology.
- Ben White et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401.
- Ben White et al, Harms to patients caused by institutions objecting to voluntary assisted dying, Research Briefing (2023).
- Ben White et al, 'Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia' (2021) *University of New South Wales Law Journal Forum* 1.

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A MODEL VOLUNTARY ASSISTED DYING BILL

BEN WHITE AND LINDY WILLMOTT*

This paper proposes a new model Voluntary Assisted Dying Bill, along with an Introduction, and Explanatory Notes to provide a brief context and explanation of several key components.

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* Australian Centre for Health Law Research, Faculty of Law, QUT. The authors gratefully acknowledge the critical review and feedback on earlier drafts of the Bill and/or the Explanatory Notes, including by Rebecca Meehan, Katrine del Villar, Dr Jayne Hewitt, Eliana Close, Dr Laura Ley Greaves, Emeritus Professor Malcolm Parker, Jodhi Rutherford, Dr Rachel Feeney, Dr Mark Thomas and interested members of the Queensland Law Society. The Bill represents our views and should not be taken to represent the views of those who provided feedback on it, the Australian Centre for Health Law Research or the Faculty of Law.

I INTRODUCTION

Voluntary assisted dying is the subject of much public, policy, parliamentary and legal discussion in Australia. Victoria's *Voluntary Assisted Dying Act 2017* (Vic) commenced on 19 June 2019 after an 18-month implementation period. This is the first time in more than twenty years that voluntary assisted dying has been lawful in Australia following the repeal of the Northern Territory legislation, *Rights of the Terminally Ill Act 1995,* by the Commonwealth in 1997.[1] There is not yet empirical research available on how the Act is functioning, although the Voluntary Assisted Dying Review Board has released its first report covering the first eleven days of the Act's operation.[2]

Victoria may soon be joined by other Australian States. At the time of writing, the Western Australian Parliament is considering its Voluntary Assisted Dying Bill 2019 (WA). This Bill resulted from a recommendation of the Joint Select Committee on End of Life Choices that voluntary assisted dying be permitted in that State.[3] The Government adopted that recommendation,[4] and, reflecting the Victorian law reform path, the Government established a Ministerial Expert Panel to advise on specific elements of a proposed voluntary assisted dying legislative framework.[5]

Further, in November 2018, Queensland referred the issue of voluntary assisted dying laws to a Parliamentary Committee[6] and South Australia took a similar course in April 2019.[7] Also in 2019, an Australian Capital Territory Parliamentary Select Committee, established to inquire into end of life choices including voluntary assisted dying, published its Report.[8] The Australian Capital Territory, like the Northern Territory,

[1] The Commonwealth Government exercised its constitutional powers to repeal the *Rights of the Terminally Ill Act 1995* (NT) just nine months after the legislation commenced operation: *Euthanasia Laws Act 1997* (Cth).
[2] Voluntary Assisted Dying Review Board, *Report on Operations 2018-2019* (Report, August 2019).
[3] Joint Select Committee on End of Life Choices, 40th Parliament of Western Australia, *My Life, My Choice* (Report No 1, August 2018), xl-xli.
[4] Government of Western Australia, 'Western Australian Government response: Joint Select Committee on End-of-Life Choices Report, *My Life, My Choice*' (Report, WCP-013515, December 2018).
[5] Department of Health, Government of Western Australia, *Ministerial Expert Panel on Voluntary Assisted Dying: Final Report* (Discussion paper, HEN-013590, June 2019).
[6] An issues paper was released in February 2019: Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, 56th Parliament of Queensland, *Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying* (Paper No 3, 14 February 2019).
[7] Joint Committee on End of Life Choices, Parliament of South Australia, 'Terms of Reference' (April 2019).
[8] ACT Legislative Assembly, *Select Committee on End of Life Choices in the ACT* (Report, March 2019), 74-96.

currently lacks constitutional power to enact voluntary assisted dying legislation.[9] However, a majority of the Select Committee suggested that the Australian Capital Territory 'gives serious consideration … to establishing an appropriate scheme' should their power to enact legislation be restored.[10] The Report also identified some proposed eligibility and safeguards for such a legislative regime.[11]

This recent flurry of activity occurs against the backdrop of longstanding efforts to reform the law in this area. At the time of writing, there have been a total of 59 Bills introduced in Australian Parliaments over a 30-year period dealing with voluntary assisted dying. Forty-five of these Bills proposed models to permit and regulate voluntary assisted dying.[12] The authors have elsewhere observed that, over recent times, these Bills have been closer to passing through the relevant Chamber in which they were introduced.[13] Reform is becoming increasingly likely.

Much of the discussion that has accompanied these reform efforts, and critique of them, has been in relation to the threshold issue of whether the law should change to permit voluntary assisted dying or not. While this will continue to be a critical issue, given the likelihood of reform, the authors submit that there should be an increased focus on the range of policy options for the way in which voluntary assisted dying is regulated, including the scope of what is permitted.[14]

When thinking about the future of voluntary assisted dying reform in Australia, there may be a temptation to simply adopt the Victorian model; it has passed through an Australian Parliament so may be regarded as 'politically feasible'.[15] Alternatively, it may be seen as

[9] These powers were removed by the Commonwealth Government by the enactment of the *Euthanasia Laws Act 1997* (Cth).
[10] ACT Legislative Assembly (n 8) 95.
[11] Ibid.
[12] See Lindy Willmott et al, '(Failed) voluntary euthanasia law reform in Australia: Two decades of trends, models and politics' (2016) 39(1) *University of New South Wales Law Journal* 1; Ben White and Lindy Willmott, 'Future of assisted dying reform in Australia' (2018) 42(6) *Australian Health Review* 616. The latest (and only) Bill not included in the two articles above is the Voluntary Assisted Dying Bill 2019 (WA). The Bills that did not propose a model for assisted dying generally sought to either overturn the prohibition on territories legislating on this topic, or to hold a referendum on law reform. For analysis of the arguments that politicians have raised for and against voluntary assisted dying when debating these Bills in parliament, see Andrew McGee et al, 'Informing the euthanasia debate: Perceptions of Australian politicians' (2018) 41(4) *University of New South Wales Law Journal* 1368.
[13] White and Willmott, 'Future of assisted dying reform in Australia' (n 12).
[14] See for example Ben White and Lindy Willmott, 'How should Australia regulate voluntary euthanasia and assisted suicide' (2012) 20 *Journal of Law and Medicine* 410.
[15] White and Willmott, 'Future of assisted dying reform in Australia' (n 12) 618.

the starting point for reform discussions with a 'plus/minus' approach taken of removing or adding components to the Victorian model.[16] This latter approach has been the case in Western Australia as the Voluntary Assisted Dying Bill 2019 (WA) draws heavily on the Victorian model but with some variations.[17]

The authors raise for consideration a different approach — a legislative model based on values that the authors consider are appropriate to underpin laws of this kind. It is suggested this is needed for two reasons. The first is that there are challenges with the Victorian model. Some of these are discussed below (briefly, because of space constraints), but a key challenge is the complexity of the legislative framework.[18] As part of designing a Bill that was sufficiently conservative to navigate through both Houses of the Victorian Parliament, the process for accessing voluntary assisted dying is complex and with many safeguards. When supporting the passage of the Victorian Bill, the Premier observed that it provided the 'safest scheme in the word, with the most rigorous checks and balances'.[19] As noted, this may be a function of the political nature of reform, but it must be questioned whether the Victorian legislation provides the optimal model for permitting and regulating voluntary assisted dying.

The second (and linked) reason is that core features of a voluntary assisted dying Bill, particularly in relation to the scope of what is permitted, the eligibility criteria and safeguards, need to be justifiable by reference to values that should underpin this kind of legislation. Providing a person access to assistance to die is a serious issue, and so the rigour of testing a Bill against a defined set of values is important. The alternative is that political compromise, while often necessary for law reform, can lead to legislation failing to reflect its overall policy objectives in important respects.

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[16] Ibid 619.

[17] Ben White et al, 'WA's take on assisted dying has many similarities with the Victorian law – and some important differences', *The Conversation* (online, 9 August 2019)<https://theconversation.com/was-take-on-assisted-dying-has-many-similarities-with-the-victorian-law-and-some-important-differences-121554>. The model Bill presented in this article was written prior to the Voluntary Assisted Dying Bill 2019 (WA) being released. However, the authors note that there are some similarities between the Western Australian Bill and the model Bill in terms of key departures from the Victorian approach.

[18] See Ben White, Lindy Willmott and Eliana Close, 'Victoria's voluntary assisted dying law: clinical implementation as the next challenge' (2019) 210(5*) Medical Journal of* Australia 207. For example, it has been questioned whether a safeguard intended to prevent coercion may also act as a barrier for eligible patients to access voluntary assisted dying: Carolyn Johnston and James Cameron, 'Discussing Voluntary Assisted Dying' (2018) 26(2) *Journal of Law and Medicine* 454.

[19] Daniel Andrews, 'Victoria State Government 'Voluntary assisted dying model established ahead of vote in Parliament' (Media release, 25 July 2017).

The authors have previously identified a set of values to guide law reform in this area, and have outlined in broad terms the model this would produce.[20] The authors continue to endorse the importance of these values and have used them as a departure point to draft a Voluntary Assisted Dying Bill. However, this Bill has also moved beyond these values as more abstract considerations. The process of drafting a Bill prompts deeper and more concrete thought, not only about the policy decisions that need to be made, but how to present them.[21]

This article is comprised of two parts: Explanatory Notes and the Bill. The Explanatory Notes explain the approach taken to drafting the Voluntary Assisted Dying Bill. They differ from traditional Explanatory Notes which tend to address each provision sequentially and explain its purpose. By contrast, the primary goal of the Explanatory Notes that follow is to explain the Bill at a global level, while still explaining some of the more important provisions in more detail. Key issues covered are the values and principles that underpin the Bill, the major policy positions taken, and the approach adopted in relation to drafting style. This is then followed by the full text of the Bill.

Voluntary assisted dying is a vexed and contested issue. Despite this complexity, over recent years there has been a shift in the national debate as successive governments put the issue of voluntary assisted dying on the political agenda. Reform is likely to be a matter of 'when' rather than 'if'.[22] As such, it is imperative now to consider carefully what shape reform should take rather than uncritically adopt the legislative model recently passed by the Victorian Government. In an attempt to widen the Australian debate, the authors offer this Bill and its Explanatory Notes for consideration. Since finalising the manuscript, the authors also note that the *Voluntary Assisted Dying Act 2019* was passed by the Western Australian Parliament.

[20] Lindy Willmott and Ben White 'Assisted dying in Australia: A values-based model for reform' in Ian Freckelton and Kerry Petersen (eds) *Tensions and Traumas in Health Law* (Federation Press, 2017), 488-99.
[21] As stated by the Commonwealth Secretariat guide on law reform: 'the interrogation that proposals are subjected to as a result of the process of instructing legislative drafters assists with the refining of the policy behind the recommendations' Commonwealth Secretariat, *Changing the Law: A Practical Guide to Law Reform* (Report 2017), 146 <http://www.calras.org/pub/Main/LawReform/Changing%20The%20Law.pdf>.
[22] White and Willmott, 'Future of assisted dying reform in Australia' (n 12).

II EXPLANATORY NOTES FOR THE VOLUNTARY ASSISTED DYING BILL 2019

These Explanatory Notes explain the approach taken to drafting the Voluntary Assisted Dying Bill 2019. This includes identifying the values and principles that underpin the Bill, the major policy positions taken, and the approach adopted in relation to drafting style. These Notes are different from the traditional Explanatory Notes which usually explain each provision sequentially. While some specific provisions are explained further below, this document is primarily aimed at explaining the Bill at a more global level. A diagram providing an overview of the process proposed by the Bill for accessing voluntary assisted dying is included in the Appendix.

A *Values Underpinning the Bill*

The values underpinning the design of this Bill are those outlined and explained in the book chapter 'Assisted Dying in Australia: A Values-based Model for Reform' in the book *Tensions and Traumas in Health Law*.[23] Those values are:

- Life;
- Autonomy;
- Freedom of conscience;
- Equality;
- Rule of law;
- Protecting the vulnerable; and
- Reducing human suffering.

Added to this list which underpinned the design of the Bill is the concept of safe and high-quality care.[24] The proposed model situates voluntary assisted dying as part of health care and as being provided within the health system. Accordingly, voluntary assisted dying must be provided in a way that is safe and of high-quality like all other health care.

[23] White and Willmott (n 20).

[24] For a discussion of the elements of safe and high-quality end of life care, see Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* (Report, 2015) <https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf>.

B *Position on Key Overarching Policy Issues*

Many of the key policy decisions are explained in the book chapter 'A Values-based Model for Reform',[25] and so will not be repeated at length below. However, drafting a Bill necessarily requires more detailed decisions to be made about how a voluntary assisted dying system should operate and some of these other overarching positions will be briefly explained (including how they differ from the Victorian model).

- Clause 6 outlines that voluntary assisted dying includes both of what has historically been called voluntary euthanasia (called practitioner administration in the Bill) and physician assisted suicide (called self-administration in the Bill). We do not endorse the Victorian approach of having self-administration as the default and primary method of voluntary assisted dying. Providing a choice of practitioner administration and self-administration for a person requesting access to voluntary assisted dying promotes the value of autonomy. Where both options are available internationally, people overwhelmingly choose practitioner administration.[26] Also, while the evidence base is limited, that which exists suggests that practitioner administration is safer than self-administration with fewer complications.[27]
- Clause 6 also explains that voluntary assisted dying must occur under medical supervision. This will clearly occur with practitioner administration when the registered medical practitioner administers the voluntary assisted dying medication. In relation to self-administration, being under the supervision of a registered medical practitioner means that the registered medical practitioner will be present while the person self-administers the voluntary assisted dying medication. We anticipate this could be done unobtrusively by the medical practitioner so as to respect the person's wishes about how their death occurs.

[25] White and Willmott (n 20).
[26] For example, in the Netherlands in 2017, of 6585 cases reported to Euthanasia Review Committees, 6306 were of euthanasia, 250 were of assisted suicide, and 29 cases involved a combination of both: Regional Euthanasia Review Committees, *Annual Report 2017* (March 2018) 10. In Canada, drawing on the last two federal government reports covering the period from 1 January 2017 to 31 October 2018, of the 4575 medically assisted deaths reported, only 2 were self-administered: Health Canada, *Fourth Interim Report on Medical Assistance in Dying Canada* (Report, April 2019) 5 (note: this does not include data from some provinces as outlined in the report).
[27] Ezekiel Emanuel et al, 'Attitudes and practices of euthanasia and physician assisted suicide in the United States, Canada and Europe' (2016) 316(1) *Journal of American Medical Association* 79, 86.

We acknowledge that such an approach has disadvantages, including: access implications for persons living in rural and remote areas;[28] burdens on medical practitioners to supervise voluntary assisted dying; and some limits on a person's autonomy in terms of timing of their death and who is present. In addition to there being ways to address these concerns, our view is that the policy benefits of the proposed approach outweigh these disadvantages for three main reasons:

1. These disadvantages only arise in relation to self-administration as by definition practitioner administration is always medically supervised. Given that where choice is available, practitioner administration is overwhelmingly chosen, these disadvantages are only likely to arise in the small number of voluntary assisted dying cases where a person specifically wants to self-administer.
2. The safety and quality of voluntary assisted dying for the person should be prioritised. This is enhanced by medical supervision.
3. The voluntary assisted dying medication will be safely managed as it will always be in the possession or under the direct supervision of a registered medical practitioner. This also means that complex provisions relating to the medication's collection, storage and disposal, such as those in the *Voluntary Assisted Dying Act 2017* (Vic), are not required. Registered medical practitioners are subject to existing regulations in relation to the dangerous medications and the Bill provides scope for regulations to address this further if needed.

- The starting point for drafting the eligibility criteria in clause 9 was broadly the approach in the *Voluntary Assisted Dying Act 2017* (Vic). While there may be cases that many regard as appropriate to allow access to voluntary assisted dying which may fall outside that legislation, eligibility criteria necessarily involve a basis for determining access and the Victorian model is a defensible approach. We have, however, departed from this model in three important respects.

  The first is that although the Bill requires a person to have a medical condition that will cause their death, it does not impose a time limit within which a person is expected to die. We adopt this approach because a time limit is arbitrary. While a

[28] While we have not included this in the Bill, permitting nurse practitioners to provide voluntary assisted dying has been one response to address access issues in Canada. Although released subsequent to drafting the Bill, we also note that the Voluntary Assisted Dying Bill 2019 (WA) grants nurse practitioners a role in voluntary assisted dying: see for example clause 53.

secondary consideration, not imposing a time limit avoids a registered medical practitioner from having to engage in the difficult task of determining prognosis and timing of death.

The second difference is that we have not required that a person be *both* (a) ordinarily resident in a State *and* (b) ordinarily resident in a State for a period of at least 12 months prior to a first request. The Bill only requires (a) as this is sufficient to achieve the policy goal of preventing non-residents having access to voluntary assisted dying in another State. The additional time-based requirement of (b) creates a further hurdle to access voluntary assisted dying for otherwise eligible persons and is unnecessary to prevent cross-border requests.

The third difference is in relation to the suffering requirement. To be eligible under the Bill, the medical condition must be causing the person 'intolerable and enduring' suffering. This is a higher threshold than under the Victorian Act but is consistent with some international approaches.

- Clauses 38 and 39 protect conscientious objection by registered health practitioners in relation to voluntary assisted dying and the ability of entities providing care and residential services to refuse access to voluntary assisted dying within their facilities. However, both provisions also create mechanisms that reflect the balance normally struck in medicine that respects conscience but values autonomy and equality in ensuring a person still has effective access to a lawful health service. As outlined in the Note at the end of Clause 38, subclause (3) is drafted sufficiently broadly to allow the person requesting access to voluntary assisted dying to be provided with contact details of an entity which can provide information that will facilitate that access to voluntary assisted dying. This provides an option that some registered medical practitioners might regard as morally preferable. This would, however, be dependent on the existence of an entity to provide such information enabling access to voluntary assisted dying. The approach of the model Bill differs from the Victorian Act which only addresses the right for a registered health practitioner to refuse to participate in various aspects of voluntary assisted dying.

C *Approach to Drafting*

1 Other legislation and Bills consulted

We adopted or adapted the drafting of the *Voluntary Assisted Dying Act 2017* (Vic) where our policy position was the same or similar, recognising that this Act had been passed already by an Australian Parliament. This includes retaining some wording that may otherwise be regarded as complex.

We also consulted a range of other sources in drafting this Bill. They include other recent Australian Bills[29] that were close to passing through the relevant Chamber in which they were introduced such as the Voluntary Assisted Dying Bill 2013 (Tas), the Death with Dignity Bill 2016 (SA) and the Voluntary Assisted Dying Bill 2017 (NSW) as well as the *Rights of the Terminally Ill Act 1995* (NT) which was in force for a 9 month period in the mid-1990s. (The Voluntary Assisted Dying Bill 2019 (WA) was not released at the time of drafting the model Bill so was not able to be considered.) Legislation regulating voluntary assisted dying overseas was also consulted but we note that drafting styles are quite different in some of these countries, especially in European civil law jurisdictions.

2 Acknowledging jurisdictional drafting styles and different laws

We recognise that legislative drafting is a specific skill and that different jurisdictions have different drafting conventions. Accordingly, our approach in drafting this Bill was to make the policy position clear, being aware that it would be revised in line with local drafting guidelines. We also acknowledge that there are alternative drafting techniques to present the policy framework proposed in this Bill.

3 Preference for brevity

Our view is that the Bill should be as short and simple as practicable. A decision was made therefore that the Bill should focus on establishing the wider legal framework for voluntary assisted dying, but not be the source of detailed procedural steps about how it is provided. In part, this is because unnecessary length and complexity can impede a clear explanation on the proposed policy position.

[29] See also the account of Australian Bills in Willmott et al (n 12); updated in White and Willmott, 'Future of assisted dying reform in Australia' (n 12)

However, we favour this approach predominantly because of our view about the appropriate role of legislation within a regulatory framework. Voluntary assisted dying should be governed by a suite of regulatory tools including legislation, regulations, policies and guidelines. We consider the appropriate function for legislation is to establish the legal framework for these decisions, but that the detailed procedural guidance is better addressed in regulations, policies and guidelines.

This is one way in which we have departed from the *Voluntary Assisted Dying Act 2017* (Vic), which is very prescriptive in its approach. We also note this means that omitting a provision in the Victorian Act from our Bill does not mean we consider that the relevant issue should not be regulated. It may simply reflect that such a matter is more appropriately dealt with in regulations or policies and guidelines. It may also be that some matters are already adequately dealt with either by existing legislation or established protocols in the health system within which voluntary assisted dying will occur.

D Specific Policy Issues Explained

Earlier in these Explanatory Notes, some key overarching policy issues were explained. Here we address a series of smaller and specific policy decisions that have been made in the course of drafting the Bill.

Some of the discussion below explains why certain safeguards in the *Voluntary Assisted Dying Act 2017* (Vic) have not been adopted. A global point to make here is that the Victorian Act is very unusual in its detail and complexity when compared with international models, the *Rights of the Terminally Ill Act 1997* (NT) and the other Australian Bills consulted. As mentioned above, some of this detailed procedural guidance in the Victorian Act is better placed in regulations, policies or guidelines.

Further, some of the Victorian Act's safeguards do not add substantive value to safeguarding vulnerable persons, may impose undue burden on persons requesting access to voluntary assisted dying and the registered health practitioners assisting them, and are inconsistent with the overarching values that we consider should guide the law in this area. For these reasons, we concluded that their inclusion in the Bill was not justified. Instead, we have focused on safeguards that we consider are needed to ensure

the voluntary assisted dying system operates as intended, and have drawn on approaches in other Australian Bills and international models.

- The Bill does not contain a prohibition on registered health practitioners initiating discussions about voluntary assisted dying with their patients as imposed by section 8 of the *Voluntary Assisted Dying Act 2017* (Vic). For reasons expanded on elsewhere,[30] this impedes the frank discussions needed for safe and high-quality end-of-life care.
- The Bill does not contain a requirement to obtain a permit from the relevant government department prior to providing access to voluntary assisted dying as required by Part 4 of the *Voluntary Assisted Dying Act 2017* (Vic). This requirement is unnecessarily bureaucratic, delays access to voluntary assisted dying, and is of limited utility as a safeguard as it is only likely to be a review of the relevant documentation.
- The wording of clause 13(3) of the Bill prescribing the required qualifications and experience of one of the registered medical practitioners is intentionally different from section 10(3) of the *Voluntary Assisted Dying Act 2017* (Vic). Under the Victorian Act, one of the registered medical practitioners must be a *medical specialist in the person's disease, illness or medical condition* (emphasis added). The interpretation of this provision is that General Practitioners and Palliative Care Physicians would not qualify as having this 'expertise and experience'. The proposed wording in this Bill is instead that either of the registered medical practitioners 'must have relevant experience in treating or managing the medical condition expected to cause the death of the person being assessed'. While retaining the same policy goal that at least one of the registered medical practitioners has particular experience with the person's medical condition, this wider wording is intended to reflect that General Practitioners and Palliative Care Physicians may have such experience.
- This Bill does not contain additional provisions in relation to notifications to the Australian Health Practitioner Regulation Agency as the existing law requiring mandatory notifications and permitting voluntary notifications is considered to be adequate.[31]

[30] See for example, Lindy Willmott et al, 'Restricting conversations about voluntary assisted dying: Implications for clinical practice' (2019) *BMJ Supportive and Palliative Care* (in press); Johnston and Cameron (n 18).

[31] See for example part 8, divisions 2 and 3 of the *Health Practitioner Regulation National Law* (Qld). Note that the provisions in part 7, division 1 of the *Voluntary Assisted Dying Act 2017* (Vic) closely resemble those in part 8, divisions 2 and 3 in the *Health Practitioner Regulation National Law (Victoria) Act 2009* (Vic).

- This Bill does not include specific provisions about intervention in voluntary assisted dying decisions by the courts or tribunals. This is because these are primarily clinical matters for the first and second medical practitioner to assess. An exception is in relation to decision-making capacity. Depending on local legislation, guardianship or civil and administrative tribunals may have jurisdiction to adjudicate a person's decision-making capacity, and if not, it may be appropriate to specifically grant such jurisdiction to a tribunal in relation to capacity. Finally, should exceptional circumstances warrant wider judicial scrutiny, Supreme Courts have been willing to consider end-of-life issues in appropriate circumstances when approached for guidance.[32]
- Clause 2 of the Bill requires an 18-month delay before the Act comes into force to permit time for implementation as has occurred in Victoria.
- Clause 5 sets out the Bill's principles, which are based on the values outlined above. We note for completeness, however, that the value of respecting the rule of law does not appear in this list of principles. While it remains an appropriate value to inform the design and implementation of voluntary assisted dying laws, it is not as relevant in guiding a person or other entity who is exercising a power or performing a function or duty under the Act.
- Definitions of capacity or decision-making capacity (defined in clause 7 of the Bill) vary by jurisdiction and so the Bill's approach may need to be adjusted to reflect this. For example, Queensland includes the requirement for the person to have 'freely and voluntarily' made the decision as part of the capacity test in its guardianship legislation.[33] In the proposed model, this requirement is addressed as part of the eligibility criteria.
- Clause 33(3) contains the safeguard that a person's final request for voluntary assisted dying must occur immediately prior to access. This ensures it is a contemporaneous request by a person with capacity who is acting freely and voluntarily in requesting access to voluntary assisted dying.
- As noted in the Bill, the criminal law of each jurisdiction varies and accordingly, Parts 7 and 8 will need to be considered in light of local laws. This would include

[32] See for example, *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84; *H Ltd v J* (2010) 107 SASR 352.
[33] See *Guardianship and Administration Act 2000* (Qld) sch 4 (definition of 'capacity') and *Powers of Attorney Act 1998* (Qld) sch 3 (definition of 'capacity').

determining the appropriate reach of existing criminal law offences, such as those relating to assisting suicide, and how they would interact with the Bill including its proposed protections from criminal liability.

III VOLUNTARY ASSISTED DYING BILL 2019

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B *Bill*

2019

A Bill

for

An Act to provide for voluntary assisted dying, in specific and restricted circumstances and subject to safeguards, for persons with an incurable, advanced and progressive medical condition that will cause death, to protect registered medical practitioners who wish to provide voluntary assisted dying and registered health practitioners who do not wish to participate in voluntary assisted dying, and for related purposes.

The Parliament of [State] enacts—

Part 1 Preliminary

1 Short title

This Act may be cited as the *Voluntary Assisted Dying Act 2019.*

2 Commencement

(1) Subject to subsection (2), this Act comes into operation on a day or days to be proclaimed.

(2) If a provision of this Act does not come into operation before [insert day 18 months after Parliament passing this Act], it comes into operation on that day.

3 Act binds all persons

This Act binds all persons, including the State.

4 Main objects of the Act

The main objects of this Act are to—

(a) provide access to voluntary assisted dying for persons with an incurable, advanced and progressive medical condition that will cause death;

(b) establish safeguards to ensure that voluntary assisted dying is accessed only by persons who meet this Act's eligibility criteria;

(c) establish the Voluntary Assisted Dying Review Board to provide oversight of voluntary assisted dying under this Act;

(d) provide protections from liability for registered health practitioners and other persons who facilitate voluntary assisted dying in accordance with this Act; and

(e) enable registered health practitioners and entities who provide a health service, residential service or professional care service to refuse to participate in voluntary assisted dying without incurring liability.

5 Principles

A person exercising a power or performing a function or duty under this Act must have regard to the following principles—

(a) human life is of fundamental importance and should be valued;

(b) a person's autonomy should be respected;

(c) freedom of conscience should be respected, including choosing to—

(i) participate in voluntary assisted dying; and

(ii) not participate in voluntary assisted dying;

(d) a person's equality should be respected and they should be free from discriminatory treatment;

(e) persons who are vulnerable should be protected from coercion and abuse;

(f) human suffering should be reduced; and

(g) the provision of voluntary assisted dying should reflect the established standards of safe and high-quality care.

6 Meaning of voluntary assisted dying

(1) ***Voluntary assisted dying*** means the administration of voluntary assisted dying medication to a person and includes steps reasonably related to such administration.

(2) To remove any doubt, ***voluntary assisted dying*** may occur through—

(a) a registered medical practitioner administering voluntary assisted dying medication to a person to bring about their death (***practitioner administration***); or

(b) a person taking voluntary assisted dying medication themselves to bring about their death under the supervision of a registered medical practitioner (***self-administration***).

(3) For the purposes of subsection (2)(b), being under the supervision of a registered medical practitioner means that the registered medical practitioner is present while the person self-administers the voluntary assisted dying medication.

7 Meaning of decision-making capacity

(1) A person has ***decision-making capacity*** in relation to voluntary assisted dying if the person is able to—

(a) understand the information relevant to the decision relating to access to voluntary assisted dying and the effect of the decision; and

(b) retain that information to the extent necessary to make the decision; and

(c) use or weigh that information as part of the process of making the decision; and

(d) communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means.

(2) For the purposes of subsection (1), a person is presumed to have decision-making capacity unless there is evidence to the contrary.

8 Definitions

The dictionary in Schedule 1 defines particular words used in this Act.

Part 2 Eligibility and requests for access to voluntary assisted dying

Division 1 Eligibility for access to voluntary assisted dying

9 Eligibility criteria

For a person to be eligible for access to voluntary assisted dying—

(a) the person must be aged 18 years or more; and

(b) the person must—

(i) be an Australian citizen or permanent resident; and

(ii) be ordinarily resident in [State]; and

(c) the person must have decision-making capacity in relation to voluntary assisted dying; and

(d) the person's decision to access voluntary assisted dying must be—

(i) enduring;

(ii) made voluntarily and without coercion; and

(e) the person must be diagnosed with a medical condition that—

(i) is incurable; and

(ii) is advanced, progressive and will cause death; and

(iii) is causing intolerable and enduring suffering.

10 Clarification of eligibility criteria

(1) Whether a person's medical condition will cause the person's death is to be determined by reference to available medical treatment that is acceptable to the person.

(2) For the purposes of subsection 9(e)(iii)—

(a) whether suffering is intolerable is to be determined by the person requesting access to voluntary assisted dying;

(b) suffering caused by a person's medical condition includes suffering caused by treatment provided for that medical condition; and

(c) suffering includes physical, psychological and existential suffering.

Division 2 Requests for access to voluntary assisted dying

11 A person may make a first request

(1) A person may make a request to a registered medical practitioner for access to voluntary assisted dying (a ***first request***).

(2) A person's first request for access to voluntary assisted dying must be—

(a) clear and unambiguous; and

(b) made by the person personally.

(3) The person may make the first request verbally or by gestures or other means of communication available to the person.

Part 3 Assessment of eligibility for access to voluntary assisted dying

Division 1 Two registered medical practitioners to assess eligibility

12 Two registered medical practitioners to assess eligibility

(1) A person may access voluntary assisted dying only if two registered medical practitioners (a ***first medical practitioner*** and a ***second medical practitioner***) assess the person as eligible for access to voluntary assisted dying.

(2) The first medical practitioner and a second medical practitioner must be independent of each other.

(3) For the purposes of subsection (2), the first medical practitioner and a second medical practitioner will not be independent of each other if—

(a) they are family members; or

(b) one medical practitioner is employed by or working under the supervision of the other medical practitioner.

13 Qualifications and experience of first and second medical practitioners

(1) Each of the first medical practitioner and second medical practitioner must—

(a) hold a fellowship with a specialist medical college; or

(b) be a vocationally registered general practitioner.

(2) Either the first medical practitioner or each second medical practitioner must have practised as a registered medical practitioner for at least 5 years after completing a fellowship with a specialist medical college or vocational registration (as the case requires).

(3) Either the first medical practitioner or each second medical practitioner must have relevant experience in treating or managing the medical condition expected to cause the death of the person being assessed.

14 Approved training

The first medical practitioner and a second medical practitioner must not commence their assessment for eligibility for access to voluntary assisted dying unless that practitioner has completed approved assessment training.

Division 2 Assessment by first medical practitioner

15 First medical practitioner may undertake first assessment

(1) A registered medical practitioner (the ***first medical practitioner***) who receives a first request from a person may undertake a ***first assessment***.

(2) The first assessment requires an examination of the person and a review of their relevant medical records.

16 First assessment

When undertaking a first assessment, the first medical practitioner must assess whether the person requesting access to voluntary assisted dying meets the eligibility criteria.

17 Further expertise required for assessment

(1) If the first medical practitioner is unable to determine whether a person requesting access to voluntary assisted dying meets one or more of the eligibility criteria, they must refer the person to a registered health practitioner or health practitioners with appropriate skills and training.

Example—

A first medical practitioner who is unable to determine whether a person has capacity in relation to voluntary assisted dying must refer the person to a registered health practitioner with expertise to undertake that assessment. This could be, for example, a psychiatrist or geriatrician.

(2) If the first medical practitioner refers the person to a registered health practitioner under subsection (1), the first medical practitioner may adopt the determination of the registered health practitioner in relation to the matter in respect of which the person was referred.

18 Information to be provided if first medical practitioner assesses person as meeting eligibility criteria

(1) If the first medical practitioner is satisfied that the person requesting access to voluntary assisted dying meets all the eligibility criteria, the first medical practitioner must inform the person about the following matters—

(a) the person's diagnosis and prognosis;

(b) the treatment options available to the person and the likely outcomes of that treatment;

(c) palliative care options available to the person and the likely outcomes of that care;

(d) the potential risks of taking voluntary assisted dying medication or having it administered;

(e) that the expected outcome of taking voluntary assisted dying medication or having it administered referred to in paragraph (d) is death; and

(f) that the person may decide at any time not to continue with their request for access to voluntary assisted dying.

(2) The first medical practitioner must also encourage the person to inform their family and other treating registered medical practitioners of the person's request for access to voluntary assisted dying.

(3) Nothing in this section affects any duty a registered medical practitioner has at common law or under any other enactment.

19 Referral to second medical practitioner

If the first medical practitioner is satisfied that the person—

(a) meets the eligibility criteria; and

(b) understands the information required to be provided under section 18,

the first medical practitioner must refer the person to a second medical practitioner for a second assessment.

Division 3 Assessment by second medical practitioner

20 Second medical practitioner may undertake second assessment

(1) A registered medical practitioner (a ***second medical practitioner***) who receives a referral from the first medical practitioner may undertake a ***second assessment***.

(2) A second assessment requires an examination of the person and a review of their relevant medical records.

21 Second assessment

When undertaking a second assessment, a second medical practitioner must assess whether the person requesting access to voluntary assisted dying meets the eligibility criteria.

22 Further expertise required for assessment

(1) If a second medical practitioner is unable to determine whether a person requesting access to voluntary assisted dying meets one or more of the

eligibility criteria, they must refer the person to a registered health practitioner or health practitioners with appropriate skills and training.

Example—

A second medical practitioner who is unable to determine whether a person has capacity in relation to voluntary assisted dying must refer the person to a registered health practitioner with expertise to undertake that assessment. This could be, for example, a psychiatrist or geriatrician.

(2) If a second medical practitioner refers the person to a registered health practitioner under subsection (1), the second medical practitioner may adopt the determination of the registered health practitioner in relation to the matter in respect of which the person was referred.

23 Information to be provided if second medical practitioner assesses person as meeting eligibility criteria

(1) If a second medical practitioner is satisfied that the person requesting access to voluntary assisted dying meets all the eligibility criteria, the second medical practitioner must inform the person about the following matters—

(a) the person's diagnosis and prognosis;

(b) the treatment options available to the person and the likely outcomes of that treatment;

(c) palliative care options available to the person and the likely outcomes of that care;

(d) the potential risks of taking voluntary assisted dying medication or having it administered;

(e) that the expected outcome of taking voluntary assisted dying medication or having it administered referred to in paragraph (d) is death; and

(f) that the person may decide at any time not to continue with their request for access to voluntary assisted dying.

(2) Nothing in this section affects any duty a registered medical practitioner has at common law or under any other enactment.

24 Outcome of first and second assessments

(1) If the first medical practitioner and a second medical practitioner are satisfied that the person—

(a) meets the eligibility criteria; and

(b) understands the information required to be provided under sections 18 and 23,

the person is eligible for access to voluntary assisted dying.

(2) If the first medical practitioner assesses a person as eligible for access to voluntary assisted dying but a second medical practitioner assesses that person as not eligible for access to voluntary assisted dying, the first medical practitioner may refer the person to another registered medical practitioner for a further second assessment.

25 First medical practitioner report to Board about eligibility determination

(1) The first medical practitioner must, within 14 days of an ***eligibility determination*** being made in relation to a person, give the Board a report about a person's eligibility determination in the approved form.

(2) The report must include a copy of the following—

(a) a record of the first request;

(b) the first assessment report;

(c) any second assessment report; and

(d) any other information required by regulation.

(3) For the purposes of this section, an eligibility determination means a determination by the first medical practitioner that—

(a) a person is eligible for access to voluntary assisted dying in accordance with subsection 24(1); or

(b) a person is not eligible for access to voluntary assisted dying in accordance with subsection 24(1).

Division 4 Transfer of first medical practitioner's role

26 Transfer of first medical practitioner's role

(1) The first medical practitioner for a person may transfer the role of first medical practitioner to another registered medical practitioner at—

(a) the request of the person; or

(b) the first medical practitioner's own initiative.

(2) The first medical practitioner for a person may transfer the role of the first medical practitioner to a second medical practitioner for the person if the second medical practitioner has assessed the person as eligible for access to voluntary assisted dying

Note—

The first and second medical practitioners' assessments that the person is eligible for access to voluntary assisted dying remain valid despite this referral and so the person will have the two assessments as required under this Act. A second medical practitioner, who has already conducted their assessment, will become the first medical practitioner who will supervise the person's voluntary assisted dying.

(3) The first medical practitioner for a person may also transfer the role of the first medical practitioner to a registered medical practitioner other than a second medical practitioner.

(4) A transfer of the role of the first medical practitioner under subsection (3) can take effect only if the new first medical practitioner has assessed the person as eligible for access to voluntary assisted dying, having conducted their own assessment in accordance with sections 15 to 18.

Note—

The purpose of this subsection is to ensure that the first medical practitioner has always undertaken their own eligibility assessment given that practitioner is supervising the person's voluntary assisted dying.

(5) The person requesting access to voluntary assisted dying must agree to the role of the first medical practitioner being transferred to the other registered medical practitioner before that transfer can take effect.

Part 4 Access to voluntary assisted dying

Division 1 Second request for access to voluntary assisted dying

27 Person assessed as eligible for access to voluntary assisted dying may make second request

(1) A person assessed as eligible for access to voluntary assisted dying in accordance with subsection 24(1) may make a written request (a ***second request***) requesting access to voluntary assisted dying.

(2) The second request must—

(a) specify that the person—

(i) makes the declaration voluntarily and without coercion; and

(ii) understands the nature and the effect of the request the person is making; and

(b) be in writing and in the approved form;

(c) be signed by the person making the request in the presence of two witnesses and the first medical practitioner.

(3) Despite subsection (2)(c), a person may sign a second request at the direction of the person making the request if—

(a) the person making the request is unable to sign the declaration; and

(b) the person signing—

(i) is aged 18 years or more; and

(ii) is not a witness to the signing of the request.

(4) A person who signs a written request on behalf of the person making the request must do so in that person's presence.

(5) If a person makes a second request with the assistance of an interpreter, the interpreter must certify on the request that the interpreter provided a true and correct translation of any material translated.

28 Witness to making of second request

(1) A person is eligible to witness the making of a second request if the person is—

(a) aged 18 years or more; and

(b) not an ineligible witness.

(2) A person is an ineligible witness for the purposes of a second request if the person—

(a) knows or believes that the person—

(i) is a beneficiary under a will of the person making the second request; or

(ii) may otherwise benefit financially or in any other material way from the death of the person making the second request; or

(b) is an owner of, or is responsible for the day-to-day operation of, any facility at which the person making the second request is receiving a health service, residential service or professional care service; or

(c) is directly involved in providing a health service, residential service or professional care service to the person making the second request.

(3) Not more than one witness may be a family member of the person making the second request.

29 Certification of witness to signing of second request

(1) A witness who witnesses a person signing a second request must—

(a) certify in writing in the second request that—

(i) in the presence of the witness, the person making the second request appeared to voluntarily and without coercion sign the second request; and

(ii) at the time the person signed the second request, the person appeared to have decision-making capacity in relation to voluntary assisted dying; and

(iii) at the time the person signed the second request, the person appeared to understand the nature and effect of making the second request; and

(b) state that the witness is not knowingly an ineligible witness.

(2) A witness who witnesses another person signing a second request on behalf of the person making it must—

(a) certify in writing in the second request that—

(i) in the presence of the witness, the person making the second request appeared to voluntarily and without coercion direct the other person to sign the second request; and

(ii) the other person signed the second request in the presence of the person making the second request and the witness; and

(iii) at the time the other person signed the second request, the person making it appeared to have decision-making capacity in relation to voluntary assisted dying; and

(iv) at the time the other person signed the second request, the person making it appeared to understand the nature and effect of making the second request; and

(b) state that the witness is not knowingly an ineligible witness.

(3) A certification and statement under subsection (1) or (2) must be signed by the witness making it in the presence of the first medical practitioner.

Division 2 Final request for access to voluntary assisted dying

30 Person may make final request for access to voluntary assisted dying

(1) A person may make a ***final request*** to the first medical practitioner for the person that the first medical practitioner provide access to voluntary assisted dying to the person if—

(a) the person has made a second request in accordance with section 27;

(b) the person has decision-making capacity in relation to voluntary assisted dying;

(c) the person's request for access to voluntary assisted dying is made voluntarily and without coercion;

(d) the person's request for access to voluntary assisted dying is enduring; and

(e) the person understands that access to voluntary assisted dying will be provided immediately after the making of the final request.

(2) The person's final request for access to voluntary assisted dying must be—

(a) clear and unambiguous; and

(b) made by the person personally.

(3) The person may make the request verbally or by gestures or other means of communication available to the person.

(4) A final request must be made in the presence of a witness.

(5) The first medical practitioner must refuse to accept the person's final request if the first medical practitioner is not satisfied of any matter under subsection (1).

31 Nature of voluntary assisted dying in final request

The person's final request must specify the nature of the voluntary assisted dying requested from the first medical practitioner, namely—

(a) practitioner administration of voluntary assisted dying medication to the person; or

(b) supervised self-administration by the person of voluntary assisted dying medication.

32 Witness to making of final request

(1) A person is eligible to witness the making of a final request if the person is—

(a) aged 18 years or more;

(b) not employed by or working under the supervision of the first medical practitioner; and

(c) not a family member of the first medical practitioner.

(2) The witness who witnesses a person making a final request must certify in writing in the approved form that—

(a) the person at the time of making the final request appeared to have decision-making capacity in relation to voluntary assisted dying;

(b) the person in requesting access to voluntary assisted dying appeared to be acting voluntarily and without coercion; and

(c) the person's request to access voluntary assisted dying appeared to be enduring.

33 Timing of final request

(1) A person's final request must be made—

(a) subject to subsection (2), at least nine days after the day on which the person made the first request; and

(b) in any case, at least one day after the day on which the second assessment that assessed the person as eligible for access to voluntary assisted dying was completed.

(2) Subsection (1)(a) does not apply if the first medical practitioner for the person considers that the person's death is likely to occur before the expiry of the time period specified in that subsection, and this is consistent with the prognosis of a second medical practitioner who conducted a second assessment for the person.

(3) A person's final request must also be made immediately before the first medical practitioner provides access to voluntary assisted dying.

Division 3 First medical practitioner may provide access to voluntary assisted dying

34 First medical practitioner may provide access to voluntary assisted dying

Upon receiving the final request from a person, the first medical practitioner for that person may provide access to voluntary assisted dying to that person in accordance with the final request.

Division 4 Management of voluntary assisted dying medication

35 Collection, storage and disposal of voluntary assisted dying medication

The collection, storage and disposal of the voluntary assisted dying medication by the first medical practitioner must occur in accordance with the requirements set out in the regulations.

Division 5 Person may decide at any time not to take any further step in relation to access to voluntary assisted dying

36 Person may decide at any time not to take any further step in relation to access to voluntary assisted dying

(1) A person requesting access to voluntary assisted dying may decide at any time not to take any further step in relation to access to voluntary assisted dying.

(2) The person may express their decision verbally or by gestures or other means of communication available to the person.

Division 6 Reporting of voluntary assisted dying

37 First medical practitioner report to Board about voluntary assisted dying

(1) The first medical practitioner must, within 14 days of providing access to voluntary assisted dying to a person, give the Board a report about the voluntary assisted dying in the approved form.

(2) The report must include a copy of the following—

(a) a record of the first request;

(b) the first assessment report;

(c) any second assessment report;

(d) the second request;

(e) a record of the final request;

(f) the witness's certification of the final request; and

(g) any other information required by regulation.

Part 5 Participation in voluntary assisted dying is voluntary

38 Registered health practitioners with conscientious objection

(1) A registered health practitioner who has a conscientious objection to voluntary assisted dying has the right to refuse to do any of the following—

(a) provide information about voluntary assisted dying;

(b) participate in any part of the request and assessment process for voluntary assisted dying;

(c) supply, prescribe or administer voluntary assisted dying medication;

(d) be present during voluntary assisted dying.

(2) A registered medical practitioner exercising a conscientious objection in accordance with subsection (1) must disclose the practitioner's conscientious objection to the person and offer to refer the person to another practitioner or entity in accordance with subsection (3).

(3) If requested, the registered medical practitioner must refer the person, or transfer their care, to—

(a) another registered medical practitioner who, in the referring registered medical practitioner's belief, does not have a conscientious objection to voluntary assisted dying; or

(b) an entity at or through which, in the referring registered medical practitioner's belief, the person will have access to another registered medical practitioner who does not have a conscientious objection to voluntary assisted dying.

Note—

Subsection (3)(b) provides for referral of a person requesting access to voluntary assisted dying to be to an entity through which the person will have access to another registered

medical practitioner who does not have a conscientious objection to voluntary assisted dying. This would permit a registered medical practitioner to provide the person requesting access to voluntary assisted dying with contact details of an entity which can provide information that will facilitate access to voluntary assisted dying.

39 Entity may refuse access to voluntary assisted dying within its facility

(1) This section applies to an entity, other than a natural person, who provides a health service, residential service or professional care service.

(2) An entity may refuse access to voluntary assisted dying, including assessments in relation to voluntary assisted dying, within its facility.

(3) Where a person who requests access to voluntary assisted dying is being cared for or resides in a facility of an entity that refuses access to voluntary assisted dying within the facility, the entity must—

(a) inform the person of the entity's decision to refuse access to voluntary assisted dying within its facility;

(b) offer to arrange a transfer of the care or residence of the person to an entity at which, in the entity's belief, access to voluntary assisted dying can be provided by a registered medical practitioner who does not have a conscientious objection to voluntary assisted dying; and

(c) take reasonable steps to facilitate that transfer.

Part 6 Voluntary Assisted Dying Review Board

This Part of the Bill is not outlined in detail because legislative provisions for statutory boards vary by jurisdiction. However, the model outlined in the Voluntary Assisted Dying Act 2017 *(Vic) is generally supported. Specific matters that the Bill should address include:*

- *establishing the Voluntary Assisted Dying Review Board and its functions, along with the powers needed to undertake those functions;*
- *determining the composition of the Board and its procedures and staffing; and*
- *the Board's monitoring role.*

In relation to the Board's monitoring role, this would need to be both for individual cases and the system as a whole. In terms of individual cases, the Board should conduct a post-hoc review of each case of voluntary assisted dying to ensure that it complied with the requirements of the Act and this duty should be specified in the Act. The Board's powers should include the ability to request further information beyond that provided by the first medical practitioner if it considers this necessary. If there are concerns about compliance, the Board should be empowered to refer that case to entities such as the police, the Coroner and the Australian Health Practitioner Regulation Agency.

The Board's monitoring role also requires oversight of the system as a whole to ensure that it is functioning as intended and to make recommendations for improvement where needed. To support this, the Board would collect and analyse data provided to it by registered medical practitioners in their reporting. It may also need to collect further information to undertake this overall monitoring role. This data (in de-identified form) should also be made publicly available for community scrutiny in the form of annual reports tabled in Parliament. The Board should also have power to undertake educational initiatives for registered health practitioners and the wider community to promote understanding of, and compliance with, the requirements of the Act.

Part 7 Protections from liability for acting in accordance with Act

40 Protection from criminal liability of person who assists or facilitates request for or access to voluntary assisted dying

A person who in good faith does something or fails to do something—

(a) that assists or facilitates any other person who the person believes on reasonable grounds is requesting access to or is accessing voluntary assisted dying in accordance with this Act; and

(b) that apart from this section, would constitute an offence at common law or under any other enactment—

does not commit the offence.

41 No liability for registered health practitioner who acts in accordance with Act

(1) A registered health practitioner who, in good faith and without negligence, acts under this Act believing on reasonable grounds that the act is in accordance with this Act is not in respect of that act—

(a) guilty of an offence; or

(b) liable for unprofessional conduct or professional misconduct; or

(c) liable in any civil proceeding; or

(d) liable for contravention of any code of conduct.

(2) To remove any doubt, subsection (1) includes when a registered health practitioner exercises a conscientious objection to voluntary assisted dying provided that occurs in accordance with this Act.

42 No liability for registered health practitioner present after voluntary assisted dying medication administered

(1) A registered health practitioner who, in good faith, does not administer life saving or life sustaining medical treatment to a person who has not requested it, and believes on reasonable grounds that the person is dying after being administered or self-administering voluntary assisted dying medication in accordance with this Act, is not, in respect of that omission to act—

(a) guilty of an offence; or

(b) liable for unprofessional conduct or professional misconduct; or

(c) liable in any civil proceeding; or

(d) liable for contravention of any code of conduct.

(2) This section does not prevent a registered health practitioner from providing medical treatment for the purpose of ensuring the person's comfort.

43 Section [insert number] of the [insert relevant criminal law Act or Code] does not apply

Section [insert number] of the [insert relevant criminal law Act or Code] does not apply to a person who knows or believes on reasonable grounds that a person is accessing voluntary assisted dying in accordance with this Act.

This provision is based on section 82 of the Voluntary Assisted Dying Act 2017 *(Vic) which states that section 463B of the* Crimes Act 1958 *(Vic) does not apply. Section 463B justifies the use of force to prevent a suicide. This means that the proposed provision in this Bill will only be needed in jurisdictions where a provision like section 463B exists authorising the prevention of a suicide.*

Part 8 Offences

The approach to and wording of offence provisions varies by jurisdiction so the below are illustrative of the standard type of offences included in Voluntary Assisted Dying Bills. Other offences may be added or the below proposed offences modified depending on how the criminal law is regulated by jurisdiction.

44 Inducing another person to request access to voluntary assisted dying

A person who, by dishonesty or undue influence, induces another to make a request for access to voluntary assisted dying is guilty of a crime.

Maximum penalty— [insert]

45 Inducing another person to access voluntary assisted dying

A person who, by dishonesty or undue influence, induces another to self-administer voluntary assisted dying medication or induces another to request that a registered medical practitioner administer that medication is guilty of a crime.

Maximum penalty— [insert]

46 False or misleading statements

A person who knowingly makes a false or misleading statement in, or in relation to, a request for access to voluntary assisted dying is guilty of a crime.

Maximum penalty— [insert]

47 Failing to report to Board

A registered medical practitioner who fails to report to the Board as required by this Act is guilty of a crime.

Maximum penalty— [insert]

Part 9 Miscellaneous

The approach to the Miscellaneous Part of the Bill will also vary by jurisdiction. Specific matters that the Bill could or should address include:

- *a requirement to review the Act's operation after 5 years;*
- *provisions regulating the use of interpreters;*
- *approval of training for registered medical practitioners by the relevant government department;*
- *confidentiality duties for those with access to personal information in the course of administering the Act;*
- *the recording of the death on the Register of Births, Deaths and Marriages;*
- *that the death is not a 'reportable death' for coronial investigation;*
- *the effect that the Act has on wills, insurance policies, contracts and other statutes;*
- *forfeiture provisions in relation to a person's estate where another person is found guilty of an offence under this Act; and*

- *the making of regulations under the Act.*

Consequential or transitional provisions will also vary by jurisdiction and so have not been included in the Bill

Schedule 1 Dictionary

Only a limited number of important terms used in this Bill are defined below as jurisdictions vary in their approaches to definitions sections. Variability also arises because jurisdictions have:

- *different acts interpretation legislation which can define commonly used legislative terms in different ways; and*
- *different local health legislation from which definitions for Voluntary Assisted Dying Bills are sometimes taken.*

approved assessment training means training approved by the [insert relevant government department official] under section 14.

Board means the Voluntary Assisted Dying Review Board.

decision-making capacity has the meaning set out in section 7.

eligibility criteria means the criteria set out in section 9 and clarified in section 10.

eligibility determination has the meaning set out in section 25(3).

family member of a person means the person's spouse or domestic partner, parent, grandparent, sibling, child or grandchild.

final request means a request from a person for access to voluntary assisted dying to a registered medical practitioner in accordance with section 30.

first assessment means an assessment undertaken in accordance with Part 3 Division 2.

first medical practitioner means the registered medical practitioner—

(a) who receives a first request from a person and undertakes a first assessment; or

(b) to whom the role is transferred in accordance with section 26.

first request means a request from a person for access to voluntary assisted dying to a registered medical practitioner in accordance with section 11.

ineligible witness has the meaning set out in section 28(2).

medical condition means a medical condition whether caused by disease, illness or injury.

practitioner administration has the meaning set out in section 6.

professional care services means any of the following provided to another person under a contract of employment or a contract for services—

(a) support or assistance;

(b) special or personal care;

(c) a disability service within the meaning of [the Disability Act].

registered health practitioner means a person registered under the *Health Practitioner Regulation National Law* to practise a health profession other than as a student.

registered medical practitioner means a person registered under the *Health Practitioner Regulation National Law* to practise in the medical profession other than as a student.

request and assessment process means, in respect of a person, the making or the conducting of the following—

(a) a first request;

(b) a first assessment;

(c) a second assessment;

(d) a second request;

(e) a final request.

second assessment means an assessment undertaken in accordance with Part 3 Division 3.

second medical practitioner means a registered medical practitioner who receives a referral from the first medical practitioner under section 19 and undertakes a second assessment.

second request means a request from a person for access to voluntary assisted dying to a registered medical practitioner in accordance with section 27.

self-administration has the meaning set out in section 6.

special or personal care means—

(a) assistance with one or more of the following—

(i) bathing, showering or personal hygiene;

(ii) toileting;

(iii) dressing or undressing;

(iv) meals; or

(b) assistance for persons with mobility problems; or

(c) assistance for persons who are mobile but require some form supervision or assistance; or

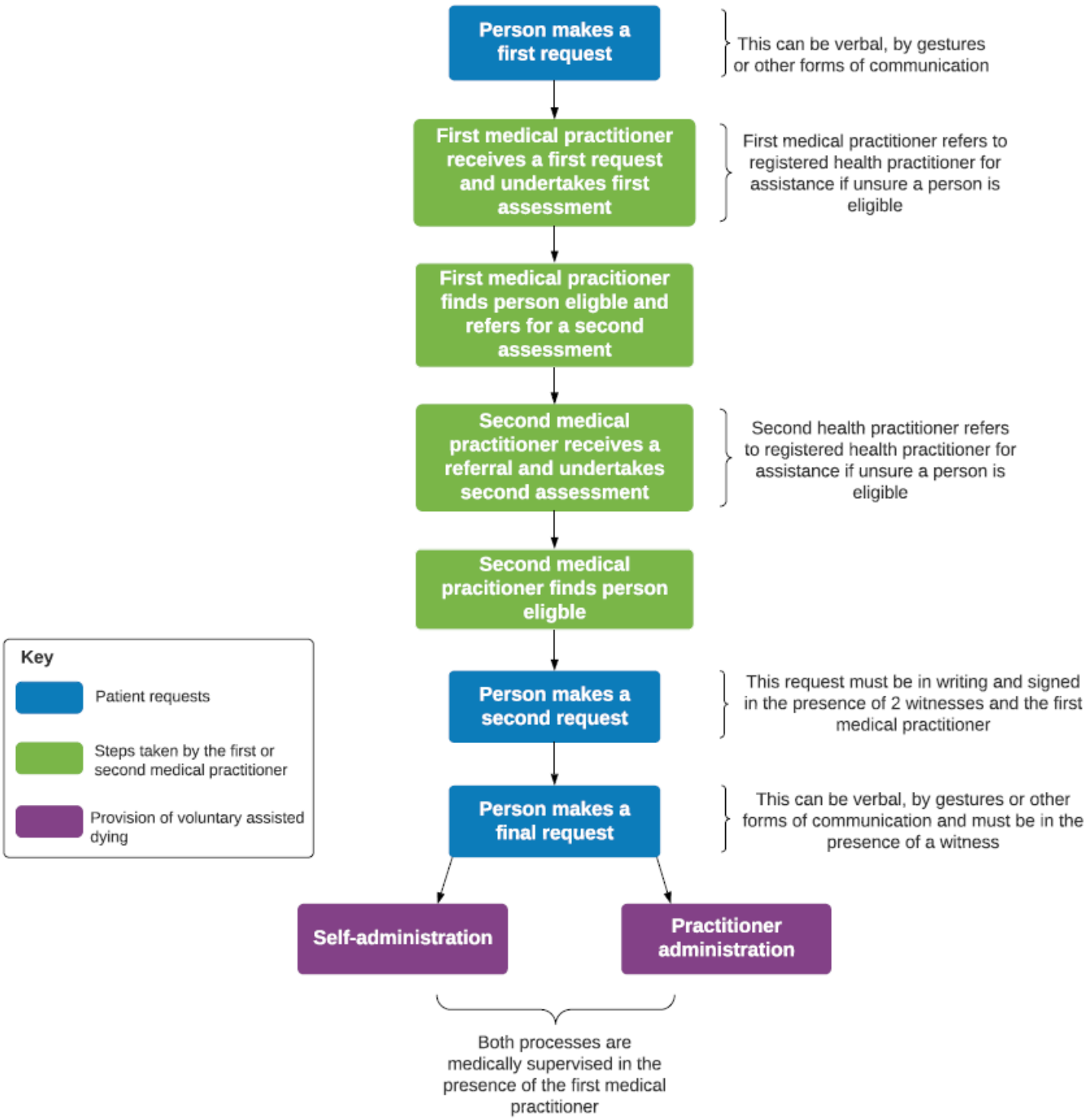
(d) assistance or supervision in administering medicine; or

(e) the provision of substantial emotional support.

voluntary assisted dying has the meaning set out in section 6.

voluntary assisted dying medication means a poison or controlled substance or a drug of dependence prescribed by the first medical practitioner for the purpose of causing a person's death

IV APPENDIX: SHORT OVERVIEW OF THE PROCESS TO ACCESS VOLUNTARY ASSISTED DYING IN THE VOLUNTARY ASSISTED DYING BILL 2019



REFERENCE LIST

A *Articles/Books/Reports*

ACT Legislative Assembly, *Select Committee on End of Life Choices in the ACT* (Report, March 2019)

Commonwealth Secretariat, *Changing the Law: A Practical Guide to Law Reform* (Report, 2017) <http://www.calras.org/pub/Main/LawReform/Changing%20The%20Law.pdf>

Department of Health, Government of Western Australia, *Ministerial Expert Panel on Voluntary Assisted Dying: Final Report* (Discussion paper, HEN-013590, June 2019)

Emanuel, Ezekiel et al, 'Attitudes and practices of euthanasia and physician assisted suicide in the United States, Canada and Europe' (2016) 316(1) *Journal of American Medical Association* 79

Government of Western Australia, 'Western Australian Government response: Joint Select Committee on End-of-Life Choices Report, *My Life, My Choice*' (Report, WCP-013515, December 2018)

Health Canada, *Fourth Interim Report on Medical Assistance in Dying Canada* (Report, April 2019)

Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, 56th Parliament of Queensland, *Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying* (Paper No 3, 14 February 2019)

Johnston, Carolyn and James Cameron, 'Discussing Voluntary Assisted Dying' (2018) 26(2) *Journal of Law and Medicine* 454

Joint Committee on End of Life Choices, Parliament of South Australia, 'Terms of Reference' (April 2019)

Joint Select Committee on End of Life Choices, 40th Parliament of Western Australia, *My Life, My Choice* (Report No 1, August 2018)

McGee, Andrew et al 'Informing the euthanasia debate: Perceptions of Australian politicians' (2018) 41(4) *University of New South Wales Law Journal* 1368

Regional Euthanasia Review Committees, *Annual Report 2017* (March 2018) 10

Voluntary Assisted Dying Review Board, *Report on Operations 2018-2019* (Report, August 2019)

Willmott, Lindy and Ben White 'Assisted dying in Australia: A values-based model for reform' in Ian Freckelton and Kerry Petersen (eds) *Tensions and Traumas in Health Law* (Federation Press, 2017)

White, Ben and Lindy Willmott, 'Future of assisted dying reform in Australia' (2018) 42(6) *Australian Health Review* 616

White, Ben and Lindy Willmott, 'How should Australia regulate voluntary euthanasia and assisted suicide' (2012) 20 *Journal of Law and Medicine* 410

White, Ben, Lindy Willmott and Eliana Close, 'Victoria's voluntary assisted dying law: clinical implementation as the next challenge' (2019) 210(5*) Medical Journal of* Australia 207

Willmott, Lindy et al, '(Failed) voluntary euthanasia law reform in Australia: Two decades of trends, models and politics' (2016) 39(1) *University of New South Wales Law Journal* 1

Willmott, Lindy et al, 'Restricting conversations about voluntary assisted dying: Implications for clinical practice' (2019) *BMJ Supportive and Palliative Care* (in press)

B *Cases*

Brightwater Care Group (Inc) v Rossiter (2009) 40 WAR 84

H Ltd v J (2010) 107 SASR 352

C *Legislation*

Euthanasia Laws Act 1997 (Cth)

Guardianship and Administration Act 2000 (Qld)

Health Practitioner Regulation National Law (Qld)

Practitioner Regulation National Law (Victoria) Act 2009 (Vic)

Powers of Attorney Act 1998 (Qld)

Rights of the Terminally Ill Act 1995 (NT)

Voluntary Assisted Dying Act 2017 (Vic)

Voluntary Assisted Dying Bill 2019 (WA)

D *Other*

Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* (Report, 2015) <https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf>

Daniel Andrews, 'Victoria State Government 'Voluntary assisted dying model established ahead of vote in Parliament' (Media release, 25 July 2017)

White, Ben et al, 'WA's take on assisted dying has many similarities with the Victorian law – and some important differences', *The Conversation* (online, 9 August 2019) <https://theconversation.com/was-take-on-assisted-dying-has-many-similarities-with-the-victorian-law-and-some-important-differences-121554>

Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study

Lindy Willmott[1], Ben P White[1], Marcus Sellars[1,2], Patsy M Yates[3]

The known: Victoria is the first Australian state to enact voluntary assisted dying legislation. The *Voluntary Assisted Dying Act 2017* (Vic) includes many safeguards to ensure that only eligible patients receive assistance to die.

The new: Doctors who have participated in voluntary assisted dying have mixed views about the operation of the system and its safeguards. Restrictions on initiating conversations with patients and limiting interactions to face-to-face meetings cause concern, as do practical problems related to system software and documentation requirements.

The implications: The Victorian voluntary assisted dying system should be reviewed to improve its processes and its access to eligible patients. Other Australian states can learn from the Victorian experience.

Abstract

Objectives: To investigate the perspectives of doctors involved with voluntary assisted dying in Victoria regarding the *Voluntary Assisted Dying Act 2017* (Vic) and its operation.

Design, setting, participants: Qualitative study; semi-structured interviews with 32 doctors who had participated in the voluntary assisted dying system during its first year of operation (commenced 19 June 2019). Doctors were interviewed during April–July 2020.

Results: Three major themes related to problems during the first year of operation of the Act were identified: the statutory prohibition of health professionals initiating discussions with their patients about voluntary assisted dying; the Department of Health and Human Services guidance requirement that all doctor–patient, doctor–pharmacist, and pharmacist–patient interactions be face-to-face; and aspects of implementation, including problems with the voluntary assisted dying online portal, obtaining documentary evidence to establish eligibility, and inadequate resourcing of the Statewide Pharmacy Service.

Conclusions: Doctors reported only limited concerns about the Victorian voluntary assisted dying legislation, but have had some problems with its operation, including implications for the accessibility of voluntary assisted dying to eligible patients. While legislative change may resolve some of these concerns, most can be ameliorated by improving the processes and systems.

Voluntary assisted dying became lawful in Victoria in June 2019 when the *Voluntary Assisted Dying Act 2017* (Vic) (the Act) commenced operation.[1] To 31 December 2020, there had been 224 deaths under the Act.[2] Other Australian states have already or are likely to legalise voluntary assisted dying in the near future.[3-7]

The Victorian legislation aims to facilitate access to voluntary assisted dying, but only for eligible patients.[8,9] The Act achieves this balance with 68 safeguards, making it the "safest, and most conservative model in the world".[10]

Doctors are central to voluntary assisted dying. They assess patient eligibility, either as coordinating practitioners (the first doctor who assesses the patient) or consulting practitioners (the second doctor, who provides an independent eligibility assessment). Doctors accompany a patient on their complex journey from the initial discussion of voluntary assisted dying to the final provision of the medication. Their perceptions of the operation of the legislation in practice are therefore critical.

In this article, we report the perspectives of doctors who have participated in the voluntary assisted dying process in Victoria during the first year of its operation.

Methods

We report our study according to the Consolidated Criteria for Reporting Qualitative Health Research.[11] Eligible doctors were those who had been involved in voluntary assisted dying in Victoria since the *Voluntary Assisted Dying Act 2017* (Vic) commenced operation, as either coordinating or consulting doctors for patients who had requested voluntary assisted dying. Potential participants could be identified because doctors are legally required to complete a specific training program before assessing the eligibility of patients for voluntary assisted dying; doctors who had consented to contact about future research were invited by email to participate in our study. In addition, we used both purposive and snowball sampling to capture a range of experiences, including number of cases of voluntary assisted dying, role (coordinating, consulting doctor), years of medical experience, speciality, location (regional, metropolitan), age, and sex.

We developed an interview guide (online Supporting Information), based on our analysis of the policy goals underlying the Act[9] and discussion by the research team, to explore participants' perceptions of a range of regulatory matters, including eligibility assessments, request and assessment processes, reporting obligations, administering the medication, and whether the legislation achieved its policy goals of balancing safeguards and providing access to eligible patients.

Author MS conducted semi-structured interviews with each participant during 14 April – 24 July 2020 on the video conferencing platform Zoom or by telephone. Recruitment ceased when theoretical saturation was reached.[12] All interviews were digitally audio-recorded and transcribed verbatim. Individual transcripts were provided to participants to view and amend (member checking).[13]

We used NVivo Plus 12 (QSR International) to store, code, and search transcripts. Author MS applied thematic analysis[12] to code the transcripts line by line and to inductively identify concepts

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describing participants' experiences and perspectives of how the Act was operating in practice. Similar concepts were subsequently grouped as themes, and, with the assistance of authors LW and BW, MS developed a coding structure to capture concepts related to participants' experiences and perspectives on global regulatory aspects of voluntary assisted dying. Despite the breadth of topics covered in the first round of coding (including concerns about assessing patient eligibility), and to avoid an overly simplified overall description of the participants' views,[13] MS undertook a second round of coding, using a coding framework that mapped each of the global regulatory aspects of voluntary assisted dying (developed with LW and BW, based on their previous research into mapping these domains[9]). These two rounds of coding permitted analysis in relation to both specific aspects of the regulatory framework identified as problematic (reported here) and broader thematic trends (to be reported separately).

Our results were independently verified for the presence of themes by LW and BW, and discrepancies were resolved by consensus. After key themes were identified, LW re-examined the data and manually coded themes.

Ethics approval

The Queensland University of Technology Human Research Ethics Committee approved our study (2000000033). Informed consent was obtained before each interview.

Results

As of 18 June 2020, 106 of 228 doctors who had undergone training for assessing the eligibility of patients for voluntary assisted dying had consented to being contacted about future research (46%) and were invited to participate in the study. Seventeen doctors responded that they were not eligible for participation because they had not been involved in voluntary assisted dying. Of the 106 doctors who consented to being contacted about future research and those contacted through snowball sampling, 12 vocationally registered general practitioners and 20 medical specialists participated in our study (Box). Participants had been involved in a median of six cases (interquartile range [IQR], 3–13.5 cases). The median duration of the interviews was 62.5 minutes (IQR, 55.2–72.5 minutes).

We identified three major themes related to problems during the first year of operation of the Act: the prohibition of health professionals initiating conversations with their patients about voluntary assisted dying; the requirement for face-to-face engagement only (based on the intersection of the Act with the Australian *Criminal Code Act 1995*);[14] and broader implementation problems. Sample comments by participants are included in the online Supporting Information.

Prohibition of health professionals initiating conversations about assisted dying

Section 8(1) of the Act prohibits initiating a discussion about voluntary assisted dying:

> A registered health practitioner who provides health services or professional care services to a person must not, in the course of providing those services to the person:
>
> a initiate discussion with that person that is in substance about voluntary assisted dying; or
>
> b in substance, suggest voluntary assisted dying to that person.[1]

Characteristics of the 32 participants in our interviews

Characteristic	Number
Sex	
Men	18
Women	14
Age group (years)	
30–39	5
40–49	8
50–59	7
60–69	10
70–75	2
Voluntary assisted dying role	
Consulting only	2
Coordinating only	14
Both consulting and coordinating	16
Number of voluntary assisted dying cases (either role)	
1–5	14
6–10	8
11–15	4
16–20	2
21–25	0
26–30	3
> 30	1
Medical practice (years)	
1–5	0
6–10	3
> 10	29
Practice as vocationally registered general practitioner or medical specialist	
1–5	5
6–10	4
> 10	23
Specialty	
General practice	12
Medical oncology	10
General medicine	3
Radiation oncology	2
Haematology	1
Nephrology	1
Anaesthetics	1
Palliative care	1
Surgery	1
Location (region)	
Major city	19
Inner regional	12
Outer regional	1

The policy aim of this prohibition is to guard against undue influence by health professionals.[8] Some doctors expressed concerns this could prevent a patient making an informed choice about treatment options, particularly patients from non-English speaking backgrounds or people with poor health literacy; that is, people less likely to learn about voluntary assisted dying from the media or other sources. Some doctors felt "morally compromised", "deceitful", or "intellectually dishonest" withholding information about voluntary assisted dying. Other participants felt this prohibition was an appropriate safeguard against unduly influencing patients, as doctors "have a lot more influence than we realise". Because of this prohibition, doctors described patients as inevitably self-selecting. For some, this made the conversation easier, as only patients who at least knew a little about voluntary assisted dying could request it.

Requirement that all interactions be face-to-face

The guidance provided by the Victorian Department of Health and Human Services requires face-to-face consultations between doctors and patients, doctors and pharmacists (including discussions about the content of voluntary assisted dying prescriptions and the transmission of prescriptions to pharmacists), and between pharmacists and patients.[15] The guidance reflects concerns that doctors and pharmacists might breach federal law should they use a "carriage service" (eg, telephone, email, or telehealth facilities) to discuss "suicide" (*Criminal Code Act 1995*, sections 474.29A and 474.29B),[14] even if acting lawfully under the Act.[16,17]

Many participants criticised the burden this requirement placed on doctors, pharmacists and patients, particularly patients in rural and remote areas, a burden exacerbated during the coronavirus disease 2019 (COVID-19) epidemic in 2020. Doctors spoke of the immense burden for very sick patients required to travel, sometimes for hours and several times, for eligibility assessments. Some also noted the burden on already busy doctors who travelled long distances to undertake assessments. Others saw merit in stipulating at least one face-to-face consultation in which they could assure themselves that the request for assisted dying was genuinely voluntary. They regarded telehealth interactions as having significant limitations, a "second rate solution" suitable only for complex cases in which face-to-face consultations were not possible.

Concerns were also expressed about requiring doctors and pharmacists to meet personally to transfer the prescription for the voluntary assisted dying medication; that is, not permitting the coordinating doctor to email it to the pharmacist. Requiring pharmacists to meet face-to-face with patients also had practical implications in terms of delays in providing voluntary assisted dying.

Implementation of the Act

Participants largely mentioned systems problems rather than the safeguards included in the Act. Three major sub-themes were identified.

First, process problems included its complexity, particularly the many forms required. However, some noted this became less of a challenge as their familiarity with the forms and requirements grew. Some doctors also expressed frustration about perceived "pedantic" checking of forms by Safer Care Victoria that did not clearly make the system safer. The frequent rejection of submitted forms caused delays, often with serious consequences for eligible terminally ill patients who had been assessed as having intolerable suffering.

This frustration was compounded by difficulties with the online portal through which doctors were required to lodge the various forms. They felt that the portal was badly designed, counterintuitive in its layout, and difficult to navigate. Concerns were also expressed about technical problems with uploading documents, with implications for busy clinicians. Some doctors suggested better training and guidelines on how to use the portal could reduce these difficulties. Despite widespread reservations about the process, some doctors noted that with time they became more efficient in navigating the portal.

Second, doctors described difficulties in generating required documentation for assessing eligibility, particularly proof that a person was an Australian citizen or permanent resident and had been ordinarily resident in Victoria for the 12 months before making a first request for voluntary assisted dying (*Voluntary Assisted Dying Act 2017* (Vic), section 9).[1] Some felt this effectively locked out patients who had lived in Victoria throughout their adult lives but could not provide documentary proof of these requirements. For those able to provide proof, compiling it could cause delays. Obtaining documentation is especially difficult at the end of life, a chaotic time for many people.

Third, after a permit for voluntary assisted dying has been issued by the Department of Health and Human Services secretary, the Statewide Pharmacy Service liaises with the doctor when the required prescription is written and meets with the doctor or patient (according to what is appropriate) when the medication is delivered. While participants praised the quality of their interactions with the Statewide Pharmacy Service, they generally believed that it was inadequately resourced and that this caused considerable delays, both in writing and transmitting the prescription and in delivering the medication to the doctor or patient.

Discussion

All governments considering voluntary assisted dying reform must strike a balance between promoting patient autonomy through accessibility and restricting its availability to eligible people, thereby ensuring that the system is safe. Compared with those of other countries, the Victorian system is more highly regulated, as illustrated by the requirement to obtain a permit before providing assistance to die.[8]

Safety can be achieved with legislative safeguards or by system design. The safeguards embedded in the Victorian system indicate the focus on safety. Some participants commented that the detailed checks and balances provided them with the confidence to participate in the system. However, it is also important to reflect on how the system operates in practice. Making voluntary assisted dying accessible to eligible patients will not be achieved if doctors find the system too onerous to navigate or if some patients die before receiving the medication.

We found that doctors perceived some important shortcomings in the current system. The implementation of the Act was strongly criticised, particularly the usability of the system portal. These challenges were burdensome for doctors and families, and increased patient and family suffering, sometimes leading patients to abandon the process or their deaths before obtaining the medication. In a case that illustrates this point, a coordinating doctor applied to the Victorian Civil and Administrative Tribunal after several requests by Safer Care Victoria for further evidence of Victorian residency during the preceding 12 months of an applicant; the tribunal determined that, based on

the information available by the time of its determination, the residency criterion had been satisfied.[18]

Two of the authors of the current article have previously noted that it is important that any complexity in system design be internally facing; that is, not experienced by patients or doctors.[19] Some strategies to improve the process for doctors could be simple, such as providing information about how the portal operates and the nature of the required documentation. Doctors reported that system useability increased with practice, but early support would have been useful.

The second major problem identified by participants was the Department of Health and Human Services requirement that all consultations be undertaken in person to avoid potential liability under federal law. Whether this concern is legally justified awaits authoritative legal determination, but doctors or pharmacists who engage in electronic communication about "suicide" are at legal risk,[20] particularly as departmental guidance prohibits such interaction. The Commonwealth legislation should be amended to remove this risk and to avoid unnecessary burdens on doctors and terminally ill patients. While good medical practice dictates that many consultations should be in person, doctors should be permitted to exercise clinical judgement about the format of their consultations.

The final concern — the prohibition of initiating conversations about voluntary dying — refers to the content of the law rather than its implementation. This concern is consistent with good medical practice and published evidence for the importance of honest and open communication, including providing patients with a range of treatment options and information on their risks and benefits.[21] However, participants differed on whether doctors should be permitted to initiate discussions, some believing the prohibition was an important protection against coercion, and suggested they would not be prepared to participate in the system without this prohibition. In Western Australia, the legal prohibition is narrower and does not prevent a treating doctor initiating discussion of voluntary assisted dying with a patient (section 10).[4] But if they do so, they must also provide information about other treatment options, including palliative care, as well as the likely outcomes.

Implications and limitations

As with all new systems, the voluntary assisted dying system in Victoria could be improved. Section 116 of the Act requires the Health Minister to review the legislation after four years of operation.[1] Our findings suggest that the process should be improved and participating doctors better supported.

Our findings also provide useful insights for Western Australia and Tasmania during their implementation phases, and for other states considering similar legislation. However, the problems identified by our Victorian study may not arise in other jurisdictions with different approaches to implementation. Further, our findings are based on the perceptions, experiences, and expertise of the doctors we interviewed, and they may not be representative of all doctors involved in the voluntary assisted program process. For instance, we recruited no neurologists, although several participants had acted as coordinating or consulting doctors for patients with neurological illnesses.

Conclusion

Safeguards ensure that systems for providing voluntary assisted dying are safe for patients and their communities. Procedural processes and delays that ensure that only eligible patients have access to assisted dying and that their requests are genuinely voluntary and enduring can be justified. However, the system must also be efficient and help doctors navigate the process. It is therefore important to consider the perceived shortcomings reported by participating doctors. While some problems might be resolved by amending the legislative framework, others might be more readily remedied by practical support for doctors, including clear guidance about using the voluntary assisted dying portal, particularly during their initial use of the system, and adjustments in system design.

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1 Parliament of Victoria. Voluntary Assisted Dying Act 2017 [Act No. 61/2017]. https://www.legislation.vic.gov.au/in-force/acts/voluntary-assisted-dying-act-2017/004 (viewed Mar 2021).

2 Voluntary Assisted Dying Review Board. Report of operations July–December 2020. Melbourne: Safer Care, Victoria, 2021. https://www.bettersafercare.vic.gov.au/sites/default/files/2021-02/VADRB_Report%20of%20operations%20Feb%2021_FINAL.pdf (viewed Mar 2021).

3 White B, Willmott L. Future of assisted dying reform in Australia. *Aust Health Rev* 2018; 42: 616–620.

4 Parliament of Western Australia. Voluntary Assisted Dying Act 2019 [No. 27 of 2019]. https://www.legislation.wa.gov.au/legislation/statutes.nsf/law_a147242.html (viewed Apr 2021).

5 Parliament of Tasmanian. End-of-Life Choices (Voluntary Assisted Dying) Act 2021 [Bill 30-XI]. https://www.legislation.tas.gov.au/view/html/asmade/act-2021-001 (viewed Apr 2021).

6 Government of South Australia. Voluntary Assisted Dying Bill [House of Assembly, No. 131]. https://www.legislation.sa.gov.au/LZ/B/CURRENT/VOLUNTARY%20ASSISTED%20DYING%20BILL%202020_HON%20KYAM%20MAHER%20MLC.aspx (viewed Apr 2021).

7 McKenna K. Queensland government to introduce voluntary assisted dying legislation into parliament next week. *ABC News* (Australia), 19 May 2021. https://www.abc.net.au/news/2021-05-18/qld-government-to-introduce-voluntary-assisted-dying-legislation/100146110 (viewed May 2021).

8 Department of Health and Human Services (Victoria). Ministerial advisory panel on voluntary assisted dying: final report. July 2017. https://www2.health.vic.gov.au/about/publications/researchandreports/ministerial-advisory-panel-on-voluntary-assisted-dying-final-report (viewed Dec 2020).

9 White B, Del Villar K, Close E, Willmott L. Does the *Voluntary Assisted Dying Act* 2017 (Vic) reflect its stated policy goals? *University of New South Wales Law Journal* 2020; 43: 417–451.

10 Office of the Premier of Victoria. Voluntary assisted dying model established ahead of vote in Parliament [media release]. 25 July 2017. https://www.premier.vic.gov.au/voluntary-assisted-dying-model-established-ahead-vote-parliament (viewed Dec 2020).

11 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.

12 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.

13 Kitto SC, Chesters J, Grbich C. Quality in qualitative research. *Med J Aust* 2008; 188:

243–246. https://www.mja.com.au/journal/2008/188/4/quality-qualitative-research

14 Parliament of Australia. Criminal Code Act 1995 [No. 12, 1995]. https://www.legislation.gov.au/Details/C2021C00132/Html/Volume_2 (viewed Apr 2021).

15 Department of Health and Human Services (Victoria). Voluntary assisted dying: guidance for health professionals. July 2019. https://www2.health.vic.gov.au/about/publications/policiesandguidelines/voluntary-assisted-dying-guidance-for-health-practitioners (viewed Dec 2020).

16 Kagi J. Doctors may face prosecution for discussing euthanasia with patients over phone, computer. *ABC News* (Australia), 23 Aug 2019. https://www.abc.net.au/news/2019-08-23/doctors-fear-prosecution-over-wa-voluntary-euthanasia-laws/11440394 (viewed Dec 2020).

17 Australian Associated Press. Risk to Vic doctors discussing euthanasia. *Canberra Times*, 27 June 2019. https://www.canberratimes.com.au/story/6243599/risk-to-vic-doctors-discussing-euthanasia/?cs=14264 (viewed Dec 2020).

18 Victorian Civil and Administrative Tribunal (Human Rights Division). NTJ *v* NTJ (Human Rights) [2020]; VCAT 547 [VCAT reference no. H121/2020]. Updated 6 May 2020. http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/vic/VCAT/2020/547.html?context=1;query=NTJ%20v%20NTJ%20(Human%20Rights);mask_path= (viewed Apr 2021).

19 White B, Willmott L, Close E. Victoria's voluntary assisted dying law: clinical implementation as the next challenge. *Med J Aust* 2019; 210: 207–209. https://www.mja.com.au/journal/2019/210/5/victorias-voluntary-assisted-dying-law-clinical-implementation-next-challenge

20 Del Villar K, Close E, Hews R, et al. Voluntary assisted dying and the legality of using a telephone or internet service: the impact of Commonwealth "carriage service" offences [preprint]. *QUT ePrints*; 207083. 16 Dec 2020; modified 17 May 2021. https://eprints.qut.edu.au/207083 (viewed May 2021).

21 Willmott L, White B, Ko D, et al. Restricting conversations about voluntary assisted dying: implications for clinical practice. *BMJ Support Palliat Care* 2020; 10: 105–110. ■

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Medical practitioners' views and experiences of being involved in assisted dying in Victoria, Australia: A qualitative interview study among participating doctors

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ABSTRACT

Rationale: On June 19, 2019, Assisted Dying (AD) was legalized in the Australian state of Victoria, joining a small but growing cohort of jurisdictions internationally where AD is permitted. Few studies have examined perspectives of doctors who have participated in AD in jurisdictions where it has become legal, despite their pivotal role in the system.
Objective: This study aimed to describe the beliefs, experiences and perspectives of doctors who had provided AD during the first 12 months of its operation in Victoria, Australia.
Method: In-depth, semi-structured interviews were conducted between April and July 2020 with 32 Victorian doctors who had been involved in the AD process during the first 12-months since it became legal in Victoria. The assumptions underpinning our methodology were guided by a phenomenological approach and reflexive thematic analysis was used to analyze the data.
Results: Five major themes were identified: a nascent approach to care, practising within clinical and legal uncertainty, confronting practices, personal sacrifices and coping amid new challenges. A thematic schema was developed, illustrating that these themes were expressed as a balance of competing tensions of identity for doctors who provided AD for their patients in practice. A major tension was not just how doctors' perceptions impacted their own wellbeing and satisfaction, but also how these challenged their continued involvement in AD and, therefore, the system's overall ability to function.
Conclusion: Our findings show that while doctors discussed AD as an ethical practice, it also involved multiple identities with varying sources of meaning, and these identities were sometimes overlapping depending on context. As other jurisdictions increasingly move to legalize AD, a greater appreciation of the different role-based and group-based challenges involved in AD may improve AD implementation strategies.

1. Introduction

The Voluntary Assisted Dying Act (Vic) (VAD Act) was passed by the Victorian parliament in November 2017 and came into effect in June 2019 (Victoria. Chief Parliamentary Counsel, 2017). Victoria joined a small but growing cohort of jurisdictions where assisted dying (AD) is permitted including Belgium, Netherlands, Luxembourg, Switzerland, Spain, Germany, Canada, eleven U.S. states and the District of Colombia. This reflects a trend internationally to legalize AD with laws also passed but not yet in force in the Australian states of Western Australia and Tasmania, and in New Zealand. Other countries are also actively contemplating law reform including Ireland, Scotland and England.

The VAD Act is significant, however, because it is regarded by many as the most conservative model internationally with 68 safeguards as part of its framework (Onwuteaka-Philipsen et al., 2019; Premier of Victoria. The Hon Daniel Andrews, 2017). The aim of the VAD Act is to facilitate timely access to AD while ensuring community safety, so that access to AD is restricted only to people who are eligible (White et al., 2020). A key element of the VAD Act is that the AD request and assessment process is dependent on a minimum of two doctors (one

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coordinating and one consulting), who have undertaken legislatively-mandated AD training and one of whom must have expertise in the patient's medical condition, to complete the AD request and assessment process. The coordinating doctor has carriage of the process while the consulting doctor provides an independent opinion on eligibility.

The VAD Act's request and assessment process requires willing doctors to support the process. Therefore, one potential challenge for patients attempting to access AD is the ability to identify qualified and trained doctors who are willing and able to assist them access AD. For example, data from other jurisdictions internationally, such as in Oregon, estimates that just 1% of actively licensed physicians provide AD (Emanuel et al., 2016; Oregon. Public Health Division. Center for Health Statistics, 2020). Similarly, a recent report from the Victorian Department of Health and Human Services shows that only 157 doctors have been involved in one or more AD cases in the 18-months since becoming legal (Victoria. Safer Care Victoria, 2021).

Barriers to AD identified by Victorian clinicians prior to AD becoming legal included concerns and uncertainties about the practicalities of legalizing AD and potential unintended consequences on families and health services (Blaschke et al., 2019), health services or wards refusing to provide AD once legal because of a belief that it is fundamentally different to the care they currently provide (e.g. palliative care) (Philip et al., 2020), and anticipating an emotional toll from providing AD and concerns about increased workload and a potential for conflict with families and other clinical staff (McDougall et al., 2019). However, Australian studies of doctors' perspectives who have participated in AD are sparse and have mostly been focused on identifying challenges to AD in anticipation of it becoming legal (McDougall et al., 2019; Blaschke et al., 2019; Philip et al., 2020). Qualitative studies of doctors from the US and Canada show that despite AD requiring a "seismic shift" (Ho et al. p. 192) in doctors' medical practices because of the novel logistical and emotional challenges it presents (Dobscha et al., 2004; Ho et al., 2021; Mathews et al., 2021), the availability of standardized mechanisms for financial reimbursement for the time taken to undertake AD (Beuthin et al., 2020; Buchbinder et al., 2019; Crumley et al., 2021; Khoshnood et al., 2018; Mathews et al., 2021) and formal emotional support during the process are insufficient (Beuthin et al., 2020; Dobscha et al., 2004; Oczkowski et al., 2021).

Given the role of doctors in assisting patients to access AD, in Victoria but in other jurisdictions internationally too, there is a need to examine the experiences, beliefs and perspectives of doctors who have been involved in AD since becoming legal, such as navigating and fulfilling the request and assessment process.

This study aimed to describe the perspectives and experiences of doctors who had provided AD during the first 12-months of its operation in Victoria, Australia and to understand how they conceptualized their professional roles in the practice of providing AD and inform ways to optimize health systems implementing AD.

2. Methods

With the aim of providing a transparent and comprehensive approach to reporting, study reporting is based on the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) (Tong et al., 2007).

2.1. Approach

The theoretical assumptions underpinning our methodology were guided by a phenomenological approach. This allowed us to remain flexible in data collection and analysis, to grasp the qualitative diversity of participants' experiences and to identify meaning (Willig, 2013). The aim of using this approach was to encounter and understand the common lived experiences of doctors who had facilitated AD for patients, without being influenced by any preconceived beliefs and opinions about how this would be experienced in practice. Patient access to AD is dependent on assessment by a minimum two doctors who have undertaken specialty training and requires exchanges with various people throughout the process (i.e. patients and families, the Secretariat of the Voluntary Assisted Dying Review Board, AD pharmacists and navigators and other colleagues involved in AD). It is therefore important to understand doctors' perceptions of providing AD because this will likely subsequently influence their patients' ability to access AD.

2.2. Sampling and recruitment

Purposive and snowball sampling was used to recruit participants. Participants were recruited through the training program doctors are required to complete before they can assess eligibility. All doctors who consented to be on the "participation in research" list compiled through the training as at June 18, 2020, one year after the Victorian system began, were invited to participate. Participants were eligible if they were a Victorian doctor who had been involved in the AD process since it became legal in Victoria. For the current study, the "involvement" criteria was satisfied if the doctor had played the role of either coordinating or consulting doctor for a patient who had requested AD. Recruitment ceased when data saturation, defined as the point at which little or no new concepts were arising from subsequent interviews, was reached (Braun and Clarke, 2006). Variation in years of work experience, specialty, number of patients assisted patients to access AD (either as coordinating or consulting physician) and regional location were considered to capture the breadth and depth of participants' experiences in obtaining authorization for a patient to access AD.

2.3. Data collection

The first author conducted all interviews between April and July 2020 using the video conferencing platform, Zoom (n = 30), or by telephone (n = 2), at a time that was convenient for participants. None of the participants were known to the interviewer (MS, a trained qualitative and health services researcher) and with participant permission, all interviews were audio-recorded and transcribed verbatim by a transcription company. Following the interviews, individual transcripts were provided to participants as an opportunity to view and amend their interview transcript to ensure comprehensiveness of the evidence collected (member checking) (Kitto et al., 2008).

An interview guide was based on a legal analysis of the VAD Act's stated policy goals and discussion among the research team (Item S1, available as online supplementary material). Participants' age, gender, location, role, specialty and years of work experience was obtained at the start of the interview.

2.4. Data analysis

Drawing on grounded theory principles (Corbin and Strauss, 1990), including iteration and constant comparison, we used a 'reflexive' approach to thematic analysis (Braun & Clarke, 2006, 2020) to analyze the qualitative data. This involved a flexible and inductive approach to analyzing qualitative data, using a systematic and scientific process, to generate new insights and elicit a richer description of the data overall (Patton, 1990). Central to this process were the researchers who interpreted meanings expressed during the interviews, to create 'stories' or themes that could be translated into implications useful for practice and policy (Braun and Clarke, 2006).

Coding formed the basis of this analysis, an iterative process of data reduction in which meaningful sections of the text are identified and synthesised into concepts (themes). Transcripts were entered into NVivo Plus (version 12; QSR International), a software package used to store, code, and search data. MS independently coded the transcripts line-by-line, and inductively identified concepts about participants' experiences and perspectives about how the law was operating in practice. Following

this, a coding framework was developed and then reviewed by LW and BW to ensure comprehensive insight and interpretation (investigator triangulation) (Kuper et al., 2008) regarding participants' experiences and perspectives about the regulatory framework underpinning AD and a subsequent round of coding was undertaken by MS.

2.5. Reflexivity

Consistent with a phenomenological approach to data collection and analysis (Braun and Clarke, 2020), the researchers adopted an open and reflective attitude to aim to bracket their own assumptions and reflect critically on the context in which the research was occurring. This included making a conscious effort to set aside what we already knew or expected about how the AD legislation would be experienced by participants. During the interviews, the interviewer made an effort to give participants time to consider and explain their views and ensure we captured a diversity of views from participants. This included avoiding leading questions, using open-ended questions, probing and adopting a non-judgmental approach to interviewing (King et al., 2018). In addition, the researchers debriefed regularly during data collection and kept memos as they familiarized themselves with the data to clarify thoughts, note insights and make connections between themes.

2.6. Ethical considerations

Ethics approval for this research was received from the Queensland University of Technology Human Research Ethics Committee (UHREC) (reference 2000000033). The study objectives and voluntary nature of the study were explained to participants, and informed consent was obtained before each interview. In addition, prior to starting the interviewer asked participants not to breach their duties of confidentiality by naming patients, family members, or other medical practitioners, and we used codes instead of names (eg, ID_01, ID_02). The interviewer removed all identifying information from the transcripts and reviewed each transcript for accuracy.

3. Results

3.1. Characteristics of participants

Of the 106 doctors invited, 32 completed the interview. Seventeen doctors provided reasons for non-participation and this was primarily due to not having had participated in AD at the time of the study. Participant characteristics are summarized in Table 1. 14 doctors had acted in the coordinating role and two the coordinating role only, with half of participants (N = 16; 50%) having experience in both coordinating and consulting roles. On average, participants had been involved in 11 AD cases (median 6 cases, interquartile range 3-13.5). The duration of interviews ranged from 33 to 90 (median 62.5 minutes, interquartile range 55.2-77.5) minutes.

Table 1
Participant demographic and clinical characteristics (n = 32).

Participant characteristics	*N*	%
Sex		
Male	18	56
Female	14	44
Age (y)		
30-39	5	16
40-49	8	25
50-59	7	22
60-69	10	31
70-75	2	6
AD role		
Consulting only	2	6
Coordinating only	14	44
Both consulting and coordinating	16	50
Years of experience as a doctor		
6-10	3	9
>10	29	91
Years of experience as either vocationally registered GP or medical specialist		
1-5	5	16
6-10	4	12
>10	23	72
Specialty		
Anaesthetics	1	3
General Medicine	3	9
General Practice	12	38
Haematology	1	3
Nephrology	1	3
Medical Oncology	10	31
Radiation Oncology	2	6
Palliative Care	1	3
Surgery	1	3
Location (region)		
Major city	19	59
Inner regional	12	38
Outer regional	1	3

3.2. Thematic framework

Our analysis identified 5 major themes: a nascent approach to care, practising within clinical and legal uncertainty, confronting practices, personal sacrifices and coping amid new challenges. Fig. 1 illustrates that these 5 themes were expressed as a balance of competing tensions of identity for doctors who provided AD for their patients in practice. The themes and respective sub-themes are described below. Examples of participant quotations to illustrate each theme are shown in Supplementary Table 1.

3.2.1. A nascent approach to care

Minimizing uncertainty and burden at end of life. Participants expressed frustration about what they perceived as death becoming increasingly medicalized in Western countries and viewed AD as a profound method for countering situations where patients "linger" on undergoing invasive treatments, which they deemed undignified and overly challenging for family. Instead, AD was perceived as a more intimate, "holistic" and person-centered approach to care because it allowed patients to communicate their preferences to doctors and family until death. Participants believed AD was distinct from other areas of end of life care where discussions about prognosis are sometimes avoided to maintain patient hope, explicit consent is not usually obtained from patients and families for end of life procedures (e.g. "terminal sedation"), or invasive treatments are provided with little clinical efficacy. Participants also believed AD had sometimes improved the bereavement process for families, giving them "complete closure" because the person's death was "planned, calm, controlled and painless".

Challenging culture and belief in medicine. While some participants felt providing AD was simply an extension of their usual practice, others found it required them to contemplate and sometimes adjust their beliefs and expectations about treatment pathways at the end of life. Similarly, some participants believed the implementation of AD had also improved the introduction of conversations about goals of care at end of life because AD was at the "pointy end" of end of life care and prioritizes patient autonomy at its core, which served as a catalyst to improve other processes within the service (ie advance care planning). Participants reflected that prior to AD becoming legal they were not obligated to put their views on AD into action because it was not legally permitted. However, the introduction of AD placed pressure on some participants to decide about whether they would be willing to participate in AD, because one of their patients had requested it. Despite this, some participants were disappointed because they felt AD was still a taboo in health and described facing opposition from colleagues when attempting to provide AD for their patients.

The need for a regulatory framework. Because AD was irreversible and considered a "completely different concept" in medicine,

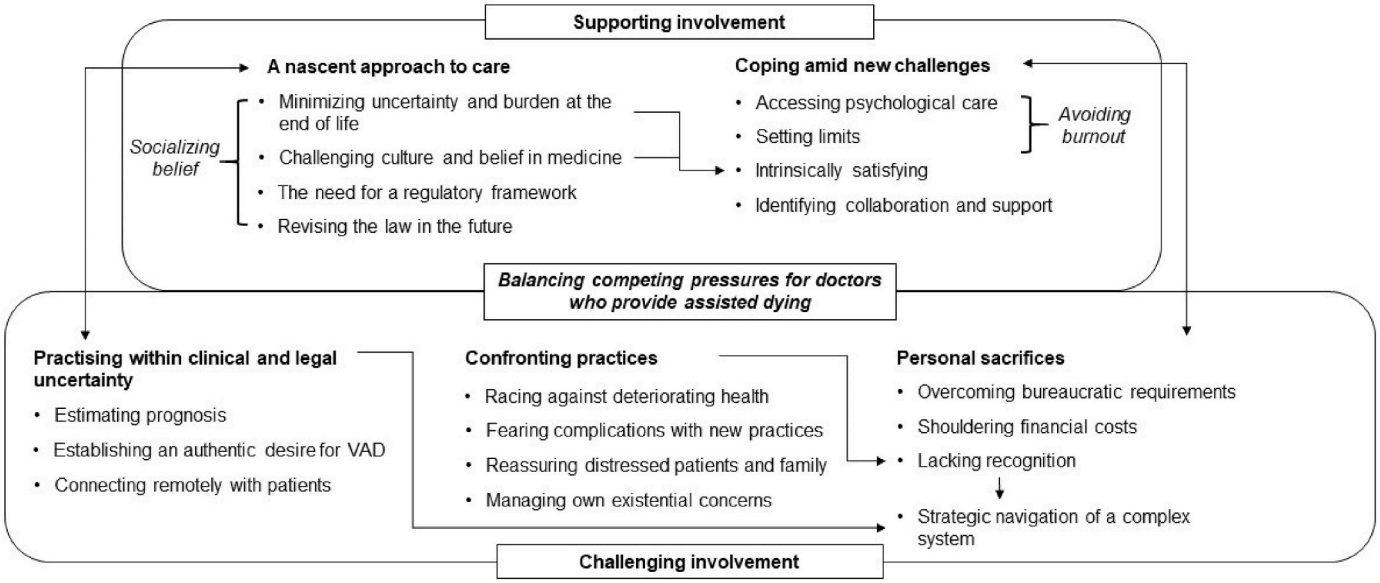

Fig. 1. Thematic schema of doctors' perspectives on participating in assisted dying.

participants deemed legal regulation surrounding AD as necessary. For some, this was because they believed having a legal framework minimized the potential of patients rushing into or being coerced into AD and deterred doctors from "stretching the rules" to allow ineligible patients to access AD. In addition, some participants believed having the requirement for a second doctor and the Voluntary Assisted Dying Review Board to review and confirm patient eligibility provided them greater legal protection, because accountability and the decision to approve AD was shared across multiple parties. Furthermore, the high-level of regulation, including a legislatively-structured assessment process, appeared to improve some participants' confidence that they were completing the process correctly and made it easier to refuse patients who were not eligible (i.e. because it was illegal).

Revising the law in future. Some participants highlighted various areas of the VAD Act that they believed should be revised in future to make it more practical and inclusive, however, a diversity of views were expressed in terms of which attributes should be changed and how those revisions should occur in practice. For the most part, participants supported making the implementation of the law more practical, but emphasized that any changes to the law needed to occur with caution because the system was completely new and they preferred instead to prioritize community safety over relaxing any eligibility criteria. However, some participants were frustrated by the safeguards and felt they had "an excess of caution", hoping that other Australian jurisdictions would take a less conservative approach to legalizing AD, and believed the VAD Act should be revised. Moreover, other participants, who similarly shared the view that any changes to the law needed to occur slowly, expressed their belief in the context of the political environment surrounding AD, believing that a diplomatic approach was needed to avoid a "slippery slope" argument being introduced in the community and challenging the legislation. Some suggestions for potential change in regulation were identified by participants included:

> *"AD is new and it should be treated with kid's gloves at the start and hopefully it becomes less regulated and less legalese with time, and becomes more practical. Because it's still very early, and impractical and clunky to implement to get done."* ID_29

> *"I'm hoping by the time I need it if I get dementia and I'm not able to have either a score for mental cognition, either a score less than whatever on two occasions a month apart or not recognizing my family or something. But that's down the track. I suppose in time advanced care directives should be able to be utilized for AD requests."* ID_21

3.2.2. *Practising within clinical and legal uncertainty*

Estimating prognosis. Participants expressed some ambivalence about having the legal requirement to estimate a patient's prognosis when assessing eligibility for AD (6 months or 12 months for neurodegenerative conditions). At a practical level, participants believed the timeframes were an "arbitrary cut-off" but more importantly they felt it was impossible to know when exactly a patient will die, acknowledging prognostication is an "inexact science". Hence, participants indicated they had discovered, as their patients' illnesses progressed, that they both under and overestimated prognosis in conducting eligibility assessments for AD. Some participants believed doctors had an "unconscious bias" and tendency to "tell patients good news" (i.e. the patient might live longer) to maintain hope for the future. Participants described needing to "make their best judgement" based on both the evidence (such as clinical trial outcomes or consultation with a colleagues/specialist), but also their "gut feeling" to estimate what happens on average. However, whilst acknowledging their own limitations, some still felt it was necessary to draw the line somewhere and others had no issue with this requirement in practice because of the patients who had requested AD, it was clear they would die within the timeframe.

> "The hardest eligibility requirement is the prognosis is less than six months because it's actually not that easy to say that, to really put a time frame on someone. And I refused one patient and said that her prognosis was longer than six months, and she died three months later. Now I just think that we think we know but we don't." ID_28

Establishing an authentic desire for AD. Some participants expressed little concern about assessing patient capacity and competence, reflecting it was part of their "day to day work" as a doctor and, for some, all of the patients who had requested AD were described as "articulate, sane and consistent" detecting no signs that patients were being coerced into AD. However, others found this process more complicated, such as when a patient's verbal or cognitive abilities had deteriorated during the assessment process, and they became restricted to nodding or tapping responses only (e.g. patients with motor neuron disease). This was because the various assessments required at each stage of AD sometimes took several weeks to complete and some patients, who were very close to death, inevitably lost the ability to speak

or experienced delirium before AD could be completed. Hence, some doctors had warned patients that if they developed "delirium and pain and confusion" they would have to "palliate the death in a different way than they had envisaged".

In addition, some doctors described their responsibility to probe and clarify a person's intent regarding AD and their ability to understand and "hold the information" to ensure they were fully informed about all the other options (including palliative care) and were not being coerced. Nevertheless, while expressing confidence in their assessments, some doctors also acknowledged it was impossible to truly know whether some outside influence was affecting the patient's decision to access AD:

> *"So you can't prove they're not being forced by someone else, but for most patients it seems pretty genuine that that's what they want to do. They seem reasonably passionate about making that decision and have clear cause to make that decision. So I haven't detected a hint of being forced by others. I accept that maybe I'm being duped, but I don't think that's the case."* ID_22

Connecting remotely with patients. Overall, participants wanted greater legal clarity regarding the guidance produced by the Department of Health and Human Services that discussions regarding AD must not occur using a "carriage service" (this would include by telephone, email or telehealth)(Victoria. Safer Care Victoria, 2020). This was because some participants had correctly identified that the requirement was not from the AD legislation, but from a federal law from 2005 that may prevent discussions regarding "suicide" using a carriage service. Hence, whereas some participants adhered to this requirement strictly; others questioned its applicability to their current practice and, in the context of COVID-19 and the additional logistical pressures this placed on doctors, patients and families, some doctors chose to ignore this requirement. Some participants justified their decision reflecting the "federal legislation was never intended to cover [AD]" and they were "happy to take the risk" believing it was unlikely the federal government would ever legally challenge them. In addition to concerns about potential legal implications of using a carriage service to discuss AD, some participants also felt the lack of clarity about the applicability of this law had caused some clinicians to become reticent and avoid discussions about AD, even with their colleagues, through a lack of understanding and fear about the legal penalties for discussing AD.

3.2.3. Confronting practices

Racing against deteriorating health. In contrast to circumstances when participants had assisted their patients to access AD, some doctors became "distressed" and encountered stressors when the patient's health had deteriorated much quicker than the request and assessment process took, even when everything was "done in the right time frame". This was because whilst participants understood administrative checks and reviews needed to take place, they also felt powerless from a clinical perspective to help their patients who were suffering and wanted to access AD, but who were also at high-risk of dying or becoming incapacitated before being approved access and receiving the medication, which sometimes took several weeks or more to occur. For example, participants believed that, despite their best efforts, the AD pharmacists were greatly under resourced causing significant delay from approval of AD to reception of the actual medication. As a result, participants had learnt to set "realistic expectations" with patients, cautioning them that they might not be able to access the medication before they die, and some refused to provide AD if they felt they patient would likely die within a 2-week period because it was too stressful and unlikely the patient would access the AD medication within that timeframe.

> "But the time from writing that prescription to delivering it to the [metropolitan hospital] and knowing that then my job is done, I find really quite stressful because I feel like sort of I'm the one that's holding up the process for the patient. I also feel quite responsible when – even when we try and go through everything and do it, and it's all done in the right time frame and nothing is held up, if the patient dies before the medication comes to them, I also carry that as well. I feel quite responsible for that, and I know I shouldn't, but I still do." ID_08

Fearing complications with new practices. Although none of the participants described an experience where either self-administration or practitioner-administration AD was unsuccessful, the practice also presented unexpected challenges and results that participants sometimes struggled with when first providing AD. Participants reported the duration to death for self-administration AD was unpredictable and varied from patient-to-patient, which caught some doctors by surprise initially, especially when the duration to death took several hours and family were present. In addition, two participants became fearful when their patients vomited after self-administering AD medication, initially worrying the medication "wouldn't be absorbed enough" for the patient to die but then finding it was still effective in both instances. Some participants (particularly GPs) also expressed fear and anxiety about practitioner-administration AD, such as not being able to access a vein because the patients are "often dehydrated", with some feeling unpractised inserting a cannula because the "nurses or junior doctors [usually] do that". This anxiety appeared to worsen when family were present because it put the attention on the doctor, when "it's supposed to be about the patient and their family", and not the doctor "fussing trying to get the syringe attached to the IV". Despite this, in practitioner administration, participants expressed relief once they "got the needle in" and reported it was a "smooth" process from there because "the person is asleep within seconds" using that approach.

Reassuring distressed patients and family. Some doctors felt personal responsibility to provide emotional support to patients and family to alleviate worry and guide them through the AD process. This included when patients expressed worry about complications occurring during AD or families becoming distressed if the death did not go as expected, such as when the self-administration medication took longer than expected to work or if the patient died before accessing AD. In addition, some family members found AD difficult because they had disagreed with the patient's decision to access AD. Support for family mainly involved being present at the death and to reassure them if the patient continued breathing longer than expected, had vomited after taking the medication or if they started to groan or make "choking noises" as they died. Despite this, some doctors felt this support only provided a "false confidence" to families when they too shared a lack of certainty about how the events were going to play out or because they recognized the patient would die whether a doctor was present or not. In addition, whilst one doctor believed it should not be mandatory for a doctor to be present when a person takes a medication (due to unnecessary delays); some participants reported that, without "providing that level of confidence", some family members would have struggled to cope emotionally during AD.

Managing own existential concerns. The introduction of AD and the requirements surrounding it required some doctors to question their own values and opinions, particularly when it came to providing practitioner administered AD. Participants described a challenging mental shift that was required from alleviating a patient's suffering to "deliberately" empowering them to "kill themselves", which appeared to lessen depending on how involved participants were in the overall process (e.g. acting in the consulting role versus administering the medication itself). Hence, practitioner administration AD appeared to be the greatest "mental hurdle" for participants because it was a "whole new ball game", with self-administration being "much more palatable" because the responsibility ultimately stayed with the patient. In addition, whilst no participants expressed regret about the role they had played in assisting their patients to die, some who had not yet had a patient eligible for practitioner administration, reflected they would not know their own personal comfort until they had been through the experience highlighting a risk that some might end up in a situation they

weren't mentally prepared for. Some participants described needing to undertake "intellectual exercises" such as compartmentalizing AD as something different from usual care or using "transference" to think from the patient's perspective to help them navigate these tensions.

> "But actually giving somebody an injection and they die on the end of the needle - I don't think that's right. I mean it's not right for me, so I don't know if I could do that [interviewee cries]" ID_17

3.2.4. Personal sacrifices

Overcoming bureaucratic requirements. Participants expressed frustration and anger about the AD request and assessment process, which mostly occurred through an online portal system, because they felt it was overly technical, administratively heavy and unintuitive and, for some, these requirements were identified as the biggest barrier in terms of their perceived ability to provide AD. Moreover, some believed this process was outside of their skill set or a "waste of their time" as a doctor, and wanted these processes to be completed by an administrative assistant before the doctor became involved in the process. Relatedly, participants were disappointed that the required AD training did not include a detailed explanation of these requirements or an overview of the portal, such that participants needed to learn as they encountered it for the first time. Some of the administrative challenges reported included: using incognito browsers, glitches on the portal, having to repeat the doctor's expertise at each assessment, identifying and scanning the patient's passport and rental and utility receipts, and amending spelling or signature errors on documents. Nonetheless, not all participants found navigating these requirements and the online portal system burdensome with doctors speaking about the coordinating role tending to discuss the logistical challenges of providing AD compared to those discussing the consulting role, which felt less demanding in these regards. In addition, some participants found the system "straightforward" or indicated that it became easier and more manageable over time and as they became more familiar with what was required.

Shouldering financial costs. Participants varied in their reported ability to receive financial compensation for AD and, as a result, being able to manage the provision of AD outside of their usual clinical practices, with some believing they had been unfairly "blackmailed" by the government to provide AD. This was because whilst legalizing the practice had compelled participants to provide AD on ethical grounds; it was also compromising from a resource allocation perspective, because funding to support the role was described as either unavailable, insufficient, or was considered insensitive to pursue (i.e. privately billing the patient). Hence, participants indicated that they had provided AD "pro bono", provided AD within an existing clinical role (such as a specialist at a hospital) and one doctor reported privately billing patients for AD. For the doctors providing AD without reimbursement, this was because (particularly older GPs) they were "semi-retired" or had decided to provide it in their "free time" because they believed was the right thing to do for their patients. However, for those who were able to provide AD within an existing role, some expressed concern that it was taking away time from this role, especially those who had a greater number of referrals for AD, because it was not formally part of their role to provide AD.

> "They are basically emotionally blackmailing us to do this for free. Because they know that if we've been looking after these patients for a while, or if another clinician comes to us who can't do it or won't do it, we take these patients on and then they basically expect us to do it for free or in our own time."ID_16

In addition, some reflected on an "irresolvable" tension - that although doctors deserve compensation for AD, that reimbursement should not be too attractive to avoid the doctors who "only do stuff for money" becoming interested in providing AD for financial gain:

> "… nobody gets remunerated for it. It's all pro bono. Which it has to be because you don't want to put a financial incentive to doctors. It's not a major thing for me. But it would color the number of doctors - it will influence the number of doctors that take on this mantel."ID_14

Lacking recognition. As a result of the various logistical and emotional challenges participants needed to overcome during AD, some participants expressed discontentment, believing the government either lacked an appreciation for how to support clinical staff in the implementation of AD, or that they did not care about how it was impacting them personally. In addition, some felt it was easier for a government entity to legislate and develop and monitor an AD system, compared to the clinical staff who are responsible for making the AD system function within a set of defined parameters, which they felt is a more difficult task to complete in practice. Hence, some participants believed politicians would be "horrified" if they were required to witness some of the challenges experienced by patients when navigating the system, and some indicated they would not participate in AD again or were unsure about whether they would participate in AD again in the future because it was too difficult to provide AD in practice.

> "There's all the stuff we normally do. So it's just something else to add to the burden of what we do [cries]. Again that's one of the reasons why it makes it so hard when I feel unappreciated by the government, which obviously isn't a person. So they've enacted this and they don't really give a shit about us." ID_17

Strategic navigation of a complex system. Whilst participants believed it was necessary to have legislation surrounding AD and an implementation framework, they also reflected on what they perceived were the limitations of attempting to legislate medicine in practice. This included the AD system requiring participants to make "black and white" judgements about patient eligibility when the reality of medicine was grey, and some participants felt the law could only ever provide "an appearance of safety" because doctors were "expert in manipulating rules for patients". Similarly, while no participants had attempted to or expressed a desire to work around the fundamental requirements of the VAD Act (e.g. giving non-eligible patients access to AD), some shared they had challenged what they perceived were some of the more flexible procedural requirements of the system, if they felt it was in the best-interests of their patient. An example was initiating a discussion with patients about AD in a "roundabout way", when such raising the topic of AD is prohibited by Victorian law. Although some participants suggested that some of these practices might be questionable "from a legal perspective" and the circumstances were not ideal, they also felt comfortable they "had a pretty good case to argue" because the boundaries of the law had not been tested yet or the current system was illogical and would eventually be revised.

> "The legislation is providing an appearance of safety because people have to go through some hoops, but doctors are the expert in manipulating rules for patients. We will, if we think it's in the best interests of the patients, and the rules are slightly flexible, we will navigate through that to support the patient." ID_25

3.2.5. Coping amid new challenges

Accessing psychological care. Whilst participants reported administrative support being available during the AD process; formal "emotional and wellbeing support" was identified as either unavailable or inadequate. GPs and doctors practising in regional locations tended to refer to AD as more of an "isolating" or lonely experience compared to doctors working in metropolitan locations or within large hospitals, who appeared to benefit from having other doctors or teams to debrief with in their daily work environment. Despite this, participants described communication from the Voluntary Assisted Dying Review Board as officious and impersonal, with some perceiving an air of secrecy surrounding the program, and hence some described facilitating AD was an

"isolating experience". Instead, participants desired a formal check-in mechanism, to see if they were experiencing any problems during the process, and an opportunity to debrief at various stages of the program. Hence, participants sought out other means of support during AD, such as through existing counselling services at their health services, colleagues or family and friends; whereas some doctors reflected they "just cope, soldier on and get onto the next job".

> *"But I think for a lot of us we found it fairly traumatic. I mean I had anxiety I didn't actually recognize as anxiety until it was over. Then I thought, oh that ulcer that I thought I had has just miraculously gone away, oh this is anxiety. So I had daily anxiety for four months trying to get this organized."* ID_26

> "*So in terms of taking care of myself? So there hasn't been any care offered that way. So I've derived my care usually from my wife, and also from talking through with some members at my local church. I suppose just a rain check really, how are you going? It is quite intensely emotional. You need to have psychological support as you're doing it, and know exactly where you should get that from."* ID_30

Setting limits. Because of the ethical, emotional, and logistical challenges brought on by participating in AD, some participants acknowledged needing to place restrictions on their level of involvement describing some scenarios they felt uncomfortable with or were unable to manage alongside their other duties. Some doctors indicated they would not coordinate AD for unknown patients from the community because they felt having a relationship improved their confidence they were "making the right decision" and because the "practicalities of [completing AD] was so time consuming" that they found they needed to complete it outside of work hours. Hence, some doctors shared that they did not "advertise the fact" that they had completed the training to avoid a "walk in service". Moreover, for some doctors, practitioner administration AD was a practice they were unwilling to provide because it conflicted with their personal values and was considered "one step closer" to causing the patient's death, which they would not feel comfortable with. Whereas, some participants, indicated they would provide practitioner administration AD but only if they had "known the patient for a long time" and felt "it was the right thing to do".

Nonetheless, some participants appeared to struggle balancing the need to "take care of [themselves]" and saying no "to disadvantaged people who are currently in need", despite the logistics and travel taking "a personal toll from a personal life, work-life balance, family life point of view". This issue was primarily because of the low number of medical specialists involved in providing AD, particularly in the initial months of implementation, which they hoped would improve over time so that the case load would fall on more doctors.

> "I don't say no. If a patient navigator calls me and says I need someone to assess a patient, I don't say no. My internal monologue has been screaming sometimes saying this just isn't fair and perhaps I need to say no, so that it puts pressure on the development of the system so that it's not being propped up by one person. But I think in order to do that, I have to disadvantage people who are currently in need, which I just can't do." ID_01

Intrinsically satisfying. While AD presented emotional and logistical challenges for participants, it was also deemed as a rewarding experience, albeit "strangely" rewarding for some. AD required participants to have in-depth discussions about what was "vital" to the person and led some to develop intimate relationships with patients and families, which some felt was unique to AD compared to other areas of end of life care. In addition, doctors felt providing AD was consistent with "being a good doctor" and they found it gratifying because they felt that they played a pivotal role in supporting patients to take control of their lives, avoid suffering and maintain dignity during "really difficult times". In addition, because the symptoms and existential distress had become so intolerable for patients accessing AD, some participants believed being approved for AD provided them a renewed sense of hope and optimism about the future. Yet participants sometimes held mixed feelings about facilitating AD because it involved an approach to death and dying considered very "surreal" or somewhat foreign compared to their usual practices. This included "bluntly" discussing a patient's end of life journey or to "set a date" for when taking the AD medication will occur. However, facilitating AD was broadly described as something that becomes "easier once you become more familiar with the process".

> "… just knowing that we did actually do what he wanted and he did it with a lot of dignity and his contact person in the tuxedo and champagne, that's sort of a nice thing. If I wasn't involved, it would have never happened and he would have died a miserable, long, prolonged death in hospital. So that's a lot of reward." ID_27

Identifying collaboration and support. Despite a lack of formal support identified by participants and some feeling disconnected to other doctors who provided AD, the AD navigators and pharmacists (funded by the Victorian Government) were felt to counter this by serving as mentors, the "key communicators" between all involved parties and providing logistical and administrative assistance to doctors. Thus, participants believed these roles were essential to the successful operation of the current AD program and "the process would fall down" without them. Some participants also indicated the AD pharmacists and navigators had taken on initiatives outside of their role to improve the quality of the AD system, based on feedback from doctors, patients and families. Types of support included: pharmacists identifying the need to provide cannulas to doctors providing practitioner administration and the navigators developing a "checklist" to remind doctors of the administrative requirements (e.g. date of birth of contact person) needed when applying for an AD permit, assisting patients to gather the documentation required for the Voluntary Assisted Dying Review Board to be able to approve access to AD and identifying specialists with relevant experience to be the second consulting doctor.

> "… they've all actually come via the navigators, and I find them fantastic. Oh my God, without the navigators I don't think there would be a system. I think it's having a human. I think the fact that you can't get through to a human on the portal is amazing." ID_04

4. Discussion

The AD legislation involved various competing tensions of identity for doctors who had provided AD during its first 12 months of operation, and for the field of medicine more broadly. Overall, doctors found the experience intrinsically satisfying when it involved empowering patients, who were suffering from incurable illness, to take control of their lives and maintain dignity. Moreover, while a highly regulated system involved an unusual and sometimes onerous amount of bureaucracy, it also improved doctors' confidence that they were acting lawfully and required them to have structured and in-depth conversations with patients and families about their treatment preferences, which some felt was unique to the experience of providing AD compared to other areas of end of life care. Hence, some doctors believed AD had challenged the usual end of life care conventions by minimizing uncertainty and burden at end of life and maximizing the opportunity for patients to take responsibility for the nature of their treatment at the end of life. Yet AD was also sometimes confronting for doctors to provide if they felt powerless racing against the patient's deteriorating health in a bureaucratic system, feared complications with new practices (e.g. practitioner administration AD) or struggled to manage their own existential concerns, such as making a conceptual leap from alleviating a person's suffering to deliberately assisting a person to die.

Although the legalization of AD requires regulatory, ethical, social and bureaucratic practices and multiple interdependent roles, it remains relatively under theorized in the social science literature (Buchbinder,

2018). However, a recent qualitative study from Canada used moral identity theory to explore how the introduction of AD impacted palliative care nurses as moral agents, showing that they navigated multiple and sometimes conflicting ethical positions and this challenged a broader narrative about the incompatibility of AD and palliative care (Wright et al., 2021). Similarly, some doctors in our study experienced moral conflict of identity, especially whilst navigating existential concerns about administering AD. Yet, for participants in our study, assisting patients to access AD was not only discussed as an ethical practice, it also involved multiple identities with varying sources of meaning, and these identities were sometimes overlapping depending on context.

For decades, social scientists have theorized about identity in two parallel but closely related directions (Hogg et al., 1995). The first, identity theory, has focussed more on role (what one does) as a basis for identity and, the second, social identity theory has viewed the group (who one is) as the basis for identity. These two theories have increasingly been considered more similar than different, and attempts have been made to link the two by integrating external social structures and the structure of the self (Stets and Burke, 2000; Stryker and Burke, 2000). Broadly, our findings may support the perspective of Stryker and colleagues given that group-based, role-based and personal identities all provided different sources of meaning to participants, and these identities could be viewed as reinforcing or conflicting with each other.

At the macro-level, group-identity seemed most important when participants reflected on themselves as actors within the broader health system, and if they believed other group members (e.g. in government or the medical landscape) did not view situations from their perspective. Encouragingly, however, participants in our study consistently referred to State funded AD navigators and pharmacists as essential to their ability to navigate the complex system, such as through mentoring and administrative assistance and by having a human to discuss their experiences with. Nonetheless, and whilst noting participants inevitably held multiple identities navigating AD, role-based identities appeared to be more common than group-based identities for doctors in our study.

A major tension was not just how doctors' perceptions impacted their own wellbeing and satisfaction, but also how these challenged their continued involvement in AD and, therefore, the system's overall ability to function. In addition, these perceptions appeared to be influenced by other evolving and sometimes dynamic factors surrounding the implementation of AD, such as their perception that it was feasible for them to work with this law based on their past and anticipated future experiences and that it may involve some personal sacrifices during the process. Identity theory proposes that self-verification is important in all encounters and broadly defines resources as dynamic processes that sustain self-verification. Similar to recent studies of doctors who provide AD in Canada (Beuthin et al., 2020; Khoshnood et al., 2018; Oczkowski et al., 2021) and using an identity theory framework (Stryker and Burke, 2000), doctors in our study drew from multiple self-sustaining resources (personal, interpersonal and structural) and some had decided to set limits on or questioned their continued involvement in AD in order to avoid burnout. This was despite the experience of providing AD being described as rewarding, albeit strangely rewarding for some, such as when patients were able to successfully navigate the complex system.

4.1. Strengths and limitations

In our study, we used purposive sampling to gain a broad range of perspectives and beliefs of doctors who have facilitated AD in the first 12 months since becoming legal in Victoria. We interviewed key informants, that is, coordinating and consulting doctors involved in AD because they have the most involvement in the request and assessment process for patient who request AD. In addition, to ensure that our analysis captured the range and depth of the data collected, we sent transcripts to participants to make any further comments or amendments (member checking) and used investigator triangulation when formulating the preliminary themes from the transcripts. However, our study has some potential limitations. The transferability of these findings to other jurisdictions where AD is legal is unknown, such as how they relate to other health care systems with variation in AD legal requirements and systems. In addition, our study reports on the VAD Act within its first 12-months of operation and some of the systems involved in facilitating AD or mechanisms to obtain support may have changed for doctors since the study was conducted. Despite this and as highlighted above, our findings have some similarities to studies published in the US and Canada where AD is also legal, such as relating to AD resources and systems to support doctors involved in AD and the need to avoid burnout in this cohort (Beuthin et al., 2020; Khoshnood et al., 2018; Oczkowski et al., 2021).

5. Conclusions

The legalization of AD in Victoria, as well as an evolving culture in medicine, socialized the belief that AD is an emerging approach for improving existing end of life outcomes, such as to minimize uncertainty and burden at end of life and facilitate patient choice in end of life care. The experience of providing AD appeared to involve multiple identities with varying sources of meaning, and these identities were sometimes overlapping depending on the context. A greater recognition of the different role-based and group based challenges and the need for multiple self-sustaining resources (personal, interpersonal and structural), including how the introduction of AD can impact doctors emotionally, financially and socially, may improve AD implementation strategies.

Author contribution

Conceptualization: Lindy Willmott, Ben White, Patsy Yates. Methodology: Lindy Willmott, Ben White, Patsy Yates, Marcus Sellars. Formal analysis: Marcus Sellars, Lindy Willmott, Ben White. All authors contributed to writing and revising the manuscript. None of the authors have any conflict of interests regarding this manuscript.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2021.114568.

References

Beuthin, R., Bruce, A., Hopwood, M.-c., Robertson, W.D., Bertoni, K., 2020. Rediscovering the art of medicine, rewards, and risks: physicians' experience of providing medical assistance in dying in Canada. SAGE Open Med. 8, 2050312120913452.

Blaschke, S.-M., Schofield, P., Taylor, K., Ugalde, A., 2019. Common dedication to facilitating good dying experiences: qualitative study of end-of-life care professionals' attitudes towards voluntary assisted dying. Palliat. Med. 33 (6), 562–569.

Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3 (2), 77–101.

Braun, V., Clarke, V., 2020. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qual. Res. Psychol. 1–25.

Buchbinder, M., 2018. Choreographing death: a social phenomenology of medical aid-in-dying in the United States. Med. Anthropol. Q. 32 (4), 481–497.

Buchbinder, M., Brassfield, E.R., Mishra, M., 2019. Health care providers' experiences with implementing medical aid-in-dying in Vermont: a qualitative study. J. Gen. Intern. Med. 34 (4), 636–641.
Chief Parliamentary Counsel, Victoria, 2017. Voluntary Assisted Dying Act 2017 (Vic) https://content.legislation.vic.gov.au/sites/default/files/2020-06/17-61aa004%20authorised.pdf.
Corbin, J.M., Strauss, A., 1990. Grounded theory research: procedures, canons, and evaluative criteria. Qual. Sociol. 13 (1), 3–21.
Crumley, E.T., Kelly, S., Young, J., Phinney, N., McCarthy, J., Gubitz, G., 2021. How is the medical assistance in dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study. BMJ Open 11 (7), e048698. https://doi.org/10.1136/bmjopen-2021-048698.
Dobscha, S.K., Heintz, R.T., Press, N., Ganzini, L., 2004. Oregon physicians' responses to requests for assisted suicide: a qualitative study. J. Palliat. Med. 7 (3), 451–461.
Emanuel, E.J., Onwuteaka-Philipsen, B.D., Urwin, J.W., Cohen, J., 2016. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. Jama 316 (1), 79–90.
Ho, A., Joolaee, S., Jameson, K., Ng, C., 2021. The seismic shift in end-of-life care: palliative care challenges in the era of medical assistance in dying. J. Palliat. Med. 24 (2), 189–194.
Hogg, M.A., Terry, D.J., White, K.M., 1995. A tale of two theories: a critical comparison of identity theory with social identity theory. Soc. Psychol. Q. 255–269.
Khoshnood, N., Hopwood, M.-C., Lokuge, B., Kurahashi, A., Tobin, A., Isenberg, S., Husain, A., 2018. Exploring Canadian physicians' experiences providing medical assistance in dying: a qualitative study. J. Pain Symptom Manag. 56 (2), 222–229 e221.
King, N., Horrocks, C., Brooks, J., 2018. Interviews in Qualitative Research. Sage.
Kitto, S.C., Chesters, J., Grbich, C., 2008. Quality in qualitative research. Med. J. Aust. 188 (4), 243–246.
Kuper, A., Lingard, L., Levinson, W., 2008. Critically appraising qualitative research. Bmj 337.
Mathews, J.J., Hausner, D., Avery, J., Hannon, B., Zimmermann, C., Al-Awamer, A., 2021. Impact of Medical Assistance in Dying on palliative care: a qualitative study. Palliat. Med. 35 (2), 447–454.
McDougall, R., Hayes, B., Sellars, M., Pratt, B., Hutchinson, A., Tacey, M., Detering, K., Shadbolt, C., Ko, D., 2019. 'This is uncharted water for all of us': challenges anticipated by hospital clinicians when voluntary assisted dying becomes legal in Victoria. Aust. Health Rev. 44 (3), 399–404.
Oczkowski, S.J., Crawshaw, D., Austin, P., Versluis, D., Kalles-Chan, G., Kekewich, M., Curran, D., Miller, P.Q., Kelly, M., Wiebe, E., 2021. How we can improve the quality of care for patients requesting medical assistance in dying: a qualitative study of health care providers. J. Pain Symptom Manag. 61 (3), 513–521 e518.
Onwuteaka-Philipsen, B., Willmott, L., White, B.P., 2019. Regulating voluntary assisted dying in Australia: some insights from The Netherlands. Med. J. Aust. 211 (10), 438–439.
Oregon. Public Health Division. Center for Health Statistics, 2020. Oregon Death with Dignity Act 2019 Data Summary https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year22.pdf.
Patton, M.Q., 1990. Qualitative Evaluation and Research Methods. SAGE Publications, inc.
Philip, J., Holmes, A., Benson, M., Boughey, M., Yoong, J., Clinch, A., Moran, J., 2020. Palliative care physicians' preparation and planning for the implementation of the voluntary assisted dying Act in Victoria. Intern. Med. J.
Premier of Victoria The Hon Daniel Andrews, 2017. Voluntary Assisted Dying Model Established Ahead of Vote in Parliament. https://www.premier.vic.gov.au/voluntary-assisted-dying-model-established-ahead-vote-parliament.
Safer Care Victoria, Victoria, 2020. Voluntary Assisted Dying Review Board. Report of Operations January-June 2020 https://www.bettersafercare.vic.gov.au/sites/default/files/2020-08/VADRB_Report%20of%20operations%20August%202020%20FINAL_0.pdf.
Safer Care Victoria, Victoria, 2021. Voluntary Assisted Dying Review Board. Report of Operations July–December 2020 https://www.bettersafercare.vic.gov.au/sites/default/files/2021-02/VADRB_Report%20of%20operations%20Feb%2021_FINAL.pdf.
Stets, J.E., Burke, P.J., 2000. Identity theory and social identity theory. Soc. Psychol. Q. 224–237.
Stryker, S., Burke, P.J., 2000. The past, present, and future of an identity theory. Soc. Psychol. Q. 284–297.
Tong, A., Sainsbury, P., Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int. J. Qual. Health Care 19 (6), 349–357.
White, B.P., Del Villar, K., Close, E., Willmott, L., 2020. Does the voluntary assisted dying act 2017 (VIC) reflect its stated policy goals? Univ. New South Wales Law J. The 43 (2), 417–451.
Willig, C., 2013. Introducing Qualitative Research in Psychology. McGraw-hill education, UK).
Wright, D.K., Chan, L.S., Fishman, J.R., Macdonald, M.E., 2021. "Reflection and soul searching": negotiating nursing identity at the fault lines of palliative care and medical assistance in dying. Soc. Sci. Med. 114366.

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Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitators

Ben P White, Ruthie Jeanneret, Eliana Close, Lindy Willmott

The known: Australian doctors involved in voluntary assisted dying have identified access barriers, including legal prohibition of telehealth consultations and raising the topic with their patients, and procedural complexity.

The new: The experiences of family caregivers of people seeking voluntary assisted dying in Victoria confirmed barriers previously identified by doctors, but also identified new problems, including institutional objection. People can nevertheless navigate the process, partly shielded from system complexity by key facilitators, including care navigators, coordinating doctors, and the Statewide Pharmacy Service.

The implications: Adequate support for doctors, navigators, and other facilitators of access is vital for the efficient functioning of the voluntary assisted dying application process.

Abstract

Objectives: To investigate barriers to and facilitators of access to voluntary assisted dying in Victoria under the *Voluntary Assisted Dying Act 2017* (Vic).

Design, setting, participants: Qualitative study; semi-structured interviews with people who had applied for voluntary assisted dying or their family caregivers, recruited via social media and interested advocacy groups; interviews conducted 17 August – 26 November 2021.

Main outcome measures: Barriers to and facilitators of access to voluntary assisted dying.

Results: We interviewed 33 participants about 28 people who had applied for voluntary assisted dying; all but one of the interviews were with family caregivers after their relatives' deaths, and all but three were conducted via Zoom. The major barriers to access identified by participants were finding trained and willing doctors to assess eligibility for voluntary assisted dying; the time required for the application process (especially given how ill the applicants were); the prohibition of telehealth consultations; institutional objections to voluntary assisted dying; and the prohibition of health practitioners raising voluntary assisted dying with their patients. The major facilitators mentioned were care navigators (both the Statewide service and local navigators); finding a supportive coordinating practitioner; the Statewide Pharmacy Service; and system flow once the process had been initiated (although not during the early days of voluntary assisted dying in Victoria). Access was particularly difficult for people in regional areas or with neurodegenerative conditions.

Conclusions: Access to voluntary assisted dying has improved in Victoria, and people generally felt supported while navigating the application process once they found a coordinating practitioner or a navigator. But this step, and other barriers, often still made patient access difficult. Adequate support for doctors, navigators and other facilitators of access is vital for the effective functioning of the overall process.

Legislation permitting voluntary assisted dying has been enacted in all Australian states; the territories may follow suit now the Australian government no longer prohibits them doing so.[1] The application process for voluntary assisted dying must be sufficiently rigorous to exclude people who are ineligible, but provide choice for those who are eligible.[2]

There is a growing body of literature on doctors' early experience in Victoria, the first Australian state to enact voluntary assisted dying legislation. They reported procedural difficulties, including complex and bureaucratic approval processes[3-6] and legal challenges, such as the prohibition of initiating conversations with patients about voluntary assisted dying[3] and federal criminal law restrictions on telehealth consultations for this purpose.[3,7-8] However, the experience of people seeking assistance to die has not been reported. Their perspectives, central to improving health care and person-centred care,[9] are critical when evaluating how voluntary assisted dying is managed.

Overseas investigations of the personal experience of voluntary assisted dying have examined communication during eligibility assessments[10-11] and the factors underlying applications for assisted dying.[12-16] Procedural barriers to and facilitators of access, as reported by people seeking assistance and their caregivers, have also been reported.[10,17-21]

Given the lack of research in Australia, we investigated the early experiences of people seeking an assisted death under the *Voluntary Assisted Dying Act 2017* (Vic),[22] focusing on barriers to and facilitators of access.

Methods

We report our study according to the Consolidated Criteria for Reporting Qualitative Research (COREQ).[23] Eligible for participation were people seeking voluntary assisted dying in Victoria and family caregivers who had supported a person during this process. We recruited participants via Twitter (@HealthLawQUT; 11 August, 12 and 19 October 2021) and through the advocacy groups Go Gentle Australia (https://www.gogentleaustralia.org.au) and Dying with Dignity Victoria (https://www.dwdv.org.au), who circulated study details via social media and in their newsletters and emails (recruitment requests to these organisations: 4 August 2021). We initially employed convenience sampling, but later (from 19 October 2021) used purposive sampling to obtain a broad representation of voluntary assisted dying applicants[24] with respect to age, gender, illness, location (metropolitan or regional), date of application for assistance, and their experience of voluntary assisted dying (died using self- or practitioner-administered medication, sought voluntary assisted dying but had not proceeded, or were not approved). Later recruitment communications included

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the specific participant characteristics sought, including direct emails from the two advocacy groups to potentially matching participants (recruitment request to the organisations: 22 October 2021).

Our interview guide (Supporting Information) was based on our analysis of the Victorian legislation,[2] interviews with doctors,[3-5] and discussions within the research team. The questions explored were the process of seeking access to voluntary assisted dying, including obtaining information, eligibility assessment, and obtaining and taking the medication used; navigating the voluntary assisted dying application process; and overall perceptions of the process. Interviews explored the applicants' experiences of seeking voluntary assisted dying; family caregivers were therefore asked to focus on their relatives' experiences.

All semi-structured interviews were conducted by authors BPW and RJ (with one a designated lead) during 17 August – 26 November 2021 as Zoom video conferences, except for two undertaken by telephone and one in person. Recruitment ceased once data saturation had been reached (information redundancy).[25] Interviews were digitally audio-recorded and transcribed verbatim. Participants could amend their transcript (member checking),[26] and some provided supplementary information at this point (eg, chronology or narrative of their experience).

We used NVivo 1.6.1 (QSR International) to store, code, and search transcripts and supplementary information. Thematic analysis was applied line by line, using codes developed deductively (based on relevant publications and iterative discussion of emerging themes) and inductively.[27] Seventeen interviews were coded by BPW and RJ (codes discussed and refined periodically), eleven by BPW alone. Authors BPW and RJ discussed each interview after its completion, and regularly conferred during the data collection and analysis phases of the study (iterative analysis). Themes were discussed and tested by all authors.

Ethics approval

Our study was approved by the Queensland University of Technology Human Research Ethics Committee (2000000270). Each participant provided informed consent in advance.

Results

We interviewed a total of 33 participants (Box 1) about 28 people who had applied for voluntary assisted dying (Box 2). All but one of the interviews were with family caregivers after their family members' deaths; one of the two applicants for voluntary assisted dying who had consented to participation died before they could be interviewed. Eight participants were recruited during the purposive sampling period. The median length of the interviews was 90 minutes (range, 56–130 minutes).

Barriers to access to voluntary assisted dying (Box 3)

Difficulty finding doctors

The main barrier to access was finding doctors willing to assist people seeking voluntary assisted dying. Identifying a coordinating practitioner (the first doctor in the process) was particularly difficult. This was especially the case when the process was new in Victoria; it was all "secret squirrel business", and no list of doctors who might be willing to assist was available.

Participants said that the difficulty in finding doctors was related to the need for one doctor to be a specialist in the illness of the applicant; conscientious objection; apprehension with regard to involvement or a lack of interest in voluntary assisted dying; and doctors not having completed or wanting to undertake the legally required training. People with neurological conditions or living outside metropolitan areas often mentioned these problems.

The time required for the voluntary assisted dying application process

Procedural delays were particularly frequent during the early days of voluntary assisted dying in Victoria, and were often linked with the difficulty of finding doctors willing to assist. Delays were greater for people living in regional areas. Participants recognised that a rigorous assessment process was needed, but many felt it took "too long" and was "overdone", and was "a complicated and drawn-out undertaking".

The time involved was particularly problematic given the physical condition of applicants for voluntary assisted dying; to be eligible, clinical expectation of death within six months (twelve months for people with neurodegenerative conditions) is required. This prerequisite was identified by many participants as needing revision. Concerns were expressed about "missing the boat", and many participants referred to the "race" to gain access to voluntary assisted dying before the applicant died, became too unwell to navigate the system, or lost the capacity or ability to communicate. For some people, late awareness of the short time remaining to them compounded their access problems.

However, some participants described the process as proceeding "really quickly". Perceptions of time could be influenced by expectations of the time required for the application process, the urgency of the need for access to voluntary assisted dying, and levels of suffering: "every day felt like a month".

Telehealth prohibition

The prohibition of using telehealth consultations during the voluntary assisted dying process was an "absolute pain", causing delays and suffering, leaving people "in tears and distressed and [in] hysterics". Although this problem was often raised by people in regional areas, metropolitan participants were also concerned about requiring very unwell people to travel. The widespread use of telehealth during the coronavirus disease 2019 (COVID-19) pandemic compounded participants' sense of its prohibition being unjustified. They did, however, acknowledge the limits of telehealth care and that its use in voluntary assisted dying should be cautious. Some thought it appropriate after a first in-person consultation, while others noted challenges for conducting some neurological assessments and for people with communication difficulties.

Institutional objection

Institutional objections were identified as access barriers for seventeen applicants for voluntary assisted dying, including institutions prohibiting eligibility assessments and barring entry to assessing doctors. Some institutions prohibited receiving or using the voluntary assisted dying medication provided by the Statewide Pharmacy Service[28] on their premises.

These objections led to delays and reduced choice. Some participants described relatives having to choose between pursuing voluntary assisted dying and being admitted to a

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1 Characteristics of the 33 interviewees

Characteristic	Number
Age (years), mean (SD)	56.6 (15.1)
20–29	1
30–39	4
40–49	7
50–59	3
60–69	13
70–79	4
80–89	1
Gender	
Women	26
Men	7
Relationship to person seeking voluntary assisted dying*	
Child (including stepchild, child in-law)	17
Spouse (including de facto partner)	10
Parent	3
Sibling	2
Close friend	1
Self	1

SD = standard deviation. * One participant spoke about two people and is included here in two categories. In five interviews, two family caregivers were interviewed together (eg, a son and daughter-in-law about the son's parent's experience). Two interviews were conducted with different family members separately about the same person. ◆

2 Characteristics of the 28 people whose experiences of seeking voluntary assisted dying were discussed in the interviews

Characteristic	Number
Age (years), mean (SD)	70.8 (15.4)
20–29	1
30–39	1
40–49	0
50–59	3
60–69	7
70–79	8
80–89	6
90–99	2
Gender	
Women	13
Men	15
Location	
Metropolitan	16
Regional*	12
Highest level of education	
Some high school	7
High school	9
University (diploma)	1
University (undergraduate degree)	7
University (postgraduate degree, including graduate diploma)	4
Primary disease, illness, medical condition	
Cancer	18
Neurological	9
Other	1
Time of voluntary assisted death or engagement with process	
July–December 2019	4
January–June 2020	6
July–December 2020	3
January–June 2021	10
July–November 2021	5
Outcome of assessment	
Assessed as eligible for voluntary assisted dying	24
Death by self-administered medication	19
Death by practitioner administered medication	3
Natural death	1
Person waiting to take medication	1
Assessed as ineligible; died	1
Death prior to completing eligibility assessment	3

SD = standard deviation. * One person classified as regional moved to a metropolitan area during the voluntary assisted dying process. ◆

hospital that did not support this aim to have their pain and symptoms managed. Some had to leave their current place of care (their "so-called 'home'" in the case of people in residential aged care facilities) to gain access, but this depended on alternatives being available.

Participants also described emotional and relationship costs of institutional objections. Some people were "terrified" about missing out, and delays and reduced choice caused "distress" and "great sadness". Some felt distrust for the institution and staff in terms of clinical recommendations, and one participant described pursuing the voluntary assisted dying process in secret.

Prohibition of health practitioners initiating discussion of voluntary assisted dying

Participants generally found problematic the prohibition of health practitioners raising the option of voluntary assisted dying with their patients. Although they understood that the intent was to ensure free choice, most were concerned that doctors were "muzzled" or "silenced". Some people found it difficult to raise the subject with their doctors, and others described conversations that were "awkward and a bit contorted" as they tried to find "the right words". Concerns were repeatedly expressed about the prohibition particularly reducing access for people from culturally and linguistically diverse backgrounds, and people with lower levels of education or poorer technology and information literacy: "If you're not exposed to it, you don't know to ask."

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3 Sample comments by participating family caregivers about barriers to access to voluntary assisted dying

Difficulty finding doctors

- [The doctor] was just matter of fact about it and said "Look, I can't do it." … when I asked him, "Well, do you know if there's any other doctors at the hospital?" … he said he would try to help, and he did try to help. Unfortunately, he then encountered the same hurdles that we encountered of no knowledge, no public registers, and there wasn't necessarily another person for him to refer us to.
- [The doctor] took up the issue [and] must have written to several dozen neurologists over several weeks outlining and requesting the need for assistance. Many never answered, others responded to say that they were objectors and others just said they were unavailable. One made an appointment … without realising the purpose and this was later quickly withdrawn. There was no data provided by anyone as to a list, for example, of specialists who might be available.

The time required for the voluntary assisted dying application process

- Like the whole process, every day just seemed like a month and every other appointment just seemed like another hurdle to jump over and another hoop to go through and another boulder to climb to get to the top of the mountain. So retrospectively, you know, all those processes needed to happen, and I get that. At the time it all just seemed like … another stage to go through.

Telehealth prohibition

- Certainly for mobility-related neurological degenerative diseases, and anything else really, the inability to telehealth is just horrendous. I mean I am supportive of a face-to-face consultation, and potentially the first one, but we were restricted in all those other times of not being able to use telehealth. Growing up in [Town], that's six and a half hours from Melbourne. You know, if you're going to tell people they can't access this medication until they're within zero to six months of dying … they're potentially ruling out all their travel time to be able to make these interviews … if we're not allowed to use telehealth.

Institutional objection

- [That] was a significant challenge and just created a whole lot of stress on what was her last day. You know, it was this frantic rush and … then having to wheel her out and she couldn't say goodbye to people. Yeah, it just was just [laughs] … you get to the top of the mountain and then you've got that last big, huge boulder to climb over. It will always be a great sadness for me that the last few precious hours on Mum's last day were mostly filled with stress and distress, having to scurry around moving her out of her so-called "home".
- She was a doctor from [another hospital], she was there to see a patient on the patient's request, she should have been allowed in and they actively stopped her.

Prohibition of health practitioners initiating discussion of voluntary assisted dying

- I think it's the rigidity of the Victorian legislation with the person having to raise the matter … it takes a fairly determined person to raise it with their health care team. I think for a whole raft of reasons, including health literacy and communication … it's a real problem with the Victorian legislation.
- I personally think it's ridiculous that the doctors can't proactively mention this. I actually think it's borderline negligent. Not on their fault, but it's the equivalent of you're withholding an important medical and lifestyle option from a patient when they're facing into this difficult scenario. To kind of withhold it from them just to me seems ridiculous and negligent, and I can come up with all sorts of other adjectives.
- [This] is just something that I feel strongly about … It should never be someone else's suggestion. It really has to come from the individual, the person … It shouldn't come from [my spouse] or my children. It needs to come from me. But equally if I don't know that it's an option for me, then I'm disempowered.

4 Sample comments by participating family caregivers about facilitators of access to voluntary assisted dying

Care navigators

- Then obviously the care navigator, which is the first port of call, they were fantastic … I keep going on about that word compassion and care … They made a very difficult situation more manageable.
- [All] the way through I've been in contact with the navigators. Without them this could not happen. It could not happen, it is not possible. I knew the whole process. I was familiar with everything. I am confident, I'm assertive. I could not have done it without them.
- [The best thing] … It would be [name of local care navigator], the liaison … there was never a time that I was unsure of the next process. We were so well informed we knew what was going on at all times.

Finding a supportive coordinating practitioner

- [If] we hadn't had a doctor of that commitment … and skill I'm not sure what would have happened. Well, the best [thing about the system] … is the support and help that we got from the doctor [who] guided us through the whole process.
- The next step was we went to his oncologist and said "Look, I have been investigating dying with dignity and I think this is the path that I would like to go down." And that changed everything with the oncologist. It made a huge difference because he was extremely supportive. We were just so, so lucky. That was fortuitous.
- I think once Mum raised it with the oncologist, the doctor that we dealt with was amazing. He made then the next steps just all come together. He was the coordinator and he was very compassionate and available … [If] in the first meeting about it, we thought, oh my God, there's this to do and that to do and we're going to have to provide this and provide that, that might have felt overwhelming … [Mum] wasn't good with paperwork … [and] I think she would have thought, oh God, this is going to be a lot of work. But I think we both felt, when we had that first meeting about it, that we were going to be well managed through it.

Statewide Pharmacy Service

- The two pharmacists that came down were just beautiful humans. They were friendly, they were kind, they were – went through everything, any questions that anyone had answered freely. They were amazing, I have nothing but absolute praise for them.
- [With] the medication the pharmacists were great. They were very comprehensive. The manual was lovely and simple. You know, it was literally do this, turn the page, do this, turn the page, do this, turn the page. It was set out from a timing perspective. They did suggest that we mix the medication before so that … was all organised and we didn't have to think about it.
- I called the [Statewide] pharmacy and they said "We can get it to you." So this was, I think on the Tuesday or Wednesday, "We can get it to you on the Monday." I just burst into tears and I said "I can't do that, because things are going quickly" … Then they said "Leave it with us, we will absolutely do our best." They called me back, and they said "We can do it on Friday."

System flow after initiation of access

- [The voluntary assisted dying] coordinator did a lot of the organisation stuff. She'd work with the oncologist, but then she'd do the running around and … the admin organisation side of it and contact the people and say "Okay, can you come in? I need another witness. Can you come in? We'll set up the date at this time." So it was like a coordinated team working together and we just were, I guess, the participants. We didn't have to go and do that. We could just sit back and it happened all around us.
- I think as I mentioned before, the biggest challenge for us was that Dad was an early adopter. So he was very, very early on in the system. So I think that many of the challenges or the barriers that we experienced were because of the lack of maturity in the broader system.

Facilitators of access to voluntary assisted dying (Box 4)

Care navigators

Participants identified the Statewide care navigators[28] as the most significant facilitators of access, "the jewel in the crown". This was particularly the case at the beginning of the process, when people and their families often struggled to locate doctors for assistance and to understand the initial procedural steps. Also important were local voluntary assisted dying navigators; for example, dedicated staff appointed by a hospital or health care service.

Participants highlighted the impact of the navigators' compassion and personal commitment to the people seeking voluntary

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assisted dying and their families. Their facilitating function seems to have increased with time, perhaps reflecting additional staff appointments to the service, broader improvements to procedural arrangements for voluntary assisted dying, and a growing pool of trained and willing doctors.

Finding a supportive coordinating practitioner

Finding a supportive coordinating practitioner was a key facilitator. Many participants described this happening by luck; for example, the applicant's usual doctor agreed to assess their eligibility or referred them to a willing colleague. Some participants described being at a loss about what to do next if their doctor was not willing to assist. For some, the coordinating doctor actively provided guidance throughout the process, fulfilling a role similar to navigators, and many participants spoke in glowing terms of their doctors' compassion and personal commitment.

Statewide Pharmacy Service

Although their interaction with people seeking voluntary assisted dying is focused on providing education and supplying the required medication, the Statewide Pharmacy Service was identified as a key facilitator. Participants described empathetic pharmacists who provided comprehensive medication administration training, tailored to people and their families, as well as a user-friendly booklet. Applicants for voluntary assisted dying and family caregivers found this "very reassuring", understood and had confidence in the process, and appreciated the offer of further advice if needed. Nevertheless, the capacity of a single state-wide pharmacy service was sometimes mentioned as a problem. Some participants reported delays in medication access, particularly in regional areas, although pharmacists tried to expedite supply in urgent cases.

System flow after initiation of access

Participants generally described the process, once a coordinating practitioner or a navigator had been found, as well supported and flowing "seamlessly". Although it was time-consuming and complicated, many participants reported that once the applicant "got through that door", the next steps "just flowed" without needing to be organised by the applicant or their caregivers. This was often linked to proactive process management by the coordinating practitioner, the Statewide or local navigators, as well as family caregiver support.

These positive experiences were generally reported by people engaged with voluntary assisted dying after the application processes had become established in Victoria. Early users did not report effective system flow, and some explicitly identified early operation problems as contributing to negative experiences.

Discussion

The application process for voluntary assisted dying in Victoria, from the perspective of applicants and their families, is generally working acceptably now that the process has become established. The more recent experience is that initial access can be difficult, but once achieved, the further steps proceed smoothly. In contrast to the procedural difficulties reported by doctors (especially during the early years of voluntary assisted dying in Victoria),[3-5] calls that applicants and family caregivers be shielded from system complexity appear to have been heard.[29]

However, participants also described barriers to access. Some reflect the experience of Victorian doctors who have reported challenges associated with not being permitted to raise voluntary assisted dying with their patients or to use telehealth services during the process, as well as difficulties for very ill people with little time available to them navigating a complex process.[3-4] Some barriers are new, such as the impact of institutional objection on access.[30] These barriers are broadly similar to those reported overseas, including the urgency imposed by the progression of a person's illness,[18] difficulties in locating a coordinating practitioner,[19] and the impact of institutional objections.[19,21,31]

The experiences of caregivers were generally consistent with those of doctors, and suggest that more needs to be done to ease access for eligible people, including efforts to further mitigate system complexity. Voluntary assisted dying care navigators (both Statewide and local), coordinating doctors, and the Statewide pharmacists are critical in this regard. As also reported overseas, participants emphasised that all three are pivotal to making a complex system functional,[17] so that its viability depends on supporting them adequately.[19] Participant reports of some navigator and pharmacist capacity limitations may indicate the need for greater support. Doctors, particularly the relatively small number who assist people seeking voluntary assisted dying,[3,32] also need support by increasing both the pool of doctors trained in this area and their remuneration.[6,33]

Our findings suggest strategies for improving access to voluntary assisted dying are needed. As people in regional areas and those with neurodegenerative conditions, in particular, reported access difficulties, attention to assisting these two groups is necessary. Some access problems are difficult because they are embedded in the Victorian legislation, such as the cumulative impact of a time-consuming application process on people for whom only limited time remains. Others could be more readily solved; for example, federal law could be amended to remove the telehealth prohibition,[7-8] and state government policy could be amended to direct objecting institutions to not impede access to voluntary assisted dying.

Limitations

We have reported the first study of the experiences of people seeking voluntary assisted dying in Victoria, albeit largely as described by their family caregivers. Purposive sampling later in our study increased the diversity of our sample, but a broader range of experiences should be explored, including those of people who requested voluntary assisted dying but were deemed ineligible or who did not seek access but may have done so had they been aware of it. The nature of our sample may mean there are barriers to voluntary assisted dying not raised by our participants. Further, as we recruited some participants via advocacy groups, they may have viewed voluntary assisted dying more favourably than the general public in Victoria. The experiences of people seeking voluntary assisted dying may differ from those reported by their family members, but the accounts of relatives can nonetheless provide insights into experiences otherwise difficult to access, given that people seeking voluntary assisted dying in Victoria are by definition terminally ill. The perspectives of applicants for voluntary assisted dying should nevertheless be directly explored. Finally, as a qualitative study based on a non-representative sample of self-selected participants in one state, our findings may not be more broadly generalisable.

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Conclusion

Access to voluntary assisted dying in Victoria appears to have improved over time as the application process has become more established. Family caregivers reported generally positive experiences once they had gained access to the voluntary assisted dying application process, but legal and practice barriers remain. Crucial to ensuring access is finding a doctor willing to assist, and navigators play a critical role supporting people to make this connection. Adequate support for doctors, navigators, and other facilitators is vital for the effective functioning of voluntary assisted dying processes.

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If you or anyone you know is experiencing distress, please call Lifeline on 13 11 14 (www.lifeline.org.au) or Beyond Blue (www.beyondblue.org.au) on 1300 22 46 36. ■

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1 White BP, Willmott, L. What next for voluntary assisted dying in Australia? *Aust Health Rev* 2023; 47: 3-4.

2 White B, Del Villar K, Close E, Willmott, L. Does the *Voluntary Assisted Dying Act 2017* (Vic) reflect its stated policy goals? *University of NSW Law Journal* 2020; 43: 417-451.

3 Willmott L, White B, Sellars M, Yates P. Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study. *Med J Aust* 2021; 215: 125-129. https://www.mja.com.au/journal/2021/215/3/participating-doctors-perspectives-regulation-voluntary-assisted-dying-victoria

4 White B, Willmott L, Sellars M, Yates P. Prospective oversight and approval of assisted dying cases in Victoria: a qualitative study of doctors' perspectives. *BMJ Support Palliat Care* 2023; doi: https://doi.org/10.1136/bmjspcare-2021-002972 [online ahead of print].

5 Sellars M, White B, Yates P, Willmott L. Medical practitioners' views and experiences of being involved in assisted dying in Victoria, Australia: a qualitative interview study among participating doctors. *Soc Sci Med* 2022; 292: 114568.

6 Rutherford J, Willmott L, White B. What the doctor would prescribe: medical practitioner experiences of providing voluntary assisted dying in Australia. *Omega (Westport)* 2021; doi: https://doi.org/10.1177/00302228211033109 [online ahead of print].

7 Del Villar K, Close E, Hews R, et al. Voluntary assisted dying and the legality of using a telephone or internet service: the impact of the Commonwealth "Carriage Service" offences. *Monash University Law Review* 2022; 47: 125-173.

8 Close E, Del Villar K, Willmott L, White BP. Voluntary assisted dying and telehealth: Commonwealth carriage service laws are putting clinicians at risk. *Med J Aust* 2021; 215: 406-409. https://www.mja.com.au/journal/2021/215/9/voluntary-assisted-dying-and-telehealth-commonwealth-carriage-service-laws-are

9 Krist AH, Tong ST, Aycock RA, Longo DR. Engaging patients in decision-making and behavior change to promote prevention. *Information Services and Use* 2017; 37: 105-122.

10 Dees MK, Vernooij-Dassen MJ, Dekkers WJ, et al. Perspective of decision-making in requests for euthanasia: a qualitative research among patients, relatives and treating physicians in the Netherlands. *Palliat Med* 2013; 27: 27-37.

11 Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Heide A, van der Wal G. How patients and relatives experience a visit from a consulting physician in the euthanasia procedure: a study among relatives and physicians. *Death Stud* 2009; 33: 199-219.

12 Nuhn A, Holmes S, Kelly M, et al. Experiences and perspectives of people who pursued medical assistance in dying: qualitative study in Vancouver, BC. *Can Fam Physician* 2018; 64: e380-e386.

13 Simmons JG, Reynolds G, Kekewich M, et al. Enduring physical or mental suffering of people requesting medical assistance in dying. *J Pain Symptom Manage* 2022; 63: 244-250.

14 Gamondi C, Pott M, Payne S. Families' experiences with patients who died after assisted suicide: a retrospective interview study in Southern Switzerland. *Ann Oncol* 2013; 24: 1639-1644.

15 Dees MK, Vernooij-Dassen MJ, Dekkers WJ, et al. "Unbearable suffering": a qualitative study on the perspectives of patients who request assistance in dying. *J Med Ethics* 2011; 37: 727-734.

16 Ganzini L, Goy ER, Dobscha SK. Oregonians' reasons for requesting physician aid in dying. *Arch Intern Med* 2009; 169: 489-492.

17 Oczkowski SJ, Crawshaw DE, Austin P, et al. How can we improve the experiences of patients and families who request medical assistance in dying? A multi-centre qualitative study. *BMC Palliat Care* 2021; 20: 185.

18 Thangarasa T, Hales S, Tong E, et al. A race to the end: family caregivers' experience of medical assistance in dying (MAiD): a qualitative study. *J Gen Intern Med* 2022; 37: 809-815.

19 Brown J, Goodridge D, Harrison A, et al. Medical assistance in dying: patients', families' and health care providers' perspective on access and care delivery. *J Palliat Med* 2020; 23: 1468-1477.

20 Buchbinder M. Access to aid-in-dying in the United States: shifting the debate from rights to justice. *Am J Public Health* 2018; 108: 754-759.

21 Wiebe E, Sum B, Kelly M, Hennawy M. Forced and chosen transfers for medical assistance in dying (MAiD) before and during the COVID-19 pandemic: a mixed methods study. *Death Stud* 2022; 46: 2266-2272.

22 Parliament of Victoria. Voluntary Assisted Dying Act 2017 (Act number 61/2017), authorised version incorporating amendments as at 19 June 2021. https://www.legislation.vic.gov.au/in-force/acts/voluntary-assisted-dying-act-2017/005 (viewed May 2023).

23 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349-357.

24 Voluntary Assisted Dying Review Board (Victoria). Report of operations: January to June 2021. Aug 2021. https://www.safercare.vic.gov.au/sites/default/files/2021-08/VADRB%20August%202021%20report%20FINAL.pdf (viewed May 2023).

25 Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018; 52: 1893-1907.

26 Kitto S, Chesters J, Grbich C. Quality in qualitative research. *Med J Aust* 2008; 188: 243-246. https://www.mja.com.au/journal/2008/188/4/quality-qualitative-research

27 Braun V, Clarke V. In: Thematic analysis: a practical guide. London: Sage Publications, 2022; pp. 236-250.

28 Department of Health (Victoria). Voluntary assisted dying. Information for people considering voluntary assisted dying. Aug 2019. https://www.health.vic.gov.au/patient-care/getting-support (viewed May 2023).

29 White B, Willmott L, Close E. Victoria's voluntary assisted dying law: clinical implementation as the next challenge. *Med J Aust* 2019; 210: 207-209. https://www.mja.com.au/journal/2019/210/5/victorias-voluntary-assisted-dying-law-clinical-implementation-next-challenge

30 White BP, Jeanneret R, Close E, Willmott L. The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions. *BMC Med Ethics* 2023; 24: 22.

31 Shaw J, Weibe E, Huhn A, et al. Providing medical assistance in dying: practice perspectives. *Can Fam Physician* 2019; 64: e394-e399.

13265377, 2023, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.5694/mja2.52004 by National Health And Medical Research Council, Wiley Online Library on [12/02/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

32 McLaren CJ, Mewett, G. Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study [letter]. *Med J Aust* 2022; 216: 210. https://www.mja.com.au/journal/2022/216/4/participating-doctors-perspectives-regulation-voluntary-assisted-dying-1

33 Haining CM, Willmott L, Towler S, White BP. Access to voluntary assisted dying in Australia requires fair remuneration for medical practitioners. *Med J Aust* 2023; 218: 8-10. https://www.mja.com.au/journal/2023/218/1/access-voluntary-assisted-dying-australia-requires-fair-remuneration-medical ■

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BMC Medical Ethics

RESEARCH

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The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions

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Abstract

Background Voluntary assisted dying became lawful in Victoria, the first Australian state to permit this practice, in 2019 via the *Voluntary Assisted Dying Act 2017* (Vic). While conscientious objection by individual health professionals is protected by the Victorian legislation, objections by institutions are governed by policy. No research has been conducted in Victoria, and very little research conducted internationally, on how institutional objection is experienced by patients seeking assisted dying.

Methods 28 semi-structured interviews were conducted with 32 family caregivers and one patient about the experience of 28 patients who sought assisted dying. Participants were interviewed during August-November 2021. Data from the 17 interviews (all with family caregivers) which reported institutional objection were analysed thematically.

Results Participants reported institutional objection affecting eligibility assessments, medication access, and taking the medication or having it administered. Institutional objection occurred across health settings and was sometimes communicated obliquely. These objections resulted in delays, transfers, and choices between progressing an assisted dying application and receiving palliative or other care. Participants also reported objections causing adverse emotional experiences and distrust of objecting institutions. Six mediating influences on institutional objections were identified: staff views within objecting institutions; support of external medical practitioners and pharmacists providing assisted dying services; nature of a patient's illness; progression or state of a patient's illness; patient's geographical location; and the capability and assertiveness of a patient and/or caregiver.

Conclusions Institutional objection to assisted dying is much-debated yet empirically understudied. This research found that in Victoria, objections were regularly reported by participants and adversely affected access to assisted dying and the wider end-of-life experience for patients and caregivers. This barrier arises in an assisted dying system that is already procedurally challenging, particularly given the limited window patients have to apply. Better regulation may be needed as Victoria's existing policy approach appears to preference institutional positions over patient's choice given existing power dynamics.

Keywords Assisted dying, Medical assistance in dying, Euthanasia, Assisted suicide, Institutional objection, Patient experience

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Background

There is an international trend to legalise assisted dying ("AD"), also known as medical assistance in dying, physician-assisted suicide and euthanasia [1]. Despite being lawful in many jurisdictions globally, AD remains controversial. Generally, health professionals can refuse to participate in AD through conscientious objection. While the appropriate scope of such objection remains contested, it is a well-recognised concept with protections in law and policy [2].

Healthcare institutions may also object to AD, yet how rights and obligations of objecting institutions are, or should be, conceptualised is less clear. While some analogies with individual conscientious objection are possible [3], there are important differences, including for example, the prospect of a wider access barrier for patients when an entire institution, as opposed to an individual health professional, objects to AD [4]. There may also be more diverse grounds for healthcare institutions to object.

Such objections are typically claimed by faith-based institutions, predominantly Catholic ones, which commonly provide a large proportion of end-of-life care [3, 5, 6]. But some argue institutions are incapable of holding a moral or ethical position based on conscience [3, 7]. An institution is a corporate organisation that, unlike an individual, cannot experience guilt or suffer moral injury from acting against its conscience. Others contend institutions may have a distinct mission and moral identity [6]. For example, Catholic institutions are centred on an "ethic of care" and Catholic values, an ethos which some argue is analogous to an individual's conscience [3, 6].

In a somewhat different vein, Shadd and Shadd skirt the debate about the existence of institutional conscience and instead contend institutions' right to object is a matter of self-governance, provided they have a "legitimate reason" for the objection, including moral or religious justifications [8]. Others respond that institutional objection must be curtailed and balanced against protecting patient interests, given the considerable harms such objections can cause [3, 9, 10]. This is important because patients seeking AD are often vulnerable by virtue of disease, illness, and/or frailty, and existing power asymmetry with institutions is more pronounced [9].

Despite bioethical engagement with institutional objection, there is limited empirical research on its impact on AD [10–13]. Studies report on objections by institutions to providing information about AD, eligibility assessments, and provision of AD medication onsite [12, 13]. In some cases, objections have resulted in forced transfers out of a facility for an AD assessment or provision, causing additional pain, suffering, and stress for patients and caregivers [10, 12–14]. In other cases, institutional objections have precluded access to AD because a transfer is unavailable or physically unbearable [4, 10, 13]. The literature also suggests broader impacts of institutional objection, including it being a risk factor for complicated grief [15], and "knock-on" effects of an institution's policy affecting the willingness of local healthcare professionals to participate in AD [12]. Existing findings about institutional objection have usually been included as part of wider reports about patients', caregivers', or health professionals' perspectives on AD more generally, and therefore the discussions of institutional objections are brief. As an increasing number of jurisdictions legalise AD, more research is needed to better understand how institutional objection can arise, the factors affecting patient experiences, and the impact of the particular regulatory context.

This article helps address this knowledge gap. It reports on institutional objection to AD in Victoria, Australia and draws on the country's first study of patient AD experiences, as reported by family caregivers. Victoria is examined as it was the first Australian state to legalise AD. Its *Voluntary Assisted Dying Act 2017* (Vic) has been operational for over three years. The Act's default method of AD is self-administration, where patients take the medication themselves (physician-assisted dying), but practitioner administration, where the medication is administered by a doctor (euthanasia) is permitted when patients are not physically capable of taking or digesting the medication [16]. Eligibility criteria include that a patient is terminally ill with doctors required to confirm that a patient is expected to die within 6 months, or 12 months for neurodegenerative conditions.

On the issue of institutional objection, the Victorian legislation is silent, an approach followed in the other states of Western Australia and Tasmania. By contrast, the legislation in South Australia, Queensland and New South Wales (the last three Australia states to legalise AD) specifically regulate institutional objection, with varying balances struck between ensuring patient access and respecting institutions' positions.

The legislative silence on institutional objection in Victoria led to regulation via policy. The Department of Health issued policy recommendations [17] and each institution manages its own institutional position and local policy development. The Department's policy guidance is permissive in that it suggests models of participation and possible steps, such as referrals to a statewide AD navigation service to facilitate access, but it does not require institutions take particular steps. Reflecting this, an analysis of publicly-available AD policies produced by objecting institutions demonstrated they contained little practical guidance that would assist patients to navigate those objections to AD [18].

This article reports on how institutional objection has manifested in practice, including the nature of objections expressed, practices institutions prohibited, views of employed staff, impact on patients, and mediating factors affecting patient experiences.

Methods

Research design

This study is part of a broader research project, involving interviews with patients, family caregivers, health professionals and regulators in Australia (as well as two case study countries, Canada and Belgium) [19]. The project seeks to understand participants' perspectives and experiences of decision-making about AD and how regulation is working in practice, to inform an optimal holistic model of regulation [20]. This article focuses on patient experiences of institutional objection while seeking AD, in the Australian state of Victoria, as reported by family caregivers.

We adopt a critical realist approach to this research, [21] and used Braun and Clarke's reflexive thematic analysis [22]. As noted below, our reflexive practice [22] included BPW and RJ conducting these interviews together, and debriefing after each interview as well as periodically discussing with the authorial team the initial analysis and interpretations of the data. A research journal was maintained and referred to throughout the data collection and analysis processes. All authors reviewed the final data collected and interpretations were shared and iteratively discussed to achieve a richer understanding of the data [23]. The method is reported according to the Consolidated Criteria for Reporting Qualitative Research [24].

Sampling and recruitment

For the wider study investigating patients' experiences of seeking AD in Victoria, Australia, participants eligible for inclusion were patients seeking AD in that state, and family caregivers who had or were supporting patients through this process. "Seeking AD" meant that the assessment process had started, but it did not have to be completed, nor did the person have to be approved for AD to be eligible to participate in this study. Participants had to be over 18 years of age.

As discussed further below, we were only able to recruit one patient in the broader study, and they did not experience institutional objection, hence this article is based solely on reports of patient experiences by family caregivers as proxy. While accounts directly from patients would have been preferable, to be eligible for AD in Victoria, patients must be terminally ill (within 6 or 12 months of death depending on their condition) and suffering intolerably, making this a challenging cohort to recruit. Many participants are too ill to participate in research once a terminal prognosis is established [25]. Challenges with recruitment of terminally-ill patients are well-recognised in end-of-life research, and after-death interviews with family caregivers are the next best way to explore patient experience [25, 26].

Recruitment occurred through social media (Twitter) and key patient interest groups Go Gentle Australia and Dying with Dignity Victoria (sharing study details via social media, newsletters, and direct emails). Initially relying on convenience sampling, we later used purposive sampling seeking a breadth of domains including patient age, sex, illness, location (metropolitan/regional), timing of seeking access, and patient experience of AD (self-administration, practitioner administration, sought AD but did not use or not approved). These later recruitment communications specifically stated the particular patient characteristics we were yet to collect data on, and this included direct emails from some of the patient interest groups noted above to potentially matching participants.

Data collection

An interview guide (Additional File 1) was developed based on our analysis of the Victorian legislation [16], previous interviews with doctors [27–29], and discussion within the research team. Key areas explored were: process of seeking AD including seeking information, eligibility assessments, and accessing and taking medication or having it administered; navigating the system; and overall perceptions of the system's operation. For cases when an institution objected to AD, discussion of this was often initiated by the participant in the course of explaining the patient's experience of the AD process. But a more general question was also asked if this issue was not specifically raised: "Did the facility facilitate access to AD or was it a barrier to access?". When an institutional objection was reported, follow up questions explored issues such as: the stage in the process where barriers arose (e.g. when AD was first raised, during eligibility assessments or at the medication stage); what the impact of the objection was; and the role of institution staff in implementing and communicating the objection.

Interviews traced the patient journey of seeking AD. Family caregivers were asked to report their perceptions of the patient's AD experience, but they also shared their personal views and experience. For example, when participants described the impact of institutional objection on them and family members other than the patient, these experiences were explored. Most of the caregivers interviewed had accompanied their family member patient throughout their AD journey, for example, caring for them at home and being present during medical appointments or clinical discussions in hospitals or

other facilities, and so were able to draw on this shared experience.

Participants provided free and informed consent. For all family caregivers, the patient whose experience they were sharing had died, and so patient consent was not sought. Some interviews involved two participants at their request, for example, two children of a deceased patient. All interviews were conducted by two authors BPW and RJ together, with one a designated lead. Interviews occurred between 17 August and 26 November 2021 via Zoom video conferencing except for two by phone and one in-person. Recruitment ceased once the research team considered there was sufficient "information power" to meet the study aims [30]. Interviews were digitally audio-recorded and transcribed verbatim. Participants had an opportunity to amend or add to their transcript (member checking) [31] and some provided additional supplementary information (e.g. chronology or narrative of patient experience).

Analysis

Analysis occurred in two main stages. The first involved thematic analysis of transcripts and participants' supplementary information line by line with codes developed both deductively (from literature and iterative discussion of emerging themes) and inductively [22]. Seventeen interviews were double coded by BPW and RJ (codes discussed and refined periodically), with BPW coding the remainder. Iterative analysis occurred while collecting data with BPW and RJ debriefing after each interview, and regularly throughout data collection and analysis. This first stage of analysis included identifying those interviews that reported institutional objection, namely when a participant perceived an institution objected to some or all aspects of AD, including when this objection may not have been expressly stated. This included where participants reported perceiving access to AD would be affected because of an institution's stated religious affiliation, or because of interactions with an institution's staff, even if it was not expressly stated that AD would not be permitted.

The second stage involved a focused analysis of this subset of interviews reporting institutional objection. Using reflexive thematic analysis, BPW recoded this data inductively line by line to develop further sub-themes about how patients experienced institutional objection [22]. These preliminary findings were iteratively discussed by all authors, who also studied all institutional objection data, to enhance the richness of analysis. This second stage included reviewing transcripts as a whole to understand institutional objection in context (e.g. impact of geographic location, nature of illness, timing of AD experience). Both stages of analysis were aided by NVivo (release 1.6.1 QSR International) which was used to store, code, and search transcripts.

Results

Twenty-eight interviews were conducted with 32 family caregivers and one patient (Table 1) in relation to the experiences of 28 patients (Table 2). The sole patient interview involved a participant who spoke about their own experience of seeking AD. In the remaining family caregiver interviews, participants reported on the experience of their family member as a patient seeking AD, all of whom were deceased at the time of interview. The median length of interviews was 90 min, with a range of 56 min to 130 min.

Seventeen of the 28 interviews (Table 1) discussed an institutional objection (distinct from conscientious objection by an individual) impacting on patient access to, or experiences of, AD. These 17 interviews were all with family caregivers (n = 20), and related to the experience of 17 patients (Table 2). The median length of these interviews was 95 min, with a range of 56 min to 130 min. The remaining eleven interviews that did not consider institutional objection are not included in this further analysis.

A broad range of themes were identified: the basis and expression of the objection; nature of the AD-related activity objected to; impact of institutional objection; spectrum of staff views within objecting institutions; and factors mediating the impact of institutional objection.

Basis and expression of institutional objection

Participants principally cited Catholic institutions as manifesting objections to AD (Box 1). Some also saw palliative care philosophy as founding objections. Sometimes these grounds overlapped. Objections occurred across public and private healthcare settings and by hospitals, palliative care units, residential aged care facilities and community care organisations.

How and when an institutional objection was expressed varied. Some institutions made "explicit statements from the start" to patients and/or caregivers. But one participant reported being surprised because a clear direction that the AD medication could not be taken onsite was communicated to them and the patient very late in the process. Some stated they already knew an institution's objection through media statements or published policy positions.

Other times, an institution's objection was gleaned only through context and interactions and not explicitly stated. One participant spoke of just getting "a sense" a transfer of the patient would be needed. Sometimes participants inferred AD was off-limits because of religious affiliation: "it's a Catholic place".

Table 1 Characteristics of interview participants (total sample and institutional objection study sample)

Characteristics	Total sample (n = 33): number (n %)	Institutional objection study sample (n = 20): number (n %)
Age (years)	Mean: 56.6	Mean: 56.9
20–29	1 (3%)	0 (0%)
30–39	4 (12%)	2 (10%)
40–49	7 (21%)	5 (25%)
50–59	3 (9%)	3 (15%)
60–69	13 (39%)	7 (35%)
70–79	4 (12%)	3 (15%)
80–89	1 (3%)	0 (0%)
Sex		
Female	26 (79%)	18 (90%)
Male	7 (21%)	2 (10%)
Relationship to patient*		
Child (including stepchild, child in-law)	17 (50%)	12 (60%)
Spouse (including de facto partner)	10 (29%)	6 (30%)
Parent	3 (9%)	2 (10%)
Sibling	2 (6%)	0 (0%)
Close friend	1 (3%)	0 (0%)
Self	1 (3%)	0 (0%)

*One participant in the overall sample spoke about two patients so is included in two categories. Percentages in that section of the table are calculated using number of relationships (34)

Box 1: Participant quotes—Basis and expression of institutional objection

Many of the palliative care organisations are run by Catholic institutions who are not in favour of voluntary assisted dying. So that was always going to be a bit of an issue for us in talking about it with [patient name]… (Family caregiver of patient with cancer)

It was in the media. Catholic-based health facilities put out a joint statement, and their joint statement was that they were conscientious objectors to the voluntary assisted dying. (Family caregiver of patient with cancer)

I knew for a start that she couldn't die there… because I'd looked it up on their website. So we didn't even pursue it. So I always knew that it wasn't going to happen. (Family caregiver of patient with neurological condition)

Practices institutions objected to

Many objecting institutions prohibited most or all of the AD process. Participants' reports centred on three key aspects (Box 2). The first was not permitting AD eligibility assessments within the institution. Particular hospitals were described as barring entry to outside doctors attending to assess a patient's eligibility. The second was precluding receipt of the medication. Some institutions denied access to the Statewide Pharmacy Service, which delivers the medication to eligible patients. The third was not allowing AD medication to be taken or administered onsite. For in-patients or those in residential care, this meant having to be discharged or transferred to access AD. In one case, the institution would allow self-administration, but not practitioner administration, onsite. In another case, for a patient at home, a community care nurse was prohibited by her employer from being present when AD occurred.

In addition to these three key aspects of the AD process, participants also gave examples of staff not being allowed to discuss AD with them or patients, refusing admission to a residential facility for a patient intending to seek AD, and concerns about death certification.

Box 2: Participant quotes—Practices institutions objected to

[T]he oncologist said he would come to the hospital to do the second appointment, and when he heard I was at [Catholic hospital], he said, "Oh, sorry, I can't come there, you'll have to wait for [patient name] to come out of hospital." (Family caregiver of patient with cancer)

That was at the time when it was likely that Mum was going to be transferred to [Catholic hospital] because her pain was so severe… [Catholic hospital]

Table 2 Characteristics of patients whose voluntary assisted dying experience was the subject of interviews (total sample and institutional objection study sample)

Characteristic	Total sample (n = 28): number (%)	Institutional objection study sample (n = 17): number (%)
Age (years)	Mean 70.8	Mean 73.2
20–29	1 (4%)	0 (0%)
30–39	1 (4%)	1 (6%)
40–49	0 (0%)	0 (0%)
50–59	3 (11%)	1 (6%)
60–69	7 (25%)	4 (24%)
70–79	8 (29%)	5 (29%)
80–89	6 (21%)	5 (29%)
90–99	2 (7%)	1 (6%)
Sex		
Female	13 (46%)	7 (41%)
Male	15 (54%)	10 (59%)
Location		
Metropolitan	16 (57%)	13 (76%)
Regional	12* (43%)	4 (24%)
Highest level of education		
Some high school	7 (25%)	6 (35%)
High school	9 (32%)	4 (24%)
University–diploma	1 (4%)	0 (0%)
University–undergraduate	7 (25%)	4 (24%)
University–postgraduate (including graduate diploma)	4 (14%)	3 (18%)
Primary disease, illness, or medical condition		
Cancer	18 (64%)	10 (59%)
Neurological	9 (32%)	6 (35%)
Other	1 (4%)	1 (6%)
Eligibility for voluntary assisted dying and death		
Assessed as eligible	24 (86%)	16 (94%)
Patient died via self-administered medication	19 (68%)	12 (71%)
Patient died via practitioner administered medication	3 (11%)	3 (18%)
Patient died but did not take medication (natural death)	1 (4%)	1 (6%)
Patient waiting to take medication	1 (4%)	0 (0%)
Patient died prior to eligibility assessment completed	3 (11%)	1 (6%)
Patient assessed as ineligible and died	1 (4%)	0 (0%)
Timing of voluntary assisted death (or engagement with process)		
July–December 2019	4 (14%)	2 (12%)
January–June 2020	6 (21%)	4 (24%)
July–December 2020	3 (11%)	1 (6%)
January–June 2021	10 (36%)	6 (35%)
July–November 2021	5 (18%)	4 (24%)

*One patient in the overall sample who was classified as regional moved to a metropolitan area during the voluntary assisted dying process.

> actually told us that if she came … that they would not allow the state pharmacist representatives to come into the hospital at all. (Family caregiver of patient with neurological condition)

> They said, "… so do you think you'd like to go [home–town name] or is there somewhere else?" Dad said, "No, I will just do it here." At that point they said "Well, actually we can't do it on hospital grounds." So Dad [said], "Well, okay, push me out to the carpark

and I'll do it there." (Family caregiver of patient with cancer)

I was saying that "I'm actually really hoping that she goes down this avenue," and … she said, "I have to stop you there … I'm so sorry, but because of where I work I'm actually not allowed to actually have a conversation with you about assisted dying at all." (Family caregiver of patient with neurological condition)

Impact of institutional objection

Participants described three key ways that institutional objection hampered patient access to or experience of AD: patient delay in accessing AD; reduced choice for patients about AD; and emotional and relationship costs for patients and family caregivers (Box 3).

Delay for patients was the principal impact, either due to prohibiting access to doctors and pharmacists, or making patients wait until they left the institution to receive or take the medication.

Patient choice was also affected. Participants described patients needing to choose between progressing the AD process or being admitted to an objecting hospital to manage pain and symptoms. In terms of missing out, one of the three patients in this study who died while seeking AD experienced an institutional objection. Their participating family caregiver considered the objection contributed to this and delays occurred because eligibility could not be assessed in that faith-based hospital. However, access to AD for this patient was challenging because of rapid illness progression and other factors.

Institutional objection also affected patient choice about place or time of taking AD medication. Participants described transfers or patients getting "shipped to a completely different hospital" or facility, including away from staff who had been caring for the patient. This often meant waiting until a bed was available in the transferring facility, resulting in delays accessing AD. Sometimes a transfer was needed back to a patient's or family's home to take the medication, which was not the patient's preferred place to die.

Participants described emotional and relationship costs to patients (and families) of access being hampered by institutional objection. Both patients and families experienced anger and frustration at being in a holding pattern of not being able to seek AD. Some patients were fearful of missing out on their choice. One participant described her mother being "absolutely terrified that they would find out and … try and stop her." Others described the stress for patients and family of uncertainty and the extra steps associated with arranging transfers to take the AD medication, impacting on what should have otherwise been a special day. Some expressed "great sadness" about patients not being able to die in a residential facility which was their home, or at the time they wanted to, or say goodbye to favourite staff. One participant described her feeling of stigma and that the family were doing something "illegal", because of the institutional position.

There were also costs to the relationship between patient-caregiver and the treating institution with some participants reporting distrust from both caregivers and patients, with "question marks over motivations". Against this "background of AD", there was a loss of confidence or trust in medical advice with one participant asking, "What's their agenda?". Another described removing all traces of AD to ensure the death could be verified by the palliative care team.

Box 3: Participant quotes—Impact of institutional objection

If we had been able to begin the access in the hospital, maybe she would have then come home and been able to complete that at home. You know, actually take part in AD at home within a day of coming home, rather than having to prolong it. [long pause] So I think institutional policies have a part to play. So allowing free access to AD doctors to access patients, if that's what the patient wants, while they're in hospital. Because some people spend an awful long time in hospital… (Family caregiver of patient with neurological condition)

[T]hat was a significant challenge and just created a whole lot of stress on what was her last day. You know, it was this frantic rush and … then having to wheel her out and she couldn't say goodbye to people. … you get to the top of the mountain and then you've got that last big, huge boulder to climb over. It will always be a great sadness for me that the last few precious hours on Mum's last day were mostly filled with stress and distress, having to scurry around moving her out of her so-called "home". (Family caregiver of patient with neurological condition)

I spoke to the doctor who had helped us with the AD application … saying that [Catholic hospital] had really wanted the cognitive assessment. He said to me, "Do not let them do a cognitive assessment… you don't know what it's going to be used for." I actually went back to [relevant staff member] at [Catholic hospital], who was absolutely lovely, and I said, "Look, this is what the doctor has said … I'm sure that's not your motivation," but s/he actually said, "I can't guarantee that it may be somehow linked in with the AD process. So why don't we not do the cognitive assessment." … So s/he … didn't say like that was the agenda. S/he just said, "Look, this whole thing is so grey and

so new … I would not want to be doing anything that could potentially jeopardise your Mum's choice in the AD thing." So s/he was actually the one that said, "We're just not going to do it." [Mum] was still able to make her own decisions, but it definitely impacted what services we got from [Catholic hospital]. Because it was always in the background of AD. What's their agenda? [C]ould it jeopardise it? And even [Catholic hospital] couldn't say that it wouldn't be used for something like that. (Family caregiver; no patient illness information provided to protect participant)

Position of staff within objecting institutions

Participants described staff within objecting institutions as having a spectrum of positions on AD (Box 4).

Some staff personally objected to AD, and this exacerbated the barrier for patients. Some participants also perceived, in addition to implementing institutional objection, some staff may have been "pushing … against the AD process" towards non-AD treatment options, or advocating for admission to care locations where AD was not possible to halt the AD process. Other staff were described as simply accepting their institution's position that AD was "out of bounds" and passively implementing that view, including by declining to discuss it.

However, participants also identified staff who they perceived disagreed with their institution. Participants described this sometimes manifesting itself as an acknowledgement of the patient's AD choice or private moral support, communicated to both patients and caregivers. Rarely, staff went further and provided support (generally surreptitiously) for the patient to navigate towards AD.

Box 4: Participant quotes—Position of staff within objecting institutions

[The staff member] said, "I can't, because of my role, there's nothing I can do to help you, I can't do anything." But she said, "I'm here for you." (Family caregiver of patient with neurological condition)

There are people that work for [Catholic palliative care organisation] that don't support it, but there are plenty of people that do. So I think they said, "We'll make a note of it. But even the people that don't support it will still care for you." (Family caregiver of patient with cancer)

Quietly in the room. Not with other people listening. So it would be a one-on-one conversation and they said to me, "You can certainly take care of [patient name] at home. There's no issue about that. It would be better for her if [patient] is at home." So they were very sympathetic. They also helped direct us to a private company. Which [long pause] … that private company knew of that particular [staff member], because they said, "[Staff member] is very sympathetic and very helpful to a lot of people." So [they] had a reputation, you would say, for looking after the patient's needs versus the institution. Which if [they] got found out, [they] would lose [their] job. [long pause] … I'd be happy for that story to be included if I could be sure that [they were] protected. (Family caregiver; no patient illness information provided to protect participant and another person)

Mediating influences on the impact of institutional objection

Six factors mediated the impact of institutional objection (Box 5). The first was staff views about AD which, given its broader significance, is a standalone theme above. The impact of institutional objection was felt more acutely by patients when staff shared that position, but mitigated when staff disagreed with it.

A second mediating factor was the support of medical practitioners coordinating the AD process (external to the institution) and the Statewide Pharmacy Service. Participants described these individuals making particular efforts to facilitate access despite institutional objections. Examples were pharmacists fast-tracking appointments to deliver medication before a patient's admission to an objecting hospital or busy medical specialists doing home visits.

A third factor was the nature of the patient's illness. Institutional objection was more problematic if a key treating hospital for a patient's illness opposed AD. This was mentioned particularly for neurological conditions.

A fourth factor was the progression or state of a patient's illness. If their illness was so advanced or their need for pain and symptom management required either being admitted into an objecting institution, or staying at an objecting institution where they were already receiving care, this impeded access more than for those who were able to leave the institution or remain at home. A transfer for such patients to another facility was sometimes an option but often this was unsatisfactory, for example because their illness was best treated at their existing hospital or because a bed was not available elsewhere. Further, for patients whose illness was more progressed, any delay was experienced more acutely because of shorter time they had to navigate through the AD process.

Fifth, a patient's geographical location affected the impact of institutional objection. If there was only one health service in an area and it restricted AD, access was more complex. One participant described that a patient's

inability to self-administer would require them to transfer away from the region to receive practitioner-administration as the local institution would not permit this.

A final mediating factor was a capable and assertive patient and/or family caregiver. Objecting institutions could be identified and navigated away from (particularly in the residential aged care setting): "the place was chosen because they would allow it [AD]". Assertive patients and caregivers also seemed more ready to challenge institutions or step past objections and seek AD privately. Some caregivers also described being able to bypass institutional objection through providing care at home, but this was not always possible. However, even participants who were highly competent and educated caregivers with health professional backgrounds found navigating institutional objection challenging.

Box 5: Participant quotes—Mediating influences on the impact of institutional objection

[T]here was … a huge conflict of interest. That the AD process is not supported by [Catholic hospital] and yet [Catholic hospital] is the hospital that you go to with motor neurone disease. (Family caregiver of patient with neurological condition)

So then we had to call the State Pharmacist and say, "You need to come really, really quickly because Mum's about to be transferred to [Catholic hospital] and you're not allowed in [Catholic hospital]." So they very kindly came a day earlier. I think it was on the day that Mum was actually transferred to [Catholic hospital]… So we did that, but that was stressful in itself. (Family caregiver of patient with neurological condition)

It wasn't an option in [rural town]. So it was only ever available as self-administered. If Dad had to have practitioner assisted, he had to be transported to [major city]. (Family caregiver of patient with cancer)

Discussion

Main findings

Most patient experiences of seeking AD were reported by participants to involve institutional objection (17/28 patient cases). These objections were primarily rooted in Catholic religion and/or moral opposition based on a palliative care philosophy. Participants identified three key processes affected: eligibility assessments, medication access, and taking/administration of the medication. Institutional objection occurred across health settings resulting in delays, transfers, choices between progressing an AD application and receiving palliative or other care, and adverse emotional and relationship experiences.

Six mediating influences on institutional objections were identified. Some compound the effect on patients, such as having a particular illness primarily cared for in an objecting institution. Others soften the impact, such as supportive staff in the institution. The schematic relationship between these themes is shown below (Fig. 1).

Implications of institutional objection as a barrier

The barriers to accessing AD caused by institutional objection can compromise the quality of a patient's end-of-life experience [9, 32]. Key factors in a "good death" include choice and control in the dying process, and receiving integrated end-of-life care including pain-free status, dignity, and emotional well-being [33]. Yet these findings suggest institutional objection can diminish patient options, require choice between progressing AD and receiving palliative care, and cause emotional discord and stress in a patient's final days.

Further, the impact of institutional objection on patient access to AD can compound existing access challenges. For example, time delays in the AD approval process can be problematic with patients "racing" to access AD before dying [34]. This is especially so in systems where eligibility criteria require a time period until death, as in Victoria (6 months or 12 months for neurodegenerative conditions) [16]. Delays from institutional objection, even if relatively brief, can threaten access altogether.

Institutional objection also exacerbated challenges for patients with neurological conditions. There were already fewer trained AD doctors in this specialty in Victoria at the time of this research [35], but patient access was reported as being further impeded due to a statewide neurological facility being an objecting institution. Given patients with neurological conditions are a recognised cohort who seek AD [35, 36], this institutional objection is problematic for access.

A linked observation, echoing Wiebe et al.'s [13] findings from Canada, is that these findings reveal a "lottery" of sorts, with some patients better able to navigate institutional objections if the right constellation of mediating factors is present. This creates inequities in care based on inappropriate considerations such as geographical location, illness, practitioners encountered, and available family and other supports.

Contested permissibility and scope of institutional objection

These findings inform debates about permissibility of institutional objections and, if allowed, their justifiable boundaries. Given the dearth of empirical research on institutional objection, the adverse impacts on patients (and caregivers) in Victoria's AD system found in this study support at least some limits to institutional power. Further, findings of variability of staff views about AD within objecting institutions may undermine arguments

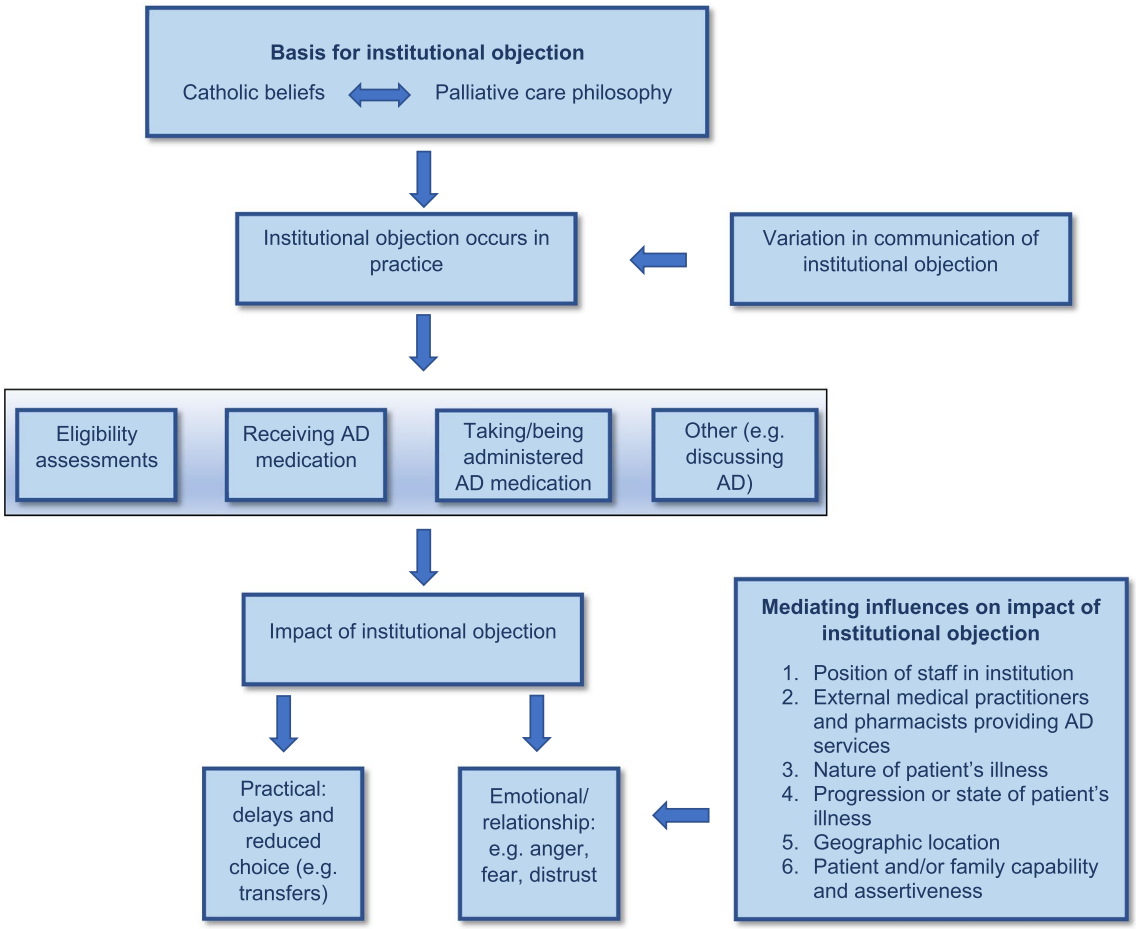

Fig. 1 Thematic schema of participants' perspectives on institutional objection in Victorian assisted dying system

to permit such objections. If safeguarding institutional "conscience" is based on protecting a broad staff consensus, such arguments are undermined by this finding, reflecting studies in other settings [37, 38].

These findings also raise questions about how best to respond to identified harms to patients from institutional objection. Should this be regulated by the state or left to practice, and if formally regulated, what model should be chosen (e.g. conscience absolutism, non-toleration or some form of reasonable accommodation) [3, 10]? There are also questions about how such regulation (if that path is chosen) should be implemented, e.g. through law, policy and/or funding mechanisms. Any regulatory response would also need to consider questions such as whether the intended duration of the care being provided by an institution impacts on its duties, and whether all stages of the AD process should be treated the same. To illustrate, legislation in the Australian state of Queensland imposes higher duties on long-term care institutions such as residential aged care facilities (which are regarded as a person's home) than on short-term places of care such as hospitals, and treats access to information about AD differently from taking or administering the medication [39].

Our observations are that the current Victorian approach, based on state-issued (optional) policy guidance, is not effective in achieving the objectives of respecting institutional positions while promoting patient access. This "soft regulation" approach appears to have allowed existing power, resource, and information asymmetry to prioritise institutions' positions over patient choice. Such an outcome is inconsistent with the wider policy goals of the *Voluntary Assisted Dying Act 2017*.[16]

A further concern was significant variation in how institutional objections were expressed. Some institutions objected explicitly, but other participants learned of objections obliquely, through progressive interactions

with staff, and sometimes only after a period of time in care. Uncertainty about institutional positions reflects existing literature [40] and is problematic because it makes informed choices about care more difficult for patients and caregivers. Regardless of views about the permissibility of institutional objections to AD, transparency and clear communication of positions are desirable.

Limitations of the study

This is one of very few empirical studies internationally to examine institutional objection to AD. Importantly, it provides evidence about the adverse impact that institutional objection can have on patients (albeit as reported by family caregivers). However, a limitation of this research is that the perception of caregivers may differ from those of patients as caregivers may be affected by grief, bereavement, and their relationship with the patient they were supporting [25, 26]. However, proxies have been found to be a reliable source of information regarding quality of end-of-life services, demonstrating high concordance with patient views [41].

Another limitation is that the perceptions of our participants reported in this study are based on their experience of interactions with particular health professionals and institutions. Other perspectives are needed and further research with a broad range of key stakeholders is warranted, including to examine wider system issues such as the role played by institutional policies and protocols in managing objections.

Our sample may also be more favourably disposed towards AD, given our recruitment methods which included via patient interest groups. Further, only three patients in this study missed out on AD. More research with this cohort is needed, including whether objections by institutions contribute to a lack of access and the issues of equity to which that gives rise. Additionally, given many patients were still able to access AD *despite* objections by institutions, further investigation is needed as to the reasons for this, including the mediating factors identified in this research (e.g. a capable and assertive patient and/or family caregiver).

Finally, further research is also needed on the intersection between individual conscientious objection and institutional objection, including how one may shape the other. Findings here were that staff positions mediated institutional objections, but more research is needed.

Conclusion

Institutional objection is a much-debated aspect of AD practice yet is empirically understudied. This research found that in Victoria, it was regularly reported by participants and adversely affected patient and caregiver experience when accessing AD. This occurs in an already procedurally challenging system, particularly given the limited window patients have to apply. Better regulation may be needed to address this issue as the existing policy approach appears to preference institutional positions over patient's choice given existing power dynamics.

Abbreviation

AD Assisted dying

Supplementary Information

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Additional file 1. Interview guide.

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Author contributions

Data was collected by BPW and RJ. BPW wrote most of the first draft of the manuscript, with other sections completed by RJ, EC and LW. BPW, RJ, EC and LW all made substantive revisions to iterative drafts of the manuscript. BPW finalised the text, which was approved by all authors. All authors read and approved the final manuscript.

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Availability of data and materials

The interview guide is available in Additional File 1. The data generated and analysed in this study are not publicly available due to confidentiality undertakings given to research participants as required by the study's ethics approval. Requests to discuss this should be directed to the corresponding author.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained from the Queensland University of Technology Human Research Ethics Committee (2000000270). This research was conducted in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research 2007 (updated 2018). All persons interviewed gave free and informed consent to participation in this research. This research was conducted in accordance with the requirements of this ethics approval.

Consent for publication

Not applicable.

Competing interests

BPW and LW were engaged by the Victorian, Western Australian and Queensland governments to provide the legislatively mandated training for doctors involved in voluntary assisted dying. RJ and EC were employed on the Victorian, Western Australian and Queensland training projects. BPW is a member of the Queensland Civil and Administrative Tribunal, the quasi-judicial review body which has jurisdiction over some voluntary assisted dying matters. LW is a member of the relevant oversight body in Queensland, the Voluntary

Assisted Dying Review Board. All views expressed in this article are those of the authors and not the organisations they are affiliated with.

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References

1. White BP, Willmott L. International perspectives on end-of-life law reform: politics. Persuasion and Persistence: Cambridge University Press; 2021.
2. Clarke S. Conscientious objection in healthcare: new directions. J Med Ethics. 2017;43(4):191–191.
3. Wicclair MR. Conscientious Objection in health care: an ethical analysis. Cambridge: Cambridge University Press; 2012.
4. Gilbert D. Faith and/in medicine: religious and conscientious objections to MAiD. Dalhous Law J. 2020;43(2):657–95.
5. Wolfe ID, Pope TM. Hospital mergers and conscience-based objections—growing threats to access and quality of care. N Engl J Med. 2020;2.
6. Durland SL. The case against institutional conscience. Notre Dame Law Rev. 2011;86(4):1655–86.
7. Annas GJ. At law: transferring the ethical hot potato. Hastings Cent Rep. 1987;17(1):20–1.
8. Shadd P, Shadd J. Institutional non-participation in assisted dying: changing the conversation. Bioethics. 2019;33(1):207–14.
9. Sumner LW. Institutional refusal to offer assisted dying: a response to Shadd and Shadd. Bioethics. 2019;33(8):970–2.
10. White BP, Willmott L, Close E, Downie J. Legislative options to address institutional objections to voluntary assisted dying in Australia. Univ New South Wales Law J Forum. 2021;3:1–19.
11. Waran E, William L. Navigating the complexities of voluntary assisted dying in palliative care. Med J Aust. 2020;213(5):204-206.e1.
12. Shaw J, Wiebe E, Nuhn A, Holmes S, Kelly M, Just A. Providing medical assistance in dying: practice perspectives. Can Fam Physician. 2018;64(9):e394–9.
13. Wiebe E, Sum B, Kelly M, Hennawy M. Forced and chosen transfers for medical assistance in dying (MAiD) before and during the COVID 19 pandemic: a mixed methods study. Death Stud. 2022;46(9):2266–72.
14. Holmes S, Wiebe E, Shaw J, Nuhn A, Just A, Kelly M. Exploring the experience of supporting a loved one through a medically assisted death in Canada. Can Fam Physician. 2018;64(9):e387–93.
15. Hashemi N, Amos E, Lokuge B. Quality of bereavement for caregivers of patients who died by medical assistance in dying at home and the factors impacting their experience: a qualitative study. J Palliat Med. 2021;24(9):1351–7.
16. White BP, Del Villar K, Close E, Willmott L. Does the Voluntary Assisted Dying Act 2017 (Vic) reflect its stated policy goals? Univ New South Wales Law J. 2020;43(2):417–51.
17. Department of Health. Victoria A. Health services information [Internet]. State Government of Victoria, Australia. 2019. http://www.health.vic.gov.au/patient-care/health-services-information. Accessed 1 Sep 2022.
18. Close E, Willmott L, Keogh L, White BP. Institutional objection to voluntary assisted dying in Victoria, Australia: an analysis of publicly available policies. J Bioethical Inq. (accepted, forthcoming).
19. Optimal Regulation of Voluntary Assisted Dying. https://research.qut.edu.au/voluntary-assisted-dying-regulation/. Accessed 25 Jan 2023.
20. White BP, Willmott L, Close E. Better regulation of end-of-life care: a call for a holistic approach. J Bioeth Inq. 2022;19(4):683–693.
21. Maxwell JA. A realist approach for qualitative research. Los Angeles: SAGE Publications, Inc; 2012.
22. Braun V, Clarke V. thematic analysis: a practical guide. London: Sage Publications Ltd; 2022.
23. Byrne D. A worked example of Braun and Clarke's approach to reflexive thematic analysis. Qual Quant. 2022;56:1391–412.
24. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
25. Addington-Hall J, McPherson C. After-death interviews with surrogates/bereaved family members: some issues of validity. J Pain Symptom Manage. 2001;22(3):784–90.
26. Williams BR, Woodby LL, Bailey FA, Burgio KL. Identifying and responding to ethical and methodological issues in after-death interviews with next-of-kin. Death Stud. 2008;32(3):197–236.
27. Willmott L, White BP, Sellars M, Yates P. Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study. Med J Aust. 2021;215(3):125–9.
28. White BP, Willmott L, Sellars M, Yates P. Prospective oversight and approval of assisted dying cases in Victoria, Australia: a qualitative study of doctors' perspectives. BMJ Support Palliat Care. 2021.
29. Sellars M, White BP, Yates P, Willmott L. Medical practitioners' views and experiences of being involved in assisted dying in Victoria, Australia: a qualitative interview study among participating doctors. Soc Sci Med. 2022;292: 114568.
30. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qual Res Sport Exerc Health. 2021;13(2):201–16.
31. Kitto SC, Chesters J, Grbich C. Quality in qualitative research. Med J Aust. 2008;188(4):243–6.
32. Sumner LW. Conscientious refusal to provide medically assisted dying. Univ Tor Law J. 2021;71(1):1–31.
33. Meier EA, Gallegos JV, Thomas LPM, Depp CA, Irwin SA, Jeste DV. Defining a good death (successful dying): literature review and a call for research and public dialogue. Am J Geriatr Psychiatry. 2016;24(4):261–71.
34. Thangarasa T, Hales S, Tong E, An E, Selby D, Isenberg-Grzeda E, et al. A race to the end: family caregivers' experience of medical assistance in dying (MAiD)—a qualitative study. J Gen Intern Med. 2022;37(4):809–15.
35. Voluntary Assisted Dying Review Board. Report of operations: January to June 2021 [Internet]. Safer Care Victoria. 2021. https://www.safercare.vic.gov.au/sites/default/files/2021-08/VADRB%20August%202021%20report%20FINAL.pdf. Accessed 30 Aug 2022.
36. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. JAMA. 2016;316(1):79–90.
37. Stulberg DB, Lawrence RE, Shattuck J, Curlin FA. Religious hospitals and primary care physicians: conflicts over policies for patient care. J Gen Intern Med. 2010;25(7):725–30.
38. Freedman LR, Stulberg DB. Conflicts in care for obstetric complications in Catholic hospitals. AJOB Prim Res. 2013;4(4):1–10.
39. Voluntary Assisted Dying Act 2021 (Qld), Part 6, Division 2.
40. Takahashi J, Cher A, Sheeder J, Teal S, Guiahi M. Disclosure of religious identity and health care practices on Catholic hospital websites. JAMA. 2019;321(11):1103–4.
41. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: Can proxies provide reliable information? Soc Sci Med. 2003;56(1):95–109.

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Chapter 27

Assisted dying in Australia: A values-based model for reform*

Lindy Willmott and Ben White

Introduction

Assisted dying demonstrates starkly the tensions and traumas of health law as Australia, like jurisdictions around the world, wrestles with proposed changes to make voluntary euthanasia and/or assisted suicide lawful. Tensions are evident in the entrenched and opposing policy positions of individuals and organisations about whether reform should occur. And even those advocating for a change in the law will disagree about what should and should not be permitted and how a permissive regime should be regulated. These different positions are often driven by different ideological perspectives and are embedded in deeply held personal values and beliefs.

Assisted dying debates raise issues of trauma too. In our sophisticated health system which boasts a very high standard of palliative care,[1] death is generally well-managed with the patient's pain and symptoms being adequately controlled. Yet, this is not always possible. There is trauma for a small cohort of people whose suffering (whether physical, psychological, or existential) cannot be satisfactorily alleviated and who seek assistance to die. This trauma can extend to their loved ones and their treating teams.

The debate over whether we should reform our law on euthanasia and assisted suicide has been particularly prominent in Australia over recent years. We have seen bills drafted in all but one Australian state,[2] parliamentary committee inquiries,[3] police investigations, action by medical

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[1] The Economist Intelligence Unit, *The 2015 Quality of Death Index: Ranking palliative care across the world* (2015) 7, 15, 23, 26. <https://www.eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>.

[2] Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1-46, 11.

[3] Most recently, see the review of end-of-life choices in Victoria: Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report* (June 2016) <https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf>.

regulators[4], and a media-fuelled public debate. There has also been considerable movement towards liberalising euthanasia and assisted suicide internationally. We will expand on both Australian and international developments shortly.

The goal of this chapter is not to rehearse all of the arguments for and against reform. Instead, we advance a values-based model for assisted dying. These values – life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, and reducing human suffering – are based on existing Australian legal principle, for example as reflected in common law, legislation or conventions or treaties that have been ratified by Australia. Drawing on these values, we conclude that the current criminal law prohibition on assisted dying cannot be justified and instead propose a model that permits and regulates assisted dying in certain circumstances. Our model is guided by the values identified but also draws on arguments based on reason and practice (consistent with the values), including the experience of assisted dying in other jurisdictions.

We acknowledge at this point two limitations of this chapter. First, there is not space here to articulate comprehensively and defend the values we propose. Nor is there scope to outline in detail the model that follows. That more detailed project will have to wait. Our purpose here is to put forward these values and this model for discussion and critique, and we do so with an awareness that a more robust case (including discussion of a wider body of literature) is not possible here.

The second limitation is that there are three important issues that have not been considered in developing our model and therefore fall outside the scope of this chapter. They are outside scope for two reasons. First, they are complex issues that require more detailed consideration than is possible in this chapter. The second reason is that they are not currently part of the mainstream Australian assisted dying debate, and so it is justifiable and appropriate to leave them to another time. We do not address the issue of assisted dying through advance directives. This issue requires a conceptual analysis (e.g., whether a present competent self should have the authority to bind a future incompetent person) as well as answers to implementation questions (e.g., rules about revocation, relationship to current advance care planning systems). We also do not address the issue of assisted dying requested by substitute decision-makers as this involves a different formulation of autonomy than that used in this chapter, and shifts the

[4] See eg *Nitschke v Medical Board of Australia* [2015] NTSC 39; *Syme v Medical Board of Australia* [2016] VCAT 2150.

discussion of the balancing of the competing values in a way that also exceeds the space constraints of this chapter. Finally, we do not consider the position of Gillick-competent minors as Australian court authority recognising limits on the power of this cohort to refuse life-sustaining treatment would require detailed analysis which is not possible here.[5]

A final point about terminology. We define 'euthanasia' in the following way:

> For the purpose of relieving suffering, a person performs a lethal action[6] with the intention of ending the life of another person.[7]

And 'voluntary euthanasia' as where:

> Euthanasia is performed at the request of the person whose life is ended, and that person is competent.[8]

'Assisted suicide' is defined as following:

> A competent person dies after being provided by another with the means or knowledge to kill him or herself.[9]

'Physician-assisted suicide' is 'where a doctor acts as the assistant'.[10]

For the purpose of this chapter, unless we indicate to the contrary, we will use the term 'assisted dying' to refer to both 'voluntary euthanasia' and 'physician-assisted suicide' as defined above.

A short history of Australian assisted dying reform

The Northern Territory was the first jurisdiction in the world to legalise voluntary euthanasia with the enactment of the *Rights of the Terminally Ill Act 1995* (NT) (*ROTTIA*).[11] Although ground-breaking reform, the Act was short-lived, and the Commonwealth overturned it a short

[5] See, eg, *X v The Sydney Children's Hospitals Network* (2013) 85 NSWLR 294 (an application from the New South Wales Court of Appeal for special leave to the High Court was dismissed as moot after the child in question turned 18 years of age: *X v The Sydney Children's Hospitals Network* [2014] HCASL 97); *Royal Alexandra Hospital for Children Trading as Children's Hospital at Westmead v J* (2005) 33 Fam LR 448; *Minister for Health v AS* (2004) 33 Fam LR 223. See further Freckelton & McGregor, Chapter 12.
[6] Note that the authors do not include within this definition positive steps taken by a person to stop treatment which action results in death (such as removing a breathing tube).
[7] Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics', above n 2, 6.
[8] Ibid.
[9] Ibid 7.
[10] Ibid.
[11] For background regarding the passage of the bill and its repeal, see ibid 8-9.

time later by enacting the *Euthanasia Laws Act 1997* (Cth). Since the enactment (and repeal) of *ROTTIA*, there have been dozens of attempts at the State, Territory and Commonwealth level to: legalise euthanasia (the majority of bills), to overturn the Commonwealth *Euthanasia Laws Act 1997* (Cth) to enable territories to legislate on the topic, and to hold a referendum on law reform.[12] Bills have been introduced in all Australian jurisdictions except Queensland.[13] In the past, the majority of the proponents of reform have been independent members of parliament, or members of the Australian Greens or the Australian Democrats.[14] More recently, private members' bills have been proposed by Labor Party and Liberal Party politicians as well.[15] Conscience votes have always been allowed when the bills have been considered in parliament.

Despite the large number of bills introduced, they have rarely reached the Committee or third reading stage. As such, there has been only limited detailed analysis of proposed legislation by our parliamentarians. More bills have lapsed rather than been defeated.[16]

A recent analysis of the bills that have been proposed revealed common features:[17]

- Most allow both euthanasia and physician-assisted suicide (including the *ROTTIA*)
- The overwhelming majority of the bills (including the *ROTTIA*) propose permissive models, that is, providing a legislative framework containing eligibility requirements and integrating safeguards which *allow* euthanasia in the described circumstances. (Other models provide defences while continuing to retain the offence of killing, and still other models provide for mitigation of penalties if killing occurs in certain circumstances.)

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[12] Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics', above n 2, 11.
[13] Though no Bill has been introduced in Queensland, in October 2016 Queensland Independent MP Peter Wellington called for a parliamentary inquiry into voluntary euthanasia and end-of-life choices: Felicity Caldwell, 'Voluntary euthanasia: Calls for Queensland Parliamentary Inquiry', *The Brisbane Times* (online), 17 October 2016 <http://www.brisbanetimes.com.au/queensland/voluntary-euthanasia-calls-for-queensland-parliamentary-inquiry-20161017-gs44ri.html>.
[14] Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics', above n 2, 11-13.
[15] For example, in October 2016 South Australian Liberal MP Dr Duncan McFetridge introduced the Death with Dignity Bill 2016, which was defeated in the South Australian Parliament following a close conscience vote: ABC News, 'Voluntary euthanasia: South Australian parliament knocks back Death with Dignity euthanasia bill', *ABC News* (online), 17 November 2016 <http://www.abc.net.au/news/2016-11-16/voluntary-euthanasia-debate-in-south-australia-goes-to-committee/8031776>. In February 2016 South Australian Labor MP Stephanie Key introduced the Voluntary Euthanasia Bill 2016, but withdrew the Bill in March 2017: South Australia, *Parliamentary Debates*, House of Assembly, 2 March 2017, 8775 (Stephanie Key, Member for Parliament, Ashford).
[16] Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics', above n 2, 15-20.
[17] Ibid 39-41.

- All permissive models (including the *ROTTIA*) provide that assistance to die would only be available to an adult who is enduring intolerable suffering and/or has a terminal illness. The person needs to be competent and the request voluntary. (Under some models, a person could receive assistance to die if they no longer had capacity, but the request was made when he or she did have capacity.)
- Generally, the person could determine for themselves whether the suffering was of a level acceptable to them, and most bills adopt a broad interpretation of the categories of suffering (often including physical, psychological, and existential).
- Most bills (including the ROTTIA) contain safeguards including requirements that the person obtain information from a range of specialists and specify a cooling off period.
- Most bills (including the *ROTTIA*) contain oversight mechanisms, commonly reporting to the Coroner.

So despite many attempts to reform the law, assisted dying remains unlawful in Australia. This has not, however, prevented people from assisting others to end their lives. From time to time, doctors have admitted to providing such assistance to patients who are approaching the end of their lives and are experiencing unbearable suffering. For the most part, such admissions by doctors have not resulted in police investigation or prosecution.[18] Also at risk are individuals who respond to requests from a terminally ill family member or friend who seeks their assistance to die. There are reasonably regular prosecutions in such cases[19] although judges frequently hand down sentences less than the maximum permitted, and often do not impose a custodial sentence on the accused in these cases.[20]

Pressure to change the law continues to build. Media interest in reform has been unparalleled, perhaps fuelled by the campaign for reform spearheaded by Andrew Denton, the high profile entertainer. Media attention is also sparked, and public debate ensues, when health professionals are investigated for assisting one of their terminally ill patients to die (as is reportedly the case for Dr Alida Lancee in Western Australia)[21] or conditions are imposed on

[18] See, eg, admissions by Dr Rodney Syme about providing assistance to die: Norman Hermant, 'Euthanasia debate: Doctor confirms he helped patients die, wants to be charged', *ABC News* (online), 8 May 2014 <http://www.abc.net.au/news/2014-05-07/doctor-confirms-he-helped-patient-die/5437686>. Despite that report, Dr Syme was not arrested or prosecuted for a criminal offence.
[19] Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16(1) *QUT Law Review* 84-112, 103-104.
[20] Ibid.
[21] Nicolas Perpitch, 'Perth doctor investigated by police after admitting hastening patient's death', *ABC News* (online), 24 August 2016 <http://www.abc.net.au/news/2016-08-24/doctor-alida-lancee-investigated-after-

their ability to practise medicine (as in the case of Dr Rodney Syme in Victoria).[22] We have also seen a great deal of political activity by members of parliament federally and in all Australian States. For example, at the Commonwealth level, the Australian Greens plan to table a bill during the current term of parliament,[23] and at State level, there are bills that have been introduced or which are being drafted in New South Wales,[24] Western Australia[25] and Tasmania.[26] In South Australia, the State where there have been more reform attempts than in any other Australian jurisdiction, the *Death with Dignity Bill* was defeated in November 2016 by just one vote.[27] Even in Queensland, where an assisted dying bill has never been introduced, Peter Wellington (an independent member of parliament) has recently called for a parliamentary inquiry into end-of-life decision-making with a goal of providing individuals with more choice.[28]

But it is currently in Victoria where reform appears most likely. At the time this book goes to print, an expert panel appointed by the Premier, the Honourable Daniel Andrews, is tasked to draft an assisted dying bill with a view to it being tabled in Victorian parliament in the second half of 2017.[29] The establishment of an expert panel follows a recommendation by the Victorian

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hastening-patient-death/7780788>. At the time of writing, there are no media reports that Dr Lancee has been charged.

[22] In 2016, the Medical Board of Australia imposed a condition on the registration of Victorian doctor, Dr Rodney Syme, following a mandatory notification from a general practitioner that Dr Syme was to assist a terminally ill patient to end his life: Julia Medew, 'Medical Board of Australia investigates euthanasia doctor Rodney Syme', *The Age* (online), 7 March 2016 <http://www.theage.com.au/victoria/medical-board-of-australia-investigates-euthanasia-doctor-rodney-syme-20160307-gnca3j.html>. The condition prevented him from engaging in '… the provision of any form of medical care, or any professional conduct in his capacity as a medical practitioner that has the primary purpose of ending a person's life'. On appeal, the Victorian Civil and Administrative Tribunal set aside the condition, 'on the basis the Tribunal is not able … to form a reasonable belief that Dr Syme's conduct places persons at serious risk or that it is necessary to take immediate action to protect public safety': *Syme v Medical Board of Australia* [2016] VCAT 2150 at [185].

[23] The Greens, 'Don't punish doctors for voluntary euthanasia: Greens' (Media Release, 25 August 2016) <http://greens.org.au/sites/greens.org.au/files/20160627_Dying%20with%20Dignity_0.pdf>. See also the *Medical Services (Dying with Dignity) Exposure Draft Bill 2014* which was released for consultation in 2014 by Greens Senator Richard Di Natale: <http://www.aph.gov.au/~/media/Committees/Senate/committee/legcon_ctte/dying_with_dignity/Exposure%20draft%20dying%20with%20dignity.pdf>.

[24] Sean Nicholls and Kate Aubusson, 'Voluntary euthanasia laws to come before NSW Parliament this year', *The Sydney Morning Herald* (online), 16 January 2017 <http://www.smh.com.au/nsw/voluntary-euthanasia-laws-to-come-before-nsw-parliament-this-year-20170115-gtrsz0.html>.

[25] Regina Titelius, 'Bid for voluntary euthanasia in WA', *PerthNow* (online), 26 March 2017 <http://www.perthnow.com.au/news/western-australia/bid-for-voluntary-euthanasia-in-wa/news-story/135bf31fc63cb14c0eb7d507814fdaee>.

[26] At the time of writing the Voluntary Assisted Dying Bill 2016, introduced in the Tasmanian House of Assembly by Labor MP Lara Giddings and Greens MP Cassy O'Connor in November 2016, is awaiting its 2nd reading: Parliament of Tasmania, Voluntary Assisted Dying Bill 2016 73 of 2016 <http://www.parliament.tas.gov.au/bills/73_of_2016.htm>.

[27] 23 votes were in favour and 24 votes opposed the Bill.

[28] Caldwell, 'Voluntary euthanasia: Calls for Queensland Parliamentary Inquiry', above n 12.

[29] Victoria Health and Human Services, *Voluntary Assisted Dying Bill Discussion Paper* (2017)

Parliament Legislative Council Legal and Social Issues Committee to legalise assisted dying in Victoria.[30] Interestingly, the legal framework recommended by the Committee has many similar features to those of the repealed *ROTTIA* (and indeed many of the bills subsequently introduced in Australian States) including that assistance would only be available to an adult who is competent at the time of the request, the request must be repeated, voluntary, and not as a result of undue influence and the adult must be at the end of their life (NT – 'terminally ill'; Vic – 'end of life')[31] and informed about their illness or disease as well as palliative care options. Under both regimes, eligibility must be assessed by more than one doctor, and safeguards are imposed in relation the assessment of capacity (NT – psychiatrist required in all cases; Vic – psychiatrist required if there are doubts about capacity). A key difference, however, is that the *ROTTIA* permitted both voluntary euthanasia and assisted suicide whereas the Victorian Committee has recommended a primarily physician assisted suicide model.

After initially leading the world, Australia has not had an assisted dying law for over twenty years, despite repeated efforts to change the law. But recent indications suggest this may soon change with momentum for reform building, particularly in Victoria. If the law does change in one Australian jurisdiction to allow assisted dying, other States and Territories are likely to follow. This follows a trend of liberalisation internationally, to which we now turn.

A brief snapshot of international assisted dying regimes

This section provides a brief overview of the international jurisdictions that permit assisted dying. The focus is on the three main areas in the world that have legislated to permit assisted dying – Europe, the United States and Canada.

Europe.

There are four jurisdictions in Europe where assisted dying is lawful: the Netherlands, Belgium, Luxembourg and Switzerland. The focus of the below discussion is the Netherlands and Belgium as they have been in operation longest (and the Luxembourg regime is similar to Belgium). There is also a brief discussion of the Swiss approach.

<https://www2.health.vic.gov.au/about/publications/researchandreports/voluntary-assisted-dying-bill-discussion-paper>.

[30] Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report*, above n 3.

[31] Note, however, that under the proposed Victorian model, the relevant condition is described as 'serious and incurable' rather than 'terminal illness' as under the Northern Territory legislation.

The Netherlands

Both voluntary euthanasia and physician-assisted suicide are permitted in the Netherlands. Under the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002*[32] doctors are protected from criminal charges provided that they adhere to the stipulated requirements for assisting patients to die. When a voluntary and well-considered request is made by a patient for assistance to bring about their death, a doctor concludes that their suffering is lasting and unbearable, and the patient holds the conviction that there is no other reasonable solution to their situation, a doctor is legally permitted to provide them with assistance to bring about their death (Art 2). It is obligatory for the doctor to have informed the patient about their situation and their options, and for the practitioner to have consulted at least one other doctor (Art 2). If the patient is between 16 and 18 years old, and has a reasonable understanding of their interests, their parents must be involved in the decision process although there is no requirement for them to agree with their child's request. If they are between 12 and 16, and have a reasonable understanding of the process, the doctor can only act on the patient's request if the parents agree. If the patient is aged 16 years or older and is no longer capable of expressing their wishes, the doctor can act on their earlier wishes if, prior to reaching this condition, the patient, who had a reasonable understanding of their interests, made a written request for assisted dying.

The Netherlands has established Regional Review Committees for assisted dying.[33] Their role is to assess whether doctors who have terminated a life on request or assisted in a suicide have acted in accordance with the requirement of due care (Art 8). They can provide information to prosecutors as they deem appropriate (Art 10).

Belgium

Belgium legalised voluntary euthanasia in designated circumstances in 2002.[34] The *Belgian Act on Euthanasia 2002* permits euthanasia[35] if the person is in 'a medically futile condition of

[32] *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002* (Netherlands).
[33] See Regional Euthanasia Review Committees, *Annual Report 2013* (2014) <https://english.euthanasiecommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports>; Guy Widdershoven, 'Euthanasia in the Netherlands: Experiences in a Review Committee' (2004) 23(3) *Medicine and Law* 687-691.
[34] See Neera Bhatia, Ben White and Luc Deliens, 'How Should Australia Respond to Media-Publicised Developments on Euthanasia in Belgium?' (2016) 23(4) *Journal of Law and Medicine* 835-848 for a discussion of the operation of the law.
[35] 'Euthanasia' is defined as 'intentionally terminating life by someone other than the person concerned, at the latter's request': *Belgian Act on Euthanasia 2002*, s 2.

constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident'.[36] The patient's request must be in writing and signed by the patient[37] and must be 'durable'.[38] The doctor must explain to the patient information regarding his or her health condition and life expectancy.[39] The doctor and patient must consider there to be no reasonable alternative to the patient's situation.[40] The doctor must also be satisfied that the patient's request is completely voluntary and that the patient is in a state of constant physical or mental suffering.[41] Belgium's Federal Control and Evaluation Committee on Euthanasia undertakes monitoring of the application of the law.

In 2013, the law was extended to permit access for children provided they have the 'capacity of discernment', that is, are able to demonstrate an understanding of the absolute consequences of such a request.[42] This is analogous to the Australian law concept of *Gillick* competence. Other requirements include that the child's parents approve the decision, the child's illness must be such that death is expected in the short term and 'they must be in great pain, with no available treatment to alleviate their distress'.[43] The doctor assisting the minor must also consult a child psychiatrist or psychologist to discuss the case.

Switzerland

The legislative regime in Switzerland differs from those in the Netherlands and Belgium in that Switzerland has not passed legislation to make either euthanasia or assisting a suicide lawful in specific circumstances.

Instead,
the law in Switzerland is governed by its Criminal Code, and under that Code, both of these acts are unlawful (euthanasia – in all circumstances; and assisted suicide – if done for selfish motives).[44] Under Article 114, any person who for commendable motives, and in particular

[36] *Belgian Act on Euthanasia 2002*, s 3§(1).
[37] *Belgian Act on Euthanasia 2002*, s 3§(4).
[38] *Belgian Act on Euthanasia 2002*, s 3§(2).
[39] *Belgian Act on Euthanasia 2002*, s 3§(2).
[40] *Belgian Act on Euthanasia 2002*, s 3§(2).
[41] *Belgian Act on Euthanasia 2002*, s 3§(2).
[42] There is no official English translation available of the recent Belgian amendments relating to children. The examination of the law here is based on this unauthorised version: Christian Munthe, 'Legalised Euthanasia for Children Regardless of Age in Belgium: The Actual Law in English', Philosophical Comment (28 August 2015) <http:// philosophicalcomment.blogspot.com.au/2014/02/legalised-euthanasia-for-children.html>.
[43] Bhatia, White and Deliens, 'How Should Australia Respond to Media-Publicised Developments on Euthanasia in Belgium?', above n 34, 842.
[44] *Criminal Code 1937* (Switzerland).

out of compassion for the victim, causes the death of a person at that person's own genuine and insistent request shall be liable to a custodial sentence not exceeding three years or to a monetary penalty.[45] Article 115 deals with assisting another to commit suicide and provides that 'any person who for *selfish motives* incites or assists another to commit or attempt to commit suicide shall, if that other person thereafter commits or attempts to commit suicide, be liable to a custodial sentence not exceeding five years or to a monetary penalty' (emphasis added).[46]

The effect of article 114 is that voluntary euthanasia is unlawful and the person performing the act commits a crime, even if the act is done for 'commendable motives' at the other's request. On the other hand, not all cases of assisting a suicide will be illegal. Assisting a suicide is only an offence if it is done for 'selfish' motives. There is unlikely to be a breach of article 115 where a person has a medical condition which causes unbearable pain and suffering, forms a desire to end his or her life to relieve that pain and suffering, and seeks assistance to achieve that goal.

The United States

In most of the United States, physician-assisted suicide is illegal. However, it is legal in seven jurisdictions: Oregon,[47] Washington,[48] Vermont,[49] California,[50] Colorado[51] and the District of Columbia[52] through legislation, and in Montana by way of court decision which concluded that consent provides a statutory defence to a charge of homicide.[53] In the legislative jurisdictions, the statutes are closely modelled on Oregon so we focus here on that jurisdiction given its two decade history of physician-assisted suicide.

Since 1997, an Oregon law (passed in 1994)[54] has permitted residents of Oregon to receive prescriptions for self-administered lethal medication from their doctors provided the patient is 'capable', namely able to make and communicate decisions about their health care, and has an

[45] *Criminal Code 1937* (Switzerland), art 114.
[46] *Criminal Code 1937* (Switzerland), art 115.
[47] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994).
[48] *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.904 (2008).
[49] *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281–93 (2013).
[50] *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (2015).
[51] *End-of-Life Options Act*, Colo Rev Stat §§ 25-48-101 – 25-48-123 (2016).
[52] *Death with Dignity Ac*t, Law 21-577 D.C (2016).
[53] *Baxter v Montana* 224 P 3d 1211 (2009).
[54] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994). See Joan Woolfrey, 'What Happens Now? Oregon and Physician-Assisted Suicide' (1998) 28(3) *Hastings Center Report* 9-17; Linda Ganzini, 'Legalised Physician-Assisted Death in Oregon' (2016) 16(1) *QUT Law Review* 76-83.

illness expected to lead to death within six months.[55] The patient must make one written and two oral requests to their physician, the latter separated by at least 15 days.[56] The patient's primary physician and a consultant must confirm the diagnosis of a terminal condition and the prognosis, determine that the patient is capable,[57] and refer the patient for counselling, if either believes that the patient's judgment is impaired by depression or some other psychiatric or psychological disorder.[58] The primary physician must also inform the patient of all feasible alternatives, such as comfort care, hospice care, and pain-control options.[59] Physicians must report all prescriptions that they write for lethal medications to the Oregon Health Division.[60]

Canada

There has been considerable judicial and legislative activity in Canada over recent years. Legislation was first enacted in Quebec with *An Act Respecting End-of-Life Care*[61] commencing operation in December 2015. The stated objective of the Act is 'to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy'.[62] Unlike the European models, the Act regulates end-of-life care more broadly and includes both palliative care and medical aid in dying.[63]

The second development affected the entire country. In *Carter v Canada (Attorney General)*,[64] the constitutionality of the provisions of the Canadian *Criminal Code* that prohibited voluntary euthanasia and assisted suicide was challenged on the basis of breaching sections 7 (the right to life, liberty and security of the person) and 15 (the right to equality) of the Canadian *Charter of Rights and Freedoms*. The case originated with Kay Carter, a woman who had a severe case of spinal stenosis. She asked her family to take her to Switzerland so that she could end her life, and they did so. Her daughter and son-in-law became the first plaintiffs in the case. Gloria Taylor subsequently joined the case as another central plaintiff. She was a woman who suffered

[55] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994), s 2.01
[56] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994), s 3.06.
[57] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994), ss 3.01 and 3.02.
[58] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994), s 3.03.
[59] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994), s 3.01.
[60] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994), s 3.11.
[61] *An Act Respecting End-of-Life Care*, R.S.Q. c. S-32.0001.
[62] *An Act Respecting End-of-Life Care*, R.S.Q. c. S-32.0001, s 1.
[63] *An Act Respecting End-of-Life Care*, R.S.Q. c. S-32.0001, s 3.
[64] *Carter v Canada (Attorney General)* [2015] 1 SCR 331. For commentary on this case, see Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions', above n 18.

from amyotrophic lateral sclerosis which causes progressive and fatal muscle weakness. She asked the court to strike down the *Criminal Code* barriers to physician-assisted death.

The Supreme Court held that the *Criminal Code* breached s7 of the Canadian *Charter of Rights and Freedoms*, which protects "the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice". The prohibitions imposed by the *Criminal Code* were overbroad and thus not in accordance with the principles of fundamental justice. That is, the prohibitions were broader than was necessary to achieve the objective of the provision, namely the protection of the vulnerable from being induced to end their lives suicide in times of weakness. The violation of s7 was not "demonstrably justified in a free and democratic society" (because the provisions limit the rights more than necessary to achieve the objectives) and so the provisions were unconstitutional. The Supreme Court issued a declaration that the relevant provisions of the *Criminal Code* were void insofar as they prohibited physician-assisted death for a competent adult who clearly consented to the termination of life and had a grievous and irremediable medical condition (including an illness, disease or disability) that caused enduring suffering that was intolerable to the individual in the circumstances of their condition. The Supreme Court also declared that 'irremediable' did not require the patient to undertake treatments that were not acceptable to him or her.

In response to the *Carter* decision, the Canadian Parliament passed a law which came into force on 17 June 2016.[65] The legislation contains a range of eligibility criteria and procedural safeguards. In terms of eligibility, the person must be an adult, be capable of making health decisions, have made a voluntary request, have given informed consent, and have a grievous and irremediable condition. The legislation provides that to have such a condition:

- the person must have a serious and incurable illness, disease or disability;
- the person must be in an advanced state of irreversible decline of capability;
- the person must have enduring physical or psychological suffering that is intolerable to them which cannot be relieved under conditions that are acceptable to them; and
- the person's natural death must be reasonably foreseeable.

[65] *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* S.C. 2016.

Core values that should underpin this area of law[66]

There will never be total agreement on whether permissive assisted dying laws should be enacted in Australia. People hold positions which are shaped by deeply held personal values and beliefs. Individuals have different value systems which will result in different positions about whether it should ever be lawful to assist another person to end his or her life. However, the law must ultimately take a position on this issue – retain the prohibition full stop, retain the prohibition but introduce a defence, or adopt a permissive regime. In this section, we articulate the core values that we contend should underpin the law: life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, and reducing human suffering.[67] These values are derived from existing Australian legal principle, as reflected in common law, legislation or conventions or treaties that have been ratified by Australia. In the section that follows, we then draw on these values to determine what the legal position should be in relation to assisted dying in Australia.

Life

The fundamental importance of human life is recognised by our legal system. The criminal law in all States and Territories makes the killing of another person unlawful unless it is authorised, justified or excused.[68] It also makes assisting another person to commit suicide unlawful.[69] Further, the value of human life is recognised by the common law, as revealed in court decisions about whether to permit the withholding or withdrawal of potentially life-sustaining treatment. In the landmark case of *Airedale NHS Trust v Bland*, for example, the House of

[66] In this section we draw heavily on the descriptions of values previously set out by two of the authors in Jocelyn Downie, Lindy Wilmott and Ben White, 'Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining treatment' (2014) 26(1) *New Zealand Universities Law Review* 24.

[67] We do not, here, discuss the value 'dignity' because it is relied upon to justify opposite conclusions on end-of-life issues by all sides of the debate. There is also no agreed upon definition. We believe that the debate about end-of-life decision-making can more usefully proceed by setting aside the term 'dignity' and instead focusing on the concepts that most commonly lie behind it – that is, equality and autonomy. We take this position for the reasons articulated in Udo Schuklenk et al, 'End of Life Decision Making in Canada: The Report by the Royal Society of Canada Expert Panel on End of Life Decision-Making (2011) 25 *Bioethics* 1-73, 38-45.

[68] LexisNexis, *Halsbury's Laws of Australia* (at 18 November 2016) 130 Criminal Law, '3 Homicide' [130-3000].

[69] LexisNexis, *Halsbury's Laws of Australia* (at 5 September 2016) 80 Civil and Political Rights, '2 Civil Rights', '2 Right to Life' [80-920].

Lords accepted that 'sanctity of life' formed part of the English legal system[70] and Australian courts have also recognised the State's interest in preserving human life.[71]

The value of life can be upheld through prohibiting assisted dying and this is the principal way in which this value is drawn upon in current debates. However, there is a sense in which the value of life can be advanced through *permitting* assisted dying. This was recognised by the Supreme Court of Canada in *Carter v Canada (Attorney General)*, which held that the current blanket prohibition on assisted suicide breached the right to life.[72] The Court's reasoning included that where suicide is legally permitted but assisted dying is not, some individuals may die earlier than they would if assisted dying were permitted. That is, they may commit suicide before they would request assisted dying because they fear losing the physical capacity to commit suicide and being trapped with no way out.[73]

Furthermore, preserving human life is not an absolute value. The law in Australia (and indeed in many common law jurisdictions throughout the world) recognises that the value of an individual's life can sometimes be outweighed by the disvalue of their suffering. In other words, a person may decide that life is no longer worth living to them. For this reason, the law allows a competent individual to refuse treatment, even if that treatment is necessary to preserve life and is recommended by doctors.[74] Where a person has completed a valid advance directive,[75] and, in some cases, where a substitute decision-maker refuses treatment,[76] the law also allows treatment to be withheld from a person who lacks decision-making capacity. While we, as a society, recognise the intrinsic value of life and the possibility of instrumental value for life (for the individual and those the individual cares about), we already acknowledge that

[70] *Airedale NHS Trust v Bland* [1993] AC 789, 859.
[71] See, eg, *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [5]-[16], and more recently a reference by a majority of the Australian High Court in *Patel v The Queen* (2012) 247 CLR 531, [87] to 'the value the law places on human life'.
[72] *Carter v Canada (Attorney General)* [2015] 1 SCR 331.
[73] *Carter v Canada (Attorney General)* [2015] 1 SCR 331, [57]-[58].
[74] See, eg, *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84; *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449; *Auckland Area Health Board v Attorney-General NZ* [1993] 1 NZLR 235, 245; *Smith v Auckland Hospital Board* [1965] NZLR 191, 219.
[75] See generally Lindy Willmott, Ben White and Shih-Ning Then, 'Withholding and Withdrawing Life-Sustaining Medical Treatment' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) [14.100] (the common law), [14.150]-[14.170]; Lindy Willmott, Ben White and Ben Matthews, 'Law, Autonomy and Advance Directives' (2010) 18 *Journal of Law and Medicine* 366. See also *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 which recognised the right of a competent adult to make a binding advance directive.
[76] See generally Willmott, White and Then, 'Withholding and Withdrawing Life-Sustaining Medical Treatment', above note 75, [14.180]-[14.230].

for some individuals who are enduring suffering that is unacceptable to them, other values can outweigh the intrinsic and instrumental value of their life.

Autonomy

The principle of respect for autonomy is a fundamental part of Australian common law. In the High Court case of *Stuart v Kirkland-Veenstra,* Gummow, Heydon and Hayne JJ recognised, in the context of a negligence action, 'an underlying value of the common law which gives primacy to personal autonomy'[77] and observed that personal autonomy is 'a value that informs much of the common law'.[78] The value of autonomy is also a core value in the context of health law. It prevails over the value of life when a competent adult, for whatever reason, refuses medical treatment even if that treatment is needed to stay alive. In *Brightwater Care Group (Inc) v Rossiter*, Martin CJ refers to the 'common law principle of autonomy and self-determination'[79] and also notes that the principle is 'well established at common law'.[80] In that case, a man with quadriplegia was being kept alive by the delivery of artificial nutrition and hydration and decided that he no longer wished to receive such medical treatment. The Western Australian Supreme Court recognised his right to self-determination, and that this prevailed over the State's interest in keeping him alive.

Although the law prioritises autonomy over life in decisions to refuse medical treatment, the current legal position is reversed if a competent adult seeks assistance to end his or her life in the context of assisted dying. The criminal law prohibits this assistance, and the fact that the person requests help to end his or her life (in the exercise of his or her autonomy) does not alter the legal position. This anomaly begs the question about the different possible meanings of the term 'autonomy' in law.[81] In the context of refusals of treatment, autonomy has generally been interpreted in Australia as the narrow right to prevent physical interference with one's bodily

[77] *Stuart v Kirkland-Veenstra* (2009) 237 CLR 215, [87].
[78] *Stuart v Kirkland-Veenstra* (2009) 237 CLR 215, [88]. See also, eg, *Cole v South Tweed Heads Rugby Club* (2004) 217 CLR 469, [14] (Gleeson CJ); *Perre v Apand Pty Ltd* (1999) 198 CLR 180, [88] (McHugh J).
[79] *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84, [48].
[80] Ibid [24]. For other examples, see *H Ltd v J* (2010) 107 SASR 352, 369 and the heading 'Common law right to self-determination' at 364; and *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [5].
[81] In philosophy, it has even more different meanings. For example, contrast the conception of autonomy articulated by John Stuart Mill (a liberal individualist) in *On Liberty* (Longman, Roberts & Green, 4th ed, 1869) with that articulated by Susan Sherwin (a feminist relational theorist) in 'A Relational Approach to Autonomy in Health Care' in Susan Sherwin (ed), *The Politics of Women's Health: Exploring Agency and Autonomy* (Temple University Press, 1998) 19.

integrity.[82] This is what requires a refusal of treatment to be respected at law. A wider view, a right to self-determination, involves having one's will respected and acted upon and would include the ability to receive assistance to die.[83]

These different views about what autonomy might mean do not detract from accepting autonomy as an appropriate value to underpin decisions about regulation of assisted dying; rather, they point to the need to clarify which sense of respecting autonomy is meant. We consider that it is the latter view of autonomy – as self-determination – that should inform regulation of decision-making for a person who is approaching the end of their life and enduring intolerable suffering. The case for embracing autonomy as self-determination starts with how autonomy is understood in contemporary Australian society. It is unlikely that Australians understand autonomy in the narrow sense of only preserving bodily integrity; if asked, they would talk in terms of the broader concept of self-determination. We note that this wider approach was also adopted by the Victorian Legislative Council Legal and Social Issues Committee when articulating the core values that they believed should underpin end-of-life care.[84] And while the narrow view has received firm and unwavering support in law, this has occurred in the context of cases involving *refusals of treatment*. The narrow view is sufficient for deciding these cases so it is not surprising that they have been confined in this way. Judges are inclined to decide cases on the narrowest possible basis and so this should be taken only as silence, and not rejection, of autonomy as self-determination.[85]

We consider that given society's understanding of autonomy as self-determination (which is reflected in the approach of the Victorian Parliamentary Committee),[86] the value of autonomy

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[82] See, eg, *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion's Case)* (1992) 175 CLR 218, 232-233, 265, 309-210; *Hunter and New England Area Health Service v A* [2009] NSWSC 761, [5], [17]; *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84 at [23], [24], [26], [31]-[32].

[83] Although in the context of decisions to withhold or withdraw potentially life-sustaining medical treatment, see Loane Skene, 'Disputes about the Withdrawal of Treatment: the Role of the Courts' (2004) 32 *Journal of Law Medicine and Ethics* 701 where she comments on the narrow and wide interpretations of the concept of autonomy. The wider approach to autonomy, again in the context of requesting potentially life-sustaining treatment, was adopted by Justice Munby at first instance in *R (Burke) v General Medical Council* [2005] QB 424, [130] where he commented that article 8 of the *Human Rights Act 1998* means that it is for a competent patient to decide the treatment he or she should or should not be given. Note however Munby J's decision and this more expansive approach to autonomy were overturned by the Court of Appeal: *R (Burke) v General Medical Council* [2006] QB 273.

[84] Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report*, above n 3, xxi.

[85] For example, in *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84 at [20], the judge explicitly noted that 'I should only answer questions directly and explicitly raised by the facts of this particular case, and refrain from making any observations with respect to any other hypothetical scenarios.'

[86] Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report*, above n 3, xxi.

proposed here should be understood in the wider sense of having one's will respected and acted upon. As with all values, however, promoting self-determination is not unqualified and is subject to the claims of other competing values.

Freedom of Conscience

Conscience is a value recognised generally by the Australian legal system[87] and respecting the conscience of health professionals in particular is also reflected in law.[88] Further support for conscience is found in position statements of peak medical bodies which endorse the need for doctors to be able to practise medicine in accordance with their conscientiously held beliefs.[89] The value of conscience suggests that doctors (and other health professionals) should not be required to participate in assisted dying where doing so is contrary to their conscience.

While the conscience of health professionals who oppose assisted dying and the need to protect them from an obligation to practise contrary to their beliefs is important and has been prominent in the Australian debate, the right to act according to conscience is not absolute. It can be overridden where competing values require. An example is a competent refusal of potentially life-sustaining treatment. Here, the law requires that such treatment not be given notwithstanding that a doctor may conscientiously believe that this is wrong because the patient will die without treatment.[90]

We also note that conscience can tilt toward *permitting* assisted dying. Some health professionals want to be able to provide assisted dying as they believe it is a part of good end-of-life care.[91] Some believe that they would fail in their duty to their patient *not* to assist them to die. Even in Australia where the practice is unlawful, a small number of doctors have

[87] *International Covenant on Civil and Political Rights,* opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 18 (signed by Australia on 18 December 1972 and ratified on 13 August 1980*); Charter of Human Rights and Responsibilities Act 2006* (Vic) s 14; *Human Rights Act 2004* (ACT) s 14.
[88] See, eg, the following with respect to abortion: *Health Act 1993* (ACT) s 84; *Medical Services Act* (NT) s 11(6)-(7); *Criminal Law Consolidation Act 1935* (SA) s 82A(5)-(6); *Health Act 1911* (WA) s 334(2).
[89] See, eg, Australian Medical Association, *Position Statement on Conscientious Objection* (28 November 2013) <https://ama.com.au/position-statement/conscientious-objection-2013>; Australian Nursing and Midwifery Federation, *Policy on Conscientious Objection* (February 2015), <http://anmf.org.au/documents/policies/P_Conscientious_Objection.pdf>; Medical Board of Australia, *Good medical practice: a code of conduct for doctors in Australia* (March 2014) [2.4.6] <http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>
[90] *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449, 475; *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84, [24]-[25]; *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [17].
[91] See, eg, College des Medicins du Quebec *Physicians, Appropriate Care and the Debate on Euthanasia: A Reflection* (2009) 2, 7 <http://www.cmq.org/publications-pdf/p-1-2009-10-01-en-medecin-soins-appropries-debat-euthanasie.pdf>

admitted to assisting their patients to die in a bid to relieve their suffering.[92] In a rare (and famous) case in which a doctor, Dr Cox, was prosecuted and ultimately convicted of attempted murder following the death of his patient. Five days before her death, Dr Cox's patient pleaded for an injection to end her life. Three days later, Dr Cox wrote in his notes: 'She still wants out and I don't think we can reasonably disagree.'[93] The current law prohibits these health professionals from following their conscience and assisting their patients to die.

Thus, while respecting conscience is important,[94] we need to recognise everyone's consciences are implicated in assisted dying policy decisions. This points to a permissive regime that does not compel health professionals to assist individuals to die, but also does not prevent health professionals from providing that assistance in certain circumstances.

Equality

The Australian legal system has made significant commitments to the value of equality through becoming a signatory to the Convention on the Rights of Persons with Disabilities,[95] and passing human rights[96] and anti-discrimination legislation.[97] These instruments endorse equality and reject discrimination, including discrimination on the basis of disability. The rule of law (which underpins the Australian legal system and itself a core value which is discussed below) also requires that the law treat people equally.[98]

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[92] See, eg, the media report by Julia Medew, 'Doctor admits giving dying man the drugs to end his life' that Dr Rodney Syme admitted giving a terminally-ill man Nembutal prior to the man's death: *The Age* (online) 28 April 2014: <http://www.theage.com.au/victoria/doctor-admits-giving-dying-man-the-drugs-to-end-his-life-20140427-zr07i.html>. See also an open letter to *The Age* newspaper calling for euthanasia law reform by 7 Melbourne doctors in which they wrote: 'It cannot be right to tolerate this totally unsatisfactory situation, where it is a matter of chance whether patients will receive the treatment which they so desperately seek and where it must be only a matter of time before some doctor is prosecuted by the state for following the dictates of his conscience': 25 March 1995, 'Helping Patients to Die', *The Age*.

[93] Dr Cox's patient, Mrs Boyes, had suffered from acute rheumatoid arthritis for 20 years, had 'developed ulcers and abscesses on her arms and legs, a rectal sore penetrating to the bone, fractured vertebrae, deformed hands and feet, swollen joints, and gangrene from steroid treatment': C Dyer, 'Rheumatologist Convicted of Attempted Murder' (1992) 305 *British Medical Journal* 731 as cited in R Magnusson, *Angels of Death: Exploring the Euthanasia Underground*, (Melbourne University Press, 2002) 25.

[94] Jocelyn Downie and Francoise Baylis, 'A test for freedom of conscience under the Canadian Charter of Rights and Freedoms: Regulating and litigating conscientious refusals in health care' (2017) *McGill Journal of Law and Health* (forthcoming).

[95] The *Convention on the Rights of Persons with Disabilities,* opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) was signed by Australia on 30 March 2007 and ratified on 17 July 2008. Pursuant to this Convention, States Parties agree to prohibit all discrimination on the basis of disability (Article 5: Equality and Non-Discrimination).

[96] *Charter of Human Rights and Responsibilities Act 2006* (Vic); *Human Rights Act 2004* (ACT).

[97] See, eg, *Disability Discrimination Act 1992* (Cth); *Anti-Discrimination Act 1991* (Qld); *Equal Opportunity Act 1984* (WA); *Anti-Discrimination Act 1977* (NSW); *Equal Opportunity Act 1984* (SA).

[98] See, eg, the second key principle identified by the Law Council of Australia in their Policy Statement on the Rule of Law: Law Council of Australia, *Policy Statement: Rule of Law Principles* (March 2011)

Equality is implicated in the assisted dying discussion in various ways – both in terms of whether assisted dying laws should be introduced, and also the substantive content of those laws. In terms of whether assisted dying should be allowed, we note that individuals without disabilities are able to end their suffering through suicide. But this option may not be open to some individuals who have a physical disability that prevents them from doing so. Prohibiting assisted dying can thus be seen as offending the value of equality through discrimination on the basis of physical disability.[99]

We turn next to how the value of equality can influence the nature of regulation. First, similar to the point above, a legislative framework that is limited to physician-assisted suicide and so requires the individual to administer the medication themselves, discriminates against those whose disability does not allow them to do this. Limiting assisted dying in this way would be inconsistent with the value of equality. Secondly, we believe that having a disability should not of itself prevent a person from receiving assistance under assisted dying legislation. That is, if the person satisfies the eligibility requirement of 'medical condition', he or she should not be regarded as ineligible because that medical condition results from a disability. More will be said on this later.

Rule of law

The Australian legal system is built upon the rule of law.[100] There is no universally accepted definition of the rule of law, and the concept is generally regarded as incorporating a range of

<https://www.lawcouncil.asn.au/lawcouncil/images/LCA-PDF/a-z-docs/PolicyStatementRuleofLaw.pdf> (discussed further below). See also Thomas Bingham, *The Rule of Law* (Penguin, 2010) ch 5.

[99] Support for this position can be found in the judgment of Justice Smith at first instance in *Carter v. Canada (Attorney General)* [2012] BCSC 886, [1158]-[1159]: 'The law, viewed as a whole, embodies the following principles: (1) persons who seek to take their own lives, but fail, are not subject to criminal sanction because there is no longer a criminal offence of suicide or attempted suicide; (2) persons who are rendered unable, by physical disability, to take their own lives are precluded from receiving assistance in order to do so by the *Criminal Code* offence of assistance with suicide. Those principles create a distinction based on physical disability. The effect of the distinction is felt particularly acutely by a subset of persons with physical disabilities represented by the plaintiff Gloria Taylor and others such as Mr. Fenker (now deceased), Mr. Morcos and Ms. Shapray – persons who are grievously and irremediably ill and physically disabled or will soon become so, are mentally competent, have full cognitive capacity, and wish to have a measure of control over their circumstances at the end of their lives. They may not wish to experience prolonged pain. They may wish to avoid the anxiety that comes with fear that future pain will become unbearable at a time when they are helpless. They may not wish to undergo palliative sedation without hydration or nutrition for reasons including concern for their families, fear for themselves or reaction against the total loss of independence at the end of their lives.'

[100] Westlaw AU, *The Laws of Australia* (at 26 April 2017) 21 Human Rights, '1 Development and Recognition of Human Rights' [21.1.140]; Peter Bailey, *The Human Rights Enterprise in Australia and Internationally* (LexisNexis, Sydney, 2009) 242–253; John Toohey, 'A Government of Laws, and Not of Men?' (1993) 4 *Public*

principles that are fundamental to a liberal western democracy. The rule of law has ancient origins, but the modern concept encompasses important principles including the separation of powers between the judiciary, executive and legislature; the equal application of laws to all; and procedural requirements, such as the availability of a fair hearing.[101] In 2011, the Law Council of Australia produced a policy statement setting out its formulation of the key principles comprising the rule of law in the Australian context.[102]

There are two important dimensions to the rule of law that are particularly important to the assisted dying debate: key principles one and two from the Law Council's policy statement. The first key principle is that the 'law must be both readily known and available, and certain and clear'.[103] This principle continues:

> The intended scope and operation of offence provisions should be unambiguous and key terms should be defined. Offence provisions should not be so broadly drafted that they inadvertently capture a wide range of benign conduct and are thus overly dependent on police and prosecutorial discretion to determine, in practice, what type of conduct should or should not be subject to sanction.[104]

This component of the rule of law is important if a decision is made to allow assisted dying. Any regulatory regime should provide sufficient clarity so individuals (health professionals and those seeking assistance) understand how the regime operates and can assess the implications of the regime for him or herself. That is, the scheme should have clearly expressed legal parameters.

Allied to this requirement is the need for regulation to have in-built protections to ensure that it is operating in the manner intended by parliament. For example, there would need to be appropriate safeguards to ensure that only individuals who are eligible receive assistance to die. Further, there should be robust oversight systems in place both in terms of reviewing individual cases for regulatory compliance, but also to address any systemic issues that may arise in relation to non-compliance.

Law Review 158, 168–169. See also *Patel v Chief Executive of Department of Labour* [1997] 1 NZLR 102,110-111; *Australian Communist Party v Commonwealth* (1951) 83 CLR 1, 60-61.

[101] Brian Z Tamanaha, *On the Rule of Law: History Politics and Theory* (Cambridge University Press, 2004) 33. See also Bingham, *The Rule of Law*, above n 97.

[102] Law Council of Australia, *Policy Statement: Rule of Law Principles*, above n 98.

[103] Ibid, Key Principle 1.

[104] Ibid.

The second key principle identified by the Law Council is that the 'law should be applied to all people equally and should not discriminate between people on arbitrary or irrational grounds'.[105] There are two aspects of this principle that are relevant in the assisted dying context. The first is determining who should be eligible to receive assistance under the legislation. For example, if a decision is made that individuals with a specified 'medical condition' are eligible, there would need to be 'a demonstrable and rational basis'[106] for excluding people who had such a medical condition from the ambit of the legislation. Different treatment of a person or group of individuals (such as those with a disability) without a rational basis would breach the rule of law. This aspect of the rule of law links with, and supports, the value of equality outlined above.

The second aspect of this principle is that 'no one should be regarded as above the law and all people should be held to account for a breach of law, regardless of rank or station'.[107] This means that compliance with law matters and further supports the case for safeguards and oversight to ensure that the law is being followed.

Protecting the vulnerable

A further value found within Australian law is protecting vulnerable persons within the community. For example, the High Court has recognised that vulnerability, albeit a wider meaning of vulnerability in terms of an inability to protect oneself from another's failure to take reasonable care, is an important feature of tort law.[108] A narrower form of vulnerability and one more akin to that raised in assisted dying debates is also protected by the common law through the equitable doctrines that permit transactions involving undue influence and unconscionable transactions to be set aside.[109] Australian law also recognises the importance of protecting the vulnerable through adult guardianship law with all Australian States and Territories recognising only decisions made by competent adults and imposing duties on others to safeguard the interests of persons who are not able to make their own decisions.[110]

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[105] Ibid, Key Principle 2. See also Bingham, *The Rule of Law*, above n 98, ch 5.
[106] Law Council of Australia, *Policy Statement: Rule of Law Principles*, above n 97, Key Principle 2.
[107] Ibid.
[108] See, eg, the High Court cases of *Woolcock Street Investments Pty Ltd v CDG Pty Ltd* (2004) 216 CLR 515 and *Barclay v Penberthy* (2012) 246 CLR 258. See also J Stapleton, 'The Golden Thread at the Heart of Tort Law: Protection of the Vulnerable' (2003) 24 *Australian Bar Review* 135, 141-149.
[109] LexisNexis, *Halsbury's Laws of Australia* (at 29 October 2015) 185 Equity, '5 Unconscionable Transactions' [185-875].
[110] For an overview of the principles that govern how decisions are made on behalf of others under guardianship legislation, see Ben White, Lindy Willmott and Shih-Ning Then, 'Adults who Lack Capacity: Substitute Decision-

But it is the criminal law, with one of its central purposes being protection of the community,[111] which provides the strongest statement about the importance of protecting the vulnerable. An illustration of this are the criminal law duties imposed on certain people to provide the 'necessaries of life' to various vulnerable groups in their care who cannot secure these necessaries themselves.[112] Protecting the vulnerable from taking their own life through the encouragement or coercion of others is also at the heart of the criminal law prohibition on assisting a suicide.[113]

The nature of vulnerability and who is vulnerable is contested.[114] Vulnerability could arise in a range of ways including because of: personal (e.g. family) or institutional (e.g. treating health professionals or hospitals) relationships that could possibly lead to coercion or undue influence; age or disability (including cognitive disability); or inadequate access to resources including financial resources or medical care. This value aims to protect those who are vulnerable to ensure they are not accessing assisted dying regimes where that is not a genuine desire on their part. Caution is needed, however, to ensure that a person is not regarded as incapable of choosing assisted death just because they belong to a group that has traditionally been regarded as vulnerable. For example, there is a risk of paternalism and not respecting autonomy and equality if a person with a disability is judged as too vulnerable to be able to access the scheme simply by virtue of that disability.[115]

This value requires that any legal response to assisted dying protect the vulnerable.[116] This justifies eligibility criteria and procedural safeguards to ensure that a person seeking assistance to die is able to make their own decision and does so free from pressure or coercion. However,

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Making' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) [7.80]-[7.95].

[111] David Lanham et al, *Criminal Laws in Australia* (Federation Press, 2006) ch 1B 'The Purposes of Criminal Law' <http://www.federationpress.com.au/pdf/Lanham%20Ch1B.pdf>.

[112] In relation to the common law, see *R v Taktak* (1988) 14 NSWLR 226. For the Code jurisdictions: Northern Territory: *Criminal Code Act 1983* (NT), s 149; Queensland: *Criminal Code Act 1899* (Qld), s 285; Tasmania: *Criminal Code Act 1924* (Tas), s 144; and Western Australia: *Criminal Code Act 1913* (WA), s 262.

[113] Margaret Otlowski, *Voluntary Euthanasia and the Common Law* (Oxford University Press, 2000) 88 discussing the Canadian Supreme Court reasoning in *Rodriguez* v. *Attorney General of British Columbia, Attorney General of Canada* [1993] 3 SCR 519.

[114] See, eg, *Seales v Attorney-General* [2015] NZHC 1239 [77]-[79]; David Mayo and Martine Gunderson, 'Vitalism Revitalized: Vulnerable Populations, Prejudice and Physician Assisted Death' (2002) July-August *The Hastings Center Report* 17-20.

[115] Anita Silvers, 'Protecting the Innocents from Physician-Assisted Suicide: Disability Discrimination and the Duty to Protect Otherwise Vulnerable Groups' in Margaret P Battin et al (eds), *Physician Assisted Suicide: Expanding the Debate* (Routledge, 1998) 133, 133, 135.

[116] This is also the view of the Victorian Parliamentary Committee in its Core Values: Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report*, above n 3, xxi.

the need to protect the vulnerable does not justify an absolute ban on assisted dying. Individuals who may be regarded as 'vulnerable' may want access to assistance to die, and the empirical evidence from permissive regimes around the world does not support the claim that the vulnerable cannot be protected.[117] While relevant studies have employed significantly different methods to gather data, they consistently find that groups who are generally regarded as 'vulnerable' are not more likely to access euthanasia or assisted dying.

In 2012, Rietjens et al published their findings from a systematic review of articles published over an 11 year period (1998-2009) that collected data about end-of-life decision-making and social factors of those who died.[118] They concluded that the administration of medication with a potential or certain life-shortening effect 'seemed generally to be practiced (sic) less often among the elderly, females and less-educated patients compared with younger, male or more educated patients'.[119] Another review of evidence was carried out more recently by Emanuel and colleagues.[120] Their study collected evidence about various aspects of euthanasia and assisted dying practices from a range of sources.[121] In terms of who is likely to access assistance to die, the researchers concluded that 'typical patients are older, white, and well-educated'.[122] Finally, a very recent published study by Blanke et al analysed 18 years of data collected in Oregon since the commencement of its legislation.[123] During this time, of the 1545 prescriptions that were written, 991 (64%) individuals died from ingesting the medication. Of

[117] In addition to the studies described next, this also represents the view of the trial judge in *Carter v. Canada (Attorney General)* [2012] BCSC 886 [852], [1242] (these findings were not disturbed by the Canadian Supreme Court who noted that the trial judge's findings were 'reasonable and open to her': ***Carter v Canada (Attorney General)*** [2015] 1 SCR 331 [109]).

[118] JAC Rietjens et al, 'Medical End-of-life Decisions: Does its Use Differ in Vulnerable Patient Groups? A Systematic Review and Meta-analysis' (2012) 74(8) *Social Science and Medicine* 1282. Note that for the purpose of this study, 'the administration of medication with a potential or certain life-shortening effect' included the provision of medication for pain relief that could also have ended life, as well as euthanasia and assisting a suicide.

[119] Ibid 1282. Note that these findings are consistent with an earlier study by Margaret P Battin et al, 'Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups' (2007) 33(10) *Journal of Medical Ethics* 591, 594-596 which reviewed data in Oregon and the Netherlands over 9 years and 15 years respectively (the latter data drawing on four death certificate surveys conducted during this period). This study concluded that those who received assistance to die 'appeared to enjoy comparative social, economic, educational, professional and other privileges': 591.

[120] Ezekiel J Emanuel et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe' (2016) 316(1) *JAMA* 79.

[121] The public literature was searched including surveys from 1947 to 2016, with a focus on original data from three main sources: surveys providing data on attitudes and practices; data from jurisdictions that have legalised euthanasia and assisted suicide that have data on prevalence and practices; and death certificate studies in the Netherlands and Belgium: Ibid 80.

[122] Ibid 79.

[123] Charles Blanke et al, 'Characterizing 18 years of the Death with Dignity Act in Oregon' (2017) *JAMA Oncology* doi: 10.1001/jamaoncol.2017.0243.

those 991 individuals, 51.4% were men, 96.6% were white, 98.6% were insured and 71.9% had some form of tertiary education.[124]

Reducing human suffering

The value of reducing human suffering is different from the preceding values in that it is specific to the end-of-life setting and is not a higher-level concept that applies across a legal system like the values of autonomy, life or freedom of conscience. As such, its recognition in law derives from analysing the particular legal areas that deal with palliative care and the relief of pain and symptom management. The common law has given great weight to the relief of pain through the doctrine of double effect which permits the hastening of death through medication provided this is necessary to relieve pain and suffering, and it is the health professional's intention to relieve pain rather than cause the person's death.[125] As such, the doctrine recognises that the value of reducing human suffering may trump that of life in some circumstances.

The doctrine of double effect is likely to be part of Australian common law[126] and appears to have been recognised in the case of *Re Baby D (No 2)*.[127] Some States have also enacted a statutory excuse for criminal responsibility to ensure appropriate palliative care can be provided where that is needed to relieve pain.[128] The Australian Capital Territory even enacted a limited right to 'receive relief from pain, suffering and discomfort to the maximum extent that is reasonable in the circumstances'.[129]

These laws show clear policy support in Australian law for the value of reducing human suffering and this is also reflected in the Victorian Standing Committee on Legal and Social Issues report which included alleviating pain and suffering as one of its core values for end-of-

[124] Ibid E3. Note that the percentages for individuals who were insured and who had some form of tertiary education quoted in the text were obtained through email correspondence with the author (dated 21 April 2017) as there were typographical errors in the published article.
[125] Ben White and Lindy Willmott, 'Double Effect and Palliative Care Excuses' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) [15.20].
[126] Ibid.
[127] *Re Baby D (No 2)* (2011) 45 Fam LR 313.
[128] White and Willmott, 'Double Effect and Palliative Care Excuses', above n 124, [15.30]-[15.110].
[129] *Powers of Attorney Act 2006* (ACT), s 86 and *Medical Treatment (Health Directions) Act 2006* (ACT), s 17. For a discussion of the likely interpretation of this 'right to pain relief', see White and Willmott, 'Double Effect and Palliative Care Excuses', above n 124, [15.30].

life regulation.[130] This legal recognition is further bolstered by widespread medical,[131] ethical[132] and policy[133] endorsement of reducing pain and managing symptoms as being critical to good end-of-life care.

While recognising the value of reducing human suffering is not controversial, the weight it carries and how it interacts with other values can be. As has been already noted, the law has prioritised relieving pain (where that is the primary intention) even if this may hasten death, but it has stopped short of allowing suffering to be a justification for intentionally ending a person's life. As we explain further below, we consider that, in some circumstances, the value of reducing human suffering supports making assisted dying lawful.

A regulatory model that reflects core values

Legislative reform is needed to make assisted dying lawful

After considering the above core values, we consider reform is needed. Allowing assistance to die enables a competent adult to assess and balance the value of their life and the disvalue of their suffering and to exercise their autonomy. This promotes both the values of life and autonomy. The value of conscience can be promoted by allowing health professionals the freedom not to participate in assisted dying as well as through an appropriately constructed system for transfers of care. The regime should ensure access to assisted dying for competent adults (autonomy) and eligibility criteria must avoid unjustifiable discrimination, including on the basis of disability (equality and the rule of law). The value of the rule of law can also be promoted through clearly expressed legal parameters about access to assisted dying and establishing safeguards and oversight mechanisms to ensure the law is followed. A regime with adequate safeguards (which empirical evidence demonstrates can be effective) can also serve the value of protecting the vulnerable. By respecting a person's decision to seek assistance to

[130] Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report*, above n 3, xxi.
[131] Australian Medical Association, *Position Statement on End of Life Care and Advance Care Planning* (5 September 2014) [1.2.3] and [3.5] <https://ama.com.au/system/tdf/documents/AMA_position_statement_on_end_of_life_care_and_advance_care_planning_2014.pdf?file=1&type=node&id=40573>
[132] See, eg, the Australian Medical Association, *Code of Ethics* (2016) [2.1.15] <https://ama.com.au/system/tdf/documents/AMA%20Code%20of%20Ethics%202004.%20Editorially%20Revised%202006.%20Revised%202016.pdf?file=1&type=node&id=46014>
[133] Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential Elements for Safe High Quality End of Life Care* (27 May 2015) [3.10] <https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf>

end their life when they are experiencing intolerable suffering, the value of reducing suffering, as assessed by that person, is also promoted. In summary, these values demonstrate the need for reform and that their sometimes competing claims can be accommodated in a regime that permits and regulates assisted dying. We favour reform by way of legislation rather than prosecutorial guidelines or evolution through case law.[134] A carefully drafted statute is more likely to provide the clarity and certainty that is critical here (promoting the rule of law).

In the remainder of this section, we outline a proposed model for assisted dying that reflects and promotes the core values. In some cases, these values push in different directions and so we explain how we have balanced them against each other in arriving at a position (expanding on some of the discussion in the values section). We also note that for some issues, the values provide a higher policy level direction for a legislative regime but do not provide guidance in relation to its specific details. To inform our thinking in these instances, we have reflected on all of the international legislative models, as well as the Act that operated briefly in the Northern Territory. We have also drawn on two proposals for reform that have currency in Australia: the Death with Dignity Bill which was narrowly defeated in South Australia in November 2016, and the Victorian model which was proposed (in broad terms) in June 2016 by the state's Legal and Social Issues Committee of the Legislative Council.

Nature of the model

Permissive or defence model[135]

A permissive decriminalisation model allows a person to assist another to end their life, but regulates the circumstances in which this will be lawful by setting out eligibility and procedural requirements as well as other safeguards. Most jurisdictions where assisted dying can be lawful adopt this model: the Netherlands, Belgium, Luxembourg, some jurisdictions in the United States (Oregon, Washington, Vermont, California, Colorado and the District of Columbia), Canada federally (amendments to their *Criminal Code*) as well as Quebec (under its separate

[134] Different ways in which changes to the law or practice could be achieved are discussed in Ben White and Lindy Willmott, 'How Should Australia Regulate Voluntary Euthanasia and Assisted Suicide?' (2012) 20 *Journal of Law and Medicine* 410, 427-432.

[135] The authors note that a 'penalty mitigation' model has also been proposed under which minor fines are imposed for conduct that remains unlawful provided certain procedural safeguards are observed: Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics', above n 2, 33. Such models have not been in any legislative regime to date.

legislation), and previously in the Northern Territory. Under the defence model, as in Montana, assisting someone to die remains unlawful, but a defence is created in certain circumstances.[136]

We favour a permissive model for the reasons outlined above as to why assisted dying should be permitted and regulated. In particular, we rely on the values of autonomy and reducing human suffering. Because allowing assisted dying is justified, we favour an approach that treats it as a lawful activity. By contrast, the defence model treats this assistance as *prima facie* criminal conduct. The framing of assisted dying as potentially lawful in a permissive model is also likely to provide more comfort to health professionals who are assisting people to die within the criteria prescribed by the regime. This model removes the stigma of the criminal law, and also the requirement of health professionals to satisfy an onus of proof to raise the relevant defence to avoid liability. Such an approach therefore removes a potential barrier for patients gaining access to what the core values conclude is a lawful and appropriate form of care.

Voluntary euthanasia, physician-assisted suicide, or both

Some models allow (or did allow) a doctor to participate in both voluntary euthanasia and physician-assisted suicide (see, for example, Canada, the Netherlands, and the Northern Territory). In the United States, however, the legislatures have adopted the more restrictive model of physician-assisted suicide. The Belgium and Quebec legislation, on the other hand, provides for voluntary euthanasia only (at least on its face).[137]

The authors favour permitting both voluntary euthanasia and physician-assisted suicide. The value of autonomy grounds the suggestion that a person be able to choose to receive assistance to die either by a doctor directly providing that assistance or by enabling the person to bring about his or her own death. The value of equality would also favour access to both. Providing only physician-assisted suicide would unfairly exclude individuals who lack the physical ability to end their own life from assisted dying regimes. The value of life would also favour

[136] See, eg, Criminal Law Consolidation (Medical Defences – End of Life Arrangements) Amendment Bill 2011 (SA). Note also Switzerland where, as discussed above, assisting a suicide for 'selfish' motives is an offence. If a person assists another to die and is charged under this provision, he or she must demonstrate that the assistance was provided for 'selfless' motives. Although the legislation does not contain a formal 'defence' provision, the legislation is more akin to a 'defence' model as it does not provide a regulatory framework to govern assisted death as occurs under the permissive models.

[137] Note that in Quebec, this is referred to as 'medical aid in dying': *An Act Respecting End-of-Life Care*, R.S.Q. c. S-32.0001, s 3(6). In relation to Belgium, although the law does not expressly permit assisted suicide, the practice does occur and is reported to the Federal Control and Evaluation Commission as such: see Bhatia, White and Deliens, 'How Should Australia Respond to Media-Publicised Developments on Euthanasia in Belgium?', above n 34, 836.

access to both as limiting access to assisted suicide could lead individuals to kill themselves earlier than they otherwise would in order not to become trapped in a body incapable of ending their own life.

Eligibility

There are four important aspects of eligibility to consider: competence; age; medical condition; and suffering.

Competence

It is the value of autonomy that primarily underpins our recommendation that assisted dying be permitted and a person must be competent to exercise that autonomous choice. This approach reflects most legislative models including those in the United States, Canada (both the federal and Quebec legislation),[138] and the repealed Northern Territory legislation which apply only to competent persons. However, this is not universally the case and in the Netherlands and Belgium, for example, a person can make a request for assistance to die in advance of losing their capacity. Despite the breadth of their legislation, however, we note that in practice it is not common for doctors to end a person's life after he or she has lost decision-making capacity and is not able to make a competent request for assistance to die.[139]

We consider that competent adults should be able to request assistance to die. Assisted dying for individuals who make a competent request to end their lives and later lose capacity is a complex issue, and is beyond the scope of this chapter.[140] However, in this regard we observe that over the past few decades in Australia, the focus of the debate has been on whether assisted

[138] We note though that in Canada the issue of advance requests for assisted dying is included in a statutorily mandated review the results of which must be placed before Parliament by December 2018.

[139] See, eg, Mette L Rurup, 'The First Five Years of Euthanasia Legislation in Belgium and the Netherlands: Description and Comparison Cases' (2011) 26(1) *Palliative Medicine* 43, 45. More recently, however, it was noted that in 2013 euthanasia based on an advance directive rose to 5.5% of all cases: Kenneth Chambaere et al, 'Recent Trends in Euthanasia and Other End-of-life Practices in Belgium' (2015) 372(12) *New England Journal of Medicine* 1179 (Supplementary Index).

[140] Some argue that a competent self does not have the moral authority to bind a (different) incompetent self: see, eg, R Dresser, 'Precommitment: A misguided strategy for securing death with dignity' (2003) 81 *Texas Law Review* 7; R Dresser, 'Dworkin on dementia: Elegant theory, questionable policy' (1995) 25(6) *The Hastings Center Report* 32; R Dresser, 'Missing persons: Legal perceptions of incompetent patients' (1994) 46 *Rutgers Law Review* 609; R Dresser, 'Life, death, and incompetent patients: Conceptual infirmities and hidden values in the law' (1986) 28 *Arizona Law Review* 373. Others argue that the choice of the competent self should prevail over the later incompetent self: see, eg, R Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (Harper Collins: London, 1993) and R Dworkin, 'Autonomy and the demented self' (1986) 64 (Suppl 2) *The Milbank Quarterly* 4. Other values can also be engaged such as the value of protecting the vulnerable when considering providing assistance to die for a person who no longer has capacity to make that decision, or who may even express an (incompetent) desire to continue living.

dying should be allowed for competent adults, and there has been only very limited discussion about advance requests for assistance to die.

Age

Most of the legislative models limit (or limited) access to assisted dying to adults: Canada,[141] the United States jurisdictions and the Northern Territory. It is only in the Netherlands[142] and Belgium[143] where this is not the case. As argued above, we believe that a person seeking assistance to die should be competent. Because adults are presumed by our legal system to be competent, all adults would prima facie be eligible to access the regime unless doctors were satisfied of incompetence.

The more challenging issue of whether assistance to die should be available to children who satisfy the test of *Gillick* competence is, as noted in the introduction, beyond the scope of this chapter given the complexity of issues raised and that it has not been part of the Australian debate.

Medical condition

The values of autonomy and life are integral in determining when a person is sufficiently unwell to qualify for assistance to die.[144] Autonomy unfettered could suggest that any competent person[145] should be able to receive assistance to die if that were his or her choice regardless of whether or not they have a medical condition. But autonomy is constrained by the value of life (and other values such as the protection of the vulnerable), and so a more nuanced approach is needed. Allowing assisted dying is also partly grounded in the value of reducing suffering and so the regime should include suffering as an eligibility criterion.

We argue that the balancing exercise involving the value of life can change as circumstances change. A justifiable approach is to recognise that the State's interest in preserving life is

[141] The Quebec legislation is also limited to adults. In Canada, the issue of mature minors is also part of the statutorily mandated review the results of which must be placed before Parliament by December 2018.
[142] As discussed above, pursuant to Article 2 of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002* (Netherlands), assistance is available to a minor between 16 and 18 years if the minor has a reasonable understanding of his or her interests and parents are involved in the decision-making, and also to a minor between 12 and 16 years if the child has a reasonable understanding and the parents agree with the decision.
[143] As discussed above, in 2013 the Belgian legislation was extended to permit access for children provided they have the 'capacity of discernment'.
[144] We note that the value of protecting the vulnerable is a critical value when formulating a legislative model around assisted dying. However, that value is better protected when considering 'safeguards' underpinning the regime and is dealt with below.
[145] Bearing in mind the restrictions suggested regarding age above.

weighty where a person is healthy, well and free from pain. But that interest is outweighed by other values such as autonomy and reducing suffering when both: (1) the person has a condition that will inevitably cause death, and (2) the person too has formed the view that the value of his or her life is outweighed by the disvalue of his or her suffering (this second aspect is discussed further below). So the State's interest in preserving life would prevent a healthy and well person who is free from pain from having assistance to die as the value of life would prevail over autonomy and reducing suffering. However, the balance between these values shifts where a person has a medical condition that will cause their death and they do not want to continue living due to their suffering. In such a case, the value of life would yield to the collective weight of the values of autonomy (as expressed in that person's choice to die) and reducing suffering.

Drawing on this balancing exercise, we argue it is justifiable, based on the values expressed, to permit assisted dying but limit access to those who have a *medical condition that will cause their death* (we also propose that there must be intolerable suffering as well and this is discussed below). The values do not, however, provide guidance as to how this medical condition criterion should be operationalised. To do this, we consider existing assisted dying models and how they have functioned in practice.

There is considerable variation in the legislative models about the qualifying medical condition that a person must have, and whether the condition must result in the death of the person (or their death within a certain period). In some jurisdictions, there is a requirement that the person has a terminal illness and be expected to die within a specified period (often six months) as in the United States jurisdictions.[146] Other models require that the person have a serious and incurable condition and that the person be at the end of their life, without expressly requiring that there be a causal link between the two (Victoria and Quebec). The relevant medical condition in Canada is that the person has a 'grievous and irremediable condition'. This condition is defined to mean that the person (among other things) has a 'serious and incurable illness', is in an 'advanced state of irreversible decline' and his or her 'natural death' is 'reasonably foreseeable'. In the South Australian bill, the person had to have an 'incurable medical condition' that would cause the person's death. In Belgium, the person must have a

[146] In Oregon, for example, a person may request medication for the purpose of ending life only if he or she has a 'terminal illness'; 'terminal illness' is defined to mean 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months': *Death with Dignity Act*, Or Rev Stat § 127.80 2.01 and 1.01 (1994).

'medically futile condition' while in Netherlands legislation does not contain a required condition.

We favour requiring a 'serious and incurable medical condition that will cause the person's death'. A medical condition should be regarded as 'incurable' by reference to available medical treatment of a kind that is acceptable to the person. For example, if a patient with cancer has already undergone two rounds of chemotherapy, the condition should not be regarded as 'curable' if he or she does not wish to undergo further chemotherapy. For a range of reasons, we also do not impose a time limit or require a particular proximity to death. First, the balancing of values exercise undertaken above does not point to the need for a specified period of time. Secondly, it is difficult to predict with any certainty when a person is likely to die, making the eligibility certification a challenging if not impossible task for the doctor.[147] Thirdly, a practical harm that can occur when temporal limits are imposed is that people who have a relevant medical condition that will cause their death but are outside the relevant time period may choose to starve themselves until they are close enough to death that the time condition is satisfied.[148]

The proposed criterion will enable people with fatal illnesses such as cancer, motor neurone disease (MND) and dementia (provided he or she retains capacity) to obtain assistance to die. We note that the application of our proposed criterion would also include a person with a medical condition such as quadriplegia who required artificial nutrition and hydration to survive.[149] In such a case, the medical condition of quadriplegia would, without medical intervention (namely the artificial hydration and nutrition), result in the person's death. This criterion would therefore be satisfied if that person was of the view that the medical treatment was unacceptable to him or her and he or she would die as a result of not having it. This may be troubling to some, for example, on the basis that allowing access for people with a disability in this way would devalue their and others' lives. However, the values of equality and the rule of law would argue against excluding a group of people who would otherwise fall within this

[147] See, eg, Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311; Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337; James Downar et al, 'The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis' (2017) 189(13) *Canadian Medical Association Journal* E484.

[148] This issue is raised in Jocelyn Downie, 'Medical Assistance in Dying: Lessons for Australia from Canada' (2017) *QUT Law Review* (forthcoming). See also Kate McKenna, 'Doctor-assisted death obtained by Sherbrooke man who starved himself to qualify' *CBC News* (online), 13 April 2016 http://www.cbc.ca/news/canada/montreal/sherbrooke-man-hunger-strike-death-1.3529392.

[149] This was the condition of Mr Rossiter in the case of *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84 (discussed above).

criterion on the basis of disability. If a person with a disability has a medical condition which, if untreated, would result in death, and that person satisfies the other eligibility requirements, we consider there to be no justification for excluding that person from assisted dying should they choose it.

Nature of suffering

In our model, the person must be 'suffering' as well as meeting the 'medical condition' criterion to qualify for assistance to die. This is because, as noted above, where these criteria are both met, the values of autonomy and reducing suffering are engaged together to outweigh the value of life. Focusing on the issue of suffering, we argue that where a person has intolerable suffering, it is open to them to conclude that the disvalue of continued life diminishes the weight that should be attached to the value of life and/or that the value of reducing suffering takes on increasing weight when balanced against the value of life.

The balancing of these values can also shed some light on how this criterion of 'suffering' should be conceptualised. First, because the above rationale for eligibility requires *both* suffering *and* a particular medical condition, it is appropriate to require that the suffering be *caused* by the medical condition or, we would argue, the treatment of the medical condition. Suffering that arises from a cause unrelated to the medical condition that will lead to death is not sufficient to outweigh the value of life. Secondly, the degree of suffering must be sufficiently high and of an enduring nature for the values of autonomy and reducing suffering to trump the value of life. Suffering that is fleeting and not sustained would be insufficient. Similarly, suffering that is not significant, as judged by the individual (see further below), would not qualify.

We suggest 'intolerability' as an appropriate standard, but note that the legislative models employ a variety of different expressions to describe the standard of suffering required including 'unbearable' (Victoria, Quebec, Netherlands and Belgium), 'intolerable' (South Australia), 'severe' (Northern Territory), and 'intolerable' (Canada). For the most part,[150] relevant regimes recognise (either expressly or implicitly) that the patient should be the one to assess whether that standard of suffering is met, and we endorse this approach. Only a subjective assessment of the relevant standard of suffering promotes the value of autonomy.

[150] Note that in the United States jurisdictions where the individual must have a 'terminal illness', there is no requirement for the person to demonstrate 'suffering'.

Most models also require the suffering to be enduring, for example by stating that the suffering be 'constant' (Belgium and Quebec), 'lasting' (Netherlands) or 'enduring' (Victoria). The authors favour a model that requires the suffering to be 'enduring'.

The final issues to be resolved here are the nature of the suffering required (physical or broader) and who assesses whether the suffering is sufficient. Here, the value of reducing human suffering is engaged. As a society, we care about individuals who are suffering as a result of a serious medical condition, and we strive to reduce their suffering. People can and do suffer in different ways: some physically and others psychologically. We argue that we should not distinguish between different kinds of suffering. Recognising only physical suffering would fail to adequately reduce suffering. We therefore favour a model that recognises suffering, whether that be physical, psychological, or existential, that is intolerable to the person. We note that this reflects the approach in most of the legislative models. Some models refer only to the term 'suffering' and it is clear from the context that the term encompasses more than physical pain (Northern Territory, Netherlands, Victoria and South Australia). Other models use express terms to include mental (Belgium) or psychological (Canada and Quebec) suffering.

To summarise then, we propose that the relevant threshold be that of 'intolerable' and 'enduring' suffering which can be physical, psychological or existential, caused by either the medical condition or the available treatment, and assessed by the individual him or herself. Only if these conditions are satisfied, would the values of autonomy and reducing suffering justifiably prevail over that of life.

Safeguards

A legislative framework permitting assisted dying must have appropriate checks and balances to ensure that only individuals meeting the eligibility criteria outlined above can receive assistance. These safeguards promote the value of the rule of law by establishing processes to ensure legal criteria are met. They also provide assurance that the value of life is promoted, and only overtaken by the values of autonomy and reducing suffering for the limited class of individuals who satisfy the eligibility criteria. In so doing, these safeguards also play an important role in protecting the vulnerable so that only competent individuals acting voluntarily, having access to all relevant information, can seek assistance to die. Further, they ensure the request is truly an autonomous one and so promote the value of autonomy. Balance in designing safeguards is important. If they are too prescriptive (difficult to satisfy), the value of autonomy will not be promoted. And if they are too easily satisfied, there will be no

confidence that the criteria of the legislation are being complied with which will undermine values such as those of life, protecting the vulnerable and the rule of law.

While the values lead us to the conclusion that robust safeguards are needed, they are of limited use in articulating precisely what those safeguards should be. So in making the recommendations below, we are guided both by various legislative models as well as international experience regarding the effectiveness and operation of those safeguards. We address a number of safeguards that are routinely found in assisted dying models: who should be involved with ensuring that the eligibility requirements are satisfied and that the request is voluntary; information that should be provided to the person; and waiting periods or other measures for assessing the enduring nature of the request.

Assessment of eligibility regarding medical condition and suffering

International models have similar safeguards to ensure eligibility regarding the medical condition. In the Victorian, South Australian and Northern Territory models, two doctors must independently confirm the diagnosis and prognosis; in the Netherlands, Oregon and Quebec, two doctors must be involved (and under the federal Canadian law, the two practitioners can be either a doctor or a nurse practitioner); and in Belgium, two doctors assess eligibility although a third doctor is required if the person is not expected to die in the near future. In terms of suffering, although we recommend a model that intolerable suffering be assessed by the person, the doctors must also be satisfied that the person has reached this view. We favour a model which requires eligibility regarding the medical condition to be confirmed by two doctors who are independent of each other following an examination of the patient and review of the patient's medical record by each doctor. Both doctors should also confirm that the patient has assessed his or her suffering as intolerable.

Assessment of capacity and voluntariness of the request

Under the legislative models described above, this assessment is generally undertaken when eligibility about the medical condition is being considered. There is some variation across models though. For example, under the Victorian and South Australian models, a psychiatrist must also be involved if there are concerns about capacity and, in South Australia at least, about

the voluntariness of the request.[151] The authors recommend that two doctors must confirm capacity of the patient and the voluntariness of the request but, if there is doubt regarding either, a doctor with relevant expertise should also be involved to assess the patient and their request. Most cases will not give rise to such doubts so the two doctors dealing with other eligibility issues can adequately assess these matters. However, further and specialised assessment is needed to ensure the decision is truly autonomous where there are doubts about the person's capacity and/or the voluntary nature of his or her decision. This may be undertaken by a psychiatrist where he or she possesses the necessary expertise required for the case but it could also be undertaken by, for example, a geriatrician with particular experience in assessing capacity of older people.

Assessment of the enduring nature of the request

Autonomy is advanced where requests for assistance to die are settled and non-ambivalent. A model which acted on a fleeting or ambivalent request would also not uphold the values of life and protecting the vulnerable. We argue therefore that the request for assistance to die must be enduring. Most legislative models contain some mechanism to prevent assistance being given to a person after just one request. Some of the models (Northern Territory, South Australia, Oregon and Canada) set out waiting periods, while others indicate that the request must be settled in other ways (Victoria – request must be 'enduring' and a reasonable amount of time has passed between the request and provision of the drug; Quebec – the wish is 'unchanged' and the doctor must talk to the patient 'at reasonably spaced intervals'; Belgium – request must be 'durable'). There is no waiting period in the Netherlands, the only requirement being that the request is 'well-considered'.

We propose that a person must make a formal request after doctors have assessed that person to be eligible, and that assistance to die be provided only after a specified time period passes after that request and the individual then reconfirms their desire for assistance. This delay and reconfirmation would provide confidence that the request was enduring. A period of 15 days is common in other legislative regimes and may be an appropriate time between an eligible request and the provision of assistance to die after reconfirmation.

[151] Note that only general principles were set out in the recommendations of the Victorian Parliamentary Committee so it is not clear whether a referral to a psychiatrist is required where the doctor has concerns about the voluntariness of the person's request.

However, the model should also contain discretion in limited cases both in relation to the specified period and the reconfirmation requirement where the doctors are satisfied that the request is enduring. For example, if the patient is expected to die before the specified period has passed, that time could be abridged if the doctor were satisfied that the request was an enduring one. Also, if the person loses capacity after making the formal request, for example as a result of receiving high doses of medication to relieve their pain, and so reconfirmation is not possible,[152] assistance should still be allowed provided the doctor remains satisfied of the enduring nature of the request.

Information to be provided

To promote the value of autonomy, the person should be provided with relevant information so that a request to receive assistance to die is fully informed. This is a feature of all legislative models. Although there are some minor variations across jurisdictions, generally doctors must provide the following information to the patient: the patient's diagnosis and prognosis; treatment options available and their likely results; palliative care options and their likely results; the medical procedure that will be used to assist a person to die and the likely risks and results; and that the person is able to rescind the request at any time. We recommend that legislation contain a requirement for two doctors to be satisfied that this information has been provided to the patient.

Oversight

An assisting dying regime needs robust oversight mechanisms to ensure that the framework operates as parliament intends. In doing so, this oversight promotes all of the values that underpin our proposed legislative model. But robust oversight mechanisms especially advance particular values. One is the rule of law. This value is promoted where oversight mechanisms monitor not only individual deaths but also any systemic issues that may arise when a legislative model is implemented. Oversight mechanisms also promote the values of life and protecting the vulnerable by reviewing the circumstances surrounding each death to ensure that assistance is provided only in accordance with the requirements of the legislation. The value of autonomy is promoted by reviewing evidence of an autonomous choice to seek assistance to die.

[152] This issue is raised in Downie, 'Medical Assistance in Dying: Lessons for Australia from Canada', above n 148.

There are two main options for oversight mechanisms: prospective or retrospective review. As their description suggests, a prospective oversight mechanism requires an independent party to review the facts *prior* to the provision of assistance to die, while a retrospective model will review evidence after death occurs. There are also a range of possibilities in terms of the body that is charged with the oversight: should existing structures be used, or new bodies established?

As was the case for safeguards, while the articulated values point to establishing robust oversight mechanisms, they do not necessarily provide precise guidance as to what that system might look like. That said, we suggest that one value – reducing suffering – is relevant to the question of the timing of the review of decision-making. The proposed legislative model requires at least two independent doctors to be satisfied of eligibility, part of which is to be satisfied of the intolerable nature of the patient's suffering. Given this safeguard, the value of reducing suffering points us towards a retrospective model rather than requiring further delay for the person who is in this intolerable state while yet another body be satisfied that he or she is eligible to receive assistance.

In terms of the body charged with oversight, we considered a variety of established or proposed models. Under the Northern Territory and proposed South Australian models, deaths are monitored by the Coroner while in Victoria, the recommendation is to report the death to a proposed Assisted Dying Review Board. International models include reporting to a Regional Review Committee through a municipal pathologist (Netherlands), the Federal Control and Evaluation Commission (Belgium), the Department of Human Services (Oregon) and the Commission on End of Life Care (Quebec). Under all of these models, reporting of the assisted dying occurs retrospectively.

We favour the establishment of a new retrospective review body dedicated to overseeing an assisted dying regime. We do note that responsibilities for reviewing individual deaths and also systemic issues around the operation of the legislation align well with the existing responsibilities of the Office of Coroner. Coroners also currently have duties and powers in relation to investigating certain types of deaths as well as making recommendations about systems improvement arising from the deaths investigated. However, oversight by the Coroner is not our favoured approach primarily because we do not consider deaths that result from a practice that is recognised as lawful should be in the same category as 'reportable deaths'

currently investigated by Coroners (which sometimes includes connotations of these deaths being 'suspicious').

By contrast, there are advantages of establishing a dedicated body (such as a review board) with sole responsibility for oversight of an assisted dying framework. This removes questions or associations of unlawful or inappropriate behaviour and the body's focus on assisted dying means it could be comprised of people with specific and relevant expertise in this area. The body's functions could include independent review of assisted dying cases (retrospectively), systems-level monitoring of the assisted dying regime (including the ability to make recommendations for systemic reform), and appropriate data collection and reporting.

Role of conscience

As discussed in the core values section, there is a long-recognised ethical principle that a doctor may refuse to provide a lawful medical service that is contrary to his or her conscience. Yet refusing to provide assistance to die has potentially significant implications for an eligible patient, particularly if the objecting doctor has been responsible for the patient's ongoing care or is the only doctor who could provide treatment for the patient due to location (for example, in regional and remote areas).

The value of conscience supports doctors not being required to participate in assisted dying where doing so contradicts their conscience (although as we noted above, for some doctors, conscience points to being able to provide assisted dying for patients). However, other important values compete with conscience. The value of autonomy is not promoted if a doctor is permitted to deny an eligible request for assistance to die on the basis of his or her views. The same is true for the value of reducing suffering if a patient with intolerable suffering is denied access to a lawful medical service. Finally, the value of equality is implicated. Some eligible patients may be less able to physically seek assistance elsewhere than others who, for example, may be able to discharge themselves from one doctor's care to travel to another doctor. Other equality considerations can also arise including the more limited access to medical care and an alternative doctor that can arise from living in a regional or remote area.

In balancing these conflicting values, we consider that a legislative model should excuse a doctor from participation if that is inconsistent with their conscience. However, an objecting doctor should be obliged to transfer the patient's care (including advising of the request for assistance to die) to a doctor who is willing to assist, and the state should establish a transfer

of care system so as to protect the conscience of objecting doctors while ensuring access for patients. Such a position would respect the value of conscience but not allow it to trump the other values outlined above which require that eligible patients be able to access to a lawful medical service.

Conclusion

Whether or not the law in Australia should be reformed to permit assistance to die is hotly contested. All would agree that individuals should receive the highest possible medical care as they approach the end of their lives. And, for the most part, good quality medical care should enable seriously ill patients to experience good deaths. However, that is not always the case, and some individuals experience intolerable suffering at the end of their lives. This suffering causes trauma to the patients themselves, their families and can lead to distress for their treating teams. Consensus will never be reached on how the law should respond to calls for reform. There will always be tensions between those who believe that a law that permits intentional killing is wrong, and those who believe that such a law can not only be justified but is necessary in a compassionate society.

In this chapter, we have sought to move this debate forward in two ways. We have first articulated a set of core values that we believe should underpin how assisted dying is regulated, and then proposed a legislative model that seeks to promote and balance these values in a principled way. This chapter is published at a critical time in our history. Legislators across the country are determining whether or not assisted dying laws should be introduced, and the nature of those laws. We offer the values and model articulated in this chapter for their consideration.

Reference List

1. The Economist Intelligence Unit, *The 2015 Quality of Death Index: Ranking palliative care across the world* (2015) 7, 15, 23, 26. <https://www.eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>.
2. Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1-46.
3. Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report* (June 2016) <https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf>.
4. Felicity Caldwell, 'Voluntary euthanasia: Calls for Queensland Parliamentary Inquiry', *The Brisbane Times* (online), 17 October 2016 <http://www.brisbanetimes.com.au/queensland/voluntary-euthanasia-calls-for-queensland-parliamentary-inquiry-20161017-gs44ri.html>.
5. ABC News, 'Voluntary euthanasia: South Australian parliament knocks back Death with Dignity euthanasia bill', *ABC News* (online), 17 November 2016 <http://www.abc.net.au/news/2016-11-16/voluntary-euthanasia-debate-in-south-australia-goes-to-committee/8031776>.
6. South Australia, *Parliamentary Debates*, House of Assembly, 2 March 2017, 8775 (Stephanie Key, Member for Parliament, Ashford).
7. Norman Hermant, 'Euthanasia debate: Doctor confirms he helped patients die, wants to be charged', *ABC News* (online), 8 May 2014 <http://www.abc.net.au/news/2014-05-07/doctor-confirms-he-helped-patient-die/5437686>.
8. Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16(1) *QUT Law Review* 84.
9. Nicolas Perpitch, 'Perth doctor investigated by police after admitting hastening patient's death', *ABC News* (online), 24 August 2016 <http://www.abc.net.au/news/2016-08-24/doctor-alida-lancee-investigated-after-hastening-patient-death/7780788>.
10. Julia Medew, 'Medical Board of Australia investigates euthanasia doctor Rodney Syme', *The Age* (online), 7 March 2016 <http://www.theage.com.au/victoria/medical-board-of-australia-investigates-euthanasia-doctor-rodney-syme-20160307-gnca3j.html>.
11. The Greens, 'Don't punish doctors for voluntary euthanasia: Greens' (Media Release, 25 August 2016) <http://greens.org.au/sites/greens.org.au/files/20160627_Dying%20with%20Dignity_0.pdf>.
12. Sean Nicholls and Kate Aubusson, 'Voluntary euthanasia laws to come before NSW Parliament this year', *The Sydney Morning Herald* (online), 16 January 2017 <http://www.smh.com.au/nsw/voluntary-euthanasia-laws-to-come-before-nsw-parliament-this-year-20170115-gtrsz0.html>.
13. Regina Titelius, 'Bid for voluntary euthanasia in WA', *PerthNow* (online), 26 March 2017 <http://www.perthnow.com.au/news/western-australia/bid-for-voluntary-euthanasia-in-wa/news-story/135bf31fc63cb14c0eb7d507814fdaee>.
14. Victoria Health and Human Services, *Voluntary Assisted Dying Bill Discussion Paper* (2017) <https://www2.health.vic.gov.au/about/publications/researchandreports/voluntary-assisted-dying-bill-discussion-paper>.
15. Regional Euthanasia Review Committees, *Annual Report 2013* (2014) https://english.euthanasiecommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports.
16. Guy Widdershoven, 'Euthanasia in the Netherlands: Experiences in a Review Committee' (2004) 23(3) *Medicine and Law* 687.
17. Neera Bhatia, Ben White and Luc Deliens, 'How Should Australia Respond to Media-Publicised Developments on Euthanasia in Belgium?' (2016) 23(4) *Journal of Law and Medicine* 835.
18. Christian Munthe, 'Legalised Euthanasia for Children Regardless of Age in Belgium: The Actual Law in English', Philosophical Comment (28 August 2015) <http://philosophicalcomment.blogspot.com.au/2014/02/legalised-euthanasia-for-children.html>.
19. Woolfrey, 'What Happens Now? Oregon and Physician-Assisted Suicide' (1998) 28(3) *Hastings Center Report* 9-17.
20. Linda Ganzini, 'Legalised Physician-Assisted Death in Oregon' (2016) 16(1) *QUT Law Review* 76.
21. Jocelyn Downie, Lindy Wilmott and Ben White, 'Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining treatment' (2014) 26(1) *New Zealand Universities Law Review* 24.
22. Udo Schuklenk et al, 'End of Life Decision Making in Canada: The Report by the Royal Society of Canada Expert Panel on End of Life Decision-Making (2011) 25 *Bioethics* 1.

23. LexisNexis, *Halsbury's Laws of Australia* (at 18 November 2016) 130 Criminal Law, '3 Homicide' [130-3000].
24. LexisNexis, *Halsbury's Laws of Australia* (at 5 September 2016) 80 Civil and Political Rights, '2 Civil Rights', '2 Right to Life' [80-920].
25. Lindy Willmott, Ben White and Shih-Ning Then, 'Withholding and Withdrawing Life-Sustaining Medical Treatment' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) [14.100] (the common law), [14.150]-[14.170].
26. Lindy Willmott, Ben White and Ben Matthews, 'Law, Autonomy and Advance Directives' (2010) 18 *Journal of Law and Medicine* 366.[1] *Stuart v Kirkland-Veenstra* (2009) 237 CLR 215, [87].
27. Susan Sherwin, 'A Relational Approach to Autonomy in Health Care' in Susan Sherwin (ed), *The Politics of Women's Health: Exploring Agency and Autonomy* (Temple University Press, 1998) 19.
28. Loane Skene, 'Disputes about the Withdrawal of Treatment: the Role of the Courts' (2004) 32 *Journal of Law Medicine and Ethics*.
29. Australian Medical Association, *Position Statement on Conscientious Objection* (28 November 2013) <https://ama.com.au/position-statement/conscientious-objection-2013>.
30. Australian Nursing and Midwifery Federation, *Policy on Conscientious Objection* (February 2015), <http://anmf.org.au/documents/policies/P_Conscientious_Objection.pdf>.
31. Medical Board of Australia, *Good medical practice: a code of conduct for doctors in Australia* (March 2014) [2.4.6] <http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>
32. College des Medicins du Quebec *Physicians, Appropriate Care and the Debate on Euthanasia: A Reflection* (2009) 2, 7 <http://www.cmq.org/publications-pdf/p-1-2009-10-01-en-medecin-soins-appropries-debat-euthanasie.pdf>.
33. Julia Medew, 'Doctor admits giving dying man the drugs to end his life', *The Age* (online) 28 April 2014: <http://www.theage.com.au/victoria/doctor-admits-giving-dying-man-the-drugs-to-end-his-life-20140427-zr07i.html>.
34. C Dyer, 'Rheumatologist Convicted of Attempted Murder' (1992) 305 *British Medical Journal* 731 as cited in R Magnusson, *Angels of Death: Exploring the Euthanasia Underground*, (Melbourne University Press, 2002) 25.
35. Jocelyn Downie and Francoise Baylis, 'A test for freedom of conscience under the Canadian Charter of Rights and Freedoms: Regulating and litigating conscientious refusals in health care' (2017) *McGill Journal of Law and Health* (forthcoming).
36. Law Council of Australia in their Policy Statement on the Rule of Law: Law Council of Australia, *Policy Statement: Rule of Law Principles* (March 2011) <https://www.lawcouncil.asn.au/lawcouncil/images/LCA-PDF/a-z-docs/PolicyStatementRuleofLaw.pdf>.
37. Thomas Bingham, *The Rule of Law* (Penguin, 2010) ch 5.
38. Westlaw AU, *The Laws of Australia* (at 26 April 2017) 21 Human Rights, '1 Development and Recognition of Human Rights' [21.1.140].
39. Peter Bailey, *The Human Rights Enterprise in Australia and Internationally* (LexisNexis, Sydney, 2009) 242–253.
40. John Toohey, 'A Government of Laws, and Not of Men?' (1993) 4 *Public Law Review* 158, 168–169.
41. Brian Z Tamanaha, *On the Rule of Law: History Politics and Theory* (Cambridge University Press, 2004) 33.
42. J Stapleton, 'The Golden Thread at the Heart of Tort Law: Protection of the Vulnerable' (2003) 24 *Australian Bar Review* 135.
43. LexisNexis, *Halsbury's Laws of Australia* (at 29 October 2015) 185 Equity, '5 Unconscionable Transactions' [185-875].
44. Ben White, Lindy Willmott and Shih-Ning Then, 'Adults who Lack Capacity: Substitute Decision-Making' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) [7.80]-[7.95].
45. David Lanham et al, *Criminal Laws in Australia* (Federation Press, 2006) ch 1B 'The Purposes of Criminal Law' <http://www.federationpress.com.au/pdf/Lanham%20Ch1B.pdf>.
46. Margaret Otlowski, *Voluntary Euthanasia and the Common Law* (Oxford University Press, 2000) 88.
47. David Mayo and Martine Gunderson, 'Vitalism Revitalized: Vulnerable Populations, Prejudice and Physician Assisted Death' (2002) July-August *The Hastings Center Report* 17-20.
48. Anita Silvers, 'Protecting the Innocents from Physician-Assisted Suicide: Disability Discrimination and the Duty to Protect Otherwise Vulnerable Groups' in Margaret P Battin et al (eds), *Physician Assisted Suicide: Expanding the Debate* (Routledge, 1998) 133.
49. JAC Rietjens et al, 'Medical End-of-life Decisions: Does its Use Differ in Vulnerable Patient Groups? A Systematic Review and Meta-analysis' (2012) 74(8) *Social Science and Medicine* 1282.

50. Margaret P Battin et al, 'Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups' (2007) 33(10) *Journal of Medical Ethics* 591.
51. Ezekiel J Emanuel et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe' (2016) 316(1) *JAMA* 79.
52. Charles Blanke et al, 'Characterizing 18 years of the Death with Dignity Act in Oregon' (2017) *JAMA Oncology* doi: 10.1001/jamaoncol.2017.0243.
53. Ben White and Lindy Willmott, 'Double Effect and Palliative Care Excuses' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) [15.20].
54. Australian Medical Association, *Position Statement on End of Life Care and Advance Care Planning* (5 September 2014) [1.2.3] and [3.5] <https://ama.com.au/system/tdf/documents/AMA_position_statement_on_end_of_life_care_and_advance_care_planning_2014.pdf?file=1&type=node&id=40573>.
55. Australian Medical Association, *Code of Ethics* (2016) [2.1.15] <https://ama.com.au/system/tdf/documents/AMA%20Code%20of%20Ethics%202004.%20Editorially%20Revised%202006.%20Revised%202016.pdf?file=1&type=node&id=46014>.
56. Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential Elements for Safe High Quality End of Life Care* (27 May 2015) [3.10] <https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf>.
57. Ben White and Lindy Willmott, 'How Should Australia Regulate Voluntary Euthanasia and Assisted Suicide?' (2012) 20 *Journal of Law and Medicine* 410.
58. Mette L Rurup, 'The First Five Years of Euthanasia Legislation in Belgium and the Netherlands: Description and Comparison Cases' (2011) 26(1) *Palliative Medicine* 43.
59. Kenneth Chambaere et al, 'Recent Trends in Euthanasia and Other End-of-life Practices in Belgium' (2015) 372(12) *New England Journal of Medicine* 1179.
60. R Dresser, 'Precommitment: A misguided strategy for securing death with dignity' (2003) 81 *Texas Law Review* 7.
61. R Dresser, 'Dworkin on dementia: Elegant theory, questionable policy' (1995) 25(6) *The Hastings Center Report* 32.
62. R Dresser, 'Missing persons: Legal perceptions of incompetent patients' (1994) 46 *Rutgers Law Review* 609.
63. R Dresser, 'Life, death, and incompetent patients: Conceptual infirmities and hidden values in the law' (1986) 28 *Arizona Law Review* 373.
64. R Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (Harper Collins: London, 1993).
65. R Dworkin, 'Autonomy and the demented self' (1986) 64 (Suppl 2) *The Milbank Quarterly* 4.
66. Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311.
67. Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337.
68. James Downar et al, 'The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis' (2017) 189(13) *Canadian Medical Association Journal* E484.
69. Jocelyn Downie, 'Medical Assistance in Dying: Lessons for Australia from Canada' (2017) *QUT Law Review* (forthcoming).
70. Kate McKenna, 'Doctor-assisted death obtained by Sherbrooke man who starved himself to qualify' *CBC News* (online), 13 April 2016 http://www.cbc.ca/news/canada/montreal/sherbrooke-man-hunger-strike-death-1.3529392.

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Perspective

Evidence-based law making on voluntary assisted dying

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Abstract. Voluntary assisted dying is a major social policy issue with significant implications for the health system, health and medical professionals and the wider community. Voluntary assisted dying is now lawful in Victoria in limited circumstances, and other states are likely to follow Victoria and legalise the practice. In the same way that we expect the making of health policy and the provision of health care to be evidence based, so too should we should expect evidence-based law making from our parliamentarians on this important topic.

What is known about the topic? The importance of evidence when making health policy and providing evidence-based medical care is well accepted. Australian states are actively considering laws about voluntary assisted dying.
What does this paper add? This paper argues that evidence-based law making by parliamentarians is needed as they deliberate proposed voluntary assisted dying laws. There has been limited recognition of the value of evidence-based approaches in the discipline of law.
What are the implications for practitioners? A failure by parliaments to adequately consider evidence can lead to suboptimal law making. When this occurs about important health issues, such as voluntary assisted dying, it leads to problematic regulatory frameworks for patients, health professionals and health systems.

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Introduction

Voluntary assisted dying (VAD) is a major social policy issue with significant implications for the health system, health and medical professionals and the wider community. VAD is now lawful in Victoria in limited circumstances, and other states are likely to follow Victoria and legalise VAD.[1] The Western Australian parliament is currently debating a VAD bill tabled in August, and Queensland and South Australia are holding parliamentary inquiries; a bill is also expected to be presented to the Tasmanian parliament within the next year. In the same way that we expect the making of health policy[2] and the provision of health care[3] to be evidence based, so too should we expect evidence-based law making from our parliamentarians.

There are diverse views on VAD across the community. Although public opinion broadly favours reform,[4] individuals, advocacy groups and organisations on both sides of the debate continue to advance conflicting viewpoints. Of interest is the recent activity by health and medical organisations releasing a spectrum of position statements. Although the Australian Medical Association[5] is against changes to the law, the Royal Australasian College of Physicians[6] and the Royal Australian College of General Practitioners[7] have both chosen not to oppose reform. Significantly, the recent Palliative Care Australia Position Statement 'neither advocates for, nor argues against' legalisation of VAD.[8] All four organisations specifically endorse that the decision about whether VAD laws should be passed is an issue for government and society. In contrast with the medical organisations, the Australian Nursing and Midwifery Federation supports law reform for a limited cohort of people.[9]

This breadth of community and organisational interest in VAD is illustrated by the thousands of submissions the Victorian, Western Australian, Queensland and South Australian parliamentary committees collectively received. Parliamentarians in Victoria and Western Australia have also reported being heavily lobbied when they were actively debating their laws. How then should parliaments weigh the diverse and often conflicting arguments about whether VAD laws should be passed?

Sometimes viewpoints will differ because of different positions about the ethics of VAD. These are matters on which people can reasonably disagree. For some, VAD is ethically wrong because it involves the intentional ending of life. Others consider VAD is ethically permissible as an appropriate response to a competent request to relieve suffering. Law making on complex social policy inevitably and appropriately involves weighing competing ethical considerations.[10]

However, some differences in views about VAD are based on claims about facts: whether or not something is happening in practice. Examples are whether vulnerable cohorts are more likely to seek VAD or whether VAD adversely affects palliative care. These are factual claims, and the extent to which they are true or not depends on evidence. There is not scope here to engage in these debates, although we note that two Australian parliamentary

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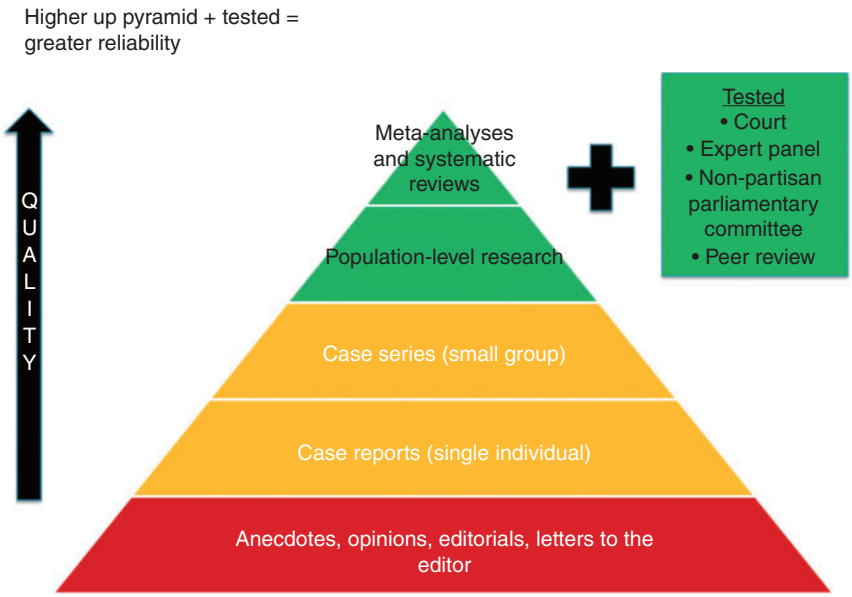

Fig. 1. Reliability of evidence pyramid for law making about voluntary assisted dying. Modified with permission from Downie.[16]

committees to date have undertaken evaluations of available evidence about VAD.[11,12] Rather, the point here is to distinguish views about the ethics of VAD from views based on facts about VAD. We do acknowledge there can be overlap: for example, claims about facts are not necessarily value free. Nevertheless, we contend this distinction remains important because claims about facts are capable of being evaluated against evidence.

The use of evidence in health and medicine is vexed and there are debates about a range of issues, including the effects of values and research design, and challenges of translating evidence into practice.[2,13] Nevertheless, the important role of evidence in making health policy and in providing evidence-based medical treatment to patients is well accepted. Evidence-based approaches are increasingly gaining traction in other fields, such as business.[10] We should also expect law makers to make their decisions based on reliable evidence. Unfortunately, Law's utilisation of evidence has lagged behind other disciplines.[10] There is also relatively little literature on the concept of evidence-based law making. Although some may conceptualise law as a subset of health policy, even if this is true there are very distinctive facets of law making that warrant careful and separate consideration of the role of evidence in parliamentary debate. For example, the legislative process, by definition, occurs in the public domain and there is an opportunity for scrutiny of such decision making that is often not present in health policy making.

One challenge for evidence-based law making is that established models from medicine for evaluating evidence in different settings[14,15] are not readily applicable to law making. (This is also a known problem in health policy.[13]) To assist with the process of assessing evidence, Downie proposed an approach specifically designed for the context of law-making about VAD (see Fig. 1).[16] This model incorporates the traditional notion of ascending reliability up a pyramid, but is adapted to reflect those types of evidence likely to be used in these debates. For example, randomised control trials are omitted. In addition, Downie's model includes external testing of that evidence not only through the usual peer review, but also by common law and policy processes such as evaluation by a court or parliamentary committee.[16]

Using this approach, the Dutch[17] and Belgian[18] research about rates of VAD over time would be regarded as reliable evidence. These are population-level studies and, through publication in top international medical journals, have been subject to rigorous peer review. Other significant evidence includes annual reports published by health departments about patients' and doctors' participation in VAD each year. The best examples are reports of data mandated to be collected under the *Oregon Death with Dignity Act 1994* (and this approach is replicated in other parts of the US). Although not in peer-reviewed journals, these reports provide insight into how VAD systems as a whole function by collecting all reported cases of VAD over an extended period; now 21 years in the case of Oregon.[19]

At the other end of the spectrum are anecdotes in media reports about a particular case or cases of VAD. These are at the bottom of the pyramid and have not been externally tested, and so are not reliable evidence. The positions against and for VAD reform of the Australian Medical Association and the Australian Nursing and Midwifery Federation respectively are also worth considering. We regard them as statements based on values, rather than purporting to be factual claims about VAD of the type discussed above. However, to the extent they may be advanced by others as a form of evidence, we consider them to be 'opinion', which is also at the bottom of the pyramid.

Parliamentarians, and indeed the wider discipline of Law, must follow the evidence-based approach increasingly expected in other fields. We should be clear though that we are not suggesting law making become just a technical exercise of implementing evidence; some limits on using evidence were

noted above. Further, we acknowledge that it is appropriate for values to play a role in what is ultimately a political exercise,[10] although those values should be disclosed by parliamentarians. Nevertheless, we call for evidence-based law making and consider this especially important for complex social issues such as VAD, where proponents of various positions make broad and often conflicting factual claims. Decisions about our laws must reflect the state of available evidence, so these claims must be rigorously evaluated. Accordingly, we call on parliaments to engage in evidence-based law making that includes careful deliberation informed by reliable evidence.

Competing interests

Ben White and Lindy Willmott have been engaged by the Victorian Government to design and provide the legislatively mandated training for doctors involved in VAD. Lindy Willmott is also a member of the board of Palliative Care Australia, but this article only represents her views. Ben White is an Associate Editor for *Australian Health Review*.

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References

1 White B, Willmott L. Future of assisted dying reform in Australia. *Aust Health Rev* 2018; 42: 616–620. doi:10.1071/AH18199

2 Baicker K, Chandra A. Evidence-based health policy. *N Engl J Med* 2017; 377: 2413–15. doi:10.1056/NEJMp1709816

3 Sackett DL, Rosenberg WM, Muir Gray JA, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. *BMJ* 1996; 312: 71. doi:10.1136/bmj.312.7023.71

4 Cartwright C. FactCheck Q&A: do 80% of Australians and up to 70% of Catholics and Anglicans support euthanasia laws? *The Conversation* 1 May 2017. Available at: https://theconversation.com/factcheck-qanda-do-80-of-australians-and-up-to-70-of-catholics-and-anglicans-support-euthanasia-laws-76079 [verified 20 November 2019].

5 Australian Medical Association. Euthanasia and physician assisted suicide 2016. 2016. Available at: https://ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016 [verified 20 November 2019].

6 The Royal Australasian College of Physicians. Statement on voluntary assisted dying – November 2018. 2018. Available at: https://www.racp.edu.au/docs/default-source/advocacy-library/racp-voluntary-assisted-dying-statement-november-2018.pdf?sfvrsn=761d121a_4 [verified 20 November 2019].

7 The Royal Australian College of General Practitioners. Voluntary assisted dying legislation. 2019. Available at: https://www.racgp.org.au/advocacy/position-statements/view-all-position-statements/clinical-and-practice-management/voluntary-assisted-dying-legislation [verified 20 November 2019].

8 Palliative Care Australia. Position statement. Palliative care and voluntary assisted dying. 2019. Available at: http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/09/2019-VAD-position-statement-Final.pdf [verified 20 November 2019].

9 Australian Nursing and Midwifery Federation (ANMF). ANMF position statement. Voluntary assisted dying. 2019. Available at: http://anmf.org.au/documents/policies/PS_Assisted_Dying.pdf [verified 20 November 2019].

10 Rachlinski JJ. Evidence-based law. *Cornell Law Rev* 2011; 96: 901–24.

11 Legislative Council Legal and Social Issues Committee. Inquiry into end of life choices: final report. Melbourne: Parliament of Victoria; 2016. Available at: https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf [verified 20 November 2019].

12 Joint Committee on End of Life Choice, Parliament of Western Australia. Report 1. My life, my choice. 2018. Available at: https://www.parliament.wa.gov.au/Parliament/commit.nsf/%28Report+Lookup+by+Com+ID%29/71C9AFECD0FAEE6E482582F200037B37/$file/Joint%20Select%20Committe%20on%20the%20End%20of%20Life%20Choices%20-%20Report%20for%20Website.pdf [verified 20 November 2019].

13 Cairney P, Oliver K. Evidence-based policymaking is not like evidence-based medicine, so how far should you go to bridge the divide between evidence and policy? *Health Res Policy Syst* 2017; 15: 35.

14 Merlin T, Weston A, Tooher R. Extending an evidence hierarchy to include topics other than treatment: revising the Australian 'levels of evidence'. *BMC Med Res Methodol* 2009; 9: 34. doi:10.1186/1471-2288-9-34

15 Guyatt GH, Oxman AD, Vist GE. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. *BMJ* 2008; 336: 924. doi:10.1136/bmj.39489.470347.AD

16 Downie J. Reliability of evidence. End-of-life law and policy in Canada. Halifax: Health Law Institute, Dalhousie University; n.d. Available at: http://eol.law.dal.ca/?page_id=966 [verified 20 November 2019].

17 van der Heide A, van Delden JJM, Onwuteaka-Philipsen BD. End-of-life decisions in the Netherlands over 25 years. *N Engl J Med* 2017; 377: 492–4. doi:10.1056/NEJMc1705630

18 Chambaere K, Vander Stichele R, Mortier F, Cohen J. Recent trends in euthanasia and other end-of-life practices in Belgium. *N Engl J Med* 2015; 372: 1179–81. doi:10.1056/NEJMc1414527

19 Oregon Health Authority. Oregon Death with Dignity Act. 2018 data summary. 2019. Available at: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf [verified 20 November 2019].

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DOES THE *VOLUNTARY ASSISTED DYING ACT 2017* (VIC) REFLECT ITS STATED POLICY GOALS?

BEN P WHITE,* KATRINE DEL VILLAR,** ELIANA CLOSE*** AND LINDY WILLMOTT****

With the commencement of the Voluntary Assisted Dying Act 2017 (Vic) in June 2019, Victoria became the first Australian State to permit voluntary assisted dying. This article considers the extent to which this novel Act reflects its stated policy goals. The first part of the article identifies the purported policy goals of the Act. This analysis draws on the explanatory material accompanying the law, in particular the expert Ministerial Advisory Panel Report which shaped the law. The article then critically evaluates the extent to which key aspects of the Act reflect those identified policy goals. Overall, the article concludes that the Voluntary Assisted Dying Act 2017 (Vic) is not consistent with its policy goals in some important respects.

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I INTRODUCTION

When the *Voluntary Assisted Dying Act 2017* (Vic) ('*VAD Act*') commenced in June 2019, Victoria became the first Australian jurisdiction in over 20 years to have an operative voluntary assisted dying ('VAD') system. It joins just a small number of jurisdictions in a handful of countries internationally that permit VAD.[1] One reason such laws are rare is that reform in this area is very difficult. VAD is seen by many as politically risky[2] and so in Australia there has been a long history of unsuccessful attempts to reform the law.[3]

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1 Currently, nine states in the United States of America, the federal government in Canada, and one Canadian province have passed laws regulating VAD: *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) (Oregon); *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.903 (2008) (Washington); *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281–93 (2013) (Vermont); *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (2015) (California); *Death with Dignity Act of 2016*, DC Code §§ 7–661 (2017) (District of Columbia); *End-of-Life Options Act*, Colo Rev Stat §§ 25-48-101–25-48-123 (2017) (Colorado); *Our Care, Our Choice Act 2018*, Hawaii Rev Stat §§ 327-1–327-25 (2018) (Hawaii); *Medical Aid in Dying for the Terminally Ill Act*, NJ Stat Ann §§ 26:16-1–26:16-20 (2019) (New Jersey); *An Act to Enact the Maine Death with Dignity Act,* 22 Me Rev Stat Ann § 2140 (2019) (Maine), note this Act commenced in September 2019; *Criminal Code of Canada,* RSC 1985, c C-46, ss 241.1-241.4 (Canada); *An Act Respecting End-of-Life Care,* RSQ 2014, c S-32.0001 (Quebec). It is also legal in Montana by virtue of the court ruling in *Baxter v Montana* 224 P 3d 1211 (Mont, 2009), but no legislation has been passed in that State. Parts of Europe have legalised VAD through legislation: *Wet Toetsing Levensbeëindiging op Verzoek en Hulp Bij Zelfdoding* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001] (The Netherlands); *Loi Relative à L'euthanasie* [Act on Euthanasia 2002] (Belgium) and *Legislation Reglementant Les Soins Palliatifs Ainsi Que L'euthanasie Et L'assistance Au Suicide 2009* [Legislation Regulating Palliative Care and Euthanasia and Assisted Suicide 2009] (Luxembourg). Assisting a person's suicide is also lawful under certain circumstances in Switzerland (discussed in Samia A Hurst and Alex Mauron, 'Assisted Suicide in Switzerland: Clarifying Liberties and Claims' (2017) 31(3) *Bioethics* 199, 199) and Germany (see recent decision of the second Senate of the Federal Constitutional Court, Zum Urteil des Zweiten Senats vom 26 February 2020, Bundesverfassungsgericht), but there is no legislation regulating its provision in these countries. Finally, a court decision in Colombia permitted VAD in 1997: Constitutional Court of the Republic of Colombia, Sentence C-239/97, Ref Expedient D-1490, 20 May 1997), which was followed by Government regulations to facilitate the practice in 2015: *Protocolo Para La Aplicación Del Procedimiento De Eutanasia En Colombia*: Government of Colombia, *Protocol for the Application of the Procedure of Euthanasia in Colombia* (Report, 2015) <https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/DE/CA/Protocolo-aplicacion-procedimiento-eutanasia-colombia.pdf>. For more information on these jurisdictions, see Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform' in Ian Freckelton and Kerry Anne Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479, 484–8.

2 Margaret Otlowski, 'Another Voluntary Euthanasia Bill Bites the Dust', *The Conversation* (online, 19 November 2013) <https://theconversation.com/another-voluntary-euthanasia-bill-bites-the-dust-19442>; Ben White and Lindy Willmott, 'Victoria May Soon Have Assisted Dying Laws for Terminally Ill Patients', *The Conversation* (online, 21 July 2017) <https://theconversation.com/victoria-may-soon-have-assisted-dying-laws-for-terminally-ill-patients-81401>; Giles Scofield, writing in the American context, goes so far as to say that 'promoting assisted suicide is politically suicidal': Giles Scofield, 'Privacy (or Liberty) and Assisted Suicide' (1991) 6(5) *Journal of Pain and Symptom Management* 280, 286.

3 For a detailed discussion of the history of attempts at law reform in Australia, see Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics'

The political challenges involved in VAD reform are evident in the *VAD Act* and the process leading to its enactment in three ways. The first is the staged and very consultative process adopted to facilitate reform. This began with a parliamentary committee of inquiry, which received extensive evidence[4] and numerous submissions from a large number of individuals and organisations.[5] In its report, the parliamentary committee recommended the enactment of legislation permitting VAD in certain circumstances.[6] The Victorian Government then adopted this recommendation and appointed a multidisciplinary Ministerial Advisory Panel ('the Panel'), whose role was to advise on the form of the legislation, taking into consideration a range of policy, clinical and legal issues.[7] The Panel also followed a consultative process, receiving written submissions,[8] and conducting 14 consultation forums across Victoria[9] to receive views as to practical ways to 'implement a compassionate, safe and practical framework' for VAD.[10] The Panel's detailed report (the '*Report*') recommended the system and processes which were ultimately largely enacted in the *VAD Act*.

A second way in which the political challenges of VAD law reform are reflected is in the design of the *VAD Act*. It is narrow in scope in terms of eligibility, with access to VAD only for competent adult residents of Victoria with an incurable disease, illness or medical condition that is advanced, progressive and will cause death within six months (or twelve months for neurodegenerative conditions).[11] That condition must also be causing suffering that cannot be relieved in a manner that the person considers tolerable.[12] Generally, the *VAD Act* only permits a person to take the lethal medication themselves (often called physician-

(2016) 39(1) *University of New South Wales Law Journal* 1. See also updated data in Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42 *Australian Health Review* 616.

4 The Committee conducted an extensive program of site visits and public hearings around Victoria over an eight-month period between July 2015 and February 2016. It held 17 days of public hearings and heard from 154 witnesses: Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report, 9 June 2016) xix ('*Parliamentary Report*').

5 The Committee received 1037 submissions; 925 from individuals in a private capacity and 112 from organisations: ibid.

6 Ibid xxxv.

7 See Margaret M O'Connor et al, 'Documenting the Process of Developing the Victorian Voluntary Assisted Dying Legislation' (2018) 42(6) *Australian Health Review* 621, 623.

8 One hundred and seventy-six written submissions were received, although some only expressed a view in support of or opposing assisted dying, and did not address the substantive content of the law: Victorian Government, *Ministerial Advisory Panel on Voluntary Assisted Dying* (Final Report, 21 July 2017) 36 ('*Report*').

9 Five of these forums were held in regional Victoria. Approximately 300 people attended the forums. The Panel noted 'each forum provided stakeholders with an opportunity to discuss, with members of the Panel, the key areas of the eligibility criteria, the voluntary assisted dying request process, and the oversight and safeguards required to implement a compassionate, safe and practical framework': ibid 37.

10 Ibid. The quality of the law reform process leading to the *VAD Act* has been commended by some commentators: Matthew Lesh, *Evidence Based Policy Research Project: 20 Case Studies* (Institute of Public Affairs, October 2018) 60–1.

11 *Voluntary Assisted Dying Act 2017* (Vic) s 9 ('*VAD Act*'). The eligibility criteria are discussed further below.

12 Ibid s 9(1)(d)(iv).

assisted suicide).[13] An exception allowing voluntary euthanasia (a medical practitioner administering the medication) arises only if a person cannot physically take or digest that medication themselves.[14]

The *VAD Act* also contains a large number of safeguards. When first introduced into Parliament, its 68 safeguards[15] led the Victorian Government to describe the Act as the 'safest, and most conservative model in the world'.[16] These safeguards include: the need for repeated requests by a person for VAD; ensuring requests are voluntary and made without coercion; assessment and confirmation that a person meets the eligibility criteria; medication management; and prescribing a designated process to access VAD. The *VAD Act* also contains mandatory reporting to an independent statutory authority throughout the process, and numerous offence provisions intended to ensure strict compliance with the legislation. The design of the Act, with its narrow scope and extensive safeguards, was intentionally crafted to attract the political support needed for it to pass both houses of the Victorian Parliament.

The third impact of the political challenges of VAD reform is inconsistency between the policy objectives of the Act and some of its provisions. Politics often requires compromise[17] and when this occurs in an ad hoc way, the overall scheme and objectives of an Act can be distorted. The final legislation that ultimately passes through Parliament may no longer completely align with the overall intended policy goals. An example of this, considered later in the article, is amendments to the *VAD Act* that occurred in Victoria's Upper House, the Legislative Council, during its review of the Voluntary Assisted Dying Bill 2017 (Vic) ('VAD Bill').

This article focuses on the third potential consequence of these political challenges. It aims to address the question: does the *VAD Act* reflect its stated policy goals? It is important to distinguish this inquiry from the question of whether or not VAD legislation, and this particular *VAD Act*, are 'good' or appropriate reforms. There are a range of views on whether VAD should be

13 Ibid ss 45, 47.

14 Ibid s 48(3)(a).

15 For a complete list of these safeguards, see *Report* (n 8) 221–8. Some of these safeguards relate to the eligibility criteria described above.

16 Daniel Andrews, 'Voluntary Assisted Dying Model Established Ahead of Vote in Parliament' (Media Release, 25 July 2017).

17 Baldwin, Cave and Lodge describe the conflicting interest groups and pressure that legislators are subject to: Robert Baldwin, Martin Cave and Martin Lodge, *Understanding Regulation: Theory, Strategy, and Practice* (Oxford University Press, 2012) 42–6.

permitted[18] and, if so, whether the Victorian VAD system is a good one.[19] These arguments for and against VAD are outside the scope of this article. Instead, it considers a proposition that all would endorse: that legislation should reflect and advance the policy objectives that it was designed to address. This goes to the effectiveness of that legislation in guiding behaviour as intended. Whether or not it is effective in doing this, in turn, has implications for societal acceptance of that legislation or what some call its 'regulatory legitimacy'.[20]

To undertake this exercise, this article is comprised of two substantive parts. It first determines the purported policy goals of the *VAD Act*. This is done through analysing the explanatory material accompanying the *VAD Act*, in particular the Report and the second reading debate. Secondly, it evaluates whether the key aspects of the *VAD Act* reflect those identified policy goals. Overall, the article concludes that the *VAD Act* is not consistent with its policy goals in some important respects.

Before undertaking this analysis, issues of terminology and some limitations of this analysis will be addressed. In relation to terminology, VAD is the term used in the *VAD Act* and is a global concept describing the two main practices in this area: voluntary euthanasia and physician-assisted suicide. As noted above, the former involves the medical practitioner administering a lethal medication and in the *VAD Act* is referred to as 'practitioner administration'. By contrast, the latter involves the medical practitioner providing a person with the medication which they then take themselves and is labelled 'self-administration' by the *VAD Act*. It is also acknowledged that this analysis is in relation to the legislation itself rather than how it might be implemented in practice. Although the *VAD Act* is supported by a suite of resources such as clinical guidance documents, models of care

18 Those who oppose VAD reform include Margaret Somerville, *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide* (McGill-Queen's University Press, 2nd ed, 2014); Ian Hayes, 'Ethical Challenges about Voluntary Assisted Dying' (2018) 39(3) *Australasian Science* 49; Jeremy Prichard, 'Euthanasia: A Reply to Bartels and Otlowski' (2012) 19(3) *Journal of Law and Medicine* 610; Brian H Le and Jennifer Philip, 'Voluntary Assisted Dying: Time to Consider the Details' (2018) 209(6) *Medical Journal of Australia* 279. Those who support VAD reform include Lorana Bartels and Margaret Otlowski, 'A Right to Die? Euthanasia and the Law in Australia' (2010) 17 *Journal of Law and Medicine* 532*;* Margaret Otlowski, *Voluntary Euthanasia and the Common Law* (Clarendon Press, 1997); Nicholas Cowdery, 'A Dignified Ending' (2017) 33 *LSJ* 28; Nicholas Cowdery, 'Will We Legalise Euthanasia?' (2017) 34 *LSJ* 26; Willmott and White (n 1).

19 For some early and contrasting discussions of the *VAD Act*, see, eg, Danuta Mendelson, 'Voluntary Assisted Dying Legislation in Victoria: What Can We Learn from the Netherlands Experience' (2017) 25(1) *Journal of Law and Medicine* 30; Ben P White, Lindy Willmott and Eliana Close, 'Victoria's Voluntary Assisted Dying Law: Clinical Implementation as the Next Challenge' (2019) 210(5) *Medical Journal of Australia* 207; Bernadette Richards, 'Assisted Dying in Australia' (2018) 15(1) *Bioethical Inquiry* 15.

20 Regulatory legitimacy is a contested concept, but Yeung reduces it to two broad aspects: whether a regime achieves its stated goals effectively, and whether it conforms with principles of good governance: see Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163, 164–5. This approach draws on Yeung's earlier work: Karen Yeung, *Securing Compliance: A Principled Approach* (Hart Publishing, 2004) 30–6. This article focuses on the first of these objectives: whether the regulation achieves its stated policy goals in an effective manner.

guidelines, medication protocols and training for medical practitioners,[21] this article is being written as the *VAD Act* commences so is focused on the legislation itself rather than the way it is implemented. The effectiveness of implementation will be important research to undertake in the future, but for present purposes, this analysis focuses on the legislation.

II WHAT ARE THE *VAD ACT*'S POLICY GOALS?

Section 1 of the *VAD Act* sets out its main purposes, which are (in summary):

a) to regulate access to VAD;
b) to establish the VAD Review Board; and
c) to make consequential amendments to other legislation.

These purposes are very broad and provide little insight into how the Act is intended to function. Instead, it is the more concrete policy goals of the Government that determine the nature of the VAD system the Act creates. In this section, those policy goals are discerned from two main (and related) sources. The first source is the Report. As described above, the *VAD Act* was developed through a staged, public process,[22] and its policy goals were explicitly set out in a manner which is unusual when developing legislation. The Panel identified nine 'guiding principles' which 'helped guide … its deliberations'.[23] These principles reflect the intended policy goals and assisted the Panel to design the legislative framework. The Panel also recommended that these principles be included in the Act to 'help guide interpretation'.[24] This was done and so the second source for discerning the policy goals of the *VAD Act* is the list of principles stated in the legislation. The Report's nine guiding principles became 10 in the Act and section 5 requires a person exercising a power or performing a function or duty under the Act to have

21 Department of Health and Human Services, State Government of Victoria, *Voluntary Assisted Dying* (Web Page, 2020) <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying>.

22 See also the description of the process by the members of the Panel itself: O'Connor et al (n 7) 621–6. The Panel's contribution to policy formulation is described in Stephen Duckett, 'The Long and Winding Road to Assisted Dying in Australia' (2019) *Australian Journal of Social Issues* 1, and see also Lesh (n 10) 60–1. For criticism of this process, in particular of the *Parliamentary Report* (n 4) (although it is not the focus of this article), see John Keown, '"Voluntary Assisted Dying" in Australia: The Victorian Parliamentary Committee's Tenuous Case for Legalization' (2018) 33(1) *Issues in Law and Medicine* 55.

23 *Report* (n 8) 43–6.

24 Ibid 46. These guiding principles were also referred to in the second reading speech of Health Minister Jill Hennessy: Victoria, *Parliamentary Debates,* Legislative Assembly, 21 September 2017, 2944 (Jill Hennessy).

regard to those principles. As discussed below, the *VAD Act's* principles largely reflect those set out in the Report.

Before turning to these principles, and analysing how they assist in discerning the key policy goals underpinning the *VAD Act*, an observation is made about a phrase that was frequently used in the Report which provides important context for considering the principles and policy goals in this section. A stated overarching goal in the development of the *VAD Act* was to design a legislative framework that is 'safe and compassionate'. This phrase, derived from the Panel's terms of reference,[25] was used repeatedly throughout the Report.[26] 'Compassion', as used in the Report, refers to understanding, sympathy, care and concern for individuals at the end of their lives[27] who are suffering and wish to reduce that suffering.[28] The term 'safe' was most commonly employed to refer to community safety, for example in relation to the careful handling of the VAD medication,[29] or in relation to the system as a whole, encompassing a range of safeguards and oversight mechanisms.[30] Interestingly, it was only infrequently used to refer to the safety of the individual potentially receiving assistance to die, for example in ensuring there was no abuse or coercion,[31] and that a request for VAD was voluntary and properly informed.[32]

The catchphrase 'safe and compassionate' may be seen as a shorthand way to reflect some of the principles underlying the *VAD Act*: namely, compassionate respect for the autonomous choices of suffering individuals at the end of their lives, and the need to ensure the safety of the community. The need to balance these considerations is outlined in the statement of the Panel's Chair, Professor Brian Owler, in presenting the Report:

> The framework focuses on the eligible person who expresses their enduring wish to end their own suffering through access to voluntary assisted dying. It respects their personal autonomy and choice. That autonomy must of course be balanced against

25 The terms of reference tasked the Panel with proposing a 'compassionate and safe legislative framework for voluntary assisted dying': *Report* (n 8) 5.

26 This phrase was used 13 times throughout: *Report* (n 8) 1, 2, 10, 11, 12 (two mentions), 21, 36, 47, 48, 188, 200 and 211. There are also four references to the inverse phrase 'compassionate and safe': *Report* (n 8) 5 (two mentions), 33 and 36. This phrase was also used four times in the second reading speech: Victoria, *Parliamentary Debates* (n 24) 2943, 2947, 2950, 2955 (Jill Hennessy). The notion of balancing compassion for the preferences of those who are suffering at the end of life with safeguards for the community was also discussed twice, using the terms 'compassion' and 'safeguards' without using the composite phrase 'safe and compassionate': Victoria, *Parliamentary Debates* (n 24) 2944, 2949 (Jill Hennessy).

27 See *Report* (n 8) 1, 13; Victoria, *Parliamentary Debates* (n 24) 2949 (Jill Hennessy).

28 See *Report* (n 8) 77, 79; 154; Victoria, *Parliamentary Debates* (n 24) 2944 (Jill Hennessy). There is also a single instance where 'compassion' is used to denote sensitivity to the needs of the family in undertaking monitoring to ensure compliance with the legislative requirements after a person's death by means of VAD: *Report* (n 8) 149.

29 Panel Recommendations 31–33 (concerning safe handling of medication): *Report* (n 8) 1, 6, 17, 26, 45, 129, 131, 135–6, 156–7, 170–1, 213.

30 For example, ibid 11, 12, 20, 21, 47, 148, 154.

31 For example, ibid 10, 18.

32 Ibid 15, 45.

> the safety of the community. We seek to provide a compassionate outcome for those people who are at the end of their life, while also addressing the concerns of the community.[33]

A Ten Principles

As noted above, although section 1 of the *VAD Act* contains express statements about its wider purposes, it is the 10 principles in section 5[34] that provide concrete insight into the policy goals underpinning the system. These principles are:

- valuing every human life equally;[35]
- respecting autonomy;[36]
- supporting informed decision making;[37]
- providing quality care that minimises suffering and maximises quality of life;[38]
- supporting therapeutic relationships;[39]
- encouraging open discussions about dying, death and people's preferences;[40]
- supporting conversations with health practitioners and family about treatment and care preferences;[41]
- promoting genuine choices;[42]
- protecting individuals from abuse;[43] and
- respecting diversity of beliefs and values, including among health practitioners.[44]

These principles directly correspond to the nine guiding principles outlined by the Panel to underpin its recommendations.[45]

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33 Ibid 1.
34 See also Victoria, *Parliamentary Debates* (n 24) 2943–4 (Jill Hennessy).
35 *VAD Act* s 5(1)(a).
36 Ibid s 5(1)(b).
37 Ibid s 5(1)(c), including providing information about medical treatment options and palliative care.
38 Ibid s 5(1)(d).
39 Ibid s 5(1)(e).
40 Ibid s 5(1)(f).
41 Ibid s 5(1)(g).
42 Ibid s 5(1)(h).
43 Ibid s 5(1)(i).
44 Ibid s 5(1)(j).
45 These principles are elaborated on in more detail: *Report* (n 8) 43–6. There are 10 principles in the legislation, rather than nine, because the legislative drafters chose to split the eighth principle in two. The Report stated: 'providing people with genuine choice must be balanced with the need to safeguard people who might be subject to abuse': *Report* (n 8) 11. By contrast, the *VAD Act* separates this into two distinct concepts – 'individuals are entitled to genuine choices regarding their treatment and care' and 'there is a

In addition to identifying these guiding principles, the Panel noted that the *Charter of Human Rights and Responsibilities Act 2006* (Vic) ('Charter') also informed its deliberations. Indeed, members of the Panel noted that the guiding principles were drawn from the Charter.[46] Seven human rights were specifically listed as being significant, including the right to equality, the right to privacy (which includes the right to personal autonomy and dignity) and the right to life.[47] The Minister's second reading speech on the introduction of the VAD Bill also contains a detailed statement of compatibility with these Charter rights.[48] She noted that the Panel 'used the [C]harter as a framework' for considering how best to respect the rights of all Victorians, and for formulating the VAD model, including the guiding principles.[49]

B Six Core Policy Goals

For the purposes of our analysis, the principles listed above can be grouped into six broader policy goals (or some may call them values).[50] Our distillation of how the 10 principles support the six policy goals that underpin the VAD legislation is represented in Table 1 (recognising of course that there are necessarily overlaps across categories).

need to protect individuals who may be subject to abuse' – and does not expressly refer to balancing: *VAD Act* ss 5(1)(h), (i).

46 O'Connor et al (n 7) 625.

47 The seven human rights listed were the rights to equality; life; protection from torture and cruel, inhuman or degrading treatment; privacy and reputation; freedom of thought, conscience, religion and belief; protection of the best interests of the child; and liberty and security of person: *Report* (n 8) 43 and Appendix 2.

48 Victoria, *Parliamentary Debates* (n 24) 2943–9 (Jill Hennessy).

49 Ibid 2943 (Jill Hennessy).

50 For a more detailed discussion of the values underpinning the law that are relevant in the context of VAD, see Willmott and White (n 1) 479–510.

Table 1: Six Policy Goals Derived from 10 Principles

Six policy goals	Relevant principles
1. To respect all human life	• Valuing every human life equally
2. To respect personal autonomy	• Respecting autonomy • Supporting informed decision making • Promoting genuine choices • Encouraging open discussions about dying, death and people's preferences • Supporting conversations with health practitioners and family about treatment and care preferences
3. To safeguard the vulnerable and the community	• Protecting individuals from abuse
4. To provide high-quality care	• Providing quality care that minimises suffering and maximises quality of life • Supporting therapeutic relationships • Encouraging open discussions about dying, death and people's preferences • Supporting conversations with health practitioners and family about treatment and care preferences
5. To respect individual conscience	• Respecting diversity of beliefs and values, including among health practitioners
6. To alleviate human suffering (compassion)	• Providing quality care that minimises suffering and maximises quality of life
Goals 2 and 3 are bolded because, as argued below, while all goals are important, these two appeared to be the dominant ones when making decisions about the scope and nature of the legislation.	

The Minister herself summarised the principles as recognising three values: 'the value of every human life, respect for autonomy and a person's preferences, choices and values, and the provision of high-quality care'.[51] The second of these values – respect for personal autonomy – encompasses the principles of supporting informed decision-making, and promoting genuine choices. The principles of open discussions and supporting conversations will also be relevant to the provision of adequate information about treatment and care options to enable genuine and autonomous choices to be made. The Minister's third value – the provision of high-quality care – incorporates the principles of supporting therapeutic relationships with health practitioners, encouraging open discussions about dying and death, and supporting conversations with family, friends and carers about treatment and care

51 Victoria, *Parliamentary Debates* (n 24) 2951 (Jill Hennessy).

preferences. In addition to the three goals mentioned by the Minister, three other important policy goals are discerned from those principles that underpin the legislation, namely: compassion to alleviate human suffering, safeguarding the vulnerable and the community, and respecting individual conscience. Each of these policy goals will be discussed briefly in turn.

1 Respect All Human Life

The equal value of every human life is the first principle in the Act[52] and was also recognised as the first guiding principle by the Panel.[53] Twice in the second reading speech, the Minister stated that the right to life is the primary or supreme value in these debates.[54] However, it was also clear, for example from the Minister's statement of compatibility tabled in accordance with the Charter, that despite the significance of the right to life, it is not absolute and can be subject to justifiable limitations.[55]

2 Respect Personal Autonomy

The Panel repeatedly referred to the need for 'genuine choice' at the end of life. This included the provision of information about treatment options, and the provision of a range of choices about treatment and care, including the ability to choose the timing and manner of one's impending death.[56] This shows the importance placed on respecting a person's individual autonomy and freedom to 'choose to end their life according to their own preferences'.[57] Similarly, the deliberate choice of the term 'voluntary assisted dying', instead of the term 'dying with dignity' used in some American jurisdictions, reflected the emphasis on individual choice from a range of available end-of-life options.[58]

However, the Panel was at pains to point out that the aim of the *VAD Act* is not to give effect to *all* personal autonomy. Rather, autonomy is to be respected in a narrower set of circumstances: to provide alternative end-of-life care for people with terminal conditions who are suffering. The Panel noted respecting autonomy does not mean allowing people 'to do whatever they want' or to 'choose whether to live or die'.[59] Instead, the autonomy protected is choice over the 'timing and manner' of a death that is otherwise inevitable.[60]

52 *VAD Act* s 5(1)(a).
53 *Report* (n 8) 43.
54 Victoria, *Parliamentary Debates* (n 24) 2943–4 (Jill Hennessy).
55 Ibid 2944 (Jill Hennessy).
56 There were 17 references to 'genuine choice' in the report: *Report* (n 8) 6, 10, 11, 22, 34 (twice), 38, 43, 44 (twice), 45 (twice), 46, 86 (twice), 99 and 117.
57 Victoria, *Parliamentary Debates* (n 24) 2945 (Jill Hennessy).
58 *Report* (n 8) 7.
59 Ibid 44.
60 Ibid.

3 Safeguard the Vulnerable and the Community

Another core concern expressed throughout the Report is the need to safeguard vulnerable individuals in the community from abuse or coercion. This principle, recognised in the Report and as a legislative principle,[61] was highly significant in the design of the system as the Report mentions the importance of safeguarding the vulnerable over 30 times.[62] Four potentially vulnerable groups that were discussed in detail were the elderly,[63] children,[64] people with disabilities,[65] and people with mental illness.[66] The critical importance of this policy goal is also reflected in the emphasis on designing a 'safe and compassionate' VAD system as required by the Panel's terms of reference. Of note though, this policy goal of a safe system was framed to include the protection not only of potentially vulnerable groups but also the wider community.

4 Provide High-Quality Care

The Victorian model situates VAD within the healthcare system as one of a number of medical choices available to a person in the context of end-of-life care.[67] This creates the imperative, as with all healthcare, for any assessment for, or provision of, VAD to be of high quality. This is reflected in the Panel's recognition of the 'critical role of health practitioners' in VAD and the importance of continuity of care within an ongoing therapeutic relationship.[68] This was also noted by the Minister in her second reading speech.[69] In particular, the Report repeatedly recognises that open discussions within an existing therapeutic relationship would be the best way to ensure that any decisions about VAD were appropriate in the context of the person's needs and preferences.[70]

5 Respect Individual Conscience

Respecting medical practitioners' freedom of conscience was part of the terms of reference given to the Panel when advising about the form of *VAD Act*.[71] Respect for 'culture, beliefs, values and personal characteristics' was one of the Report's

61 Ibid 11, 22, 46; *VAD Act* s 5(1)(i).
62 *Report* (n 8) 5, 17 (twice), 18, 24, 51, 58, 63, 80, 82, 84, 87, 88 (3 times), 89, 91, 106, 127, 148, 180, 210 (3 times), 211 (3 times), 212 (3 times), 213, 215.
63 This was discussed in depth in ibid 88–90, and mentioned again at 180.
64 Ibid 53–54.
65 Ibid 84, 91.
66 Ibid 82.
67 Victoria, *Parliamentary Debates* (n 24) 2949–50 (Jill Hennessy).
68 *Report* (n 8) 45.
69 Victoria, *Parliamentary Debates* (n 24) 2952–3 (Jill Hennessy).
70 *Report* (n 8) 186 (Panel Recommendation 58). See also *Report* (n 8) 20, 92, 99, 101, 190.
71 Ibid 5.

guiding principles[72] and was likewise included as a legislative principle in the *VAD Act*.[73] The right to freedom of thought, conscience, religion and belief was also noted as one of the core Charter rights engaged in the legislation.[74]

The Panel explains what conscientious objection to VAD means for medical practitioners, referring to this issue on several occasions in its Report.[75] The *VAD Act* respects the right of medical practitioners to choose on conscientious grounds not to participate in the provision of VAD, while continuing to provide holistic care to relieve the suffering and meet the needs of persons in their care.[76] But the Panel emphasised that this must not impede individuals who wish to access VAD from doing so.[77]

6 Alleviate Human Suffering (Compassion)

Compassion was a significant driver at the macro policy level for the *VAD Act*, as reflected in earlier discussions about the need for a 'safe and compassionate' framework. This policy goal aims to alleviate the suffering of individuals at the end of their lives.[78] However, as the Panel shifted to operationalise its recommendations, compassion appeared to assume a less significant role. For example, it receives only limited recognition in the Report and legislative principles and indeed it was sometimes subsumed within two other policy goals. The first was respecting autonomy, with some references framed in terms of compassionate respect for autonomous choices to receive assistance to die.[79] The other was high-quality care, with both the Report and legislative principles referring to 'quality care to minimise the person's suffering'.[80] This may indicate that compassion played an important role in deciding whether or not to enact a VAD law, but then had less influence on the shape of that law; a notable exception is the eligibility requirement relating to suffering discussed below.

C Two Dominant Policy Goals: Respecting Autonomy and Safeguarding the Vulnerable and Community

As the discussion in relation to the policy goal of compassion shows, there are different ways in which policy goals can shape law. Some may establish important macro-level policy settings but do very little beyond that, whereas other goals may

72 Ibid 11, 22.
73 *VAD Act* s 5(1)(j).
74 See *Report* (n 8) 211; Victoria, *Parliamentary Debates* (n 24) 2947 (Jill Hennessy).
75 *Report* (n 8) 2, 15, 21, 40, 107, 109–11, 143, 190, 206, 214.
76 Ibid 40.
77 See, eg, ibid 15.
78 See ibid 1, 13 and Victoria, *Parliamentary Debates* (n 24) 2949 (Jill Hennessy).
79 *Report* (n 8) 13 and Victoria, *Parliamentary Debates* (n 24) 2949–50 (Jill Hennessy). Reference was also made to a compassionate framework allowing individual choice, and not requiring a person to demonstrate unbearable suffering to be eligible for VAD: *Report* (n 8) 77–8.
80 *VAD Act* s 5(1)(d) and *Report* (n 8) 11.

be integral in shaping the contours of the law and the detail of what is permitted and what is not. Sometimes policy goals will do both.

Although all six of the identified policy goals were important in framing the *VAD Act*, two goals were particularly dominant in determining the content of that law: respecting autonomy and safeguarding the vulnerable and community. This is evident from the number of references throughout the Report and the second reading speech to the need to balance freedom of choice with safeguards for vulnerable individuals and the wider community, as well as the frequent repetition of the key phrase: a 'safe and compassionate' system for VAD.

The eighth guiding principle in the Report explicitly states: 'providing people with genuine choice must be balanced with the need to safeguard people who might be subject to abuse'.[81] The need to balance these (potentially) competing policy objectives is also recognised in frequent statements such as: '[p]romoting individual autonomy and providing appropriate safeguards are critical, and neither aim is paramount. Instead, they must be balanced'.[82] Although all policy goals were important, this suggests that striking an appropriate balance between these two competing goals was a particular focus in the development of the *VAD Act*.

Minister Hennessy's second reading speech presenting the VAD Bill reinforces this conclusion. Although all 10 principles were listed at the outset of the speech,[83] it was her concluding paragraph that best captured the purpose of the legislation:

> This bill establishes a *safe* and compassionate framework to give Victorians who are suffering the ability to choose the timing and manner of their death. The bill provides a rigorous process with *safeguards* embedded at every step to ensure that only those who meet the eligibility criteria and who are making an *informed, voluntary and enduring decision* will be able to access voluntary assisted dying. The clear and considered details reflected in this bill will provide the Victorian community with the confidence that voluntary assisted dying can be *safely* provided to give Victorians *genuine choice* at the end of their lives.[84]

For this reason, the policy goals of respecting autonomy and safeguarding the vulnerable and the community are often discussed in more detail than the other policy goals in the analysis that follows.

III DOES THE *VAD ACT* REFLECT THESE POLICY GOALS?

81 *Report* (n 8) 22.

82 Ibid 210. See also Ibid 11, 15, 43, 87, 210, 211; Victoria, *Parliamentary Debates* (n 24) 2943 (Jill Hennessy).

83 Victoria, *Parliamentary Debates* (n 24) 2943 (Jill Hennessy).

84 Ibid 2955 (Jill Hennessy) (emphasis added).

The following analysis of whether the *VAD Act* reflects its stated policy goals is arranged according to the main components of the Act: method of VAD permitted; eligibility criteria; the process of requesting VAD, being assessed and then accessing VAD; conscientious objection by health practitioners; and oversight, reporting and compliance. The length and complexity of the *VAD Act* means that the discussion below can be only an overview of its key provisions. Further, and again for reasons of scope, this analysis pays particular attention to aspects of the VAD Act that do *not* comply with the identified policy goals. As legislation is generally expected to implement its stated objectives, it is this divergence that is of most interest in this article. A final point to note in relation to this analysis is that, as mentioned above in relation to respecting autonomy and safeguarding the vulnerable and the community, there will sometimes be tension between different policy goals.[85] Advancing one goal may require reduced recognition of another. The process of this balancing exercise will be outlined as necessary in the analysis below.

A Method of VAD Permitted

1 Overview of Law

The default method of VAD permitted under the *VAD Act* is self-administration; in other words, a medical practitioner prescribing medication which the person takes themselves.[86] It is only if a person is 'physically incapable of the self-administration or digestion' of the medication[87] that they can ask a medical practitioner to administer it (practitioner administration). This limited exception to permit practitioner administration was included to avoid discrimination on the basis of disability where a person's condition would preclude self-administration.[88] The *VAD Act* contains additional safeguards when the person receives practitioner administration: an independent witness of the person's request to administer the VAD medication must certify the person's apparent capacity and voluntariness, and the enduring nature of the request to die.[89]

2 Conformity with Policy Goals

The key policy goals of relevance here are: safeguarding the vulnerable, respect for autonomy and providing high-quality care. For the Panel, the most important goal appeared to be safeguarding the vulnerable, for example from

85 Yeung also recognises this: Yeung, *Securing Compliance: A Principled Approach* (n 20) 31.

86 A co-ordinating medical practitioner applies for a 'self-administration permit', which enables the medical practitioner to prescribe and supply a lethal substance in a sufficient dose, and authorises the person concerned to possess that substance and administer it to themselves: *VAD Act* ss 45, 47.

87 Ibid s 48(3)(a).

88 *Report* (n 8) 141; Victoria, *Parliamentary Debates* (n 24) 2953 (Jill Hennessy).

89 *VAD Act* ss 46, 65(2).

coercion. Its report noted that '[w]hen a person self-administers a lethal dose of medication it is a final indication that their decision is voluntary'.[90] A person physically taking the medication themselves could also be seen as advancing the policy goal of autonomy in that it ensures the choice for VAD is truly the person's.

However, the Panel must have reached the view that practitioner administration of VAD medication is also safe with appropriate additional safeguards. This is reflected in their report and subsequently in the proposed legislation, as per the safeguards noted above. These safeguards are designed to ensure capacity and voluntariness of a person's request so that vulnerable people are not coerced into making requests for VAD. This raises the question though: if it is accepted that practitioner administration is safe, can safeguarding the vulnerable be a defensible basis for restricting VAD primarily to self-administration? Indeed, it could be argued that practitioner administration, which requires additional checks on capacity and voluntariness at the time VAD is provided, may better protect the vulnerable than permitting a person to self-administer unsupervised, which may occur at a later date when capacity has been lost. In a similar vein, later self-administration may also provide less protection against coercion.

In terms of respecting autonomy, the limitations placed on access to practitioner administration of VAD do not accord with this policy goal. The Report refers repeatedly to the importance of choosing the 'timing and *manner'* (emphasis added) of a person's death, yet only one of the two possible lawful methods of VAD is open to the majority of eligible people. The policy goal of respecting autonomy would be better achieved if a person was able to choose to self-administer the VAD medication or have assistance from a medical practitioner for practitioner administration.[91] This choice between self-administration and practitioner administration is available in a number of the other jurisdictions which permit VAD,[92] and where both options are available, available data show practitioner administration is overwhelmingly used.[93] Some people may find self-

90 *Report* (n 8) 141.

91 See Willmott and White (n 1) 479, 490–492, 500–501.

92 *Criminal Code of Canada* s 241.1 (definition of 'medical assistance in dying'); *Wet Toetsing Levensbeëindiging op Verzoek en Hulp Bij Zelfdoding* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001] art 2.1(f) (The Netherlands). Other countries which allow a choice between euthanasia and assisted dying are Belgium, Luxembourg and Colombia: Emanuel Ezekiel et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe' (2016) 316(1) *Journal of the American Medical Association* 79, 79. While the law in Belgium does not address physician-assisted suicide directly, the Federal Control and Evaluation Committee for Euthanasia in Belgium considers it to be a form of euthanasia: at 82.

93 For example, in the Netherlands in 2017, of 6,585 cases reported to Euthanasia Review Committees, 6,303 were of euthanasia, 250 were of assisted suicide, and 29 cases involved a combination of both: Regional Euthanasia Review Committees, *Annual Report 2017* (Report, May 2017) 10. In Canada, drawing on the last two federal government reports covering the period from 1 January 2017 to 31 October 2018, of the 4,575 medically assisted deaths reported, only 2 were self-administered (note: this does not include data from some provinces as outlined in the report): Health Canada, *Fourth Interim Report on Medical Assistance in Dying Canada* (Report, April 2019) 5. Belgium does not differentiate in its reporting between euthanasia and assisted suicide, but data shows that for the period 2016–17, of 4337 deaths, 23 were by oral ingestion of barbiturates, 10 by other methods, and the remaining 4,304 (99%)

administration to be an unacceptable option, or an unduly burdensome option, even if it is physically possible for them. Others may prefer practitioner administration because it may be safer (see below). It is not simply the ability to choose an option which leads to death, but the choice of a particular option for causing death which is preferred by some individuals.

The third key policy goal is to provide high-quality care and it could be argued that this goal is better served when people also have access to practitioner administered VAD rather than only self-administration. Although there is limited evidence, a Dutch study found that, while both means of providing VAD can experience complications and technical problems, the rate of these is higher with self-administration when compared with practitioner administration.[94] This suggests practitioner administration may be safer, and the legislative prohibition on practitioner administration for those able to self-administer precludes these people from accessing a potentially safer option.[95]

3 Conclusion

Limiting practitioner administration of VAD to those who are physically unable to administer or ingest the medication themselves is not consistent with the policy goals of the *VAD Act*. In particular, respecting autonomy and providing high-quality care would favour allowing eligible persons to choose whether to

were by intravenous injection: Commission Fédérale de Contrôle et D'évaluation de L'euthanasie, *Huitième Rapport aux Chambres Législatives Années 2016 – 2017*, (Report, 17 July 2018) 6.

94 The study reported on three types of problems: technical problems (eg, difficulty administering the medication); complications (eg, spasm, nausea, and vomiting); and problems with completion (eg, longer time than expected to death). In all categories, physician assisted suicide cases had higher rates of clinical problems compared to euthanasia. Technical problems arose in approximately 10% of cases of physician-assisted suicide (versus approximately 4% of euthanasia cases); complications arose in approximately 9% of physician assisted suicide cases (versus approximately 4% of euthanasia cases) and problems with completion arose in 14% of physician assisted suicide cases (versus 5% of euthanasia cases). The study found approximately 2% of physician assisted suicide patients awoke from a coma, and approximately 12% took longer than anticipated to die or never lost consciousness, compared to less than 1% and 4% respectively of euthanasia cases: Johanna Groenewoud et al, 'Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands' (2000) 342(8) *New England Journal of Medicine* 551, 555. More robust data from other jurisdictions which permit both euthanasia and physician assisted suicide are needed to support this conclusion: see Christopher Harty et al, 'Oral Medical Assistance in Dying (MAiD): Informing Practice to Enhance Utilization in Canada' (2019) 66(9) *Canadian Journal of Anesthesia* 1106. Data on complications from the US States of Oregon and Washington are available, but as these States permit only physician-assisted suicide, comparison with the rate of complications in euthanasia cases is not possible: Ezekiel et al (n 92) 86. Nevertheless, complication rates for physician assisted suicide appear to vary. The most recent statistics from Oregon found that just 2.8% of cases had reported complications (although in 52.6% of cases whether or not there were complications was unknown): Oregon Health Authority, *Oregon Death with Dignity Act 2018 Data Summary* (Report, 25 April 2019) 12. Riley also provides recent evidence of complications experienced with lethal injections of medication: Sean Riley, 'Navigating the New Era of Assisted Suicide and Execution Drugs' (2017) 4(2) *Journal of Law and the Biosciences* 424.

95 In the Netherlands, it is recommended to have a physician present during an assisted suicide, to be able to administer a lethal injection if the assisted suicide fails. This occurred in 21 out of 114 cases of assisted suicide in the study in question: Groenewoud et al (n 94) 554–6.

receive VAD by self-administration or from their medical practitioner. This allows a person both greater choice as to the manner of their death and access to the safer of the two options. Arguments about safeguarding the vulnerable lack traction in this setting, given that practitioner administration is permitted by the *VAD Act* with appropriate safeguards, therefore recognising practitioner administration as a safe VAD option.

B Eligibility Criteria

1 Overview of Law

Section 9(1) of the *VAD Act* states that '[f]or a person to be eligible for access to voluntary assisted dying':

> (a) the person must be aged 18 years or more; and
> (b) the person must–
> (i) be an Australian citizen or permanent resident; and
> (ii) be ordinarily resident in Victoria; and
> (iii) at the time of making a first request, have been ordinarily resident in Victoria for at least 12 months; and
> (c) the person must have decision-making capacity in relation to voluntary assisted dying; and
> (d) the person must be diagnosed with a disease, illness or medical condition that–
> (i) is incurable; and
> (ii) is advanced, progressive and will cause death; and
> (iii) is expected to cause death within weeks or months, not exceeding 6 months [or 12 months if the disease, illness or medical condition is neurodegenerative];[96] and
> (iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.

Disability and mental illness alone are not grounds to access VAD,[97] however, the Panel noted that having a disability or a mental illness does not preclude a person from accessing VAD if all the eligibility criteria are met.[98]

2 Conformity with Policy Goals

Before considering the four domains of the *VAD Act's* eligibility criteria – age, capacity, residence and nature of disease, illness or medical condition – it is noted

96 The words in square brackets have been inserted based on *VAD Act* s 9(4).
97 *VAD Act* ss 9(2)–(3).
98 Panel Recommendation 5: see *Report* (n 8) 80–2 (in respect of mental illness); Panel Recommendation 6: at 83–5 (in respect of disability).

that globally these requirements reflect a balancing of several of the identified policy goals. The threshold choice to allow VAD reflects the policy goals of respecting autonomy and the compassionate alleviation of human suffering (in relation to the latter, recognising that suffering is one of the eligibility requirements). But limiting VAD to those whose deaths are expected to occur within six months (or 12 months in the case of neurodegenerative conditions) reflects the policy goal of respecting all human life, by ensuring that only people who are close to death are eligible to request VAD. Excluding people from accessing VAD on the basis of disability or mental illness alone may be seen as safeguarding the vulnerable. The capacity and age requirements advance the policy goal of safeguarding vulnerable people by ensuring that only competent adults are able to request assistance to die, but a requirement to have capacity to access VAD also promotes autonomy. Finally, the decision to restrict access to Victorian residents was designed to ensure that VAD occurs in the context of an ongoing, caring therapeutic relationship,[99] which is part of the policy goal of providing high-quality care.

(a) Illness, Disease or Medical Condition

Of the four domains, it is the criterion of the illness, disease or medical condition of the person seeking access to VAD that is the most complex in terms of analysing its compliance with the policy goals.

(i) Will Cause Death

The requirement to have a condition that 'will cause death' reflects a tension between both respecting autonomy and alleviating human suffering on the one hand and respecting all human life on the other. Some other jurisdictions have chosen to preference autonomous choice and the alleviation of suffering by allowing wider access to VAD by individuals who do not have a terminal illness. For example, one of the criteria in Belgium is that a person has a 'medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated'.[100] Nevertheless, on balance, the requirement in the *VAD Act* that the person have a medical condition that will cause death is a defensible balancing of its stated policy goals. As the Panel stated, the purpose of the *VAD Act* was not to foster *all* autonomous choices in relation to the end of life, but only choices concerning the timing and manner of deaths that were already inevitable and impending.[101]

99 Ibid 56; Victoria, *Parliamentary Debates* (n 24) 2948 (Jill Hennessy).

100 *Loi Relative à L'euthanasie* [Act on Euthanasia 2002] s 3§1.

101 See *Report* (n 8) 44.

(ii) Six Months until Death

The position in relation to time limits is less able to be justified in light of the policy goals. First, the policy goals individually and when balanced collectively do not necessarily indicate a particular time from death as being an appropriate point at which to grant access to VAD. The selection of a six-month period is arbitrary.[102] This is illustrated by the fact that a 12-month period was initially included in the Report[103] and the VAD Bill that was originally passed by the Victorian Legislative Assembly.[104] While this was the initial preferred policy position, as will be discussed shortly below, this time limit was halved in the Bill presented to the Legislative Council after political negotiations, ultimately resulting in the six-month limit in the *VAD Act*.

One justification for this time limit could be that balancing the policy goals of respect for autonomy and respect for human life led the Panel and Parliament to restrict access to VAD to those who are in the process of dying.[105] But selecting a time period – of six months or some other duration – to restrict access to VAD to a cohort who are in the process of dying has problems. Prognostication about time until death is notoriously difficult.[106] Different diseases have different trajectories, and some are more predictable than others.[107] Studies, as well as anecdotal reports,[108] also demonstrate that a significant percentage of people predicted to die

102 Willmott and White (n 1) 503–4.

103 Panel Recommendation 2: *Report* (n 8) 22. See also *Report* (n 8) 13, 68, 70.

104 The Voluntary Assisted Dying Bill 2017 (Vic) ('VAD Bill'), as introduced and passed by the Victorian Legislative Assembly, stated that a person was eligible to receive VAD if they were suffering from an incurable and progressive condition that was 'expected to cause death within … 12 months': at cl 9.

105 This is similar to the restrictions contained within the US laws in force at that time: *Death with Dignity Act 1997*, Or Rev Stat §§ 127.800–127.995 (1994) (Oregon); *Death with Dignity Act 2009*, Wash Rev Code §§ 70.245.010–70.245.903 (2008) (Washington); *Patient Choice at End of Life Act 2013*, Vt Stat Ann §§ 5281–93 (2013) (Vermont); *End of Life Option Act 2016*, Cal Health and Safety Code §§ 443–443.22 (2015) (California); *End of Life Options Act 2016*, §§ 25-48-101–25-48-123 (2017) (Colorado). See *Report* (n 8) 221.

106 Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311, 324; Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337; James Downar et al, 'The "Surprise Question" for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-analysis' (2017) 189(13) *Canadian Medical Association Journal* E484. Glare and colleagues observe that predictions estimating that a certain percentage of patients will survive for a certain time have a 50–75% accuracy rate, whereas predictions estimating the time the patient will survive are only 25% accurate: Paul Glare et al, 'Predicting Survival in Patients with Advanced Disease' (2008) 44(8) *European Journal of Cancer* 1146, 1147. In the Victorian debate on the VAD Bill, Ms Crozier also noted evidence from Washington and Oregon of a considerable proportion of people diagnosed as eligible for VAD being expected to live less than 6 months, whose deaths occur 1–2 years or longer after this diagnosis: Victoria, *Parliamentary Debates,* Legislative Council, 21 November 2017, 6221 (Georgina Crozier).

107 Lynn et al (n 106) 326–7; Downar et al (n 106).

108 Mr Ondarchie referred to his own father's death, which was predicted to occur within three months, but did not in fact occur for another 21 months: Victoria, *Parliamentary Debates,* Legislative Council, 14 November 2017, 5837 (Craig Ondarchie).

within six months are still alive after two to three years.[109] Lynn and colleagues have concluded that, because prognoses are unavoidably ambiguous:

> Deciding who should be counted 'terminally ill' will pose such severe difficulties that it seems untenable as a criterion for permitting physician-assisted suicide. Allowing physicians (or anyone else) to decide who is terminally ill without standards or guidance will result in uneven application with unjustified variations across diseases, across physicians, and across regions.[110]

Accordingly, this criterion does not sufficiently respect the value of life, as prognostic uncertainty may inappropriately grant access to VAD to people who have more (perhaps much more) than six months of life remaining.[111] This criterion may also fail to respect autonomy and alleviation of human suffering through the inappropriate exclusion of people who are suffering and close to death, if this proximity to death is not recognised by medical practitioners.[112]

Although problematic for the reasons outlined above, perhaps the best justification for adopting a six-month time period is that it could be seen as a practical compromise representing an imperfect proxy for being close to death. This reflects a pragmatic choice to preference certainty in the legislation (although the uncertainty of this eligibility criterion is noted above) even if doing so means it can only approximately reflect the policy goals of the *VAD Act*.

(iii) Twelve Months until Death for Neurological Conditions

As noted above, when the Legislative Assembly passed the VAD Bill, the eligibility criterion required that death was expected to occur within 12 months. This was reduced to six months when the VAD Bill was presented to the Legislative Council, and this ultimately became law. An exception was made, however, for persons with neurodegenerative conditions, who remained eligible for VAD if their death was expected within 12 months. If a time limit in itself is questionable, having different time limits for different conditions requires a compelling justification. For reasons outlined below, it is argued that this justification is absent.

The stated reason for this differential treatment was a concern that people with neurodegenerative conditions might either lose capacity to apply for, or to self-

109 Lynn and colleagues have demonstrated that 20–40% of those predicted to have a 50% chance to die within the next six months are still alive after two to three years. Even among those predicted to have only a 20% chance of surviving six months, up to 10% survive for two to three years: Lynn et al (n 106) 321–2.

110 Ibid 334.

111 Statistics from Washington and Oregon quoted in the Victorian debate bear this out: Victoria, *Parliamentary Debates* (n 106) 6221 (Georgina Crozier).

112 Colleen Cartwright, 'The Six-Month Amendment Could Defeat the Purpose of Victoria's Assisted Dying Bill' *The Conversation* (online, 23 November 2017) <https://theconversation.com/the-six-month-amendment-could-defeat-the-purpose-of-victorias-assisted-dying-bill-87941>.

administer, VAD medication if the eligibility period was restricted to six months.[113] This cannot be justified by reference to the policy objectives of the *VAD Act*. In relation to capacity, allowing only people with neurodegenerative conditions this additional time to access VAD before they lose capacity to request it gives greater protection to the autonomous choices only of a narrow class of individuals.[114] No such provision is made in relation to people with other illnesses which may affect a person's decision-making capacity.[115] Further, the concern to ensure access to self-administration is misplaced, given the law permits practitioner administration where a person is no longer physically capable of taking or ingesting the VAD medication.

(b) Adult with Decision-Making Capacity

The policy goals of respecting autonomy and safeguarding the vulnerable align with the eligibility criteria that a person must be an adult and must have decision-making capacity to access VAD.[116] In relation to the requirement to be an adult, although it may be argued that this devalues the autonomy of competent minors or that 18 years of age is an arbitrary line to draw, the Panel and the Victorian Government formed the view that children do not have sufficient maturity or capacity for abstract reasoning to make difficult decisions concerning death and dying. This accordingly renders them vulnerable, which justified the need to protect them, by imposing a prohibition on minors accessing VAD.[117] This view is not inconsistent with the legal position in Australia which recognises that there are limits on the ability of minors to request the withdrawal of life-saving medical treatment.[118] It also reflects the consensus in the majority of overseas jurisdictions that access to assisted dying be limited to adults.[119] Only Belgium, the Netherlands and Colombia permit requests for VAD to be made by children under the age of 18, and this occurs in practice only in very rare cases.[120]

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113 Victoria, *Parliamentary Debates,* Legislative Council, 16 November 2017, 6098 (Gavin Jennings); Victoria, *Parliamentary Debates,* Legislative Council, 21 November 2017, 6216 (Gavin Jennings). No evidence was cited showing that people with neurodegenerative conditions tend to lose capacity earlier than people with other kinds of terminal illness.

114 For example, recent data from Canada found that from 1 January to 31 October 2018, neurodegenerative conditions accounted for just 11% of all cases of medical assistance in dying, while 16% were due to circulatory and respiratory conditions, and another 9% from other causes or unknown. The majority (64%) were cancer-related: Health Canada (n 93) 6.

115 Cartwright observes that '[p]atients suffering from conditions such as congestive cardiac failure, chronic obstructive pulmonary disease and chronic renal (kidney) failure can be given such strong medication at the end of life, which may render them incapable of clear decision-making': Cartwright (n 112).

116 Willmott and White (n 1) 501.

117 *Report* (n 8) 54, 215; Victoria, *Parliamentary Debates* (n 24) 2947–8 (Jill Hennessy).

118 *X v Sydney Children's Hospitals Network* (2013) 85 NSWLR 294. See also *Royal Alexandra Hospital for Children Trading as Children's Hospital at Westmead v J* (2005) 33 Fam LR 448; *Minister for Health v AS* (2004) 33 Fam LR 223.

119 See *Report* (n 8) 53.

120 In the Netherlands between 2002 and 2014, only five cases of euthanasia involving minors were reported: Judith Rietjens, Lenzo Robijn and Agnes van der Heide, 'Euthanasia for Minors in Belgium' (2014) 312(12) *Journal of the American Medical Association* 1258; Ezekiel et al (n 92) 84. In Belgium,

In relation to requiring decision-making capacity at the time of accessing VAD, not permitting advance requests was argued to advance the policy goals of respecting autonomy and safeguarding the vulnerable. For example, the Panel considered that the person making a final choice for VAD at the point it is provided ensures the voluntary nature of the decision and avoids 'manipulation and abuse'.[121] There are contrary views, however, and many argue, for example, that recognition of advance requests is needed to give appropriate respect to a person's autonomy.[122] Nevertheless, requiring capacity at the time of accessing VAD may be regarded as a defensible position in light of the *VAD Act's* stated policy goals. Not recognising advance requests in the *VAD Act* is also consistent with the majority of overseas jurisdictions. Only Belgium, the Netherlands and Luxembourg permit advance requests for VAD and they are only acted on infrequently in those jurisdictions.[123]

(c) Residency Requirements

From the Report, the *VAD Act's* requirements in relation to residency appear to be based primarily on it being 'Victorian legislation that is intended to apply to

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euthanasia of minors became lawful in 2014, with the first three cases involving children (aged 9, 11 and 17) reported between 2016 and 2017: Commission Fédérale de Contrôle et D'évaluation de L'euthanasie (n 93) 11–12. On 9 March 2018, Colombia passed a resolution permitting euthanasia of children aged seven or over: Ministerio de Salud y Protección Social [Department of Health and Social Protection], *Resolución Número 825 de 2018* [Resolution 825 of 2018], 9 March 2018. This resolution was issued in compliance with judgment T-544 of 2017, in which the Constitutional Court required the Department to issue a 'procedure to give effect to the right to die with dignity for children and adolescents': *Judgment T-544 of 2017* (Unreported, Constitutional Court of Colombia, Magistrate Ortiz Delgado, 25 August 2017). See Nubia Leonor Posada-González and Nora Helena Riani Llano, 'Eutanasia: Conceptos de la Fundación Colombiana de Ética y Bioética FUCEB, Dirigidos a la Corte Constitucional (Sentencia T-721-17) y al Ministerio de Salud y Protección Social (Borrador de Resolución Sobre Sentencia T-544-2017 de Eutanasia Infantil)' (2018) 22(1) *Persona y Bioética* 148.

121 *Report* (n 8) 61–3.

122 See, eg, Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Alfred A Knopf, 1993); Paul T Menzel and Bonnie Steinbock, 'Advance Directives, Dementia, and Physician-Assisted Death' (2013) 41(2) *Journal of Law, Medicine & Ethics* 484; Thaddeus Mason Pope, 'Medical Aid in Dying: When Legal Safeguards Become Burdensome Obstacles', *The ASCO Post* (online, 25 December 2017) <https://www.ascopost.com/issues/december-25-2017/medical-aid-in-dying-when-legal-safeguards-become-burdensome-obstacles/>. See also the discussion of 'key concepts' in this area: Council of Canadian Academies, *The State of Knowledge on Advance Requests for Medical Assistance in Dying* (Report, 2018) 48–58.

123 Emily Tomlinson and Joshua Stott, 'Assisted Dying in Dementia: A Systematic Review of the International Literature on the Attitudes of Health Professionals, Patients, Carers and the Public, and the Factors Associated with These' (2015) 30(1) *International Journal of Geriatric Psychiatry* 10, 11; Sigrid Dierickx et al, 'Euthanasia for People with Psychiatric Disorders or Dementia in Belgium: Analysis of Officially Reported Cases' (2017) 17(1) *BMC Psychiatry* 203. For some discussion of the complexity of the issue, see Johannes van Delden, 'The Unfeasibility of Requests for Euthanasia in Advance Directives' (2004) 30 *Journal of Medical Ethics* 447; Paul Mevis et al, 'Advance Directives Requesting Euthanasia in the Netherlands: Do They Enable Euthanasia for Patients Who Lack Mental Capacity?' (2016) 4(2) *Journal of Medical Law and Ethics* 127; David Gibbes Miller, Rebecca Dresser and Scott Y H Kim, 'Advance Euthanasia Directives: A Controversial Case and its Ethical Implications' (2019) 45(2) *Journal of Medical Ethics* 84; Menzel and Steinbock (n 122).

Victorian residents'.[124] Perhaps the only policy goal that could be said to be relevant is that of providing high-quality care. The Panel observed that while European jurisdictions do not expressly impose residency requirements, they are 'considered to be enforced' through requiring an ongoing therapeutic relationship.[125] The Panel also noted the undesirability of 'death tourism'[126] or 'suicide tourism'[127] in jurisdictions such as Switzerland where VAD is available to non-residents, which a residency requirement would prevent.

That said, while a residence requirement might exclude some cases where a person has only limited contact with a medical practitioner who provides VAD, it does little to promote high-quality care and may in fact impede it in some cases where a non-resident's primary medical practitioner is based in Victoria.[128] In summary, the identified policy goals provide only limited support for imposing residence requirements and some other broader justification may be needed to support them.

3 Conclusion

Some of the *VAD Act's* eligibility criteria align with its stated policy goals. The need to be an adult with decision-making capacity can be said to reflect the goals of respecting autonomy and safeguarding the vulnerable. Likewise, requiring a person to have an illness that will cause death defensibly balances the goals of respecting autonomy, alleviating suffering and respecting all human life. However, the imposition of the general time limit of six months until death is harder to justify by reference to these policy goals, and having a different expected time until death for different conditions cannot be justified at all. Residency requirements are also questionable from the perspective of the stated policy goals.

124 *Report* (n 8) 56. Note that the requirement to be a resident 12 months prior to the first request was not recommended by the Panel but was introduced in the Legislative Council amendments.

125 Ibid.

126 Rohith Srinivas, 'Exploring the Potential for American Death Tourism' (2009) 13(1) *Michigan State University Journal of Medicine and Law* 91; Alexander R Safyan, 'A Call for International Regulation of the Thriving Industry of Death Tourism' (2011) 33(2) *Loyola of Los Angeles International and Comparative Law Review* 287; Mary Spooner, 'Swiss Irked by Arrival of "Death Tourists"' (2003) 168(5) *Canadian Medical Association Journal* 600.

127 The name likely stems from a documentary concerning the death in Switzerland of Chicago man Craig Ewert: 'The Suicide Tourist', *Frontline* (CTV, 14 November 2007). See Saskia Gauthier et al, 'Suicide Tourism: A Pilot Study on the Swiss Phenomenon' (2015) 41 *Journal of Medical Ethics* 611; Charles Foster, 'Suicide Tourism May Change Attitudes to Assisted Suicide, but Not through the Courts' (2015) 41 *Journal of Medical Ethics* 620.

128 The Panel briefly acknowledged the 'potential for cross-border issues to arise' but then affirmed its position: *Report* (n 8) 57. There is an established (rebuttable) presumption of interpretation that State laws apply only to regulate conduct within the territory of the legislating State: *Jumbunna Coal Mine NL v Victorian Coal Miners' Association* (1908) 6 CLR 309, 363 (O'Connor J). See also *Interpretation of Legislation Act 1984* (Vic) s 48. However, laws that apply only to residents of one State may infringe upon the guarantee in s 117 of the *Constitution*, unless a relevant exception applies: Amelia Simpson, 'The (Limited) Significance of the Individual in Section 117 State Residence Discrimination' (2008) 32(2) *Melbourne University Law Review* 639.

C VAD Request and Assessment Process, and Access to VAD

1 Overview of Law

The process for requesting, being assessed for and then accessing VAD is very complex so the following discussion can only provide a brief overview of the main steps involved.

(a) A First Request and Two Independent Assessments

The *VAD Act* specifies a very detailed request and assessment process which is triggered by a first request made by a person to a medical practitioner. The request for VAD must be made by the person themselves and it must be clear and unambiguous.[129]

When a medical practitioner receives a first request from the person, if that practitioner is available and willing to be involved, they become the 'co-ordinating medical practitioner'.[130] They then conduct the first eligibility assessment[131] and, if the person is eligible, the co-ordinating medical practitioner will refer the person to another medical practitioner.[132] If that second medical practitioner accepts the referral, they become the 'consulting medical practitioner', and will conduct the second eligibility assessment (called the 'consulting assessment').[133]

Two important safeguards are relevant here. The first is that the *VAD Act* specifically prohibits all registered health practitioners[134] from initiating a discussion about VAD (directly or indirectly) or suggesting VAD to a person, in the course of providing care.[135] The second safeguard is that the medical practitioners who wish to be involved with VAD must have particular qualifications and experience.[136] Both must be either a medical specialist or a vocationally registered general practitioner,[137] and one must have practised for at

129 The patient 'may make the request verbally or by gestures or other means of communication available to the person': *VAD Act* s 11(3).

130 Ibid s 15.

131 Ibid s 16.

132 Ibid s 22.

133 Ibid ss 23–5.

134 '[R]egistered health practitioner' is defined as a person registered under the *Health Practitioner Regulation National Law*, which includes the professions of dentist, chiropractor, doctor, medical radiation practitioner, nurse, midwife, occupational therapist, optometrist, osteopath, paramedic, pharmacist, physiotherapist, podiatrist and psychologist, as well as Chinese medicine practitioner and Aboriginal and Torres Strait islander health practitioner: *Health Practitioner Regulation National Law Regulation 2018* (Cth) reg 4.

135 *VAD Act* s 8.

136 Ibid s 10.

137 Vocationally registered general practitioners are those who are Fellows of the Royal Australian College of General Practitioners or of the Australian College of Rural and Remote Medicine, or on the Vocational

least five years after completing their fellowship with a specialist medical college or vocational registration.[138] One of the medical practitioners must also have expertise and experience in the disease, illness or medical condition expected to cause the person's death.[139]

(b) Providing Information and Ensuring Voluntary and Enduring Requests

If the co-ordinating medical practitioner or the consulting medical practitioner assesses a person as being eligible for VAD, they must provide certain information to the person. This includes information about diagnosis, prognosis and possible treatment options, as well as that the person may decide at any time not to seek VAD.[140] The medical practitioners must be satisfied that this information is understood and also that the person is acting voluntarily and their request for access to VAD is enduring.[141]

(c) Two Further Requests and a Waiting Period

A person who has been assessed as eligible to access VAD by the co-ordinating and consulting medical practitioners must then make two further requests for VAD. One is a written declaration, witnessed by two people,[142] that VAD is sought voluntarily and that the nature and effect of seeking VAD is understood.[143] The second is the 'final request' which can be made verbally.[144] This final request must be made at least nine days after the first request and at least one day after the consulting assessment,[145] although the nine day period can be shortened if the person is likely to die first.[146]

The last step in this stage is for the person to appoint a 'contact person', whose duties include returning unused VAD medication to the pharmacy and being a contact point for the VAD Review Board ('the Board') (the Board is discussed further below).[147]

Register with Medicare. For information, see Quality Practice Accreditation, 'Vocationally registered GP's' (Information Sheet) <https://files.gpa.net.au/resources/QPA_Vocationally_registered_GPs.pdf>.

138 *VAD Act* s 10(2).

139 Ibid s 10(3).

140 Ibid ss 19, 28. In full, this includes information about: their diagnosis and prognosis; the treatment options available and their likely outcomes; the palliative care options available and their likely outcomes; the potential risks of taking the VAD medication for the purpose of causing death; that the expected outcome of taking the VAD medication is death; that they may decide at any time not to continue the process; and that they are encouraged to tell their usual registered medical practitioners (eg their GP and/or specialists, if they are not the co-ordinating medical practitioner) of their VAD request.

141 Ibid ss 20, 29.

142 Ibid s 35.

143 Ibid s 34.

144 Ibid s 37. This request may also be made by gestures or other means of communication available to the patient.

145 Ibid s 38(1).

146 Ibid s 38(2).

147 Ibid s 39.

(d) Accessing VAD

After undertaking a 'final review' to ensure the VAD process has been complied with,[148] the co-ordinating medical practitioner may then apply to the Department of Health and Human Services ('the Department') for a VAD permit for either self-administration by the person or practitioner administration.[149] The Department will decide whether or not to issue the permit for the person to receive VAD within three business days.[150]

For self-administration, on prescribing the VAD medication, the co-ordinating medical practitioner must inform the person about how to take the medication, how it must be stored (in a locked box),[151] there being no obligation to proceed with VAD, and duties (including on the contact person) to return unused VAD medication to the pharmacy.[152] The dispensing pharmacist also must inform the person of this same information when dispensing the VAD medication[153] and include some of this information on the labelling statement.[154] Once dispensed, the person may take the VAD medication at a time of their choosing.

Where VAD is provided through practitioner administration, the co-ordinating medical practitioner is responsible for the VAD medication,[155] so the above information requirements do not apply. The person must make a further (fourth) request for VAD (an 'administration request'), in the presence of an independent witness,[156] immediately before the co-ordinating medical practitioner administers the VAD medication.[157] The co-ordinating medical practitioner must be satisfied that the person has capacity, is acting voluntarily and without coercion and the request for VAD is enduring.[158]

2 Conformity with Policy Goals

Many parts of the *VAD Act* outlining the VAD request and assessment process, and how access to VAD is provided, advance the legislation's stated policy goals.

148 Ibid s 41.
149 Ibid s 43.
150 *Voluntary Assisted Dying Regulations 2018* (Vic) reg 7.
151 There is also a statutory duty imposed on the patient to store the VAD medication in a locked box: *VAD Act* s 61.
152 Ibid s 57.
153 Ibid s 58.
154 The labelling statement must warn of the purpose of the dose, state the dangers of self-administration, state that the VAD medication is required to be stored in a locked box of certain specifications, and state that any unused or remaining medication must be returned to the dispensing pharmacy: Ibid s 59.
155 Ibid s 46(c).
156 Ibid s 64(4). The witness must be aged 18 or over, and be independent of the co-ordinating medical practitioner: at s 65(1). The witness must also be present when the VAD medication is administered and certify this: at s 65(2).
157 Ibid s 64. The final request may be made verbally or by gestures or other means of communication: at s 64(3).
158 Ibid ss 64(1), (5).

One example is the requirement to provide information to a person seeking VAD at key points in the process. This clearly aligns with policy goals such as respecting autonomy and promoting high-quality care by ensuring any decision to seek VAD is fully informed. Another is the waiting period of nine days between first and final requests. The policy intent of ensuring the person's request is 'enduring and well-considered'[159] reflects the policy goals of respecting human life, safeguarding the vulnerable, and respecting autonomy.

As noted above, alignment between legislation and its policy goals is unremarkable and indeed is to be expected. Accordingly, and particularly given it is not feasible to comprehensively review all of the detailed processes outlined in the *VAD Act*, this analysis focuses on three key areas where the law's stated policy goals may not be advanced: the prohibition on initiating VAD discussions, pre-authorisation permits and overall complexity of the system.

(a) Prohibition on Health Practitioners Initiating Conversations about VAD

Most problematic in the request and assessment process is the prohibition on initiating conversations about VAD. Section 8(1) of the *VAD Act* states:[160]

> A registered health practitioner who provides health services or professional care services to a person must not, in the course of providing those services to the person–
>
> (a) initiate discussion with that person that is in substance about voluntary assisted dying; or
>
> (b) in substance, suggest voluntary assisted dying to that person.

The policy intent of this provision was 'to ensure a person is not coerced or unduly influenced into accessing voluntary assisted dying and to demonstrate the request for voluntary assisted dying is the person's own voluntary decision'.[161] This prohibition attempts to further the two central goals of the *VAD Act*: safeguarding the vulnerable and promoting autonomy. The Report prefaced this recommendation with a discussion of elder abuse and abuse of persons with a disability,[162] and considered that the prohibition on raising VAD was justified because '[h]ealth practitioners have considerable influence over the decisions and treatment options their patients may consider'.[163] The Panel also recognised the importance of providing people with appropriate information about VAD and other

159 *Report* (n 8) 125.

160 Breach of section 8 can lead to sanctions for unprofessional conduct or professional misconduct: *VAD Act* s 8(3).

161 *Report* (n 8) 91.

162 Ibid 90–1.

163 Ibid 92–3. See also the Explanatory Memorandum of the VAD Bill, which stated more explicitly that purpose of this prohibition was to 'protect individuals who may be open to suggestion or coercion by registered health practitioners': Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 2.

end-of-life options,[164] which has implications for the policy goal of providing high-quality care.

Despite the stated policy intent, this prohibition on initiating discussions about VAD conflicts with the policy goal of respecting autonomy. This is illustrated by the fact that a person asking for all possible end-of-life options to inform their treatment decisions cannot be told about VAD unless they know to ask about it first and do so. It is also highlighted by contrasting this prohibition with some of the relevant legislative principles in the *VAD Act* that underpin the policy goal of respecting autonomy: supporting informed decision making;[165] encouraging open discussions about dying, death and people's preferences;[166] supporting conversations with health practitioners and family about treatment and care preferences;[167] and promoting genuine choices.[168]

Further, the prohibition is problematic because precluding the open dialogue needed at the end of life between health practitioners and persons may compromise the policy goal of providing high-quality care. There are no other lawful medical services that health practitioners are similarly prevented from raising, and this prohibition does not exist in any overseas jurisdictions that have legalised VAD.[169] A final concern is the uncertainty about the scope of the provision:[170] what conversations would it prohibit and what would be permitted?[171] Given medical practitioners' lack of knowledge in other areas of end-of-life law,[172] this could have a chilling effect on open discussions about end-of-life care if health practitioners are uncertain about the permissible boundaries of discussions.

In summary, although this prohibition may align with the policy goal of safeguarding the vulnerable (and some may dispute the premise that medical practitioners would be influential in a person's decision to make a request), the

164 The Report noted 'although a health practitioner should never initiate a discussion about voluntary assisted dying, when asked for information it is important that they are able to provide it, or at least explain where such information may be found': *Report* (n 8) 93.

165 *VAD Act* s 5(1)(c).

166 Ibid s 5(1)(f).

167 Ibid s 5(1)(g).

168 Ibid s 5(1)(h).

169 Carolyn Johnston and James Cameron, 'Discussing Voluntary Assisted Dying' (2018) 26(2) *Journal of Law and Medicine* 454. We note, however, that as this article was being written, Western Australia passed its *Voluntary Assisted Dying Act 2019* (WA). That Act includes a similar prohibition on 'health care worker[s]' but is more limited in scope because it does not apply to medical practitioners or nurse practitioners if they also provide certain information to the patient about treatment options and palliative care: s 10.

170 Johnston and Cameron (n 169) 454.

171 For some of the complexities about permissible discussions in light of this prohibition, see Lindy Willmott et al, 'Restricting Conversations about Voluntary Assisted Dying with Patients: Implications for Clinical Practice' (2020) 10(1) *BMJ Supportive and Palliative Care* 1. See also Bryanna Moore, Courtney Hempton and Evie Kendal, 'Victoria's Voluntary Assisted Dying Act: Navigating the Section 8 Gag Clause' (2020) 212(2) *Medical Journal of Australia* 67.

172 Ben White et al, 'Doctors' Knowledge of the Law on Withholding and Withdrawing Life-sustaining Medical Treatment' (2014) 201(4) *Medical Journal of Australia* 229; Ben White et al, 'The Knowledge and Practice of Doctors in Relation to the Law That Governs Withholding and Withdrawing Life-Sustaining Treatment from Adults Who Lack Capacity' (2016) 24(2) *Journal of Law and Medicine* 356.

significant conflict with respecting autonomy and the risk to high-quality care means it is not consistent with the *VAD Act's* policy goals overall.

(b) Pre-Authorisation of VAD by Government Permit[173]

The requirement to obtain a permit from the Department *prior* to providing VAD to a person is unusual, as most other VAD systems rely on *post hoc* reporting mechanisms.[174] The stated policy intent in the Report for the permit requirement was 'to establish clear monitoring and accountability for the safe prescription of the lethal dose of medication for voluntary assisted dying'.[175] This reflects the policy goal of safeguarding the vulnerable and the community, but it also appears to address the policy goal of respecting all human life by scrutinising proposed VAD before it is provided. In support of the permit requirement, the Panel cited stakeholder concerns that 'review after the fact may produce evidence of wrongdoing, but … voluntary assisted dying is irreversible'.[176]

Pre-authorisation permits also have implications for other policy goals. The delay of up to three business days is a constraint on a person's autonomy. This time also extends the period during which an eligible person is enduring suffering, so sits awkwardly with the policy goal of alleviating that suffering. This may represent an appropriate compromise between competing policy goals if the permit system is effective in ensuring only eligible persons can have access to VAD. However, this is unlikely to be so. Although the nature of the scrutiny proposed by the Department is unclear, the focus of the permit issuing process appears to be ensuring that all of the relevant prescribed forms have been completed appropriately and submitted. Such a procedurally-focused review is unlikely to be an effective safeguard to ensure compliance in practice with the substantive criteria of the legislation, making the cost to the policy goals of respecting autonomy and alleviating suffering unjustifiable.

173 There are other models that propose pre-authorisation of VAD, such as requiring prior court approval. Such approaches raise different considerations from those below; for example, court approval is more effective in safeguarding the vulnerable given the substantive review but comes with greater cost and delay. For a wider discussion of pre-authorisation in this context, see Yeung, 'Regulating Assisted Dying' (n 20).

174 An exception is Colombia, which requires prior approval by independent committee: Ezekiel et al (n 92) 81.

175 *Report* (n 8) 134.

176 Ibid 133. Concerns about a retrospective review system have also been recently expressed in relation to a case of euthanasia of a patient with dementia in the Netherlands: Miller, Dresser and Kim (n 123) 88. See also more general concerns about the limits of the retrospective system of oversight in David Gibbes Miller and Scott Y H Kim, 'Euthanasia and Physician-Assisted Suicide Not Meeting Due Care Criteria in the Netherlands: A Qualitative Review of Review Committee Judgements' (2017) 7(10) *BMJ Open* 1. For example, they note that the Dutch review process, which is retrospective, in practice focuses on procedural criteria and professionalism of medical practitioners, rather than whether the substantive eligibility criteria are met.

(c) Overall Complexity

The final issue to note in relation to the request and assessment process and gaining access to VAD is the complexity of the scheme as a whole. As outlined earlier, the *VAD Act* was proclaimed to be the 'safest, and most conservative model in the world',[177] with much made of its extensive safeguards. Many of those safeguards are in the request and assessment process and they are specified in great detail in the *VAD Act*. This highly prescriptive detail in the legislation itself is unusual[178] and as a result, the *VAD Act* is significantly longer than other VAD legislation internationally.

As briefly described above, the VAD system requires at least three formal requests (four in the case of practitioner administration), two independent assessments of the person, and repeated checks of informed consent, the enduring nature of the decision, voluntariness and coercion. Appropriate witnesses[179] (and sometimes interpreters) must be organised and the co-ordinating medical practitioner must also obtain a permit before prescribing VAD medication or administering it.[180] An appropriate contact person must be found and properly appointed, and in the case of self-administration, the person must then obtain the medication and store it in a locked box.[181]

The goal of this process is to be rigorous in ensuring those who are not eligible do not gain access to VAD.[182] This advances the policy goal of safeguarding the vulnerable and the community, and it also promotes the goal of respect for human life by permitting VAD only in accordance with a strict process.[183] It is also designed to promote autonomy and high-quality care, with the Panel noting that the purpose behind the three request process is twofold: to ensure the request for VAD is 'voluntary, considered and enduring' and to provide 'multiple opportunities for a person and their assessing medical practitioners to discuss the person's request'.[184] The VAD system, at least on its face, meets these key goals.

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177 Andrews (n 16).

178 More commonly, such prescriptive detail is placed in the Act's regulations or clinical or administrative guidelines.

179 *VAD Act* ss 34–6, 65.

180 Ibid ss 47, 48.

181 Ibid s 61.

182 *Report* (n 8) 112.

183 The Panel justified the stages in the request and assessment process with reference to preventing 'doctor shopping', stating that

> even if a person finds one medical practitioner willing to break the law by providing an assessment that a person meets the eligibility criteria even though they do not, this medical practitioner would also need to find another medical practitioner willing to collude with them. Even if they are able to do this, the Department and the Voluntary Assisted Dying Review Board would be able to identify irregularities or wrong doing before a permit for prescription is given.

Ibid 122.

184 Ibid 113.

However, when these procedural steps are viewed as a whole, there are concerns that persons will find accessing VAD very difficult.[185] A process that is described as rigorous could be experienced as onerous, and the process outlined above is also complex. This may complicate, or even frustrate, the policy goals of respecting autonomy and alleviating suffering by precluding, or at least delaying, eligible persons' access to VAD. These persons – who by definition must be suffering and generally be expected to die within six months – may find the process overwhelming and too difficult to navigate and consequently choose not to proceed. Those who do start the process might die (or lose capacity) before they make their way through it, or give up part way through. This complexity may be particularly difficult for persons from diverse cultural and linguistic backgrounds, especially if interpreters are required, as they must be accredited professionals and not a family member.[186] Even if a person is able to navigate the process, the hurdles involved and the stress in navigating them could intensify the person's suffering.

The nature of the VAD process and what it requires may also mean that few medical practitioners will agree to be involved. For example, the duties of a co-ordinating medical practitioner, who oversees the process as a whole, are significant both from a clinical and administrative perspective. (The substantial reporting duties on medical practitioners involved in VAD and the implications for their participation are also discussed further below at Part III(E).) A lack of medical practitioners willing to participate would further compromise the policy goals of autonomy and alleviation of suffering as well as the provision of high-quality care.

In conclusion, while the policy goals of safeguarding the vulnerable and the community, and respecting all human life are advanced by the rigorous VAD process, its many stages and complexity may pose a risk to access and undermine the policy goals of respecting autonomy and alleviating suffering. Although these issues can be identified on the face of the legislation, how and whether these competing policy goals are achieved will depend on how the legislation is implemented. It is possible that good design of the VAD system may mean that its complexity can be 'internally facing' and may not impede access for eligible persons nor create burdens for the medical practitioners involved.[187] Firm conclusions on this will have to wait until after the law has commenced and its operation has been evaluated.

3 Conclusion

185 The Panel itself acknowledged this risk. It recognised 'that the person who has requested access to voluntary assisted dying is suffering … so the process should not create undue burden or anxiety or be a tick-box process … [and] should be undertaken in the spirit of person-centred care': Ibid 112. See also White, Willmott and Close (n 19).

186 *VAD Act* s 115. Similar considerations apply to those with communication difficulties who require a speech pathologist to assist in interpreting.

187 White, Willmott and Close (n 19) 207.

In general, the main parts of the process for requesting VAD, having eligibility assessed, and then receiving access to it, align with the *VAD Act's* stated policy goals. The primary policy advanced is safeguarding the vulnerable, but there is also recognition of respecting human life, respecting autonomy and promoting high-quality care. However, policy goals do not appear to be met, and may be impeded, by prohibiting health practitioners from discussing VAD with persons and through the requirement to obtain pre-authorisation for VAD via a government permit. Further, when the process is viewed in its entirety, its complexity may limit the *VAD Act's* fulfilment of the key policy goals of respecting autonomy and alleviating suffering. While individual components or safeguards may be justifiable, a global assessment of them reveals a different picture. This has implications for the overall design of VAD systems which will be revisited in the article's conclusion.

D Conscientious Objection

1 Overview of Law

The *VAD Act* allows medical practitioners and other health practitioners to conscientiously object to participate in VAD. Section 7 protects the right of health practitioners to refuse to:

- provide information about VAD;
- participate in the request and assessment process;
- apply for a VAD permit;
- supply, prescribe or administer a VAD substance;
- be present at the time of administration of a VAD substance; or
- dispense a prescription for a VAD substance.

Other provisions also anticipate conscientious objection. One is the requirement to accept or refuse the role of co-ordinating or consulting medical practitioner within 7 days.[188]

2 Conformity with Policy Goals

The right of medical practitioners and other health practitioners to refuse to provide information about or participate in VAD[189] clearly advances the policy

188 *VAD Act* ss 13(1)(b), 23(1)(b).

189 The Report contained two recommendations specifically with the policy intent of respecting individual conscience. They are: Panel Recommendation 18 – that medical practitioners have a right to conscientiously object, and Panel Recommendation 39 – that where the co-ordinating and consulting

goal of respect for individual conscience.[190] Notably, however, there is no duty to refer a person to another medical practitioner who is willing to be involved in VAD. The Panel considered, but rejected, such an approach,[191] instead relying on existing obligations of medical practitioners under their code of conduct not to impede persons' access to lawful care or treatment.[192] The absence of a specific legislative duty to refer stands in stark contrast to the very detailed and prescriptive process outlined for other matters in the *VAD Act*.

While promoting respect for conscience, the lack of a legislative duty to refer may impede access to a lawful end-of-life option.[193] If this happens in relation to VAD, this would compromise the realisation of other important policy goals: respect for autonomous choices, alleviation of suffering and the provision of high-quality care.

E Oversight, Reporting and Compliance

1 Overview of Law

The *VAD Act* contains a number of mechanisms for monitoring VAD and ensuring compliance with the legislative regime.

(a) Board Oversight of the System

The Board is a new independent statutory body[194] that has overall oversight of the VAD system. Its primary function is to monitor activity under the *VAD Act* to ensure compliance.[195] This includes reviewing each case where VAD has been requested, to ascertain compliance with legal requirements. The Board must also

medical practitioner both conscientiously object to administering a lethal injection, they may transfer care to a different medical practitioner who is willing to administer the medication: *Report* (n 8) 24, 27.

190 For further discussion of the value of conscience in the Australian legal system, see Willmott and White (n 1). In Victoria, this is reflected in the right to freedom of thought, conscience, religion and belief contained in the *Charter of Human Rights and Responsibilities 2006* (Vic) s 14. See also the *Report* (n 8) 214.

191 *Report* (n 8) 109–11.This duty exists under Victorian law governing termination of pregnancy: *Abortion Law Reform Act 2008* (Vic) s 8.

192 *Report* (n 8) 15, 110. See Medical Board of Australia, *Good Medical Practice: A Code of Conduct for Doctors in Australia* (Guideline, March 2014) para 2.4.6 <http://www.medicalboard.gov.au/ Codes-Guidelines-Policies.aspx>.

193 Although a legislative duty to refer may provide stronger normative force than simply relying on existing ethical duties, it still may not be effective. For example, there is evidence that the legislative duty to refer when a medical practitioner has a conscientious objection to a termination of pregnancy is being ignored or evaded by some Victorian medical practitioners: Louise Anne Keogh et al, 'Conscientious Objection to Abortion, the Law and Its Implementation in Victoria, Australia: Perspectives of Abortion Service Providers' (2019) 20 *BMC Medical Ethics* 11:1–15.

194 The Board is established by the *VAD Act* s 92. This model of a separate body, independent of the health department, follows the European models in place in Belgium, the Netherlands and Luxembourg, rather than in the US States, where monitoring is done within existing health departments: *Report* (n 8) 159.

195 *VAD Act* ss 93(1)(a), (b).

evaluate overall patterns and trends of access to VAD, such as discerning possible instances of 'doctor shopping':[196] that is, overuse of one or more medical practitioners who repeatedly find a person to be eligible for VAD despite other medical practitioners finding them to be ineligible.

The Board will be supported in its oversight function by the mandatory reporting obligations imposed on medical practitioners, dispensing pharmacists and others by the *VAD Act*, as outlined in Table 2. In addition to reporting to the Board, all deaths of people who were the subject of a VAD permit are notifiable to the Coroner,[197] although these deaths are not investigated as possible suicides.

196 *Report* (n 8) 168.

197 A medical practitioner attending a person who has died must notify if the person was the subject of a VAD permit, and state their knowledge or belief whether or not the person died as a result of VAD, or VAD was not administered: *VAD Act* s 67(2). These deaths are also notifiable to the Registrar of Births, Deaths and Marriages: at s 67(1). However, VAD is not required to be recorded as the cause of death on the death certificate: *Report* (n 8) 150–3.

Table 2: Reporting to the Board

Matter reported	Person reporting	Form or other document	Legislative provision
That a person was assessed as eligible or ineligible for VAD after a first assessment	Coordinating medical practitioner	First assessment report form (Form 1)	*VAD Act* s 21
That a person was assessed as eligible or ineligible for VAD after a consulting assessment	Consulting medical practitioner	Consulting assessment report form (Form 2)	*VAD Act* s 30
That the request and assessment process has been completed	Coordinating medical practitioner	Final Review Form (Form 5). Note that attached to this Form are copies of Forms 1, 2, 3 (Written declaration) and 4 (Contact person appointment form).	*VAD Act* s 41
That a self-administration permit or practitioner administration permit has been issued (or has been amended)	Secretary of Department of Health and Human Services	VAD permit (or its amendment)	*VAD Act* s 49 (and s 51 for amendment)
That VAD medication was dispensed	Dispensing pharmacist	VAD substance dispensing form (Form 6)	*VAD Act* s 60
That any returned VAD medication was disposed of	Dispensing pharmacist	VAD substance disposal form (Form 7)	*VAD Act* s 63
That VAD was administered to a person by a medical practitioner	Coordinating medical practitioner	Coordinating medical practitioner administration form (Form 8)	*VAD Act* s 66
That an application for review has been lodged with VCAT That VCAT has made an order or determination	Principal Registrar of VCAT	Notice of application to VCAT Copy of VCAT's order or determination	*VAD Act* s 69(c)

(b) Victorian Civil and Administrative Tribunal Review of Eligibility Decisions

The Victorian Civil and Administrative Tribunal ('VCAT') has a more limited role in relation to VAD. It has jurisdiction only to review assessments by a co-ordinating or consulting medical practitioner about residency and decision-making

capacity, as these are questions of fact.[198] VCAT does not review clinical issues such as disease-related eligibility criteria.

(c) Health Practitioners' Duties to Report

Registered health practitioners (including medical practitioners, nurses, allied health practitioners and pharmacists)[199] are required to report colleagues to the Australian Health Practitioner Regulation Agency (AHPRA) if they believe another registered health practitioner has initiated a discussion about VAD or suggested it to a person, or has offered to provide VAD to a person not eligible under the Act.[200] This reporting obligation also applies to health practitioners' employers, such as hospitals or institutional care providers.[201]

(d) Offences

The *VAD Act* adds several new offences, which are designed to promote compliance with the Act and deter people from intentionally acting outside the law.[202] These offences relate to:

- coercing a person to access VAD;[203]
- administering VAD medication to a person who has been issued a self-administration permit;[204]
- acting contrary to a practitioner administration permit;[205]
- a contact person failing to return unused or remaining VAD medication after the person's death;[206]
- falsifying forms and statements;[207] and
- failing to report to the Board.[208]

198 *VAD Act* s 68 and Part 6.
199 See *Health Practitioner Regulation National Law Regulation 2018* (Cth) for definition of registered health practitioner.
200 *VAD Act* s 75.
201 Ibid s 76.
202 The offence provisions are broadly modelled on offences in force in some US States: *Report* (n 8) 179.
203 This includes both inducing a person to request access to VAD, and inducing a person to self-administer VAD medication: *VAD Act* ss 85, 86. The maximum penalty in both cases is 5 years imprisonment.
204 *VAD Act* s 84. The maximum penalty is life imprisonment.
205 Ibid s 83. The maximum penalty is life imprisonment.
206 Ibid s 89. The maximum penalty is 12 months imprisonment or 120 penalty units or both.
207 Ibid ss 87, 88. The maximum penalty for both offences is 5 years imprisonment for a natural person, or 2400 penalty units for a body corporate. The value of a penalty unit changes annually, and is set by the Treasurer: *Monetary Units Act 2004* (Vic) s 5(3). From 1 July 2018 to 30 June 2019, one penalty unit was $161.19, so the maximum penalty was $386,856.
208 *VAD Act* s 90. The maximum penalty for this offence is 60 penalty units, which at the time of writing was $9,671.40.

(e) Protection from Criminal and Civil Liability

The *VAD Act* specifically protects medical practitioners who provide VAD in accordance with the Act from any criminal or civil liability, or liability for professional misconduct or contravention of a professional code of conduct.[209] It also protects those (including health practitioners, family or carers) who assist or facilitate a request for VAD.[210] These legal protections provide certainty and confidence for those who help a person to access VAD in accordance with the Act.

2 Conformity with Policy Goals

Collectively, these provisions of the *VAD Act* are designed to ensure that the VAD system operates as intended: that VAD is provided within the law and that unlawful behaviour does not occur. In this way, these provisions generally advance the overall key policy goals of protecting human life and safeguarding the vulnerable and the community, while ensuring that human suffering can be alleviated through people exercising their autonomy within the law. It could be further argued, though, that some of these provisions give greater emphasis to particular policy goals. For example, the Board's oversight of all cases of VAD and the reporting that underpins this[211] are especially aimed at safeguarding the vulnerable. Offence provisions also safeguard the vulnerable and the community, and, arguably, those that prohibit the causing of death outside the Act are also aligned with the policy goal of respecting all human life.

Accordingly, when looking at these provisions in general, each can be justified as aligned with policy goals of the Act. One concern, though, is that when these provisions are considered cumulatively, they become burdensome such that the balance between permitting eligible persons access to VAD on the grounds of autonomy and compassion and safeguarding the vulnerable is tilted so as to hinder reasonable access to VAD. The prime example is the volume of reporting, particularly that required of the co-ordinating medical practitioner. This may mean that health practitioners decline to be involved in VAD due to these burdens, especially when added to the significant duties noted above in relation to the request, assessment and access processes. While the manner in which these reporting duties will be implemented is not yet clear, it is at least noted on the face of the legislation that this reporting burden may deter involvement and hinder access to VAD, thus potentially compromising the policy goals of respect for autonomy and alleviation of suffering.

209 Ibid s 80. This includes protecting a health practitioner or paramedic who does not administer life-saving treatment to a person who is dying after the administration of VAD medication: at s 81.

210 Ibid s 79.

211 Researchers agree that reporting all cases of VAD is important to safeguard the quality of the process: Tinne Smets et al, 'Reporting of Euthanasia in Medical Practice in Flanders, Belgium: Cross Sectional Analysis of Reported and Unreported Cases' (2010) 341(7777) *British Medical Journal* 819, 825.

IV CONCLUSION

Stepping beyond entrenched arguments for and against VAD, this article evaluated instead whether the *VAD Act* reflects its own stated policy goals. It first analysed the Report that provided the foundation for the Act, along with its legislative principles, to discern six key policy goals that underpin the legislation:

- To respect all human life;
- To respect personal autonomy;
- To safeguard the vulnerable and the community;
- To provide high-quality care;
- To respect individual conscience; and
- To alleviate human suffering (compassion).

The article then analysed the major parts of the *VAD Act* to determine whether they reflected those identified policy goals. A failure to align with goals was the focus of this analysis, as legislation that achieves intended objectives is to be anticipated. The overall conclusion was that there are important respects in which the Act fails to reflect its own policy goals. Key examples of this are: having self-administration as the default means of providing VAD and allowing practitioner administration only in very limited circumstances; requiring time limits to death and those time limits varying depending on the nature of a person's illness; prohibiting medical practitioners from raising VAD with persons; and creating a system that when considered globally is very complex and arguably burdensome for persons seeking access to VAD and medical practitioners.

While being critical in relation to these findings of policy misalignment, it is important to consider how and why they occurred. It was suggested earlier that the design of the Act was a reflection of the political strategy necessary for it to pass the Victorian Parliament. Indeed, the original Bill, which was already very narrow and with many safeguards, was not conservative enough initially to pass Victoria's upper house, the Legislative Council. It is suggested that decisions about the design of the law, including by the Panel, were shaped by an awareness of what might be needed to secure necessary political support. This is not to suggest that the Panel's deliberations were purely political, and without careful regard to its nine guiding principles underpinning the six policy goals set out above. However, it is argued that the Panel, and the Victorian Government in drafting the VAD Bill, also had regard to more pragmatic considerations such as what sort of law would be capable of attracting the necessary political support. This understandable intrusion of politics into decision-making about policy is one reason the *VAD Act* does not adequately reflect its stated policy goals in some key respects.

This policy misalignment was also exacerbated by the need for more overt political compromise. As noted above, alterations to the VAD Bill were required for the Legislative Council to pass the *VAD Act*. Arguably, such late changes to Bills are not principle-based decisions but rather pragmatic concessions needed to garner sufficient support to pass a law. As such, instead of being new ways to advance the legislation's stated policy goals, these 'add-ons' can often actually be in conflict with those goals. An example of this, as mentioned earlier, is the changes to the period of time expected until the person's death. The original VAD Bill that was passed by the Victorian Legislative Assembly provided for a 12-month period. This period was then halved to six months, except for a subset of medical conditions that had a neurological basis, for which cases the 12-month period was retained.[212] The imposition of a time limit, and particularly different time limits for different conditions, was critiqued earlier in this article as inconsistent with stated policy goals. This is an obvious example of where overt but necessary political compromise caused policy misalignment.

The analysis in this article has focused on the legislation itself rather than implementation. It is acknowledged, however, that it is possible for effective implementation to address some of the ways in which the legislation fails to best reflect its policy goals.[213] One example is the complexity of, and the burdens imposed by, the VAD request and assessment processes, and the corresponding duties of reporting. It is possible that well-designed systems could facilitate access to VAD for eligible persons and avoid undue burdens for medical practitioners, while still effectively safeguarding the vulnerable. While those responsible for the law's implementation should be mindful of opportunities to better advance policy goals, this will not always be possible. Some gaps between policy goals and the *VAD Act* are structurally embedded in the legislation and cannot be alleviated. An example is eligibility limits relating to expected times until death and the prohibition on raising VAD with persons.

A final observation is to note is that this analysis has implications for wider VAD reform in Australia as other states actively consider law reform in this area. As this article was being written, Western Australia passed its *Voluntary Assisted Dying Act 2019* (WA), following reports by a Parliamentary Committee[214] and then a Ministerial Expert Panel.[215] Both Queensland and South Australia have established Parliamentary Committees whose terms of reference include VAD, with the Queensland Committee recommending VAD reform.[216] A draft

212 See Part III(B)(2)(ii) 'Six Months until Death'.

213 White, Willmott and Close (n 19).

214 Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice* (First Report, 23 August 2018).

215 Government of Western Australia, Department of Health, *Ministerial Expert Panel on Voluntary Assisted Dying* (Final Report, July 2019).

216 Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Voluntary Assisted Dying* (Report No 34, 31 March 2020) 105 (Recommendation 1); Joint Committee on End of Life Choices, Parliament of South Australia, *Terms of Reference* (April 2019).

Tasmanian Bill has been released for consultation by the Hon Michael Gaffney[217] and a Bill is also expected to be introduced into the New South Wales parliament within the foreseeable future.[218] The default position for other states is likely to be adopting the Victorian model, or at least to use it as a starting point for their proposed law.[219] This was the case with the Western Australian Act which is very similar to the Victorian law. However, this analysis has concluded that the *VAD Act* does not advance its stated policy goals in important respects. This suggests critical review is needed by other states considering reform. A more principled approach is suggested,[220] with each aspect of proposed laws being tested against those principles or policy goals to ensure policy coherence of the law.

This needs to be done individually in relation to each aspect of the law but it must also be done globally in relation to the law as a whole and how it will operate. The claim of the Victorian VAD system to be the most conservative in the world has implications for access for VAD. The many safeguards and processes that form part of that claim, when considered in total, are likely to present challenges for persons seeking access to VAD and medical practitioners. These concerns were specifically identified in this article both in relation to reporting and also the processes for requesting, being assessed and then accessing VAD. It is only when the Act as a whole is considered that the complexity in the VAD system becomes clear.

When thinking about the politics of reform, it can be tempting to only consider each safeguard or process individually. Each may have merit and advance a particular policy goal. It may also be difficult politically to argue that a specific safeguard is not needed, particularly if it appears to achieve at least some useful purpose. However, when the safeguards are aggregated, the VAD system as a whole can become very complex and unwieldly, and slowly take the legislation away from its policy goals. This 'policy drift by a thousand cuts' – the incremental loss of policy focus through accumulation of individual safeguards without reference to the whole – is a key issue for other states to consider when evaluating their proposed VAD reforms. It is suggested that each part of the law be evaluated both on its own, and also for its impact on the functioning of the overall system. This is needed to enable VAD laws to meet their policy goals, in particular, the

217 End-of-Life Choices (Voluntary Assisted Dying) Bill 2020 (Tas) <http://www.parliament.tas.gov.au/LC/gaffney/EOL.pdf>.

218 Carla Mascarenhas, 'Port Macquarie State Election Candidates Debate Assisted Dying for the Terminally Ill', *Port Macquarie News* (online, 26 February 2019) <https://www.portnews.com.au/story/5925502/state-election-candidates-debate-assisted-dying-for-the-terminally-ill/>.

219 White and Willmott, 'Victoria May Soon Have Assisted Dying Laws for Terminally Ill Patients' (n 2). Note, however, that this is not the case in Queensland: see Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland (n 216) 105 (Recommendation 1), which proposed instead that the starting point for reform be the draft Bill outlined in Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

220 Willmott and White (n 1) 484–8. Such a model is presented in Bill form in White and Willmott (n 219).

two key goals at the core of the design of the *VAD Act*: safeguarding the vulnerable while respecting the autonomy of eligible persons who wish to access to VAD.

Reference list

1. Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform' in Ian Freckelton and Kerry Anne Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479.
2. 2 Margaret Otlowski, 'Another Voluntary Euthanasia Bill Bites the Dust', *The Conversation* (online, 19 November 2013) <https://theconversation.com/another-voluntary-euthanasia-bill-bites-the-dust-19442>.
3. Ben White and Lindy Willmott, 'Victoria May Soon Have Assisted Dying Laws for Terminally Ill Patients', *The Conversation* (online, 21 July 2017) <https://theconversation.com/victoria-may-soon-have- assisted-dying-laws-for-terminally-ill-patients-81401>.
4. Giles Scofield, 'Privacy (or Liberty) and Assisted Suicide' (1991) 6(5) *Journal of Pain and Symptom Management* 280.
5. Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) University of New South Wales Law Journal 1.
6. Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42 Australian Health Review 616.
7. Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report, 9 June 2016).
8. Margaret M O'Connor et al, 'Documenting the Process of Developing the Victorian Voluntary Assisted Dying Legislation' (2018) 42(6) *Australian Health Review* 621.
9. Victorian Government, *Ministerial Advisory Panel on Voluntary Assisted Dying* (Final Report, 21 July 2017).
10. Matthew Lesh, *Evidence Based Policy Research Project: 20 Case Studies* (Institute of Public Affairs, October 2018).
11. Daniel Andrews, 'Voluntary Assisted Dying Model Established Ahead of Vote in Parliament' (Media Release, 25 July 2017).
12. Robert Baldwin, Martin Cave and Martin Lodge, *Understanding Regulation: Theory, Strategy, and Practice* (Oxford University Press, 2012).
13. Margaret Somerville, *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide* (McGill-Queen's University Press, 2nd ed, 2014).
14. Ian Hayes, 'Ethical Challenges about Voluntary Assisted Dying' (2018) 39(3) *Australasian Science* 49.
15. Jeremy Prichard, 'Euthanasia: A Reply to Bartels and Otlowski' (2012) 19(3) *Journal of Law and Medicine* 610.
16. Brian H Le and Jennifer Philip, 'Voluntary Assisted Dying: Time to Consider the Details (2018) 209(6) *Medical Journal of Australia* 279.
17. Lorana Bartels and Margaret Otlowski, 'A Right to Die? Euthanasia and the Law in Australia' (2010) 17 *Journal of Law and Medicine* 532.
18. Margaret Otlowski, *Voluntary Euthanasia and the Common Law* (Clarendon Press, 1997).
19. Nicholas Cowdery, 'A Dignified Ending' (2017) 33 *LSJ* 28; Nicholas Cowdery, 'Will We Legalise Euthanasia?' (2017) 34 *LSJ* 26.
20. Danuta Mendelson, 'Voluntary Assisted Dying Legislation in Victoria: What Can We Learn from the Netherlands Experience' (2017) 25(1) *Journal of Law and Medicine* 30.

21. Ben P White, Lindy Willmott and Eliana Close, 'Victoria's Voluntary Assisted Dying Law: Clinical Implementation as the Next Challenge' (2019) 210(5) *Medical Journal of Australia* 207.
22. Bernadette Richards, 'Assisted Dying in Australia' (2018) 15(1) *Bioethical Inquiry* 15.
23. Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163.
24. Karen Yeung, *Securing Compliance: A Principled Approach* (Hart Publishing, 2004).
25. Department of Health and Human Services, State Government of Victoria, *Voluntary Assisted Dying* (Web Page, 2020) <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life- care/voluntary-assisted-dying>.
26. Stephen Duckett, 'The Long and Winding Road to Assisted Dying in Australia' (2019) *Australian Journal of Social Issues* 1.
27. John Keown, '"Voluntary Assisted Dying" in Australia: The Victorian Parliamentary Committee's Tenuous Case for Legalization' (2018) 33(1) *Issues in Law and Medicine* 55.
28. Emanuel Ezekiel et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe' (2016) 316(1) *Journal of the American Medical Association* 79.
29. Regional Euthanasia Review Committees, *Annual Report 2017* (Report, May 2017).
30. Health Canada, *Fourth Interim Report on Medical Assistance in Dying Canada* (Report, April 2019).
31. Commission Fédérale de Contrôle et D'évaluation de L'euthanasie*, Huitième Rapport aux Chambres Législatives Années 2016 – 2017*, (Report, 17 July 2018).
32. Johanna Groenewoud et al, 'Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands' (2000) 342(8) *New England Journal of Medicine* 551.
33. Christopher Harty et al, 'Oral Medical Assistance in Dying (MAiD): Informing Practice to Enhance Utilization in Canada' (2019) 66(9) *Canadian Journal of Anesthesia* 1106.
34. Oregon Health Authority, *Oregon Death with Dignity Act 2018 Data Summary* (Report, 25 April 2019).
35. Sean Riley, 'Navigating the New Era of Assisted Suicide and Execution Drugs' (2017) 4(2) *Journal of Law and the Biosciences* 424.
36. Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311.
37. Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337.
38. James Downar et al, 'The "Surprise Question" for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-analysis' (2017) 189(13) *Canadian Medical Association Journal* E484.
39. Paul Glare et al, 'Predicting Survival in Patients with Advanced Disease' (2008) 44(8) *European Journal of Cancer* 1146.
40. Colleen Cartwright, **'**The Six-Month Amendment Could Defeat the Purpose of Victoria's Assisted Dying Bill' *The Conversation* (online, 23 November 2017) <https://theconversation.com/the-six-month- amendment-could-defeat-the-purpose-of-victorias-assisted-dying-bill-87941>.
41. Judith Rietjens, Lenzo Robijn and Agnes van der Heide, 'Euthanasia for Minors in Belgium' (2014) 312(12) *Journal of the American Medical Association* 1258.
42. Nubia Leonor Posada-González and Nora Helena Riani Llano, 'Eutanasia: Conceptos de la Fundación Colombiana de Ética y Bioética FUCEB, Dirigidos a la Corte

Constitucional (Sentencia T- 721-17) y al Ministerio de Salud y Protección Social (Borrador de Resolución Sobre Sentencia T-544- 2017 de Eutanasia Infantil)' (2018) 22(1) *Persona y Bioética* 148.
43. *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Alfred A Knopf, 1993).
44. Paul T Menzel and Bonnie Steinbock, 'Advance Directives, Dementia, and Physician-Assisted Death' (2013) 41(2) *Journal of Law, Medicine & Ethics* 484.
45. Thaddeus Mason Pope, 'Medical Aid in Dying: When Legal Safeguards Become Burdensome Obstacles', *The ASCO Post* (online, 25 December 2017) <https://www.ascopost.com/issues/december-25-2017/medical-aid-in-dying- when-legal-safeguards-become-burdensome-obstacles/>.
46. Council of Canadian Academies, *The State of Knowledge on Advance Requests for Medical Assistance in Dying* (Report, 2018).
47. Emily Tomlinson and Joshua Stott, 'Assisted Dying in Dementia: A Systematic Review of the International Literature on the Attitudes of Health Professionals, Patients, Carers and the Public, and the Factors Associated with These' (2015) 30(1) *International Journal of Geriatric Psychiatry* 10.
48. Sigrid Dierickx et al, 'Euthanasia for People with Psychiatric Disorders or Dementia in Belgium: Analysis of Officially Reported Cases' (2017) 17(1) *BMC Psychiatry* 203.
49. Johannes van Delden, 'The Unfeasibility of Requests for Euthanasia in Advance Directives' (2004) 30 *Journal of Medical Ethics* 447.
50. Paul Mevis et al, 'Advance Directives Requesting Euthanasia in the Netherlands: Do They Enable Euthanasia for Patients Who Lack Mental Capacity?' (2016) 4(2) *Journal of Medical Law and Ethics* 127.
51. David Gibbes Miller, Rebecca Dresser and Scott Y H Kim, 'Advance Euthanasia Directives: A Controversial Case and its Ethical Implications' (2019) 45(2) *Journal of Medical Ethics* 84.
52. Rohith Srinivas, 'Exploring the Potential for American Death Tourism' (2009) 13(1) *Michigan State University Journal of Medicine and Law* 91.
53. Alexander R Safyan, 'A Call for International Regulation of the Thriving Industry of Death Tourism' (2011) 33(2) *Loyola of Los Angeles International and Comparative Law Review* 287.
54. Mary Spooner, 'Swiss Irked by Arrival of "Death Tourists"' (2003) 168(5) *Canadian Medical Association Journal* 600.
55. 'The Suicide Tourist', Frontline (CTV, 14 November 2007).
56. Saskia Gauthier et al, 'Suicide Tourism: A Pilot Study on the Swiss Phenomenon' (2015) 41 *Journal of Medical Ethics* 611.
57. Charles Foster, 'Suicide Tourism May Change Attitudes to Assisted Suicide, but Not through the Courts' (2015) 41 *Journal of Medical Ethics* 620.
58. Amelia Simpson, 'The (Limited) Significance of the Individual in Section 117 State Residence Discrimination' (2008) 32(2) *Melbourne University Law Review* 639.
59. Quality Practice Accreditation, 'Vocationally registered GP's' (Information Sheet) <https://files.gpa.net.au/resources/QPA_Vocationally_registered_GPs.pdf>.
60. Carolyn Johnston and James Cameron, 'Discussing Voluntary Assisted Dying' (2018) 26(2) *Journal of Law and Medicine* 454.
61. Lindy Willmott et al, 'Restricting Conversations about Voluntary Assisted Dying with Patients: Implications for Clinical Practice' (2020) 10(1) *BMJ Supportive and Palliative Care* 1.

62. Bryanna Moore, Courtney Hempton and Evie Kendal, 'Victoria's Voluntary Assisted Dying Act: Navigating the Section 8 Gag Clause' (2020) 212(2) *Medical Journal of Australia* 67.
63. Ben White et al, 'Doctors' Knowledge of the Law on Withholding and Withdrawing Life-sustaining Medical Treatment' (2014) 201(4) *Medical Journal of Australia* 229.
64. Ben White et al, 'The Knowledge and Practice of Doctors in Relation to the Law That Governs Withholding and Withdrawing Life- Sustaining Treatment from Adults Who Lack Capacity' (2016) 24(2) *Journal of Law and Medicine* 356.
65. David Gibbes Miller and Scott Y H Kim, 'Euthanasia and Physician-Assisted Suicide Not Meeting Due Care Criteria in the Netherlands: A Qualitative Review of Review Committee Judgements' (2017) 7(10) *BMJ Open* 1.
66. Medical Board of Australia, *Good Medical Practice: A Code of Conduct for Doctors in Australia* (Guideline, March 2014) para 2.4.6 <http://www.medicalboard.gov.au/ Codes- Guidelines-Policies.aspx>.
67. Louise Anne Keogh et al, 'Conscientious Objection to Abortion, the Law and Its Implementation in Victoria, Australia: Perspectives of Abortion Service Providers' (2019) 20 *BMC Medical Ethics* 11:1–15.
68. Tinne Smets et al, 'Reporting of Euthanasia in Medical Practice in Flanders, Belgium: Cross Sectional Analysis of Reported and Unreported Cases' (2010) 341(7777) *British Medical Journal* 819.
69. Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice* (First Report, 23 August 2018).
70. Government of Western Australia, Department of Health, *Ministerial Expert Panel on Voluntary Assisted Dying* (Final Report, July 2019).
71. Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland*, Voluntary Assisted Dying* (Report No 34, 31 March 2020) 105 (Recommendation 1).
72. Joint Committee on End of Life Choices, Parliament of South Australia, *Terms of Reference* (April 2019).
73. Carla Mascarenhas, 'Port Macquarie State Election Candidates Debate Assisted Dying for the Terminally Ill', *Port Macquarie News* (online, 26 February 2019) <https://www.portnews.com.au/story/5925502/state-election-candidates-debate-assisted-dying-for-the- terminally-ill/>.
74. Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

COMPARATIVE AND CRITICAL ANALYSIS OF KEY ELIGIBILITY CRITERIA FOR VOLUNTARY ASSISTED DYING UNDER FIVE LEGAL FRAMEWORKS

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Eligibility criteria determine a crucial question for all voluntary assisted dying frameworks: who can access assistance to die? This article undertakes a critical and comparative analysis of these criteria across five legal frameworks: existing laws in Victoria, Western Australia, Oregon and Canada, along with a model Bill for reform. Key aspects of these criteria analysed are capacity requirements; the nature of the medical condition that will qualify; and any required suffering. There are many similarities between the five models but there are also important

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We disclose that Ben White and Lindy Willmott were engaged by both the Victorian and Western Australian governments to design and provide the legislatively mandated training for doctors involved in voluntary assisted dying. Jayne Hewitt was the project manager for the Victorian training project and Rebecca Meehan, Laura Ley Greaves and Eliana Close were employed on the project. Eliana Close and Katrine Del Villar were also employed on the Western Australian training project. James Cameron was a Senior Legal Policy Officer at the Department of Health and Human Services (Victoria) and developed and implemented the *Voluntary Assisted Dying Act 2017* (Vic). Jocelyn Downie was a member of the Royal Society of Canada Expert Panel on End-of-Life Decision-Making, a member of the plaintiffs' legal team in *Carter v Canada (Attorney General)* [2015] 1 SCR 331, a member of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. Rebecca Meehan is an employee of Queensland Parliament, but this article only represents her views. Ben White is a recipient of an Australian Research Council Future Fellowship (project number FT190100410: Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying) funded by the Australian government. The authors gratefully acknowledge the research assistance of Emily Bartels.

differences which can have a significant impact on who can access voluntary assisted dying and when. Further, seemingly straightforward criteria can become complex in practice. The article concludes with the implications of this analysis for designing voluntary assisted dying regulation. Those implications include challenges of designing certain yet fair legislation and the need to evaluate voluntary assisted dying frameworks holistically to properly understand their operation.

I INTRODUCTION

Internationally, voluntary assisted dying ('VAD') is permitted in an increasing number of jurisdictions. In Europe, VAD is legal in certain circumstances in the Netherlands,[1] Belgium[2] and Luxembourg.[3] Further, in Switzerland,[4] and more recently in Germany,[5] assisting a person to self-administer lethal medication in certain circumstances has been decriminalised. In the United States of America ('US'), there are now ten states and one district where VAD is lawful, with ten having legalised the practice by passing legislation[6] and one through judicial decision.[7] VAD is also permitted in Canada[8] and Colombia.[9]

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1 *Wet Toetsing Levensbeëindiging op Verzoek en Hulp Bij Zelfdoding 2001* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001] (The Netherlands).

2 *Loi Relative à L'euthanasie 2002* [Act on Euthanasia 2002] (Belgium).

3 *Legislation Reglementant les Soins Palliatifs ainsi que L'euthanasie et L'assistance au Suicide 2009* [Legislation Regulating Palliative Care and Euthanasia and Assisted Suicide 2009] (Luxembourg).

4 *Schweizerisches Strafgesetzbuch 1937* [Swiss Criminal Code 1937] (Switzerland) art 115: 'Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty'.

5 Bundesverfassungsgericht [German Constitutional Court], 2 BvR 2347/15,ECLI:DE:BVerfG:2020:rs20200226.2bvr234715, 26 February 2020 reported in (2020) BverfG1.

6 *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.897 (1994) ('*Oregon Act*'); *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.903 (2008); *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281–93 (2013); *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (West 2015); *Death with Dignity Act of 2016*, DC Code §§ 7-661.01–7-661.16 (2017) (District of Columbia); *Colorado End-of-Life Options Act*, Colo Rev Stat §§ 25-48-101–25-48-123 (2017); *Our Care, Our Choice Act*, Haw Rev Stat §§ 327L-1–327L-25 (2018); *Medical Aid in Dying for the Terminally Ill Act*, NJ Stat Ann §§ 26:16-1–26:16-20 (West 2021); *Maine Death with Dignity Act*, 22 Me Rev Stat Ann § 2140 (2019); *Elizabeth Whitefield End-of-Life Options Act*, NM Stat § 3 (2021).

7 *Baxter v Montana*, 224 P 3d 1211 (Mont, 2009). Pope argues that VAD is also lawful in North Carolina through a 'standard of care' approach. There is no legislation, regulation or court case that permits VAD, but VAD is not prohibited under current law. See Thaddeus Pope, 'Medical Aid in Dying: Key Variations Among U.S. State Laws' (2020) 14(1) *Journal of Health and Life Sciences Law* 25, 35.

8 Across Canada through the *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.4 ('Canadian *Criminal Code*') and in Quebec also through the *Act Respecting End-of-Life Care*, RSQ 2014, c S-32.0001. The criteria in these laws are similar but not identical. However, because the federal law applies across the whole of Canada, this article focuses on the eligibility criteria contained in the Canadian *Criminal Code*.

9 A court decision in Colombia permitted VAD in 1997: *Sentence C-239/97*, Republic of Colombia Constitutional Court, Ref Expedient D-1490, 20 May 1997, which was followed by government regulations to facilitate the practice in 2015: Ministry of Health and Social Protection, *Protocolo para la Aplicación del Procedimiento de Eutanasia en Colombia* [Protocol for the Application of the Procedure of

Australia too has seen law reform in this area. In November 2017, the *Voluntary Assisted Dying Act 2017* (Vic) ('*Victorian Act*') was passed. It came into force on 19 June 2019, permitting VAD in Australia for the first time in 20 years.[10] This was followed in December 2019 by the enactment of the *Voluntary Assisted Dying Act 2019* (WA) ('*WA Act*'), after an extensive parliamentary debate which followed reviews by a Parliamentary Committee[11] and a Ministerial Expert Panel.[12] These laws may herald a shift in political thinking, because despite a long history of unsuccessful attempts of reform,[13] it appears that the climate in Australia may now be more conducive to change.[14] As this article was being finalised for publication, Tasmania passed VAD legislation,[15] there is a Bill before the South Australian[16] and Queensland[17] Parliaments, and a Bill is also proposed in 2021 in New South Wales.[18]

A key policy question for Australian and international legislators when designing such laws is who should be permitted to access VAD. The primary means by which access is regulated is through eligibility criteria. Although generally only a small part of the legislation in terms of the number of provisions, eligibility criteria play a significant role in determining the breadth of VAD laws. Broad eligibility criteria exclude very few individuals from VAD, whereas narrow and tightly constrained criteria can significantly limit access.

This article is the first in a two-part series[19] that critically analyses the scope and operation of eligibility criteria in five VAD legal frameworks. In particular, the articles consider these two questions: for what medical conditions, and at what stage in the trajectory of those conditions, would a person be eligible to access VAD? While eligibility criteria commonly contain provisions unrelated to a person's health state, such as residency and age requirements, the most contentious

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Euthanasia in Colombia] (Report, 2015) <https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/DE/CA/Protocolo-aplicacion-procedimiento-eutanasia-colombia.pdf>.

10 VAD was briefly permitted in the Northern Territory by the *Rights of the Terminally Ill Act 1995* (NT) but this legislation was overturned later by the *Euthanasia Laws Act 1997* (Cth).

11 Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice* (Report No 1, 23 August 2018).

12 Ministerial Expert Panel on Voluntary Assisted Dying, Department of Health (WA), *Final Report* (Report, June 27 2019) ('*MEP Report*').

13 For a detailed discussion of the history of attempts at law reform in Australia, see Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1. See also updated data in Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616 ('Future of Assisted Dying Reform').

14 White and Willmott, 'Future of Assisted Dying Reform' (n 13) 618–19.

15 *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas). This will take effect in October 2022, after a prescribed implementation period: s 2.

16 Voluntary Assisted Dying Bill 2020 (SA).

17 Voluntary Assisted Dying Bill 2021 (Qld).

18 Michael Koziol, 'Fresh Bid to Legalise Assisted Dying Set to Test NSW Government', *Sydney Morning Herald* (online, 13 December 2020) <https://www.smh.com.au/politics/nsw/fresh-bid-to-legalise-assisted-dying-set-to-test-nsw-government-20201209-p56m2t.html>.

19 The second article is Ben P White et al, 'Who is Eligible for VAD? Nine Medical Conditions Assessed Against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* (forthcoming) ('Who is Eligible for VAD?').

discussion when debating eligibility under VAD laws has been in relation to when, and with what medical conditions, a person could seek access to VAD.[20]

This first article undertakes a critical analysis of the eligibility criteria outlined in five selected models of VAD, with a particular focus on those criteria that are relevant to a person's health state. Key aspects of those criteria are: the nature of the medical condition or illness a person must have, and the requirement to retain decision-making capacity when seeking VAD. The criteria in three Australian models have been chosen for review: the *Victorian Act*, the *WA Act*, and a model Voluntary Assisted Dying Bill 2019 ('Model Bill')[21] recommended by the Queensland Parliamentary Inquiry considering VAD as the proposed basis for reform.[22] The Victorian legislation has served as a basis for both the *WA Act* and the Model Bill, although both incorporate important differences.

Additionally, the review includes two other important common law comparators.[23] The first is Oregon's *Death with Dignity Act 1994* ('*Oregon Act*').[24] It is the original legislation in the US and has largely been copied by other states in that country. It was also cited as an important departure point when designing the Victorian model.[25] The second law considered is Canada's federal law about VAD (called 'MAiD': medical assistance in dying), which is contained in its *Criminal Code* ('Canadian *Criminal Code*').[26] Shared legal heritage means Canada is a

20 For example, in Victoria, the debate on the eligibility criteria ranged over people with neurological disease, an insulin dependent diabetic who decides to stop taking insulin, renal disease, terminal cancer, people with disabilities, loneliness, incontinence, autism and mental illness: Victoria, *Parliamentary Debates*, Legislative Council, 21 November 2017, 6216–24, 6232–9. In Western Australia, the debate on the eligibility clause was briefer, but canvassed a person with gangrene who refuses amputation and a diabetic who refuses insulin (Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9199–201), as well as people with autism and mental illnesses such as schizophrenia, anorexia and depression (Western Australia, *Parliamentary Debates*, Legislative Council, 22 October 2019, 7978–9 (Rick Mazza)).

21 Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1 ('Model Bill').

22 Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) 105, 'Recommendation 1' ('*Queensland Parliamentary Report*').

23 We note that the New Zealand Parliament passed its *End of Life Choice Act 2019* (NZ) in late 2019 (which would only take effect if approved by a public referendum, as subsequently occurred in late 2020). However, this occurred only after this analysis in this article was finalised and accordingly, we will not consider this Act further. Also not included are the European models and Colombia. This is because these jurisdictions are culturally more distinct from Australia than other common law countries, and their laws operate within quite different legal systems.

24 *Oregon Act*, Or Rev Stat §§ 127.800–127.995 (1994).

25 For example, in relation to the eligibility criteria: preference for self-administration at a time of the person's choosing without a medical practitioner needing to be present; a prescribed waiting period before VAD can be accessed; review and reporting: Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report, 9 June 2016) 217–18, 228 ('*LSIC Report*'). There are also numerous references to similarities between the *Oregon Act* and the proposed Victorian law in the Ministerial Advisory Panel on Voluntary Assisted Dying, Department of Health and Human Services (Vic), *Final Report* (Report, 31 July 2017) ('*MAP Report*'). See examples just in relation to the eligibility criteria: at 53, 55, 56, 63, 69.

26 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.4. The Canadian law has undergone various iterations (including through amendments made through Bill C-14, *An Act to Amend the Criminal Code*

natural comparator for Australia when considering law reform.[27] Canada's MAiD law has been considered, and Canadian experts consulted, in Australian reviews of VAD,[28] for example, in respect of its terminology requiring the person's medical condition to be 'incurable',[29] and in relation to the requirement of unbearable or intolerable suffering.[30]

After critically analysing each of the varying approaches to eligibility, this article undertakes a comparative analysis of the five jurisdictions to identify important areas of similarity and difference. Although this work establishes the foundation for the consideration of medical conditions that follows in the second article, this legal analysis is significant in its own right and has implications for designing VAD regulation, which are identified in Part IV.

The second article then applies this analysis to evaluate whether different medical conditions would be eligible for VAD under the five regimes. These conditions are: cancer (specifically colorectal cancer), motor neurone disease, chronic obstructive pulmonary disease, chronic kidney disease, dementia (specifically Alzheimer's disease), anorexia, spinal cord injury, Huntington's disease and frailty. This diverse group of conditions was chosen with a view to illustrate how the various eligibility criteria would apply in a range of settings. Regard was had to considerations such as those conditions most likely to be relied upon to access VAD, common causes of death in Australia, and conditions in the literature that have sparked controversy about access to VAD.

The analysis in the second article demonstrates how changes in the framing of eligibility criteria can have an impact on who is included or excluded from accessing VAD, and at what point this access may be possible in their illness trajectory. This has implications for law reform, for example, when certain conditions may be seen by the public as important in the case for allowing VAD, but people with those conditions would not be eligible for VAD under the law as drafted. Another conclusion from this research is that concrete thinking is needed when designing VAD laws. While criteria can be considered in the abstract, it is this practical exercise of ascertaining where eligibility criteria will draw lines that is critical. While these decisions have been made for Victoria and Western Australia as their Acts have passed, there is scope to inform the remaining Australian jurisdictions (and indeed other countries) considering VAD reform.

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and to Make Related Amendments to Other Acts (Medical Assistance in Dying), 1st Sess, 42nd Parl, 2016 ('Bill C-14') and Bill C-7, *An Act to Amend the Criminal Code (Medical Assistance in Dying)*, 1st Sess, 43rd Parl, 2020 ('Bill C-7')).

27 White and Willmott, 'Future of Assisted Dying Reform' (n 13) 618; Stephen Kirchner, Sean Speer and Jason Clemens, 'Policy Reforms in Australia and What They Mean for Canada' (Research Paper, Fraser Institute, 3 December 2013) <https://ssrn.com/abstract=2392622>. See also, particularly in relation to reform of the common law by reference to United Kingdom and Canadian examples: *Cook v Cook* (1986) 162 CLR 376, 390 (Mason, Wilson, Deane and Dawson JJ); James Allsop, 'Some Reflections on the Sources of Our Law' (2014) 11(4) *Judicial Review* 365, 371–2.

28 The Ministerial Expert Panel in Western Australia met with four Canadian experts and one from Oregon in drafting the VAD legislation: *MEP Report* (n 12) 126. Note that Quebec was also considered in Victoria's *MAP Report*: see above n 25.

29 See, eg, *MEP Report* (n 12) 33–4 (although they did not adopt this criterion).

30 See *LSIC Report* (n 25) 217.

We conclude this introduction with two practical matters. The first is about the scope of analysis of the eligibility criteria. The focus of this two-part series is on the contentious issue of the impact that a person's medical condition has on their eligibility to access VAD. Accordingly, the analysis which follows emphasises criteria such as whether a condition is incurable or likely to cause death, and gives less consideration to other criteria, such as age and residency requirements.

The second practical matter is about terminology. In general, the terminology in relation to VAD used in the *Victorian Act* (and subsequently mirrored in the Model Bill and the *WA Act*) will be adopted. VAD therefore includes both 'self-administration' (where the person takes the prescribed medication themselves, sometimes called physician-assisted suicide or dying) and 'practitioner administration' (where the person is administered the medication by a doctor, or nurse practitioner in Western Australia or Canada, sometimes called voluntary euthanasia). However, when considering Canadian law, the specific defined term used in that law (MAiD) will be used. The article will also refer to a person's 'medical condition'. This is meant in a broad sense, whether that condition is caused by disease, illness, disability, or injury, although we note some VAD laws specifically address these latter concepts.

II ELIGIBILITY CRITERIA OF FIVE MODELS

A Introduction

This section outlines the eligibility criteria in the five VAD models: three Australian models in chronological order (the *Victorian Act*, the Model Bill and the *WA Act*) and then the *Oregon Act* and the Canadian *Criminal Code*. As noted above, while all eligibility criteria are noted for completeness, this article focuses on analysing those criteria particularly relevant to determining which medical conditions may provide access to VAD. A final point to note is that the Canadian eligibility criteria have been subject to extensive discussion, including academic commentary specifically aimed at interpreting these criteria, as well as some judicial and now legislative consideration, and this is reflected in the extended treatment of this jurisdiction's law below. By contrast, the Australian models are very new and have been subject to very limited critical analysis to date, and so are addressed more succinctly.

B *Voluntary Assisted Dying Act 2017* (Vic)

The *Victorian Act* came into force on 19 June 2019 after a planned 18-month implementation period and permits access to VAD after a rigorous process that requires at least three requests from an eligible patient and at least two assessments by qualified and trained medical practitioners. VAD is intended usually to be self-administered, as practitioner administration is permitted only when a person

is physically incapable of taking or digesting the medication themselves.[31] The Victorian law was described by the Victorian government at the time of introduction to Parliament as the safest and most conservative VAD model in the world.[32]

Part of this claim is based on the Act's eligibility criteria. Section 9(1) of the *Victorian Act* outlines the primary eligibility criteria and states that '[f]or a person to be eligible for access to voluntary assisted dying':

(a) the person must be aged 18 years or more; and

(b) the person must–

(i) be an Australian citizen or permanent resident; and

(ii) be ordinarily resident in Victoria; and

(iii) at the time of making a first request, have been ordinarily resident in Victoria for at least 12 months; and

(c) the person must have decision-making capacity in relation to voluntary assisted dying; and

(d) the person must be diagnosed with a disease, illness or medical condition that–

(i) is incurable; and

(ii) is advanced, progressive and will cause death; and

(iii) is expected to cause death within weeks or months, not exceeding 6 months [or 12 months if the disease, illness or medical condition is neurodegenerative];[33] and

(iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.

Section 9 continues and clarifies that disability and mental illness alone are not grounds to access VAD.[34] However, the mere fact of a disability or a mental illness will not preclude a person from accessing VAD if the eligibility criteria are met.[35]

1 Decision-Making Capacity

Subsection 9(1)(c) requires the person to have decision-making capacity in relation to VAD and this is assessed at multiple points during the process.[36] If VAD is provided by practitioner administration, capacity is also specifically assessed at that final point in time. For self-administration, capacity is assessed at each stage during the request and assessment process but not at the time of ingestion, as this is done later at a time of the person's choosing and without a practitioner necessarily being present.

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31 *Voluntary Assisted Dying Act 2017* (Vic) ss 46, 48 ('*Victorian Act*').

32 Daniel Andrews, 'Voluntary Assisted Dying Model Established Ahead of Vote in Parliament' (Media Release, Premier of Victoria, 25 July 2017) 1 <https://www.premier.vic.gov.au/voluntary-assisted-dying-model-established-ahead-of-vote-in-parliament> ('Andrews Media Release').

33 The words in square brackets have been inserted based on *Victorian Act 2017* (Vic) s 9(4).

34 Ibid ss 9(2)–(3).

35 *MAP Report* (n 25). See 'Ministerial Advisory Panel Recommendation 5' in respect of mental illness: at 80–2. See also 'Ministerial Advisory Panel Recommendation 6' in respect of disability: at 83–5.

36 *Victorian Act 2017* (Vic) ss 16, 25, 36, 47, 48, 64.

A person has decision-making capacity if they meet four requirements. The person must be able to understand the relevant information, retain that information, use or weigh the information as part of a decision-making process, and communicate their decision.[37] There is a presumption that an adult has decision-making capacity, and to displace that presumption, it must be demonstrated they do not meet one of the four requirements.[38] Under the legislation, a person is unable to make a request for VAD in advance of losing decision-making capacity by means of an advance directive.[39]

The decision-making capacity assessment only requires doctors to assess whether the person meets the four requirements, not whether they consider the person's decision to be wise.[40] The limited basis on which a doctor may determine a person does not have decision-making capacity is further explained in the Guidance for Health Practitioners produced by the Victorian Department of Health and Human Services.[41] As that document makes clear, the presence of depression or other mental illness does not necessarily mean a person lacks decision-making capacity. What is being assessed is whether the person meets the four requirements listed and mental illness does not necessarily prevent this.

Consistent with other Victorian legislation,[42] the *Victorian Act* also recognises decision-making capacity is decision specific, that information may be tailored to meet a person's particular needs, and that people may be supported to make decisions. The Act adopts an inclusive approach to assessing decision-making capacity, recognising that people may understand or communicate things in different ways and that this does not necessarily mean they cannot make decisions for themselves.[43] The Act also recognises a person may have decision-making capacity if they are able to make a decision through the use of practicable supports.[44] These provisions recognise people using non-standard forms of communication or receiving some form of support should not be excluded from accessing VAD on this basis.

2 Disease, Illness or Medical Condition that Is Incurable

Subsection 9(1)(d)(i) of the *Victorian Act* requires the relevant disease to be 'incurable'. The Explanatory Memorandum explains that this assessment is based on the individual's circumstances and comorbidities, but whether a disease is 'incurable' is a question of 'whether there is a clinically indicated treatment that

37 Ibid s 4.
38 Ibid s 4(2).
39 *Medical Treatment Planning and Decisions Act 2016* (Vic) s 8A as inserted by *Victorian Act 2017* (Vic) s 140.
40 Ibid s 4(4)(c).
41 Department of Health and Human Services (Vic), 'Voluntary Assisted Dying: Guidance for Health Practitioners' (Clinical Guideline, 4 July 2019) 34 <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/coordinating-consulting-medical-practitioner-information> ('Guidance for Health Practitioners').
42 See, eg, *Medical Treatment Planning and Decisions Act 2016* (Vic) s 4; *Powers of Attorney Act 2014* (Vic) s 4.
43 *Victorian Act 2017* (Vic) s 4(3).
44 Ibid s 4(4)(d).

will cure the disease'.[45] During the parliamentary debate, Minister Jennings further clarified this by stating that '[t]his is an objective test based on available medical treatments'.[46]

The Explanatory Memorandum also recognises that '[t]here is a difference between *managing* the symptoms of a disease, illness or medical condition and *curing* it, which requires the complete eradication of the disease, illness or medical condition'.[47] For example, renal dialysis manages kidney disease, but it does not cure the disease. The fact that a person refuses treatment for a curable disease does not make it incurable (although refusing treatment may allow the condition to progress to the point that it becomes incurable). This suggests the assessment of whether a disease is incurable is a medical assessment based on available treatments and that a person will not be eligible if they are refusing treatment for an otherwise curable condition.

3 Disease, Illness or Medical Condition that Is Advanced and Progressive

It is not sufficient that a disease is incurable; it must also be advanced and progressive.[48] These criteria mean the person's condition must be deteriorating and this deterioration must be at an advanced stage.

Neither the term 'advanced' nor the term 'progressive' is defined. The Department of Health and Human Services' Guidance for Health Practitioners suggests a condition will be progressive if 'the patient is experiencing an active deterioration'.[49] Applying the ordinary meaning of the term 'advanced' suggests the condition must have significantly progressed along its expected trajectory. When applied in conjunction with the term 'progressive', it must be expected the person will continue to decline along this trajectory. This would prevent access by people in the earlier stages of a terminal condition. The extent to which a condition is advanced and progressive may also cause confusion, as both criteria are ultimately a question of degree and one may ask how far advanced a condition needs to be or what constitutes progression. In practice, the effect of these criteria and any potential confusion are likely to be limited. This is because of the further requirement that death must be expected within 6 months (or 12 months for a neurodegenerative condition). In order to meet these timeframes, it is likely the person's condition would be advanced and progressive, which gives context to what is meant by these terms.

4 Disease, Illness or Medical Condition that Will Cause Death and Is Expected to Cause Death Within 6 or 12 Months

The relevant condition must be one that will cause death. The necessary connection between the condition and the ultimate cause of death has not been explained in either parliamentary debates or subsequent health policies. For many

45 Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3 cl 9.
46 Victoria, *Parliamentary Debates*, Legislative Council, 21 November 2017, 6218 (Gavin Jennings).
47 Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3 cl 9 (emphasis added).
48 *Victorian Act 2017* (Vic) s 9(d)(ii).
49 'Guidance for Health Practitioners' (n 41) 37.

conditions, death may be the result of organ failure that is a predictable but not necessary outcome of the condition. For example, a metastatic cancer may hinder the functioning of the digestive system, which may result in malnourishment and dehydration that causes death. It is suggested that the requirement that a condition will cause death will be fulfilled if the condition causes a chain of events that will result in death.

Under subsection 9(1)(d)(iii) of the *Victorian Act*, the medical condition must be expected to cause death within 6 months, except in the case of neurodegenerative conditions where the relevant time is 12 months. The assessment of this criterion is complex because 'most prognostication tools have been developed to assist in identifying patients' needs and to plan care and support, not for determining a timescale for death'.[50] The words 'expected to' in this criterion appear to recognise prognosis is not an exact science and cannot be as definitive as some of the other eligibility criteria.

While the requirement for the condition to be 'incurable' must be based on an objective assessment of clinically indicated treatments, an assessment of whether the disease will cause death and will do so within the requisite timeframe must consider the individual and the treatments acceptable to them. The Explanatory Memorandum explains that, in assessing the timeframe within which a person is expected to die, a medical practitioner must consider the 'individual's own particular circumstances, including their condition, their comorbidities, and the available treatments that they are prepared to accept, noting the right to refuse medical treatment'.[51] This recognises that conditions progress in different ways in different people. It also recognises that if a person has an incurable condition but there are treatments that could slow the progress of that disease, they should not be required to undergo all such treatments prior to accessing VAD. For example, a person who chooses not to undergo further chemotherapy for quality of life reasons may still be eligible for VAD even if that treatment may temporarily prolong their life.

5 Disease, Illness or Medical Condition Is Causing Suffering

The final criterion in subsection 9(1)(d)(iv) of the *Victorian Act* is that the condition must be causing suffering that cannot be relieved in a manner deemed tolerable by the person. The use of the term 'suffering' recognises that a condition may cause more than physical pain to a person, and that existential distress or other forms of suffering caused by the condition may also be sufficient.[52] This assessment has two parts. First, the person's suffering must be caused by their condition. Second, the suffering must not be able to be relieved in a manner deemed tolerable by the person. Whether suffering can be relieved is a 'subjective' assessment, assessed by the person.[53]

50 Ibid 38.

51 Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3 cl 9.

52 Guidance for Health Practitioners (n 41) 39.

53 Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3 cl 9; see also Victoria, *Parliamentary Debates*, Legislative Assembly, 21 September 2017, 2949 (Jill Hennessy).

C Model Voluntary Assisted Dying Bill 2019

The Model Bill was written by two of the authors and publicly released in April 2019 as a submission to the Queensland Parliament's inquiry into aged care, end of life and palliative care, and voluntary assisted dying.[54] The final report from that inquiry recommended that the Queensland government use the Bill 'as the basis for a legislative scheme for voluntary assisted dying'.[55] The goal of the Model Bill was to state preferred policy positions on VAD and represent those positions in the concrete form of a draft Bill that could be considered by jurisdictions undertaking reform. Although initially submitted to a Queensland law reform exercise, the Model Bill was written not only for that State and was proposed for consideration by other Australian States too.

The Model Bill is based on a series of values that had been articulated earlier as appropriate to guide design of a VAD law.[56] The values articulated as relevant were: life; autonomy; freedom of conscience; equality; rule of law; protecting the vulnerable; and reducing human suffering. In addition, influenced by the Victorian Ministerial Advisory Panel,[57] added to this list was the concept of safe and high quality care.[58]

The Model Bill also drew heavily on the *Victorian Act*, recognising that the Act had already been subject to intense scrutiny when debated and passed by an Australian Parliament. (The *WA Act* was not released at the time and so could not be considered.) Accordingly, the Bill adopted or adapted the drafting of the *Victorian Act* where the Model Bill's policy position was the same or similar. However, the application of these values did lead to some key differences between the *Victorian Act* and the Model Bill.[59] One key difference is that the Model Bill proposes that people be given a choice between self-administration and practitioner administration, and that VAD be medically supervised.[60] There are also some differences in relation to eligibility criteria.

Clause 9 of the Model Bill contains the eligibility criteria for access to VAD:

(a) the person must be aged 18 years or more; and

54 The Model Bill (n 21) was first published as a submission at <https://eprints.qut.edu.au/128753/> in April 2019 and was subsequently published as Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

55 *Queensland Parliamentary Report* (n 22) 105, 'Recommendation 1'. The Model Bill (n 21) was also referred to in the Western Australian reform process: *MEP Report* (n 12) 78. The Model Bill is currently being considered by the Queensland Law Reform Commission as part of its role in developing proposed VAD legislation: Queensland Law Reform Commission, *Queensland's Laws Relating to Voluntary Assisted Dying* (Terms of Reference, 21 May 2020) <https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0004/651379/vad-tor.pdf>.

56 These values are set out in Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479, 488–99 ('Assisted Dying in Australia').

57 *MAP Report* (n 25) 11, 22, 46. See also Ben P White et al, 'Does the *Voluntary Assisted Dying Act 2017* (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417 ('Does the *VAD Act* (Vic) Reflect Its Stated Policy Goals?').

58 See Explanatory Notes: White and Willmott, 'Model Bill' (n 21) 6.

59 Ibid 7–14 ('Explanatory Notes').

60 Ibid 19–20 cl 6.

(b) the person must –

(i) be an Australian citizen or permanent resident; and

(ii) be ordinarily resident in [State]; and

(c) the person must have decision-making capacity in relation to voluntary assisted dying; and

(d) the person's decision to access voluntary assisted dying must be –

(i) enduring;

(ii) made voluntarily and without coercion; and

(e) the person must be diagnosed with a medical condition that –

(i) is incurable; and

(ii) is advanced, progressive and will cause death; and

(iii) is causing intolerable and enduring suffering.

Clause 10 then clarifies certain aspects of the eligibility criteria. One clarification is that whether a person's medical condition will cause death is to be 'determined by reference to available medical treatment that is acceptable to the person'.[61] This is consistent with the Victorian position above but is made explicit in the Bill. The other clarifications relate to the nature of suffering required and stipulate that suffering:[62]

- is to be subjectively determined (again consistent with the *Victorian Act* but explicitly stated in the Bill);
- includes suffering caused by treatment for the medical condition; and
- includes physical, psychological and existential suffering (again explicit in the Bill but consistent with the Victorian approach).

Because of the Model Bill's similarity with the *Victorian Act*, the focus of the discussion here will be on the ways in which the Model Bill is different on the issue of eligibility. It is anticipated that, given the intentional use of the same or similar wording as in the *Victorian Act*, the analysis outlined above would also be generally applicable to the Model Bill.

The most significant difference in relation to eligibility is that the Bill does not include the Victorian requirement that death is expected within a specified timeframe. It was considered that a specified time limit is arbitrary.[63] Further, while a secondary consideration, not imposing a time limit avoids a registered medical practitioner having to engage in the difficult task of determining prognosis and timing of death.[64] In this way, the Model Bill is wider than the *Victorian Act* in that it does not limit access to VAD to a window of temporal proximity to death. However, despite the absence of a time limit, the Model Bill's other requirements

61 Ibid 21 cl 10(1).

62 Ibid 21 cl 10(2).

63 Ibid 8 ('Explanatory Notes'); Willmott and White, 'Assisted Dying in Australia' (n 56) 503.

64 White and Willmott, 'Model Bill' (n 21) 9 ('Explanatory Notes'); Willmott and White, 'Assisted Dying in Australia' (n 56) 503–4.

cumulatively operate to restrict eligibility to persons suffering with an advanced, progressive and incurable medical condition that will cause death.

The Model Bill also differs from the *Victorian Act* in relation to suffering. It requires 'intolerable and enduring suffering', which is arguably higher than the level of suffering required under the Victorian legislation.

Another difference relevant to the medical conditions that may be eligible for access to VAD is the definition of decision-making capacity. Clauses 7(1) and (2) of the Model Bill define capacity in terms that correspond to the Victorian definition in sections 4(1) and (2) of that Act. However, the Model Bill does not include the extended explanation of capacity contained in the *Victorian Act* as noted above, for example, in relation to supported decision-making. The Model Bill's requirement that VAD be medically supervised also has implications for capacity in that immediately prior to VAD being provided, whether by self-administration or practitioner administration, the registered medical practitioner must ensure the person requesting VAD still has capacity.[65]

There are two final differences which are noted for completeness but are unlikely to impact on whether or not a person's medical condition will satisfy the eligibility requirements. One is that the Model Bill includes, as part of its eligibility criteria, a requirement that the person's decision to access VAD is enduring and made voluntarily and without coercion. While the *Victorian Act* does require assessment of these factors at various points during the request and assessment process,[66] this is not part of its formal eligibility criteria. In practice, this may not be significant given this aspect of decision-making is assessed under both systems. The other difference is residency. Under the Model Bill, only one of Victoria's residency requirements is included: namely, being a resident of the State. There is no 12-month residency limit prior to a first request being made for VAD.

D *Voluntary Assisted Dying Act 2019* (WA)

Following extensive consultation over a two-year period, the Voluntary Assisted Dying Bill 2019 (WA) was introduced into the Western Australian Parliament in August 2019 and after lengthy debate was passed in December 2019.[67] The *WA Act* broadly follows the approach of the *Victorian Act*. Some departures from the *Victorian Act* were designed to accommodate differences in the geography and demography of Western Australia.[68] Other departures reflect different policy positions. One notable example is that although the *WA Act* retains self-administration as the default approach, in some circumstances, practitioner

65 White and Willmott, 'Model Bill' (n 21) 31–3 pt 4 div 2.

66 *Victorian Act 2017* (Vic) ss 20(1)(c), 29(1)(c), 34(2)(a)(i).

67 Between August 2017–18, a Joint Select Committee inquired into end-of-life choices for Western Australians. The Committee recommended the introduction of voluntary assisted dying legislation, and in support of this recommendation the government appointed a Ministerial Expert Panel to consult and develop a legislative framework for WA. The Panel's report was tabled in Parliament on 27 June 2019: see *MEP Report* (n 12).

68 Western Australia, *Parliamentary Debates*, Legislative Assembly, 7 August 2019, 5136 (Roger Cook, Minister for Health). The most significant of these was to allow for the use of telehealth in certain circumstances.

administration can be chosen by a person, in consultation with their medical practitioner. This can occur where the medical practitioner advises the person that self-administration would be inappropriate having regard to the person's ability to self-administer, the person's concerns about it, and the most suitable method of VAD for the patient.[69]

The differences between the *Victorian Act* and the *WA Act* in terms of eligibility criteria are more subtle. Subsection 16(1) of the *WA Act* contains the eligibility criteria that must be met for access to VAD:

a) the person has reached 18 years of age;

b) the person –

   (i) is an Australian citizen or permanent resident; and

   (ii) at the time of making a first request, has been ordinarily resident in Western Australia for a period of at least 12 months;

c) the person is diagnosed with at least 1 disease, illness or medical condition that –

   (i) is advanced, progressive and will cause death; and

   (ii) will, on the balance of probabilities, cause death within a period of 6 months or, in the case of a disease, illness or medical condition that is neurodegenerative, within a period of 12 months; and

   (iii) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable;

d) the person has decision-making capacity in relation to voluntary assisted dying;

e) the person is acting voluntarily and without coercion; and

f) the person's request for access to voluntary assisted dying is enduring.

As in Victoria, the *WA Act* states that disability and mental illness alone are not grounds to access VAD.[70] However, also like in Victoria, extrinsic material confirms that provided the eligibility criteria are met, the presence of a disability or a mental illness in itself will not preclude a person from accessing VAD.[71]

Because the eligibility criteria in the *WA Act* are so similar to those in the *Victorian Act*, the remaining discussion will focus on key areas of difference, and where appropriate, comparisons with the Model Bill.[72] A key difference between the *WA Act* and both the *Victorian Act* and Model Bill is that in Western Australia there is no requirement for an eligible condition to be 'incurable'. In Victoria, whether or not a disease, illness or condition is incurable is viewed as an objective test based on available medical treatments.[73] This explanation was provided in the context of

69 *Voluntary Assisted Dying Act 2019* (WA) s 56(2) ('*WA Act*').

70 Ibid s 16(2).

71 Explanatory Memorandum, Voluntary Assisted Dying Bill 2019 (WA) 6 cl 15.

72 One minor difference noted but not considered further is that the *WA Act*, like the *Victorian Act*, requires a person to be ordinarily resident in the State for at least 12 months before the first request for VAD, but it does not repeat the (superfluous) requirement in the *Victorian Act* to also be ordinarily resident in the State: *WA Act 2019* (WA) s 16(1)(b); *Victorian Act 2017* (Vic) s 9(1)(b).

73 Victoria, *Parliamentary Debates*, Legislative Council, 21 November 2017, 6218 (Gavin Jennings).

discussion about the ability of medical practitioners to accurately prognosticate about how long a person may have to live.[74] The presence of an incurable illness that was advanced and progressive would strongly indicate that the end of life was near. In considering a legislative framework for Western Australia, the Ministerial Expert Panel ('MEP') did not specifically engage with the concept of an incurable disease,[75] but instead explored whether a person should have a 'terminal' condition in order to be eligible to access VAD.[76] They formed the view that including a criterion that an illness or disease is 'advanced, progressive and will cause death' clearly 'emphasise[s] the terminal nature of the illness or disease'.[77] Consequently, further qualification of the type of illness, disease or condition was not seen as being required, and the *WA Act* does not refer to an 'incurable' condition. In debate on the Bill, the government indicated that they considered the term 'incurable' just reiterated existing criteria.[78] The Premier, Mark McGowan also observed that including a criterion of 'incurable' might require a person to undergo treatment they wish to refuse, or exhaust all treatment options,[79] potentially including experimental treatment in 'some far-flung place around the world'.[80] This would 'cut across the fundamental principle of patient autonomy'.[81]

In contrast, providing a timeframe within which a person is expected to die was seen as an important safeguard in the legislative framework.[82] The Model Bill does not require medical practitioners to engage with the challenging problem of estimating when a person might die, in part, because any suggested timeframe would be arbitrary. While substantially reflecting the *Victorian Act*, the *WA Act* seeks to address the prognostic challenge of estimating when a person might die by requiring the assessment of life expectancy on the balance of probabilities.[83] That is, a medical practitioner must be satisfied that it is more likely than not[84] that the person will die within 6 months (or 12 months in the case of a person with a neurodegenerative condition).[85] In determining if a disease, illness or condition is likely to cause the death of a person, the medical practitioner can take account of the person's individual circumstances, their comorbidities and their treatment

74 Ibid.
75 Although the MEP did refer to the fact that Canada's and Luxembourg's laws require an incurable condition: *MEP Report* (n 12) 33.
76 Ibid 33–4.
77 Ibid 34.
78 Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson). See also Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan).
79 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan). See also Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).
80 Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).
81 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6603 (Roger Cook).
82 *MEP Report* (n 12) 36–40.
83 *WA Act 2019* (WA) s 16(1)(c)(ii).
84 See generally John Dyson Heydon, *Cross on Evidence* (LexisNexis Butterworths, 12th ed, 2020) 387–9.
85 *WA Act 2019* (WA) s 16(1)(c)(ii).

choices,[86] making it more than a pure mathematical exercise in probabilities. Traditionally, the 'balance of probabilities' has been reserved for tribunals trying to determine particular facts from competing or contradictory claims.[87] Parliamentary debate sheds little light on this terminology, other than to observe that 'the test is easily understood and has case law to support it',[88] and is commonly used and well understood by medical practitioners.[89] The MEP originally recommended the use of the phrase 'reasonably foreseeable', and did not mention 'balance of probabilities'.[90] However, legal officers within the government felt that 'reasonably foreseeable' was not clear enough, and that 'balance of probabilities' provided the 'greatest clarity' and 'most utility'.[91] How it does so, and how or if it differs from 'expected' or 'reasonably foreseeable', was not explained. It was confirmed, however, in parliamentary debates that this new wording was not intended to import a lower standard than is contained in the *Victorian Act*.[92]

The *WA Act*, like the *Victorian Act* and the Model Bill, requires a person seeking access to VAD to have decision-making capacity in relation to VAD and requires capacity to be assessed at several points throughout the process. Like Victoria, the final assessment of capacity occurs at the point of practitioner administration, or for self-administration, at the conclusion of the request and assessment process (but not at the time of later ingestion). The *WA Act*, however, defines decision-making capacity in slightly different terms from the *Victorian Act*,[93] presumably to promote consistency with other Western Australian legislation defining decision-making capacity.[94] However, the similarity in approach means that its effect is likely to be the same. The *WA Act*, like the Model Bill, also does not have the extended explanation of capacity found in the *Victorian Act*.

For completeness, it is noted that the *WA Act* mirrors the Model Bill in including a requirement that the person's decision to access VAD must be enduring, made voluntarily and without coercion as part of the eligibility criteria.[95] Although different from the *Victorian Act*, as suggested above, the practical effect of this difference is likely to be insignificant.

86 Explanatory Memorandum, Voluntary Assisted Dying Bill 2019 (WA) 5 cl 15.
87 James Allsop et al, 'Are You Sure?' (2019) 47(2) *Australian Bar Review* 122, 124.
88 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6582 (Mark McGowan), 6606 (Roger Cook).
89 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6606 (Roger Cook); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).
90 *MEP Report* (n 12) 36–9.
91 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6606–7 (Roger Cook); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).
92 Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).
93 *WA Act 2019* (WA) s 6.
94 See, eg, *Mental Health Act 2014* (WA) s 15.
95 *WA Act 2019* (WA) ss 16(1)(e), (f).

E *Death with Dignity Act* (Oregon)

The *Oregon Act*[96] was passed through a ballot initiative process. At the November 1994 election, Oregon's citizens voted directly to approve the law by 51 to 49 percent.[97] However, a series of constitutional challenges delayed the implementation of the law by three years,[98] until the injunction against the operation of the law was lifted on 27 October 1997.[99] In November 1997, Oregonians rejected a direct ballot designed to repeal the *Oregon Act*, by a margin of 60 to 40 percent.[100] The law has been operational since that time.[101]

The *Oregon Act*, on which legislation in other US states is based,[102] has a rigorous assessment process that has been described as 'so carefully crafted, so narrowly drawn, and so laden with procedural safeguards that it may well demand more energy and fortitude to comply with it than some terminally ill people are likely to have'.[103] The model of VAD in Oregon is restricted to a doctor prescribing medication which the patient self-administers. There is no provision for practitioner administration.

The *Oregon Act* provides that to be eligible to request assistance to die a person must be:[104]

> An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die …

96 *Oregon Act*, Or Rev Stat §§ 127.800–127.995 (1994).

97 Patrick M Curran Jr, 'Regulating Death: Oregon's *Death with Dignity Act* and the Legalization of Physician-Assisted Suicide' (1998) 86(3) *Georgetown Law Journal* 725, 728.

98 It was argued that the legislation violated a number of constitutional rights, including due process and equal protection rights under the Fourteenth Amendment; the free exercise of religion and freedom of association rights under the First Amendment; and statutory rights under the *Americans with Disabilities Act of 1990*, 42 USC §§ 12101–213; section 504 of the *Rehabilitation Act of 1973*, 29 USC §§ 701–96l; and the *Religious Freedom Restoration Act of 1993*, 42 USC §§ 2000bb–bb4. The District Court of Oregon found the Act violated the equal protection clause, and issued injunctions preventing the law commencing: *Lee v Oregon*, 869 F Supp 1491 (D Or, 1994) (issuing preliminary injunction); *Lee v Oregon*, 891 F Supp 1429 (D Or, 1995) (equal protection opinion); *Lee v Oregon*, 891 F Supp 1439 (D Or, 1995) (issuing permanent injunction). On appeal, the Ninth Circuit Court held that the plaintiffs lacked standing: *Lee v Oregon*, 107 F 3d 1382 (9th Cir, 1997), and the Supreme Court refused leave to appeal: *Lee v Harcleroad*, 522 US 927 (1997). For discussion of these cases, see Brian Boyle, 'The Oregon *Death with Dignity Act*: A Successful Model or a Legal Anomaly Vulnerable to Attack' (2004) 40(5) *Houston Law Review* 1387, 1393–5.

99 Curran (n 97) 729; Boyle (n 98) 1391.

100 Curran (n 97) 729; Raphael Cohen-Almagor and Monica G Hartman, 'The Oregon *Death with Dignity Act*: Review and Proposals for Improvement' (2001) 27(2) *Journal of Legislation* 269, 274.

101 The law has been subject to, and survived, later litigation not directly challenging the statute itself, but alleging that a medical practitioner who prescribed drugs for assisted dying was not prescribing for a 'legitimate medical purpose' within the meaning of the federal *Controlled Substances Act*, 21 USC §§ 821–32, and consequently risked having his or her registration revoked: *Oregon v Ashcroft*, 192 F Supp 2d 1077 (D Or, 2002); *Oregon v Ashcroft*, 368 F 3d 1118 (9th Cir, 2004); *Gonzales v Oregon*, 546 US 243 (2006). For discussion of these cases, see Boyle (n 98) 1396–9.

102 See above n 6 for the legislation in other US states.

103 Alan Meisel, Kathy L Cerminara and Thaddeus M Pope, *The Right to Die: The Law of End-of-Life Decisionmaking* (Wolters Kluwer, 3rd ed, 2016) 12–91 §12.06[A][1].

104 *Oregon Act*, Or Rev Stat § 127.805(1) (1994).

Age or disability is specifically noted as being insufficient, of itself, to qualify for assistance to die.[105] Each of the Act's eligibility criteria, aside from being an adult and residence, will be considered separately below.

1 Capacity

To make a request for VAD a person must be 'capable', which is defined as having 'the ability to make and communicate health care decisions to health care providers'.[106] Communication can be made through persons familiar with the patient's manner of communicating if necessary. Capacity must be assessed by the patient's attending physician and consulting physician in every case before VAD is authorised,[107] and may additionally be evaluated by a psychiatrist or psychologist if there is concern that the person might be 'suffering from a psychiatric or psychological disorder or depression causing impaired judgment'.[108] The *Oregon Act* does not allow a person to request VAD in an advance directive.[109] While the person must have decision-making capacity at the time of the request and assessment process, capacity does not need to be assessed again at the point a person ingests the medication.[110]

2 Terminal Disease

A person must be 'suffering from a terminal disease'[111] to be eligible to receive assistance to die in Oregon. 'Terminal disease' is defined to mean 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months'.[112] This means that a person with a chronic illness, such as Parkinson's disease or multiple sclerosis, which is incurable but will not of itself result in death, is not eligible under the legislation.[113]

'Medically confirmed' means that the diagnosis of a terminal disease is determined by two doctors: the attending physician and the consulting physician. The 'attending physician' is the doctor who has primary responsibility for the care of the patient and treatment of the terminal disease.[114] The attending physician

105 Ibid § 127.805(2).
106 Ibid § 127.800(3).
107 Ibid §§ 127.815(1)(a), 127.820.
108 Ibid § 127.825. These words were added by amendments in 1999: Meisel, Cerminara and Pope (n 103) 12–92.4 §12.06[A][1]. The Act specifically prohibits access to VAD for this cohort being evaluated until it is determined that 'the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment': *Oregon Act*, Or Rev Stat § 127.825 (1994). As to the role of depression in impairing decision-making, see Linda Ganzini, 'Legalised Physician-Assisted Death in Oregon' (2016) 16(1) *QUT Law Review* 76, 81–3.
109 See Ganzini (n 108) 77.
110 Note that Ganzini (n 108) raises concern about the possibility that a person may have lost capacity by that stage: at 81.
111 *Oregon Act*, Or Rev Stat § 127.805(1) (1994).
112 Ibid § 127.800(12).
113 This distinction is made by IG Finlay and R George, 'Legal Physician-Assisted Suicide in Oregon and The Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups' (2011) 37(3) *Journal of Medical Ethics* 171, 173.
114 *Oregon Act*, Or Rev Stat § 127.800(2) (1994).

makes the initial diagnosis that the disease is terminal. This medical opinion is then confirmed by a consulting physician, after examining the patient and the patient's relevant medical records.[115]

Neither 'incurable' nor 'irreversible' is defined, so it is unclear whether the statute would include a person who refused available medical treatment which has a chance of curing or reversing the process of disease, thus rendering an otherwise non-fatal condition terminal.[116] Oregon's *Guidebook for Health Care Professionals* suggests that '[d]oubts concerning the patient's diagnosis, prognosis, and volition should be resolved against provision of medication'.[117] That is, where the doctor is uncertain whether or not the patient qualifies as terminally ill, they should refuse a request for VAD. However, this guidance does not directly address the issue of treatment refusal. In practice, the application of 'incurable and irreversible' may vary according to the condition from which the person is suffering. For example, an Oregon doctor stated that he declined a request for VAD from a diabetic patient who was refusing insulin treatment, but he would accept a request from a person with treatable lymphoma who was refusing chemotherapy.[118] The application of the statutory criteria may also vary according to the views of the assessing doctor, as other doctors have stated they would not accept a request from a person refusing lymphoma treatment.[119]

3 Suffering

There is no separate requirement under the *Oregon Act* that a person be in pain, or experiencing any suffering.[120] In this sense, the phrase 'suffering from a terminal illness' means having or experiencing such an illness.

4 Voluntary

To be eligible for VAD, a person must have 'voluntarily expressed his or her wish to die'.[121] The criteria for voluntariness are not defined in the *Oregon Act*, or in rules or regulations made under the Act.[122] However, witnesses are required to

115 Ibid § 127.800(8).

116 The Oregon Health Authority (unhelpfully) states that: 'The Act does not specify whether or not all treatment options must be exhausted prior to a prescription being written': Oregon Health Authority, 'Public Health's Role: Oregon's *Death with Dignity Act*', (Web Page) <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ohdrole.aspx>.

117 Kelly Hagan, 'Liability and Negligence' in Patrick Dunn and Bonnie Reagan (eds), *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*, (Centre for Ethics in Health Care, Oregon Health and Science University, 2007) ch 15, Guideline 15.10 <https://www.wsha.org/wp-content/uploads/Death-with-Dignity_Death-with-dignity-guidebook.pdf>.

118 Anita Hannig, 'Author(iz)ing Death: Medical Aid-in-Dying and the Morality of Suicide' (2019) 34(1) *Cultural Anthropology* 53, 70.

119 Ibid.

120 See Herbert Hendin and Kathleen Foley, 'Physician-Assisted Suicide in Oregon: A Medical Perspective' (2008) 106(8) *Michigan Law Review* 1613, 1615.

121 *Oregon Act*, Or Rev Stat § 127.805(1) (1994).

122 James L Werth Jr and Howard Wineberg, 'A Critical Analysis of Criticisms of the Oregon *Death With Dignity Act*' (2004) 29(1) *Death Studies* 1, 20; Michaela Estelle Okninski, 'Commentary on Undue

sign, as part of a person's request for assisted dying, that the person 'appears to be … not under duress, fraud or undue influence'.[123] It has been suggested that acting voluntarily involves excluding external influences such as duress, fraud or undue influence.[124]

F Canadian *Criminal Code*

In February 2015, in *Carter v Canada (Attorney General)* ('*Carter*'),[125] the Supreme Court of Canada struck down the *Criminal Code* prohibition on voluntary euthanasia and assisted suicide, ruling it was contrary to the Canadian *Charter of Rights and Freedoms* ('*Charter*'):

> The appropriate remedy is therefore a declaration that s. 241(*b*) and s. 14 of the *Criminal Code* are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. 'Irremediable', it should be added, does not require the patient to undertake treatments that are not acceptable to the individual.[126]

In response to this decision, albeit after 16 months,[127] the Canadian Parliament passed *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)* in June 2016 ('Bill C-14').[128] This legislation permits 'medical assistance in dying' (MAiD), after a person seeking

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Influence Provisions under Oregon's *Death with Dignity Act* and California's *End of Life Option Act*' (2017) 25(1) *Journal of Law and Medicine* 77, 80. Clinical criteria to assess voluntariness have been proposed in David Orentlicher, Thaddeus Mason Pope and Ben A Rich, 'Clinical Criteria for Physician Aid in Dying' (2016) 19(3) *Journal of Palliative Medicine* 259.

123 *Oregon Act*, Or Rev Stat § 127.897 (1994).

124 For this interpretation, see Okninski (n 122) 80. A witness' ability to attest to voluntariness has been questioned by Hendin, Foley and White who note that there is no requirement that the witnesses be independent of the person, or even that they know the person: Herbert Hendin, Kathleen Foley and Margot White, 'Physician-Assisted Suicide: Reflections on Oregon's First Case' (1998) 14(3) *Issues in Law and Medicine* 243, 254–5. Note also that Okninski has suggested that the *Oregon Act* does not provide sufficient protection against external factors which may overbear a person's will, because doctors are not required to report refusals of requests on the ground of concerns about voluntariness. This allows doctor shopping until a person or their relative finds a doctor willing to certify that a request for assistance to die is voluntary. Okninski cited anecdotal evidence of the Kate Cheney case, in which two doctors and a psychiatrist refused Ms Cheney's request because of concerns of undue influence or coercion by her daughter, before a doctor was found who was willing to write a prescription for lethal medication: Okninski (n 122) 82–3, citing Kathleen Foley and Herbert Hendin, 'Physician-Assisted Suicide in Oregon: A Medical Perspective' (2008) 24(2) *Issues in Law and Medicine* 121, 131–2. We note, however, that the source of information about Kate Cheney for the Foley and Hendin paper is a 1999 newspaper article.

125 *Carter v Canada (Attorney General)* [2015] 1 SCR 331 ('*Carter*'). For commentary on this case, see Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16(1) *QUT Law Review* 84, 96–8.

126 *Carter* [2015] 1 SCR 331, 390 [127] (emphasis in original).

127 The Court suspended the declaration of invalidity for 12 months to allow the Canadian government to develop a legislative response to the judgment: *Carter* [2015] 1 SCR 331, 396 [147]. The suspension was then extended by a further four months due to a period of legislative inactivity because of an election: *Carter v Canada (Attorney General)* [2016] 1 SCR 13.

128 Bill C-14, 1st Sess, 42nd Parl, 2016, amending the Canadian *Criminal Code*, RSC 1985, c C-46, ss 14, 226, 241. Although note that provincial legislation permitting VAD was first enacted in Quebec which commenced operation in December 2015: *Act Respecting End-of-Life Care*, RSQ c S-32.0001.

access for this assistance has been found to be eligible through a rigorous assessment process. MAiD includes both practitioner administration and self-administration, although, to date, self-administration has been very rarely used.[129]

For a person to be eligible for MAiD, Bill C-14 required that:

241.2(1)

(a) they are eligible – or, but for any applicable minimum period of residence or waiting period, would be eligible – for health services funded by a government in Canada;

(b) they are at least 18 years of age and capable of making decisions with respect to their health;

(c) they have a grievous and irremediable medical condition;

(d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and

(e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

Bill C-14 stated that a person has a grievous and irremediable medical condition if:

(a) they have a serious and incurable illness, disease or disability;

(b) they are in an advanced state of irreversible decline in capability;

(c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and

(d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.[130]

Aspects of Bill C-14 were controversial from the outset, in particular the requirement that to amount to a grievous and irremediable medical condition a person's natural death must be 'reasonably foreseeable'.[131] Critics argued that this criterion violated the *Charter*, was too uncertain and was not an accurate reflection of the Supreme Court's reasoning in *Carter*.[132] On 11 September 2019, in

129 Christopher Harty et al, 'Oral Medical Assistance in Dying (MAiD): Informing Practice to Enhance Utilization in Canada' (2019) 66(9) *Canadian Journal of Anaesthesia* 1106.

130 Bill C-14, 1st Sess, 42nd Parl, 2016, s 3, inserting Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2).

131 'Reasonably foreseeable' is not defined in the legislation. It is widely accepted that 'reasonably foreseeable' is not limited to situations in which: death is solely caused by the grievous and irremediable condition; death is imminent; the patient has a fatal condition; the patient is terminally ill; or the patient has an expected remaining lifespan of six months (as in Oregon, for example). See *AB v Canada (Attorney General)* (2017) 138 OR (3d) 139; Jocelyn Downie and Jennifer A Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (IRPP Report, 1 March 2018) <https://irpp.org/research-studies/interpreting-canadas-medical-assistance-in-dying-maid-legislation> ('IRPP Report').

132 See, eg, Jocelyn Downie and Kate Scallion, 'Foreseeably Unclear: The Meaning of the 'Reasonably Foreseeable' Criterion for Access to Medical Assistance in Dying in Canada' (2018) 41(1) *Dalhousie Law Journal* 23; James Downar and Louise Hugo Francescutti, 'Medical Assistance in Dying: Time for Physicians to Step up to Protect Themselves and Patients' (2017) 189(25) *Canadian Medical Association Journal* E849. The primary source of uncertainty over 'reasonably foreseeable' death is how close to death

Truchon v Procureur Général du Canada ('*Truchon*'),[133] Baudouin J of the Quebec Superior Court accepted aspects of these arguments, and ruled that the 'reasonably foreseeable' eligibility criterion was constitutionally invalid.[134] In response to the *Truchon* decision, on 17 March 2021, *An Act to Amend the Criminal Code (Medical Assistance in Dying)* ('Bill C-7') was passed and came into force.[135] Bill C-7 makes three changes to the law that are of particular relevance to this article:

1. It repeals the eligibility criterion in section 241.2(2)(d) that a person's natural death must be reasonably foreseeable;[136]
2. It explicitly stipulates that (until 17 March 2023) for the purposes of determining whether someone has a serious and incurable illness, disease, or disability, mental illness is not considered an illness, disease, or disability;[137] and
3. It permits two forms of requests for MAiD made in advance of loss of decision-making capacity (a 'final consent waiver' and 'advance consent' explained in detail below).[138]

1 Decision-Making Capacity

The first eligibility criterion, in section 214.2(1)(a) of the Canadian *Criminal Code*, which we will not consider in detail, is that a person must be eligible for health services in Canada. The second criterion, in section 241.2(1)(b), is that a person accessing MAiD must be capable of making decisions with respect to their health. Two independent health practitioners must be of the opinion that this criterion and the other eligibility requirements are satisfied.[139] The capacity

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a person must be to satisfy this requirement. On a narrow interpretation, a temporal link to death is required and that period of time must not be too remote, even though the medical or nurse practitioner does not have to estimate a specific length of time. On a broader interpretation, this criterion would be satisfied if *either* death is predicted in a period of time that is not too remote *or* there is a predictable cause of death. This latter interpretation is supported by, for example, College of Physicians and Surgeons of Nova Scotia, 'Professional Standard Regarding Medical Assistance in Dying' (Professional Standard, 14 December 2018) <https://cpsns.ns.ca/wp-content/uploads/2018/12/ProfessionalStandard_MedicalAssistanceInDying_Dec2018.pdf>. In contrast, when introducing Bill C-7 Justice Minister David Lametti appeared to endorse a narrower standard, although his office later clarified via email that the definition had not changed: Joan Bryden, 'Lametti Sows Uncertainty over Meaning of Foreseeable Death in Assisted-Dying Bill', *National Newswatch* (online, 3 March 2020) <https://www.nationalnewswatch.com/2020/03/03/lametti-sows-uncertainty-over-meaning-of-foreseeable-death-in-assisted-dying-bill-2/#.Xl8BMkBuLvV>.

133 (2019) 158 WCB (2d) 246.

134 Baudouin J suspended her declaration of invalidity for six months, giving the government until 11 March 2020 to amend the legislation (should it wish to do so). The government obtained four extensions of this deadline and had until 26 March 2021 to pass Bill C-7. See Joan Bryden 'Feds Get Another Month to Reform Assisted-Dying Law as Bill Stalls in the Commons' *CBC News* (online, 25 February 2021) <https://www.cbc.ca/news/politics/assisted-death-maid-1.5928316>; *Truchon v Procureur Général du Canada* (2021) 171 WCB (2d) 65.

135 Bill C-7, 1st Sess, 43rd Parl, 2020 came into force on 17 March 2021 <https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent>.

136 Ibid s 1(1), repealing Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d).

137 Bill C-7, 1st Sess, 43rd Parl, 2020, s 1(2), inserting Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2.1).

138 Bill C-7, 1st Sess, 43rd Parl, 2020, s 1(7), inserting Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(3.2) ('final consent – waiver'), (3.5) ('advance consent – self-administration').

139 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(3)(a), (e), (f).

requirement is phrased more broadly in the Canadian *Criminal Code* than in the Australian models, which state that the person must have decision-making capacity for VAD specifically. In practice, however, capacity assessments are similar in Canada because it is understood that capacity in the health care context (and MAiD is understood to be a form of health care) is decision specific.

The test for capacity is framed somewhat differently depending on the Canadian province or territory, but all provincial/territorial statutes centre on understanding the proposed treatment and appreciating the consequences of the decision.[140] Several provinces state that a person is capable of making a treatment decision if they: 1) understand the information that is relevant to making the decision; and 2) appreciate the reasonably foreseeable consequences of both choosing the treatment and not choosing the treatment.[141] Other jurisdictions adopt additional,[142] or slightly different criteria.[143]

Canada is unique amongst the jurisdictions considered in this article in permitting two limited forms of advance request for MAiD, through the 'final consent waiver' and 'advance consent – self-administration'. The default position in Canada is that a person must have capacity when making the request for MAiD and later when giving express consent immediately before it is provided.[144] However, this latter requirement can be waived for persons in two circumstances. First, for individuals whose natural death is reasonably foreseeable who have lost capacity after they have been found eligible for MAiD ('final consent waiver').[145] The final consent waiver is only valid if the person satisfies all eligibility criteria and safeguards in the legislation, and they have entered into a written agreement with a doctor or nurse practitioner to provide MAiD on a specified day.[146] The doctor or nurse practitioner must also have informed the person about the risk of losing capacity prior to the day specified.[147] If the person loses capacity, MAiD can be provided on or before the specified day. Despite this final consent waiver, the doctor or nurse practitioner must not administer the substance if the person resists or refuses by words, sounds or gestures.[148] Second, for persons (whether natural

140 See, eg, *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 7; *Health Care Directives and Substitute Health Care Decision Makers Act*, SS 2015, c H-0.002, s 2(1); *Health Care Directives Act*, CCSM 1993, c H27, s 2; *Health Care Consent Act*, SO 1996, c 2, sch A s 4.

141 *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care Directives Act*, CCSM 1993, c H27, s 2; *Health Care Consent Act*, SO 1996, c 2, sch A s 4.

142 The Saskatchewan legislation adopts the two criteria used in Ontario, Alberta and Manitoba, and also requires that a person must be able to communicate a decision about the proposed treatment: *Health Care Directives and Substitute Health Care Decision Makers Act*, SS 2015, c H-0.002, s 2(1).

143 In British Columbia, the *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 7 requires the health care provider to assess whether the adult demonstrates that they understand information about the proposed treatment.

144 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(1)(b), (e), (3)(a), (h), (3.1)(a), (k).

145 Ibid s 241.2(3.2).

146 Ibid s 241.2(3.2)(a)(i), (ii).

147 Ibid s 241.2(3.2)(a)(iii).

148 Ibid s 241.2(3.2)(c). Note also that section 241.2(3.3) clarifies that 'involuntary words, sounds or gestures made in response to contact do not constitute a demonstration of refusal or resistance for the purposes of paragraph (3.2)(c)'.

death is reasonably foreseeable or not) who enter into a written arrangement with their provider for MAiD to be provided should self-administration fail. In such circumstances, if the person has lost capacity, the practitioner was present at the time of self-administration, and the person has not died within the specified period, the provider-administered MAiD is permitted.[149]

2 Grievous and Irremediable Medical Condition

The most complex aspect of the eligibility criteria for MAiD is the requirement that the person have a grievous and irremediable medical condition. Section 241.2(2) of the Canadian *Criminal Code* states that a person will have a grievous and irremediable medical condition if:[150]

> (a) they have a serious and incurable illness, disease or disability;
>
> (b) they are in an advanced state of irreversible decline in capability; and
>
> (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable.

(a) Serious and Incurable Illness, Disease or Disability

The first requirement for a 'grievous and irremediable medical condition' is that the person must have a serious and incurable illness, disease or disability.[151] A key issue is whether the medical condition must be incurable by any means, or whether it is limited to means that are acceptable to the patient.[152] Parliament did not define 'incurable' in the Canadian *Criminal Code*, nor did the government define it in its glossary to Bill C-14, and there is no case law on point. One interpretation is that 'incurable' should be viewed from an objective perspective because the government did not reference treatments acceptable to the person in the legislation,

149 Ibid s 241.2(3.5).

150 Ibid s 241.2(2).

151 Ibid s 241.2(2)(a).

152 Note that this aspect of the Canadian *Criminal Code* is one of the grounds for a 2016 constitutional challenge launched by Julia Lamb and the British Columbia Civil Liberties Association shortly after Bill C-14 was passed ('*Lamb*'). For background on the case see the interim ruling: *Lamb and British Columbia Civil Liberties Association v Canada (Attorney General)* (2017) 5 BCLR (6th) 175. See also Julia Lamb and British Columbia Civil Liberties Association, 'Notice of Civil Claim', Notice of Civil Claim in *Lamb and British Columbia Civil Liberties Association v Canada (Attorney General)*, Supreme Court of British Columbia, No S-165851, 27 June 2016 <http://eol.law.dal.ca/wp-content/uploads/2016/07/Lamb-v-Canada.pdf> ('*Lamb* Claim'). This litigation is now adjourned indefinitely. Lamb and the British Columbia Civil Liberties Association argued, in part, that the legislation is overbroad and violates the *Canada Act 1982* (UK) c 11, sch B pt I ('*Charter*') for those individuals who have a grievous and irremediable medical condition that is curable, but only by treatment options unacceptable to the patient. Note that the Attorney General in its Response to Civil Claim argued that the law does not infringe the *Charter* (or alternatively, if it does is a reasonable limit under section 1), but does not directly address the issue of treatments that are acceptable to the person: 'Response to Civil Claim', Response to Civil Claim in *Lamb and British Columbia Civil Liberties Association v Canada (Attorney General)*, Supreme Court of British Columbia, No S-165851, 27 July 2016 <https://bccla.org/wp-content/uploads/2016/08/2016-07-27-Response-to-Civil-Claim.pdf>.

as it did in relation to the criterion of suffering.[153] The other interpretation, now widely accepted by MAiD assessors and providers' lawyers based on *Carter*, and statements made in Parliament, is that incurable should be interpreted by reference to treatment that is acceptable to the person.[154]

Section 241.2(2.1) of the Canadian *Criminal Code* stipulates that a mental illness is not considered to be an illness, disease or disability under section 241.2(2)(a). This exclusion will be automatically repealed on 17 March 2023 by operation of a 'sunset clause' included in Bill C-7.[155]

(b) Advanced State of Irreversible Decline in Capability

A second requirement for a 'grievous and irremediable medical condition' is that the person must be 'in an advanced state of irreversible decline in capability'.[156] Again, there are no court decisions that consider the criterion,[157] and there are several aspects that are potentially unclear:[158] does the decline relate to cognitive as well as physical function; does it relate to stabilised as well as ongoing declines in capability? The latter uncertainty is significant, for example, to individuals who have had a precipitous decline in capability (such as from a previous traumatic injury) but who have stabilised. Downie and Chandler argue that such a person would satisfy the criterion,[159] although we note that this interpretation is somewhat broader than the wording in the glossary that accompanied Bill C-14. The glossary

153 In other words, if the government had intended for 'incurable' to mean only by means that a person found acceptable, the government would have specified this in the provision itself: see discussion in IRPP Report (n 131) 16–19.

154 Ibid. Downie and Chandler take the view that this criterion should be interpreted as 'in the professional opinion of the medical or nurse practitioner, the person cannot be cured by means acceptable to that person': at 17. In other words, a medical practitioner has concluded that there are no clinical options that would satisfy the individual's assessment of what is acceptable to them. Downie and Chandler raise a number of grounds for this including that such an approach is consistent with the position taken by the Supreme Court in *Carter*, and reflects the position taken by the Canadian Minister of Health and Senior Counsel for the Department of Justice when C-14 was before the Parliament: IRPP Report (n 131)18. The Minister of Health and Senior Counsel for the Department of Justice both stated when appearing before the Senate that 'incurable' should be interpreted as meaning by any means acceptable to the patient: Canada, *Parliamentary Debates*, Senate, 1 June 2016, 766 (Dr Jane Philpott) <https://sencanada.ca/Content/SEN/Chamber/421/Debates/pdf/041db_2016-06-01-e.pdf>; Evidence to Standing Senate Committee on Legal and Constitutional Affairs, Parliament of Canada, Ottawa, 6 June 2016, (Carole Morency, Joanne Klineberg) <www.parl.gc.ca/content/sen/committee/421/LCJC/52666-E.HTM>.

155 Bill C-7, 1st Sess, 43rd Parl, 2020, s 6 specifies that the exclusion of mental illness as a sole underlying condition will be automatically repealed two years after Bill C-7 received royal assent, ie on 17 March 2023. This grace period is intended to enable the government of Canada to commission an independent expert panel review of safeguards, protocols and guidance for MAiD and mental illness, and to allow the federal government and provincial and territorial governments enough time to develop these: Government of Canada, 'About Mental Illness and MAiD', *Medical Assistance in Dying* (Web Page, 30 June 2021) <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>.

156 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

157 Note that one of the arguments in *Lamb* (now adjourned indefinitely) was that the applicant is precluded from MAiD because she was not in an advanced state of irreversible decline, which she argued infringes her section 7 *Charter* right to life, liberty, and security of the person: *Lamb* Claim, Supreme Court of British Columbia, No S-165851, 27 June 2016.

158 See IRPP Report (n 131) 23–6.

159 Ibid.

states that a person must be '*in* an irreversible decline towards death', which could suggest that the decline needs to be ongoing.[160] There is also uncertainty around the standard against which the decline is judged. Downie and Chandler argue that assessment should be relative to the individual's prior capability rather than some objective standard.[161]

(c) Intolerable Suffering

The third requirement of 'grievous and irremediable medical condition' is that *either* the illness, disease, disability *or* state of decline must be causing enduring physical or psychological suffering that is intolerable to the person.[162] The legislation frames this as a subjective inquiry; the provision refers to suffering that cannot be relieved under conditions the person considers acceptable.

3 Voluntary Request

Like the Model Bill and the *WA Act*, the Canadian *Criminal Code* includes a voluntary request as an eligibility criterion for MAiD. Section 241.2(1)(d) specifically notes that the request must not be made as a result of external pressure. A number of safeguards listed in sections 241.2(3) and 241.2(3.1) are designed to promote and ensure the voluntariness of the request.[163]

4 Informed Consent

The final eligibility criterion is that the person must 'give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care' and, for persons whose natural death has not become reasonably foreseeable, have been 'informed of the means available to relieve their suffering, including, where appropriate, counselling services, mental health and disability support services, community services and palliative care'.[164] The legislation also requires that a person's request for MAiD must occur after they were informed by a medical or nurse practitioner that they have a grievous and irremediable medical condition.[165]

160 'Glossary', *Department of Justice* (Web Page, 7 July 2021) <https://www.justice.gc.ca/eng/cj-jp/ad-am/glos.html#archived> (emphasis added).

161 IRPP Report (n 131) 23–6.

162 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c).

163 The medical or nurse practitioner ('MAiD provider') must ensure the request is made in writing, signed and dated, and witnessed by one independent witness: ibid ss 241.2(3)(c), (3.1)(c). The MAiD provider must also inform the person they may withdraw their request at any time and in any manner: at ss 241.2(3)(d), (3.1)(d); and must give the person an opportunity to withdraw the request immediately before providing MAiD: at s 241(3.1)(k); except where the requirements for a final consent waiver or advance consent have been met under sections 241.2(3.2) or (3.5) respectively.

164 Ibid ss 241.2(1)(e), (3.1)(g).

165 Ibid s 241.2(3.1)(b)(ii).

The Canadian *Criminal Code* requirement for informed consent intersects with provincial and territorial health care consent legislation[166] and the common law.[167] For example, for an adult to provide consent, British Columbia legislation imposes obligations on the health care provider to give the adult specified information including information about the person's condition, the nature of the proposed health care, the associated risks and benefits and alternative courses of health care. The health care provider must also give the adult an opportunity to ask questions and receive answers about the proposed health care.[168]

The common law has established that a health care provider seeking informed consent 'generally, should answer any specific questions posed by the patient as to the risks involved and should, without being questioned, disclose to him the nature of the proposed operation, its gravity, any material risks and any special or unusual risks attendant upon the performance of the operation'.[169]

Across Canada, the various laws taken together require the individual requesting MAiD to have any questions they ask answered by their health care provider and to be informed: that they have a grievous and irremediable medical condition; of the nature of MAiD; of material, special or unusual risks, and potential benefits of MAiD and other available treatment options (including no treatment); and of available means to relieve suffering, including palliative care.

III COMPARATIVE ANALYSIS OF KEY ELIGIBILITY CRITERIA RELATING TO A PERSON'S MEDICAL CONDITION

The purpose of this part is to undertake a comparative analysis of the eligibility criteria relevant to a person's medical condition and their access to VAD across the five models outlined above. The key criteria in this analysis are outlined below in Table 1, and the comparative issues that can have a significant impact on a person's access to VAD are explored below.

166 Consent to health care is a matter of provincial/territorial jurisdiction. See, eg, *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 6; *Health Care Directives and Substitute Health Care Decision Makers Act*, SS 2015, c H-0.002, s 2(1); *Health Care Directives Act*, CCSM 1993, c H27, s 2; *Health Care Consent Act*, SO 1996, c 2, sch A s 4.

167 *Reibl v Hughes* [1980] 2 SCR 880. See College of Physicians and Surgeons of Alberta, 'Informed Consent for Adults' (Advice to the Profession, August 2019) <http://www.cpsa.ca/wp-content/uploads/2016/02/AP_Informed-Consent-for-Adults.pdf>; College of Physicians and Surgeons of Alberta, 'Informed Consent' (Standards of Practice, June 2016) <http://www.cpsa.ca/standardspractice/informed-consent/>. See also Louise Bélanger-Hardy, 'Informed Choice in Medical Care' in Joanna N Erdman, Vanessa Gruben and Erin Nelson (eds), *Canadian Health Law and Policy* (LexisNexis, 5th ed, 2017) 329.

168 *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 6.

169 *Hopp v Lepp* [1980] 2 SCR 192, 210.

Table 1 Comparative Table of Key Criteria Relevant to Medical Conditions and Eligibility for Access to VAD[170]

Capacity					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Nature of capacity[171]	decision-making capacity in relation to voluntary assisted dying	decision-making capacity in relation to voluntary assisted dying	decision-making capacity in relation to voluntary assisted dying	capable	capable of making decisions with respect to their health
Nature of medical condition[172]					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Prospect of cure	incurable	incurable	–	terminal disease, that is incurable and irreversible	incurable
Stage and nature of condition	advanced and progressive	advanced and progressive	advanced and progressive	–	serious; advanced state of irreversible decline in capability
Prospect and timing of death	will cause death and this is expected within weeks or months, not exceeding 6 months or 12 months for neuro-degenerative conditions	will cause death	will on balance of probabilities cause death within 6 months or 12 months for neuro-degenerative conditions	will, within reasonable medical judgment, produce death within 6 months	–

170 For ease of presentation, this table includes only the words in the various legislation and does not include a discussion of how particular concepts have been interpreted.

171 For the purpose of this article, the added complexity of whether capacity is assessed only at the time of a request for VAD, or also at the time of administration of VAD, is not separately considered.

172 Although some jurisdictions use more precise terminology, such as 'disease, illness or medical condition' (*Victorian Act 2017* (Vic) s 9(1)(d)), in this table the phrase 'medical condition' is employed for simplicity.

Specific statement about mental illness	mental illness alone is not eligible	–	mental illness alone is not eligible	ineligible if suffering from a psychiatric or psychological disorder or depression causing impaired judgment	mental illness is not an illness, disease or disability for the purpose of assessing the eligibility criteria
Suffering					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Nature and source of suffering	medical condition is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable	medical condition is causing intolerable and enduring suffering (subjective, includes suffering from treatment and can be physical, psychological and existential)	medical condition is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable	–	medical condition or state of decline causes the person enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable

A Prospect and Timing of Death

There are two key points in relation to the prospect and timing of death required under the VAD models. First, as noted in Table 1, the time expected to death varies. Some models specify a time limit: 6 months in Oregon,[173] or 6 or 12 months depending on the medical condition in Victoria and Western Australia.[174] In contrast, the Model Bill specifies no time limit or other temporal restriction on eligibility, but does require that a person has a condition that will cause death.[175] The broadest approach is the amended Canadian law, which does not require temporal proximity and in some cases permits access for those without an expected

173 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).
174 *Victorian Act 2017* (Vic) ss 9(1)(d)(iii), 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii).
175 White and Willmott, 'Model Bill' (n 21) 21 cl 9(e)(ii) simply states that the medical condition 'will cause death'.

death.[176] Although the operation in practice of these different legal approaches will be potentially qualified by interaction with other eligibility criteria, the criterion relating to prospect and timing of death plays a significant role in controlling access to VAD.

Second, there is also variability in wording about the level of certainty a doctor must have, or the 'standard of proof' that they must apply, in determining whether death will occur within that specified time. Formulations vary, with judgments about death to be made based on what is 'expected' (Victoria),[177] estimated to occur on 'the balance of probabilities' (Western Australia)[178] or assessed using 'reasonable medical judgment' (Oregon).[179] Of these three jurisdictions, perhaps most noteworthy is the Western Australian choice to use 'balance of probabilities'. This terminology was a considered departure from the Victorian drafting ('expected'), yet parliamentary debates suggest that the standard in Western Australia is not lower than under the *Victorian Act*.[180] Instead, the Western Australian government considered that the 'balance of probabilities' test was adopted because it is easily understood by clinicians and is a concept which 'provides the greatest clarity and most utility'.[181] All provide some discretion for doctors in determining prognosis, no doubt recognising the known difficulty of prognostication in relation to death. This was perhaps most explicitly recognised in the Canadian legislation between 2016 and 2021, which permitted a doctor to conclude that a person's death is reasonably foreseeable (an eligibility criterion at the time) 'without a prognosis necessarily having been made as to the specific length of time that they have remaining'.[182]

B Suffering

The models analysed also display significant variation in the level of suffering which must be experienced before a person is able to access VAD. There are three different thresholds of suffering across the five models of VAD. The first, the Oregon model, does not impose a suffering criterion (although the statute is worded to require a person to be 'suffering from a terminal disease').[183] Under the *Victorian Act* and *WA Act*, a person must be experiencing suffering, and this must not be able to 'be relieved in a manner that the person considers tolerable'.[184] The Canadian *Criminal Code* and the Model Bill contain the highest threshold, requiring that a

176 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2). Note though that whether a person's natural death has become reasonably foreseeable is relevant to which set of procedural safeguards must be followed before a person is eligible to access MAiD: at s 241.2 (3), (3.1).
177 *Victorian Act 2017* (Vic) s 9(1)(d)(iii).
178 *WA Act 2019* (WA) s 16(1)(c)(ii).
179 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).
180 Western Australia, *Parliamentary Debates*, Legislative Council, 26 Nov 2019, 9196 (Stephen Dawson).
181 Ibid.
182 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d), as repealed by Bill C-7, 1st Sess, 43rd Parl, 2020, s 1(1).
183 *Oregon Act*, Or Rev Stat § 127.805(1) (1994). Suffering here is used as meaning having a terminal illness.
184 *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii).

person be experiencing suffering that is 'intolerable' to them, is enduring, and (in Canada) that 'cannot be relieved under conditions that they consider acceptable'.[185]

Another key difference across models is the cause of the suffering. Under the *Victorian Act* and the *WA Act*, the terminal medical condition must be the cause of a person's suffering to be eligible for VAD.[186] The Model Bill additionally recognises that the treatment for that condition may also be considered in assessing a person's suffering.[187] The Canadian approach is different again, as either the person's 'illness, disease or disability' or their 'state of decline' (that is, their advanced state of irreversible decline in capability) can be the cause of their suffering.[188]

Despite these differences, in the four models where suffering is required, there are also a number of similarities. One is that suffering is assessed subjectively by the person seeking VAD in all models.[189] This may mean that the differences in the suffering thresholds described above are less significant in practice if the requisite suffering is to be determined subjectively. Another is that suffering is broadly understood to encompass not only physical pain, but also psychological and existential suffering.[190]

C Access to VAD and Mental Illness

The VAD models differ in their treatment of the issue of mental illness. Four jurisdictions specifically address the impact of mental illness on possible access to VAD. The *Victorian Act* and the *WA Act* specifically state that mental illness on its own will not be sufficient to render a person eligible for VAD.[191] However, a person with a mental illness who also suffers from another medical condition that otherwise meets the criteria is still capable of qualifying under these models. The Canadian *Criminal Code* states (until the sunset clause takes effect on 17 March 2023) that mental illness cannot be considered to be an illness, disease or disability for the purposes of assessing whether the patient has a serious and incurable illness, disease or disability. But, similar to the two Australian models, the Canadian law does not exclude access if mental illness is comorbid with another serious and incurable condition. The *Oregon Act* makes specific mention of mental illness, precluding access to VAD if a person is suffering from a psychological or psychiatric disorder or depression that causes impaired judgment. Once the person

185 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c); White and Willmott, 'Model Bill' (n 21) 21 cl 9(e)(iii).

186 *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii).

187 White and Willmott, 'Model Bill' (n 21) 21 cl 10(2)(b).

188 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c).

189 In Victoria and Western Australia, whether the suffering can be relieved in a manner that the person considers tolerable is subjectively assessed: *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii). Under the Model Bill and in Canada, it is the suffering itself that is subjectively assessed by a person to be intolerable (as well as the proposed methods of relief, in Canada): White and Willmott, 'Model Bill' (n 21) 21 cl 10(2)(a); Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c).

190 Canada includes 'physical or psychological suffering': Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c), whereas the Model Bill includes 'physical, psychological and existential suffering': White and Willmott, 'Model Bill' (n 21) 21 cl 10(2)(c).

191 *Victorian Act 2017* (Vic) s 9(2); *WA Act 2019* (WA) s 16(2).

has been clinically assessed and determined not to have impaired judgment,[192] the person may access VAD if they have a terminal illness. Only the Model Bill does not explicitly address mental illness. However, the way in which its other eligibility criteria are drawn makes it very unlikely that access only on the basis of mental illness would occur.[193]

D Impact of Refusing Potentially Life Sustaining Treatment

A refusal of potentially life sustaining treatment has relevance for two statutory criteria: an 'incurable' condition, and a condition that will 'cause death'. This issue is handled differently under the various models, and these differences are significant in terms of access to VAD. First, can a person be said to have an 'incurable' condition if they are refusing treatment that presents a reasonable prospect of a cure? The meaning of 'incurable' and the impact of treatment refusals is not explained in the legislation of the four jurisdictions which use this pivotal criterion.

In Victoria, extrinsic material states that whether a person's medical condition is incurable is a medical assessment based on available treatments and a person will not be eligible if they are refusing treatment for an otherwise curable condition.[194] The Model Bill uses the same language as the *Victorian Act* and would be interpreted in the same way. By contrast, in Canada, the practice appears to be that incurability is being determined having regard to treatments acceptable to the patient, although there are arguments that can be made to the contrary that treatment refusals should not be considered.[195] There is no available material to assist in the interpretation of this term in the *Oregon Act*.[196] Refusal of potentially life sustaining treatment is a scenario which is likely to occur in practice. It would be desirable for legislation to give clear guidance to doctors about whether patients can make their condition incurable, and become eligible for VAD, through treatment refusal.

The impact of refusals of potentially life sustaining treatment generally appears clearer in relation to the criterion of whether a medical condition will cause death, and within a certain period of time. In Victoria, extrinsic materials show that the requirement that a condition will cause death within 6 or 12 months will take account of the right to refuse treatments the person finds unacceptable.[197] Identical language is used in the *WA Act*, so that legislation is likely to be interpreted similarly. The Model Bill makes this explicit with a provision clarifying that whether a medical condition will cause death 'is to be determined by reference to available medical

192 *Oregon Act*, Or Rev Stat § 127.825 (1994).

193 This is because in general mental illnesses are not terminal conditions. The majority of mental illnesses are cyclical, and do not progress naturally towards death. Note, however, the consideration of potential eligibility for access to VAD for anorexia, given that it is a mental illness which may be said in extreme cases to cause death: see White et al, 'Who is Eligible for VAD?' (n 19).

194 Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3–4 cl 9. See discussion above at Part II(B)(2).

195 See discussion above at Part II(F)(2)(a).

196 See discussion above at Part II(E)(2).

197 Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3–4 cl 9.

treatment that is acceptable to the person'.[198] The *Oregon Act*, however, provides no guidance on this issue for courts or medical practitioners.

Significantly, in Western Australia, the government specifically chose not to include 'incurable' as a legislative criterion. This was because it was considered implicit in the criterion of a medical condition which is advanced, progressive and will cause death. It was also considered inappropriate to require a person to exhaust all treatment options when there is a long-established right to refuse treatment.[199] Although members of both Houses of Parliament sought to amend the VAD Bill (WA) to include 'incurable' as a criterion,[200] these amendments were rejected[201] and not included in the *WA Act*. Drawing on the analysis above, this means that in Western Australia, a person with a curable or treatable condition may be able to refuse treatment and become eligible to access VAD because they then (after treatment refusal) have a condition that will cause death. Examples given in parliamentary debates were an operable tumour[202] and gangrene which was curable with amputation.[203]

This is in contrast to the *Victorian Act* and the Model Bill where incurability in the eligibility criteria functions as a limit on when access to VAD may be possible. Under those models, a person with a curable condition (such as an operable tumour or gangrene) will not be eligible for VAD, even if the person refuses the suggested treatment for that condition, because their condition will not be medically assessed to be 'incurable'. Some Members of Parliament in Western Australia have expressed concern that omitting incurability widens the category of people who may have access to VAD in that State.[204]

IV IMPLICATIONS OF COMPARATIVE ANALYSIS FOR DESIGN OF VAD REGULATION

The above analysis has demonstrated some important similarities and differences across five models of VAD laws. The purpose of eligibility criteria is to

198 White and Willmott, 'Model Bill' (n 21) 21 cl 10(1).

199 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).

200 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6601 (Margaret Quirk); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9199 (Nick Goiran).

201 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6605; Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9202.

202 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Michael Nahan).

203 Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6603–4 (Margaret Quirk); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9199 (Nick Goiran).

204 See, eg, Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6602 (David Honey); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Michael Mischin).

draw lines determining who should be able to access VAD. Within the five models considered, when analysing the criteria as a whole, it is apparent that these lines are drawn in quite different places. Canada has the most permissive eligibility criteria in its MAiD law, especially since Bill C-7 removed the reasonable foreseeability criterion introduced in Bill C-14. At the other end of the spectrum, the *Victorian Act*, *WA Act* and *Oregon Act* are much more conservative.[205] This comparative analysis has important implications for the design of VAD regulatory systems more broadly. This section shifts beyond the specifics of these legal models and considers the wider questions they give rise to for policymakers and legislators proposing laws in this area.

A Challenge of Translating Policy Goals into Legislation

One implication is the long-standing policy challenge of using words in legislation to accurately reflect a stated policy intent. The translation of broader social objectives into concrete legal rules is a challenging exercise.[206] Problems can arise not only in the selection of words, but also their interpretation, both by the courts and by those at the coalface who are charged with implementing the law. An ideal law is precise and can be applied consistently in relation to a wide variety of situations to which the law is intended to apply.[207] But legal rules are 'inherently indeterminate', both because language is imprecise, and because they are subject to interpretation by others.[208]

Precision in wording can require compromises in terms of the congruence of the law with the policy goals underpinning it. An example of this is the imposition of a specified time limit to death in Victoria, Western Australia and Oregon.[209] An advantage of such an approach is it gives a concrete frame of reference for doctors and others to use when determining eligibility (we put aside for the moment difficulties of prognostication[210]). However, a precise time limit could be seen as an inadequate proxy for the wider policy intent: namely, identifying the cohort of people (those who are dying) for whom VAD should be made available. It can also

205 This finding resonates with claims made by the Victorian government at the time of the *Victorian Act 2017* (Vic) passing: see Andrews Media Release (n 32).

206 Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163, 168–70. See also White et al, 'Does the *VAD Act* (Vic) Reflect Its Stated Policy Goals?' (n 57).

207 Law Council of Australia, 'Rule of Law Principles' (Policy Statement, March 2011) <https://www.lawcouncil.asn.au/docs/f13561ed-cb39-e711-93fb-005056be13b5/1103-Policy-Statement-Rule-of-Law-Principles.pdf>.

208 Yeung (n 206) 169. See also Julia Black, *Rules and Regulators* (Clarendon Press, 1997).

209 In Victoria and Western Australia, a person must be suffering from a condition which is expected to cause death within 6 months, or 12 months if the condition is neurodegenerative: *Victorian Act 2017* (Vic) ss 9(1)(d)(iii), 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii). In Oregon, death must be anticipated within 6 months: *Oregon Act*, Or Rev Stat § 127.800(12) (1994). In contrast, the Canadian *Criminal Code* includes no such time limit.

210 Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311; Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337; James Downar et al, 'The "Surprise Question" for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-Analysis' (2017) 189(13) *Canadian Medical Association Journal* E484; Paul Glare et al, 'Predicting Survival in Patients with Advanced Disease' (2008) 44(8) *European Journal of Cancer* 1146, 1147.

operate arbitrarily, in that there may be very little to distinguish between a person who is expected to die within the specified time limit, and those with similar conditions whose prognosis is slightly longer. Rigidly applied, it also gives rise to injustices in some situations, such as where people are terminally ill and suffering, but are forced to continue to suffer until they are close enough to death to meet the eligibility time period.

An alternative is to use words that better reflect the policy intent but may be less precise. '[N]atural death' being 'reasonably foreseeable' was an example of such an approach in Canada.[211] Although this drafting technique avoids the pitfalls of arbitrary time limits, it greatly increases the uncertainty surrounding the class of person to whom the legislation applies, as the extensive debate that has occurred in Canada about this terminology demonstrates. Such imprecision is problematic for doctors and others making assessments about eligibility for VAD.[212] This uncertainty can only be definitively resolved in an individual case through court decision, which is a costly and slow process, and judicial consideration of legislative terms can still fail to provide useful guidance in practice for other cases. Such uncertainty could, however, potentially be reduced through the use of other regulatory tools, such as guidelines or policy, to supplement law and provide greater clarity.

B Operation of Eligibility Criteria Is Shaped by Wider VAD System

A second implication for VAD regulation is that the operation of eligibility criteria inevitably interacts with how the wider VAD system is designed. One illustration of this is the criterion of capacity. All models require that a person must have capacity at the point access to VAD is granted, and the concept of capacity is defined in broadly similar terms. However, differences in the way VAD is administered have significant effects on the timing of these capacity assessments, and thus on who may access VAD.

For Victoria, Western Australia and Oregon, capacity is required at the point of the final request for VAD. Where VAD occurs by self-administration, this means that capacity is last assessed when the person is approved to receive the VAD medication.[213] But this medication can be taken later, without medical or other supervision, and there is no testing of capacity at that point when the medication is actually taken. By contrast, where practitioner administration is authorised in Victoria and Western Australia, a person must have capacity at the time of

211 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d), as repealed by Bill C-7, 1st Sess, 43rd Parl, 2020, s 1(1).

212 Ministerial Advisory Panel on Voluntary Assisted Dying, Department of Health and Human Services (Vic), *Interim Report of the Ministerial Advisory Panel: Consultation Overview, Voluntary Assisted Dying Bill* (Report, April 2017) 21–3.

213 In terms of the final stage in the self-administration process where there is a legislative requirement to have capacity: in Victoria, this is the point at which the medical practitioner applies for a self-administration permit on behalf of a person: *Victorian Act 2017* (Vic) s 47(3)(a). In Western Australia, this is at the point of final request: *WA Act 2019* (WA) s 51(3)(f)(i). In Oregon, this is immediately prior to writing a prescription: *Oregon Act*, Or Rev Stat § 127.830 (1994). See also the definition of 'qualified patient': *Oregon Act*, Or Rev Stat § 127.800(11) (1994).

administering the medication,[214] because the last request is made at the same time as VAD is administered.

For Canada, the position is similar to the extent that capacity must be assessed both when making a request for MAiD, and, with two exceptions, immediately before it is provided;[215] this latter point being at the time of administering the medication for practitioner administration and when prescribing or providing the medication for self-administration. However, if a person's death is reasonably foreseeable, there is an exception to this requirement of capacity at the time of MAiD provision if the conditions for a final consent waiver are met.[216] Whether a person's natural death is reasonably foreseeable or not, there is also an exception to the requirement of capacity at the time of MAiD provision for provider-administered MAiD where self-administration has failed and the conditions for an 'advance consent' are met.[217] Under the Model Bill, capacity must be present during assessment and when VAD is provided.[218] VAD under this latter model, whether by self-administration or practitioner administration, is always medically supervised[219] and there is a final check of capacity at that point.[220] In short, although all models require a person to have capacity to request VAD, the overarching design of the VAD law results in this having different implications for those different models.

Another illustration is that there are sometimes fluid boundaries between whether a matter is stated to be a criterion of eligibility or a procedural step. It is possible conceptually for these parts of the legislation to be seen as distinct: one deals with the threshold question of access and the other relates to procedures that must be followed to receive access. However, these five models do reflect that some legislators have conceived certain aspects of their VAD law in different ways.

One example is the issue of 'informed consent'. This is stated to be part of the eligibility criteria in Canada, but not in the Australian models nor in Oregon. However, the need to provide information and ensure it is understood is an important part of the procedural steps outlined in these latter jurisdictions. Another example is that the requirement that a decision be made freely and voluntarily is a criterion of eligibility in the Model Bill, the *WA Act*, the Canadian *Criminal Code* and the *Oregon Act*, but in Victoria is tested at various points as a procedural issue. Thirdly, that the decision is enduring is a condition of eligibility in the Model Bill and the *WA Act*, but is tested through process in the other jurisdictions.

In practice, it may not be significant whether various issues are part of the threshold question of access or tested during various procedural steps. This may simply reflect a preference of legislators in terms of drafting or their understanding

214 *Victorian Act 2017* (Vic) ss 64(1)(b), 65(2)(a)(i); *WA Act 2019* (WA) s 59(5)(a).
215 *Canadian Criminal Code*, RSC 1985, c C-46, s 241.2(3)(a), referring to the eligibility criteria in s 241.2(1), including capacity in s 241.2(1)(b).
216 Ibid s 241.2(3.2) ('final consent – waiver').
217 Ibid s 241.2(3.5) ('advance consent – self-administration').
218 White and Willmott, 'Model Bill' (n 21) 23 cl 16, 25 cl 21, 28 cl 26(2), 30–2 cls 29(1)(a)(ii),29(2)(a)(iii), 30(1)(b), 32(2)(a).
219 Ibid 19–20 cl 6.
220 Ibid 31–3 cls 30(1)(b), 32(2)(a), 33(3).

of how conceptually these matters contribute to the VAD system as safeguards. However, this distinction could potentially be significant, so reflection on whether a safeguard is better conceived as an eligibility criterion or process matter is important. For example, if the enduring nature of a person's request is imputed on the basis of them requesting VAD at three points in the process, this is different from requiring an enduring decision as a formal part of eligibility. A person could be prevaricating regularly over time and be regarded as not having made an enduring and settled decision to seek VAD, yet still have three points in time at which they were requesting it.

A final point to note about the operation of eligibility criteria is that it is shaped not only by the *design* of the wider VAD system, but it is also affected by how the system *functions in practice*. Thus, while a particular person may meet the legal eligibility criteria for VAD, their access to VAD depends upon a system that facilitates that, including access to willing doctors.[221]

C Regulation Operates Holistically

A third design point to make is that a system of regulation operates holistically. This means that looking at a single aspect of the eligibility criteria without understanding its role in the wider framework can be misleading. That is, it is important to examine eligibility criteria cumulatively and in context. This is the intention of the legislators in constructing the criteria in this way and this has significant implications for who can access VAD. As described above, the Model Bill provides a good example of this: if the focus is restricted to the fact that the Bill does not impose a time limit until death, it may seem to be very broadly drafted. But when aggregated with the requirement for a medical condition that is incurable, advanced and progressive, the scope for access to VAD is considerably narrowed. This is not to make the case for wide or narrow criteria for access to VAD, but to argue for a holistic assessment of cumulative eligibility criteria to properly represent the intent and scope of a VAD law.[222]

Taking a holistic view is also an important consideration more generally when designing VAD regulation. While it may be politically attractive to add numerous safeguards to VAD legislation, including in the eligibility criteria, there is a risk of what we have called elsewhere 'policy drift by a thousand cuts' if the cumulative effect of these individual safeguards is not properly considered.[223] For example, it is possible that a series of provisions designed to make VAD legislation safe, when aggregated, can in fact make access to VAD cumbersome or even unworkable.

221 We thank an anonymous reviewer for this point.

222 This does not always happen: see, eg, comments of Archbishop Aspinall about the Model Bill (n 21) which wrongly suggest it would permit persons with dementia to access VAD in Jamie Walker, 'Euthanasia Law A Life of its Own', *The Australian* (online, 31 August 2019) <https://www.theaustralian.com.au/nation/euthanasia-law-a-life-of-its-own/news-story/86c0fdfa059b99893526f65f5a0e7987>.

223 White et al, 'Does the *VAD Act* (Vic) Reflect Its Stated Policy Goals?' (n 57) 451.

V CONCLUSION

The purpose of eligibility criteria is to determine who will and will not be permitted to access VAD. As such, they play an important role in determining the scope of VAD laws, and are (rightly) heavily debated in parliaments considering reform. This article has analysed the key eligibility criteria relevant to the medical condition of a person seeking access to VAD under five different legal models. Three of the models were Australian: the recently enacted legislation in Victoria and Western Australia, along with a Model Bill under consideration in Queensland. The remaining two VAD models analysed were from the common law jurisdictions of Oregon and Canada.

Comparative analysis is an established part of law reform processes[224] and so the evaluation undertaken above not only sheds light on how those laws should operate locally but also provides insights for other jurisdictions considering VAD reforms. Regulation permitting VAD remains relatively novel worldwide, so analysis of these individual models provides important insight for parliamentary committees, law reform bodies and parliamentarians. The article has also considered what global lessons might be learned from how these five models operate. The preceding section considered important implications for designing VAD regulation generally, such as how eligibility criteria intersect with other parts of the VAD laws and the importance of evaluating criteria holistically to understand properly their legal effect.

The analysis undertaken in this article also provides a platform for the next article in this series. Having explained and analysed the relevant legal criteria for accessing VAD in the five jurisdictions, the second article will consider how these criteria will apply to specific medical conditions. What medical conditions might meet the criteria for access to VAD, and at what point in an illness trajectory will access be possible? This is different from the more conceptual and legal analysis already undertaken, but is critically important for optimal law reform. If parliamentarians intend to grant or deny access to VAD for particular medical conditions, then concrete testing of proposed eligibility criteria in relation to those conditions is essential.

224 Mark Van Hoecke, 'Methodology of Comparative Legal Research' [2015] *Law and Method* 1.

Reference list

1. Thaddeus Pope, 'Medical Aid in Dying: Key Variations Among U.S.State Laws' (2020) 14(1) *Journal of Health Sciences and Life Sciences Law* 25.
2. Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1.
3. Ben White and Lindy Willmott,'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616.
4. Michael Koziol, 'Fresh bid to legalise assisted dying set to test NSW government', *Sydney Morning Herald* (online, 13 December 2020) <https://www.smh.com.au/politics/nsw/fresh-bid-to-legalise-assisted-dying-set-to-test-nsw-government-20201209-p56m2t.html>.
5. Ben P White et al, 'Who is Eligible for VAD? Nine Medical Conditions Assessed Against Five Legal Frameworks' (2022) (forthcoming).
6. Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law andHuman Dignity* 1.
7. Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) ('*Queensland Parliamentary Report*').
8. Legal and Social Issues Committee, Parliament of Victoria, *Inquiry Into End of Life Choices* (Final Report, 9 June 2016) 217–18.
9. Government of Victoria, Department of Health and Human Services, Ministerial Advisory Panel on Voluntary Assisted Dying, *Final Report* (Report, 31 July 2017).
10. Stephen Kirchner, Sean Speer and Jason Clemens, Fraser Institute, *Policy Reforms in Australia and What They Mean for Canada* (Report, December 2013) <https://ssrn.com/abstract=2392622>.
11. James Allsop, 'Some Reflections on the Sources of Our Law' (Conference Paper,
12. Department of Health and Human Services, Government of Victoria, *Voluntary Assisted Dying: Guidance forHealth Practitioners* (Clinical Guideline, July 2019) 34 <https://www2.health.vic.gov.au/hospitals-and-health- services/patient-care/end-of-life-care/voluntary-assisted-dying/coordinating-consulting-medical-practitioner-information>.
13. Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.
14. Queensland Law Reform Commission, *Queensland's Laws Relating to Voluntary Assisted Dying* (Terms of Reference, 2020) <https://www.qlrc.qld.gov.au/data/assets/pdf_file/0004/651379/vad-tor.pdf>).
15. Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017).
16. Ben P White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.
17. John Dyson Heydon, *Cross on Evidence* (LexisNexis Butterworths, 11th ed, 2017) 395.
18. James Allsop et al, 'Are You Sure?' (2019) 47(2) *Australian Bar Review* 124.
19. Patrick M Curran Jr, 'Regulating Death: Oregon's Death with Dignity Act and the Legalization of Physician-Assisted Suicide' (1998) 86(3) *Georgetown Law Journal* 725.
20. Brian Boyle, 'The Oregon Death with Dignity Act: A Successful Model or a Legal Anomaly Vulnerable to Attack' (2004) 40(5) *Houston Law Review* 1387.
21. Raphael Cohen-Almagor and Monica G. Hartman, 'The Oregon Death with Dignity Act:Review and Proposals for Improvement' (2001) 27(2) *Journal of Legislation* 269.
22. Alan Meisel, Kathy Cerminara and Thaddeus Pope, *The Right to Die: The Law of End-of-Life Decisionmaking* (Wolters Kluwers, 3rd ed, 2016) 12.
23. Linda Ganzini, 'Legalised Physician-Assisted Death in Oregon' (2016) 16(1) *QUT Law Review* 76.
24. IG Finlay and R George, 'Legal Physician-Assisted Suicide in Oregon and The Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups—Another Perspective on Oregon's Data' (2011) 37(3) *Journal of Medical Ethics* 171.

25. Task Force to Improve the Care of Terminally-Ill Oregonians, Patrick Dunn and Bonnie Reagan (eds), *The Oregon Death With Dignity Act: A Guidebook for Health Care Professionals* (Centre for Ethics in Health Care,Oregon Health and Science University, 2007) Guideline 15.10 <https://www.wsha.org/wp- content/uploads/Death-with-Dignity_Death-with-dignity-guidebook.pdf>.
26. Anita Hannig, 'Author(iz)ing Death: Medical Aid-in-Dying and the Morality of Suicide' (2019) 34(1) *Cultural Anthropology* 53.
27. Herbert Hendin and Kathleen Foley, 'Physician-Assisted Suicide in Oregon: A Medical Perspective'(2008) 106(8) *Michigan Law Review* 1613.
28. James Werth Jr and Howard Wineberg, 'A Critical Analysis of Criticisms of the Oregon Death With Dignity Act' (2004) 29(1) *Death Studies* 1.
29. Michaela Okninski, 'Commentary on Undue Influence Provisions under Oregon's Death with Dignity Act and California's End of Life Option Act' (2017) 25(1) *Journal of Law and Medicine* 77.
30. David Orentlicher, Thaddeus MPope and Ben A Rich, 'Clinical Criteria for Physician Assisted Aid in Dying' (2016) 19(3) *Journal of Palliative Medicine* 259.
31. Herbert Hendin, Kathleen Foley and Margot White, 'Physician-Assisted Suicide: Reflections on Oregon's First Case' (1998) 14(3) *Issues in Law & Medicine* 243.
32. Kathleen Foley and Herbert Hendin, 'Physician Assisted Suicide in Oregon: A Medical Perspective' (2008) 24(2) *Issues in Law and Medicine* 131.
33. Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16(1) *QUT Law Review* 84.
34. Christopher Harty et al, 'Oral Medical Assistance in Dying (MAiD): Informing Practice to Enhance UtilizationIn Canada' (2019) 66(9) *Canadian Journal of Anaesthesia* 1106.
35. Jocelyn Downie and Jennifer A Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (IRPP Report, March 2018) <https://irpp.org/research-studies/interpreting-canadas-medical-assistance-in-dying- maid-legislation/>.
36. Jocelyn Downie and Kate Scallion, 'Foreseeably Unclear: The Meaning of the 'Reasonably Foreseeable' Criterion for Access to Medical Assistance in Dying in Canada' (2018) 41(1) *Dalhousie Law Journal* 23.
37. James Downar and Louise Hugo Francescutti, 'Medical Assistance in Dying: Time for Physicians to Step Up and Protect Themselves and Patients' (2017) 189(25) *Canadian Medical Association Journal* E849.
38. College of Physicians and Surgeons of Nova Scotia, *Professional Standard Regarding Medical Assistance in Dying* (Professional Standard, 14 December 2018) <https://cpsns.ns.ca/wp-content/uploads/2018/12/ProfessionalStandard_MedicalAssistanceInDying_Dec2018.pdf>.
39. Joan Bryden, 'Lametti Sows Uncertainty Over Meaning of Foreseeable Death in Assisted-Dying Bill', *National Newswatch* (online, 3 March 2020) <https://www.nationalnewswatch.com/2020/03/03/lametti-sows-uncertainty-over-meaning-of-foreseeable- death-in-assisted-dying-bill-2/#.Xl8BMkBuLvV>.
40. College of Physicians and Surgeons of Alberta, *Informed Consent forAdults* (Advice to the Profession, August 2019) <http://www.cpsa.ca/wp-content/uploads/2016/02/AP_Informed-Consent-for-Adults.pdf>.
41. College of Physicians and Surgeons of Alberta, *Informed Consent* (Standard of Practice, June 2016) <http://www.cpsa.ca/standardspractice/informed-consent/>.
42. Louise Belanger-Hardy, 'Informed Choice in Medical Care' in Joanna Erdman, Vanessa Gruben and Erin Nelson (eds), *Canadian Health Law andPolicy* (LexisNexis, 5th ed, 2017).
43. Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *Kings Law Journal* 163.
44. Law Council of Australia, *Rule of Law Principles* (Policy Statement, March 2011 <https://www.lawcouncil.asn.au/lawcouncil/images/LCA-PDF/a-z docs/PolicyStatementRuleofLaw.pdf>.
45. Julia Black, *Rules and Regulators* (Clarendon Press, 1997).
46. Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311.
47. Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337.
48. James Downar et al,'The "Surprise Question" for Predicting Death in Seriously Ill

Patients: A Systematic Review and Meta-Analysis'(2017) 189(13) *Canadian Medical Association Journal* E484.
49. Paul Glare et al, 'Predicting Survival in Patients With Advanced Disease' (2008) 44(8) *European Journal of Cancer* 1146.
50. Government of Victoria, Department of Health and Human Services, Ministerial Advisory Panel on Voluntary Assisted Dying, *Interim Report of the Ministerial Advisory Panel: Consultation Overview, VoluntaryAssisted Dying Bill* (Interim Report, April 2017) 21.
51. Jamie Walker, 'Euthanasia Law A Life of its Own', *The Australian* (online, 31 August 2019).
52. M van Hoecke, 'Methodology of Comparative Legal Research' (2015) *Law & Method* 1.

Australian Centre for Health Law Research

Voluntary assisted dying research: a policy briefing

This briefing summarises research about voluntary assisted dying (VAD) conducted by Professors Ben White and Lindy Willmott (with colleagues).

1 Australia should have VAD laws: they are ethical and VAD can be safely regulated

» There is a strong ethical case for allowing a limited cohort of patients, who are already dying, to choose VAD.

» Reliable evidence about VAD systems internationally and now in Australia shows that VAD can be safely regulated.

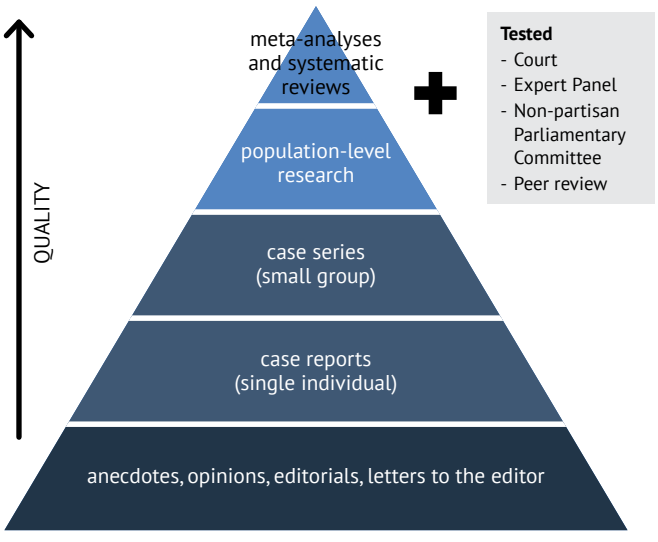
» Politically, legalising VAD has been challenging. Only narrow and conservative VAD models have passed in Australia.

2 VAD laws must be evidence-based and consistent with intended policy goals

» Law reform must be based on reliable evidence (see the "reliability pyramid").

» VAD laws must be designed to meet their intended policy goals.

Higher up pyramid + tested = greater reliability



3 There is now a broad "Australian VAD model" but each jurisdiction should pass a law most appropriate for its circumstances

» Although based on the same model, Victoria, Western Australia, Tasmania and South Australia have all taken slightly different approaches to regulating VAD.

» Jurisdictions should learn from how existing laws work in practice and design a law that is most appropriate for its circumstances (e.g. unique geography and population distribution).

4 Designing VAD laws requires seeing how the entire legal framework operates

» Evaluating a VAD law must be based on how it will work as a whole, and not by considering individual provisions in isolation.

» For example, numerous eligibility criteria for accessing VAD work together in these laws. Concern about one criterion when considered in isolation may resolve if all criteria are considered as a whole.

» The process of designing VAD laws should include testing how eligibility criteria affect who can access VAD and for what medical conditions.

5 "Piling on" ad hoc safeguards to already sound VAD laws does not make laws safer and can make them worse

» Ad hoc safeguards have been added during parliamentary processes to already sound proposals for VAD laws.

» This led to inconsistency and incoherence in those laws without improving patient or community safety.

6 VAD systems must be workable so eligible patients can access VAD

» The complex Victorian VAD law and system make patient access to VAD challenging.

» Key problems include:

- doctors are not allowed to raise the topic of VAD with patients
- the need to obtain a government permit to access VAD, and
- the complexity of the administrative process when applying for VAD.

7 The Commonwealth Criminal Code must be changed: it is an unjust barrier for patients seeking VAD and their doctors

» The Code makes illegal using a "carriage service" (e.g. email, telephone, fax, telehealth) in relation to "suicide". This creates risk for doctors and others who are otherwise acting legally under State VAD systems.

» This means some steps in the VAD process must be done face-to-face. This is causing hardship and delay for patients and doctors.

» For constitutional law reasons, States cannot resolve this issue.

» The Commonwealth Government should amend this law so it will not apply to lawful VAD systems.

8 Institutions should not have power to prevent their patients or permanent residents from accessing VAD

» There is some limited evidence that institutions are blocking access to VAD in Victoria. Some institutions in other States have also indicated they will block access.

» Legislation should permit an institution to not participate but must ensure eligible patients and permanent residents can still access VAD.

9 Effective implementation of VAD is challenging but very important

» How a VAD system operates depends not only on the law, but also system design, including factors such as IT, navigation and support services.

» Sufficient time and resources are needed to effectively implement VAD laws. And once implemented, VAD systems should be kept under constant review.

» VAD laws are complex so implementation should aim to make the patient, family and doctor experience as smooth and simple as possible.

» Effective training for practitioners involved in VAD (and others) is critical as is a user-friendly IT system.

A compilation of the 37 research papers this policy briefing is based on is available here:
https://research.qut.edu.au/voluntary-assisted-dying-regulation/other-resources

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Reference list

1. Voluntary assisted dying research: a policy brief
2. Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) Griffith Journal of Law and Human Dignity 1.
3. Lindy Willmott and Ben White, 'Assisted dying in Australia: A Values-based Model for Reform' in Kerry Petersen and Ian Freckelton (eds), Tensions and traumas in health law (The Federation Press, Australia,2017) ch 26.
4. Bob Douglas, Lindy Willmott and Ben White, The right to choose an assisted death: Time for legislation? (Report, 2013).
5. Ben White and Lindy Willmott, 'How should Australia regulate voluntary euthanasia and assisted suicide?' (2012) 20(2) Journal of Law and Medicine 410.
6. Ben White and Lindy Willmott, 'Evidence-based law making on voluntary assisted dying' (2020) 44 Australian Health Review 544.
7. Ben White, Lindy Willmott, Jocelyn Downie, Andrew Geddis and Colin Gavaghan, 'Assisted dying and evidence-based law-making: a critical analysis of an article's role in New Zealand's referendum' (2020) 133(1520) New Zealand Medical Journal 83.
8. Ben White and Lindy Willmott, 'Future of assisted dying reform in Australia' (2018) 42 Australian Health Review 616.
9. Andrew McGee, Kelly Purser, Christopher Stackpoole, Ben White, Lindy Willmott and Juliet Davis, 'Informing the euthanasia debate: Perceptions of Australian politicians' (2018) 41(4) University of New South Wales Law Journal 1368.
10. Lindy Willmott, Ben White, Christopher Stackpoole, Kelly Purser and Andrew McGee, '(Failed) voluntary euthanasia law reform in Australia: Two decades of trends, models and politics' (2016) 39(1) University of New South Wales Law Journal 1.
11. Neera Bhatia, Ben White and Luc Deliens, 'How should Australia respond to media-publicised developments on euthanasia in Belgium?' (2016) 23(4) Journal of Law and Medicine 835.
12. Lindy Willmott and Ben White, 'Private thoughts of public representatives: Assisted death, voluntary euthanasia and politicians' (2003) 11(1) Journal of Law and Medicine 77.
13. Lindy Willmott, Ben White, Marcus Sellars and Patsy Yates, 'Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study' (2021) Medical Journal of Australia (early online).
14. Ben White, Lindy Willmott, Marcus Sellars and Patsy Yates, 'Prospective oversight and approval of assisted dying cases in Victoria, Australia: a qualitative study of doctors' perspectives' (2021) BMJ Supportive and Palliative Care (early online).
15. Jodhi Rutherford, Lindy Willmott and Ben White, 'What the Doctor Would Prescribe: Physician Experiences of Providing Voluntary Assisted Dying in Australia' (2021) Omega – Journal of Death and Dying (early online).
16. Rosalind McDougall, Ben White, Danielle Ko, Louise Keogh and Lindy Willmott, 'Junior doctors and conscientious objection to voluntary assisted dying: ethical complexity in practice' (2021) Journal of Medical Ethics (early online).
17. Lindy Willmott, Ben White, Danielle Ko, James Downar and Luc Deliens, 'Restricting conversations about voluntary assisted dying: implications for clinical practice' (2020) 10(1) BMJ Supportive and Palliative Care 105.
18. Carmelle Peisah, Linda Sheahan and Ben White, 'Biggest decision of them all – death and assisted dying: capacity assessments and undue influence screening' (2019) 49(6) Internal Medicine Journal 792.

19. Ben White, Lindy Willmott, Katrine Del Villar, Jayne Hewitt, Eliana Close, Laura Ley Greaves, James Cameron, Rebecca Meehan and Jocelyn Downie, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) University of New South Wales Law Journal (forthcoming).
20. Ben White, Eliana Close, Lindy Willmott, Katrine Del Villar, Jocelyn Downie, James Cameron, Jayne Hewitt, Rebecca Meehan and Laura Ley Greaves, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) University of New South Wales Law Journal (forthcoming).
21. Lindy Willmott, Katrine Del Villar and Ben White, 'Voluntary assisted dying in Victoria, Australia: A values-based critique' in Sue Westwood (ed), Regulating the End of Life: Death Rights (Routledge, 2021) ch 4.
22. Lindy Willmott, Ben White and Katrine Del Villar, 'Voluntary Assisted Dying: Human Rights Implications for Australia' in Paula Gerber and Melissa Castan (eds), Contemporary Perspectives on Human Rights Law in Australia (Thomson Reuters, 2021) vol 2, ch 11.
23. Ben White, Lindy Willmott, Eliana Close and Jocelyn Downie, 'Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia' (2021) No 3 University of New South Wales Law Journal Forum 1.
24. Ben White, Katrine Del Villar, Eliana Close and Lindy Willmott, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) University of New South Wales Law Journal 417.
25. Katrine Del Villar, Eliana Close, Rachel Hews, Lindy Willmott and Ben White, 'Voluntary assisted dying and the legality of using a telephone or internet service: The impact of Commonwealth 'Carriage Service' offences' (2021) Monash University Law Review (forthcoming).
26. Kelly Purser, Lindy Willmott, Ben White, Eliana Close and Tina Cockburn, 'End of Life Decision-Making, Advance Care Planning and Estate Planning During a Pandemic' in Belinda Bennett and Ian Freckelton (eds), Pandemics, Public Health Emergencies and Government Powers: Perspectives on Australian Law (The Federation Press, 2021) ch 21.
27. Katrine Del Villar, Lindy Willmott and Ben White, 'Suicides, Assisted Suicides and 'Mercy Killings': Would Voluntary Assisted Dying Prevent these 'Bad Deaths'?' (2021) 46(2) Monash University Law Review (forthcoming).
28. Katrine Del Villar, Lindy Willmott and Ben White, 'Assisted Suicides and 'Mercy Killings': Voluntary Requests, or Vulnerable Adults? A Critique of Criminal Law and Sentencing' (2021) University of New South Wales Law Journal (forthcoming).
29. Ben White and Jocelyn Downie, 'Prosecutorial guidelines for voluntary euthanasia and assisted suicide: Autonomy, public confidence and high quality decision-making' (2012) 36(2) Melbourne University Law Review 656.
30. Jocelyn Downie and Ben White, 'Prosecutorial Discretion in Assisted Dying in Canada: A Proposal for Charging Guidelines' (2012) 6(2) McGill Journal of Law and Health 113.
31. Ben White, Lindy Willmott, Eliana Close, Jayne Hewitt, Rebecca Meehan, Laura Ley Greaves, Malcolm Parker and Patsy Yates, 'Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration' (2021) 36(3) Journal of Palliative Care 162.

WHO IS ELIGIBLE FOR VOLUNTARY ASSISTED DYING? NINE MEDICAL CONDITIONS ASSESSED AGAINST FIVE LEGAL FRAMEWORKS

BEN P WHITE, LINDY WILLMOTT, KATRINE DEL VILLAR, JAYNE HEWITT, ELIANA CLOSE, LAURA LEY GREAVES, JAMES CAMERON, REBECCA MEEHAN AND JOCELYN DOWNIE*

Eligibility criteria in voluntary assisted dying legislation determine access to assistance to die. This article undertakes the practical exercise of analysing whether each of the following nine medical conditions can provide an individual with access to voluntary assisted dying: cancer, motor neurone disease, chronic obstructive pulmonary disease, chronic kidney disease, Alzheimer's disease, anorexia, frailty, spinal cord injury and Huntington's disease. This analysis occurs across five legal frameworks: Victoria, Western Australia, a model Bill in Australia, Oregon and Canada. The article argues that it is critical to evaluate voluntary assisted dying legislation in relation to key medical conditions to determine the law's boundaries and operation. A key finding is that some frameworks tended to grant the same access to voluntary assisted dying, despite having different eligibility criteria. The article concludes with broader regulatory insights for designing voluntary assisted dying frameworks both for jurisdictions considering reform and those reviewing existing legislation.

I INTRODUCTION

A key challenge for regulators designing a voluntary assisted dying ('VAD') system is to determine who has access to VAD and in what circumstances. The primary mechanism to control access is the eligibility criteria in VAD legislation. In the first article in this two-part series,[1] we undertook a critical and comparative

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analysis of eligibility criteria in five VAD frameworks. The Australian frameworks considered were: the *Voluntary Assisted Dying Act 2017* (Vic) ('*Victorian Act*'); the *Voluntary Assisted Dying Act 2019* (WA) ('*WA Act*'); and a model Voluntary Assisted Dying Bill 2019 ('Model Bill')[2] drafted for consideration by other Australian states and recommended by the Queensland Parliamentary Inquiry considering VAD as the proposed basis for reform.[3] The international models were Oregon's *Death with Dignity Act 1994* ('*Oregon Act*')[4] and Canada's *Criminal Code* ('Canadian *Criminal Code*').[5] A comparative analysis of these criteria across the five selected regimes

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We disclose that Ben White and Lindy Willmott were engaged by the Victorian, Western Australian and Queensland Governments to design and provide the legislatively mandated training for doctors involved in voluntary assisted dying. Jayne Hewitt was the project manager for the Victorian training project and Rebecca Meehan, Laura Ley Greaves and Eliana Close were employed on the project. Eliana Close and Katrine Del Villar were also employed on the Western Australian and Queensland training projects. James Cameron was a Senior Legal Policy Officer at the Department of Health and Human Services (Victoria) and developed and implemented the *Voluntary Assisted Dying Act 2017* (Vic). Rebecca Meehan is an employee of Queensland Parliament, but this article only represents her views. Jocelyn Downie was a member of the Royal Society of Canada Expert Panel on End-of-Life Decision-Making, a member of the plaintiffs' legal team in *Carter v Canada (Attorney General)* [2015] 1 SCR 331, a member of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. Ben White is a recipient of an Australian Research Council Future Fellowship (project number FT190100410: Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying) funded by the Australian Government. The authors gratefully acknowledge the research assistance of Emily Bartels.

1 Ben P White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663 ('Comparative and Critical Analysis of Key Eligibility Criteria for VAD').

2 The Model Bill was drafted by two of the authors: Ben White and Lindy Willmott, '*Voluntary Assisted Dying Bill 2019'* (Model Bill, Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology, April 2019) <*https://eprints.qut.edu.au/128753/9/128753.pdf*>. The Model Bill was subsequently published as *Ben White and Lindy Willmott*, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1 ('Model Bill').

3 Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) 105, 'Recommendation 1' ('*Queensland Parliamentary Report*'). After this article was submitted for publication, voluntary assisted dying ('VAD') laws were enacted in Queensland, as well as in Tasmania and South Australia: *Voluntary Assisted Dying Act 2021* (Qld); *End-of-Life-Choices (Voluntary Assisted Dying) Act 2021* (Tas); *Voluntary Assisted Dying Act 2021* (SA). In New South Wales, the Voluntary Assisted Dying Bill 2021 (NSW) has passed the Legislative Assembly and will be considered by the Legislative Council in 2022.

4 *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) ('*Oregon Act*').

5 *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.4 ('Canadian *Criminal Code*'). Until recently, the Canadian *Criminal Code* prohibited all forms of assisted dying. In 2015, the blanket prohibition was found to violate the Canadian *Charter of Rights and Freedoms* ('*Charter*') and was struck down by the Supreme Court of Canada in *Carter v Canada (Attorney General)* [2015] 1 SCR 331 ('*Carter*'). In 2016,

demonstrated many similarities but also significant differences in who would be eligible to access VAD. The article concluded with implications of these analyses from a regulatory perspective for designing VAD legislation.

This second article addresses more practical implications. Drawing on the earlier legal analysis, it considers the *application* of the eligibility criteria from those five frameworks to nine medical conditions. It considers whether a person with any of those particular medical conditions may be eligible for VAD under the frameworks and, if so, at what point in their condition's trajectory. The concrete application of these eligibility criteria to medical conditions is critical to determine a VAD law's boundaries in practice. As this article demonstrates, changes in framing of eligibility criteria in the different jurisdictions can affect access to VAD, and at what stage in a person's medical condition access might be possible.

The nine medical conditions considered were: cancer (specifically colorectal cancer),[6] motor neurone disease ('MND'), chronic obstructive pulmonary disease ('COPD'), chronic kidney disease ('CKD'), dementia (specifically Alzheimer's disease),[7] anorexia, frailty, spinal cord injury ('SCI') and Huntington's disease. These conditions were chosen to illustrate how various eligibility criteria would apply to a diverse range of conditions. It was not feasible to examine all possible medical conditions, so our starting point was the typical conditions for which VAD is sought in Victoria, Oregon, and Canada (the three jurisdictions considered where data concerning VAD is available).[8] Data from Oregon and Canada on deaths due to VAD demonstrate that the three most common underlying conditions are

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the federal Parliament passed legislation (Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, 1st Sess, 42nd Parl, 2016 ('Bill C-14')) to amend the Canadian *Criminal Code* to make it consistent with the *Charter* and provide a regulatory framework for medical assistance in dying ('MAiD'). In 2019, a Quebec court found that Bill C-14's 'reasonably foreseeable' eligibility criterion violated the *Charter* and struck it down: *Truchon v Procureur Général du Canada* [2019] QCCS 3792 ('*Truchon*'). In 2021, the Canadian *Criminal Code* was further amended through Bill C-7, *An Act to Amend the Criminal Code (Medical Assistance in Dying)*, 2nd Sess, 43rd Parl, 2021 (as passed by the House of Commons 17 March 2021) ('Bill C-7'). Amendments of particular relevance for this article include: removing the original eligibility criterion 'natural death has become reasonably foreseeable': see Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d), as enacted; adding a two year blanket exclusion of access for persons with mental illness as their sole underlying medical condition (in force until 17 March 2023): Bill C-7, 2nd Sess, 43rd Parl, 2021, cls 1(2), 1(2.1) and 6 (as passed by the House of Commons 17 March 2021); and permitting VAD to be provided to someone after they have lost decision-making capacity if, before losing capacity but after having been found to be eligible for VAD and after their death has become reasonably foreseeable, they came to a written arrangement with their VAD provider to provide VAD after they lose decision-making capacity ('final consent waiver'): Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(3.2); Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 1(3.2) (as passed by the House of Commons 17 March 2021).

6 To facilitate detailed engagement with the VAD eligibility criteria, it was necessary to select one particular kind of cancer, given the variation in nature and trajectory of different kinds of cancer.

7 As was the case for cancer, it was necessary to consider one particular type of dementia to facilitate detailed engagement with the VAD eligibility criteria.

8 The *Voluntary Assisted Dying Act 2019* (WA) ('*WA Act*') commenced on 1 July 2021, so no data is currently available. The Model Bill (n 2) is not operational.

cancer,[9] neurological conditions (including MND)[10] and respiratory conditions (such as COPD).[11] There is only very limited publicly-reported data on VAD deaths in Victoria (due to privacy concerns), but those which are reported are consistent with the two international jurisdictions: cancer (78%), neurodegenerative diseases (15%) and 'other' diseases (7%), with listed examples of these other diseases including respiratory conditions such as COPD.[12] Anecdotal reports about the Victorian system also suggest that cancer, neurological disease and respiratory conditions are the most prevalent conditions.[13] However, considering only conditions for which VAD is commonly sought would not explore the potential boundaries of the legislation for other conditions and would be a self-limiting approach. Therefore, we also examined conditions for which people were accessing VAD in more permissive regimes such as the Netherlands, Belgium[14] and Canada.[15] We also included medical conditions discussed in the VAD literature,[16]

9 In Oregon in 2019, 68.1% of deaths due to VAD involved people with cancer: Oregon Health Authority, *Oregon Death with Dignity Act 2019 Data Summary* (Report, 25 February 2020) 6, 10–11 ('*Oregon Data Summary*'). In Canada in 2018, the figure was 67.2%: Health Canada, *First Annual Report on Medical Assistance in Dying in Canada 2019* (Report, July 2020) 22 ('*Canadian First Annual Report*').

10 In Oregon in 2019, neurological disease accounted for 13.8% of VAD deaths, with 10.1% from amyotrophic lateral sclerosis, a form of Motor Neurone Disease ('MND'), alone: *Oregon Data Summary* (n 9) 10–11. In Canada in 2019, 10.4% of VAD deaths involved people with neurological conditions: *Canadian First Annual Report* (n 9) 22.

11 In Oregon in 2019, 7.4% of VAD deaths involved people with respiratory disease: *Oregon Data Summary* (n 9) 10–11. Canada's statistics indicate 10.8% of VAD deaths involved respiratory conditions: *Canadian First Annual Report* (n 9) 22.

12 Voluntary Assisted Dying Review Board (Vic), *Report of Operations: January to June 2020* (Report, August 2020) 10. This report contains very limited data concerning the medical condition of people accessing VAD. In addition to the above data, the only other significant information provided is a break-down of cancer data into the four most common types of cancer for which VAD deaths occurred (but not for colorectal cancer which is considered later). As a result, the Voluntary Assisted Dying Review Board (Vic)'s VAD data is not discussed further.

13 An oncologist involved in numerous VAD applications estimates at least 70% of cases of VAD in Victoria involve people with cancer: Cameron McLaren, 'An Update on VAD: (Almost) A Year in Review', *Dying with Dignity Victoria* (Web Page, 16 June 2020) 3 < https://www.dwdv.org.au/wp-content/uploads/2020/07/One_Year_of_VAD-Dr_Cameron_McLaren.pdf>. Another Victorian general practitioner who has provided VAD states that after one year in operation, '[c]ancer has been the most common reason, then neurological disorders like motor neurone disease, with some cardiovascular and respiratory diseases': Nick Carr, 'Choosing When to Go: What the Nation Can Learn from Victoria's Embrace of Voluntary Assisted Dying', *Crikey* (online, 18 June 2020) <https://www.crikey.com.au/2020/06/18/voluntary-assisted-dying-laws-one-year-on/>. One family's story confirms at least one Victorian with MND died from VAD in the first six months that the *Voluntary Assisted Dying Act 2017* (Vic) ('*Victorian Act*') was operational: Bridget Rollason and Mary Gearin, 'More than 130 Victorians Apply to End Their Lives in First Six Months of State's Assisted Dying Laws', *ABC News* (online, 19 February 2020) <https://www.abc.net.au/news/2020-02-19/assisted-dying-laws-victoria-used-by-more-than-50-people/11979962>.

14 As noted in the first article in this series, these jurisdictions are not included in this article because their laws operate within quite different legal systems and they are culturally more distinct from Australia than other common law countries: White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1).

15 Canada is one of the most permissive VAD regimes and a shared legal heritage makes Canada a natural comparator for Australia here.

16 Jocelyn Downie and Kate Scallion, 'Foreseeably Unclear: The Meaning of the "Reasonably Foreseeable" Criterion for Access to Medical Assistance in Dying in Canada' (2018) 41(1) *Dalhousie Law Journal* 23.

including those described as controversial, such as Alzheimer's disease[17] and one kind of mental illness, anorexia.[18] The resulting list, therefore, included not only typical conditions when VAD is permitted but also conditions that help determine boundaries of VAD frameworks.

These nine conditions are structured using the Australian models as a departure point. Part II considers medical conditions where access to VAD is possible (or even likely, such as for cancer), but may depend on prognosis or illness trajectory (such as for COPD). Part III then considers medical conditions for which access to VAD is either clearly not permitted or very unlikely under the Australian models. Examples include Alzheimer's and Huntington's diseases. Part IV explores similarities and differences across models and considers the effects of differently

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See also Jocelyn Downie and Jennifer A Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (Report, Institute for Research on Public Policy, 1 March 2018) ('*IRPP Report*').

17 VAD for people with dementia is possible, for example, in the Netherlands and Belgium: Dominic R Mangino et al, 'Euthanasia and Assisted Suicide of Persons with Dementia in the Netherlands' (2020) 28(4) *American Journal of Geriatric Psychiatry* 466; Sigrid Dierickx et al, 'Euthanasia for People with Psychiatric Disorders or Dementia in Belgium: Analysis of Officially Reported Cases' (2017) 17(1) *BMC Psychiatry* 203. For a systematic review of public attitudes, and the attitudes of health professionals and individuals with dementia, see Emily Tomlinson and Joshua Stott, 'Assisted Dying in Dementia: A Systematic Review of the International Literature on the Attitudes of Health Professionals, Patients, Carers and the Public, and the Factors Associated With These' (2015) 30(1) *International Journal of Geriatric Psychiatry* 10. For some ethical arguments on the issue, see Paul T Menzel and Bonnie Steinbock, 'Advance Directives, Dementia, and Physician-Assisted Death' (2013) 41(2) *Journal of Law, Medicine and Ethics* 484; Inez D de Beaufort and Suzanne van de Vathorst, 'Dementia and Assisted Suicide and Euthanasia' (2016) 263(7) *Journal of Neurology* 1463. For a discussion of the recent prosecution in the Netherlands for VAD for a person with dementia, see Eva Constance, Alida Asscher and Suzanne van de Vathorst, 'First Prosecution of a Dutch Doctor since the Euthanasia Act of 2002: What Does the Verdict Mean?' (2020) 46 *Journal of Medical Ethics* 71. The Canadian *Criminal Code* allows access to VAD for some individuals with dementia (those who still have decision-making capacity and those who have lost it): Jocelyn Downie and Stefanie Green, 'For People with Dementia, Changes in MAiD Law Offer New Hope', *Policy Options* (online, 21 April 2021) <https://policyoptions.irpp.org/magazines/april-2021/for-people-with-dementia-changes-in-maid-law-offer-new-hope/>; Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(3.2).

18 VAD is permissible for people with mental illness who meet the other eligibility criteria in the Netherlands and Belgium: Scott YH Kim, Raymond G De Vries and John R Peteet, 'Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014' (2016) 73(4) *JAMA Psychiatry* 362; Dierickx et al (n 17). The use of VAD for mental illness remains controversial: see, eg, Brendan Kelly and Declan McLoughlin, 'Euthanasia, Assisted Suicide and Psychiatry: A Pandora's Box' (2002) 181(4) *British Journal of Psychiatry* 278; Kathleen Sheehan, K Sonu Gaind and James Downar, 'Medical Assistance in Dying: Special Issues for Patients with Mental Illness' (2017) 30(1) *Current Opinion in Psychiatry* 26. The Canadian *Criminal Code* permits VAD for people with mental illness so long as they also have a serious and incurable physical illness, disease, or disability. The *Criminal Code* explicitly states that mental illness is not considered to be a serious and incurable illness, disease, or disability for the purposes of establishing eligibility: Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2.1). However, this exclusion will be automatically repealed on 17 March 2023, due to a 'sunset clause' set out in Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 6 (as passed by the House of Commons 17 March 2021) enacted to enable the federal government to have time to commission an independent expert panel to conduct a review and make recommendations regarding protocols, guidance and safeguards for MAiD for persons with mental illness, and to allow provincial and territorial governments time to prepare for 2023: Government of Canada, 'About Mental Illness and MAiD', *Medical Assistance in Dying* (Web Page, 18 March 2021) <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>.

drafted eligibility criteria. Parts V and VI discuss implications for regulators and policymakers designing VAD regulation.

This article, like the previous article, focuses on the eligibility criteria most relevant to the person's medical condition. This includes criteria dealing with the nature of the condition such as, for example, whether it needs to be incurable, advanced or progressive or likely to cause death (and, if so, within a specified period). It also includes the requirement for decision-making capacity, which is important because various medical conditions can have implications for a person's capacity.

The article does not consider other criteria unrelated to medical conditions, such as age and residency, and presumes they are met. The article also does not consider criteria about patient suffering. While suffering is linked to the nature of a medical condition, in all jurisdictions analysed, 'suffering' is assessed subjectively, that is, by the person seeking VAD.[19] Because 'suffering' is an individual experience, one person may experience the requisite suffering for one medical condition but may not for another condition. Likewise, one person with a particular medical condition may be suffering but another person in an identical medical state may not. As such, it is not possible to exclude or include a particular condition as being *capable* of satisfying the VAD criteria on the basis of the 'suffering' criterion.

This article adopts terminology used in the *Victorian Act* (subsequently mirrored in the *WA Act* and Model Bill). VAD therefore includes both 'self-administration'[20] and 'practitioner administration'.[21] 'Medical condition' refers broadly to any condition caused by disease, illness, disability, or injury, although we note some VAD laws specifically address these latter concepts.

Finally, we note the limitation that this analysis has in only considering whether a medical condition is *capable* of providing access to VAD. Whether or not a specific person would qualify depends not only on their condition, but also its progression when seeking access, whether treatments are available (and acceptable to the person), and whether they meet the other eligibility criteria. Further, we acknowledge that clinical characterisation of some conditions described may be contentious. For example, whether or not a condition should be regarded as incurable may be disputed. The article outlines our views on each medical condition, informed by the expertise of our clinical authors, and considers how that condition may typically affect a person seeking access to VAD. But in all cases, access to VAD will depend on an individual assessment of a person in relation to relevant eligibility criteria. It is possible that a person with a condition which would generally provide access to VAD is ineligible; it is also possible that a person with a condition generally not providing access to VAD meets the relevant criteria.

19 See, eg, *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii).

20 The person takes the prescribed medication themselves; sometimes this is called physician-assisted suicide or physician-assisted dying.

21 The person is administered the medication by a doctor, or nurse practitioner in Western Australia or Canada; sometimes this is called voluntary euthanasia.

II MEDICAL CONDITIONS FOR WHICH ACCESS TO VAD IS POSSIBLE UNDER ALL FRAMEWORKS

A Colorectal Cancer

1 Nature of Condition

Many cancers may make a person eligible for VAD. Colorectal cancer was selected as an example because it is the second most common cause of cancer in both men and women in Australia (after prostate cancer for men and breast cancer for women) and can cause death.[22] The severity of the disease varies depending on the extent to which it has spread. Stage I of the disease, where the tumour is confined to the bowel wall, has a 90% survival rate and low risk of recurrence when treated in accordance with current clinical guidance.[23] If diagnosed later, the tumour may have invaded the bowel wall (Stage II), and/or metastasised to lymph nodes (Stage III). This may progress to metastases in other parts of the body (Stage IV), which has a 13% five-year relative survival rate in Australia.[24] Treatment options depend on the extent of disease. The majority of people with extensive metastatic disease are diagnosed as incurable[25] and have a median survival of five to six months with supportive care[26] or 11 months with multi-drug chemotherapy.[27]

2 Victoria

To be eligible under the *Victorian Act*, a person's colorectal cancer must be incurable, advanced and progressive, with a prognosis of six months or less.[28] The most significant issue in assessing eligibility is prognostication. For example, if the cancer has metastasised to lymph nodes and people in a similar condition have a survival rate of 33%, is the condition incurable? Similarly, it may be difficult to identify an exact timeframe for the disease's progression. Nevertheless, this ambiguity is unlikely to be significant when the criteria are considered collectively. For example, if it is unclear whether or not a person's cancer is curable, death is unlikely to be expected within six months, making the person ineligible regardless.

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22 Australian Government, Australian Institute of Health and Welfare, *Cancer in Australia 2019* (Report, Cancer Series No 119, Catalogue No CAN 123, 21 March 2019) vii.

23 Cancer Australia, 'Relative Survival by Stage at Diagnosis (Colorectal Cancer)', *National Cancer Control Indicators* (Web Page, 1 April 2019) <https://ncci.canceraustralia.gov.au/outcomes/relative-survival-rate/relative-survival-stage-diagnosis-colorectal-cancer>.

24 Ibid.

25 Yvette HM Claassen et al, 'Survival Differences with Immediate Versus Delayed Chemotherapy for Asymptomatic Incurable Metastatic Colorectal Cancer' (2018) 11 *Cochrane Database of Systematic Reviews* CD012326:1–33.

26 Werner Scheithauer et al, 'Randomised Comparison of Combination Chemotherapy Plus Supportive Care with Supportive Care Alone in Patients with Metastatic Colorectal Cancer' (1993) 306(6880) *British Medical Journal* 752, 754.

27 Ibid. See also Alex Grothey et al, 'Survival of Patients with Advanced Colorectal Cancer Improves with the Availability of Fluorouracil-Leucovorin, Irinotecan, and Oxaliplatin in the Course of Treatment' (2004) 22(7) *Journal of Clinical Oncology* 1209, reporting a median 3.5 month increase in survival following treatment with a different combination of active agents: at 1209.

28 *Victorian Act 2017* (Vic) ss 9(1)(d)(i)–(iii).

The clearest cases are Stage IV colorectal cancer. A person's disease at this point is likely to be incurable, advanced and progressive, and their death could be expected within six months without active treatment. As such, advanced metastatic colorectal cancer is clearly capable of satisfying the eligibility criteria. Access to VAD at earlier stages of the disease would depend on the progression of an individual's condition and whether it meets the eligibility criteria.

3 Western Australia

Eligibility under the *WA Act* for colorectal cancer will be similar to the *Victorian Act*. One key difference is that the *WA Act* does not require the cancer be incurable.[29] Considered in isolation, the absence of this criterion may broaden access to earlier stages of the disease. However, when viewed holistically with other eligibility criteria – that the condition is advanced and progressive, and expected on the balance of probabilities to cause death within six months – the lack of an incurable criterion is unlikely to make a significant difference in practice.

4 Model Bill

Access to VAD under the Model Bill will be similar to the *Victorian Act*, but some people may be able to access VAD earlier in the trajectory of the disease because of the absence of a specified time limit until death. Again, the operation of the criteria holistically is significant. Determinations that the colorectal cancer is incurable, advanced and progressive, and is expected to cause death,[30] become more important in terms of controlling access in the absence of a required prognosis until death.

Whether or not there is a cure is determined objectively by the doctor; to grant access to VAD, they must be satisfied the disease is incurable and will cause death.[31] A conclusion that colorectal cancer is incurable will also likely mean it has reached an advanced state, while the presence of metastases or local advancement would indicate the disease is progressive. As with Victoria and Western Australia, patients with Stage IV advanced metastatic cancer will very likely be eligible. However, the absence of a specific time limit until death makes it more likely that access to VAD before Stage IV is also possible (again, provided the above criteria are met).

5 Oregon

In Oregon in 2019, 3.2% of VAD deaths were patients with colorectal cancer.[32] Colorectal cancer can meet the requirements to be a terminal disease in the *Oregon Act*: that is, incurable and irreversible, and expected (within reasonable medical judgment) to produce death within six months.[33]

29 *WA Act 2019* (WA) ss 16(1)(c)(i)–(ii).
30 Model Bill (n 2) cl 9(e).
31 Ibid cl 9(e)(i)–(ii).
32 *Oregon Data Summary* (n 9) 10.
33 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

6 Canada

The Canadian *Criminal Code*[34] allows access to VAD for colorectal cancer[35] at an earlier stage than the other frameworks. Under the *Criminal Code*, the cancer must be 'serious and incurable',[36] but incurability appears to be interpreted in practice as the point at which the patient refuses treatment or has tried everything available for a condition that, without treatment, is fatal.[37] The person must also be 'in an advanced state of irreversible decline in capability' and this can be caused by, or be independent of, the serious and incurable disease. So, for example, a very frail elderly person with early-stage colorectal cancer refusing all treatment (including surgery at Stage I) may be eligible, while a person who is otherwise healthy and at Stage I would not be eligible (as they are not in an advanced state of irreversible decline in capability).

7 Summary

Cancers are often discussed as the paradigmatic case for access to VAD.[38] It is therefore unsurprising that advanced metastatic colorectal cancer fits within the eligibility criteria in each legislative scheme. While there may be some challenges applying an individual criterion to colorectal cancer, when the criteria are applied holistically, the boundaries of eligibility are relatively clear. Under the *Victorian Act*, *WA Act* and *Oregon Act*, Stage IV colorectal cancer is likely to be eligible, and earlier stages of the disease might also qualify, depending on an individual's circumstances. Earlier access will be more readily available under the Model Bill, as there is no six months prognosis requirement. The Canadian *Criminal Code*[39] is the most permissive, with access potentially as early as Stage I for people who refuse active treatment and are in an advanced and progressive state of decline due to other comorbid conditions. Several factors underpin this difference in Canada: incurability appears to be based on treatments acceptable to the patient; there is no requirement of temporal proximity until expected death; and a person's state of decline is considered holistically rather than being limited only to that caused by the specific condition (here colorectal cancer).

34 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.1−241.2.

35 Note that cancer is the most common underlying condition for individuals who receive VAD in Canada: *Canadian First Annual Report* (n 9) 22.

36 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

37 *IRPP Report* (n 16) 16–19. See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(2)(a).

38 See, eg, Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report, June 2016) 199–202; Department of Health and Human Services (Vic), *Ministerial Advisory Panel on Voluntary Assisted Dying* (Final Report, 31 July 2017) 12, 78 ('*MAP Report*').

39 Canadian *Criminal Code*, RSC 1985, c C-46.

B Motor Neurone Disease

1 Nature of Condition

MND[40] comprises a rare group of diseases where the nerve cells that control the body's muscles degenerate and subsequently die.[41] It has a prevalence of 8.7 per 100,000 people in Australia.[42] MND causes progressive loss of innervation to muscle groups which leads to weakness, spasticity and wasting.[43] Over time, MND impairs a person's ability to walk, speak, swallow and breathe. The disease is incurable and fatal, but its rate of progression varies significantly depending on the subtype of MND and individual factors. Fifty percent of people with MND die within thirty months and less than 20% survive beyond five years from the onset of symptoms.[44] Average life expectancy is two and a half years.[45]

In approximately half of cases, cognition is not affected, but 15% of people have significant impairment with frontotemporal dementia and the remaining 35% experience mild or moderate cognitive impairment, with executive function being most commonly affected.[46]

2 Victoria and Western Australia

People with MND are likely to qualify for access to VAD in these States at some point in their disease trajectory. MND is an incurable and progressive disease that will cause death. However, the illness would need to have progressed to an advanced stage and the person's prognosis would also need to be that death was expected within 12 months (a longer period applies to a neurological condition).[47] A lack of capacity could preclude access in some cases, given executive function is sometimes impaired, and particularly when a person experiences frontotemporal dementia.

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40 In North America, this condition is more commonly referred to as amyotrophic lateral sclerosis or 'ALS'. It is also sometimes referred to as Lou Gehrig's disease. This was the relevant condition of a disproportionate number of applicants in court challenges to prohibitions on assisted dying: *Rodriguez v British Columbia (Attorney-General)* [1993] 3 SCR 519; *Carter* [2015] 1 SCR 331 (Gloria Taylor); *R* (*Pretty) v Director of Public Prosecutions* [2002] 1 AC 800; *R (Conway) v Secretary of State for Justice* [2017] EWHC 2447 (Admin); *R (Newby) v Secretary of State for Justice* [2019] EWHC 3118 (Admin).

41 'What is Motor Neurone Disease (MND)?', *MND Australia* (Web Page, 2020) <https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd>.

42 Deloitte Access Economics, *Economic Analysis of Motor Neuron Disease in Australia* (Report, November 2015) 14 ('*Economic Analysis of MND*').

43 Matthew C Kiernan et al, 'Amyotrophic Lateral Sclerosis' (2011) 377(9769) *Lancet* 942, 944, 948.

44 Kevin Talbot, 'Motor Neuron Disease: The Bare Essentials' (2009) 9(5) *Practical Neurology* 303, 303.

45 *Economic Analysis of MND* (n 42) 19, citing Susan T Paulukonis et al, 'Survival and Cause of Death among a Cohort of Confirmed Amyotrophic Lateral Sclerosis Cases' (2015) 10(7) *PLOS One* e0131965:1–11, 6.

46 GM Ringholz et al, 'Prevalence and Patterns of Cognitive Impairment in Sporadic ALS' (2005) 65(4) *Neurology* 586.

47 *Victorian Act 2017* (Vic) s 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii).

3 Model Bill

People with MND would also be eligible under the Model Bill. The key difference from Victoria and Western Australia is the absence of a specified time limit, which means that a person is not required to wait until they are expected to die within 12 months. This potentially provides earlier access to VAD, provided of course that the person's MND is assessed as being advanced. This might also enable access to VAD for people whose MND affects capacity before that capacity is lost.

4 Oregon

In Oregon, MND is the second most common underlying condition for which people receive VAD, after cancer; 10.1% of all persons who died in 2019 under the Oregon scheme had the disease.[48] Provided a person retains decision-making capacity, MND is a qualifying terminal illness, as it is an incurable and irreversible disease that will produce death.[49] However, the category of persons who are eligible may be narrower in Oregon than in Victoria and Western Australia, as the person must be within six months of death rather than 12 months.[50]

5 Canada

A person with MND can be eligible for VAD in Canada.[51] MND meets the serious and incurable disease criterion on diagnosis.[52] A person with MND may therefore be eligible whenever they reach an advanced state of irreversible decline in capability. Given the traditional progression of MND, this decline is unlikely to have occurred at the point of diagnosis, unless the person already had another condition that caused such a decline.

The 'final consent waiver' provision of the Canadian *Criminal Code*[53] allows a person whose natural death is reasonably foreseeable, who meets the eligibility criteria, and who is at risk of losing decision-making capacity, to make arrangements to receive VAD after they have lost capacity. To take advantage of the provision, they must make a 'written arrangement' with their provider for VAD to be provided on a specified date. Then, if they lose decision-making capacity, VAD can be provided on or before that date (in accordance with the conditions set out in the written arrangement). It has been stated that in cases of MND, a person's natural death is reasonably foreseeable at the point of diagnosis,[54] so this option of

48 *Oregon Data Summary* (n 9) 10–11.

49 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

50 Ibid.

51 The *Canadian First Annual Report* (n 9) does not provide data specifically on MND but indicates that neurological conditions comprised 10.4% of VAD deaths in the last reporting period: at 22.

52 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

53 Ibid s 241.2(3.2). See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(1).

54 The Minister for Health in parliamentary debates stated that for MND/ALS, a person's death would be reasonably foreseeable at the point of diagnosis 'because it usually happens within a matter of months or

exercising the final consent waiver provision will be available to eligible persons with MND at risk of losing decision-making capacity.

6 Summary

A person diagnosed with MND can access VAD under all five frameworks. The key difference is the timing of this access. Oregon has the most restrictive law, requiring a person to be within six months of death, followed by Victoria and Western Australia with 12 months. The Model Bill does not impose a time limit, but access is constrained by the need for a person's condition to be advanced. This is similar to the position in Canada, but the ability to consider a person's state of decline holistically, not just the decline caused by MND, creates potentially wider access. Canada's final consent waiver provision also permits broader access, ie, when an eligible person has lost decision-making capacity.

C Chronic Obstructive Pulmonary Disease

1 Nature of Condition

COPD is an incurable and progressive lung disease characterised by chronic airflow limitation, resulting from a mix of emphysema and small airways disease, such as bronchitis.[55] It is the fifth leading cause of death in Australia for both men and women.[56] Increasing airway narrowing and lung destruction causes symptoms to worsen over time. The symptoms include breathlessness, coughing and more frequent and persistent chest infections. COPD can progress from Stage I (mild or early-stage) through to Stage IV (often called end-stage COPD), when people may struggle to breathe even at rest. If a person's respiratory function is so compromised that they lack sufficient oxygen, this may cause confusion and affect a person's decision-making capacity.[57]

People can live for many years with the disease, but it does shorten life, particularly when the COPD is advanced.[58] Prognostication is incredibly difficult because the trajectory of COPD is 'chaotic',[59] with slow, chronic decline over time interspersed with acute exacerbations, any of which may cause death.[60]

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years': Canada, *Parliamentary Debates*, Senate, 1 June 2016, 1700 (Jane Philpott). See also Downie and Scallion (n 16) 48–9.

55 Global Initiative for Obstructive Lung Disease, *Pocket Guide to COPD Diagnosis, Management and Prevention: A Guide for Health Care Professionals* (Report, 2019) 2.

56 Australian Government, Australian Institute of Health and Welfare, *Deaths in Australia* (Web Report, 25 June 2021) <https://www.aihw.gov.au/getmedia/743dd325-7e96-4674-bb87-9f77420a7ef5/Deaths-in-Australia.pdf.aspx?inline=true>.

57 Fiona AHM Cleutjens et al, 'Domain-Specific Cognitive Impairment in Patients with COPD and Control Subjects' (2016) 12 *International Journal of Chronic Obstructive Pulmonary Disease* 1.

58 Robert M Shavelle et al, 'Life Expectancy and Years of Life Lost in Chronic Obstructive Pulmonary Disease: Findings from the NHANES III Follow-up Study' (2009) 4(1) *International Journal of Chronic Obstructive Pulmonary Disease* 137.

59 Amanda Landers et al, 'Severe COPD and the Transition to a Palliative Approach' (2017) 13(4) *Breathe* 310, 311.

60 Ibid.

2 Victoria and Western Australia

COPD is incurable, progressive and can cause death, particularly when a person has end-stage COPD. A person would need to be at an advanced stage in their illness to be eligible for VAD, particularly given the requirement that death be expected or likely to occur within six months.[61] Challenges of prognostication with COPD may present a particular barrier to access.

Decision-making capacity must also be considered as end-stage COPD patients may experience a chronic lack of oxygen in the blood, affecting brain functioning and cognition. This may mean that a person with COPD, despite earlier qualifying for VAD, could lose the required capacity as their illness worsens.[62]

3 Model Bill

A person with COPD could access VAD under the Model Bill. Absence of a specified time until death means both that difficulties of prognostication are avoided, and that earlier access may be possible. The person's COPD would still need to be 'advanced',[63] but it would be possible for a doctor to conclude that all eligibility criteria are met at an earlier point than under the *Victorian Act* or *WA Act*. Therefore, without a requirement to predict timing of death, access to VAD may be provided once a doctor is satisfied that the disease is advanced and will ultimately cause death.

4 Oregon

In Oregon, 7.4% of deaths in 2019 listed the underlying illness as '[r]espiratory disease [eg, COPD]'.[64] COPD is 'incurable and irreversible', and so, provided the person retained capacity and reasonable medical judgment confirmed death will occur within six months, a person would be eligible for VAD.[65] Uncertainty about disease trajectory could affect the timing of access to VAD.

5 Canada

In Canada, 10.8% of VAD deaths in 2018 involved individuals with respiratory conditions.[66] Under the Canadian *Criminal Code*,[67] a person with COPD could satisfy the eligibility requirements to access VAD as it is a 'serious' and 'incurable' illness. Because there is no specified time until death required for a person to be eligible, a person would not have to have reached end-stage. However, because the person must be in an 'advanced state of irreversible decline in capability',[68]

61 *Victorian Act 2017* (Vic) s 9(1)(d)(iii); *WA Act 2019* (WA) s 16(1)(c)(ii).
62 *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).
63 Model Bill (n 2) cl 9(e)(ii).
64 *Oregon Data Summary* (n 9) 11.
65 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).
66 *Canadian First Annual Report* (n 9) 22.
67 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(1)–(2).
68 Ibid s 241.2(2)(b).

a person is unlikely to satisfy this criterion at a very early stage without another comorbid condition causing such decline.

As with MND, because COPD makes a person's natural death reasonably foreseeable, a person with COPD, if they were at risk of loss of capacity, would also be able to access VAD after they have lost capacity through the final consent waiver provision.[69]

6 Summary

The trajectory to death for COPD patients is unpredictable. A chronically unwell person may live for an extended period of time, experiencing a series of acute events but recovering from them. The different criteria relating to proximity to death in the five frameworks may be practically significant for this condition, with earlier access to VAD in those frameworks which do not specify a requisite time to death. Another key issue is decision-making capacity. If the progression of COPD affects capacity, this may exclude access for those who would otherwise qualify for VAD. As noted above, in Canada, a person may nevertheless be able to access VAD after losing capacity if they have completed a final consent waiver.

D Chronic Kidney Disease

1 Nature of Condition

CKD involves decreased kidney function (which is determined by the rate at which the kidneys filter wastes from the blood), or markers of kidney damage, or both, for a period of at least three months.[70] In most cases, CKD is irreversible, and therefore incurable.[71] In Australia, CKD is estimated to contribute to 11% of all deaths with it being the underlying cause in 21% of those deaths.[72]

In the early stages of CKD, people may not notice symptoms associated with their reduced kidney function, but as the disease progresses and toxins accumulate, nearly all body systems can be affected. Fluid retention, hypertension, cardiovascular dysfunction and neurological changes are some of the effects of CKD.[73] Patients with CKD are also susceptible to alterations in cognitive function, including stroke and dementia, and this may affect decision-making capacity.[74]

69 Ibid s 241.2(3.2).

70 Adeera Levin et al, 'KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease' (2013) 3(1) *Kidney International Supplements* 1, 19–24.

71 Ibid 19.

72 Australian Government, Australian Institute of Health and Welfare, *Chronic Kidney Disease* (Web Report, 15 July 2020) <https://www.aihw.gov.au/reports/chronic-kidney-disease/chronic-kidney-disease-compendium/contents/deaths-from-chronic-kidney-disease>.

73 Carol Mattson Porth and Glenn Maftin, *Pathophysiology: Concepts of Altered Health States* (Lippincott Williams and Wilkins, 8th ed, 2009) 859.

74 Ria Arnold et al, 'Neurological Complications in Chronic Kidney Disease' (2016) 5 *Journal of the Royal Society of Medicine Cardiovascular Disease* 1.

CKD has five stages. Stage I is the least severe, with each stage becoming progressively worse until Stage V, 'end-stage', where the kidneys fail completely.[75] Not all individuals with CKD will progress to end-stage kidney disease and for those that do, the progression is frequently non-linear.[76] This makes prognostication difficult.[77]

2 Victoria and Western Australia

By the later stages of CKD, a person would have a medical condition that is 'advanced and progressive'.[78] There are two challenging aspects under the *Victorian Act* and *WA Act*, however. First, because the disease's trajectory varies, establishing a six-month prognosis may be difficult.[79] Second, since alterations in cognitive function are possible in the latter stages, if a person loses decision-making capacity for VAD, they will not be eligible.[80]

3 Model Bill

The absence of the prognosis requirement under the Model Bill means that earlier access to VAD may be possible than in Victoria or Western Australia. However, the CKD would still need to have reached the stage of being advanced and progressive.[81] Capacity issues remain the same as under the *Victorian Act* and *WA Act*.[82]

4 Oregon

A very small percentage of Oregonians access VAD on the basis of CKD.[83] CKD satisfies the disease criterion under the *Oregon Act*, as it is incurable and irreversible and can be a terminal condition.[84] As in Australia, prognosticating about six months until death and potential loss of capacity present challenges for eligibility.

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75 Andrew S Levey et al, 'Definition and Classification of Chronic Kidney Disease: A Position Statement from Kidney Disease: Improving Global Outcomes (KDIGO)' (2005) 67(6) *Kidney International* 2089, 2094.

76 National Clinical Guideline Centre (UK), 'Chronic Kidney Disease (Partial Update): Early Identification and Management of Chronic Kidney Disease in Adults in Primary and Secondary Care' (Clinical Guidelines No 182, National Institute for Health Care Excellence, July 2014) ch 7 <https://www.ncbi.nlm.nih.gov/books/NBK328138/>.

77 Depending on the person's age and stage of CKD, it can be managed conservatively with diet and observation, by renal replacement therapy with dialysis, or by kidney transplantation: Angela C Webster et al, 'Chronic Kidney Disease' (2017) 389(10075) *Lancet* 1238. The following analysis does not address those circumstances where a person with CKD may be eligible for, or has received, a kidney transplant.

78 *Victorian Act 2017* (Vic) s 9(1)(d)(ii); *WA Act 2019* (WA) s 16(1)(c)(i).

79 *Victorian Act 2017* (Vic) s 9(1)(d)(iii); *WA Act 2019* (WA) s 16(1)(c)(ii).

80 *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).

81 Model Bill (n 2) cl 9(e)(ii).

82 Ibid cl 9(c).

83 'Kidney failure' is included in the 'Other illnesses' category, which comprised six individuals (3.2% of VAD deaths) in Oregon in 2019: *Oregon Data Summary* (n 9) 11, 13.

84 *Oregon Act*, Or Rev Stat §127.800(12) (1994).

5 Canada

A person with CKD will meet the serious and incurable condition requirement on diagnosis.[85] However, they must also be in an 'advanced state of irreversible decline'.[86] Barring a comorbid condition causing such a decline, a person is unlikely to satisfy this criterion at the very early stages of CKD. However, once the CKD and/or the comorbid condition cause the required state of decline, the person may be eligible.

Because the natural death of a person with CKD can be reasonably foreseeable, a person who is at risk of losing capacity after the finding of eligibility will be able to access VAD after they lose capacity through the final consent waiver provision.[87]

6 Summary

The uncertain trajectory of CKD and difficulties for prognostication may create challenges for access to VAD in Victoria, Western Australia and Oregon, where death must be expected within six months. This is less of a barrier under the Model Bill and in Canada. The potential for cognitive decline associated with CKD may also limit access. In Canada, however, it is possible for a person to exercise the final consent waiver provision and access VAD after they have lost decision-making capacity.

III MEDICAL CONDITIONS FOR WHICH ACCESS TO VAD IS VERY UNLIKELY IN MOST JURISDICTIONS

A Alzheimer's Disease

1 Nature of Condition

Dementia, which refers to a number of neurological conditions where the major symptom is a global decline in brain function,[88] is the second leading cause of death in Australia.[89] Alzheimer's disease ('Alzheimer's') is the most common form of dementia, affecting up to 70% of people with dementia.[90] Alzheimer's is incurable and its symptoms progressively worsen over time, although the rate at which this occurs varies. Despite this variability, Alzheimer's is usually divided

85 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

86 Ibid s 241.2(2)(b).

87 Ibid s 241.2(3.2).

88 The four most common forms of dementia, accounting for over 90% of total cases, are Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease: Leela R Bolla, Christopher M Filley and Robert M Palmer, 'Dementia DDx: Office Diagnosis of the Four Major Types of Dementia' (2000) 55(1) *Geriatrics* 34.

89 Australian Bureau of Statistics, *Causes of Death, Australia, 2018* (Catalogue No 3303.0, 25 September 2019).

90 Kirsten Fiest et al, 'The Prevalence and Incidence of Dementia due to Alzheimer's Disease: A Systematic Review and Meta-Analysis' (2016) 43(Supp1) *Canadian Journal of Neurological Sciences* S51.

into three broad stages: mild, moderate and advanced.[91] The disease is fatal, usually through complications of the disease, such as swallowing issues or pneumonia. Life expectancy for Alzheimer's varies depending on factors such as whether a person is already of advanced age, but appears to range from three to ten years.[92]

Memory and cognition are specifically affected. For example, persons with moderate Alzheimer's may struggle to remember things that occurred minutes previously. Communication is also affected, both in terms of understanding what is being said and responding.

2 Victoria and Western Australia

It is very unlikely that a person with Alzheimer's will be eligible to access VAD under the *Victorian Act* or *WA Act*. Although Alzheimer's is an incurable disease that is progressive and will cause death,[93] it impairs decision-making capacity.[94] By the time a person has reached an advanced state of their disease and is expected to die within 12 months (the longer time limit applies to neurodegenerative conditions),[95] it is very unlikely they would have capacity to make decisions about VAD.[96]

3 Model Bill

The position is the same under the Model Bill. Even without a time limit until death, it remains very unlikely that a person would retain the requisite decision-making capacity when they have advanced Alzheimer's.[97]

4 Oregon

Access to VAD on the basis of Alzheimer's in Oregon is also very unlikely for the same reasons as in Victoria and Western Australia.[98] Indeed, access is even less likely given the shorter time limit of six months until death.[99]

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91 There are also other scales used such as the seven stages in the 'Global Deterioration Scale for Assessment of Primary Degenerative Dementia': Barry Reisberg et al, 'The Global Deterioration Scale for Assessment of Primary Degenerative Dementia' (1982) 139(9) *American Journal of Psychiatry* 1136.

92 O Zanetti, SB Solerte and F Cantoni, 'Life Expectancy in Alzheimer's Disease (AD)' (2009) 49(Supp 1) *Archive of Gerontology and Geriatrics* 237; Ee Heok Kua et al, 'The Natural History of Dementia' (2014) 14(3) *Psychogeriatrics* 196.

93 *Victorian Act 2017* (Vic) s 9(1)(d)(ii); *WA Act 2019* (WA) s 16(1)(c)(i).

94 *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).

95 *Victorian Act 2017* (Vic) s 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii).

96 Carmelle Peisah, Linda Sheahan and Ben White, 'Biggest Decision of Them All – Death and Assisted Dying: Capacity Assessments and Undue Influence Screening' (2019) 49(6) *Internal Medicine Journal* 792.

97 Model Bill (n 2) cl 9(c).

98 This is consistent with the position described here: 'Advance Care Planning for Alzheimer's Disease or Dementia', *Death with Dignity* (Web Page, 2020) <https://www.deathwithdignity.org/alzheimers-dementia-directive/>.

99 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

5 Canada

Alzheimer's qualifies as a serious and incurable condition upon diagnosis, so the critical issue is whether a person's Alzheimer's or another comorbid condition is causing them to be in an 'advanced state of irreversible decline in capability' before they lose decision-making capacity.[100]

There have been a small number of cases in Canada where people with dementia as their sole underlying medical condition accessed VAD.[101] For example, Mary Wilson received VAD after being diagnosed with Alzheimer's at least four years earlier. Her case was referred to the College of Physicians and Surgeons of British Columbia by the coroner, who raised concerns about whether Ms Wilson had a grievous and irremediable medical condition. The College investigated and concluded that Ms Wilson met the eligibility requirements for VAD in the Canadian *Criminal Code*,[102] and the assessing physicians acted reasonably and appropriately when considering the issues of capacity and consent.[103]

Access to VAD for people with dementia before they lose decision-making capacity is also supported in professional guidance given by the Canadian Association of MAiD Assessors and Providers.[104] The guideline indicates individuals with dementia will be in an advanced state of irreversible decline in capability just prior to when they are likely to lose capacity, so clinicians should assess and monitor a person's capacity and grant access to VAD at this point, also known as the '10 minutes to midnight' approach.

Access to VAD for some people with dementia after they lose decision-making capacity is also possible. If a person with dementia has been found to be eligible for VAD, they can exercise the final consent waiver provision of the Criminal Code and make arrangements for VAD to be provided after they lose decision-making capacity.

100 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

101 Kelly Grant, 'From Dementia to Medically Assisted Death: A Canadian Woman's Journey, and the Dilemma of the Doctors Who Helped', *Globe and Mail* (online, 12 October 2019) <https://www.theglobeandmail.com/canada/article-from-dementia-to-medically-assisted-death-a-canadian-womans-journey/>. See also the case of Gayle Garlock: CBC Radio, 'B.C. Man is One of the First Canadians with Dementia to Die with Medical Assistance', *CBC* (online, 27 October 2019) <https://www.cbc.ca/radio/thesundayedition/the-sunday-edition-for-october-27-2019-1.5335017/b-c-man-is-one-of-the-first-canadians-with-dementia-to-die-with-medical-assistance-1.5335025>. These cases occurred when the legislation retained the eligibility requirement of 'natural death' being 'reasonably foreseeable'.

102 Canadian *Criminal Code*, RSC 1985, c C-46.

103 Letter from JG Wilson, Senior Deputy Registrar of the Complaints and Practice Investigations Department of the College of Physicians and Surgeons of British Columbia to Dr Konia Jane Trouton, Dr [redacted] and Dr Paulo Campos Pereira, 6 December 2018 (College File No IC 2018-0034) <https://www.theglobeandmail.com/files/editorial/News/nw-na-maid-1011/marywilson-decision.pdf> ('College Investigation Regarding Death of Mary Wilson').

104 Canadian Association of MAiD Assessors and Providers, 'Medical Assistance in Dying (MAiD) in Dementia' (Clinical Guidance Document, 2019) <https://camapcanada.ca/wp-content/uploads/2019/05/Assessing-MAiD-in-Dementia-FINAL-Formatted.pdf>.

6 Summary

Access to VAD on the basis of Alzheimer's is very unlikely under the *Victorian Act*, *WA Act* and *Oregon Act*. The requirements to have both decision-making capacity and a condition which is advanced and expected to cause death within a certain time period will exclude access to VAD. The same result occurs under the Model Bill, despite a lack of timeframe until death being required, as the person with advanced Alzheimer's is similarly very unlikely to have decision-making capacity.

In contrast, under the Canadian law it is possible for a person to retain capacity at the point at which their Alzheimer's causes them to have reached an 'advanced state of irreversible decline in capability'. We consider it significant that the 'advanced' here is in relation to the person's decline and not in relation to the stage of their Alzheimer's. In addition, an individual with Alzheimer's in Canada who is assessed to have capacity and found to meet the eligibility criteria for VAD may exercise the final consent waiver provision and make a written arrangement to have VAD provided after they lose decision-making capacity.

B Anorexia

1 Nature of Condition

Anorexia nervosa is an eating disorder and serious mental illness. It is a complex condition that combines behavioural disorder, mental disorder and physical illness.[105] Anorexia commonly results in significant physical impairments, including anaemia, osteoporosis and type II diabetes. In severe cases, starvation caused by anorexia can be life-threatening, due to kidney failure, cardiac arrest, suicide, or other complications.[106] Anorexia affects between 0.3% and 1.5% of Australian women, and between 0.1% and 0.5% of Australian men.[107]

While anorexia is not in itself a terminal illness,[108] in some cases, the physical consequences of long-term starvation can become life-threatening. Some describe

105 Anorexia involves an intense and obsessive fear of gaining weight, leading to severe food restriction (or purging after eating), often coupled with excessive exercise, resulting in extreme weight loss: Michael J Devlin and Joanna E Steinglass 'Feeding and Eating Disorders' in Janis Cutler (ed), *Psychiatry* (Oxford University Press, 3rd ed, 2014) 291.

106 National Eating Disorders Collaboration, *Eating Disorders Prevention, Treatment and Management: An Evidence Review* (Report, March 2010) 6 ('*NEDC Report*'); Allan S Kaplan and Blake D Woodside, 'Biological Aspects of Anorexia Nervosa and Bulimia Nervosa' (1987) 55(5) *Journal of Consulting and Clinical Psychology* 645.

107 *NEDC Report* (n 106) 7, based on international epidemiological data reported in James I Hudson et al, 'The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication' (2007) 61(3) *Biological Psychiatry* 348.

108 Around half of patients recover to normal weight and remission of symptoms, a third experience symptom improvement, and only 20% develop chronic anorexia: Hans-Christoph Steinhausen, 'The Outcome of Anorexia Nervosa in the 20th Century' (2002) 159(8) *American Journal Psychiatry* 1284, 1286.

this as 'end-stage anorexia'[109] or 'terminal psychiatric disease'.[110] Mortality rates vary between 3% and 25%.[111] In some particularly refractory cases of anorexia, treatment has been assessed as futile, and palliative care[112] or VAD[113] has been offered, although both the terminology and the futility of ongoing treatment are disputed.[114]

It remains unresolved whether the physical sequalae of end-stage anorexia are considered to be part of the anorexia or separate, comorbid physical conditions. This is relevant for those VAD frameworks where a specific condition granting access is needed. English and Australian end-of-life cases outside of the VAD context suggest that a person's medical condition should be viewed holistically, and not atomised into separate components of illness, symptoms and consequences.[115]

A further unresolved issue is whether a severely ill anorexic person can have capacity to consent to or refuse medical treatment. Capacity can be compromised by disorders of values[116] affecting the ability to choose between treatment options,

109 Margery Gans and William B Gunn Jr, 'End Stage Anorexia: Criteria for Competence to Refuse Treatment' (2003) 26(6) *International Journal of Law and Psychiatry* 677; Amy T Campbell and Mark P Aulisio, 'The Stigma of "Mental" Illness: End Stage Anorexia and Treatment Refusal' (2012) 45(5) *International Journal of Eating Disorders* 627.

110 Joseph O'Neill, Tony Crowther and Gwyneth Sampson, 'Anorexia Nervosa: Palliative Care of Terminal Psychiatric Disease' (1994) 11(6) *American Journal of Hospice and Palliative Medicine* 36.

111 Ibid; Gans and Gunn Jr (n 109).

112 Amy Lopez, Joel Yager and Robert E Feinstein, 'Medical Futility and Psychiatry: Palliative Care and Hospice Care as a Last Resort in the Treatment of Refractory Anorexia Nervosa' (2010) 43(4) *International Journal of Eating Disorders* 372. See also the case of Mrs Black, a 45-year-old with a 25-year history of anorexia, referred to in Gans and Gunn Jr (n 109) at 678, and the cases of 'Alison' and 'Emily' described in Campbell and Aulisio (n 109) at 628. See also *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639; *An NHS Foundation Trust v X* [2014] EWCOP 35 ('*NHS v X*').

113 In at least two cases from the Netherlands, women with anorexia accessed VAD. The first involved a 25-year-old woman who, after 16 years of treatment, weighed 19 kilograms, whose anorexia was considered irremediable, and who was assessed to have competence to request VAD: Barney Sneiderman and Marja Verhoef, 'Patient Autonomy and the Defence of Medical Necessity: Five Dutch Euthanasia Cases' (1996) 34(2) *Alberta Law Review* 374, 393–5. The second involved a woman who suffered from anorexia nervosa, recurrent depression, a personality disorder and a somatoform pain disorder. In later years her anorexia was less significant than her other mental illnesses, and there was no suggestion that she was dying of starvation or its physical effects. She was treated extensively for many years, both in hospital and in the community, including with electroconvulsive therapy, pain medication, and cognitive behavioural therapy, but her condition continued to deteriorate: '2016-01, Psychiatrist, Psychiatric Disorders, No Reasonable Alternative', *Regional Euthanasia Review Committees* (Web Page, 1 January 2016) <https://english.euthanasiecommissie.nl/judgments/d/d-psychiatric-disorders/documents/publications/judgments/2016/2016-01/2016-01> ('Regional Euthanasia Review Committees').

114 Cynthia Geppert, 'Futility in Chronic Anorexia Nervosa: A Concept Whose Time Has Not Yet Come' (2015) 15(7) *American Journal of Bioethics* 34, 36.

115 The courts have determined physical illness is part of mental illness in three cases that authorised force feeding of a person who was starving themselves due to mental illness, holding that feeding was 'medical treatment' for symptoms of the person's mental illness: *Adult Guardian v Langham* [2006] 1 Qd R 1; *Australian Capital Territory v JT* (2009) 4 ACTLR 68, 77 [62] (Higgins CJ); *B v Croydon Health Authority* [1995] Fam 133, 138–9 (Hoffman LJ).

116 Louis C Charland, 'Ethical and Conceptual Issues in Eating Disorders' (2013) 26(6) *Current Opinion in Psychiatry* 562; Jacinta AO Tan et al, 'Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values' (2006) 13(4) *Philosophy, Psychiatry, and Psychology* 267.

and disorders of executive function affecting rationality of decisions.[117] Starvation also affects cognitive function, including comprehension and reasoning.[118] Some believe that each person with anorexia must be individually assessed to determine whether decision-making capacity is present despite these impairments.[119] However, others suggest that people with anorexia may *a priori* lack capacity, at least concerning treatment of that condition.[120] There has been at least one reported case in the Netherlands where a young woman with severe anorexia was held to have capacity to choose VAD.[121]

2 Victoria

A person with anorexia will ordinarily not be able to access VAD for this condition. This is because the *Victorian Act* specifically excludes access to VAD based solely on a mental illness.[122] Of course, access for a person with anorexia would be possible if they were eligible on the basis of another qualifying medical condition such as cancer or liver failure.[123]

However, there is an argument, drawing on one of the unresolved issues noted above, that anorexia could provide access to VAD. If a person's severe and enduring anorexia has caused substantial and ongoing physical harm (for example, heart disease or kidney failure), then access is not sought for a mental illness but rather for the person's physical condition. A weakness in this argument

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117 Geppert (n 114).

118 Tan et al (n 116) 270.

119 Sam Boyle, 'How Should the Law Determine Capacity to Refuse Treatment for Anorexia?' (2019) 64 *International Journal of Law and Psychiatry* 250, 257–8; Campbell and Aulisio (n 109); Heather Draper, 'Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification' (2000) 14(2) *Bioethics* 120. Gans and Gunn Jr (n 109) articulate a series of specific criteria for determining whether an anorexic person has capacity to choose to die: 693–4.

120 Christopher J Williams, Lorenzo Pieri and Andrew Sims, 'Does Palliative Care Have a Role in Treatment of Anorexia Nervosa? We Should Strive to Keep Patients Alive' (1998) 317(7152) *British Medical Journal (Clinical Research Edition)* 195, 196; Charland (n 116). In *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639, Jackson J acknowledged that a person with anorexia may never have capacity to make decisions concerning treatment for that condition: at [49]–[53]. Note though in *NHS v X* [2014] EWCOP 35, while Ms X was found to lack capacity in relation to decisions about treatment for her anorexia, she was found to have capacity to make decisions about her end-stage liver disease: at [30], [33]–[34] (Cobb J).

121 Sneiderman and Verhoef (n 113). The second Dutch case mentioned above also involved a woman with anorexia but this condition was no longer as prominent in her overall mental condition by the time she was seeking VAD: Regional Euthanasia Review Committees (n 113). There are also reports of cases where a person with anorexia has been able to access VAD in Canada: see, eg, Joan Bryden, 'Exclusion of Mental Illness in Assisted Dying-Bill Slammed by Psychiatrists', *CFJC Today* (Web Page, 22 November 2020) <https://cfjctoday.com/2020/11/22/exclusion-of-mental-illness-in-assisted-dying-bill-slammed-by-psychiatrists/>.

122 *Victorian Act 2017* (Vic) s 9(2). The definition of 'mental illness' in section 3 of the *Victorian Act 2017* (Vic) refers to section 4(1) of the *Mental Health Act 2014* (Vic), which defines 'mental illness' as 'a medical condition that is characterised by a significant disturbance of thought, mood, perception or memory'. Anorexia is both a thought disorder and a mood disorder and would therefore fall within this definition.

123 For example, in *NHS v X* [2014] EWCOP 35, Ms X suffered both severe anorexia (a mental illness) and end-stage liver disease (a physical illness which was caused by her alcohol dependence disorder).

is that it relies on anorexia being seen as separate from its physical consequences. This is inconsistent with the broad approach that the courts have taken when conceptualising the physical outcomes of a mental illness. It also sits awkwardly with the proposed interpretation of the *Victorian Act* that a condition may be regarded as causing death if it causes a chain of events that will result in death.[124] Without an authoritative ruling on those issues, it is not possible to be certain about eligibility under the *Victorian Act* on the basis of anorexia.

In any event, a lack of decision-making capacity is very likely to preclude access. Currently, no English[125] or Australian cases[126] have found a person with severe anorexia to have capacity to make decisions refusing treatment for anorexia.[127] A similar outcome is likely in relation to VAD, particularly given that the application of other eligibility criteria mean that this could only arise for severe and enduring cases (see below).

In the highly unlikely event that these hurdles are passed, it is possible that the other eligibility criteria could be met in a small number of cases of severe and enduring anorexia.[128] People suffering the medical sequelae of prolonged starvation may expect death to occur within six months. By this stage, the condition is likely be considered to be advanced and progressive. Further, the person's condition may be considered 'incurable' if all available treatments have not been effective in alleviating the patient's symptoms, or if body systems are failing due to prolonged starvation.

3 Western Australia

Applying the above reasoning, there is also a very limited prospect of access to VAD for anorexia under the *WA Act*. We note, however, that as the condition does not have to be incurable, the possibility of a cure if further treatment is attempted will not be a barrier to accessing VAD.[129]

4 Model Bill

While there is a higher likelihood than in Victoria that people with severe and enduring anorexia may be permitted to access VAD under the Model Bill, access still remains unlikely given issues of decision-making capacity.

The Model Bill has two relevant differences from the *Victorian Act*. The first is that there is no specific statement precluding access to VAD on the basis of

124 See White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(B)(4).

125 *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639; *An NHS Trust v L* [2013] EWHC 4313 (Fam); *NHS v X* [2014] EWCOP 35; *Re W (Medical Treatment: Anorexia)* [2016] EWCOP 13; *Cheshire & Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56.

126 *Fletcher v Northern Territory* (2017) 324 FLR 11.

127 However, a person with severe anorexia has been held to have capacity to refuse treatment for comorbid liver disease: *NHS v X* [2014] EWCOP 35.

128 This term is defined as anorexia which is clinically severe, treatment resistant and long lasting: see Anna C Ciao, Erin C Accurso and Stephen A Wonderlich, 'What Do We Know About Severe and Enduring Anorexia Nervosa?' in Steven Touyz et al (eds), *Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide* (Routledge, 2016) 1.

129 Contrast the result in England in the case of *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639.

mental illness. This means there is no need to determine whether the person's physical condition is caused by anorexia or can be considered to be separate. In other words, the relevant 'medical condition' may be anorexia with its associated physical complications.

The second major difference is that a specific time until death is not required. The Model Bill still requires the condition be incurable and will cause death.[130] The causation condition is assessed on the basis of treatment that is acceptable to the person. This means that access to VAD will be limited to the identified cohort of people with severe and enduring anorexia. However, the absence of a requirement of temporal proximity may enable a person to request VAD at an earlier stage than in Victoria. This earlier assessment for VAD could potentially mean that capacity is less affected by the physical symptoms of starvation which increasingly affect cognition over time.

Despite the above, the requirement that a person retain capacity to make decisions in relation to VAD where it is sought on the basis of anorexia is likely to remain a significant barrier to access.

5 Oregon

The phrasing of the mental illness exclusion in the *Oregon Act* may make it more difficult for a person with severe and enduring anorexia to access VAD. Although not subject to judicial interpretation, the exclusion of a 'psychiatric or psychological condition or depression impairing judgment'[131] is likely to apply more broadly than a test of decision-making capacity. It would be difficult to maintain that a person with a severe and life-threatening eating disorder, which of its nature centrally affects thoughts and values about eating, did not have some form of impaired judgment, even if this impairment fell short of losing decision-making capacity. The law in Oregon states that a person with such a condition impairing judgment must not be given access to VAD until they are no longer suffering from impaired judgment.[132] This amounts to a categorical exclusion in contrast with the *Victorian Act*[133] and *WA Act*[134] which still allow access to VAD for person with a mental illness provided they have another qualifying medical condition.

6 Canada

Under the Canadian *Criminal Code*, similar to the *Victorian Act* and *WA Act*, mental illness cannot be considered an 'illness, disease or disability',[135] so a person with anorexia as a sole underlying medical condition is ineligible for VAD. However, on 17 March 2023, the mental illness exclusion will be automatically

130 Model Bill (n 2) cls 9(e)(i)–(ii).
131 *Oregon Act*, Or Rev Stat (1994) § 127.825.
132 Ibid § 127.825.
133 *Victorian Act 2017* (Vic) s 9(2).
134 *WA Act 2019* (WA) s 16(2).
135 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(2)(a), (2.1).

repealed and so people with anorexia as their sole underlying condition will be potentially eligible for VAD.

A subset of persons with anorexia – those who have 'serious and incurable' comorbid physical conditions as a result of their anorexia – may already be able to meet the criteria of an 'advanced state of irreversible decline in capability' and therefore could qualify for VAD despite the mental illness exclusion.[136]

Access to VAD for some people with anorexia and a comorbid physical condition after loss of decision-making capacity is also possible. If such a person is found to be eligible for VAD, while they have decision-making capacity, they can exercise the final consent waiver provision and make a written arrangement for VAD to be provided after they lose decision-making capacity.

7 Summary

Three of the frameworks (Victoria, Western Australia, and Canada until 2023) aim to specifically preclude people with anorexia from accessing VAD on that basis (because it is a mental illness). However, because anorexia affects eating behaviour, in some extreme cases it can cause physical conditions with life-threatening consequences. Possible access to VAD in Victoria and Western Australia depends on these physical conditions being seen as distinct from the mental illness. This is less of an issue for the Model Bill, which does not specifically prohibit access on the basis of mental illness. Under the Canadian *Criminal Code*,[137] a person's decline in capability may be caused by these resulting physical conditions or the anorexia. However, anorexia explicitly does not qualify as a 'serious and incurable illness, disease or disability' and the physical sequelae may not unless they independently amount to an 'illness, disease or disability'.

Access to VAD under all frameworks also depends on the person with severe and enduring anorexia (the application of other eligibility criteria would restrict any potential access to VAD to this cohort) having decision-making capacity. Applying the presumption of capacity, each individual should be carefully assessed to evaluate whether or not their anorexic thoughts and values undermine their capacity to choose VAD. However, as discussed above, retaining capacity is likely to be a barrier to accessing VAD for persons with severe and enduring anorexia (except in Canada for a person eligible to exercise the final consent waiver provision in the *Criminal Code*).

C Frailty

1 Nature of Condition

Frailty is a state of increased vulnerability to adverse health outcomes such as loss of mobility, falls, hospitalisation, disability and death.[138] It reflects the cumulative effects of disease and physiological changes that can occur as people age. It is

136 Ibid s 241.2(2)(b).

137 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2).

138 Andrew Clegg et al, 'Frailty in Elderly People' (2013) 381(9868) *Lancet* 752, 752.

multidimensional, and clinical manifestations vary widely. Consequently, frailty is generally considered a syndrome rather than a disease.[139] Prevalence is difficult to ascertain,[140] but estimates suggest that over 415,000 Australians experience frailty.[141] The physical indicators of frailty have traditionally included reduced activity, slowing of mobility, weight loss, and exhaustion,[142] but more recently the contribution of psychological, social and environmental factors to frailty have been acknowledged.[143] Consistently, longitudinal studies have reported that physical frailty also predicts the onset of future cognitive decline and dementia.[144] Frailty can progress through a number of stages[145] and is characterised by an inability to recover to baseline function after a minor stressor, such as an infection.[146]

Those who are frail are at increased risk of institutionalisation, morbidity and ultimately mortality, and generally experience a poorer quality of life than those who are not frail.[147] However, without a definitive diagnosis like cancer or heart disease that explains the physical decline, it is often the social, psychological and existential factors that cause the most distress.[148] The absence of a single underlying and diagnosable medical illness or disease means that it is more difficult to demarcate a point of physical decline where death becomes imminent in those who are frail.[149] Consequently, older frail people find themselves in an 'uncertain and dwindling process of dying'.[150]

2 Victoria, Western Australia, Model Bill and Oregon

Without a single underlying and diagnosable illness or disease, frailty does not provide a concrete medical condition that will cause death. This is required under

139 Matteo Cesari et al, 'Frailty: An Emerging Public Health Priority' (2016) 17(3) *Journal of the American Medical Directors Association* 188, 190.

140 Shelly Sternberg et al, 'The Identification of Frailty: A Systematic Literature Review' (2011) 59(11) *Journal of the American Geriatrics Society* 2129. Prevalence of frailty ranged from 5% to 58%: at 2131.

141 Danielle Taylor et al, 'Geospatial Modelling of the Prevalence and Changing Distribution of Frailty in Australia – 2011 to 2027' (2019) 123 *Experimental Gerontology* 57.

142 Linda P Fried et al, 'Frailty in Older Adults: Evidence for a Phenotype' (2001) 56(3) *Journal of Gerontology: Medical Sciences* M146.

143 RE Pel-Littel et al, 'Frailty: Defining and Measuring of a Concept' (2009) 13(4) *Journal of Nutrition, Health and Aging* 390, 392.

144 Marco Canevelli, Matteo Cesari and Gabor Abellan van Kan, 'Frailty and Cognitive Decline: How Do They Relate?' (2015) 18(1) *Aging: Biology and Nutrition* 1363.

145 See, eg, Kenneth Rockwood et al, 'A Global Clinical Measure of Fitness and Frailty in Elderly People' (2005) 173(5) *Canadian Medical Association Journal* 489.

146 Clegg et al (n 138).

147 Pel-Littel et al (n 143) 391.

148 Anna Lloyd et al, 'Physical, Social, Psychological and Existential Trajectories of Loss and Adaptation Towards the End of Life for Older People Living with Frailty: A Serial Interview Study' (2016) 16(1) *BMC Geriatrics* 176:1–15.

149 Ibid.

150 C Nicholson et al, 'Living on the Margin: Understanding the Experience of Living and Dying with Frailty in Old Age' (2012) 75(8) *Social Science and Medicine* 1426, 1427.

the *Victorian Act*,[151] *WA Act*[152] and *Oregon Act*,[153] and the Model Bill,[154] so access to VAD is not possible on the basis of frailty alone under these frameworks.

3 Canada

Individuals can and have received VAD in Canada on the basis of 'complex disease/clinical frailty'.[155] This would involve a determination that a person's frailty constitutes a serious and incurable illness, disease or disability, or that one or more of the person's underlying illnesses, diseases or disabilities contributing to their overall frailty were serious and incurable.[156] To access VAD, the person must also be in an 'advanced state of irreversible decline in capability' which could be caused by a person's frailty or other conditions.[157]

4 Summary

Access to VAD for frailty is not possible under the *Victorian Act*, *WA Act*, *Oregon Act* or the Model Bill. They require a specified medical condition that will cause death, and frailty does not meet this criterion. By contrast, in Canada, VAD for frailty is possible. Although a serious and incurable illness, disease or disability is required to access VAD, there is no need to demonstrate that it will cause death. Further, in Canada, the advanced state of irreversible decline in capability is assessed globally rather than requiring it to be caused by a particular condition, allowing consideration of a person's frailty holistically.

D Spinal Cord Injury

1 Nature of Condition

SCI is damage to the spinal cord resulting in loss of mobility or sensation. This encompasses both tetraplegia (previously called quadriplegia) and paraplegia. Tetraplegia is caused by an injury to the upper spinal cord, resulting in some degree of impairment to all four limbs and pelvic organs, and which may affect breathing. Paraplegia is an injury lower down the spinal cord, resulting in loss of function

151 *Victorian Act 2017* (Vic) s 9(1)(d)(ii).
152 *WA Act 2019* (WA) s 16(1)(c)(i).
153 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).
154 Model Bill (n 2) cl 9(e)(ii).
155 The most recent federal report on VAD in Canada indicates that 6.1% of deaths fall in the category of 'other condition', and notes that '[t]he category of "other conditions" includes a range of conditions, with frailty commonly cited': *Canadian First Annual Report* (n 9) 22. Data from British Columbia also indicate some VAD deaths in Canada are due to frailty. From 2016–2018 on Vancouver Island, 6.3% of VAD deaths were reported as having 'complex disease/frailty' as the underlying illness: W David Robertson and Rosanne Beuthin, *A Review of Medical Assistance in Dying on Vancouver Island: The First Two Years: July 2016–2018* (Report, November 2018) 6. Likewise, data from VAD assessments in British Columbia indicated four individuals with 'extreme frailty' (and an average age of 92.3 years) had medically assisted deaths: Ellen Wiebe et al, 'Reasons for Requesting Medical Assistance in Dying' (2018) 64(9) *Canadian Family Physician* 674, 676.
156 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).
157 Ibid s 241.2(2)(b).

from the chest down, sparing the arms.[158] SCI can affect sensation, control of the limbs and bowel and bladder function. This can be complete or incomplete.[159] SCI may be caused by a single traumatic incident, such as an accident, injury, stroke, or as a complication of medical care or surgery.[160] It may also result from the progression of a degenerative disease such as multiple sclerosis. The following discussion focusses on stable SCI, not degenerative SCI.[161]

The further up the spinal cord the injury occurs, the more serious the symptoms of SCI. Some individuals with tetraplegia require a ventilator to breathe,[162] but many do not. Some require artificial nutrition and hydration, but others are able to ingest food and drink orally.[163] Some are completely paralysed from the neck down, whereas others have partial movement in their arms and hands.[164] Many are wheelchair-bound, but others retain limited mobility.[165]

The prevalence of SCI in Australia is less than 0.1% of the population.[166] SCIs are generally persisting conditions[167] which are neither progressive nor fatal, but people with SCI have a higher mortality rate and lower life expectancy.[168] They appear to be more susceptible to diseases such as pneumonia, influenza and heart disease.[169]

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158 Steven C Kirshblum et al, 'International Standards for Neurological Classification of Spinal Cord Injury (Revised 2011)' (2011) 34(6) *Journal of Spinal Cord Medicine* 535.

159 This is sometimes referred to as 'complete' or 'incomplete' paralysis, using the American Spinal Injury Association Impairment Scale: Timothy T Roberts, Garrett R Leonard and Daniel J Cepela, 'Classifications in Brief: American Spinal Injury Association (ASIA) Impairment Scale' (2017) 475(5) *Clinical Orthopaedics and Related Research* 1499.

160 For the causes of SCI in Australia, see Amanda Tovell, *Spinal Cord Injury, Australia, 2014–15* (Report, Australian Government, Australian Institute of Health and Welfare, Injury Research and Statistics Series No 113, Catalogue No INJCAT 202, 16 May 2018) vi, 39 ('*SCI, Australia Statistics*').

161 Where a person has a progressive SCI due to a degenerative disease such as multiple sclerosis or a cancerous tumour, eligibility for VAD will be determined by the underlying condition of which the SCI is a symptom.

162 Rita Galeiras Vázquez et al, 'Respiratory Management in the Patient with Spinal Cord Injury' (2013) *BioMed Research International* 168757:1–12.

163 Ginette Thibault-Halman et al, 'Acute Management of Nutritional Demands after Spinal Cord Injury' (2011) 28(8) *Journal of Neurotrauma* 1497.

164 Christopher S Ahuja et al, 'Traumatic Spinal Cord Injury: Repair and Regeneration' (2017) 80(3 Supp 1) *Neurosurgery* S9.

165 Jan Mehrholz, Joachim Kugler and Marcus Pohl, 'Locomotor Training for Walking After Spinal Cord Injury' (2012) 11 *Cochrane Database of Systemic Reviews* CD006676:1–42.

166 World Health Organization, The International Spinal Cord Society and Jerome Bickenbach (ed), *International Perspectives on Spinal Cord Injury* (Report, 2013) 15–16 ('*International Perspectives on SCI*'). The figure for non-traumatic SCI is based on data from Victoria only, extrapolated to the rest of the country, and includes both children and adults. See generally PJ O'Connor, 'Prevalence of Spinal Cord Injury in Australia' (2005) 43 *Spinal Cord* 42.

167 Tovell, *SCI, Australia Statistics* (n 160) 2, 4.

168 Ibid 2.

169 *International Perspectives on SCI* (n 166) 24–5; JW Middleton et al, 'Life Expectancy After Spinal Cord Injury: A 50-Year Study' (2012) 50 *Spinal Cord* 803; RJ Soden et al, 'Causes of Death After Spinal Cord Injury' (2000) 38 *Spinal Cord* 604.

2 Victoria and Western Australia

Under the *Victorian Act* and *WA Act*, people with SCI will not generally be eligible for VAD, because both statutes specifically state that a person is not eligible for VAD only because of disability.[170]

3 Model Bill

The Model Bill, unlike the *Victorian Act* and *WA Act*, does not specifically exclude people with disability from accessing VAD, but a person with a stable SCI will still be ineligible for VAD. Although their SCI is incurable, it is not progressive.[171]

4 Oregon

In Oregon, a person with SCI would not qualify for VAD on that basis as the legislation states that no person shall qualify for assistance to die 'solely because of … disability'.[172]

5 Canada

Individuals with SCIs as their sole underlying medical condition may be eligible for VAD in Canada if they are in an 'advanced state of irreversible decline in capability'.[173] Tetraplegia and paraplegia are serious and incurable disabilities. In the Canadian case of *Truchon v Procureur Général du Canada*, two wheelchair-bound individuals with serious and incurable disabilities were held to be eligible to access VAD.[174] However, both plaintiffs in that case had degenerative conditions,[175] not a stable SCI (the focus of this section). It is less clear whether a person satisfies the criterion of 'an advanced state of irreversible decline in capability' where the person has an SCI which involves a significant loss of function but is not progressive or degenerative. Some commentators, such as Jocelyn Downie and Jennifer Chandler, consider a decline in capability as a result of an SCI which has since stabilised to satisfy this criterion, whereas others believe the decline must be ongoing.[176]

170 *Victorian Act 2017* (Vic) s 9(3); *WA Act 2019* (WA) s 16(2).
171 Model Bill (n 2) cls 9(e)(i)–(ii).
172 *Oregon Act*, Or Rev Stat § 127.805(2) (1994).
173 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).
174 *Truchon* [2019] QCCS 3792.
175 Jean Truchon had cerebral palsy coupled with degenerative spinal stenosis and myelomalacia, and Nicole Gladu suffered from degenerative post-polio syndrome.
176 White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(2)(b). Note, however, if a person with an SCI refuses life-sustaining medical treatment (or preventive care where the refusal leads to the need for life-saving medical treatment), this would eventually put them into an advanced state of irreversible decline and would be likely to render them eligible for VAD: see Jocelyn Downie and Matthew Bowes, 'Refusing Care as a Legal Pathway to Medical Assistance in Dying' (2019) 2(2) *Canadian Journal of Bioethics* 73.

6 Summary

A person with SCI will not be eligible for VAD on that basis in Victoria, Western Australia or Oregon because those jurisdictions specifically exclude disability as the sole reason for access to VAD. Under the Model Bill, a person with a stable SCI will also not be eligible for VAD, because the condition is not progressive. In Canada, however, a person with a stable SCI may be eligible for VAD if the eligibility criteria are interpreted to include a 'decline in capability' which has since stabilised, although the position is not yet resolved.

E Huntington's Disease

1 Nature of Condition

Huntington's disease ('Huntington's') is a progressive neurodegenerative disease, characterised by constant and uncontrollable jerking motions along with behavioural changes and cognitive decline.[177] This article considers adult-onset Huntington's, which typically develops between 30 to 50 years of age,[178] however it can manifest at any age from infancy.[179] If one parent has Huntington's, a child has a 50% chance of developing the condition.[180] It is incurable[181] and death typically occurs around 15 to 25 years after the first symptoms, usually from disease complications (such as pneumonia).[182]

Traditionally, five stages of Huntington's are used in research: early, early intermediate, late intermediate, early advanced and advanced.[183] Clinically, three stages – early, middle and late stages – are more often used. It is likely that during the middle to late stages, a person would lose decision-making capacity and lose independence in daily activities.[184]

177 Sara Parodi and Maria Pennuto, 'Huntington's Disease: From Disease Pathogenesis to Clinical Perspectives' in Kevin Guillory and Alex M Carrasco (eds), *Huntington's Disease: Symptoms, Risk Factors and Prognosis* (Nova Science Publishers, 2013) 1.

178 National Institute of Neurological Disorders and Stroke, 'Huntington's Disease: Hope Through Research' (Publication, NIH Publication No 17-NS-19, 31 December 2018) 5 <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Huntingtons-Disease-Hope-Through>.

179 Francis O Walker, 'Huntington's Disease' (2007) 369(9557) *Lancet* 218, 218.

180 Ian Freckelton, 'The Legal Ramifications of Huntington's Disease' in Kevin Guillory and Alex M Carrasco (eds), *Huntington's Disease: Symptoms, Risk Factors and Prognosis* (Nova Science Publishers, 2013) 93, 96.

181 Ibid 98.

182 Ibid 97.

183 The Huntington's Disease Functional Capacity Scale was developed by Ira Shoulson: Ira Shoulson and Stanley Fahn, 'Huntington Disease: Clinical Care and Evaluation' (1979) 29 *Neurology* 1, 2; Ira Shoulson, 'Huntington Disease: Functional Capacities in Patients Treated with Neuroleptic and Antidepressant Drugs' (1981) 31(10) *Neurology* 1333.

184 'How Does Huntington's Disease Progress?', *Huntington's NSW and ACT* (Web Page, 2019) <https://webarchive.nla.gov.au/awa/20160301160906/http://www.huntingtonsnsw.org.au/information/hd-facts/how-does-huntingtons-disease-progress>. See Ian Freckelton, 'Huntington's Disease and the Law' (2010) 18(1) *Journal of Law and Medicine* 7.

2 Victoria and Western Australia

Huntington's is an incurable disease (required in Victoria only),[185] which is progressive and will cause death. When a person has a prognosis of 12 months until death, the disease will be in the 'late' stage, so will satisfy the 'advanced' criterion. However, at this point, the person would likely have lost decision-making capacity. As with Alzheimer's disease, these two criteria cannot be fulfilled simultaneously, precluding access to VAD.

3 Model Bill

There will be a similar outcome under the Model Bill. While the Model Bill does not require a prognostic timeframe, the disease must still be 'advanced'.[186] This is likely to be the case only when Huntington's has reached the 'late' stage, at which point a person would have lost decision-making capacity.

4 Oregon

A person with Huntington's will not be eligible for VAD in Oregon. The disease is 'incurable and irreversible',[187] but the person will likely not retain capacity at the point when the disease is expected to 'produce death within six months'.[188]

5 Canada

Huntington's is a 'serious and incurable' disease so eligibility for VAD depends on whether the patient will be in an 'advanced state of irreversible decline in capability'.[189] Particularly if this criterion is assessed by reference to the individual's prior capability rather than an objective standard,[190] a person may reach an advanced state of irreversible *physical* decline relatively early in the disease process. This criterion may therefore be satisfied in the middle stage of Huntington's, rather than the advanced stage. If a person with Huntington's retains decision-making capacity at that point, they will be able to access VAD.

Additionally, if a person wants to access VAD after losing decision-making capacity, they will be able to make arrangements under the final consent waiver provisions for VAD to be provided then. This is possible because Huntington's makes a person's natural death reasonably foreseeable (a condition for the exercise of the final consent waiver provision).[191]

185 *Victorian Act 2017* (Vic) s 9(1)(d)(ii).
186 Model Bill (n 2) s 9(e)(ii).
187 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).
188 Ibid § 127.805(1).
189 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(2)(a)–(b).
190 *IRPP Report* (n 16). See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(2)(b).
191 See *IRPP Report* (n 16).

6 Summary

A person with Huntington's will not be eligible for VAD in Victoria, Western Australia, under the Model Bill or in Oregon. The person will likely not have decision-making capacity at the requisite advanced stage of the disease, or when prognostic timelines are satisfied. By contrast, the Canadian *Criminal Code*'s framing of the person being in an 'advanced state of irreversible decline of capability',[192] rather than the condition itself being advanced, means access to VAD is possible. The physical symptoms of a person's Huntington's may have reached such a point while the person retains decision-making capacity. Also significant in Canada, given the known trajectory of Huntington's, a person may choose to exercise the final consent waiver provision to access VAD after losing capacity.

IV COMPARATIVE ANALYSIS OF ELIGIBILITY OF DIFFERENT MEDICAL CONDITIONS

This section undertakes a holistic comparative analysis of eligibility for VAD for each of the nine medical conditions across the five legal models. This comparative *practical* analysis (as opposed to the earlier comparative legal analysis[193]) is aided by Table 1 (below). This table cannot comprehensively represent all of the foregoing discussion and so focuses on those aspects critical for possible access to VAD.

We also mention two other limitations. The first is that this analysis is based on the nine medical conditions examined; other conditions may reveal other issues. The second is that because this is primarily a comparative analysis, it does not provide the basis to reach firm conclusions about what constitutes an optimal VAD model.[194] Differences observed between VAD models do not, without more, indicate which model is better or worse. However, the findings below relating to eligibility will facilitate a further (and deeper) consideration of VAD law and practice. As part of this, some comparisons reveal potentially undesirable outcomes.

192 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

193 White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1).

194 Although we note that two of the authors have done this in relation to the Model Bill: see (n 2).

Table 1 Is Access to VAD Possible? Comparative Analysis of Eligibility for Nine Medical Conditions across Five Legal Frameworks

Condition/ Jurisdiction	Victoria	Western Australia	Model Bill	Oregon	Canada
Medical Conditions for Which Access to VAD is Possible under All Frameworks					
Colorectal Cancer	Yes, by later stages and once death expected within 6 months	Yes, by later stages and once death expected within 6 months	Yes, by later stages and without curative options	Yes, once death expected within 6 months and without curative options	Yes, once no curative options the person will accept, and person in advanced state of irreversible decline in capability
Motor Neurone Disease ('MND')	Yes, once death expected within 12 months, provided capacity retained	Yes, once death expected within 12 months, provided capacity retained	Yes, once condition is advanced, provided capacity retained	Yes, once death expected within 6 months, provided capacity retained	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*
Chronic Obstructive Pulmonary Disease ('COPD')	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, once condition is advanced and will cause death, provided capacity retained	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*
Chronic Kidney Disease ('CKD')	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained.	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*

Medical Conditions for Which Access to VAD is Very Unlikely in Most Jurisdictions (exceptions are in bold)					
Alzheimer's Disease	Very unlikely because capacity not retained when death expected within 12 months	Very unlikely because capacity not retained when death expected within 12 months	Very unlikely because capacity not retained when condition becomes advanced	Very unlikely because capacity not retained when death expected within 6 months	**Possible** if person retains decision-making capacity (or final consent waiver)* when in an advanced state of irreversible decline in capability
Anorexia	No, because a mental illness. Remote possibility for severe cases on basis of physical sequalae, provided capacity retained	No, because a mental illness. Remote possibility for severe cases on basis of physical sequalae, provided capacity retained	Possible but highly unlikely because capacity in doubt if other eligibility requirements met	No, because a mental illness 'impairing judgment'	**Possible** only if physical sequelae constitute 'a serious and incurable illness, disease or disability', and only if have capacity at that point (or final consent waiver)* Possible even where sole underlying medical condition after 17 March 2023 (when exclusion of mental illness is repealed)
Frailty	No, because no single medical condition will cause death	No, because no single medical condition will cause death	No, because no single medical condition will cause death	No, because no single medical condition will cause death	**Yes**, if person is in advanced state of irreversible decline in capability
Spinal Cord Injury ('SCI')	No, because a disability	No, because a disability	No, because not progressive	No, because a disability	**Probably**, if person interpreted to be in advanced state of irreversible decline in capability
Huntington's Disease	No, because capacity not retained when death expected within 12 months	No, because capacity not retained when death expected within 12 months	No, because capacity not retained when condition becomes advanced	No, because capacity not retained when death expected within 6 months	**Yes**, if person retains capacity (or final consent waiver)* when they are in an advanced state of irreversible decline in capability

***** Where a person's natural death is reasonably foreseeable, a final consent waiver is possible in Canada, provided the person meets the eligibility criteria for VAD. This is noted in Table 1 only in relation to cases where loss of decision-making capacity was discussed in the text.

A Access to VAD Shows a Clear Distinction between the Canadian Model and All Other Models

Two clear overall conclusions emerge from the comparative practical analysis. The first is that there is a great deal of similarity across the Victorian, Western Australian, Model Bill and Oregonian frameworks in terms of access to VAD, despite significant differences in terms of whether a disease must be 'incurable' or whether death must be expected within a particular timeframe. The second is that access to VAD is much broader in Canada.

All five frameworks contemplate VAD for colorectal cancer, MND, COPD and CKD. Access is less straightforward for medical conditions with uncertain trajectories to death such as COPD and CKD, but is nonetheless possible. This is not to say, however, that timing of access to VAD is the same. Generally, access is available latest in Oregon (always six months) and in Victoria and Western Australia (generally six months but 12 months for neurodegenerative conditions). The Model Bill provides earlier access for these medical conditions as the Bill does not stipulate that death must be anticipated within a specified time limit, and indeed this helps avoid some issues with predicting timing of death for conditions with uncertain trajectories. The Canadian framework provides the earliest access to VAD for these conditions: whenever a person has reached an 'advanced state of irreversible decline in capability', which is interpreted broadly.

Our analysis demonstrates that the other medical conditions considered (Alzheimer's, anorexia, frailty, SCI and Huntington's) are generally precluded from VAD under the eligibility criteria in the *Victorian Act*,[195] *WA Act*[196] and *Oregon Act*,[197] and the Model Bill.[198] But the position is different under Canadian law where access is possible (and sometimes probable) for all of these medical conditions. The eligibility criteria in the Canadian *Criminal Code*[199] are broader, due to three (interrelated) factors.

The first is that access to VAD does not depend on proximity or likelihood of death. The second is that to establish a 'grievous and irremediable medical condition',[200] the Canadian criteria do not require a causal connection between the 'serious and incurable illness, disease or disability' and the 'advanced state of irreversible decline in capability'.[201] By contrast, the other frameworks require that the condition *cause* the relevant outcome (death in those models). The third factor is that the requirement that a person's condition is 'advanced' is framed differently: Canadian law requires an advanced decline in *capability of the person*,[202] whereas other models assess whether the person's *medical condition* itself has reached an advanced state. These last two features mean that a person's advanced state of

195 *Victorian Act 2017* (Vic) s 9.
196 *WA Act 2019* (WA) s 16.
197 *Oregon Act*, Or Rev Stat § 127.805 (1994).
198 Model Bill (n 2) cl 9.
199 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(1).
200 Ibid s 241.2(1)(c).
201 Ibid ss (2)(a)–(b).
202 Ibid s 241.2(2)(b).

irreversible decline in capability can be assessed globally, taking into account their entire health status and all possible medical conditions (not just the qualifying condition).

B Impact of Time Limits until Death on Access to VAD

Eligibility criteria address not only the question of *whether* VAD can be accessed, but *when*. This comparative practical analysis demonstrates the impact of including an eligibility requirement that a person be expected to die within a specified time period. This is best illustrated by comparing access to VAD under the *Victorian Act*[203] (a time limit of six and sometimes 12 months until death) with the Model Bill[204] (very similar eligibility criteria, but no time limit, requiring only that the condition cause death). For eight of the nine conditions considered in this article, potential eligibility under the Model Bill was the same as in Victoria.[205] The sole possible exception was for anorexia, which possibly could be eligible under the Model Bill (although highly unlikely) since it does not specifically exclude mental illness. In other words, the six or 12 month time limit until death in Victoria had no impact on restricting the medical conditions that would permit access to VAD when compared with the Model Bill. This is because the Model Bill's requirement for a person's medical condition to be 'advanced' constrains access to similar cases.[206]

This raises questions about the utility of requiring a time until death in VAD eligibility criteria. If the purpose is to exclude access to VAD for certain medical conditions, then it does not appear to be necessary, at least in relation to these medical conditions. However, if the purpose is to reserve VAD only for those who are at the end of their lives,[207] it is effective. One of the conclusions of this comparative analysis is that the time limits in the *Victorian Act*, *WA Act* and *Oregon Act* restrict access to a later stage in a person's medical condition than under the Model Bill.

Such a time-based approach has a number of undesirable outcomes. One examined above is the difficulty a time limit can cause for prognostication, particularly for medical conditions with an unpredictable trajectory to death. This can mean that a person whose condition will cause death may not be eligible because the nature of their illness does not provide a reliable guide to how far away their death may be. Another undesirable outcome is the additional suffering that a person, who is otherwise eligible for VAD, must endure while waiting to

203 *Victorian Act 2017* (Vic) s 9(1)(d)(iii).

204 Model Bill (n 2) cl 9(e).

205 This same result also applies in relation to the *WA Act 2019* (WA) s 16(1)(c)(ii) and *Oregon Act*, Or Rev Stat § 127.800(12) (1994). The rationale for the specific comparison between the *Victorian Act* and the Model Bill is the relevant wording of the eligibility criteria in the two frameworks is almost identical but for the imposition of a time limit until death in Victoria.

206 Model Bill (n 2) cl 9(e)(ii).

207 Indeed, the intention of the *Victorian Act* was that VAD would only be available for those people who are 'close to death' and at the 'end of life': *MAP Report* (n 38) 13–14.

fall within the prescribed proximity until death.[208] Requiring a specified time limit until death also risks preventing otherwise eligible people from accessing VAD, if the delay until death is approaching means that they are no longer well enough to navigate the assessment process. We consider that jurisdictions contemplating reform should reflect on these undesirable outcomes and whether a specified time limit until death is justifiable.

C Impact of Decision-Making Capacity on Medical Conditions that Will Permit Access to VAD

All five frameworks require a person to have decision-making capacity to access VAD. Capacity issues specifically arose in six of the nine conditions considered: MND, COPD, CKD, Alzheimer's, anorexia and Huntington's.[209] The progression of some conditions can have a consequential impact on decision-making capacity. For example, COPD can cause a lack of oxygen to the brain. For other conditions, such as Alzheimer's and Huntington's, a lack of decision-making capacity is a defining feature of the condition and a key reason why VAD is generally not permitted for these conditions (except in Canada).

This demonstrates the significant implications that decision-making capacity has for access to VAD. Advance directives or requests for VAD have been proposed as a mechanism to address these issues, but there have been challenges with the uptake and useability of such tools in jurisdictions where they are lawful and for which there are data.[210] Nevertheless, community desire remains high for mechanisms to support access to VAD for conditions such as Alzheimer's after a loss of capacity.[211] This has led to some jurisdictions specifically identifying

208 Ben P White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal 417, 433 ('Does the VAD Act Reflect Its* Stated Policy Goals?').

209 Of course, even for conditions which do not of themselves specifically impair capacity, the progression of those conditions or side effects can raise capacity issues, for example pain and symptom management can require taking medication that can impair capacity.

210 Research also suggests advance directives or requests for VAD are often not followed in practice: Marike E de Boer et al, 'Advance Directives for Euthanasia in Dementia: Do Law-Based Opportunities Lead to More Euthanasia?' (2010) 98(2–3) *Health Policy* 256; Mette L Rurup et al, 'Physicians' Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands' (2005) 53(7) *Journal of the American Geriatrics Society* 1138. Use of these directives remains controversial: Paul Mevis et al, 'Advance Directives Requesting Euthanasia in the Netherlands: Do They Enable Euthanasia for Patients Who Lack Mental Capacity?'(2016) 4(2) *Journal of Medical Law and Ethics* 127; Karin R Jongsma, Marijke C Kars and Johannes JM van Delden, 'Dementia and Advance Directives: Some Empirical and Normative Concerns' (2019) 45(2) *Journal of Medical Ethics* 92; David Gibbes Miller, Rebecca Dresser and Scott YH Kim, 'Advance Euthanasia Directives: A Controversial Case and Its Ethical Implications' (2019) 45(2) *Journal of Medical Ethics* 84. There is not yet any data in Canada for advance requests made through 'final consent – waiver' or 'advance consent – self administration' (under ss 241.2(3.2), (3.5) of the Canadian *Criminal Code*, RSC 1985, c C-46).

211 People with Alzheimer's desire to have access to assisted dying, including via advance directives: Alzheimer's Australia Victoria, 'A Good Death is My Right' (Discussion Paper, April 2017) 9–10; Dementia Australia, Ministerial Expert Panel on Voluntary Assisted Dying: A Response from Dementia Australia, *Ministerial Expert Panel on Voluntary Assisted Dying* (May 2019) 7; *Queensland Parliamentary Report* (n 3) 123–5.

this issue as warranting further consideration.[212] We support this, and recommend jurisdictions contemplating reform actively investigate how this complex policy issue could be addressed. Some recognition of the desire for VAD after loss of capacity is found in Canada through the final consent waiver. The '10 minutes to midnight' approach for assessing capacity of individuals with dementia has been another Canadian response to this issue (although it maintains the requirement that a person has capacity immediately prior to the provision of VAD).

D Impact of Excluding Types of Medical Conditions from Access to VAD

A legislative drafting device employed in some VAD frameworks is excluding particular categories of conditions from access to VAD. The two excluded conditions in these frameworks are disability (Victoria, Western Australia and Oregon)[213] and mental illness (all frameworks except the Model Bill).[214] One limitation of this analysis is that only one type of mental illness (anorexia) and one disability (SCI) were considered. More robust testing is needed in relation to a range of mental illnesses and disabilities but this comparative analysis does identify some important questions.

Excluding disability as a ground for VAD under some statutes did not create different outcomes between those laws and the Model Bill for stable SCI. In relation to anorexia, however, there may be a different outcome. Under the Model Bill, access to VAD, though highly unlikely, may be possible for a small cohort of persons with severe and enduring anorexia whose illness is objectively considered to be incurable, is advanced and progressive and likely to cause death. (However, the person, despite the severity of their condition, must retain capacity to seek VAD and this is highly unlikely.) Although these criteria are identical in the *Victorian Act*, and very similar in the *WA Act*, the specific exclusion of mental illness in those jurisdictions likely precludes access to VAD, assuming that the physical sequelae of the illness are not considered a separate terminal condition providing access.

As mentioned, more analysis is needed to assess access to VAD for a range of mental illnesses. We note that anorexia is atypical of mental illnesses, in that it can result in life-threatening physical conditions which can be fatal. But this analysis

212 In Canada, the Minister of Justice and the Minister of Health were required to initiate an independent review into advance requests for VAD within six months of the initial legislation passing: Bill C-14, 1st Sess, 42nd Parl, 2016, cl 9.1(1). The result was the following report: Council of Canadian Academies, *The State of Knowledge on Advance Requests for Medical Assistance in Dying: The Expert Panel Working Group on Advance Requests for MAiD* (Report, 12 December 2018). This issue will again be considered during a Parliamentary review in response to Bill C-7: Department of Justice, 'Canada's New Medical Assistance in Dying (MAID) Law', *Government of Canada* (Web Page, 19 March 2021) <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html>. In Queensland, the parliamentary committee inquiring into VAD recommended further research into the issue of advance requests for VAD by persons with dementia: *Queensland Parliamentary Report* (n 3) 127 'Recommendation 7'. See also the 'Statement of Reservation' of Michael Berkman MP, supporting further research into this issue: at 197–8.

213 *Victorian Act 2017* (Vic) s 9(3); *WA Act 2019* (WA) s 16(2); *Oregon Act*, Or Rev Stat § 127.805(2) (1994).

214 *Victorian Act 2017* (Vic) s 9(2); *WA Act 2019* (WA) s 16(2); *Oregon Act*, Or Rev Stat § 127.825 (1994). The exclusion of access to VAD on the basis of mental illness in Canada is proposed in Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 1(2) (as passed by the House of Commons 17 March 2021), amending Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2.1).

invites the question whether a blanket exclusion from access to VAD based on mental illness is justifiable when the eligibility criteria are otherwise met.[215]

V IMPLICATIONS OF ANALYSIS OF MEDICAL CONDITIONS FOR DESIGN OF VAD REGULATION

The comparative legal analysis in the first article[216] in this two-part series identified important implications for designing VAD regulation. This Part extends that work and focuses on what the comparative *practical* analysis of access to VAD for different medical conditions reveals about design of VAD regulation.

A Test Eligibility Criteria in Relation to Medical Conditions to Ensure Criteria Operate as Intended

The purpose of eligibility criteria is to determine who will and will not be permitted to access VAD. Careful testing of these criteria by reference to a wide range of medical conditions prior to legislating enables policymakers to determine if the proposed criteria will operate in practice as intended. As the analysis presented here demonstrates, it also highlights whether when criteria are applied holistically (see below), there are some criteria that may be redundant. An example might be a specified time until death (as discussed above), depending on policymakers' intent. Evaluating which medical conditions could facilitate access to VAD should also continue *after* a VAD law is passed. Such a review requires robust data collection including about who is accessing VAD and on the basis of which medical conditions. Such data should also include who is being refused access to VAD and the role (if any) of individuals' medical conditions in those decisions.

B Eligibility Criteria Operate Holistically

As observed in the preceding article, eligibility criteria in VAD frameworks are intended to operate holistically.[217] This was clear on the face of the legislation and from the comparative legal analysis, but became particularly apparent when these

215 Udo Schuklenk and Suzanne van de Vathorst, 'Treatment-Resistant Major Depressive Disorder and Assisted Dying' (2015) 41(8) *Journal of Medical Ethics* 577; Justine Dembo, Udo Schuklenk and Jonathan Reggler, '"For Their Own Good": A Response to Popular Arguments Against Permitting Medical Assistance in Dying (MAiD) where Mental Illness Is the Sole Underlying Condition' (2018) 63(7) *Canadian Journal of Psychiatry* 451; Isra Black, 'Suicide Assistance for Mentally Disordered Individuals in Switzerland and the State's Positive Obligation to Facilitate Dignified Suicide' (2012) 20(1) *Medical Law Review* 157, 164–5. Note also the Canadian Council of Academies work on mental illness as sole underlying medical condition to access VAD: Council of Canadian Academies, *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition: The Expert Panel Working Group on MaiD Where a Mental Disorder is the Sole Underlying Medical Condition* (Report, 12 December 2018). The Canadian government will commission an independent expert review into the requisite protocols, guidance and safeguards to apply to VAD requests based on mental illness as a sole underlying condition, with recommendations due by 17 March 2022: Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 3.1 (as passed by the House of Commons 17 March 2021).

216 White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1).

217 Ibid Part IV(C).

criteria were applied to the nine medical conditions. An illustration of this is that differently formulated eligibility criteria can achieve the same result in terms of which medical conditions permit access to VAD.

For example, in Victoria and under the Model Bill,[218] a person's condition must be 'incurable', but this is not required in Western Australia. In Victoria and Western Australia, doctors must prognosticate about time until death, but this is not required in the Model Bill.[219] Yet across these three frameworks, applying the criteria holistically, the same medical conditions provided access to VAD (save perhaps a possible difference in the exceptional case of anorexia). This is because the absence of one aspect of the criteria in a particular framework was compensated for by the collective operation of the other components. This should alert policymakers to consider whether each individual criterion is required, or whether a particular criterion may be redundant given the presence of other, determinative, factors.

A holistic application of eligibility criteria means not only applying all criteria concurrently but also considering causal relationships between them. Systematically applying five frameworks to nine selected medical conditions revealed how causal relationships between criteria (or their absence) have a significant impact on access to VAD. All frameworks except Canada require a causal relationship between the person's medical condition and expected death, which narrows eligibility. In contrast, the Canadian model does not require a causal link between the 'serious and incurable condition' and the 'advanced state of irreversible decline' a person experiences.[220] As a result of this (and other factors), access to VAD in Canada is broader than under the other frameworks.

C Challenge of Translating Policy Goals into Legislation

The challenges of designing VAD legislation that reflects its desired policy goals and is capable of being consistently interpreted and applied as intended were noted earlier in the comparative legal analysis.[221] These challenges were further illuminated by applying the five frameworks to the nine medical conditions. In relation to reflecting policy goals, crafting eligibility criteria that are not either over-inclusive or under-inclusive when compared with the objectives underpinning the law presents a specific challenge for rule design.[222] In other words, there is a risk

218 *Victorian Act 2017* (Vic), s 9(1)(d)(i); Model Bill (n 2) cl 9(e)(i).

219 *Victorian Act 2017* (Vic), ss 9(1)(d)(iii) and 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii); Model Bill (n 2) cl 9(e).

220 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a)–(b).

221 White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part IV(A); Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163.

222 Yeung (n 221) 168. A discussion of the policy goals underpinning these frameworks is beyond the scope of this paper. The principles guiding the Victorian VAD law are contained in *MAP Report* (n 38) 43–6 and evaluated in White et al, '*Does the VAD Act Reflect its* Stated Policy Goals?' (n 208). In relation to Western Australia, see Ministerial Expert Panel on Voluntary Assisted Dying, Department of Health (WA), *Final Report* (Report, 27 June 2019). The values underpinning the model Bill are set out in Model Bill (n 2) 6; Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform' in Ian Freckelton and Kerry Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479. The Canadian law is based on *Charter* rights as identified in the *Charter* (n 5).

that individuals whom the policy intent was to permit access to VAD are excluded by the legislation, or a risk that those whom the intent was to exclude from VAD can obtain access.

This was demonstrated in the comparative practical analysis where mental illness is specifically excluded as a basis for VAD. To some extent, this is an attempt to create a clear rule and certainty in relation to eligibility (putting aside definitional questions such as what constitutes a mental illness and how to characterise any physical sequelae). By preferencing certainty through directly excluding a category of cases, the difficulty of determining whether a person with a mental illness could otherwise qualify for VAD is avoided. But this may not be consistent with the law's overall policy goals as reflected in the generic eligibility criteria (or at least reflects inconsistency within those goals) and risks under-inclusion.

This is illustrated in Victoria where the Ministerial Advisory Panel, whose recommendations underpinned the Act, supported a blanket exclusion of access to VAD on the basis of mental illness 'because it is not a medical condition that "will cause death"'[223] and, therefore, could not satisfy the eligibility criteria. However, this is inconsistent with the analysis above in relation to at least one mental illness: anorexia, which is capable of causing death in severe cases. If the Panel was intending only to use the blanket exclusion as a clear means of confirming the operation of the eligibility criteria, then this may not be the intended result. Further, the Panel's stated policy intent was: 'To ensure people with mental illness are afforded the same rights and protections as other members of the community and that people with mental illness who meet all of the eligibility criteria are not unreasonably denied access to voluntary assisted dying'.[224] The explicit exclusion of mental illness may be inconsistent with this stated policy intent. If the intention was to exclude mental illness because such conditions were considered an inappropriate basis to access VAD, then this additional exclusion warrants express justification at a policy level.

The other major regulatory challenge in relation to the five VAD frameworks relates to rule indeterminacy and interpretation.[225] In the process of applying the various eligibility criteria to nine medical conditions, it became clear that how and when some criteria were met for particular conditions was not straightforward. Examples include: when does a medical condition become 'advanced' and 'progressive', and what constitutes an 'advanced state of irreversible decline in capability'? But even requirements such as an expected time until death, which can ostensibly appear more concrete and certain, have been shown to be unclear and difficult to apply in practice in some situations. Indeed, challenges of prognostication could mean that determining likely time until death is more uncertain than other eligibility criteria, such as for particular conditions that have strong clinical criteria for determining when they become 'advanced' and 'progressive'.

This breadth in interpreting the criteria could be seen as positive because this permits some flexibility for doctors to apply them to individual patients in

223 *MAP Report* (n 38) 81.
224 Ibid 82.
225 Yeung (n 221) 168–9.

a meaningful way. However, this ambiguity may lead to doctors (and regulators) applying these concepts inconsistently in practice. This is a known challenge not only in designing VAD laws but in regulation more generally.[226] Another concern is that where there is uncertainty, eligibility criteria may be applied conservatively to avoid possible liability. A response to these concerns is to provide other support to guide consistent application of the criteria in practice that aligns with the framework's intent.

D Developing Guidance and Support to Interpret VAD Frameworks

Consistent interpretation of VAD frameworks to advance the intended policy goals is desirable. The comparative analysis of the medical conditions revealed how, particularly for conditions for which eligibility may be difficult to assess, it may be desirable to develop guidance about implementation of VAD frameworks in practice. From a legal perspective, clarification of legislation often occurs via case law and this has occurred in Canada during the relatively short period that VAD has been in operation.[227] However, this may not occur; we are not aware of any cases interpreting Oregon's law, despite being operational for over 20 years. Further, courts can only address issues raised by the parties' factual situation, not every situation where interpretive clarification is needed. Reliance on judicial clarification is also problematic as by definition the individuals concerned are seriously ill and suffering, and may not be able or have time to pursue legal challenges through courts.

Accordingly, other tools of regulation are needed to guide decision-making under the VAD frameworks. In Canada, guidelines and policies have been produced by medical regulators and the Canadian Association of MAiD Assessors and Providers.[228] Decisions by regulators in particular cases, if made public by the regulator or the clinician investigated, may also contribute to interpretation of statutory provisions.[229] And one of the authors, academic Jocelyn Downie, has

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226 Ibid 168–70; Lutz-Christian Wolff, 'Law and Flexibility: Rule of Law Limits of a Rhetorical Silver Bullet' (2011) (11) *Jurisprudence* 549.

227 Judicial interpretation of the Canadian legislative criteria has occurred in one case *AB v Canada (Attorney-General*) [2017] ONSC 3759 (meaning of 'natural death has become reasonably foreseeable'). In Victoria, the Victorian Civil and Administrative Tribunal has interpreted the meaning of the 'residence' criterion in the *Victorian Act*: *NTJ v NTJ (Human Rights)* [2020] VCAT 547. We also note that clarification of legislation can also occur by amending the legislation itself.

228 For example, Canadian Association of MaiD Assessors and Providers, 'The Clinical Interpretation of 'Reasonably Foreseeable'' (Clinical Practice Guideline, June 2017); Canadian Association of MAiD Assessors and Providers, *Assessment for Capacity to Give Informed Consent for Medical Assistance in Dying (MAiD) Review and Recommendations* (White Paper, April 2020); Canadian Association of MAiD Assessors and Providers, 'Medical Assistance in Dying (MAiD) in Dementia' (Clinical Guideline, May 2019); College of Physicians and Surgeons of Nova Scotia, 'Professional Standard Regarding Medical Assistance in Dying (MAiD)' (Guideline, 5 May 2021) <https://cpsns.ns.ca/resource/medical-assistance-in-dying/>. Policies of other medical colleges are available at the End-of-Life Law and Policy in Canada webpage: Health Law Institute, Dalhousie University, 'Clinical Guidance Documents', *End-of-Life Law and Policy in Canada* (Web Page, 2020) <http://eol.law.dal.ca/?page_id=2657>.

229 Two regulatory decisions that have been made publicly available are those in relation to Mary Wilson (discussed above) and Ms S: see College Investigation Regarding Death of Mary Wilson (n 103); Complaints and Practice Investigations Department, College of Physicians and Surgeons of British

worked with colleagues to clarify key terms in the Canadian *Criminal Code*. This has occurred in a variety of ways including through a policy roundtable process which produced a report with recommended interpretations.[230]

Regulatory bodies with responsibility for VAD oversight can also help guide behaviour. For example, in the Netherlands, the Regional Euthanasia Review Committees publish detailed summaries of VAD cases.[231] These summaries are also indexed in terms of various domains, most importantly for present purposes into straightforward cases and non-straightforward cases, as well as those cases where the 'due care criteria' were complied with and those where it was not. This publicly available guidance can help to promote consistent interpretation of the law. A VAD oversight body may also be able to provide prospective guidance in particular cases or on particular topics. For example, the remit of such a body could include providing advice on a complex case about which a doctor wanted reassurance, or issuing an opinion about a category of case, such as VAD for anorexia given the unresolved issues raised above.

The Canadian and other work described above has, however, been primarily reactive in that they occurred after the law had passed. It is also possible, and desirable, to utilise wider tools of regulation to promote consistent understanding and application of eligibility criteria before the law commences. One example in Australian models is the mandatory training doctors must undertake prior to assessing a patient's eligibility for VAD.[232] This establishes a minimum baseline understanding of the legislative framework and provides guidance on how it should be interpreted.[233]

VI CONCLUSION

In this article and its companion article, we have undertaken comparative legal and practical analyses of five VAD frameworks in relation to nine medical conditions. This has generated new insights into these legal models and implications

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Columbia, *Final Disposition Report of the Inquiry Committee* (Report, CPS File No IC 2017-9836, 13 February 2018) <http://eol.law.dal.ca/wp-content/uploads/2017/11/College-letter-.pdf>. In relation to the latter decision, see Jocelyn Downie, 'Has Stopping Eating and Drinking Become a Path to Assisted Dying', *Policy Options* (online, 23 March 2018) <https://policyoptions.irpp.org/magazines/march-2018/has-stopping-eating-and-drinking-become-a-path-to-assisted-dying/>.

230 *IRPP Report* (n 16). Downie has also written a series of academic papers analysing and interpreting various aspects of the legislation: Downie and Scallion (n 16); Jocelyn Downie and Justine Dembo, 'Medical Assistance in Dying and Mental Illness Under the New Canadian Law' (2016) 9 *Journal of Ethics in Mental Health* 1; Downie and Bowes (n 176); Gus Grant and Jocelyn Downie, 'Time to Clarify Canada's Medical Assistance in Dying Law' (2018) 64(9) *Canadian Family Physician* 641.

231 'Judgments', *Regional Euthanasia Review Committees* (Web Page, 2018) <https://english.euthanasiecommissie.nl/judgments/>.

232 *Victorian Act 2017* (Vic) ss 17, 26; *WA Act 2019* (WA) ss 25, 36; Model Bill (n 2) cl 14.

233 Ben P White et al, 'Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration' (2021) 36(3) *Journal of Palliative Care* 162. Guidance for health practitioners is also provided in other forms: see, eg, Department of Health and Human Services (Vic), 'Voluntary Assisted Dying: Guidance for Health Practitioners' (Clinical Guideline, 4 July 2019).

of their design in practice. We acknowledge that the comparative methodology does not permit strong normative conclusions about an optimal VAD framework; different does not necessarily mean better or worse.[234] That said, these analyses have revealed significant undesirable outcomes in some aspects of these frameworks, highlighted doubts about their effectiveness in achieving stated policy goals, and identified important considerations for policymakers contemplating VAD reform.

VAD reform in further states is being actively considered in Australia.[235] Other countries are also contemplating reform, including the United Kingdom,[236] parts of Europe[237] and other states in the United States.[238] These papers have implications for those reform exercises. In Australia, a particular issue is whether other states should follow the 'Victorian model', as Western Australia has substantially done, or take a different path.[239] There can be a tendency to adopt an existing framework, but uncritical acceptance of the Victorian approach must be avoided.[240] These comparative analyses raise important questions about the *Victorian Act*'s operation in practice, and provide other models for policymakers to consider.

Further, the comparative practical analysis demonstrates the critical importance of testing the operation and boundaries of proposed VAD laws against a range of medical conditions. The exercise of determining which medical conditions might permit access to VAD, and when, as well as those medical conditions which

234 John C Reitz, 'How to Do Comparative Law' (1998) 46(4) *The American Journal of Comparative Law* 617, 624–5.

235 After this article was submitted for publication, voluntary assisted dying laws were passed in three Australian states: the *End-of-Life-Choices (Voluntary Assisted Dying) Act 2021* (Tas); the *Voluntary Assisted Dying Act 2021* (SA) and the *Voluntary Assisted Dying Act 2021* (Qld), respectively. In NSW, the Voluntary Assisted Dying Bill 2021 (NSW) has passed the Legislative Assembly and is set to be debated in the Legislative Council in 2022.

236 See, eg, the discussion of legislative and judicial developments in the United Kingdom in relation to VAD in *R (Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431, [18]–[48] (Etherton MR, Leveson P and King J).

237 For example, in Portugal, two laws decriminalising VAD have been passed by Parliament but vetoed by the President: 'Portugal's President Vetoes Law Legalising Euthanasia', *Euronews* (online, 30 November 2021) <https://www.euronews.com/2021/11/30/portugal-s-president-vetoes-law-legalising-euthanasia>. Spain passed the *Ley Orgánica de regulación de la euthanasia 2021* [Organic Law for the Regulation of Euthanasia] (Spain), which commenced in June 2021. In Germany, in February 2020, the Constitutional Court declared § 217 of the *Strafgesetzbuch* [Criminal Code] (Germany), which criminalised the provision of assisted suicide services, to be unconstitutional: Bundesverfassungsgericht [German Constitutional Court], 2 BvR 2347/15, 26 February 2020 reported in (2020) BVerfG, Urteil des Zweiten Senats vom 26 Februar 2020, Rn 1-343.

238 For an updated list of ongoing legislative activity in relation to VAD in the United States, see 'In Your State', *Death with Dignity* (Web Page) <https://www.deathwithdignity.org/in-your-state/>.

239 Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616.

240 The *Victorian Act* has been the subject of critical analysis from a range of normative perspectives including: its own stated regulatory goals (White et al, 'Does the VAD Act Reflect Its Stated Policy Goals?' (n 208)); ethical and legal values (Lindy Willmott, Katrine Del Villar and Ben White, 'Voluntary Assisted Dying in Victoria, Australia: A Values-Based Critique' in Sue Westwood (ed), *Regulating the Ending of Life: Death Rights* (Routledge, 2020) 55) and human rights (Lindy Willmott, Ben White and Katrine Del Villar, 'Voluntary Assisted Dying: Human Rights Implications for Australia' in Paula Gerber and Melissa Castan (eds), *Contemporary Perspectives on Human Rights Law in Australia* (Thomson, 2020) vol 2).

would not be eligible for access to VAD, can help ensure frameworks operate as intended. Perhaps the most striking conclusion from this practical comparative analysis is how, putting aside Canada, different eligibility criteria appeared to make limited difference to access to VAD, and primarily only in relation to timing of that access. This suggests potential redundancy in some criteria. While some may argue that this redundancy does not matter (perhaps comfortable with this out of an abundance of caution), including criteria not required to control access to VAD can add unnecessary complexity and uncertainty to assessing eligibility. This can cause undesirable outcomes of inconsistency and undue conservatism in decision-making. It is also important to consider when designing reform are those areas identified in this review as problematic or challenging. They included the question of whether a requirement for a time until death is appropriate, as well as the vexing issue of capacity and VAD.

These reflections also apply to jurisdictions with existing VAD laws. It is critical that the current law continues to be reviewed to see if it can be improved. Indeed, many jurisdictions when passing VAD laws have mandated that reviews of the legislation occur after a specified period of time.[241] Such a review should include issues that new jurisdictions would grapple with (as per above) but there is also scope after a VAD law is in operation to collect data about its functioning in practice. This data was considered in the analysis above, primarily for Canada and Oregon.[242] Generating concrete evidence about who is receiving access to VAD and who is being *refused* access helps determine whether eligibility criteria are operating as intended at the time the law passed. Such a review of how the law is being interpreted in practice also provides opportunities to support current approaches or correct them as needed. We have noted a range of regulatory tools that could be utilised to achieve this.

We can expect that VAD reform efforts will continue in Australia and overseas. And even if reform occurs and law passes, attention then shifts to carefully reviewing the operation of those laws in practice. The comparative legal and practical analyses undertaken in this two-article series provide an opportunity to inform and support considered law reform and evaluation of that law in Australia and abroad.

241 See *Victorian Act 2017* (Vic) ss 116(1)–(3); *WA Act 2019* (WA) ss 164(1)–(2); Model Bill (n 2) pt 9; Bill C-14, 1st Sess, 42nd Parl, 2016, cls 10(1)–(2); Bill C-7, 2nd Sess, 43rd Parl, 2021, cls 3.1, 5 (as passed by the House of Commons 17 March 2021).

242 Fewer data were available at time of publication from Victoria.

Reference List

1. Ben P White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2020) (forthcoming).
2. Ben White and Lindy Willmott, ' Voluntary Assisted Dying Bill 2019' (Model Bill, Australian Centre for health Law Research, Faculty of Law, Queensland University of Technology, April 2019) <https://eprints.qut.edu.au/128753/>.
3. Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.
4. Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020).
5. Oregon Health Authority, *Oregon Death with Dignity Act 2019 Data Summary* (Report, 25 February 2020).
6. Health Canada, *First Annual Report on Medical Assistance in Dying in Canada 2019* (Report, July 2020).
7. Voluntary Assisted Dying Review Board, Victoria State Government, *Report of Operations: January to June 2020* (Report, August 2020).
8. Cameron McLaren, 'An Update on VAD: (Almost) A Year in Review', *Dying with Dignity Victoria* (online, 16 June 2020) <https://www.dwdv.org.au/sb_cache/associationnews/id/122/f/One_Year_of_VAD-Dr_Cameron_McLaren.pdf, 3>.
9. Nick Carr, 'Choosing When to Go: What the Nation Can Learn from Victoria's Embrace of Voluntary Assisted Dying', *Crikey* (online, 18 June 2020) <https://www.crikey.com.au/2020/06/18/voluntary-assisted-dying-laws-one-year-on/>.
10. Bridget Rollason and Mary Gearin, 'More than 130 Victorians Apply to End their Lives in First Six Months of State's Assisted Dying Laws' *ABC News* (online, 19 February 2020) <https://www.abc.net.au/news/2020-02-19/assisted-dying-laws-victoria-used-by-more-than- 50-people/11979962>.
11. Jocelyn Downie and Kate Scallion, 'Foreseeably Unclear: The Meaning of the "Reasonably Foreseeable" Criterion for Access to Medical Assistance in Dying in Canada' (2018) 41(1) *Dalhousie Law Journal* 23.
12. Jocelyn Downie and Jennifer A. Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (IRPP Report, 1 March 2018).
13. Dominic R Mangino et al, 'Euthanasia and Assisted Suicide of Persons with Dementia in the Netherlands' (2020) 28(4) *American Journal of Geriatric Psychiatry* 466.
14. Sigrid Dierickx et al, 'Euthanasia for People with Psychiatric Disorders or Dementia in Belgium: Analysis of Officially Reported Cases' (2017) 17(1) *BMC Psychiatry* 203.
15. Emily Tomlinson and Joshua Stott, 'Assisted Dying in Dementia: A Systematic Review of the International Literature on the Attitudes of Health Professionals, Patients, Carers and the Public, and the Factors Associated With These' (2015) 30(1) *International Journal of Geriatric Psychiatry* 10.
16. Paul T Menzel and Bonnie Steinbock, 'Advance Directives, Dementia, and Physician-Assisted Death' (2013) 41(2) *Journal of Law, Medicine and Ethics* 484.
17. Inez D de Beauford and Suzanne van de Vathorst, 'Dementia and Assisted Suicide and Euthanasia' (2016) 263(7) *Journal of Neurology* 1463.
18. Eva Constance Alida Asscher and Suzanne van de Vathorst, 'First prosecution of a Dutch doctor since the Euthanasia Act of 2002: what does the verdict mean?' (2020) 46 *Journal of Medical Ethics* 71.
19. Jocelyn Downie and Stefanie Green, 'For people with dementia, changes in MAiD law offer new hope' (2021) *Policy Options* <https://policyoptions.irpp.org/magazines/april-2021/for-people-with-dementia-changes-in- maid-law-offer-new-hope/>.
20. Scott Y H Kim, Raymond G De Vries and John R Peteet, 'Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014' (2016) 73(4) *JAMA Psychiatry* 362.
21. Brendan Kelly and Declan McLoughlin, 'Euthanasia, Assisted Suicide and Psychiatry: A Pandora's Box' (2002) 181(4) *British Journal of Psychiatry* 278.
22. Kathleen Sheehan, K Sonu Gaind and James Downar, 'Medical Assistance in Dying: Special Issues for Patients with Mental Illness' (2017) 30(1) *Current Opinion in Psychiatry* 26.

23. Government of Canada, 'About Mental Illness and MAiD', Medical Assistance in Dying (webpage, 18 March 2021) <https://www.canada.ca/en/health- canada/services/medical-assistance-dying.html>.
24. Australian Government, Australian Institute of Health and Welfare, 'Cancer in Australia 2019' (Media Release, Cancer Series No 119, Catalogue No CAN 123, 21 March 2019). <https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2019/formats>.
25. Cancer Australia, 'Relative Survival by Stage at Diagnosis (Colorectal Cancer)', *National Cancer Control Indicators* (Web Page, 1 April 2019) <https://ncci.canceraustralia.gov.au/outcomes/relative-survival- rate/relative-survival-stage-diagnosis-colorectal-cancer>.
26. Yvette H M Claassen et al, 'Survival Differences with Immediate Versus Delayed Chemotherapy for Asymptomatic Incurable Metastatic Colorectal Cancer' (2018) 11 *Cochrane Database Systematic Review* CD012326:1–33.
27. Werner Scheithauer et al, 'Randomised Comparison of Combination Chemotherapy Plus Supportive Care with Supportive Care Alone in Patients with Metastatic Colorectal Cancer' (1993) 306(6880) *British Medical Journal* 752.
28. Alex Grothey et al, 'Survival of Patients With Advanced Colorectal Cancer Improves with the Availability of Fluorouracil-Leucovorin, Irinotecan, and Oxaliplatin in the Course of Treatment (2004) 22(7) *Journal of Clinical Oncology* 1209.
29. Legal and Social Issues Committee, Parliament of Victoria, *Inquiry Into End of Life Choices* (Final Report, June 2016).
30. Ministerial Advisory Panel on Voluntary Assisted Dying, Department of Health and Human Services, Victoria State Government, *Final Report* (Report, 31 July 2017).
31. 'What is Motor Neuron Disease (MND)?', *MND Australia* (Web Page, 2020) <https://m.mndaust.asn.au/Home.aspx>.
32. Deloitte Access Economics, *Economic Analysis of Motor Neuron Disease in Australia* (Report, November 2015).
33. Matthew C Kiernan et al, 'Amyotrophic Lateral Sclerosis' (2011) 377(9769) *Lancet* 942.
34. Kevin Talbot, 'Motor Neuron Disease: The Bare Essentials' (2009) *Practical Neurology* 9(5) 303.
35. Susan T Paulukonis et al, 'Survival and Cause of Death Among a Cohort of Confirmed Amyotrophic Lateral Sclerosis Cases' (2015) 10(7) *PLOS One* e0131965:1–11.
36. Ringholz GM et al**, '**Prevalence and Patterns of Cognitive Impairment in Sporadic ALS' (2005) *Neurology* 65(4) 586.
37. Global Initiative for Obstructive Lung Disease, *Pocket Guide to COPD Diagnosis, Management and Prevention: A Guide for Health Care Professionals* (Report, 2019).
38. Australian Government, Australian Institute of Health and Welfare, *Deaths in Australia* (Web Report, 17 July 2019) <https://www.aihw.gov.au/reports/life-expectancy-death/deaths/data>.
39. Fiona A H M Cleutjens et al, 'Domain-Specific Cognitive Impairment in Patients with COPD and Control Subjects' (2016) 12 *International Journal of Chronic Obstructive Pulmonary Disease* 1.
40. Robert M Shavelle et al, 'Life Expectancy and Years of Life Lost in Chronic Obstructive Pulmonary Disease: Findings from the NHANES III Follow-up Study' (2009) 4(1) *International Journal of COPD* 137.
41. Amanda Landers et al, 'Severe COPD and the Transition to a Palliative Approach' (2017) 13(4) *Breathe* 310.
42. Adeera Levin et al, 'KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease' (2013) 3(1) *Kidney International Supplements* 1.
43. Australian Government, Australian Institute of Health and Welfare, *Chronic Kidney Disease* (Web Report, 15 July 2020) <https://www.aihw.gov.au/reports/chronic-kidney-disease/chronic-kidney-disease- compendium/contents/deaths-from-chronic-kidney-disease>.
44. Carol Mattson Porth and Glenn Maftin, *Pathophysiology: Concepts of Altered Health States* (Lippincott Williams and Wilkins, 8th ed, 2009).
45. Ria Arnold et al, 'Neurological Complications in Chronic Kidney Disease' (2016) 5 *Journal of the Royal Society of Medicine Cardiovascular Disease* 1.
46. Andrew S Levey et al, 'Definition and Classification of Chronic Kidney Disease: A Position Statement from Kidney Disease: Improving Global Outcomes (KDIGO)' (2005) 67(6) *Kidney International* 2089.
47. National Clinical Guideline Centre (UK), *Chronic Kidney Disease (Partial Update): Early Identification and Management of Chronic Kidney Disease in Adults in Primary and Secondary Care* (NICE Clinical Guidelines No 182, July 2014) <https://www.ncbi.nlm.nih.gov/books/NBK328138/>.

48. Angela C Webster et al, 'Chronic Kidney Disease' (2017) 389(10075) *Lancet* 1238.
49. Leela R Bolla, Christopher M Filley and Robert M Palmer, 'Dementia DDx: Office Diagnosis of the Four Major Types of Dementia' (2000) 55(1) *Geriatrics* 34.
50. Australian Bureau of Statistics, *Causes of Death, Australia, 2018* (Catalogue No 3303.0, 25 September 2019).
51. Kirsten Fiest et al, 'The Prevalence and Incidence of Dementia Due to Alzheimer's Disease: A Systematic Review and Meta-Analysis' (2016) 43(Supp1) *Canadian Journal of Neurological Sciences* S51.
52. Barry Reisberg et al, 'The Global Deterioration Scale for Assessment of Primary Degenerative Dementia' (1982) 139(9) *American Journal of Psychiatry* 1136 .
53. O Zanetti, S B Solerte and F Cantoni, 'Life Expectancy in Alzheimer's Disease (AD)' (2009) 49(Supp 1) *Archive of Gerontology and Geriatrics* 273.
54. Ee Heok Kua et al, 'The Natural Hstory of Dementia' (2014) 14(3) *Psychogeriatrics* 196.
55. Carmelle Pesiah, Linda Sheahan and Ben white, 'Biggest Decision of Them All – Death and Assisted dying: Capacity Assessments and Undue Influence Screening' (2019) 49(6) *Internal Medicine Journal* 792.
56. 'Advance Care Planning for Alzheimer's Disease or Dementia', *Death with Dignity* (Web Page, 2020) <https://www.deathwithdignity.org/alzheimers-dementia- directive/>.
57. Kelly Grant, 'From Dementia to Medically Assisted Death: A Canadian Woman's Journey, and the Dilemma of the Doctors Who Helped', *Globe and Mail* (online, 12 October 2019) <https://www.theglobeandmail.com/canada/article-from-dementia-to-medically-assisted-death-a-canadian- womans-journey>.
58. CBC Radio, 'B.C. Man is One of the First Canadians With Dementia to Die With Medical Assistance', *CBC* (online, 27 October 2019) <https://www.cbc.ca/radio/thesundayedition/the-sunday-edition-for-october-27-2019-1.5335017/b-c-man-is- one-of-the-first-canadians-with-dementia-to-die-with-medical-assistance-1.5335025>.
59. Letter from J G Wilson, Senior Deputy Registrar of the Complaints and Practice Investigations Department of the College of Physicians and Surgeons of British Columbia to Dr Konia Jane Trouton, Dr [redacted] and Dr Paulo Campos Pereira, 6 December 2018 (College File No IC 2018-0034) <https://www.theglobeandmail.com/files/editorial/News/nw-na-maid-1011/marywilson-decision.pdf>.
60. Canadian Association of MAiD Assessors and Providers, *Medical Assistance in Dying (MAiD) in Dementia* (Clinical Guidance Document, 2019) <https://camapcanada.ca/wp-content/uploads/2019/05/Assessing-MAiD- in-Dementia-FINAL-Formatted.pdf>.
61. Michael J Devlin and Joanna E Steinglass 'Feeding and Eating Disorders' in Janis Cutler (ed), *Psychiatry* (Oxford University Press, 3rd ed, 2014).
62. National Eating Disorders Collaboration, *Eating Disorders Prevention, Treatment and Management: An Evidence Review* (Report, March 2010).
63. Allan S Kaplan and Blake D Woodside, 'Biological Aspects of Anorexia Nervosa and Bulimia Nervosa' (1987) 55(5) *Journal of Consulting and Clinical Psychology* 645.
64. James I Hudson et al, 'The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication' (2007) 61(3) *Biological Psychiatry* 348.
65. Hans-Christoph Steinhausen, 'The Outcome of Anorexia Nervosa in the 20th Century' (2002) 159(8) *American Journal Psychiatry* 1284.
66. Margery Gans and William B Gunn Jr, 'End stage Anorexia: Criteria for Competence to Refuse Treatment' (2003) 26(6) *International Journal of Law and Psychiatry* 677.
67. Amy T Campbell and Mark P Aulisio, 'The Stigma of "Mental" Illness: End Stage Anorexia and Treatment Refusal' (2012) 45(5) *International Journal of Eating Disorders* 627.
68. Joseph O'Neill, Tony Crowther and Gwyneth Sampson, 'Anorexia Nervosa: Palliative Care of Terminal Psychiatric Disease' (1994) 11(6) *American Journal of Hospice and Palliative Medicine* 36.
69. Amy Lopez, Joel Yager and Robert E Feinstein, 'Medical Futility and Psychiatry: Palliative Care and Hospice Care as a Last Resort in the Treatment of Refractory Anorexia Nervosa' (2010) 43(4) *International Journal of Eating Disorders* 372.
70. Barney Sneiderman and Marja Verhoef, 'Patient Autonomy and the Defence of Medical Necessity: Five Dutch Euthanasia Cases' (1996) 34(2) *Alberta Law Review* 374.

71. '2016-01, Psychiatrist, Psychiatric Disorders, No Reasonable Alternative', *Regional Euthanasia Review Committees* (Judgment, 1 January 2016) <https://english.euthanasiecommissie.nl/judgments/d/d-psychiatric-disorders/documents/publications/judgments/2016/2016-01/2016-01>.
72. Cynthia Geppert, 'Futility in Chronic Anorexia Nervosa: A Concept Whose Time Has Not Yet Come' (2015) 15(7) *American Journal of Bioethics* 34.
73. Louis C Charland, 'Ethical and Conceptual Issues in Eating Disorders' (2013) 26(6) *Current Opinion in Psychiatry* 562.
74. Jacinta A O Tan et al, 'Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values' (2006) 13(4) *Philosophy, Psychiatry, and Psychology* 267.
75. Sam Boyle, 'How Should the Law Determine Capacity to Refuse Treatment for Anorexia?' (2019) 64 *International Journal of Law and Psychiatry* 250.
76. Heather Draper, 'Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification' (2000) 14(2) *Bioethics* 120.
77. Christopher J Williams, Lorenzo Pieri and Andrew Sims, 'Does Palliative Care Have a Role in Treatment of Anorexia Nervosa? We Should Strive to Keep Patients Alive' (1998) 317(7152) *British Medical Journal (Clinical Research Edition)* 195.
78. Joan Bryden, 'Exclusion of Mental Illness in Assisted Dying-Bill Slammed by Psychiatrists', *CFJC Today* (Web Page, 22 November 2020) <https://cfjctoday.com/2020/11/22/exclusion-of-mental-illness-in-assisted-dying-bill-slammed-by- psychiatrists/>.
79. Anna C Ciao, Erin C Accurso and Stephen A Wonderlich, 'What Do We Know About Severe and Enduring Anorexia Nervosa?' In Steven Touyz, Daniel Le Grange, Hubert Lacey and Phillipa Hay (eds), *Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide* (Routledge, 2016) 1–1.
80. Andrew Clegg et al, 'Frailty in Elderly People' (2013) 381(9868) *Lancet* 752.
81. Matteo Cesari et al, 'Frailty: An Emerging Public Health Priority' (2016) 17 *Journal of the American Medical Directors Association* 188.
82. Shelly Sternberg et al, 'The Identification of Frailty: A Systematic Literature Review' (2011) 59(11) *Journal of the American Geriatrics Society* 2129.
83. D Taylor et al, 'Geospatial Modelling of the Prevalence and Changing Distribution of Frailty in Australia— 2011 to 2027' (2019) 123 *Experimental Gerontology* 57.
84. Linda P Fried et al, 'Frailty in Older Adults: Evidence for a Phenotype' (2001) 56(3) *Journal of Gerontology: Medical Sciences* M146.
85. R E Pel-Littel et al, 'Frailty: Defining and Measuring of a Concept' (2009) 13(4) *Journal of Nutrition, Health and Aging* 390.
86. Marco Canevelli, Matteo Cesari and Gabor Abellan van Kan, 'Frailty and Cognitive Decline: How Do They Relate?' (2015) 18(1) *Aging: Biology and Nutrition* 1363.
87. Kenneth Rockwood et al, 2005. 'A Global Clinical Measure of Fitness and Frailty in Elderly People' (2005) *Canadian Medical Association Journal* 173(5): 489–9.
88. Anna Lloyd et al, 'Physical, Social, Psychological and Existential Trajectories of Loss and Adaptation Towards the End of Life for Older People Living With Frailty: A Serial Interview Study' (2016) 16(1) *BMC Geriatrics* 176:1–15.
89. C Nicholson et al, 'Living on the Margin: Understanding the Experience of Living and Dying with Frailty in Old Age' (2012) 75(8) *Social Science and Medicine* 1426.
90. W David Robertson and Rosanne Beuthin, *A Review of Medical Assistance in Dying on Vancouver Island: The First Two Years: July 2016–2018* (Report, November 2018).
91. Ellen Wiebe et al, 'Reasons for Requesting Medical Assistance in Dying' (2018) 64(9) *Canadian Family Physician* 674.
92. Steven C Kirshblum et al, 'International Standards for Neurological Classification of Spinal Cord Injury (Revised 2011)' (2011) 34(6) Journal of Spinal Cord Medicine 535.
93. Timothy T Roberts, Garrett R Leonard and Daniel J Cepela, 'Classifications in Brief: American Spinal Injury Association (ASIA) Impairment Scale' (2017) 475(5) *Clinical Orthopaedics and Related Research* 1499.
94. Amanda Tovell, Australian Government, Australian Institute of Health and Welfare, *Spinal Cord Injury, Australia, 2014–15* (Injury Research and Statistics Series No 113, Catalogue No INJCAT 202, 16 May 2018) vi, 39.
95. Rita Galeiras Vázquez et al, 'Respiratory Management in the Patient with Spinal Cord Injury' (2013) BioMed Research International 168757:1–12.

96. Ginette Thibault-Halman et al, 'Acute Management of Nutritional Demands After Spinal Cord Injury' (2011) 28(8) *Journal of Neurotrauma* 1497.
97. Christopher S Ahuja et al, 'Traumatic Spinal Cord Injury—Repair and Regeneration' (2017) 80(3 Supp 1) *Neurosurgery* S9.
98. Jan Mehrholz, Joachim Kugler and Marcus Pohl, 'Locomotor Training for Walking After Spinal Cord Injury' (2012) 11 *Cochrane Database of Systemic Reviews* CD006676:1–42.
99. World Health Organization, The International Spinal Cord Society and Jerome Bickenbach J (ed), *International Perspectives on Spinal Cord Injury* (Report, 2013).
100. P J O'Connor, 'Prevalence of Spinal Cord Injury in Australia' (2005) 43 *Spinal Cord* 42.
101. J W Middleton et al, 'Life Expectancy After Spinal Cord Injury: A 50-Year Study' (2012) 50 *Spinal Cord* 803.
102. R J Soden et al, 'Causes of Death After Spinal Cord Injury' (2000) 38 *Spinal Cord* 604.
103. Jocelyn Downie and Matthew Bowes, 'Refusing Care as a Legal Pathway to Medical Assistance in Dying' (2019) 2(2) *Canadian Journal of Bioethics* 73.
104. Sara Parodi and Maria Pennuto, 'Huntington's Disease: From Disease Pathogenesis to Clinical Perspectives' in Kevin Guillory and Alex M Carrasco (eds), *Huntington's Disease: Symptoms, Risk Factors and Prognosis* (Nova Science Publishers, 2013) 1.
105. National Institute of Neurological Disorders and Stroke, *Huntington's Disease: Hope Through Research* (NIH Publication No 17-NS-19, 31 December 2018) <https://www.ninds.nih.gov/Disorders/Patient-Caregiver- Education/Hope-Through-Research/Huntingtons-Disease-Hope-Through>.
106. Francis O Walker, 'Huntington's Disease' (2007) 369(9557) *Lancet* 218.
107. Ian Freckelton, 'The Legal Ramifications of Huntington's Disease' in Kevin Guillory and Alex M Carrasco (eds), *Huntington's Disease: Symptoms, Risk Factors and Prognosis* (Nova Science Publishers, 2013) 93.
108. The Huntington's Disease Functional Capacity Scale was developed by Ira Shoulson: Ira Shoulson, *Clinical Care of the Patient and Family with Huntington's Disease* (Huntington Society of Canada, 1980) 8.
109. Ira Shoulson, 'Huntington Disease: Functional Capacities in Patients Treated with Neuroleptic and Antidepressant Drugs' (1981) 31(10) *Neurology* 1333.
110. 'How Does Huntington's Disease Progress?', *Huntington's NSW and ACT* (Web Page, 2019) <https://www.huntingtonsnsw.org.au/information/hd-facts/how-does-huntingtons-disease-progress>.
111. Ian Freckelton, 'Huntington's Disease and the Law' (2010) 18 *Journal of Law and Medicine* 7.
112. Ben P White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.
113. Marike E de Boer et al, 'Advance Directives for Euthanasia in Dementia: Do Law-Based Opportunities Lead to More Euthanasia?' (2010) 98(2) *Health Policy* 256.
114. Mette L Rurup et al, 'Physicians' Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands' (2005) 53(7) *Journal of the American Geriatrics Society* 1138.
115. Paul Mevis et al, 'Advance Directives Requesting Euthanasia in the Netherlands: Do They Enable Euthanasia for Patients Who Lack Mental Capacity?'(2016) 4(2) *Journal of Medical Law and Ethics* 127.
116. Karin R Jongsma, Marijke C Kars and Johannes J M van Delden, 'Dementia and Advance Directives: Some Empirical and Normative Concerns' (2019) 45(2) *Journal of Medical Ethics* 92.
117. David Gibbes Miller, Rebecca Dresser and Scott Y H Kim, 'Advance Euthanasia Directives: A Controversial Case and its Ethical Implications' (2019) 45(2) *Journal of Medical Ethics* 84.
118. Alzheimer's Australia Victoria, *A Good Death is My Right* (Discussion Paper, April 2017).
119. Dementia Australia, *Submission to the Ministerial Expert Panel on Voluntary Assisted Dying* (Discussion Paper, May 2019).
120. Council of Canadian Academies, *The State of Knowledge on Advance Requests for Medical Assistance in Dying: The Expert Panel Working Group on Advance Requests for MAiD* (Report, 12 December 2018).
121. Government of Canada, Department of Justice 'Canada's New Medical Assistance in Dying Law' (webpage, 19 March 2021) <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html>.
122. Udo Schuklenk and Suzanne van de Vathorst, 'Treatment-Resistant Major Depressive Disorder and Assisted Dying' (2015) 41(8) *Journal of Medical Ethics* 577.

123. Justine Dembo, Udo Schuklenk and Jonathan Reggler, '"For Their Own Good": A Response to Popular Arguments Against Permitting Medical Assistance in Dying (MAiD) where Mental Illness Is the Sole Underlying Condition' (2018) 63(7) *Canadian Journal of Psychiatry* 451.
124. Isra Black, 'Suicide Assistance for Mentally Disordered Individuals in Switzerland and the State's Positive Obligation to Facilitate Dignified Suicide' (2012) 20(1) *Medical Law Review* 157.
125. Council of Canadian Academies, *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition: The Expert Panel Working Group on MAiD Where a Mental Disorder is the Sole Underlying Medical Condition* (Report, 12 December 2018).
126. Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163.
127. Ministerial Expert Panel on Voluntary Assisted Dying, Department of Health, Government of Western Australia, *Final Report* (Report, 4 June 2019).
128. Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model For Reform' in Ian Freckelton and Kerry Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479.
129. Lutz-Christian Wolff, 'Law and Flexibility—Rule of Law Limits of a Rhetorical Silver Bullet' (2011) *Jurisprudence* 549.
130. Canadian Association of MAiD Assessors and Providers, *The Clinical Interpretation of 'Reasonably Foreseeable'* (Clinical Practice Guideline, June 2017).
131. Canadian Association of MAiD Assessors and Providers, *Assessment for Capacity to Give Informed Consent for Medical Assistance in Dying (MAiD) Review and Recommendations* (White Paper, April 2020).
132. Canadian Association of MAiD Assessors and Providers, *Medical Assistance in Dying (MAiD) in Dementia* (Clinical Guideline, May 2019).
133. 'Professional Standard Regarding Medical Assistance in Dying (MAiD)', College of Physicians and Surgeons of Nova Scotia (Web Page, May 8, 2021) <https://cpsns.ns.ca/resource/medical-assistance-in-dying/>.
134. Health Law Institute, Dalhousie University, 'Clinical Guidance Documents', *End of Life Law and Policy in Canada* (Web Page, 2020) <http://eol.law.dal.ca/?page_id=2657>.
135. Complaints and Practice Investigations Department, College of Physicians and Surgeons of British Columbia, 'Final Disposition Report of the Inquiry Committee' (Report, CPS File No IC 2017-9836, 13 February 2018) <http://eol.law.dal.ca/wp-content/uploads/2017/11/College-letter-.pdf>.
136. Jocelyn Downie, 'Has Stopping Eating and Drinking Become a Path to Assisted Dying', Policy Options (online, 23 March 2018) <https://policyoptions.irpp.org/magazines/march-2018/has-stopping-eating-and- drinking-become-a-path-to-assisted-dying/>.
137. Jocelyn Downie and Justine Dembo, 'Medical Assistance in Dying and Mental Illness Under the New Canadian Law' (2016) *Journal of Ethics in Mental Health* 1.
138. Gus and Jocelyn Downie, 'Time to Clarify Canada's Medical Assistance in Dying Law' (2018) 64(9) *Canadian Family Physician* 641.
139. 'Judgments', *Regional Euthanasia Review Committees* (Web Page, 2018) <https://english.euthanasiecommissie.nl/judgments/>.
140. Ben P White et al, 'Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration' (2020) *Journal of Palliative Care* (early online), <https://doi.org/10.1177/0825859720946897>.
141. Victorian Department of Health and Human Services, Victoria State Government, *Voluntary Assisted Dying: Guidance for Health Practitioners* (Clinical Guideline, 4 July 2019).
142. John C Reitz, 'How to Do Comparative Law' (1998) 46(4) *The American Journal of Comparative Law* 617.
143. Michael Koziol, 'Fresh bid to legalise assisted dying set to test NSW government', *Sydney Morning Herald* (online, 13 December 2020) <https://www.smh.com.au/politics/nsw/fresh-bid-to-legalise-assisted-dying-set-to-test-nsw-government- 20201209-p56m2t.html>.
144. 'Portugal MPs in Move to Legalise Euthanasia', *BBC News*, (online, 21 February 2020) <https://www.bbc.com/news/world- europe-51588601>.
145. Sydney Morning Herald, 'Spanish Parliament votes to legalise euthanasia' (online, 18 December 2020) <https://www.smh.com.au/world/europe/spanish-parliament-votes-to-legalise-euthanasia-20201218- p56oll.html>.
146. 'In Your State', *Death With Dignity* (Web Page, 2 August 2020) <https://www.deathwithdignity.org/in-your-state/>.

147. Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616.
148. Lindy Willmott, Katrine Del Villar and Ben White, 'Voluntary Assisted Dying in Victoria, Australia: A Values-Based Critique' in Sue Westwood (ed), *Regulating the Ending of Life: Death Rights* (Routledge, 2020).
149. Lindy Willmott, Ben White and Katrine Del Villar, 'Voluntary Assisted Dying: Human Rights Implications for Australia' in Paula Gerber and Melissa Castan (eds), *Contemporary Perspectives on Human Rights Law in Australia* (Thomson, 2020).

Harms to patients caused by institutions objecting to voluntary assisted dying

Delays, emotional suffering and reduced patient choice

What is this research about?

Victoria is the first Australian state to permit voluntary assisted dying (VAD). Health practitioners can conscientiously object to VAD but the law does not say anything about institutions (hospitals, palliative care units, and residential aged care facilities). In this Australian-first study, we gathered evidence on how objections by institutions affect patients seeking VAD.

What did we do?

We did 28 interviews with 32 family caregivers and one patient about the experience of seeking VAD in Victoria. 17 of those interviews discussed some experience with an institution objecting to VAD. We analysed what people said about institutional objection and its impact on patients.

What did we find?

The objections people described generally occurred in Catholic facilities or palliative care settings (e.g. palliative care units within hospitals).

Objections by institutions stopped some or all of the VAD process happening onsite. Most commonly patients were not allowed to:

- Have eligibility assessments (i.e. meet with a doctor to be assessed for VAD)
- Take delivery of the VAD medication from the pharmacy (when they were approved as eligible for VAD)
- Take the VAD medication or have it administered to them.

"They would not allow the state pharmacist representatives to come into the hospital at all."

"Oh, sorry, … you'll have to wait for [patient name] to come out of hospital."

People described a range of harms that objections by institutions caused:

- Delays in patients being able to access VAD
- Patients transferring out of a facility to seek VAD
- Patients having to choose between continuing the VAD process or staying in a facility to receive palliative or other care
- Emotional suffering by patients and families
- Patients and families distrusting objecting institutions.

"It will always be a great sadness for me that the last few precious hours on Mum's last day were mostly filled with stress and distress, having to scurry around moving her out of her so-called 'home'."

Some things made dealing with institutional objection easier such as:

- Supportive staff working at the facility, or
- Having an assertive family member who could advocate.

Some things made dealing with institutional objection more difficult such as:

- Facility staff being opposed to VAD, or
- Patients being so ill it was difficult to move to a more supportive facility.

What should happen next?

1. Objecting institutions should be aware of these harms to patients and try to avoid them. They should find ways to support patients' choice for VAD that avoid or minimise conflict with the institution's values. One option is to not participate in VAD but allow outside doctors and pharmacists access to institutions to undertake the VAD process for patients who make that choice.

"So allowing free access to VAD doctors to access patients, if that's what the patient wants, while they're in hospital. Because some people spend an awful long time in hospital…"

2. Better regulation may also be needed. Victoria's VAD legislation does not deal with institutional objection – unlike the law in Queensland, South Australia and New South Wales. The Victorian Department of Health has a policy that guides how institutions can manage objections, but this is not binding. As a result, institutions currently have a lot of power to object to VAD. There is a strong argument to limit that power of institutions to object to VAD when this harms patients.

For more information

This research briefing is based on Ben P White, Ruthie Jeanneret, Eliana Close and Lindy Willmott, "The impact on patients of objections by institutions to voluntary assisted dying: a qualitative study of family caregivers' perceptions" *BMC Med Ethics* **24**, 22 (2023). More information about study limitations, research ethics and disclosures are available in the article: **https://doi.org/10.1186/s12910-023-00902-3**.

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LEGISLATIVE OPTIONS TO ADDRESS INSTITUTIONAL OBJECTIONS TO VOLUNTARY ASSISTED DYING IN AUSTRALIA

BEN P WHITE,* LINDY WILLMOTT,** ELIANA CLOSE*** AND JOCELYN DOWNIE****

Voluntary assisted dying is being considered by parliaments and law reform bodies across Australia. Although individual conscientious objection is routinely considered in these deliberations, an institution's desire to object to providing voluntary assisted dying has received very little attention. After briefly considering the concept of institutional objection in voluntary assisted dying, this article examines the available (albeit limited) Australian evidence on this practice. Institutional objection is happening in Victoria (where voluntary assisted dying is lawful) and is likely to occur in other Australian states. The article proposes that regulation is needed and presents three models for parliaments and law reformers to consider. The first is 'conscientious absolutism', which grants institutions unrestricted ability to object to voluntary assisted dying. The second

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We disclose that Ben White and Lindy Willmott were engaged by the Victorian and Western Australian Governments to design and provide the legislatively-mandated training for doctors involved in voluntary assisted dying in those States. Both have also developed a model Bill for voluntary assisted dying for parliaments to consider. Eliana Close was employed on both voluntary assisted dying training projects. Jocelyn Downie was a member of the Royal Society of Canada Expert Panel on End of Life Decision-Making, a member of the plaintiffs' legal team in *Carter v Canada (A-G)* [2015] 1 SCR 331, a member of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. Ben White is a recipient of an Australian Research Council Future Fellowship (project number FT190100410: Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying) funded by the Australian Government.

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is a 'compromise or reasonable accommodation' model, which aims to accommodate both institutional objection and a person's wish to access voluntary assisted dying. Different balances can be struck; we propose a model that prioritises a patient's interests. The third model is 'non-toleration', which would refuse to allow an institution to object at all. While there can be debate about the optimal model, the issue of institutional objection to voluntary assisted dying must be addressed.

I INTRODUCTION

After decades of unsuccessful attempts to legalise voluntary assisted dying ('VAD'),[1] the past few years have witnessed a flurry of reform activity in Australia. In Victoria, the *Voluntary Assisted Dying Act 2017* (Vic) ('*Victorian VAD Act*') commenced operation in June 2019. Western Australia largely followed the Victorian model and its *Voluntary Assisted Dying Act 2019* (WA) is due to commence operation on 1 July 2021. As this article was being published, Tasmania also passed its *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) which is anticipated to commence in 2022. A VAD Bill has been introduced in South Australia,[2] one will be considered in Queensland in May 2021,[3] and New South Wales is likely to see such a Bill tabled in 2021 as well.[4]

Reflecting the contested nature of VAD legislation, such laws almost universally contain provisions to respect conscientious objections by individual health professionals. Both the Victorian and Western Australian laws state that a health professional has a right to refuse involvement with any aspect of the VAD process.[5] A more controversial issue, which has received limited consideration in Australia, is whether an *institution* should be able to prohibit access to VAD or any VAD-related activities (which include eligibility assessments and providing

1 A detailed discussion of attempts at law reform in Australia is available in: Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1. See also further Bills in Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616.

2 Voluntary Assisted Dying Bill 2020 (SA).

3 The Queensland Premier referred the issue to the Queensland Law Reform Commission to draft a Bill for the Government's consideration: Queensland Law Reform Commission, *Queensland's Laws Relating to Voluntary Assisted Dying* (Terms of Reference, 2020) <https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0004/651379/vad-tor.pdf>. See also Queensland Law Reform Commission, *A Legal Framework for Voluntary Assisted Dying* (Consultation Paper No 79, October 2020) <https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0003/658506/qlrc-wp-79-2020.pdf>.

4 Michael Koziol, 'Fresh Bid to Legalise Assisted Dying Set to Test NSW Government', *The Sydney Morning Herald* (online, 13 December 2020) <https://www.smh.com.au/politics/nsw/fresh-bid-to-legalise-assisted-dying-set-to-test-nsw-government-20201209-p56m2t.html>.

5 *Voluntary Assisted Dying Act 2017* (Vic) s 7 ('*Victorian VAD Act*'); *Voluntary Assisted Dying Act 2019* (WA) s 9.

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information about VAD) within its facility.[6] The Victorian and Western Australian Acts are silent on this issue. However, this is important because institutions that object have the power to significantly curtail individuals' ability to access what is a lawful medical service.[7] When this occurs for reasons of conscience, this is problematic, particularly when these institutions are the sole providers of specialist end-of-life care in a particular geographic area.[8] This effectively creates barriers to access and the impact on patients can be extreme; those who are eligible for VAD are already experiencing intolerable suffering and such institutional objections can compound this.

Although the Victorian and Western Australian Acts do not address institutional objection, it is possible for legislation to regulate it. The Voluntary Assisted Dying Bill 2019, a model Bill that was recommended by the Queensland parliamentary inquiry considering VAD as the proposed basis for reform,[9] contains such a provision.[10] A proposed amendment to regulate institutional objections was also debated, though ultimately not passed, in the Legislative Council of Tasmania during debate on the *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas).[11]

During the debates in Tasmania, many parliamentarians expressed grave concern that institutions (particularly residential aged care facilities) would create unjustified barriers for individuals who were approaching the end of their lives, suffering intolerably, and seeking VAD. For example, Ms Forrest stated: 'I am really struggling with why we would require someone to be moved from their home because an organisation's policy was that they did not want to be involved in the matter'.[12] Indeed, several politicians expressed surprise that institutions

6 See, eg, Philip Shadd and Joshua Shadd, 'Institutional Non-Participation in Assisted Dying: Changing the Conversation' (2019) 33(1) *Bioethics* 207; LW Sumner, 'Institutional Refusal to Offer Assisted Dying: A Response to Shadd and Shadd' (2019) 33(8) *Bioethics* 970.

7 See, eg, Sumner (n 6) 971.

8 See, eg, Udo Schuklenk, 'Conscience-Based Refusal of Patient Care in Medicine: A Consequentialist Analysis' (2019) 40(6) *Theoretical Medicine and Bioethics* 523; Sumner (n 6) 971.

9 Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T490.pdf> ('Queensland Parliamentary Report'). In Recommendation 1, the Committee recommended the Queensland Government use a draft voluntary assisted dying ('VAD') Bill written by two of the authors as the basis for legalising VAD in Queensland. For the model Bill, see: Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1, 15–43.

10 White and Willmott (n 9) 36.

11 The amendment proposed by Dr Bastian Seidel would require institutions that object to VAD to transfer a patient to a healthcare facility that does not object: Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 2 (Bastian Seidel). Note also that clause 19(3) in the (defeated) Death with Dignity Bill 2016 (SA) addressed institutional objection to VAD. This clause indicated that an institution could refuse to provide VAD, but if it did so it must ensure the refusal is brought to the attention of individuals before being admitted, and if the person had already entered the institution without being aware of the objection, arrange a transfer.

12 Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 5 (Ruth Forrest).

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could legally prevent health professionals from entering facilities for this purpose.[13]

This article explores how institutional objections to VAD in Australia are currently regulated, the potential consequences of such objections, and possible legislative responses. We commence by examining the concept of institutional objection, including a comparison with conscientious objection by individuals. We then outline how institutional objection is regulated in Victoria (by policy), evidence of the impact of such objection on individuals in Victoria, and likely outcomes in other parts of Australia if VAD is enacted. We also consider the recent Canadian experience to identify potential outcomes of institutional objections. We conclude by offering some regulatory options to govern institutional objection for parliaments and other bodies deliberating on VAD reform.

II THE CONCEPT OF INSTITUTIONAL CONSCIENTIOUS OBJECTION[14]

Conscientious objection in medicine can refer to a desire not to participate in providing a healthcare service based on concerns to 'preserve or maintain moral integrity'.[15] It is conceptually distinct from non-participation based on clinical judgment – that to provide a particular treatment would not be in accordance with good medical practice.[16] It is also to be distinguished from pragmatic reasons for non-participation, based on lack of expertise, financial or technological resources.[17]

13 See, eg, Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 5–6 (Ruth Forrest), 10 (Meg Webb), 15–16 (Bastian Seidel).

14 This article does not consider institutional objections made on the basis of institutional capacity (eg, not having the required human resources or equipment). We do briefly note here, though, that such objections may be difficult to sustain as VAD does not require specialised equipment or human resources that cannot be brought into a facility.

15 Mark R Wicclair, 'Conscientious Objection in Medicine' (2000) 14(3) *Bioethics* 205, 213. See generally Morten Magelssen, 'When Should Conscientious Objection Be Accepted?' (2012) 38(1) *Journal of Medical Ethics* 18; Sara Fovargue and Mary Neal, '"In Good Conscience": Conscience-Based Exemptions and Proper Medical Treatment' (2015) 23(2) *Medical Law Review* 221, 222. See also Stephen Smith, who defines conscience from an individual perspective as 'an internal mental process focused on an inward-looking choice to engage in particular behaviour on the basis of a moral value': Stephen W Smith, 'The Responsibilities of Conscience in Healthcare Decisions: Moving Towards a Collaborative Framework' (2020) 79(1) *Cambridge Law Journal* 120, 124. While these authors defend the right to conscientiously object on the basis of preserving moral integrity, others frame the issue in terms of harm to the doctor and the health service: see, eg, Julian Savulescu, 'Conscientious Objection in Medicine' (2006) 332(7536) *British Medical Journal* 294.

16 See Fovargue and Neal (n 15) 224–5; Smith (n 15) 129; Nadia N Sawicki, 'Mandating Disclosure of Conscience-Based Limitations on Medical Practice' (2016) 42(1) *American Journal of Law and Medicine* 85, 91–2.

17 Shadd and Shadd (n 6) 208, 211.

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While an individual's right to conscientiously object is traditionally recognised in law and policies,[18] it is more contentious whether an institution itself can have a 'conscientious objection'. Individuals are self-evidently moral agents, and possess human rights, including the right to freedom of religion, thought and conscience.[19] The status of institutions is less clear. Some argue there is no basis for an institution to have such an objection, as 'bricks and mortar' cannot have moral beliefs as people do.[20] Others consider a healthcare institution to be more than just a building, and view it as 'a group of people organized according to a series of roles and relationships designed to deliver the social good of healthcare'.[21] According to this view, institutions may have a distinctive mission, ethos and moral values, and should be recognised as having a conscience.[22] A middle ground, advanced by Wicclair, is to argue that while hospitals do not possess a conscience like individuals do, they could still justify claims to refuse a service on the basis of their identity and integrity. Nevertheless, they have obligations to prevent harm to patients, promote health and respect autonomy, which can outweigh identity or integrity-based claims.[23]

Institutional objections to VAD may be made by a range of different institutions, including hospitals, residential aged care facilities and other long-term care facilities, and hospices or other short-term care facilities.[24] Institutions may object to participating in VAD on at least three levels: 1) VAD administration; 2) eligibility assessments; and 3) providing information or referring individuals to facilitate VAD.[25] Firstly, an institution may not wish to have administration of

18 Wicclair, 'Conscientious Objection in Medicine' (n 15). For the contrary view, that an individual health practitioner should not be able to object on conscientious grounds, see Savulescu (n 15) 294; Julian Savulescu and Udo Schuklenk, 'Doctors Have No Right to Refuse Medical Assistance in Dying, Abortion or Contraception' (2017) 31(3) *Bioethics* 162, 165.

19 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 18. See also Sumner (n 6) 972.

20 Daphne Gilbert, 'Faith and/in Medicine: Religious and Conscientious Objections to MAiD' (2020) 43(2) *Dalhousie Law Journal* 1, 38. Gilbert argues that under Canadian law, religious institutions do not have the right to refuse to offer medical assistance in dying ('MAiD': the Canadian term for VAD), a publicly-funded and legal health service. See also George J Annas, 'At Law: Transferring the Ethical Hot Potato' (1987) 17(1) *The Hastings Center Report* 20, 21: 'Hospitals are corporations that have no natural personhood, and hence are incapable of having either "moral" or "ethical objections" to actions. … [H]ospitals don't practice medicine, physicians do'. Sumner (n 6) says it is 'debatable' whether institutions can have conscience rights: at 972 n 14.

21 Shadd and Shadd (n 6) 208.

22 See Cameron Flynn and Robin Fretwell Wilson, 'Institutional Conscience and Access to Services: Can We Have Both?' (2013) 15(3) *American Medical Association Journal of Ethics* 226, 227; Daniel P Sulmasy, 'What Is Conscience and Why Is Respect for It So Important?' (2008) 29(3) *Theoretical Medicine and Bioethics* 135; Kevin W Wildes, 'Institutional Identity, Integrity, and Conscience' (1997) 7(4) *Kennedy Institute of Ethics Journal* 413, 416. In New Zealand, a court has held that institutions may have 'an entrenched moral ethos through which it operates' and have a right to freedom of conscience: *Hospice New Zealand v A-G* [2020] NZHC 1356, [103] (Mallon J). Mallon J held that there is nothing in the *End of Life Choice Act 2019* (NZ) that requires institutions to offer VAD: at [103]–[117], [214].

23 Mark R Wicclair, 'Conscientious Refusals by Hospitals and Emergency Contraception' (2011) 20(1) *Cambridge Quarterly of Healthcare Ethics* 130.

24 See Shadd and Shadd (n 6) 208.

25 Carpenter and Vivas note three types of individual objection to VAD: objection to administration, objection to participation in consultation and assessment, and, less commonly, objection to providing a direct referral: Travis Carpenter and Lucas Vivas, 'Ethical Arguments Against Coercing Provider

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VAD occur in its facility.[26] It may achieve this by forbidding its staff or outside health professionals from administering or prescribing VAD medication to patients, and/or it may prohibit individuals themselves from taking it in the facility. Secondly, an institution may prohibit consultations or eligibility assessments for VAD occurring within the facility, whether conducted by staff or outside health professionals.[27] Thirdly, an institution may refuse to refer a patient to other institutions or health professionals who provide VAD services or object to providing information about VAD.

A common basis for institutional objection is religious belief. The Catholic Church has made prominent statements on VAD, with its most recent pronouncement concluding that 'euthanasia … is an intrinsically evil act',[28] and that complicity by '[a]ny formal or immediate material cooperation in such an act is a grave sin against human life'.[29] This is significant as Catholic hospitals and institutions (eg, hospices and long-term care facilities) provide a significant proportion of end-of-life care in Australia.[30] Other religions, including Judaism and Islam, have expressed the same viewpoint.[31] This has led some religious organisations to refuse to permit VAD assessments or administration in their

Participation in MAiD (Medical Assistance in Dying) in Ontario, Canada' (2020) 21 *BMC Medical Ethics* 46:1–5, 1–2. Institutional objections may also extend to a refusal to allow individuals to complete paperwork relating to VAD onsite: see, eg, Jennie Russell, 'Paralyzed, Terminally Ill Man Had to Sign Assisted-Dying Papers in Bus Shelter', *CBC News* (online, 2 November 2018) <https://www.cbc.ca/news/canada/edmonton/convenant-health-assisted-dying-edmonton-1.4888114> ('CBC Coverage of Bob Hergott'); Jennie Russell, 'Unassisted Death', *CBC News* (online) <https://newsinteractives.cbc.ca/longform/unassisted-death> ('CBC Coverage of Doreen Nowicki').

26 See, eg, the case of a Victorian patient discussed below: Eswaran Waran and Leeroy William, 'Navigating the Complexities of Voluntary Assisted Dying in Palliative Care' (2020) 213(5) *Medical Journal of Australia* 204.

27 In Victoria, some institutions (such as facilities run by Catholic Health Australia, discussed below) have indicated that they will refuse to participate in assessment or administration of VAD.

28 Congregation for the Doctrine of the Faith, '*Samaritanus Bonus*: On the Care of Persons in the Critical and Terminal Phases of Life' (Letter, 22 September 2020) 8 <http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20200714_samaritanus-bonus_en.html>. This position is also reflected in Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* (2001). The Code states in its section on euthanasia: 'It is never permissible to end a person's life (whether that decision is made to relieve a patient's suffering by euthanasia, to comply with the wishes of the family, to assist suicide, or to vacate a bed)': at 46 [5.20].

29 Congregation for the Doctrine of the Faith (n 28) 9 (emphasis omitted).

30 The South Australia End of Life Choices Report notes that approximately 13% of palliative care in Australia is provided in Catholic hospitals, and in South Australia the Catholic Church is the largest provider of private palliative care beds: Joint Committee on End of Life Choices, Parliament of South Australia, *Report of the Joint Committee on End of Life Choices* (Report, 13 October 2020) 12.

31 Rhiannon Shine, 'Voluntary Euthanasia Legislation Leaves WA's Religious Communities Debating Doctrine and Death', *ABC News* (online, 10 August 2019) <https://www.abc.net.au/news/2019-08-10/where-do-different-religions-stand-on-voluntary-euthanasia/11399138>; Jewish Care, 'Voluntary Assisted Dying' (Position Statement, April 2019).

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facilities.[32] They may, however, be willing to provide information about VAD, refer to an external source of information,[33] or facilitate a transfer of care.[34]

Institutional objections need not be grounded in religion.[35] An example of this is an objection based on an institution's philosophy of palliative care, which for some[36] (but not others)[37] warrants a strict separation from VAD. For other institutions, objections to VAD may be grounded in their view about the purpose of medicine; namely, to promote health and preserve life, rather than to take life.

III EXISTING EVIDENCE ABOUT LAW AND POLICY RESPONSES

A Victoria

The *Victorian VAD Act* is silent on institutional objection.[38] Instead, the Department of Health and Human Services ('DHHS') has addressed this issue using a series of policy documents aimed directly at institutions.[39] The DHHS

32 Catholic Health Australia, 'Our Enduring Commitment to End of Life Care: Catholic Health and Aged Care Services in Australia' (Report, February 2019) ('CHA Taskforce Document'); Catholic Health Australia, 'CHA VAD Response Taskforce: Clinical Governance Recommendations' (Report, February 2019) ('CHA Clinical Governance Recommendations'); Catholic Health Australia, 'Catholic Health and Aged Care Services Response to the "Voluntary Assisted Dying Act"' (Media Statement, 19 June 2019) ('CHA Media Statement'); Jewish Care (n 31).

33 Jewish Care (n 31).

34 CHA Media Statement (n 32) 1.

35 Andrew McGee, 'Voluntary Assisted Dying: Should Conscientious Objection Be Unconditional?' (2020) 50(2) *Journal of Pharmacy Practice and Research* 117, 118.

36 Australian and New Zealand Society of Palliative Medicine, 'The Practice of Euthanasia and Physician-Assisted Suicide' (Position Statement, September 2020); Waran and William (n 26) 205. This position was also advanced by Hospice New Zealand in *Hospice New Zealand v A-G* [2020] NZHC 1356, [18] (Mallon J).

37 Palliative Care Australia, 'Palliative Care and Voluntary Assisted Dying' (Position Statement, September 2019) ('PCA Position Statement'). The PCA Position Statement also draws a distinction between VAD and palliative care, but suggests palliative care practitioners may decide whether to be involved in VAD.

38 Conscientious objection is addressed in section 7 of the *Victorian VAD Act 2017* (Vic), but this is limited to registered health practitioners. Section 7 indicates registered health practitioners may refuse to: provide information; participate in the request and assessment process; apply for a VAD permit; supply, prescribe, or administer the medication; be present at the time of administration; or dispense a VAD prescription. The *Victorian VAD Act 2017* (Vic) does not specify whether the health practitioner must refer the patient or disclose their conscientious objection.

39 Department of Health and Human Services, State Government of Victoria, 'Voluntary Assisted Dying Model of Care Pathways for Health Services' (Guidance, January 2019) <https://www2.health.vic.gov.au/~/media/Health/Files/Collections/Policies%20and%20guidelines/V/VAD%20Model%20of%20care%20pathways%20for%20health%20services> ('DHHS Model of Care Pathways'); Department of Health and Human Services, State Government of Victoria, 'Preparing for Voluntary Assisted Dying: *Voluntary Assisted Dying Act 2017*' (Guidance, 24 April 2019) <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/preparing-for-voluntary-assisted-dying>; Department of Health and Human Services, State Government of Victoria, 'Voluntary Assisted Dying Guidance for Aged Care Providers' (Guidance, 17 April 2019) <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/vad-guidance-aged-care-providers>; Department of Health and Human Services, State Government of Victoria, 'Voluntary Assisted Dying Safety and Quality Guidance for Health Services' (Guidance, January 2019); Department of Health and Human Services, State Government of Victoria, 'Health Service Participation in Voluntary

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instructs health services to assess their capacity to provide VAD, and determine whether it is congruent with their 'staff or service mix' and the health service's values.[40] The guidance indicates that 'most health services will fall into one of three high-level pathways':[41]

- Pathway A: Single service – Health services that are willing and able to provide VAD within their facilities;
- Pathway B: Partnership service – Institutions that can provide access to some elements of VAD but require assistance from existing external partnerships and referral pathways;[42] and
- Pathway C: Information and support service – Health services that either choose or are not able to provide VAD, including those that do not provide end-of-life care. The DHHS guidance indicates that organisations who adopt Pathway C 'will be able to provide' support and information about VAD and '[a]ll health services should be prepared to respond to requests for information about, or access to, voluntary assisted dying'.[43]

The DHHS guidance characterises institutional objection both as a matter of conscience and as a matter of self-governance.[44] It suggests an institution that objects to VAD will typically fall under Pathway C.[45] A health service is not obliged to refer the patient to a VAD provider, but must not 'inhibit a person's

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Assisted Dying' (Guidance, August 2018) <https://www2.health.vic.gov.au/~/media/Health/Files/Collections/Factsheets/V/VAD-health-service-participation> ('DHHS Health Service Participation'); Department of Health and Human Services, State Government of Victoria, 'Health Service Policy Guidance for Voluntary Assisted Dying' (Guidance, 12 June 2019) <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/Health-service-policy-guidance-for-voluntary-assisted-dying>. All Department of Health and Human Services policy documents aimed at institutions can be found here: 'Health Services Information', *Department of Health and Human Services, State Government of Victoria*, (Web Page) <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-services-information>.

40 DHHS Model of Care Pathways (n 39) 3. See also DHHS Health Service Participation (n 39) 1.

41 DHHS Model of Care Pathways (n 39) 9.

42 For example, partnering with general practitioners to conduct VAD assessments.

43 DHHS Model of Care Pathways (n 39) 3, 9.

44 The DHHS Model of Care Pathways (n 39) document invites institutions to assess their staff or service mix and their organisational values. It states: 'After assessing the capacity of their service to provide voluntary assisted dying, a health service may determine they do not have the appropriate staff or service mix to provide access to voluntary assisted dying, or that providing access to voluntary assisted dying would not be consistent with the values of the health service': at 3. See also Shadd and Shadd (n 6). Cf Sumner (n 6).

45 The DHHS Model of Care Pathways (n 39) document states that Pathway C 'is likely to include health services that do not provide care to people who are at the end of their life as well as health services that have chosen not to provide voluntary assisted dying': at 9. Note, however, that Pathway B may apply depending on the nature of the objection (eg, if the objection extends only to providing access to VAD and does not include the provision of information or eligibility assessment). For example, an aged care facility might choose to partner with general practitioners to provide VAD assessments but object to their residents consuming the VAD medication onsite.

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access to treatment'.[46] Additionally, health services should inform the patient 'as soon as practicable that they will not assist them'[47] and health professionals (in accordance with professional codes of conduct) must not use their objection to 'impede access to treatments that are legal'.[48] The policies strongly suggest (but do not require) that organisations nominate a VAD contact, but if no one is designated, organisations may direct patients to the Statewide Care Navigator Service ('VAD Navigators'), which can provide information, support and referrals.[49]

On its face, the DHHS policy position suggests, at a minimum, that objecting institutions should provide information and support to those seeking VAD, and should consider how to provide 'compassionate person-centred care' to those who request information or access to VAD.[50] However, the policies allow latitude for institutions to depart from this, with the DHHS indicating that '[h]ealth services may adapt the care pathways'.[51]

Some organisations have created specific policies stating that they will not permit access to VAD. For example, Catholic Health Australia ('CHA'), the largest non-governmental grouping of hospitals and aged care providers in Australia, will not provide VAD in its facilities.[52] Their taskforce document in response to the *Victorian VAD Act* does not explicitly mention referral, but indicates that organisations under the CHA umbrella 'will not facilitate or participate in assessments' for the purpose of VAD.[53]

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46 DHHS Health Service Participation (n 39) 1.

47 Ibid.

48 DHHS Model of Care Pathways (n 39) 6. The DHHS Model of Care Pathways document puts forward this language from the Medical Board of Australian Code of Conduct. It also addresses nursing and pharmacy professional codes of conduct.

49 Department of Health and Human Services, State Government of Victoria, 'The Statewide Voluntary Assisted Dying Care Navigator Service' (Fact Sheet, September 2019) <https://www2.health.vic.gov.au/Api/downloadmedia/%7B443D45A2-9F81-4BCB-9D3A-EE3B36FD3306%7D> ('DHHS VAD Care Navigators').

50 DHHS Model of Care Pathways (n 39) 3.

51 Ibid 7.

52 CHA Taskforce Document (n 32). This statement was contributed to by CHA member organisations: Calvary Health Care; Cabrini; Mercy Health; St John of God; St Vincent's Health; and Vita Maria Catholic Homes ('VMCH'). See also CHA Media Statement (n 32).

53 CHA Taskforce Document (n 32) 2. It appears that at least some organisations under the Catholic Health umbrella will facilitate referrals or transfers of care. The CHA Media Statement (n 32) that accompanied the commencement of the *Victorian VAD Act 2017* (Vic) indicates that '[e]ach of our services has a system in place that will respond respectfully and compassionately to any questions about "VAD". This includes coordinating transfer of care to other providers if a patient/resident wishes to seek "VAD". We will not impede access to the provision of "VAD" elsewhere': at 1. Note, also, that guidance has been issued by the Australian Medical Association in its broad statement on conscientious objection in medicine. The statement also addresses institutional objection and may inform Victorian health providers' responses. It states that institutions may object to providing certain services, and if this occurs the institution should visibly inform the public so potential patients can seek care elsewhere. It indicates that where a patient admitted to an institution requests VAD, doctors should still be allowed to refer the patient to a VAD provider outside the facility. In other words, the organisation should not limit its staff from making appropriate referrals. This guidance is likely to pose difficulties for religious organisations that would seek to limit VAD referrals: see 'Conscientious Objection: 2019', *Australian Medical Association* (Web Page, 27 March 2019) [3.1]–[3.2] <https://ama.com.au/position-statement/conscientious-objection-2019>.

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To date, evidence of how VAD is operating in practice is limited. Waran and William describe a transfer of care due to an institutional objection to VAD.[54] A 53-year-old woman sought VAD for metastatic breast cancer, but after she was assessed as eligible, she required admission to a palliative care unit to manage her worsening symptoms. Since the woman could not return home, she sought to take the VAD substance in the unit but was refused because of the organisation's policy against providing VAD.[55] She was then referred to another site within the same health service, which also objected. She was eventually transferred to a third venue in the service and was able to take the VAD substance on her preferred date. In describing the case, the authors emphasise the position taken by the DHHS: there is no duty for a health service to refer a patient, but health services must not actively inhibit a patient's access. It is not clear from the article whether the original palliative care unit facilitated the referral or used the VAD Navigators.

There has also been a media report of institutional objection where a patient in a Catholic hospice was not permitted to take delivery of their VAD substance after pharmacists were refused entry to the premises.[56] As a result, the patient needed to be transported out of the hospice and to a hospital where they were then able to receive their VAD substance. In addition, although not an institutional objection of the type discussed in this article, that media report also described a decision by a large palliative care service to decline to certify deaths of patients who had died at home from VAD. Although at this early stage there is only anecdotal evidence that institutional objection is occurring in Victoria, given that there is no legislative requirement for institutions to permit access or make a referral, and that the government policy confirms this, we anticipate that institutions will continue to object to VAD.

B Other Australian Jurisdictions

There is no reason to believe the situation in relation to institutional objections will be different in other Australian states if and when VAD legislation is enacted. Some religious institutions have adopted a position at a national level, so institutions affiliated with these entities can reasonably be expected to have similar objections.[57]

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54 Waran and William (n 26).

55 Waran and William (n 26) describe that the policy was also grounded in 'the need to minimise misperceptions' about the role of the palliative care unit: at 204. The Royal Australasian College of Physicians ('RACP') statement on VAD was cited to justify this stance, which recommends 'voluntary assisted dying must not be seen as part of palliative care': Royal Australasian College of Physicians, 'Statement on Voluntary Assisted Dying' (Position Statement, November 2018) 2 (emphasis omitted).

56 Melissa Cunningham, '"Discriminatory and Unethical": Palliative Care Service Criticised Over Failure to Verify Euthanasia Deaths', *The Age* (online, 17 April 2021) <https://www.theage.com.au/national/discriminatory-and-unethical-palliative-care-service-criticised-over-failure-to-verify-euthanasia-deaths-20210415-p57jif.html>.

57 See, eg, CHA Clinical Governance Recommendations (n 32); CHA Taskforce Document (n 32).

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As mentioned, the VAD legislation in Western Australia is silent on whether a non-participating institution must refer or facilitate transfer of a patient who wishes to access VAD. The Catholic Church is committed to ensuring Catholic hospitals, aged care facilities and palliative care facilities in Western Australia remain 'VAD free spaces',[58] suggesting they will permit neither VAD assessment nor administration. Anglican, Jewish and Muslim leaders in Western Australia have also expressed opposition to VAD.[59] It is anticipated that healthcare and aged care facilities run by these religious institutions may well prohibit the assessment or administration of VAD, or provision of information about VAD, or referrals out occurring within their facilities.

In Queensland, members of the Presbyterian Church, the Anglican Church, the Baptist Church and the Catholic Church all expressed their opposition to VAD before the parliamentary inquiry.[60] Similarly, in Tasmania, CHA has stated that Catholic hospitals and aged care facilities will not provide VAD prescriptions nor administer a lethal injection.[61] They will also not allow external providers to enter the facility to conduct VAD consultations, and will not be making specific referrals to non-objecting institutions.[62]

It seems, however, that some institutions which object to VAD on the ground of conscience will refer individuals to a central government coordination and referral agency, rather than provide a direct referral to a known VAD provider.[63]

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58 Don Sproxton, 'Euthanasia in Western Australia' (Speech, 2019 Australian Catholic Youth Festival, 8 December 2019) <http://perthcatholic.org.au/Our_Archdiocese-Bishop-Speeches_Statements_and_Letters-2019-Speech__Euthanasia_in_Western_Australia.htm>.

59 Shine (n 31). However, not all religious institutions in Western Australia are opposed to VAD. The Buddhist Council expressed support for the legislation, and the Uniting Church has put forward a resolution to allow VAD assessment and administration to occur within its facilities: see, eg, Synod of the Uniting Church in Western Australia, 'Proposal 9: Voluntary Assisted Dying Task Group' (Policy Proposal, September 2020) <https://unitingchurchwa-startdigital.netdna-ssl.com/wp-content/uploads/2020/09/VAD-Task-Group-3.pdf>.

60 Queensland Parliamentary Report (n 9) 50. Similar views were expressed by religious groups to other parliamentary inquiries: see, eg, Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report No 174, June 2016) 213 <https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf>; Select Committee on End of Life Choices in the ACT, Parliament of the Australian Capital Territory, *End of Life Choices in the ACT* (Report, March 2019) 89–90 <https://www.parliament.act.gov.au/__data/assets/pdf_file/0004/1334992/9th-EOLC-Report.pdf>.

61 This includes the four hospitals run by Calvary Healthcare and around nine aged care facilities operated by Southern Cross Care in Tasmania: Marilyn Rodrigues, 'Peak Health Group Rejects Dying Bill', *Catholic Weekly* (online, 17 September 2020) <https://www.catholicweekly.com.au/peak-health-group-rejects-dying-bill/>.

62 Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 15 (Bastian Seidel). The Anglican Church has also publicly voiced its opposition to VAD: Sue Bailey, 'Two Churches Have Strongly Opposed an Assisted Dying Bill Being Prepared for Parliament', *The Advocate* (online, 22 September 2019) <https://www.theadvocate.com.au/story/6399252/assisted-dying-proposal-rebuffed-by-churches/>.

63 In Victoria, the Department of Health and Human Services established a Statewide Voluntary Assisted Dying Care Navigator Service to provide this referral function: DHHS VAD Care Navigators (n 49). In the first year of the *Victorian VAD Act 2017* (Vic), this service provided support to 613 people (the data does not state whether these supports were a result of institutional objections): Voluntary Assisted Dying Review Board, 'Report of Operations: January–June 2020' (Report, 31 August 2020) 5

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C Some Illustrative Canadian Examples

Allowing institutional objections to VAD can sometimes result in patients being transferred seamlessly and painlessly to another institution, community space, or home for assessments and provision of VAD. However, as the longer Canadian experience with VAD has shown,[64] it can also result in indignity, extreme pain, and loss of access. There is insufficient scope here to report all such reported cases, but those described below are illustrative.[65]

Two cases that resulted in indignity were Doreen Nowicki and Bob Hergott. Doreen Nowicki was a woman in her late 60s with advanced motor neurone disease.[66] She was living in a continuing care facility run by a Catholic provider. She was taken from her bed with a mechanical lift, put in a wheelchair, and brought out of the facility to benches situated across the street (off the property) for her VAD eligibility assessment. This was intensely distressing for her. Bob Hergott, a 72-year-old man also with motor neurone disease, had to leave the hospital where he had been an in-patient for five years, cross the street in the rain to a bus shelter, and meet the two witnesses required as he signed his form requesting VAD.[67]

An institutional objection can also result in extreme pain to the patient. Ian Shearer was an 87-year-old man with spinal stenosis.[68] His pain medications were reduced to ensure he would have decision-making capacity following the transfer. The ambulance was more than three hours late. The time waiting for the ambulance was increasingly painful and the trip across the streets of Vancouver was agonising.

Institutional objections have also resulted in limitations or removal of access. Gerald Wallace was an 80-year-old man with pancreatic cancer in a rural hospital run by a Catholic organisation.[69] He was prevented from accessing VAD and died

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<https://www.bettersafercare.vic.gov.au/sites/default/files/2020-08/VADRB_Report%20of%20operations%20August%202020%20FINAL_0.pdf>. The *End of Life Choice Act 2019* (NZ) has mandated the creation of a support and referral group in its legislation: at s 25.

64 As noted above, in Canada, VAD is referred to as 'medical assistance in dying' ('MAiD'), but we use the term VAD in this section for consistency with the rest of the article.

65 We do not have full information on the scope of the problem as the data is not collected in all jurisdictions. However, in Alberta, a province that collects and publishes data on this issue, between 17 June 2016 and 30 April 2020 (noting, though, that the website states it is current as of April 2020 but actually only includes data up to end of 2019), 125 patients were transferred from faith-based (109) or non-participating (16) sites to a participating facility or the patient's home. This data suggests that 10% of VAD deaths in Alberta follow a transfer from a faith-based site: 'Data & Statistics: Medical Assistance in Dying', *Alberta Health Services* (Web Page, 28 February 2021) <https://www.albertahealthservices.ca/info/Page14930.aspx>.

66 CBC Coverage of Doreen Nowicki (n 25).

67 CBC Coverage of Bob Hergott (n 25).

68 Tom Blackwell, 'BC Man Faced Excruciating Transfer after Catholic Hospital Refused Assisted-Death Request', *National Post* (online, 27 September 2016) <https://perma.cc/DE36-V9TA>.

69 Jennie Russell, 'Camrose Man Died in Pain after Covenant Health Hindered Access to Assisted-Dying Services, Son Says', *CBC News* (online, 1 December 2018)

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in pain. Additionally, Horst Saffarek, an elderly man whose lungs were failing, was admitted to a Catholic hospital.[70] He was found eligible for VAD but the hospital refused to allow it to be provided on their premises. He had to be transferred to a city more than an hour away, but he died before he was able to access VAD.

IV THREE POSSIBLE MODELS OF LEGAL REGULATION

The limited evidence in Australia about institutional objection, as discussed in Part III(A) and (B), reveals that some institutions in Victoria are currently objecting to VAD in various ways and this is likely to occur in other states that legalise VAD. These objections, as also shown in the longer Canadian experience, can adversely affect individuals who are eligible for VAD but cannot access it in such institutions. Governments exploring VAD reform must consider this issue and the appropriate regulatory response, whether that is prohibiting institutions from conscientiously objecting, not restricting this ability in any way, or a compromise of these two extremes. Ultimately, a government's position will depend on how it balances institutional and individual interests. At the heart of this decision is how best to weigh an individual's ability to access VAD against an institution's desire not to permit access to VAD within its facility.[71]

This balancing exercise has been subject to extensive debate[72] and there is not scope in this article to engage further with those arguments. Instead, our goal is to describe possible regulatory models that chart three broad options, and briefly observe the implications of each model for institutional and individual interests.

The three regulatory responses proffered draw on Wicclair's terminology in relation to conscientious objection by individuals,[73] and are framed as:

- 'conscience absolutism' – permitting institutional objections without limit;
- 'compromise or reasonable accommodation' – permitting institutional objections but imposing limits on them; and
- 'non-toleration' – institutional objections are not permitted.

But before considering these three options, we raise two threshold issues. The first is whether a regulatory response should comprise of legislation or policy. We propose that legislation is optimal (which would allow for accompanying policy), and regulatory responses in Part IV(B) and (C) below are framed accordingly. Policy alone is a weaker form of regulation with less coercive force.

<https://www.cbc.ca/news/canada/edmonton/camrose-man-died-in-pain-after-covenant-health-hindered-access-to-assisted-dying-services-son-says-1.4927739>.

70 'Should Catholic Hospitals Have to Provide Access to Medically Assisted Dying?', *CBC Radio* (online, 11 January 2018) <https://www.cbc.ca/radio/thecurrent/the-current-for-january-11-2018-1.4481312/should-catholic-hospitals-have-to-provide-access-to-medically-assisted-dying-1.4482372>.

71 Flynn and Wilson (n 22) 228–9.

72 See Carpenter and Vivas (n 25); Flynn and Wilson (n 22); Gilbert (n 20); Shadd and Shadd (n 6); Sumner (n 6).

73 Mark R Wicclair, 'Preventing Conscientious Objection in Medicine from Running Amok: A Defense of Reasonable Accommodation' (2019) 40(6) *Theoretical Medicine and Bioethics* 539.

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While a policy approach is often appropriate to regulate aspects of healthcare, we consider this is not the case where the proposed policy response conflicts with deeply-held views of the target of regulation (here, institutions). The stronger normative and coercive force of law is more likely to be needed here, particularly if an individual citizen is seeking to rely on it to compel an institution (often large and well-resourced) to comply with regulation.[74] Further, a legislative approach ensures any changes occur only with the transparency and public accountability of parliamentary consideration.

The second threshold point we make is that, regardless of which regulatory response is adopted, it should require organisations to disclose their objections publicly.[75]

A 'Conscience Absolutism'

The first regulatory option is for legislation to enshrine the ability of an institution to object. The model gives all weight to an institution's position on VAD and no weight at all to the patient's interests, and enables institutions that effectively have a monopoly on the provision of specialist services to bar individuals from accessing legally-available health services.[76]

Such an approach would bestow greater powers on institutions to object than individuals, upon whom law and ethics in medicine traditionally impose at least some compromise or accommodation duties – eg, providing information or effective referral.[77] Allowing absolutism for institutions could effectively deprive eligible people of access to VAD, even more so than objections by individual health professionals. While changing doctors is not straightforward, it generally remains possible, whereas for a person unable to move from an institution, absolutism is a veto on that person's ability to access VAD.[78] Even if a person was able to move, they may require the cooperation or assistance of the institution to facilitate the transfer, which absolutism would allow them to withhold.

74 We note it would be possible, however, to design a policy response which may nevertheless be effective in ensuring compliance by institutions – eg, if linked to accreditation or funding requirements.

75 A provision requiring such disclosure was included in the Voluntary Euthanasia Bill 2016 (SA) clause 21(3)(a). We do not propose this disclosure being a ground for refusing access to VAD. Rather, we consider the utility of such a provision is to help avoid situations, where possible, of a person finding out subsequent to their admission or residence that the facility objects to access to VAD.

76 See, eg, Schuklenk (n 8).

77 It is worth noting that while the *Voluntary Assisted Dying Act 2019* (WA) section 20(5) requires conscientiously objecting health professionals to provide certain information to their patients, the *Victorian VAD Act 2017* (Vic) s 7 imposes no accommodation duties on doctors who conscientiously object.

78 Sumner (n 6) 972.

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B 'Compromise or Reasonable Accommodation' of Institutional Objection

This section outlines how legislation could present a 'compromise or reasonable accommodation' model for institutional objection to VAD. Such an approach recognises that institutional objections to VAD will occur and allows them, but aims to regulate them to ensure as little impact on the person seeking VAD as possible, while still permitting some degree of institutional objection. This need not imply legislative endorsement of these objections; the focus is instead on creating processes to facilitate a person's access to VAD where objections occur. Two of the authors included a clause in their model VAD Bill which aimed to address this by requiring the objecting institution to arrange a transfer if requested.[79] However, in light of the impacts of institutional objections on patients in practice, as described earlier in the article, more may be needed to better support access to VAD when institutions object.

While there are various compromise models that could be designed, in our view, all compromise models should, at a minimum, require institutions to provide information about VAD and facilitate effective referral to a VAD provider. This obligation does not require an objecting institution to endorse VAD, or to be involved with its assessment or administration. Although some organisations may consider that providing information or directly referring to a VAD provider makes them complicit in the activity to which they object,[80] a workable alternative is to connect individuals with a central coordination service (such as the VAD Navigators in Victoria).[81] Therefore, our discussion below focuses on the two other aspects of VAD provision that institutions may object to: conducting VAD assessments and administration.

A final general point is that this compromise or reasonable accommodation category is very broad: legislation could be drawn to require either very little compromise or a great deal of compromise from objecting institutions. The below approach is one put forward for consideration which weighs the balance between individual and institution in favour of the person seeking access to VAD. As explained below, we have struck the balance in favour of the patient when the institutional objection will unduly compromise the patient's interests. This is because the patient, who is close to death and intolerably suffering, is in a vulnerable position.

1 Nature of Provision: No New Rights for Institutions; Creates Process Only

Under this model, legislation should provide that 'nothing in this section creates a right for an institution to refuse to provide access to VAD'. This addresses concerns raised in the Tasmanian debates[82] that legislatively regulating this issue

79 White and Willmott (n 9) 36. See also Voluntary Euthanasia Bill 2016 (SA) cl 21(3)(b). Such a clause was also reflected in amendments proposed in Tasmania to its *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas): see Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 2 (Bastian Seidel).

80 Congregation for the Doctrine of the Faith (n 28) 8, 14.

81 This is also the position that has been adopted in Alberta and Quebec, Canada: Gilbert (n 20) 9.

82 See, eg, Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 10 (Meg Webb).

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might be seen as implicit recognition of institutional objections and conscience rights.[83] Further, the provision should be framed as establishing a process to ensure a person's access to VAD is not unreasonably denied. For example, it could state: 'An institution wishing to refuse a person's request to access VAD within a facility must follow the process outlined in this section'.

2 Would the Patient's Interests Be Unduly Compromised by Requiring Access to VAD Outside the Facility?

One way to accommodate both an institution's objection and a person's desire to access VAD is for VAD assessments and administration to occur outside the facility. This could occur by transferring a person's care or residence to another, non-objecting, institution. However, it is also possible for VAD to occur without a formal transfer. For instance, a person in a residential aged care facility may remain living there but, if well enough to do so, may leave the facility for VAD assessments and then again attend elsewhere to take the VAD medication at a time of their choosing. Determining when this should be required would depend both on establishing criteria to assess the impact on the patient's interests, and identifying who would decide whether these criteria were met.

To address the undesirable consequences for persons seeking VAD outlined above, this criteria could include that it is not appropriate for an institution to refuse access to VAD where:

- that would cause harm to the person (eg, this could be pain or a deterioration of their condition from the required transfer);
- that would prejudice a person's access to VAD (eg, the transfer logistics to another institution mean a person is likely to lose capacity or die first; or pain medication required to manage the transfer means they are likely to lose capacity);
- that would cause undue delay (and thereby extended intolerable suffering) in accessing VAD; or
- access to VAD is not reasonably possible at another institution (eg, another institution will not accept a transfer or the institution is the only facility in the district that could manage the patient in their condition).

Given the criteria (which are medical in nature or at least involve navigating the health system), we consider it appropriate that whether they are met is decided by a doctor. We would propose a doctor who is chosen by or acceptable to the patient. A doctor employed by an objecting institution may not be free to adopt a position contrary to the institution, although we note that a patient might choose to nominate a doctor working in an objecting institution if they considered that doctor was independent.

83 This provision would not, of course, create a right or duty to provide VAD.

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This may raise issues if the objecting institution considers that granting permission for this doctor to meet with the person is facilitating access to VAD and so is inconsistent with the institutional objection. However, failing to allow this access to the facility by the doctor could preclude a person's access to VAD altogether, so this is required to appropriately balance institutional and individual interests.

3 Obligations Where Access to VAD Will Occur Outside the Objecting Institution

Where the criteria above mean that access to VAD will occur outside the objecting institution, the institution must offer and take reasonable steps to facilitate this access. For instance, this may require supporting a transfer of the care or residence of the person to a place at which VAD can be assessed or provided by a doctor who does not have a conscientious objection to VAD.

Further, a person must not experience financial detriment because of such a transfer, which could in some instances have financial implications for a person so serious as to create an unconscionable or insurmountable barrier. This detriment could range from the cost of transport between institutions through to costs due to complex financial arrangements associated with entry into and exit from a residential aged care facility. Because the need for a transfer arises from the institution's objection, the legislation should provide that no financial detriment will occur as a result.

4 Obligations Where Access to VAD Will Occur Inside the Objecting Institution

Where the criteria above mean that access to VAD will occur inside the objecting institution, the legislation should provide that access must be permitted by the institution. This is based on a person's claim to access VAD outweighing an institution's objection, when both outcomes cannot be achieved. Not taking this approach would effectively mean that a person who is unable to be reasonably transferred or leave the institution for periods to access VAD would be prevented from accessing VAD by an institution that is objecting.

The legislation should state that an objecting institution will be required to permit a person to access VAD within the institution and will take reasonable steps to allow this where transfer is not possible or unduly harms the person's interests. This may include permitting existing staff (who are willing) to be involved in conducting VAD assessments or administering the VAD medication to this person, or allowing other doctors to visit the person onsite and provide the assistance required. The institution would also not be allowed to impede a person self-administering VAD medication onsite.

C 'Non-Toleration' of Institutional Objection

Under this model, legislation would prohibit an institution from preventing access to VAD on the basis of an objection. The provision could be framed broadly

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and prohibit an institution from impeding access of a person seeking VAD.[84] For clarity, it may be desirable for the legislation to specify that the institution could not prohibit entry to its facility of any health professional for the purpose of discussing VAD with a patient, assessing eligibility for VAD, or providing VAD. The institution also could not prohibit a patient from self-administering a VAD substance.

Under this approach, VAD would be available to all eligible individuals who wish to access it, not just for those for whom transfer would be problematic (as canvassed above). This model gives the strongest recognition of the three approaches to the right of an individual to access VAD despite an institution's objection.

V CONCLUSION

This article aims to highlight an important, but largely neglected, aspect of the VAD debate in Australia: objections by institutions when a person seeks lawful access to VAD. Patients and residents being cared for or residing in such institutions may effectively be denied access to VAD or have to overcome significant barriers to access it. There is evidence of institutional objection in Australia, and experience in Canada demonstrates the impact these objections can have on individuals who wish to access VAD and are experiencing intolerable suffering.

This article proposes three possible legislative models to regulate institutional objection. One is conscientious absolutism: legislation that enshrines the ability of an institution to object and imposes no limitation on that right. This model will have adverse outcomes for some individuals, particularly those who are unable to transfer from that facility, as they are effectively deprived of choice, unable to move, and without access to VAD. This prioritises the institutional position at the expense of the individual. At the other end of the spectrum, non-toleration, where an institution is prohibited from exercising an objection in any circumstances, the individual is prioritised even if the institution may be in a position and willing to transfer their care.

The middle ground, the 'compromise or reasonable accommodation' model, is a legislative option worthy of consideration. It does not grant absolute priority to either the institution or the individual seeking VAD, but seeks to accommodate both. The specific compromise model proposed in this article, however, does prioritise the individual if both positions cannot be reasonably accommodated.

Parliaments and law reform bodies considering VAD reform must consider the issue of institutional objection, and select a policy position on how to balance the

84 A stricter version would be to require institutions to employ staff capable of and willing to be involved in the provision of VAD.

desire of an institution to determine what practices are permitted within their facilities and the interests of an individual seeking access to VAD, a lawful medical service. As argued above, this should not be left to policy alone and is an issue that should be explicitly addressed in VAD legislation.

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“This is perfect, thank you”: Gratitude for voluntary assisted dying

What is the research about?

While there are anecdotal reports about people being grateful for voluntary assisted dying (VAD), the concept of gratitude for VAD has not been fully explored. This research examines expressions of gratitude from those involved in seeking VAD.

What did we do?

We interviewed 32 family caregivers and one patient about the experience of 28 patients seeking VAD in Victoria. We analysed what people said about gratitude for VAD.

We also created six research poems. This arts-based research method uses people’s words from one or more interviews to create poetry. It helps share the direct voices of patients and family caregivers about their gratitude for VAD and reflects how important it was to them.

What did people say about gratitude for VAD?

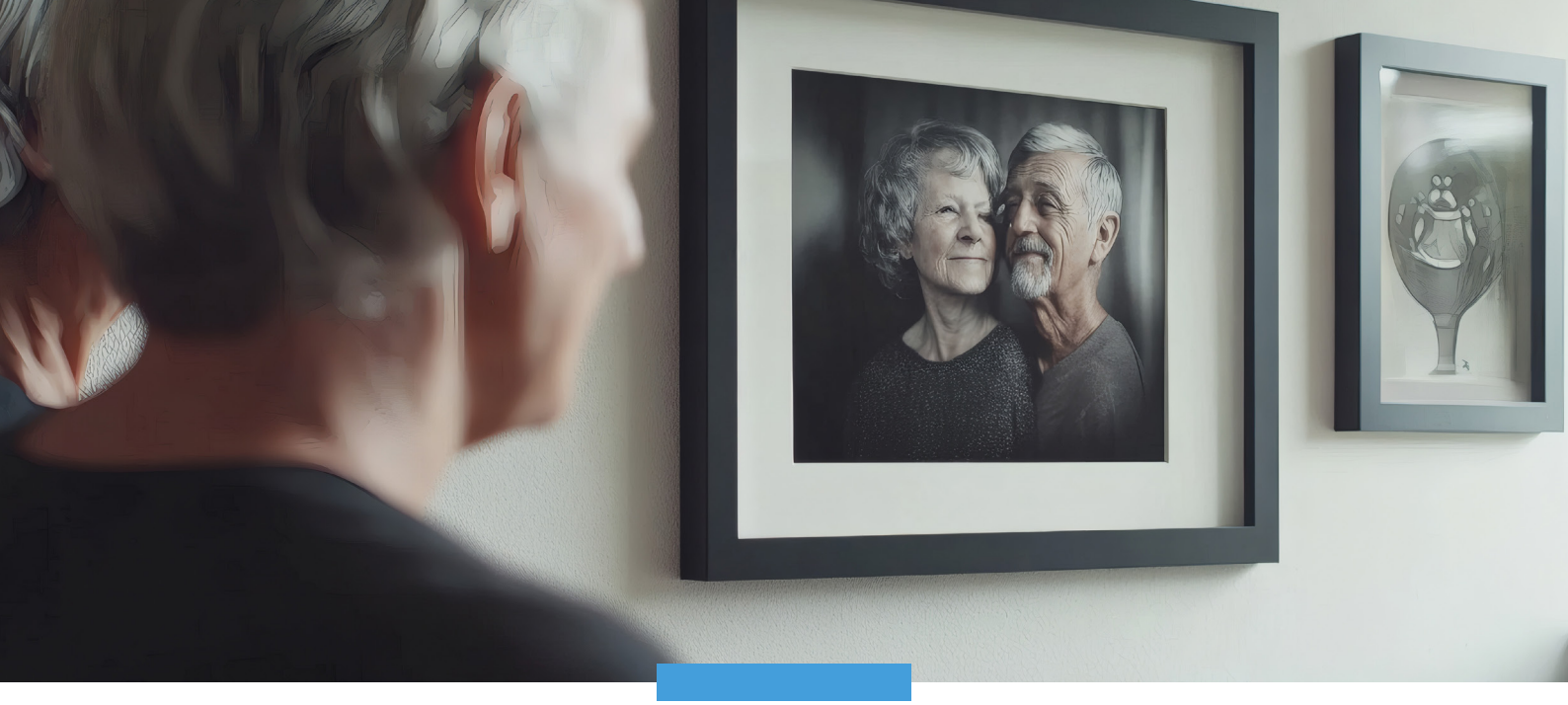
Gratitude was very important for the people we interviewed. They spoke about gratitude often and with deep emotion. Gratitude was also reported as being mixed with other feelings, such as sadness about a loved one’s death.

People expressed gratitude for VAD because it:

- Helped avoid a bad death or dying in a “long and protracted and unkind” way
- Enabled a good death. This is reflected in this research’s title: “This is perfect, thank you”
- Provided “choice”, “control” and “empowerment”. VAD gave people “a choice when everything was being taken away” by their illness
- Gave “peace”, “relief” and “comfort” to know that VAD was an option

People expressed gratitude to:

- Health professionals who supported the VAD process. This included state-funded VAD care navigators, local VAD hospital or health service coordinators, doctors who assessed patient eligibility and guided patients and families through the process, and pharmacists who provided the VAD medication.
- “Everybody who got the [VAD] legislation through”. Many people specifically thanked “lawmakers” and the Victorian Government. Some thanked Daniel Andrews, the then Premier of Victoria.



Research poetry

The six research poems we created aim to represent what people felt was important about gratitude. They were created using a series of direct quotes from interviews.

I've bought insurance

I could jump off a high building
Or lay down in front of a train
They're homemade methods
A do-it-yourself thing

The particular method I had in mind
Had some uncertainty about it
You can make mistakes
You could screw up

Before the VAD application
It's as though I had a motor car and
was driving it around
Not looking to have an accident
But aware the accident could occur

Now I've bought insurance
I know that I can use it if and when I need it
This is so far above all the homemade methods
I was very grateful to get it

The loveliest way to die

I know he felt lucky
Yes, she was lucky you might say

What dad got was beyond beautiful
She died very peacefully in the end

A kind, peaceful, gracious death
But she was in a coma which was
not what she planned for her ending

To choose the time and place
It would have been the loveliest way to die

At home, surrounded by family
She wanted to have her family in that room

He got his final wish
To have music playing, candles going

"I love you", they were his last words
To say goodbye, quietly and gently

He had the final say
She couldn't have that and that will haunt me

** The left-aligned lines express gratitude from multiple voices for VAD enabling a good death. In contrast, the right-aligned words in italics express regret from a person whose loved one missed out their choice of VAD.*

Peeling away an onion

Cancer had taken so many things away from him
His health
His hobbies
His peer group
You become very, very isolated
Culturally, we are afraid
Afraid of saying the wrong thing
So people say…
Nothing
Like peeling away an onion, he lost everything
Other than this core part of him
His ability to go with agency

Thank you Dan

Mum had to stand right at the end and
give that little speech
To thank everybody for making this possible
"Thanks to everybody who got the
legislation through"
(We're hovering thinking she's going to fall over)

"Thank you Dan"
What he did, what his government managed to get through
Under some quite extraordinary opposition
Monumental

They were his last words
Apart from "I love you"

And then she swallowed the medication

** The "Dan" referred to in this poem is Daniel Andrews, the Premier of Victoria at the time the VAD laws passed.*

This is perfect, thank you

She was sitting in the doctor's surgery
In the waiting room
Her voice was going by then
Everything was being taken away from her
She was so scared of what was happening
Terrified about drowning to death
How long and protracted and unkind those deaths are

She was told she had motor neurone disease
She looked at me and she said "I'm happy now"
What was happening to her was terminal
She knew she would be able to have the choice
She felt comfort, relief
She had a way out

He received this medication, he felt lucky
That empowerment was given back to him
"It's mine, I've got this"
I know that I can use it when I need it
He had control
You could see the difference
The most happy and peaceful in a long time

She had no choices with how the
disease panned out
She couldn't make any other decisions
When almost everything else had
been taken away
It allowed him to keep something of himself
At home, surrounded by her family
He had the final say
She would be able to avoid the worst ending

He died with dignity
Out of pain
Respectful
I'm grateful that he got to go his way

** This poem draws on the voices of multiple people and we retained their pronouns to show these different voices.*

Mixed feelings

He had the final say
He got to go his way

It's awful in one sense
But we're so blessed in another

I want that for my loved one
But it's still not right

Because dad's not here
I wish he was here

For more information

This research briefing is based on Ben P White, Ruthie Jeanneret, Sarah Holland-Batt and Evonne Miller, '"This is perfect, thank you": Research poetry on gratitude for voluntary assisted dying in Victoria, Australia' (2025) Australasian Journal on Ageing (early online). More information about study limitations, research ethics and disclosures are available in the article: **https://doi.org/10.1111/ajag.70019**.

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This research was funded by the Australian Research Council Future Fellowship project 'Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying' (FT190100410). For more information about this project, including other publications: **https://research.qut.edu.au/voluntary-assisted-dying-regulation/**

How best to regulate voluntary assisted dying in Australia

What is the research about?

Australian voluntary assisted dying (VAD) systems are highly regulated. This regulation aims to make the system safe by screening out people who are not eligible for VAD. It also aims to support access to VAD so that people who are eligible and want this option can have it. Despite the important role of regulation in making VAD systems safe and accessible, little is known about which approaches to regulating VAD are most effective.

What did we do?

We interviewed 92 people – 39 doctors and 55 'regulators' – in the first two Australian states to have VAD: Victoria and Western Australia. We used a broad definition of 'regulator' in this study to include:

- people working in government entities such as
  - health departments
  - VAD Boards
  - VAD service roles
- people working in non-government bodies such as
  - medical associations
  - insurers
  - advocacy groups.

We asked both doctors and regulators about their thoughts on the best way to regulate doctors who are providing VAD.

What did doctors and regulators say?

1. VAD requires special and specific regulation

VAD is different from other areas of medicine. Most interviewees thought VAD required special and specific regulation because of its seriousness. Some doctors, however, thought the current regulation went too far and was excessive.

> **'There is no activity in health care, other than a few very small things, that has this degree of oversight and regulation.'**

2. Effective VAD regulation draws on multiple regulatory tools

A range of tools are effective in regulating VAD. These include law, policies and guidelines, training and education, and advice from peers (including communities of practice).

Different tools play different roles in guiding doctors in their VAD practice, and these tools work together. For example, law can set rules for when VAD is legal but clinical guidance may come from other tools like guidelines or communities of practice where doctors can 'calibrate [conduct]' amongst their peers.

'There are some advantages in a professional practice document because it starts to set the professional standards as different to the rules [law].'

'You need a mix of approaches. I don't think there's a single way of regulating behaviour that … work[s] for all types of practitioners or all types of people … different people are motivated by different things.'

3. Educative approaches to VAD regulation are generally more effective

Educating doctors is more effective in guiding practice than punishing them. It is better to be 'gently herding' rather than 'shaming people'. '99 percent of them [doctors]' want to follow regulation but 'for the one percenters, deterrence is important'. Punitive measures are needed in exceptional cases.

4. VAD regulation is effective when doctors perceive it as acceptable

When doctors perceive VAD regulation as legitimate and appropriate, it is more likely to reach their 'hearts and minds' and to be followed. This can happen when doctors consider the regulation:

- has a logical purpose or benefit: 'if there's a clear, logical explanation behind something, then we'll follow that.'
- is evidence-based
- resonates or accords with how doctors practise medicine
- was developed or delivered by them: 'a sense of co-design or autonomy and it's not unilateral'
- reflects how medicine is generally regulated.

5. VAD regulation is effective when it is nimble and responsive to doctors' needs

Regulation is more likely to guide doctors' VAD practice if it provides the required guidance and information at the time when it is needed. This includes:

- having information available in the right form and at the right time
- availability of human support to answer questions, both on VAD system issues and clinical guidance: 'If you need help, give us a phone call. If we don't know the answer, we'll find the right person.'
- system responsiveness so identified system problems are fixed.

They want to know: what can I do for my patient today? So, providing the information in a way that's chunked up, that supports that decision making at the right time… is [what doctors] generally need.

What should happen next?

1. VAD regulation should continue to use different regulatory tools (e.g. law, policy, training, etc). Which tools are used and how they are used should be based on their capability to guide behaviour. However, overall design of the system must ensure these regulatory tools work together to avoid duplication, fragmentation and inconsistency.

2. VAD regulation should preference educative approaches to support doctors providing VAD to follow regulation. But punitive measures should be available and used where needed (e.g. in cases of serious or repeated breaches).

3. To enhance doctors' acceptance of and compliance with VAD regulation, it should:
   - be based on justifiable purposes that are transparently communicated to doctors
   - be developed through a co-design process in consultation with reputable sources (i.e. members of the medical profession) and driven by evidence
   - align with how medicine is regulated generally, unless there is a reason for regulating VAD differently.

4. VAD regulation should provide practically useful guidance to doctors and be accessible when they need it (e.g. when a patient makes a VAD request). Access to designated personnel with VAD expertise (e.g. Care Navigators) is very helpful as are clinical mentors.

5. VAD regulation and systems should be responsive to feedback about needed improvement. This is particularly important when a VAD system is new.

For more information

This research briefing is based on Ben P White, Casey M Haining and Lindy Willmott, 'How best to regulate voluntary assisted dying: A qualitative study of perceptions of Australian doctors and regulators' (2025) 33 *Medical Law Review* (early online). More information about study limitations, research ethics and disclosures are available in the article: **https://doi.org/10.1093/medlaw/fwae045**

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Do people know that voluntary assisted dying is now legal in Queensland?

What is the research about?

Voluntary assisted dying (VAD) became legal for eligible terminally-ill individuals in Queensland on 1 January 2023. People need to be aware that VAD is a legal end-of-life option so they can discuss it with their health practitioner if they want to. Little is currently known about community understanding of VAD in Queensland. This study is the first in Australia, and one of the few globally, to examine community knowledge of VAD as a legal option.

What did we do?

We conducted an online survey of 1,000 Queensland adults 17 months after VAD became legal. We set quotas for age, gender, and geographical location to ensure the people we surveyed matched the Queensland population.

Our survey asked:

- Whether people knew VAD was legal in Queensland
- Whether people knew how to access VAD if they wanted to
- Where people would look for information about VAD.

What did we find?

1. Awareness that VAD is legal is low

Our research showed relatively low levels of knowledge that VAD is legal in Queensland. Only 33% of people surveyed correctly identified that VAD is legal. But this awareness was higher for those people surveyed who are health practitioners (62%).

People mainly found out that VAD was legal through the media (especially news reporting) and through professional or personal experiences like being a health practitioner or knowing someone who had asked about or requested VAD.

2. Few people know how to access VAD

Only 26% of people surveyed knew how to access VAD if they wished to. This means many people may not know how to seek VAD even if they knew it was legal.

3. Preferred sources of information about VAD

Most people surveyed (86%) said they would seek information about VAD online, particularly via search engines. They would also seek information from health practitioners, especially doctors.

4. **People called for improved access to information about VAD**

People surveyed wanted information about VAD to be more available. To increase awareness, they suggested using social media campaigns, advertising, and sharing information through Centrelink, health clinics, and other trusted community channels.

What should happen next?

1. **Community information and education initiatives**

Information about VAD is already available but more needs to be done to ensure it reaches the public.

Public awareness campaigns are needed to share this information, for example, through online platforms, news, social media, television, radio, health services, and government agencies. Tailored information is needed to support awareness of diverse groups.

2. **Targeted education initiatives for patients who may be eligible for VAD**

Patients who may be eligible for VAD should receive information about the eligibility criteria so they know if VAD can be one of their options. They should also receive information about the steps to take if they want to choose VAD and who to contact for more information.

3. **Health practitioner education and training**

Health practitioners, particularly GPs and specialists working in end-of-life care, are trusted sources of information about VAD. Targeted training is needed for these practitioners so they can confidently discuss VAD with patients and families. However, information about VAD should also be included in broader health education and training for all health practitioners.

For more information

This research briefing is based on Ben P White, Rachel Feeney and Lindy Willmott, 'Community knowledge of voluntary assisted dying: A cross-sectional survey of the public in Queensland, Australia' (2025) *Death Studies* (early online). More information about study limitations, research ethics and disclosures are available in the article: **https://doi.org/10.1080/07481187.2025.2452490**

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This research was supported by the Queensland Health project "Survey of Queenslanders' views on voluntary assisted dying".

Insights from Queensland's implementation of voluntary assisted dying

What is the research about?

Australian voluntary assisted dying (VAD) laws are very similar. But how VAD is implemented by each state and territory makes a big difference. There are novel features in how Queensland implemented VAD:

1. A government Health Service Directive (HSD) required all 16 Health and Hospital Services (HHSs) to have a 'model of care' for providing VAD.
2. The VAD Support and Pharmacy Service (QVAD SPS) combines the care coordinator service (which supports patient access to VAD) and the statewide pharmacy service (which supplies VAD medication). It also includes practitioners, usually nurses, who can provide VAD.

This is the first research into how the Queensland VAD system is working.

What did we do?

We interviewed 24 people involved with VAD delivery across 15 of the 16 HHSs. Participants included HHS VAD Coordinators, nurse practitioners and nurses who administered VAD for patients, and QVAD SPS staff. We asked them how the Queensland VAD system was operating in practice.

What did we find?

1. **VAD is accessed almost exclusively through the public sector via HHSs, influenced by the HSD**

Unlike other Australian states, about 90% of VAD is provided through the public sector. This is because the HSD requires each HHS to have a local model of care. Participants saw value in the HSD requiring HHSs to engage with VAD.

> **I think the directive was great. I think that that really socialised VAD ... We had to have a guideline in place to really set up those systems of governance.**

2. **Local models of care vary**

The HSD did not prescribe a model of care leading to 'huge variety' in implementation. While all HHSs had a VAD Coordinator, their role and allocated workload time varied.

> **They simply said, 'Just add this [VAD Coordinator] to your job as [current position].'**

The VAD workforce provided by HHSs also varied. Some only had the VAD Coordinator while other HHSs also appointed doctors and nurses to provide VAD.

3. **Nurses play significant roles in facilitating access to VAD and providing it**

HHSs generally implemented a nurse-led VAD model. Most VAD Coordinators were nurses, so they generally established HHS processes and often facilitated VAD applications to reduce burdens on doctors.

Unlike other Australian VAD systems, nurses in Queensland also regularly administer VAD for patients. For some nurses, administering VAD was a core role, with a few providing more than 20 times.

4. **QVAD SPS has an integral role in supporting HHSs and as back-up VAD providers to ensure statewide access**

Participants were glowing about QVAD SPS's support for HHSs and Coordinators, patients and families.

> **This [HHS] service wouldn't have survived without QVAD Support.**

Much of QVAD SPS's work focused on 'gap-filling' to ensure statewide access, particularly early on. QVAD SPS staff were not originally intended to administer VAD but this became necessary when HHSs lacked local capacity.

> **It's been gap-filling ... when a patient's priority has been that they've needed it, and nobody else has been able to go and do it.**

5. **More resourcing is needed within HHSs**

Many participants were concerned VAD was under-resourced in their HHS. Some felt HHSs were just 'ticking the box of the HSD'. Some participants reported not having enough time for their work, particularly given demand was higher than expected. Under-resourcing also led to VAD positions being temporary, creating job insecurity and risks to service continuity.

Despite QVAD SPS support and the rewarding nature of supporting patient choice, some participants described feeling burnt out and overloaded.

What should happen next?

1. **State governments should issue directions**, similar to Queensland's HSD, that each public health district will provide access to VAD. This will support statewide VAD access and through the public health system. These directions should include minimum requirements for a local VAD service.
2. **VAD services must be adequately resourced** to meet demand.
3. **Part of adequate resourcing is a larger and well-supported VAD workforce.** System design should facilitate greater participation by nurse practitioners and nurses to provide VAD (where legally permitted). In Queensland, wider workforce participation should include the private sector.
4. **State governments should explore different VAD care models.** For example, QVAD SPS's distinctive model has ensured statewide access.

For more information

This research briefing is based on Ben P White, Amanda Ward, Rachel Feeney, Laura Ley Greaves and Lindy Willmott, 'Models of care for voluntary assisted dying: A qualitative study of Queensland's approach in its first year of operation' (2024) *Australian Health Review* (early online). More information about study limitations, research ethics and disclosures is available in the article: **https://doi.org/10.1071/AH24199**

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RESEARCH ARTICLE

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'This is perfect, thank you': Research poetry on gratitude for voluntary assisted dying in Victoria, Australia

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Abstract

Objective: To undertake the first scholarly examination in Australia of how those involved in seeking voluntary assisted dying (VAD) discuss the concept of gratitude for this new end-of-life choice. The article shares findings through research poetry, an arts-based form of research where poems are developed from data (here, interview transcripts).

Methods: Twenty-eight semi-structured qualitative interviews were conducted with 33 participants (32 family caregivers; one patient). Participants were asked about their VAD experience, with caregivers also asked about the experience of their family member. Data were thematically analysed, focusing on expressions of gratitude for VAD. Miller's five-step process was adopted to create the research poetry.

Results: Gratitude for VAD was a significant concept for participants. We identified three gratitude themes relating to what people were grateful for, who people were grateful to and other feelings mixed in with their gratitude, such as ambivalence. We created six poems to illuminate these findings and give voice to the gratitude expressed by patients and family caregivers about VAD.

Conclusions: Gratitude for VAD was emphasised by participants as an important part of their experience and something that can help family caregivers cope after a VAD death. Expressions of gratitude can support health professionals providing VAD and create support for law reform in other jurisdictions. Research poetry reflecting this gratitude can contribute to reducing the stigma attached to VAD and enhance awareness of this relatively new end-of-life choice. More research is needed into the emotional experience of those involved in seeking and receiving VAD in Australia.

KEYWORDS

assisted suicide, euthanasia active voluntary, gratitude, research poetry, voluntary assisted dying

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1 | INTRODUCTION

This is the first Australian study, and one of the few internationally, that examined how patients and family caregivers express gratitude for voluntary assisted dying (VAD). The article reports findings through research poetry, an arts-based form of research where poems are developed from data,[1,2] here, participants' direct words from qualitative interviews. Research poetry is slowly gaining traction in ageing research,[1–4] prompted by its capacity to amplify the voice of participants and generate emotional engagement with research findings.[1,2]

Voluntary assisted dying is when a person seeks to take, or have administered to them, medication that will cause them to die.[5] Voluntary assisted dying has been lawful for decades in places such as the Netherlands, Belgium, Switzerland and the US state of Oregon, but ongoing reform has seen legalisation in various forms in 17 countries, including Canada, Austria, Spain, Germany, New Zealand and Australia.[5] Law reform to allow VAD has been challenging historically,[6] but the trend for more jurisdictions to permit the practice is likely to continue.[7] The path to reform in Australia has been particularly notable[8,9] with VAD laws passing in all six Australian states[10] and the Australian Capital Territory[11] since 2017. The remaining territory, the Northern Territory, is also considering reform.[12]

Underpinning reform has been a desire from patients and the wider community (particularly older people) for additional choice at the end of life.[10] Yet, there is limited research in Australia on the experience and perceptions of patients seeking VAD and their families. Existing literature generally focuses on barriers and facilitators to access.[13–16] That research found that supportive doctors and state VAD services (e.g. VAD care navigators) are vital to facilitate access to VAD, while complex eligibility assessment processes, regulatory barriers and objections by institutions and individual doctors impair access. There is also research on how patients and family caregivers can act as 'regulators' to guide system behaviour.[17–19]

There is a small body of empirical research with patients and families internationally, which mentions, but does not focus on, gratitude for VAD. This includes gratitude for having a VAD law,[20] having greater control and the option to choose VAD when unbearably suffering,[20–23] being supported to achieve a peaceful death[23,24] and being able to say final goodbyes.[20,21,24]

In Australia, only one article reports on gratitude and VAD, but only briefly and in the wider context of family grief (e.g. 'meaning-making in grief' was enabled by VAD being a planned death and appreciation for avoidance of suffering).[25] There is, however, evidence from grey literature, including reports of VAD oversight bodies, that patients and family caregivers express gratitude.[26–28] Further, one arts-based knowledge translation project documented personal stories of those seeking VAD and their families,[29] including reports of gratitude for VAD.[30]

This article draws on semi-structured interviews, primarily with family caregivers of people seeking VAD in Victoria (the first Australian state to legalise VAD), and reports on gratitude expressed about this new end-of-life choice. The article presents a thematic analysis of the data as well as research poetry for each theme.

Policy impact

Gratitude for voluntary assisted dying (VAD) can help families after a death and support health professionals providing VAD. It can also foster support for law reform in jurisdictions where VAD is not yet lawful. Research poetry representing this gratitude can help address the stigma attached to VAD and the low public awareness of this choice.

2 | METHODS

2.1 | Eligibility

This research was part of an international study examining VAD regulation in Australia, Canada and Belgium.[31,32] The data reported here are from semi-structured, qualitative interviews. Participants were eligible if they were (a) patients seeking VAD in Victoria, whether or not they were approved for VAD; or (b) family caregivers who had supported or were supporting a patient through VAD and could report on their perceptions of the patient's experience (and their own).

2.2 | Recruitment and sampling

Participants were recruited through Twitter/X posts and advertising on the project website. Patient interest groups *Go Gentle Australia* and *Dying with Dignity Victoria* also shared study details via social media, newsletters and emails. Convenience sampling was used initially. Purposive sampling was also employed to seek demographic and experiential diversity, including diversity in patient age, gender, illness, location (metropolitan/regional), timing of seeking access and patient experience of VAD (self-administration, practitioner administration,

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sought VAD but did not use it or was not found eligible). Reports from the Victorian VAD Review Board assisted in determining these diversity domains.[33] Purposive sampling was primarily achieved through direct emails from the above-mentioned patient interest groups to potentially matching participants. Recruitment ceased when the dataset had sufficient 'information power' to meet the wider study aims.[34,35]

2.3 | Data collection

Data were collected via semi-structured, qualitative interviews between August 2021 and October 2022. BPW (health law and regulation professor) and RJ (lawyer and PhD student) conducted all interviews together, with one as a designated lead.

Twenty-eight interviews were conducted with 33 participants (32 family caregivers; one patient) (Table 1). Interviews related to 28 patient experiences are shown in Table 2. The article generally reported on the perspectives of older persons with 23 of 28 patient experiences and 18 of 33 interview participants being 60 years or older (Tables 1 and 2). Interviews ranged from 56 to 130 minutes (mean 90).

TABLE 1 Characteristics of interview participants ($n = 33$).

Characteristic	Number
Age (years), mean 56.6, SD 15.1	
20–29	1
30–39	4
40–49	7
50–59	3
60–69	13
70–79	4
80–89	1
Gender	
Women	26
Men	7
Relationship to person seeking voluntary assisted dying[a]	
Child (including stepchild, child-in-law)	17
Spouse (including de facto partner)	10
Parent	3
Sibling	2
Close friend	1
Self	1

[a]One participant spoke about two patients, so is included in two categories; hence, percentages in this latter section of the table are calculated using the number of relationships (34). To further clarify the relationship between interviewees and patients, five of the interviews each involved two family caregivers being interviewed together about their family member's experience of voluntary assisted dying (e.g. a son and daughter-in-law speaking about their parent's experience). Two interviews were conducted with different family members separately about the same patient experience.

BPW and RJ debriefed after each interview and maintained a reflexive journal. All participants provided free and informed consent prior to the interview. All family caregiver interviews were conducted after the patient had died, so additional patient consent was not sought.

Interviews were conducted via Zoom, except for two by telephone and one in-person. All interviews were digitally audio-recorded and transcribed verbatim (to standard conversational level) by a professional company subject to a confidentiality agreement. Participants could amend or add to their transcript (member checking).[36]

The interview guide stepped participants through the process of seeking VAD (Appendix S1). Family caregivers were asked to not only focus on the patient's experience but also report their own experiences. Interview prompts included the experience of getting and using the medication, as well as feelings and motivations.

2.4 | Thematic analysis

Transcripts and any additional information provided by participants during member checking were thematically analysed line by line. Codes for the wider study were developed inductively and deductively, drawing on iterative discussion of initial themes.[37] An example of a deductive code relevant for this article from the literature was 'VAD motives' (i.e. why did a person seek VAD) while 'gratitude' was an inductive code identified early in analysis that was prominent in the data. BPW and RJ both coded 17 interviews (double coding) and BPW then coded the remainder. Codes were discussed and iteratively refined throughout data collection, analysis and in research team discussions. Analysis was aided by NVivo (release 1.6.1 QSR International).

Next, for the purposes of this paper, a more granular thematic analysis was undertaken of the subset of coded data about gratitude. This included the specific 'gratitude' code as well as other codes relating to feelings or motivations, decisions to take the VAD medication and the 'thing that worked best' in the VAD system. Data were included only if there was an express statement of gratitude, or BPW considered the participant was clearly raising the concept of gratitude. BPW analysed these data inductively line by line to identify domains in the concept of gratitude. Full transcripts were reviewed as appropriate to understand patient experience globally. RJ reviewed this subset of data again and SHB and EM reviewed a series of key data extracts selected by BPW and RJ.

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TABLE 2 Characteristics of persons seeking voluntary assisted dying whose experiences were the subject of interviews ($n = 28$).

	Number
Characteristic	
Age (years), mean 70.8, SD 15.4	
20–29	1
30–39	1
40–49	0
50–59	3
60–69	7
70–79	8
80–89	6
90–99	2
Gender	
Women	13
Men	15
Location	
Metropolitan	16
Regional[a]	12
Highest level of education	
Some high school	7
High school	9
University—diploma	1
University—undergraduate	7
University—postgraduate (including graduate diploma)	4
Primary disease, illness or medical condition	
Cancer	18
Neurological	9
Other	1
Eligibility for voluntary assisted dying and death	
Assessed as eligible	24
Person died via self-administered medication	19
Person died via practitioner administered medication	3
Person died but did not take medication (natural death)	1
Person waiting to take medication	1
Person died prior to eligibility assessment completed	3
Person assessed as ineligible and died	1
Timing of voluntary assisted death or engagement with process	
July–December 2019	4
January–June 2020	6
July–December 2020	3
January–June 2021	10
July–November 2021	5

[a]One person classified as regional moved to a metropolitan area during the voluntary assisted dying process.

2.5 | Research poetry

The research poetry component illustrating identified domains of gratitude was led by RJ, with BPW providing ideas for poem content from data analysis and BPW, SHB and EM all contributing to the creative process. Research poetry drawing on participant voices provided an authentic way to reflect the magnitude of emotion they repeatedly expressed about gratitude for VAD.

Miller's five-step approach was used: immersion, creation, critical reflection, ethics and engagement.[3] Immersion occurred during thematic analysis and while creating the poetry. Key data were extracted into a Word document. Researchers read and re-read the data extracts 'until the text reveal[ed] its key messages'.[3]

Creation occurred initially through BPW identifying striking phrases, which could evoke emotion or new insights. Examples were powerful metaphors (e.g. 'I've bought insurance') or unusual phrasing inviting seeing the topic in different ways (e.g., 'Thank you Dan'). RJ built on these phrases to create initial draft poems. Filler words were removed, sentence structures and order of words were changed for poetic impact, while ensuring poems remained true to participants' words and meaning. No words were added or modified (including pronouns); however, some were repeated. Some poems used one transcript, whereas others drew on multiple transcripts.[3] See Table 3 for a poem creation example and the decision to create polyvocal poems.

Critical reflection occurred through the research team reviewing the initial poems and discussing ideas for refinement, including length, imagery, repetition, tone and highlighting contrasting feelings. After this discussion, BPW reviewed the initial drafts and suggested specific refinement, and then RJ updated the poems, including drafting a further poem ('The loveliest way to die') to elucidate contrasting experiences. The decision to nest poems within the relevant theme/subtheme was also made to illustrate themes in an engaging way (Tables 4–9). The poems were further refined through additional critical reflection. In particular, the research team considered the rationales for the polyvocal poems adding a statement for each poem explaining choices made.

Ethical engagement included sending the draft article to participants who were included in the poems for comment. Seven participants replied. One simply acknowledged receipt, but the other six were all positive about presenting findings through research poetry (including references to emotions it evoked). Five reported that their deceased family members would have approved, with reference to the person's legacy and their words

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TABLE 3 Poem creation decisions.

Example of creating a research poem	
Interview transcript (Patient 1, male, 88)	**Poem**
The main difficulty for me was not - well, how can I say it - not [0:14:46] about how awkward this is going to do and how difficult. It was my uncertainty about the efficiency of the method. **The particular method** that **I had in mind**, which seemed the best in my circumstances that was available, **had some uncertainty about it**. **You can make mistakes**, or if you did this wrong or that wrong **you could screw up** on it. So that was my main concern, about how efficient it would be ... It was a great sense of relief. My whole attitude towards this medication is **it's as though previously if I had a motor car and was driving it around** everywhere without insurance that I'd be **not looking to have an accident but aware** that **the accident could occur** and I'd be grateful if I insured my car. **Now**, this is the same. **I've bought insurance**. That is sitting there, and **if and when I need it, I know that I can use it**. [0:59:28 - If the opposite had occurred] the action would be my health has got to a point that I've had enough or I definitely have decided to go, then a very I assume safe method is sitting there waiting for me to use. The previous method which is still sitting there in the room, the equipment for **a do-it-yourself thing before the VAD application**, has got some difficulties with it, some uncertainties with it. And I was very grateful to have what is a - I think they call it the - oh god, I can't think of the word. Anyway, a well above acceptable method from all the other - **I** mean we **could** go and **jump off a high building or lay down in front of a train**. **They're** methods. But **this is so far above all the homemade methods** that **I was very grateful to get it**.	**I've bought insurance** I could jump off a high building Or lay down in front of a train They're homemade methods A do-it-yourself thing The particular method I had in mind Had some uncertainty about it You can make mistakes You could screw up Before the VAD application It's as though I had a motor car and was driving it around Not looking to have an accident But aware the accident could occur Now I've bought insurance I know that I can use it if and when I need it This is so far above all the homemade methods I was very grateful to get it
Choice to use polyvocal poems Polyvocal poems were made for three key reasons: (1) the theme was represented so strongly in multiple transcripts and drawing on multiple transcripts highlighted the common experience and the strength of the theme; (2) to juxtapose different experiences; and/or (3) to improve the poem's artistic quality. Because gratitude is only one part of our data for the wider study, participants' comments on gratitude formed only one (small) part of transcripts. This meant that to construct poems that were engaging to read, aesthetically interesting, and best reflected (our interpretation) of the participants' comments, multiple voices were used.	

being immortalised. Five participants also reported the poetry (and wider gratitude findings) resonated with their experience and that of their family member who sought VAD. Some minor changes were made to the article after this feedback (additional context for a quote and some methods suggestions); no changes were suggested to poems.

In respect of engagement with poetry, EM (research poet) and SHB (poet) are expert poets. While drafting the poems, RJ read a combination of research and literary poetry for inspiration.

2.6 | Research ethics

This research was conducted in accordance with ethics approval from the Queensland University of Technology Human Research Ethics Committee (2000000270).

3 | RESULTS

Gratitude was expressed by the sole patient speaking about their own gratitude, family caregivers reporting on a patient's expressions of gratitude and family caregivers expressing their own feelings of gratitude. We identified three themes on gratitude relating to what people were grateful for, who people were grateful to and other feelings mixed in with their gratitude, such as ambivalence.

3.1 | What people were grateful for

Gratitude for the choice of VAD was spontaneously raised by many participants. This was often accompanied by statements of how important this was to them, with some participants physically showing emotion during this part of the interview (e.g. speaking with emphasis, crying). Its

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significance was also demonstrated by several participants who, when asked to identify the best part of their experience, named gratitude for VAD. We identified four subthemes, with participants often expressing more than one.

The first was gratitude that VAD would allow the patient to avoid a bad death. Participants described the sorts of deaths they and patients were concerned about and had seen: those that were 'long and protracted and unkind' and involved suffering both with pain and loss of dignity. Some participants described patients' feelings of fear about how they might die, for example, 'I know he felt lucky [to have VAD], because he was terrified about drowning to death' (Family caregiver 1, female, 31). One participant expressed gratitude for VAD because it meant not having to take their life in other ways which, unlike VAD, may not work and might cause suffering (Table 4).

The second sub-theme was the converse: patients and family caregivers were grateful for a good death (Table 5). Reflecting literature on what constitutes a 'good death',[38] this included having choice about the process of dying, being at a preferred place of death and surrounded by loved ones, participating in meaningful

TABLE 4 I've bought insurance.

I could jump off a high building
Or lay down in front of a train
They're homemade methods
A do-it-yourself thing

The particular method I had in mind
Had some uncertainty about it
You can make mistakes
You could screw up

Before the VAD application
It's as though I had a motor car and was driving it around
Not looking to have an accident
But aware the accident could occur

Now I've bought insurance
I know that I can use it if and when I need it
This is so far above all the homemade methods
I was very grateful to get it

– Patient 1, male, 88

This is a univocal poem representing the experience of the sole patient interviewee in our study. We chose to construct this research poem using a single voice because it provided a complex and stirring account of this participant's desire to end their own life by any means necessary, and their gratitude for having VAD as a simpler, more reliable and non-painful means of death compared to other methods such as suicide. We decided it was important to convey, undisturbed, the voice of the only patient we were able to interview for the study. We also felt that the discussion of VAD as an insurance policy was a striking metaphor that encapsulated relief and gratitude about the availability of VAD in an artistic and aesthetic way.

TABLE 5 The loveliest way to die.

I know he felt lucky

Yes, she was lucky you might say

What Dad got was beyond beautiful

She died very peacefully in the end

A kind, peaceful, gracious death

But she was in a coma which was not what she planned for her ending

To choose the time and place

It would have been the loveliest way to die

At home, surrounded by family

She wanted to have her family in that room

He got his final wish

To have music playing, candles going

"I love you", they were his last words

To say goodbye, quietly and gently

He had the final say

She couldn't have that and that will haunt me

– Family caregiver 1, female, 31; Family caregiver 3, female, 48; Family caregiver 4, female, 66; Family caregiver 5, female, 62; Family caregiver 6, male, 78; Family caregiver 7, female, 53; Family caregiver 8, male, 66; Family caregiver 9, female, 60; Family caregiver 10, female, 79

– Family caregiver 11, female, 64

This is a polyvocal poem representing voices from eight interviews (10 participants). The voices captured in the left-aligned text represent the interviews with the first set of family caregivers listed above. The italicised and indented words draw on only one interview with Family caregiver 11, female, 64.

We made a choice to draw on multiple voices in the left-aligned text because the discussion of gratefulness for having a good death came through strongly and was echoed by many participants. Most of the patients whose experiences were reported in our study achieved access to VAD and were, according to reports of family caregivers, grateful that VAD provided a 'good' death for them. By using multiple voices, we sought to illuminate the strength and consistency of views about VAD being a good, peaceful, and kind death.

The italicised and indented text represents only one voice. This was an artistic choice to highlight the sense of isolation and disappointment that the participant expressed as a result of the patient they supported missing out on their choice for VAD. We sought to highlight that this patient wished for the same things in their death as those who did achieve access to VAD and there was symmetry between what was wished for in the experiences of those who accessed VAD and those who missed out. The choice to juxtapose this experience and the disappointment of missing out against positive experiences was intended to reflect the relative strength of the positive experiences as opposed to the negative experiences that were reported in our study. The patient whose experience was discussed in Family caregiver 11's interview was one of only four patients whose experiences were reported in our study who missed out on their choice for VAD, with most patients being able to experience the kind of VAD death they had wished for.

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predeath rituals, and having pain and other symptoms well-managed.

One participant reported their loved one's final words before drinking the medication:

> He looked around and he says, "This is perfect, thank you," and then he drinks it.
> (Family caregiver 2, female, 36)

Family caregivers also expressed gratitude for the quality of their loved ones' deaths through VAD: for example, 'a kind, peaceful, gracious death'. One family caregiver said:

> What Dad got was beyond beautiful... everything to a T. ... It was too perfect... he got his final wish and he died with dignity, no pain, no anything, and he was heard.
> (Family caregiver 3, female, 48)

By contrast, one participant, whose loved one lost decision-making capacity during the VAD assessment process and was unable to access it, expressed her deep sadness about VAD not being possible.

A third sub-theme was gratitude for the 'choice', 'control' and 'empowerment' of having VAD available (Table 6). A part of this sub-theme that was emotionally significant for participants was patients retaining 'a choice when everything was being taken away' by the illness:

> The best thing [about VAD] – I think [patient] probably said it best – it allowed him to keep something of himself when almost everything else had been taken away [by cancer].
> (Family caregiver 2, female, 36)

> I am grateful that he got to go his way, and not by that ... [H]e always said: he didn't want MND [Motor Neurone Disease] to win. He didn't want it to completely [take over] his life, so I think he had the final say.
> (Family caregiver 9, female, 60)

Family caregivers also reported their own feelings about the importance of choice for the patient:

> The biggest positive was seeing how empowering the option to have VAD was for Dad. It gave him so much comfort knowing that he had this option that was in his control.
> (Family caregiver 12, female, 25)

> It was his choice ... [and] the cancer never gave him a choice. He took that back and that's the only power he got back ... the best part was actually watching Dad, his shoulders drop and the relief to go "Thank fuck for that." [laughs]
> (Family caregiver 3, female, 48)

The fourth and related sub-theme was gratitude for the 'peace', 'relief' and 'comfort' the choice of VAD brought (Table 7). This was important for the patients in our study:

> It was a great sense of relief ... if and when I need it, I know that I can use it.
> (Patient 1, male, 88)

Family caregiver participants also reported their loved ones expressing similar thoughts:

> He just kept using the language of "I feel so relieved that this is an option for me. This kind of makes this whole process feel just a lot more manageable."
> (Family caregiver 1, female, 31)

TABLE 6 Peeling away an onion.

Cancer had taken so many things away from him
His health
His hobbies
His peer group
You become very, very isolated
Culturally, we are afraid
Afraid of saying the wrong thing
So people say...
Nothing
Like peeling away an onion, he lost everything
Other than this core part of him
His ability to go with agency

– Family caregiver 2, female, 36

This is a univocal poem representing an interview with Family caregiver 2. Although the sentiment encapsulated in this research poem about the staged erosion of meaningful aspects of life was expressed in multiple interviews, we felt that this transcript, on its own, best encapsulated this theme. Our choice to only use only one participant's voice was primarily an artistic one because we felt that the metaphor of 'peeling away an onion' was powerful and expressed artfully by this participant such that we did not need to draw on further transcripts to convey the theme.

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TABLE 7 This is perfect, thank you.

She was sitting in the doctor's surgery
In the waiting room
Her voice was going by then
Everything was being taken away from her
She was so scared of what was happening
Terrified about drowning to death
How long and protracted and unkind those deaths are

She was told she had motor neurone disease
She looked at me and she said "I'm happy now"
What was happening to her was terminal
She knew she would be able to have the choice
She felt comfort, relief
She had a way out

He received this medication, he felt lucky
That empowerment was given back to him
"It's mine, I've got this"
I know that I can use it when I need it
He had control
You could see the difference.
The most happy and peaceful in a long time.

She had no choices with how the disease panned out.
She couldn't make any other decisions.
When almost everything else had been taken away.
It allowed him to keep something of himself.
At home, surrounded by her family.
He had the final say.
She would be able to avoid the worst ending.

He died with dignity.
Out of pain.
Respectful.
I'm grateful that he got to go his way.

– Patient 1, male, 88; Family caregiver 1, female, 31; Family caregiver 2, female, 36; Family caregiver 3, female, 48; Family caregiver 4, female, 66; Family caregiver 5, female, 62; Family caregiver 6, male, 78; Family caregiver 8, male, 66; Family caregiver 9, female, 60; Family caregiver 12, female, 25; Family caregiver 13, female, 61; Family caregiver 14, female, 46; Family caregiver 15, female, 41; Family caregiver 16, female, 45; Family caregiver 17, female, 57; Family caregiver 18, male, 46; Family caregiver 19, female, 46; Family caregiver 20, female, 62; Family caregiver 21, female, 37.

This is a polyvocal poem, representing voices from interviews with the sole patient interviewee, Patient 1, and the above family caregivers. Pronouns have not been changed. This poem represents all the voices of participants whose data were coded to this specific theme. We decided that a polyvocal poem using all voices was powerful in conveying the strength of this theme. Our choice was also an artistic one to make the poem more engaging and to provide a panoptic sense of the overarching theme of 'what people were grateful for', rather than it representing a particular sub-theme.

> I noticed a great sense of relief in my mother to know that she had it there … relief of knowing she had a way out when she wanted to.
>
> (Family caregiver 13, female, 61)

3.2 | Who were people grateful to

Often, participants' expressions of gratitude were directed towards health professionals who were supporting the VAD process. This includes state-funded VAD care navigators, local VAD hospital or health service coordinators, doctors who assessed patient eligibility and guided patients and families through the process, and pharmacists who provided the VAD medication.

> When [the doctor] said "yes" he agreed with the diagnosis [to confirm eligibility for VAD]; she held his hands and said "Thank you." Yeah, it was a very, very powerful, emotional time.
>
> (Family caregiver 13, female, 61)

> We had given letters to the VAD team afterwards to say "thank you".
>
> (Family caregiver 3, female, 48)

> [All] the way through I've been in contact with the navigators … I could not have done it without them.
>
> (Family caregiver 5, female, 62)

The other main group towards whom gratitude was expressed was those who enabled VAD law to pass. A number of participants specifically thanked 'lawmakers' and the Victorian Government, with particular mention of the then Premier (Daniel Andrews) (Table 8).

> Mum had to stand right at the end and give that little speech … before taking the medication … she's looking at us and saying "Thanks to everybody who got the legislation through."
>
> (Family caregiver 22, female, 57)

> [Dad] thanked the government at the end. He said "I want to thank the government for giving me this and thank all the doctors that helped me" … he said "I just want to thank the government for giving me this opportunity."

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TABLE 8 Thank you Dan.

Mum had to stand right at the end and give that little speech.
To thank everybody for making this possible.
"Thanks to everybody who got the legislation through".
(We're hovering thinking she's going to fall over).

"Thank you Dan".
What he did, what his government managed to get through.
Under some quite extraordinary opposition.
Monumental.

They were his last words.
Apart from "I love you".

And then she swallowed the medication.

– Family caregiver 7, female, 53; Family caregiver 22, female, 57; Family caregiver 23, male, 66.

This is a polyvocal poem representing three voices of family caregivers. Family caregiver 22's voice is represented in the left-aligned text and was included because of the powerful imagery it conveys (and was a story powerfully told in the interview). Family caregiver 23's and Family caregiver 7's voices are represented in the italicised and indented text and Family caregiver 23 provided the title. We felt the title reflected the personal nature of VAD – a very familiar and informal expression of personal gratitude from a citizen to the most senior politician in the State.

Further choices to make this a polyvocal poem were twofold. First, it is unusual to see lawmakers thanked for passing law (as noted in the Discussion below) and it struck the research team as unusual that multiple participants raised this in their interviews. In particular, it was striking that patients chose to spend some of their last moments thanking governments and lawmakers. It highlights the real and human impact of democratic, lawmaking processes on people's lives (and deaths) and we wanted to encapsulate that by drawing on these three unique but similar experiences. The second rationale related to the quality of the poems. We felt that the quality of the research poem was strengthened by combining the voices, rather than only using one, to convey the gratitude people felt towards those involved in passing the law.

> ... They were his last words ... apart from "I love you" and all that sort of stuff.
>
> (Family caregiver 7, female, 53)

> I wrote a letter to Dan [Andrews]... [F]or what he did, what him and his government managed to get through under some quite extraordinary opposition, disgraceful opposition ... so I felt the need to send him a brief little letter and just say "Thank you Dan and your group and thank you to the VAD people for having achieved something that is monumental."
>
> (Family caregiver 23, male, 66)

TABLE 9 Mixed feelings.

He had the final say
He got to go his way

It's awful in one sense
But we're so blessed in another

I want that for my loved one
But it's still not right

Because Dad's not here
I wish he was here

– Family caregiver 9, female, 60; Family caregiver 3, female, 48

This polyvocal poem represents the voices of Family caregiver 9 (normal text) and Family caregiver 3 (italicised text). The choice to merge these two voices to create a polyvocal poem was primarily an artistic one. This is an example of the point noted above of including more than one voice in cases of limited data. While both transcripts conveyed the mixed feelings and ambivalence felt by participants about their loved one's death, we felt that when discussed together the poem was aesthetically and artistically stronger than if we had included only one voice.

3.3 | Other feelings are mixed with gratitude

Gratitude for the choice of VAD was often reported as mixed or entwined with other feelings (Table 9). Generally, this involved acknowledging sadness from their loved one's death:

> But [VAD] was beyond fabulous ... but it's still not right because Dad's not here. So, it's awful in one sense, but we're so blessed in another and so was he.
>
> (Family caregiver 3, female, 48)

4 | DISCUSSION

Gratitude for VAD was an important concept expressed by participants, both in relation to their own experience of VAD and, for family caregivers, the patient's experience they reported. They expressed being grateful for avoiding bad deaths and enabling good deaths. They were also grateful for the choice, control and empowerment VAD brought, as well as feelings of peace, relief and comfort knowing VAD was available. These aspects of gratitude for VAD resonated broadly with the international literature. Further, although there is no Australian scholarly research specifically on gratitude for VAD, these findings resonated with grey literature, including oversight board reports.[26–28]

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Another finding of this research was to whom this gratitude was directed. Unsurprisingly, gratitude was expressed towards health professionals who assist patients and family caregivers seeking VAD. This reflected Australian literature on facilitators and barriers to accessing VAD, where health professionals were identified as essential for system function.[13]

But perhaps more striking and unusual was the repeated gratitude from participants for the government, lawmakers and others who enabled the law to pass. This may be partially due to Victoria's VAD law being new so the work to pass and implement the law was fresh in people's minds. Also potentially relevant is that lawmakers were granted a conscience vote; hence, support for VAD was their choice, not a party edict. Again, this gratitude—both for governments and health professionals, as noted above—is reported often in VAD oversight board reports.[26–28]

The concept of gratitude can impact how a VAD system functions. For family caregivers, as noted above (mixed feelings theme) and in the limited research on grief after VAD in Australia[25] and internationally,[20,21,23] gratitude can help buoy families after losing a loved one. Gratitude from patients and family caregivers for health professionals supporting them with VAD can also help sustain the VAD workforce.[39,40] This may be particularly important in Australia, with limited health professionals providing VAD and ongoing workforce sustainability issues.[41–44]

Gratitude for VAD may also be of interest for jurisdictions contemplating passing VAD laws. These are difficult public policy decisions, and law reform has historically been difficult.[6] While there are various considerations in deciding whether to legalise VAD, understanding how these laws are being perceived by system users can inform reform debates.

Beyond reporting findings about gratitude, we have also represented the voices of patients and family caregivers more directly through poetry. For a topic such as VAD, poetry can help represent the depth of emotion and gratitude people feel. It can also amplify participants' words and voice to increase their representation.[1] By using poetic enquiry, we sought to speak *with* rather than *for* participants.[2] This is particularly appropriate because autonomy is an important reason why people seek VAD.[45–47] By using participants' voices directly,[3] we sought to refocus control back to patients and family caregivers and their experiences.

Finally, poetry can evoke emotional and empathic responses.[1] It may also invite open conversations.[4] VAD is a new end-of-life choice in Australia, and the reform process was difficult.[8] Scholarship globally highlights that secrecy and stigma about VAD remain even in more established systems, potentially impacting bereavement.[17,21,23,48] Secrecy and stigma may be amplified because VAD is sought mostly by older persons, and ageing narratives often focus on healthy ageing.[1] Through research poetry, this article aimed to invite open and empathic conversations to help reduce stigma and secrecy about VAD.

4.1 | Limitations

This study draws on the first interviews with family caregivers and a patient seeking VAD in Victoria. Early system users can only provide a point-in-time perspective. For instance, we anticipate higher expressions of gratitude for a new VAD law. Another limitation is that interviews were primarily with family caregivers whose perceptions may differ from patients' due to grief, bereavement and their relationship with the patient.[49–51] Finally, our sample may be more favourably disposed towards VAD, given some recruitment was via patient interest groups.

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CONFLICT OF INTEREST STATEMENT

Ben P. White has received funding from the Australian Research Council, the National Health and Medical Research Council, Commonwealth and state governments and philanthropic organisations for research and training about the law, policy and practice relating to end-of-life care. In relation to voluntary assisted dying, he (with colleagues) has been engaged by the Victorian, Western Australian and Queensland governments to design and provide the legislatively mandated training for health practitioners involved in voluntary assisted dying in those states. He (with Lindy Willmott) was also engaged by the

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Western Australian Government to be involved in the statutory review of the *Voluntary Assisted Dying Act 2019* (WA). In addition, he (with Lindy Willmott) has also developed a model bill for voluntary assisted dying for parliaments to consider. Ruthie Jeanneret was employed on the Victorian, Western Australian and Queensland training projects.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

Ethics approval was obtained from the Queensland University of Technology Human Research Ethics Committee (2000000270). This research was conducted in accordance with the Australian National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research 2007 (updated 2018). This research was conducted in accordance with the requirements of this ethics approval. All persons interviewed gave free and informed consent to participate in this research.

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REFERENCES

1. Holland-Batt S, Miller E. Literary, found and research poetry: new approaches to representations of aging and aged care. *Gerontologist*. 2023;63(10):1647-1652. doi:10.1093/geront/gnad056
2. Miller E, Donoghue G, Holland-Batt S. "You could scream the place down": five poems on the experience of aged care. *Qual Inquiry*. 2015;21(5):416. doi:10.1177/1077800415572396
3. Miller E. Creating research poetry: a nursing home example. In: Humble A, Radina E, eds. *How Qualitative Data Analysis Happens: Move beyond "Themes Emerged"*. Routledge; 2018:18-33.
4. Gerber K, Brijnath B, Lock K, Bryant C, Hills D, Hyorth L. "Unprepared for the depth of my feelings" – capturing grief in older people through research poetry. *Age Ageing*. 2022;51(3):1. doi:10.1093/ageing/afac030
5. White BP. An introduction to voluntary assisted dying law, regulation and practice. In: White BP, ed. *Research Handbook on Voluntary Assisted Dying Law, Regulation and Practice*. Edward Elgar; 2025.
6. White BP, Willmott L, Downie J, et al. International perspectives on reforming end-of-life law. In: White BP, Willmott L, eds. *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence*. Cambridge University Press; 2021:250-275.
7. White BP. The future of voluntary assisted dying. In: White BP, ed. *Research Handbook on Voluntary Assisted Dying Law, Regulation and Practice*. Edward Elgar; 2025.
8. Willmott L, White B, Stackpoole C, Purser K, McGee A. (Failed) voluntary euthanasia law reform in Australia: two decades of trends, models and politics. *Univ N S W Law J*. 2016;39(1):41-46.
9. Willmott L, White BP. The challenging path to voluntary assisted dying law reform in Australia: Victoria as a successful case study. In: White BP, Willmott L, eds. *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence*. Cambridge University Press; 2021:250-275.
10. Waller K, Del Villar K, Willmott L, White B. Voluntary assisted dying in Australia: a comparative and critical analysis of state laws. *Univ N S W Law J*. 2023;46(4):1421-1470.
11. Voluntary Assisted Dying Act 2024 (ACT).
12. Northern Territory Government. Report into voluntary assisted dying in the Northern Territory: final report 2024. 2024. Accessed November 22, 2024. https://cmc.nt.gov.au/__data/assets/pdf_file/0018/1420722/vad-report-2024.pdf
13. White B, Jeanneret R, Close E, Willmott L. Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitators. *Med J Aust*. 2023;219(5):211-217. doi:10.5694/mja2.52004
14. White B, Jeanneret R, Close E, Willmott L. The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions. *BMC Med Ethics*. 2023;24(1):22. doi:10.1186/s12910-023-00902-3
15. White B, Jeanneret R, Willmott L. Barriers to connecting with the voluntary assisted dying system in Victoria, Australia: a qualitative mixed method study. *Health Expect*. 2023;26(6):2695-2708. doi:10.1111/hex.13867
16. Haining C, Willmott L, White B. Comparing voluntary assisted dying laws in Victoria and Western Australia: Western Australian Stakeholders' perspectives. *J Law Med*. 2023;30(3):716-744.
17. Jeanneret R, Close E, Willmott L, Downie J, White B. Patients' and caregivers' suggestions for improving assisted dying regulation: a qualitative study in Australia and Canada. *Health Expect*. 2024;27(3):e14107. doi:10.1111/hex.14107
18. Jeanneret R, Close E, Willmott L, White B. Regulatory action' by patients and family caregivers to overcome barriers to accessing voluntary assisted dying: a qualitative study in Victoria, Australia. *Univ N S W Law J*. 2024;47(3): 705-743.
19. Jeanneret R, Close E, Willmott L, White B. Patients and caregivers as 'regulatory actors' in healthcare systems: assisted dying as a case study. *Med Law Int*. 2024;24(3):164-191. doi:10.1177/09685332241274972
20. Srinivasan EG. Bereavement and the Oregon death with dignity act: how does assisted death impact grief? *Death Stud*. 2019;43(10):647-649. doi:10.1080/07481187.2018.1511636
21. Frolic A, Swinton M, Murray L, Oliphant A. Double-edged MAiD death family legacy: a qualitative descriptive study. *BMJ Support Palliat Care*. 2018;14:E845-E850. doi:10.1136/bmjspcare-2020-002648
22. Loggers E, Starks H, Shanon-Dudley M, et al. Implementing a death with dignity program at a comprehensive cancer center. *N Engl J Med*. 2013;368(15):1417-1420. doi:10.1056/nejmsa1213398

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23. Russell H. The double-edged experience: preparedness, duality and the pathways of grief after voluntary assisted dying. 2023. Accessed November 22, 2024. https://www.churchilltrust.com.au/fellow/hayley-russell-vic-2022/
24. Schutt KCH. Exploring how family members experience Medical Assistance in Dying (MAiD). 2020. Thesis, Trinity Western University; March 2020.
25. La Brooy C, Russell H, Lewis S, Komesaroff P. The impact of voluntary assisted dying on grief and bereavement for family members and carers in the Australian state of Victoria: a qualitative study. *Health Soc Care Community*. 2024;2024:3172357. doi:10.1155/2024/3172357
26. Voluntary Assisted Dying Board Western Australia. Annual report 2022–23. 2023. Accessed November 22, 2024. https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2022-23.pdf
27. Tasmanian Government Department of Health. Voluntary Assisted Dying Commission annual report 2022–23. 2023. Accessed November 22, 2024. https://www.health.tas.gov.au/sites/default/files/2023-11/voluntary_assisted_dying_commission_annual_report_2022-23.pdf
28. Victoria State Government Department of Health, Voluntary Assisted Dying Review Board. Annual report July 2022 to June 2023. 2023. Accessed November 22, 2024. https://www.safercare.vic.gov.au/sites/default/files/2023-08/VADRB%20Annual%20Report%202022-23.pdf
29. HEAL. The first 100 days of Voluntary Assisted Dying (VAD) at Metro North. QUT Creative Industries, Education and Social Justice. Accessed November 22, 2024. https://research.qut.edu.au/heal/projects/the-first-100-days-of-voluntary-assisted-dying-vad-at-metro-north/
30. HEAL. Kay's VAD story about husband John Fraser: grateful for the availability of voluntary assisted dying. QUT Creative Industries, Education and Social Justice. Accessed November 22, 2024. https://research.qut.edu.au/heal/kay-vad-story-about-husband-john-fraser-grateful-for-the-availability-of-voluntary-assisted-dying/
31. QUT. Optimal regulation of voluntary assisted dying. Accessed November 22, 2024. https://research.qut.edu.au/voluntary-assisted-dying-regulation/.
32. White BP. Holistic Approaches to Regulation of Voluntary Assisted Dying. In: White BP, ed. *Research Handbook on Voluntary Assisted Dying Law, Regulation and Practice*. Edward Elgar; 2025.
33. Safer Care Victoria. Voluntary Assisted Dying Review Board report of operations: January to June 2021. State of Victoria; 2021. Accessed July 13, 2023. https://www.safercare.vic.gov.au/sites/default/files/2021-08/VADRB%20August%202021%20report%20FINAL.pdf
34. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. 2016;26(13):1753. doi:10.1177/1049732315617444
35. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health*. 2021;13(2):201-216. doi:10.1080/2159676X.2019.1704846
36. Kitto S, Chesters J, Grbich C. Quality in qualitative research. *Med J Aust*. 2008;188(4):243-246. doi:10.5694/j.1326-5377.2008.tb01595.x
37. Braun V, Clarke V. *Thematic Analysis: A Practical Guide*. SAGE Publications Ltd; 2022.
38. Saman M, Espinal-Arango S, Mohapatra A, Jada AR. What would it take to die well? A systematic review of systematic reviews on the conditions for a good death. *Lancet*. 2021;2(9):E593-E600.
39. Beuthin R, Bruce A, Hopwood M, Robertson D, Bertoni K. Rediscovering the art of medicine, rewards, and risks: physicians' experience of providing medical assistance in dying in Canada. *Sage Open Med*. 2020;8:1-5. doi:10.1177/2050312120913452
40. Pesut B, Thorne S, Stoch J, Chambaere K, Grieg M, Burgess M. Riding an elephant: a qualitative study of nurses' moral journeys in the context of medical assistance in dying (MAiD). *J Clin Nurs*. 2020;29(19–20):3870-3881. doi:10.1111/jocn.15427
41. Victoria State Government Department of Health. Voluntary Assisted Dying Review Board: annual report July 2023 to June 2024. 2024. Accessed November 22, 2024. https://www.health.vic.gov.au/voluntary-assisted-dying/voluntary-assisted-dying-review-board
42. Voluntary Assisted Dying Board Western Australia. Annual report 2023–24. 2024. Accessed November 22, 2024. https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2023-24.pdf
43. Government of South Australia. Voluntary Assisted Dying Review Board: annual report 2022–23. 2023. Accessed November 22, 2024. https://www.sahealth.sa.gov.au/wps/wcm/connect/c502e159-2307-4b27-9968-a06c41d219ad/23116.1+Voluntary+Assisted+Dying+Annual+Report_V9_WEB3.pdf?MOD=AJPERES
44. White BP, Ward A, Feeney R, Ley Greaves L, Willmott L. Models of care for voluntary assisted dying: a qualitative study of Queensland's approach in its first year of operation. *Aust Health Rev*. 2024;48:693-699. doi:10.1071/ah24199
45. Ganzini L, Goy ER, Dobscha SK. Oregonians' reasons for requesting physician aid in dying. *Arch Intern Med*. 2009;169(5):489. doi:10.1001/archinternmed.2008.579
46. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, Vissers KC, van Weel C. "Unbearable suffering": a qualitative study on the perspectives of patients who request assistance in dying. *J Med Ethics*. 2011;37(12):727-734. doi:10.1136/jme.2011.045492
47. Hendry M, Pasterfield D, Lewis R, Carter B, Hodgson D, Wilkinson C. Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying. *Palliat Med*. 2013;27(1):13-26. doi:10.1177/0269216312463623
48. Yan H, Bytautas J, Isenberg SR, et al. Grief and bereavement of family and friends around medical assistance in dying: scoping review. *BMJ Support Palliat Care*. 2023;13(4):414-428. doi:10.1136/spcare-2022-003715
49. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? *Soc Sci Med*. 2003;56(1):95-109. doi:10.1016/s0277-9536(02)00011-4
50. Addington-Hall J, McPherson C. After-death interviews with surrogates/bereaved family members: some issues of validity. *J Pain Symptom Manag*. 2001;22(3):784-790. doi:10.1016/s0885-3924(01)00330-x

17416612, 2025, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/ajag.70019 by National Health And Medical Research Council, Wiley Online Library on [16/06/2025]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

51. Williams BR, Woodby LL, Bailey FA, Burgio KL. Identifying and responding to ethical and methodological issues in after-death interviews with next-of-kin. *Death Stud*. 2008;32(3):197-236. doi:10.1080/07481180701881297

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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Models of care for voluntary assisted dying: a qualitative study of Queensland's approach in its first year of operation

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ABSTRACT

Objective. Voluntary assisted dying (VAD) began in Queensland in January 2023 but little is known about its practical operation. This research examined models of care for providing VAD in Queensland. **Methods.** Semi-structured interviews were conducted with 24 participants involved with VAD delivery across Queensland's 16 Health and Hospital Services (HHSs). Participants included HHS VAD Coordinators, nurse practitioners and nurses who acted as administering practitioners, and Queensland VAD Support and Pharmacy Service (QVAD SPS) staff. **Results.** Five themes about Queensland VAD models of care were developed: VAD is accessed almost exclusively through the public sector via HHSs, influenced by a Health Service Directive; local models of care vary; nurses play significant roles facilitating access to and providing VAD; QVAD SPS has been instrumental supporting HHSs and ensuring statewide access as back-up VAD provider; and VAD services need more resourcing. **Conclusions.** The Queensland approach to providing VAD has been largely successful in ensuring patient access across the state. However, it differs from previous Australian VAD models with access predominantly through the public sector, greater roles played by nurse practitioners/nurses, and VAD being provided by QVAD SPS. Under-resourcing and consistency in provision of VAD services remain challenges.

Keywords: euthanasia, health system funding, health systems, health workforce, implementation, models of care, physician-assisted dying, voluntary assisted dying.

Introduction

All Australian states and the ACT have voluntary assisted dying (VAD) laws. The Northern Territory is actively considering reform.[1] There is a broad 'Australian model' with narrow eligibility criteria and many procedural safeguards (Box 1).[2] However, states have implemented VAD laws differently.

In Queensland, where VAD has been available since January 2023, Queensland Health issued a Health Service Directive (HSD) requiring each of its 16 Health and Hospital Services (HHSs) to provide a VAD service (Box 2).[3] Each HHS was required to establish 'a model of care to provide timely, publicly funded voluntary assisted dying services for eligible people' including 'all steps of the voluntary assisted dying process'. The HSD did not prescribe a model of care or its implementation. HHSs did not receive dedicated funding for providing VAD.[4]

Another key implementation feature is the Queensland VAD Support and Pharmacy Service (QVAD SPS).[4] It differs from other states in that it:

- Combines in a single service:
  - a care coordinator service established under the Act 'to provide support, assistance and information to people'[5] – QVAD Support;[6] and
  - a statewide pharmacy service to supply VAD medication – QVAD Pharmacy.[7]

Box 1. **Brief overview of Australian VAD laws**[A]

Eligibility criteria

- A person must be an adult, have decision-making capacity, be seeking VAD voluntarily and without coercion, meet residency requirements, have a qualifying disease, illness or medical condition, and be experiencing suffering.
- The medical condition must be advanced and progressive, and one that will cause death, in most jurisdictions, within 6 months or 12 months for neurodegenerative conditions. (Queensland has a global 12-month timeframe; the ACT does not have a timeframe and refers to people 'approaching the end of their life'.)

Request and assessment process

- A person must make three separate requests for VAD.
- Eligibility criteria must be assessed by at least two independent medical practitioners (one can be a nurse practitioner in the ACT).

Other example safeguards

- Restrictions on how VAD may be raised with patients, including Victoria and South Australia prohibiting registered health practitioners from initiating a discussion about VAD.
- Mandatory training for health practitioners involved in assessing and providing VAD along with required minimum qualifications/experience.
- Oversight Boards which review individual cases of VAD and report publicly on collected aggregate data.
- Four states require prospective approval of VAD from a Board or government official.

[A]Because of differences in Australian VAD laws, this Box provides only a general overview and does not address some local variations.[2]

Box 2. **Extracts from Health Service Directive 'Access to voluntary assisted dying'**[3]

Purpose

This directive outlines the mandatory requirements for Queensland Health Hospital and Health Services to safely and effectively:

- manage and respond to requests for information about and access to voluntary assisted dying, and
- deliver voluntary assisted dying services.

....

Outcomes

Hospital and Health Services will achieve the following outcomes:

- Each Hospital and Health Service establishes a model of care to provide timely, publicly funded voluntary assisted dying services for eligible people.
- People who request information about voluntary assisted dying receive appropriate information and support from the Hospital and Health Service.
- Eligible people who request access to voluntary assisted dying are supported through the process by the Hospital and Health Service and receive safe, high quality, person-centred care.
- Hospital and Health Service employees are informed, educated, competent, and aware of their rights, responsibilities, and local policies and procedures in order to meet their legislative obligations.

....

Access requirements

Hospital and Health Services must establish a model of care to provide timely, publicly funded voluntary assisted dying services for eligible people. This includes services required to enable a person to complete all steps of the voluntary assisted dying process, from first request to administration of the voluntary assisted dying substance. It is not a requirement that voluntary assisted dying services are provided at every Hospital and Health Service facility, however, consideration should be given to a person's preferences around location of service delivery and place of death. These services must be delivered under the governance of the Hospital and Health Service.

....

- Has interdisciplinary staff with nursing and social work care coordinators, pharmacists and a psychologist, led by a palliative care physician.
- Includes practitioners, primarily nurses, authorised to provide VAD as part of QVAD Support (Queensland law permits doctors, nurse practitioners and nurses to be 'administering practitioners').

This is the first empirical study of Queensland's VAD system, examining models of care for providing VAD using qualitative interviews with HHS VAD coordinators, nurses providing VAD and QVAD SPS staff.

Methods

Recruitment

Recruitment used purposive sampling across two phases. Phase one (part of a wider study) recruited nurses who provided VAD as 'administering practitioners'. QVAD SPS forwarded study details to all eligible nurses. Most of these nurses were also a VAD Coordinator in their HHS or worked for QVAD SPS. Phase two sought VAD Coordinators from remaining HHSs (whether or not a nurse who had provided VAD) and the wider QVAD SPS team for statewide insights. Phase two participants were recruited at a clinical symposium and via direct email to remaining HHS VAD Coordinator email addresses. Snowball recruitment was used throughout. Recruitment ceased on data saturation (information redundancy).[8]

Data collection

Twenty-four semi-structured interviews occurred between October 2023 and March 2024 by BPW, AW and LW (with one a designated lead). BPW attended all, AW all except one and LW four interviews. All but one were Zoom video conferences (one via telephone) and lasted between 34 and 92 min. Interviews were audio-recorded and transcribed verbatim. Participants could amend their transcript (member checking),[9] and some provided supplementary information (e.g. VAD death numbers).

Our interview guide (Supplementary material file S1) was based on analysis of the Queensland VAD system,[2,10] similar research from other jurisdictions[11–14] and research team discussions. Open-ended questions explored system operation, with novel features of Queensland's implementation specifically explored.

Analysis

NVivo 14 (QSR International) was used to store and code transcripts and supplementary information. Thematic analysis was applied using codes developed deductively (based on previous research and field knowledge, e.g. role of VAD coordinators and impact of resourcing, and iterative discussion of early themes) and inductively.[15] Interviews were coded by AW using a framework developed with BPW and LW and periodically refined. BPW and AW undertook iterative analysis during data collection including discussions and/or shared journalling about key implications after each interview and periodic review of data as a whole (e.g. after the first nine interviews). Themes developed were discussed and tested by all authors.

Ethics

Study approval was by Queensland University of Technology Human Research Ethics Committee (2000000270). Participants provided informed consent.

Results

Twenty-four participants were interviewed with representation from 15 of the 16 HHSs (Table 1). Interviewees were primarily nurses (19) with two doctors and three other health professionals. Five themes were developed about Queensland VAD models of care.

Table 1. Characteristics of interviewees (n = 24).[A]

Characteristic	Number of participants
Age (years)	
31–39	7
40–49	5
50–55	11
56–75	1
Gender	
Female	22
Male	2
Profession	
Nurse practitioner/nurse	19
Social work/allied health	3
Doctor	2
Location of primary practice	
Metropolitan	12
Regional	7
Rural/remote	5
Work setting	
HHS VAD coordinator	14
QVAD SPS	5
Other roles[B]	5

[A]One interview was conducted with an additional participant but no system perspective was obtained, so that participant is not included in this study.
[B]Other roles were: members of HHS VAD teams actively involved in providing VAD (but not a VAD Coordinator), and one nurse participant who was not part of a VAD team but had a relevant clinical leadership role in their HHS which led to VAD provision.

Voluntary assisted dying is accessed almost exclusively through the public sector via Health and Hospital Services, influenced by the Health Service Directive

Participants described the vast majority of VAD being accessed through the public sector, including rural general practitioners (GPs) working within a HHS or specifically employed by it for VAD work. A QVAD SPS participant, drawing on the fact that its service issues all VAD medication in Queensland, put the figure at 'about 90%'.

Participants identified the HSD's influence because it mandated a local model of care for public access to VAD in each HHS. Participants perceived the HSD positively because it required at least some engagement in all HHSs.

> I think the directive was good. I think it was great. I think that that really socialised VAD. We had to have a policy in place. We had to have a guideline in place to really set up those systems of governance.

Local models of care vary

An outcome of the HSD not prescribing how a model of care should be implemented is 'huge variety' in models.

> However it [the HSD] wasn't prescriptive in any way. And some HHSs embraced this better than others. Some HHSs provided funding for dedicated authorised medical practitioners and authorised nurses as well as administrative staff. And other HHSs did not provide that support.

All HHSs had a VAD Coordinator who served as a contact point. This was generally a nurse, with some allied health such as social workers. But the nature of these roles varied. Some Coordinators had a navigating role supporting patients, families and health professionals while others played only an arms-length facilitative role (e.g. just connecting patient with doctors).

The VAD workforce within HHSs also varied. Some Coordinators were designated appointments with allocated VAD workloads. Some HHSs also had a team supporting VAD that may include medical, nursing or administrative appointees (and occasionally all). However, some HHSs did not have a dedicated workforce, and VAD Coordinators performed their role without workload recognition and on top of existing job/s.

> They simply said, 'Just add this [VAD Coordinator] to your job as [current position]'.

> So what happened was in some of these smaller – and in larger ones as well – that people who were already fully employed were also given the title of, 'You're the VAD service provider as well'.

> So we have no funding …. We've got no admin. We've got nothing. We just do it.

Participants reported variation in governance and oversight. Some described clear reporting lines and strong support from HHS management. Others described a lack of clarity about reporting – 'no-one knows what I do' – and unsupportive or disinterested HHS leadership.

Nurses play significant roles in facilitating access to voluntary assisted dying and providing it

Nurse practitioners and nurses play a significant role in VAD in Queensland. HHSs generally opted for a nurse-led response (most VAD Coordinators are nurses), with one participant observing this was a cost-effective path to HSD compliance.

Nurses, generally as VAD Coordinators, often led the establishment of HHS VAD processes. They often facilitated VAD applications to reduce administrative and logistical burdens on doctors, freeing them to undertake exclusively medical roles like eligibility assessments.

Appointing nurses as Coordinators or within HHS VAD teams resulted in nurses acting as administering practitioners. Fifteen of 19 nurses interviewed had undertaken practitioner administration. Some nurse participants described accompanying patients through the VAD process and at all appointments (including eligibility assessments), culminating in them being the administering practitioner.

For some participants, practitioner administration was a core role, with a few providing this more than 20 times. In some HHSs where practitioner administration is common, some reported this role being primarily undertaken by nurses.

> I see everybody that comes through, all the referrals come through. I go and visit them at home or in a ward … [W]herever they are, I'll go and see them and talk them through the whole process from the beginning. Make that initial introduction because I'll be the one that supports them through the process. … We have a different model here in VAD. We agreed way at the beginning with the SMOs [senior medical officers] that it made sense for me to do the things that I can do. And for them to spend time doing the things that they can do that I can't do. So that's why I ended up having so many administrations. It makes sense for me to do the administering. It's better to use your time to do the coordinating and the consulting and the final requests that I can't do.

Queensland Voluntary Assisted Dying Support and Pharmacy Service has an integral role in supporting Health and Hospital Services and as back-up voluntary assisted dying providers to ensure statewide access

QVAD SPS is an integral part of Queensland's approach to VAD. Participants were glowing about its work, including support provided to HHSs and VAD Coordinators, and patients and families through QVAD Support.

> This [HHS] service wouldn't have survived without QVAD Support.

Some particularly valued that QVAD SPS was interdisciplinary with care coordinators and pharmacists in the same team.

Although assisting all HHSs, much QVAD Support work focused on 'gap-filling' where VAD was not available locally. Participants also spoke about QVAD SPS's efforts to build this capacity in these regions.

> Probably the first three months of the year, we didn't have anyone here, we had no authorised doctors … so it was basically just QVAD Access that we were using, so they were flying doctors up, and almost every week. We were really busy right from the beginning, there was no lead in period, it was just right from the start.

This gap-filling role included QVAD SPS staff acting as administering practitioners. Administration was not an intended QVAD Support function but this was needed in HHSs without local capacity, or in complex cases whereadditional experience was beneficial. This role was often fulfilled by QVAD SPS nurses (linked with above theme), and was sometimes acknowledged as challenging given limited time to establish patient relationships.

> It's been gap-filling for want of a better term when a patient's priority has been that they've needed it, and nobody else has been able to go and do it. They reach out to us and then we'll, one of us is asked, obviously, no one's forced into doing anything, if we would like to go and do an administration. And then we travel and do the administration.

More resourcing is needed within Health and Hospital Services

Many participants were concerned VAD was under-resourced in their HHS. Some described HHSs 'ticking the box of the HSD' so it had VAD in theory, but the practice was quite different.

> There's absolutely no money here for us … no one wants to pay for it. … It's law, it's legislation, you have to provide the service. So find some money and get on with it, basically.

There were also reports that Coordinators and other clinical VAD roles had insufficient time for the work volume, particularly given higher than expected demand. Participants in HHSs with dedicated medical VAD roles (compared with nurse-only models) appreciated this structural access to doctors, who are needed for VAD eligibility assessments, as this facilitated timely progress for patients through the VAD approval process. A few HHSs with large VAD workloads valued administrative support given the paperwork and time-intensive nature of assessment processes.

Linked with under-resourcing was the temporary nature of VAD appointments. Many participants reported job insecurity made them vulnerable and risked VAD service continuity. However, some described recent improvements in resourcing within their HHS including making roles permanent and allocated VAD time within workload.

> I am just hellishly lucky that our health service realised that they would need to make permanent positions and have done so. Albeit a bit slightly slower than we hoped. But all the other health services, they're still working on temporary contracts and things because nobody's got any money and nobody wants to give any money from any other service to run this service. So I think that was a real miss that there should have been some way of ongoing funding for this. You can't really demand that health service runs a service but then just say, 'But we're not going to give you any financial assistance to do so'. But then you can't not run a service because then we're breaking an HSD.

These factors led to some participants feeling burnt out and overloaded, commonly compounded by the isolation of being a 'lone practitioner'. Many reported no alternative support in their HHS: 'I haven't [been able to] have a holiday'. However, many described feeling supported by QVAD SPS with the VAD process and personally (including through its community of practice). Another protective factor was the rewarding nature of supporting patients to have their choice of VAD.

Discussion

VAD access in Queensland has been shaped by implementation, especially the HSD and QVAD SPS. Significantly, the vast majority of VAD (~ 90%) is accessed through the public sector. This appears to be different from other states. While available data is not definitive, GP VAD participation can be a useful proxy given GPs primarily work in the private sector. Data in VAD Review Board reports varies (e.g.

registered for VAD training versus *participating* in VAD) but GPs account for 81% of practitioners in Tasmania,[16] 60% in South Australia,[17] 59% in Victoria,[18] and 45% in Western Australia,[19] suggesting VAD access is spread across public and private sectors elsewhere. Also noteworthy is Queensland's statewide VAD availability. Queensland has VAD practitioners in each HHS area[4] while Victoria and Western Australia report areas without them.[18,19]

Both features of access in Queensland – public sector access and statewide availability – were reportedly driven by the HSD mandating each HHS have a local model of VAD care. The HSD is a stronger policy response than adopted in previous states with VAD. For example, Victoria's 'VAD model of care pathways for health services' allowed services, including public health services, to choose their level of involvement in VAD.[20] The least involved pathway was to provide only 'information and support',[20–23] the pathway chosen by most organisations in the first 2 years of operation.[24] The resulting inequities in patient access to VAD due to variations in approaches by institutions is problematic.[25]

The role of nurse practitioners and nurses in Queensland is also striking. For example, 15 of our sample had provided practitioner administration, consistent with Queensland Board data that 14 nurse practitioners and nurses had undertaken this role in the first 6 months.[4] By contrast, the only report of nursing engagement as administering practitioners (permitted in WA, Tasmania and NSW) is in WA with one nurse practitioner providing practitioner administration over the last 2 years.[19]

Again, the HSD likely leads to greater nursing participation, particularly as administering practitioners. HSD obligations were usually met by HHSs through nursing appointments, generally as VAD Coordinators. This greater nursing involvement with patients through accompanying them in the VAD process may remove the known barrier to undertaking practitioner administration of not having a prior patient relationship.[19] The 'gap-filling' role of QVAD Support has also contributed to greater nursing participation in VAD as its nursing staff acted as administering practitioners when needed, although generally without the same opportunity to establish patient relationships.

The QVAD Support service has also had wider and significant impact on access, particularly in ensuring statewide availability. Its ability to provide assessments and/or administration to meet unmet demand in HHSs has been pivotal. Although not an anticipated function of QVAD Support, this was needed to ensure statewide access despite the HSD and other initiatives like the QVAD Access travel scheme (similar to other states).

This research also identified challenges for Queensland's VAD implementation. A key issue is resourcing, particularly in HHSs where the model of care was reportedly tokenistic. Limited guidance in the HSD about the content of models of care led to significant variation. Greater direction about minimum requirements for a local VAD service may be beneficial, informed by research about optimal models of care.

Further, a larger VAD workforce is needed, even in HHSs with well-established VAD services, to meet 'significant'[4] demand and for workforce sustainability, a recognised issue nationally.[4,13,19,26,27] Initiatives in some HHSs of increased medical appointments and making VAD roles permanent are important to consider. Resourcing and sustainability are also important for QVAD SPS as their practitioner administration roles are time and resource intensive. Additional HHS VAD capability may assist with reducing this load, as may QVAD SPS's efforts to build local capacity.

Resourcing also includes seeking opportunities for greater private sector participation, particularly through primary care. While reliable public sector access should be preserved to ensure equity, access is enhanced when VAD is available in a range of settings. GPs are the first port of call for many patients,[12] but a key barrier is the lack of remuneration, particularly from Medicare.[26] More research on the lack of VAD provision outside the public sector in Queensland is needed.

Limitations

A study strength is recruitment reach with participants from 15 of 16 Queensland's HHSs, as well as a considerable number of QVAD SPS staff. However, participants were all employees of Queensland Health and so had limited insight into VAD in the private sector (albeit a very small component of VAD in Queensland). Another strength is that this is the first reported study of Queensland VAD practice. However, the VAD system's first year of operation represents a point in time and (as participants noted) the system is evolving. Finally, most participants were nurses and perspectives of other key participants, particularly doctors, are needed (Ley Greaves L, Willmott L, Feeney R, White BP, unpubl. data).

Conclusion

Despite Australian states having similar VAD laws,[2] implementation has a significant impact on VAD practice. Key differences in Queensland's VAD system stem from its HSD mandating all HHSs to have a model of care for public access to VAD and its distinctive QVAD SPS. This has led to enhanced statewide access to VAD and through the public sector, and an increased role in VAD for nurse practitioners and nurses. However, resourcing and consistency in VAD provision remain challenging. More research is needed as to what constitutes an optimal model of care for VAD services.

Supplementary material

Supplementary material is available online.

References

1 Department of the Chief Minister and Cabinet. Voluntary assisted dying. Darwin: Northern Territory Government of Australia; 2024. Available at https://cmc.nt.gov.au/project-management-office/voluntary-assisted-dying [cited 22 July 2024].
2 Waller K, Del Villar K, Willmott L, White B. Voluntary assisted dying in Australia: a comparative and critical analysis of state laws. *Univ NSW Law J* 2023; 46(4): 1421–1470.
3 Queensland Health. Access to voluntary assisted dying. Brisbane: Queensland Government; 2023. Available at https://www.health.qld.gov.au/system-governance/policies-standards/health-service-directives/voluntary-assisted-dying [cited 22 July 2024].
4 Voluntary Assisted Dying Review Board. Annual Report 2022-2023. Queensland, Australia: Queensland Government; 2024. 42 p.
5 Voluntary Assisted Dying Act 2021 (Qld) s 156.
6 Queensland Health. Queensland Voluntary Assisted Dying Support Service (QVAD-Support). Brisbane: Queensland Government; 2023. Available at https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/voluntary-assisted-dying/support/qvad-support [cited 22 July 2024].
7 Queensland Health. Information on voluntary assisted dying substances: Voluntary Assisted Dying Pharmacy Service (QVAD-Pharmacy). Brisbane: Queensland Government; 2024. Available at https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/voluntary-assisted-dying/voluntary-assisted-dying-substances#-section_voluntary-assisted-dying-pharmacy-service-(qvad-pharmacy) [cited 22 July 2024].
8 Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, *et al.* Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018; 52(4): 1893–1907. doi:10.1007/s11135-017-0574-8
9 Kitto SC, Chesters J, Grbich C. Quality in qualitative research. *Med J Aust* 2008; 188(4): 243–246. doi:10.5694/j.1326-5377.2008.tb01595.x
10 Queensland Health. Voluntary assisted dying. Brisbane: Queensland Government; 2023. Available at https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/voluntary-assisted-dying [cited 22 July 2024].
11 Haining CM, Willmott L, White BP. Comparing voluntary assisted dying laws in Victoria and Western Australia: Western Australian stakeholders' perspectives. *J Law Med* 2023; 30(3): 716–744.
12 White BP, Jeanneret R, Willmott L. Barriers to connecting with the voluntary assisted dying system in Victoria, Australia: a qualitative mixed method study. *Health Expect* 2023; 26(6): 2695–2708. doi:10.1111/hex.13867
13 White BP, Jeanneret R, Close E, Willmott L. Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitators. *Med J Aust* 2023; 219(5): 211–217. doi:10.5694/mja2.52004
14 Willmott L, White BP, Sellars M, Yates PM. Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study. *Med J Aust* 2021; 215(3): 125–129. doi:10.5694/mja2.51123
15 Braun V, Clarke V. Thematic analysis: a practical guide. London: Sage Publications; 2022.
16 Voluntary Assisted Dying Commission. Annual Report 2022-2023. Hobart: Department of Health; 2023. 42 p.
17 Voluntary Assisted Dying Review Board. Quarterly Report 1 April 2023 to 30 June 2024. Adelaide: Department of Health and Wellbeing; 2024. 10 p.
18 Voluntary Assisted Dying Review Board. Annual Report July 2023 to June 2024. Melbourne: Safer Care Victoria; 2024. 41 p.
19 Voluntary Assisted Dying Board Western Australia. Annual Report 2022-23. Perth: Government of Western Australia Department of Health; 2023. 66 p.
20 Victorian Government. Voluntary assisted dying model of care pathways for health services. Melbourne: Victorian Government; 2019.
21 Close E, Willmott L, White BP. Regulating voluntary assisted dying practice: a policy analysis from Victoria, Australia. *Health Policy* 2021; 125(11): 1455–1474. doi:10.1016/j.healthpol.2021.09.003
22 Close E, Willmott L, Keogh L, White BP. Institutional objection to voluntary assisted dying in Victoria, Australia: an analysis of publicly available policies. *J Bioeth Inq* 2023; 20(3): 467–484. doi:10.1007/s11673-023-10271-6
23 O'Connor M, Mandel C, Mewett G, Catford J, McMaugh J. Implementing voluntary assisted dying in Victoria, Australia. *Int J Health Plann Manage* 2021; 36(3): 602–609. doi:10.1002/hpm.3126
24 McLaren CJ, Mewett G. Update on voluntary assisted dying in Australia. *Med J Aust* 2021; 215(3): 115–116. doi:10.5694/mja2.51152
25 White BP, Jeanneret R, Close E, Willmott L. The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions. *BMC Med Ethics* 2023; 24(1): 22. doi:10.1186/s12910-023-00902-3
26 Haining CM, Willmott L, Towler S, White BP. Access to voluntary assisted dying in Australia requires fair remuneration for medical practitioners. *Med J Aust* 2023; 218(1): 8–10. doi:10.5694/mja2.51787
27 Rutherford J, Willmott L, White BP. What the doctor would prescribe: physician experiences of providing voluntary assisted dying in Australia. *Omega* 2023; 87(4): 1063–1087. doi:10.1177/00302228211033109

Data availability. The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. The interview guide is available in Supplementary material file S1.

Conflicts of interest. Ben P. White and Lindy Willmott have received funding to conduct research on VAD from the Australian Research Council, state governments (including the Queensland Government) and philanthropic organisations. They were also engaged by three Australian state governments (Victoria, Western Australia and Queensland) to develop the legislatively mandated training for health practitioners providing VAD in those states. Lindy is a member of the Queensland Voluntary Assisted Dying Review Board, the oversight body in Queensland. Rachel Feeney was engaged as a clinical consultant for the VAD Training Education Module for Healthcare Workers in Queensland. Laura Ley Greaves was employed by a Queensland HHS for the purpose implementing VAD and has also been engaged in VAD training projects.

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Voluntary assisted dying in Queensland: doctors' perceptions of its first year of operation

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ABSTRACT

Objective. Voluntary assisted dying (VAD) became legal in Queensland in January 2023. This research examines the perceptions of doctors who have no in-principle objection to VAD, about the first year of VAD operation. **Methods.** Semi-structured interviews were conducted with 27 doctors 1 year after VAD had been in operation. **Results.** Three themes were developed: VAD is largely accepted as an end-of-life option and there is a collaborative approach with palliative care; VAD is being delivered as a public medical service, providing high-quality, timely access; and despite provision as a public medical service, there are remaining system access issues. **Conclusions.** The first year of VAD in Queensland has been generally positive, however, ongoing system access issues need to be addressed to ensure long-term sustainability of the service.

Keywords: doctors' experience, euthanasia, health system, health workforce, implementation, medical aid in dying, voluntary assisted dying.

Introduction

All Australian states and the Australian Capital Territory now have voluntary assisted dying (VAD) laws. Reform is also being considered in the Northern Territory.[1] In Queensland, VAD has been available since 1 January 2023.[2] All Australian laws follow a similar 'Australian model' of VAD, which is highly regulated with strict eligibility criteria and assessment processes.[3] There are, however, variations in individual state laws and their implementation. Notable features of Queensland's law and implementation, and how they are different from elsewhere, are outlined in Table 1.

The combination of Queensland's law and implementation, particularly the requirement for each Hospital and Health Services (HHS) to provide VAD services and resulting dedicated medical roles for VAD provision throughout the state and Queensland Voluntary Assisted Dying Support and Pharmacy Service (QVADSPS), has led to a distinctive system where over 90% of VAD provision occurs through the public system within Queensland Health.[4] This model differs from elsewhere in Australia, where provision of VAD has been spread across the public and private sectors.[5] As of June 2024, there were 187 authorised doctors in Queensland, 121 of whom had been involved in at least one case of VAD.[6] More than 25% of authorised doctors had been involved with over 20 cases each.[6]

Challenges in the operation of VAD systems within the first year are common and have been reported both in Victoria, Australia,[7–9] and internationally.[10,11] As a new service, there are unknowns, including how VAD would work in practice, and unexpected impacts on those involved, such as emotional tolls and time burdens.[7–9,11]

While there is some research on how VAD in Queensland is operating from a system perspective,[5] little is known about doctors' perceptions of VAD in Queensland. Yet this is vital to understand given the critical role doctors play in Queensland's VAD system. Queensland's distinctive model of VAD and the limited number of doctors involved means the perceptions of doctors are important in terms of sustainability of their

Table 1. Features of VAD in Queensland.

VAD law	
Features of Queensland VAD law that differ from elsewhere	**How they differ**
In order to participate in a VAD role, doctors must be authorised by the Chief Medical Officer of Queensland. Requirements for this include: holding general registration for 5 years or specialist registration for 1 year; have a relevant scope of practice, which includes experience in care towards the end of life; and have practiced twice the minimum hours required for registration with Australian health practitioner regulatory authority.	Other states have different lengths of registration and expertise requirements.
The two eligibility assessments required by Queensland VAD law can be completed by any authorised doctor.	This is different from e.g. Victoria where one must be completed by a specialist in the patient's illness or disease.
Doctors, nurse practitioners, and nurses can be administering practitioners in Queensland.	Some other states also take this approach and allow nurse practitioners and/or nurses to undertake this role.
Queensland's eligibility for VAD includes having a disease, illness or medical condition which is expected to cause death within 12 months.	This is 6 months in all other states (apart from 12 months for neurological conditions).
Distinct features of implementation	
Health Service Directive (HSD)	Queensland Health issued a Health Service Directive (HSD) to each of the 16 Hospital and Health Services (HHSs) in Queensland, requiring them to establish a model of care to provide timely publicly funded access to VAD for eligible people.The HSD required each HHS to have the capacity to complete all steps of the VAD process, from first request to administration of the VAD substance. The model of care adopted was left to the discretion of each HHS.
Medical roles for VAD provision	As a result of the HSD, some HHSs developed dedicated medical roles for VAD provision. Some HHSs had multiple positions for medical roles, and were able to take on both eligibility assessments of patients. Others had more limited or no designated medical roles.
Queensland Voluntary Assisted Dying Support and Pharmacy Service (QVADSPS)	QVADSPS has a care coordinator service (QVAD Support) which provides VAD support to patients and practitioners (a similar service has been established in other states), which in Queensland is combined with a statewide pharmacy service (QVAD Pharmacy) which supplies the VAD substance. QVADSPS is led by a palliative care physician and includes nurses, social workers, pharmacists, and a psychologist.

participation, sustainability of the system as a whole, and for patient access to VAD. Drawing on semi-structured qualitative interviews, this is the first paper to report on doctors' perceptions of the first year of VAD in Queensland.

Methods

This paper reports on semi-structured interviews conducted with 27 doctors after VAD had been in operation for 1 year. It is part of a wider longitudinal qualitative study exploring doctors' perceptions of VAD in Queensland before and 1 year after the law began.

Participants in the wider study were doctors in Queensland who had no in-principle objection to VAD and met the criteria to become VAD practitioners. Initial participant recruitment included study information on social media, medical societies, hospital and health service networks, and snowballing. Recruitment methods are reported in full elsewhere.[12] Participants included in this paper were those who agreed to be interviewed again, this time after the law had been in operation for 1 year; no additional recruitment was needed for this second set of interviews.

These semi-structured interviews were conducted by LLG from January to April 2024. The interview guide was developed within the research team, drawing on their VAD expertise. Open-ended questions explored participants' experiences with VAD and whether any change in practice had been observed since the commencement of operation. All interviews were recorded as Zoom conferences and lasted between 13 and 74 min (average of 36 min). Interviews were transcribed verbatim by LLG, de-identified, and sent to participants for member checking and approval for use in analysis.

LLG used Braun and Clarke's reflective thematic analysis to analyse data from this second set of interviews.[13] The data were coded line by line by LLG, and the approach to coding was both deductive and inductive to allow for all topics raised to be coded. Both semantic (descriptive) and latent (interpretive) content were coded for. Codes were generated into themes by LLG. The preliminary coding and themes were discussed and tested by all authors. NVivo 1.6.1

(QSR International) was used to store, code, and organise the data.

Ethics

This study was approved by Queensland University of Technology Human Research Ethics Committee: 2022/5020 and Royal Brisbane and Women's Hospital (RBWH) Queensland Health Human Research Ethics Committee approval: HREC/2022/QRBW/86914. All participants provided informed consent prior to interview.

Results

Twenty-seven doctors participated in this second round of interviews (Table 2). Although all doctors had no in-principle objection to VAD, they had varying degrees of involvement in VAD during the first year. Fifteen successfully applied to become authorised practitioners, of which 14 participated in at least one VAD case. Eight participants did not participate in VAD directly but were involved in other ways, such as providing specialist letters on patients' conditions or referring patients to the local HHS VAD service. Four participants had no involvement with or discussions about VAD within the first year. Three themes were developed about participants' perceptions of the first year of VAD in Queensland. Quotes supporting each theme can be found in Table 3.

Voluntary assisted dying is largely accepted as an end-of-life option

Participants reported initially being concerned about how VAD would work. However, most participants noticed no significant change in practice once VAD became available, and initial concerns subsided. Hospitals, both in the public and private system, were generally felt to be well prepared once VAD became available. Conscientiously objecting religious organisations had clear plans and procedures in place for patients who requested VAD. These outcomes were perceived to be reflective of the preparation that occurred during the implementation period (from the passing of the legislation to commencement of its operation).

Over the course of the first year, VAD was generally accepted as a legitimate end-of-life option. There were efforts to normalise VAD by discussing it as an end-of-life choice, but one separate from palliative care. As a result, some perceived that more discussions about death and dying occurred after commencement than before VAD was available. Other participants perceived general end-of-life care was initially conflated with VAD. This led to a reluctance from some patients and families to accept end-of-life care, although this also improved over the course of the year.

Table 2. Participant demographics.

Demographic	Number of participants
Gender	
Male	16
Female	11
Age range (years)	
20–29	1
30–39	5
40–49	13
50–59	4
60–69	2
70–79	2
Geographical area	
Greater Brisbane	12
Regional	12
Rural	3
Primary specialty[A]	
General practitioner (GP)	12
Oncologist	4
Geriatrician	3
Palliative care physician	3
Neurologist	2
Respiratory physician	2
Anaesthetist	1
Sector of practice	
Public	14
Private	8
Both	5
Length of practice (years)	
0–10	3
11–20	11
21–30	7
31–40	3
41–50	3

[A]Primary specialty as the specialty the participant practised under if they had more than one fellowship or specialty.

The integration between VAD and palliative care in Queensland has been generally good. Doctors reported VAD and palliative care teams working collaboratively to provide good patient care. Participants perceived this was assisted by key leadership within the Queensland VAD system having palliative care expertise and leading the integration of VAD in some palliative care education as an end-of-life option. A few exceptions to this integrated approach

Table 3. Participant quotes supporting the three themes.

Theme	Quotes
VAD is largely accepted as an end-of-life option	I don't think, as I said, I've changed my practice or anything, but if I look back, I think it was a more positive experience than I expected it to be, but predominantly because there wasn't the bumps in the road that I potentially expected there to be. (P10)
	I think just general acceptance is the main thing. I think generally people are calm about it. (P1)
	We talk about death so much more than we've ever done in a hospital setting. It's a good thing. It's a really good thing. (P3)
	I do think there is an issue here with, because of so much focus on VAD in the general discourse or patients wise, it has conflated between palliative care and VAD. That patients who deserve palliative care but for whatever reason think that it's leading to VAD, so I think that education process needs to continue for the general public. (P20)
	When we started off, [a palliative care practitioner] was involved in setting up the support service across the state. So we tend to play tag in terms of our education. They talk about palliative care in their education, and ensure that the interface is integrated. And we [talk about VAD] on this side. So we've had a number of representations in forums and in large conferences where we do joint sort of ventures. So even having exhibitor tables, we'll have the pall care and VAD stand together. (P19)
	We receive a lot of support from [palliative care]. So they are now actively referring people to us. Some of the clinicians are more comfortable discussing VAD as an end-of-life option, just presenting it as an option to the person. And when we need their support around the time of administration or when there are changes to the person's conditions, they will keep us informed, we keep them informed. So, we work collaboratively quite well, which makes very much more positive experience both for people and family. (P27)
	Was there a change? Nobody really said much. They referred the individual patients and that was really about sum total of it. (P29)
VAD as a public medical service	That was the feedback we got from people was they couldn't believe the promptness, the fact we were doing home visits to them and that it wasn't costing them anything. So they found it to be a very high quality service. (P3)
	I've found QVAD so supportive and approachable that you certainly don't feel, you feel like you can contact them if you need anything, even if that is just a bit of advice. So it's been good. (P18)
	The support from [QVAD Support] is the only thing that really keeps this program going. I think if we were just set on our own devices and we just had the VAD review board or something seeing us and we had the pharmacist maybe, and that was kind of it, I think it would be, it'd fall in a heap and there would be a lot more problems. But it's been very positive to have that level of support. (P3)
	In terms of timely access and making sure they follow through, which means I've had colleagues burning the candles at both ends to try and ensure that people have timely access. (P19)
	It's tricky because we're trying to build a service that doesn't make any money for anyone, technically. There's no specific payment from my consults. So from [the health services] perspective it's a drain on their budget. (P3)
	The first six months were, there was a lot of uncertainty. We all came on board on temporary sessions. We did not have any clarity, there was no clarity around what our budget was going to look like, what level of workforce we were going to be able to have, what we'd required for the first six months. (P27)
	We don't have capacity to offer after hours services, but we still do it and still have to attend to people's needs after hours. But it's not a great program. (P27)
System access issues	Patient issues:
	The outcome is that by the time a lot of these people get the information that they need, they get to us late. We try to start the process. Sometimes we expedite processes to see and even then a lot of these people don't get what they want to. (P27)
	System issues – Criminal code:
	So the [criminal code] is a massive obstacle to rapid implementation for rural patients. So particularly our very remote patients. So between the fact they have to receive the paper scripts, so we have to post a paper script. And the post up here, it takes like a week and then someone to travel with the meds. It's ridiculous. (P2)
	I think that having to post a script is one of the biggest limiting factors particularly when trying to expedite a case and trying to do something urgently for someone. (P27)
	Centralised pharmacy:
	A little tricky rurally to coordinate, you need to have a little bit of notice if you have a particular day that you want to get medication to yourself or to your patient. They have been incredibly helpful and accommodating and very willing to have

(*Continued on next page*)

Table 3. (*Continued*)

Theme	Quotes
	a discussion about ways around different things or looking at flights. So in my experience, the staff have been great and very accommodating. (P18)
	The pharmacists have to fly all around the state delivering the drug. And the rural patients are very disadvantaged because it relies on people being able to go to them, which means there is only a certain number of practitioners. So that's tricky. (P28)
	Admissions:
	Bed availability for a planned admission for IV administration [has been an issue]. For me, offering this service, voluntary assisted dying is all about the patient being in control. But that can be a bit tricky when then they don't want to die at home, they want to die in hospital, but the hospital needs to be able to accommodate them. So that can be a little bit of a challenge, but often that's easy to overcome. (P18)

were noted in some objecting institutions and with some individuals who held conscientious objections.

Participants not directly involved in VAD reported no significant change in practice. Some appreciated the option of discussing, as part of usual practice, what VAD entailed. Others valued being able to easily refer a patient to the VAD service when required, similar to other referrals.

Voluntary assisted dying as a public medical service

Participants reported VAD in Queensland was predominantly provided through the public system. This was attributed to the state-based QVAD Support and the Health Service Directive (HSD) issued to each HSS.

QVAD Support was reported to provide an extremely valuable centralised service of information and support for all those involved in VAD, including patients and health practitioners. QVAD Support also provided additional authorised practitioners to assist in areas without enough practitioners to meet VAD demand. This was of particular importance in providing access in rural areas. They also supported practitioners in the administration of the VAD substance, which again was reported to be very beneficial.

VAD, as a public medical service, provided patients with a high-quality service and timely access to VAD. Although this public provision of VAD was deemed important for equitable access, it was still reliant on individual practitioners to meet these expectations and provide the VAD service.

There were also perceived downsides to VAD as a public medical service. This included budget concerns for local HHSs, as there were no activity-based payments for VAD and no additional funding from Queensland Health to support its provision. As a result, some HHSs had no designated medical roles for VAD and relied on individual doctors to accept VAD referrals and provide the service in addition to existing roles. For those with designated VAD roles, funding was initially temporary and caused uncertainty about these roles' longevity. Additionally, VAD was not considered an emergency service, so designated VAD roles were only staffed during business hours. This resulted in individual practitioners working out of hours in order to provide this high quality VAD service.

System access issues

Despite VAD's acceptance within the health system and its establishment within the public health service, participants identified access issues based on patient, practitioner, and system-level factors.

Patient factors

Patient factors influencing access included a lack of awareness of VAD as an option or how to access it. This resulted in some patients requesting VAD late in their clinical trajectory, therefore being unable to complete or even start the process before dying. This resulted in calls for more education, both for health practitioners and the public, as there was ongoing confusion about what is VAD.

Practitioner factors

Practitioner factors influencing access included a limited number of VAD practitioners, including in rural areas. A small number of practitioners are relied on to provide a significant number of VAD cases, some also covering large geographical areas. This also required QVAD Support to be involved in more cases than expected.

System factors

There were three main system factors affecting timely access to VAD. First, the Commonwealth Criminal Code limits VAD communication over a carriage service (e.g. telephone, internet). Queensland Health Guidance requires parts of the assessment process to be conducted in person[14] but this was not always possible in a timely way because of practitioner availability. These restrictions also require the VAD substance prescriptions to be posted to the authorised pharmacy, potentially causing delays.

The second system factor is the single centralised pharmacy model. Again, due to the Criminal Code, pharmacists must deliver and discuss the VAD substance in person.

Pharmacists, therefore, must fly from one central location to various parts of Queensland. Restrictions in availability and cancelled or rebooked travel can cause delays while a patient deteriorates. The pharmacy staff themselves were described as very helpful, trying to do what they can and working well within current system design. Some participants suggested a de-centralised system where other pharmacies could make up the VAD substance locally to reduce delays.

Finally, admissions to hospital for parts of the VAD process caused difficulty in some public institutions due to bed pressures. This was particularly so if admission was desired on a particular day. There was a lack of doctors willing to accept patients for a VAD administration admission, even if the administration was carried out by another practitioner. This was of ongoing concern as there were few other options for patients not wishing to die at home.

Discussion

Participants reflected positively on the first year of VAD in Queensland with its distinctive system design,[5] leading to a high quality, timely VAD service provided through the public system, consistent with other reports of the first year of VAD in Queensland.[4,5] Some of these positive outcomes were not anticipated by these same participants interviewed earlier during implementation. At that time, participants expressed concern about an unknown workforce, unclear service provision, and how VAD would be incorporated into medical practice.[15] Although these concerns did not eventuate, certain system-level concerns expressed by participants during implementation persisted during the first year, including concerns about telehealth use and rural access.[15] The positive results might be attributed to work undertaken during Queensland's implementation period to prepare for VAD, including Queensland Health's HSD and the establishment of QVAD Support. Queensland also had the benefit of drawing on other states' experiences of implementing VAD, and participant reports suggest this is an improvement from the more varied implementation of VAD reported elsewhere.[10,16–18]

The effective collaboration with palliative care services was also positive and reflects the early experience of VAD in Western Australia.[19] This was facilitated by key leadership within the VAD system having palliative care expertise and the integration of VAD into broader end-of-life education. In countries such as Belgium and the Netherlands, where VAD is an established medical practice, palliative care and VAD are routinely provided concurrently.[20–22] However, this has not been the experience in all jurisdictions, and the distinctive service design in Queensland may be worth considering by other jurisdictions implementing VAD.

Participants also identified ongoing challenges for Queensland's VAD system. The Commonwealth Criminal Code remains a long-standing challenge for patients, families, practitioners, and system functioning.[23–26] The centralised pharmacy model of Queensland allows a single point of contact, providing useful support and information for practitioners and the public, but participants identified limitations of this model and resulting delays for patients. A centralised approach is also used in other Australian states, although international jurisdictions such as Canada use a different model where local pharmacies make up the VAD substance.[27,28] A decentralised model could be adopted in Queensland to address delays, but the potential implications of this change should be evaluated, including a loss of standardisation, such as in education provided to practitioners and patients.

The Queensland model of VAD as a public medical service has supported equitable patient access, but access barriers remain, particularly in rural Queensland. In addition to the Criminal Code and central pharmacy service, a lack of authorised practitioners in rural areas is an ongoing concern, reflecting workforce concerns reported elsewhere in Australia.[8,9] Despite QVAD Support providing additional VAD assessments and supporting local practitioners to improve access for rural patients, there is still a reliance on a relatively small pool of individual practitioners to provide VAD in rural areas. This was also the experience in rural Canada after the introduction of VAD.[29] For the sustainability of the service and the well-being of those who provide VAD, service design needs to avoid over-reliance on specific practitioners.[5] Further infrastructure and funding are needed to ensure the system can function sustainably, including sufficient designated roles for VAD provision to meet demand within the public system.

Limitations

As the VAD service is still relatively new, our findings on the first year of operation may not translate to more established services. Participants in this study were doctors with no in-principle objection to VAD and do not represent a full range of opinions on VAD, including those with objections, limiting the generalisability of findings to broader medical populations. Further and ongoing research is needed to explore VAD system operation over time.

Conclusion

Participants generally reported positively about the first year of VAD in Queensland, with VAD provided as a public medical service, delivered in a high-quality and timely way, with broadly positive collaboration with palliative care. Ongoing system access issues were reported, however, including delays with a centralised pharmacy model, compounded by the restrictions resulting from the Criminal Code, and the over-reliance on individual doctors to provide this high-quality service. System issues must be addressed in order to ensure sustainability of Queensland's VAD system.

References

1 Northern Territory Government. Report into Voluntary Assisted Dying in the Northern Territory. July 2024. p. 130. Available at https://cmc.nt.gov.au/_data/assets/pdf_file/0018/1420722/vad-report-2024.pdf
2 QLD. Voluntary Assisted Dying Act. 2021. Available at https://www.legislation.qld.gov.au/view/html/asmade/act-2021-017
3 Waller K, Villar KD, Willmott L, White BP. Voluntary assisted dying in Australia: A comparative and critical analysis of state laws. *UNSWLJ* 2023; 46: 1421.
4 Graves T. Voluntary assisted dying in Queensland, the first year. *Emerg Med Australas* 2024; 36(2): 326–8. doi:10.1111/1742-6723.14386
5 White BP, Ward A, Feeney R, Ley Greaves L, Willmott L. Models of care for voluntary assisted dying: a qualitative study of Queensland's approach in its first year of operation. *Aust Health Rev* 2024; 48: 693–9. doi:10.1071/AH24199
6 Voluntary Assisted Dying Review Board QG. Voluntary Assisted Dying Review Board Annual Report 2023-2024. Queensland Government; 2024. p. 37. Available at https://www.health.qld.gov.au/_data/assets/pdf_file/0019/1362124/vad-annual-report-2023-24.pdf
7 Rutherford J, Willmott L, White BP. What the Doctor Would Prescribe: Physician Experiences of Providing Voluntary Assisted Dying in Australia. *Omega* 2021; 87: 1063–87. doi:10.1177/00302228211033109
8 Sellars M, White BP, Yates P, Willmott L. Medical practitioners' views and experiences of being involved in assisted dying in Victoria, Australia: A qualitative interview study among participating doctors. *Soc Sci Med* 2022; 292: 114568. doi:10.1016/j.socscimed.2021.114568
9 Lamba GT, LaBrooy C, Lewis S, Olver I, Holmes A, Stewart C, *et al.* Voluntary assisted dying: impacts on health professionals. *Aust Health Rev* 2024; 48: 720–8. doi:10.1071/AH24142
10 Snelling J, Young J, Beaumont S, Diesfeld K, White B, Willmott L, *et al.* Health care providers' early experiences of assisted dying in Aotearoa New Zealand: an evolving clinical service. *BMC Palliat Care* 2023; 22(1): 101. doi:10.1186/s12904-023-01222-4
11 Winters JP, Pickering N, Jaye C. Because it was new: Unexpected experiences of physician providers during Canada's early years of legal medical assistance in dying. *Health Policy* 2021; 125(11): 1489–97. doi:10.1016/j.healthpol.2021.09.012
12 Ley Greaves L, Willmott L, Feeney R, White BP. Assisted dying: participation barriers and facilitators – qualitative interview study of doctors' perceptions. *BMJ Support Palliat Care* 2024; spcare-2024-004985. doi:10.1136/spcare-2024-004985
13 Braun V, Clarke V. Thematic Analysis: A Practical Guide. SAGE Publications; 2021. 376 p.
14 Queensland Health VADU. Guidance for practitioners - Discussions about voluntary assisted dying over carriage service. Queensland Government; 2023. Available at https://www.health.qld.gov.au/_data/assets/pdf_file/0032/1196384/guidance-for-practitioners-discussions-about-vad-over-carriage-service.pdf
15 Ley Greaves L, Willmott L, Feeney R, White BP. Preparing for Voluntary Assisted Dying: A qualitative analysis of practitioners' perceptions of voluntary assisted dying before the law begins in Queensland, Australia. *Death Stud* 2025; 1–15. doi:10.1080/07481187.2025.2502985
16 Booth S, Eleftheriou P, Moody C. Implementing voluntary assisted dying in a major public health service. *Med J Aust* 2021; 214(8): 343–6. doi:10.5694/mja2.50982
17 Fujioka JK, Mirza RM, Klinger CA, McDonald LP. Medical assistance in dying: implications for health systems from a scoping review of the literature. *J Health Serv Res Policy* 2019; 24(3): 207–16. doi:10.1177/1355819619834962
18 Frolic A, Oliphant A. Introducing Medical Assistance in Dying in Canada: Lessons on Pragmatic Ethics and the Implementation of a Morally Contested Practice. *HEC Forum* 2022; 34(4): 307–19. doi:10.1007/s10730-022-09495-7
19 Auret K, Pikora TJ, Briand BC. Still safe; still respectful: a mixed methods study exploring the early experiences of a rural community hospice in providing voluntary assisted dying. *BMC Palliat Care* 2025; 24(1): 78. doi:10.1186/s12904-025-01713-6
20 Bergman TD, Pasman HRW, Onwuteaka-Philipsen BD. Complexities in consultations in case of euthanasia or physician-assisted suicide: a survey among SCEN physicians. *BMC Fam Pract* 2020; 21(1): 6. doi:10.1186/s12875-019-1063-z
21 Van Wesemael Y, Cohen J, Onwuteaka-Philipsen BD, Bilsen J, Distelmans W, Deliens L. Role and Involvement of Life End Information Forum Physicians in Euthanasia and Other End-of-Life Care Decisions in Flanders, Belgium. *Health Serv Res* 2009; 44(6): 2180–92. doi:10.1111/j.1475-6773.2009.01042.x
22 Dierickx S, Deliens L, Cohen J, Chambaere K. Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: A population-based mortality follow-back study. *Palliat Med* 2018; 32(1): 114–22. doi:10.1177/0269216317727158
23 Villar KD, Close E, Hews R, White BP. Voluntary assisted dying and the legality of using a telephone or internet service: The impact of Commonwealth 'carriage service' offences. *Monash Uni Law Rev* 2021; 47(1): 125..
24 White BP, Jeanneret R, Close E, Willmott L. Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitators. *Med J Aust* 2023; 219: 211–7. doi:10.5694/mja2.52004
25 Willmott L, White BP, Sellars M, Yates PM. Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study. *Med J Aust* 2021; 215(3): 125–9. doi:10.5694/mja2.51123
26 Haining CM, Willmott L, White BP. Accessing voluntary assisted dying in regional Western Australia: early reflections from key stakeholders. RRH; 2023. Available at https://www.rrh.org.au/journal/article/8024 [cited 21 February 2025].
27 Crumley ET, Kelly S, Young J, Phinney N, McCarthy J, Gubitz G. How is the medical assistance in dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study. *BMJ Open* 2021; 11(7): e048698. doi:10.1136/bmjopen-2021-048698
28 Beuthin R, Bruce A, Hopwood MC, Robertson WD, Bertoni K. Rediscovering the art of medicine, rewards, and risks: Physicians' experience of providing medical assistance in dying in Canada. *SAGE Open Med* 2020; 8: 2050312120913452. doi:10.1177/2050312120913452
29 Durant KL, Kortes-Miller K. Physician snapshot: the forming landscape of MAiD in northwestern Ontario. *Palliat Care Soc Pract* 2020; 14: 2632352420932927. doi:10.1177/2632352420932927

Data availability. The data that support this study cannot be publicly shared due to ethical or privacy reasons and may be shared upon reasonable request to the corresponding author if appropriate.

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Review of the Voluntary Assisted Dying Act 2019 (WA): Research Report

Lindy Willmott, Ben P White and Casey M Haining*

The Voluntary Assisted Dying Act 2019 (WA) was passed in December 2019, and came into effect on 1 July 2021. The legislation requires that the Act is reviewed at set intervals with the first review occurring as soon as practicable after the second anniversary of the Act's operation. An independent three-person panel was appointed to carry out the review. This article reports on one aspect of the review process which involved carrying out semi-structured interviews and focus groups with key stakeholders and formulating recommendations based on the data collected (and other evidence). Thematic analysis resulted in the identification of six main themes: awareness of Voluntary Assisted Dying (VAD); accessing and navigating the VAD system; eligibility assessment; prescription, administration, disposal and post-death; VAD workforce; and VAD system design. Overall, the findings reveal that the WA VAD system is working well; however, several issues with the current system remain.

Keywords: *Voluntary assisted dying; law reform; Western Australia; statutory review; qualitative; recommendations*

I. Introduction

Western Australia (WA) was the second Australian jurisdiction to pass Voluntary Assisted Dying (VAD) laws.[1] The *Voluntary Assisted Dying Act 2019* (WA) (*WA VAD Act*) came into force on 1 July 2021. The law was preceded by a Joint Select Committee Inquiry into End-of-Life Choices. The Committee made recommendations about advance care planning, palliative care and the implementation of VAD in its Final Report, *My Life, My Choice*,[2] released in August 2018. The WA Government then established

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Conflict of interest declaration: The authors declare that Ben P White and Lindy Willmott were engaged by the Victorian, Western Australian and Queensland Governments to design and provide the legislatively mandated training in each of these States for medical practitioners (and nurse practitioners and nurses as appropriate) involved in voluntary assisted dying. Casey M Haining was employed on the Queensland project as a legal writer and engaged as a research fellow for the purposes of carrying out the statutory review of the Western Australian VAD Act. Lindy Willmott is a member of Queensland's Voluntary Assisted Dying Review Board.

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[1] Victoria was the first State with its *Voluntary Assisted Dying Act 2017* (Vic) which commenced operation in June 2019. See CM Haining, L Willmott and BP White, "Comparing Voluntary Assisted Dying Laws in Victoria and Western Australia: Western Australian Stakeholders' Perspectives" (2023) 30(3) JLM 714.

[2] Joint Select Committee on End of Life Choices, *My Life, My Choice Report* (Western Australian Government, 2018) <https://www.parliament.wa.gov.au/parliament/commit.nsf/(Report+Lookup+by+Com+ID)/71C9AFECD0FAEE6E482582F200037B37/$file/Joint+Select+Committe+on+the+End+of+Life+Choices+-+Report+for+Website.pdf>.

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a Ministerial Expert Panel to undertake consultation and develop legislation.[3] The Panel's Final Report was tabled on 27 June 2019 and informed the drafting of the *Voluntary Assisted Dying Bill 2019*. The Bill was introduced into Parliament in August 2019 and passed in December 2019. The *WA VAD Act* commenced operation following an 18-month implementation period.

The Act obliges the Minister for Health to "review the operation and effectiveness" of the Act at set intervals, with the first review occurring as soon as practicable after the 2nd anniversary of the Act's operation.[4] An independent three-person panel (Panel), comprising Dr Elissa Campbell, Dr Sally Talbot MLC and Dr Simon Towler, were appointed by the Minister to conduct the Review.

The Panel's terms of reference require it to consider:

- the effectiveness and the operation of the Act, as passed by the Parliament in 2019, in providing for and regulating access to voluntary assisted dying (VAD); and
- the extent to which current processes provided under the Act are operating to support persons eligible for VAD in Western Australia.

The Panel was not seeking feedback on whether VAD should be precluded or whether there should be changes to eligibility criteria for patients or practitioners involved in the VAD process.[5]

The Review comprised a two-stage consultation process. Stage One was managed by the Department of Health (DoH) and invited key stakeholders to complete an online survey to identify the most significant issues. The online survey was open between 10 November and 8 December 2023.

A research team from the Australian Centre for Health Law Research, Queensland University of Technology (QUT) were engaged by the DoH to carry out Stage Two of the Review. This Stage involved carrying out targeted interviews and focus groups to explore some of the main issues identified in Stage One.[6] The authors delivered a Research Report to the Panel to inform its deliberations. This article is an edited version of that Report.[7]

II. Authors' Process

The authors were responsible for conducting semi-structured interviews and focus groups among key stakeholders (identified by the Panel). Stakeholders included representation from VAD health practitioners who are currently involved in provision (including medical practitioners and a nurse practitioner), VAD Statewide Care Navigator Service (SWCNS), VAD Statewide Pharmacy Service (SWPS), VAD Advocacy Groups, health service providers' VAD Coordinators, VAD Board, VAD Board Secretariat, End of Life Care Program Team at the DoH and family caregivers who supported a person through the VAD process. Not all stakeholders identified by the Panel agreed to participate or responded to the authors' invitations to participate.[8] The authors made several attempts to recruit health practitioners who were no longer involved in VAD provision (using contact details provided by the DoH); however, that recruitment was unsuccessful.

[3] DoH, *Ministerial Expert Panel on Voluntary Assisted Dying: Final Report* (Western Australian Government, 2019) <https://www.health.wa.gov.au/~/media/Files/Corporate/general-documents/Voluntary-assisted-dying/PDF/voluntary-assisted-dying-final-report.pdf>.

[4] *Voluntary Assisted Dying Act 2019* (WA) s 164.

[5] DoH, *Voluntary Assisted Dying Act 2019 Review* (Government of WA, 2023) <https://consultation.health.wa.gov.au/ced-clr-vad/vad-act-review/>.

[6] The authors were provided with desired participant categories and a list of contact details of specific individuals within each stakeholder group that the Panel wanted contacted.

[7] Edits were made to reduce the word count and format the Report to make it suitable for publication in this journal. Additional participant quotes from the original Report can be found in Supplementary Material 1. The original report can be found here <https://eprints.qut.edu.au/254209/>.

[8] The authors supplemented the Panel's original list to account for declined invitations and non-responders. To do this, the authors drew on an additional list provided by the DoH which contained contact details of personnel who participated in Stage One of the consultation process.

Ethics approval was obtained by QUT's University Human Research Ethics Committee [ID 20000002700]. Interview and focus group guides were developed by the authors and tailored to reflect the intended stakeholder group. Themes explored in the guides were informed by the researchers' knowledge of VAD, previous research, and themes identified from a preliminary analysis of Stage One data (based on a draft report supplied by the DoH to the authors).[9] Each guide sought specific feedback on: accessing the VAD system, assessment stages and application of eligibility criteria, dispensing, administration and disposal of the VAD substance, and post death supports and bereavement. The guides also offered an opportunity for participants to reflect on the WA VAD system as a whole. The Panel reviewed the interview and focus group guides and approved their use.

A total of eight semi-structured interviews/focus groups (comprising between 2 and 7 participants) were carried out explicitly for this Review and took place via Zoom between October 2023 and April 2024. Semi-structured interviews and focus groups were conducted by all three researchers, with one researcher taking the lead for each. For the purposes of analysis, the authors also drew on previous qualitative interview data from research carried out in WA, in 2022, by the same researchers.[10] This supplemental data captured perspectives from family caregivers, and aged care and palliative care organisations (including those not supportive of VAD) (n = 5). Only data from previous participants who were members of the stakeholder groups above, and who had provided extended consent to have their data used to inform the Review, were re-analysed for the purposes of this Report. Demographics of all participants whose data was analysed for the purpose of this Report have been recorded in Table 1.

TABLE 1. Participant Demographics

Total sample (n=38)		
Participant type	Health practitioners	6
	Family caregivers	6
	Other	26
Gender identity	Female	27
	Male	11
Age	30–39	5
	40–49	9
	50–59	10
	60–69	7
	70+	7
Location	Metropolitan	35
	Regional	3
Health practitioner characteristics (n=6)		
Number of cases	<20	2
	20–50	1
	50–100	1
	100+	2
Regional experience (including RASS)		4

[9] The authors were provided with an early analysis of the Stage One data by the DoH in January 2024: DoH, *Voluntary Assisted Dying Act 2019 Review – Stage 1: Early Draft Results* (Western Australian Government, 2024).

[10] For further details on the study's methodology see Haining, Willmott and White, n 1, 730–732.

TABLE 1. continued

Patient demographics (n=5)*		
Gender	Female	1
	Male	4
Age at death	60–69	2
	70–79	2
	80+	1
Primary diagnosis	Cancer	4
	Other	1
Death	Death from the VAD substance	4
	Non-VAD death	1

* No patients were included in the sample. However, six family caregivers who took part in this study were able to reflect on the experiences of five patients; two participants reflected on the same patient. One family caregiver's loved one was unable to complete the process.

Field notes were completed following each interview and focus group. Interviews and focus groups were transcribed by a professional transcription company. Transcripts were de-identified and sent to each participant who was provided with the opportunity to review and edit their data. Participants were also invited to provide the researchers with any supplementary documentation or send through additional thoughts they wanted to be included in the analysis. Data were imported into NVivo 14 and analysed using Braun and Clarke's approach to thematic analysis.[11] Data familiarisation occurred by relistening to each interview, focus group and reading through each transcript in full multiple times. This process informed a coding framework which was reviewed, revised and agreed upon by all authors based on their recollection of the data and previous VAD research. The coded data was then organised into themes, which were reviewed and refined by all the authors, and have been reported on in this Report.

A. Limitations

As is the case for all empirical research, this research has limitations. Firstly, the sample comprises a range of key stakeholders, but is ultimately small. While the sample contains representation from a variety of stakeholder groups, it does not include representation from patients undergoing the process, conscientious objectors, or VAD-trained practitioners who are no longer providing. Additionally, participants were contacted based on lists of desired participants determined by the Panel and DoH and, therefore, may not be representative of their respective groups, particularly among larger stakeholder groups such as health practitioners.

The limited sample means that some specific issues with the *WA VAD Act* may not have been raised and, therefore, are not addressed in this Report. This is because only issues explicitly referred to during the focus groups and interviews were included within the analysis. The authors note other specific issues (such as the wording in the *WA VAD Act* in relation to interpreters, the challenge of finding eligible witnesses for the purposes of the written declaration, and difficulties of intravenous (IV) access in relation to practitioner administration) have been raised publicly elsewhere.[12] Because these matters have been identified elsewhere and were not discussed by participants during interviews/ focus groups,

[11] V Braun and V Clarke, "Using Thematic Analysis in Psychology" (2006) 3(2) *Qualitative Research in Psychology* 77.

[12] For reflections on issues relating to interpreters see Voluntary Assisted Dying Board Western Australia, *Annual Report 2021-22* (2022) 39 <https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2021-22.pdf> (*WA VADB 2021-2022 Report*). For reflections on the difficulty in finding witnesses see Go Gentle Australia, *Stephen Had a Peaceful Death* (13 December 2022) <https://www.gogentleaustralia.org.au/stephens_voluntary_assisted_dying_experience>; For reflections on the difficulties with IV access see Voluntary Assisted Dying Board Western Australia, *Annual Report 2022-23* (2023) 56 <https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board- Annual-Report-2022-23.pdf> (*WA VADB 2022-2023 Report*).

they have not been considered in this Report. Nevertheless, the authors consider that the methodology adopted for this research will have identified the broad range of issues with the *WA VAD Act's* operation and effectiveness.

There are also limitations inherent in the study design. For example, the interview and focus group guides used were necessarily broad to capture a range of themes. Therefore, some of the minutia and intricacies of the WA VAD system may not have been captured or directly probed. Similarly, there is potential that participants' responses may have been affected by the group dynamic. For example, participants may have been more careful in their responses (particularly with respect to sensitive information) than if they had participated in a one-on-one semi-structured interview.

III. Key Findings

Data analysis revealed that, apart from some notable issues, the WA VAD system is working well, once a patient is connected to the system. The *WA VAD Act* has provided an additional end-of-life choice for eligible Western Australians. The success of the WA VAD system has largely been attributed to the VAD workforce, including the statewide services and VAD Coordinators, who have been widely praised for their compassion and dedication to delivering person-centred care. Similar positive sentiments about the WA VAD system have been expressed elsewhere.[13] Data analysis resulted in the identification of six main themes: awareness of VAD; accessing and navigating the VAD system; eligibility assessment; prescription, administration, disposal and post-death; VAD workforce; and VAD system design.

In reporting the results, the authors have described the data relevant to the theme, evaluated the available evidence (participants' views and additional relevant evidence),[14] identified relevant issues and potential responses to address such issues. Where appropriate, the authors have also formulated recommendations. In total, the authors independently formulated 25 recommendations.[15] These recommendations have been broadly categorised (and colour-coded) across three groups: (1) Recommendations that address the three "priority issues" identified below and so should be implemented as soon as possible (black) (2) Recommendations that should be implemented as a next level priority as soon as possible (grey), and (3) Recommendations for consideration in future reviews (white).

For the sake of completeness, this Report considers all significant issues raised by participants. While not all issues resulted in a response by way of recommendation, the authors encourage the DoH to monitor all the issues identified and consider whether a response may be needed now or in the future.

The authors' approach to developing recommendations has been to identify the problematic issue/s which need to be addressed. Having identified these issues, the authors then provide the Panel with a range of possible responses for its consideration. In some instances, the optimal solution will be to amend the *WA VAD Act*. Where this is the authors' view, this will be clearly stated. However, the authors recognise that reliance on legislative solutions alone has limitations. Amending the *WA VAD Act* depends on parliamentary consensus which may or may not be present, and law reform can take time. There may, therefore, be a need for non-legislative responses such as issuing (or revising) policies and other forms of guidance, developing training and education, implementing practice changes and adjusting system design. Such responses have the advantage of being able to be implemented more quickly. The range of possible responses identified by the authors may also be seen to work together. To illustrate, a change in policy may provide an immediate response to mitigate a known problem, pending future law reform.

Finally, while there are a range of issues canvassed and recommendations made in this Report, the authors have identified three priority issues affecting the operation and effectiveness of the *WA VAD Act*. These priority issues, along with the relevant recommendations needed to address them, are set out below:

[13] See, eg, Haining, Willmott and White, n 1; *VADB 2021-2022* Report, n 12; *VADB 2022-2023* Report, n 12.

[14] This included peer-reviewed literature, VAD Board Reports and media accounts.

[15] The Panel and DoH were given the opportunity to comment on a draft of the final Report. This feedback was considered by the authors. However, the final Report and recommendations were developed by the authors alone. See Supplementary Materials for all recommendations.

1. Lack of public knowledge about the VAD system and difficulties associated with connecting to the system
   - Improve community knowledge that VAD is a legal end-of-life option (Recommendation 1)
   - Improve health practitioner knowledge of VAD, especially of medical practitioners, and educate these practitioners about their existing legal obligations when they receive a first request for VAD (Recommendations 2 and 4)
   - Develop strategies to ensure medical practitioners provide information about VAD when requested by a patient (Recommendation 6).
2. Individuals and institutions, either intentionally or otherwise, impeding a patient's ability to access VAD
   - Develop strategies to ensure medical practitioners provide information about VAD when requested by a patient (Recommendation 6)
   - Impose obligations on all entities providing health, aged, residential and other care to facilitate access to VAD (Recommendation 8).
3. Limited VAD workforce to meet current demands and concerns for the current workforce's sustainability
   - Develop strategies and explore opportunities to increase the VAD workforce (Recommendation 19)
   - Review current VAD practices and workload of existing VAD workforce (including VAD providers and those who have a role in VAD such as statewide services and VAD Coordinators) to ensure they are appropriately remunerated and supported (Recommendation 21).

A. Awareness of VAD

VAD laws were passed in WA in 2019 and, since July 2021, VAD has been available as a lawful end-of-life choice. Victoria was the first State to pass VAD laws in 2017, and the remaining four States and the Australian Capital Territory passed legislation between 2021 and 2024.[16] The Northern Territory is actively considering introducing laws.[17] During this period of reform, there has been considerable national coverage of, and discussion about, VAD. This has been important because access to VAD ultimately relies on individuals knowing that it is a lawful end-of-life option. Indeed, the need to improve awareness of VAD among the community and health practitioners has been identified as one of the WA VAD Board's strategic objectives.[18] This section provides an overview of participants' perceptions about the current levels of awareness of VAD among the community and the health profession.

1. Community Awareness

In order for the community to be able to access VAD, they need to be aware that it is a lawful end-of-life option available to them. Awareness may arise through a person's own channels or discussions with health practitioners. Community awareness can also occur through other avenues. For instance, VAD stories occasionally feature in mainstream media, and there have been efforts by the VAD Board and the SWCNS, as well as other groups (such as Dying with Dignity Western Australia) to host community forums and webinars to raise awareness.[19] However, given VAD is a relatively new end-of-life choice

[16] VAD laws are in effect in all States: *Voluntary Assisted Dying Act 2017* (Vic), *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas), *Voluntary Assisted Dying Act 2021* (Qld), *Voluntary Assisted Dying Act 2021* (SA) and *Voluntary Assisted Dying Act 2022* (NSW). The *Voluntary Assisted Dying Act 2024* (ACT) will come into effect on 3 November 2025.

[17] An expert advisory panel has been set up in the Northern Territory to develop a framework for VAD. See Department of the Chief Minister and Cabinet, *Voluntary Assisted Dying* (Northern Territory Government, 2024) <https://cmc.nt.gov.au/project-management-office/voluntary-assisted-dying>.

[18] The WA VAD Board's Strategic Plan 2023 to 2026 outlines six strategic objectives, including to "[c]ontribute to community/health practitioner awareness and understanding of voluntary assisted dying, relevant to person (sic), role and stage of life". See *WA VADB 2022-2023 Report*, n 12, 58.

[19] For examples see DoH, *End of Life Care: Voluntary Assisted Dying,* (Government of Western Australia) <https://www.healthywa.wa.gov.au/_Articles/A_E/End-of-life-care>; *WA VADB 2022-2023 Report*, n 12, 52; A Cox, "Voluntary Assisted Dying Board of WA Visits Geraldton to Ensure Community's Questions are Answered", *Geraldton Guardian*, 11 March 2024 <https://www.geraldtonguardian.com.au/news/geraldton-guardian/voluntary-assisted-dying-board-of-wa-visits-geraldton-to-ensure-communitys-questions-are-answered-c-13901837>.

available to Western Australians, it is likely that there are significant knowledge gaps within the community.[20] Raising patients' awareness empowers them to connect with the system and access VAD. This is particularly important in cases where patients may not be able to access VAD via their usual care team.

Participants' Submissions and Evidence

Participants acknowledged that in the absence of any studies or polling, it is difficult to gauge the level of community awareness of VAD in WA. There was a sense that knowledge had increased over time due to increasing national discussion and discourse about VAD, or through knowledge of someone who had been through the process. There have been accounts where patients and their families have been motivated to share their VAD story in the media to help raise awareness about VAD and help break down stigma.[21] Participants noted that any time VAD featured in the media (whether positively or negatively), this correlated with an increase in VAD enquiries:

> It was only just the other day I was talking to someone about voluntary assisted dying and they said, "It's a pity I've got to go to Switzerland to access it". And I went, "Well hang on a minute, no we've had it in the state for nearly three years". [Participant 24]

Despite this perception of an increasing level of awareness, overall community knowledge of VAD, like knowledge of end-of-life and death literacy more generally, was believed to be patchy across the State. Participants indicated that there were still people in the community who were unaware that VAD is available. Levels of awareness also appeared to vary regionally:

> We definitely see differences in the regions. Death literacy and awareness around end-of-life options is really different across each individual region of WA, and even subsets within that region. If I think about our Great Southern there's a really different understanding about what end-of-life care could look like in Kalgoorlie than there is in Esperance. Things are really, really different … depending on their cultural awareness and understanding. I think we are still a long way from there being broad community understanding that VAD is an available option. [Participant 3]

Participants identified that people were more likely to be aware of VAD if they knew of someone who went through the process, or if a health practitioner raised VAD with them. In WA, medical practitioners and nurse practitioners are able to raise the topic of VAD with patients, provided at the same time they also inform the person about palliative and treatment options available to the person, and the likely outcomes of that care and treatment.[22] This aspect of the law has been favoured over more restrictive approaches taken in other States where health practitioners are prohibited from raising VAD.[23] Indeed, the current prohibitions were perceived to constrain raising awareness about VAD and, as will be discussed subsequently, act as a barrier to connecting with the system (see Part IIIB1).

Notably, however, while the ability of certain health practitioners to raise VAD was viewed favourably, this would only be effective when the particular health practitioner knew about VAD which, as will

[20] Lack of awareness of VAD has been reported elsewhere see BP White, R Jeanneret and L Willmott, "Barriers to Connecting with the Voluntary Assisted Dying System in Victoria, Australia: A Qualitative Mixed Method Study" (2023) 26 *Health Expectations* 2695, 2700.

[21] R Hirini, "First Known Aboriginal Voluntary Assisted Dying (VAD) Patient Mary-Ellen Passmore Dies in Perth Hospital", *The West Australian*, 30 July 2021 <https://thewest.com.au/news/health/first-known-aboriginal-voluntary-assisted-dying-vad-patient-mary-ellen-passmore-dies-in-perth-hospitalng-b881946986z>. See also R Jeanneret et al, "'Regulatory Action' by Patients and Family Caregivers to Overcoming Barriers to Accessing Voluntary Assisted Dying: A Qualitative Study in Victoria, Australia" (2024) 47(3) *UNSW Law Journal* (forthcoming).

[22] *Voluntary Assisted Dying Act 2019* (WA) s 10.

[23] *Voluntary Assisted Dying Act 2017* (Vic) s 8; *Voluntary Assisted Dying Act 2021* (SA) s 12. For empirical evidence on the prohibition's impact see Haining, Willmott and White, n 1, 733–734; J Rutherford, L Willmott and BP White, "What the Doctor Would Prescribe: Physician Experiences of Providing Voluntary Assisted Dying in Australia" (2021) 87(4) OMEGA 1063, 1071–1072; BP White et al, "Access to Voluntary Assisted Dying in Victoria: A Qualitative Study of Family Caregivers' Perceptions of Barriers and Facilitators" (2023) 219(5) *Medical Journal of Australia* 211, 213–214; White, Jeanneret and Willmott, n 20, 2702–2703; L Willmott et al, "Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study" (2021) 215(3) *Medical Journal of Australia* 125, 126–127.

subsequently be discussed in Part IIIA2, is not always the case. Participants observed that people living in regions with limited (or no) VAD providers were less likely to be aware of VAD:

> [In] regional areas … [I get] a lot of the feedback … in particular areas [that] their doctors are very transient and often the GPs [General Practitioners] are only there for a short amount of time. They might be overseas doctors that come in and they're also not aware that this is legislation and not aware of what even to do. [There's] often … this cultural religious influence there as well … I definitely think our regional patients still … struggle with access. [Participant 4]

Moreover, participants perceived that those who frequently engaged with the health care system (eg those who regularly attended hospitals for treatment) were more likely to have contact with medical and nurse practitioners and hence tended to be more aware of VAD, compared to those who were predominately receiving community care. Indeed, those receiving community care were less likely to come into contact with medical practitioners and nurse practitioners compared to other health care workers such as registered nurses and social workers, who are currently prohibited from raising VAD:

> I actually think there's probably greater awareness amongst the people that I see, who are presenting frequently to hospitals than possibly within the medical fraternity. [Participant 5]

Participants observed that there were efforts to raise awareness of VAD, particularly when the law commenced operation. Participants acknowledged community visits by the VAD Board and others (eg SWCNS) with the goal of raising awareness. While such efforts have been praised, participants identified scope to do more, including ongoing public education. Previous research has identified the need for broad scale community education to raise awareness of VAD, particularly because widespread awareness of VAD does not exist given its recent introduction into the Australian health care system:[24]

> There was a lot of community awareness … leading up to the commencement of voluntary assisted dying, and when we look back at it now some of it's not really that good … [the] websites and so on … maybe one of the things out of this Review is to say, "Let's go out there and educate the public again, because it's now three years … and it's time for a boost I think". [Participant 23]

Participants also identified that while VAD resources are available, finding them often depended on the patient (or their loved ones) knowing VAD existed which, as discussed above, was not always the case. The fact that VAD was seldom mentioned in end-of-life resources more broadly was believed to contribute to this lack of awareness:

> In terms of community awareness, another issue that I certainly struggle with and have heard from our patients on a number of occasions, is that there's no information about VAD available in other end-of-life care documents. Which is really, really challenging. Patients say they go to an appointment, they're sitting in a waiting room, or they have contact with a specialist service or care provider, they get information on absolutely everything, but VAD is not there. If they didn't know that it was available before, they're certainly not going to find any reference to it with[in] all of the other resources. Which is really overwhelming and challenging when you think you're being given everything that's available and there's a clear absence. [Participant 5]

Issue Identified

VAD is still a relatively new end-of-life option. There is a need for broad scale initiatives to help raise public awareness of VAD.

Recommended Responses

A public communication and engagement strategy to increase community awareness of VAD should be developed and implemented. The authors recognise that the Access Standard addresses the issue of "access to information about voluntary assisted dying" and raise for consideration whether the authors' proposed strategy should be formally included within the Standard.[25]

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[24] White, Jeanneret and Willmott, n 20, 2701.

[25] The Access Standard is issued by the CEO of the DoH pursuant to s 156 of the *Voluntary Assisted Dying Act 2019* (WA). The Access Standard sets out the ways in which WA intends to facilitate access to "(a) the services of medical practitioners and other persons who carry out functions under the Act, (b) prescribed substances and (c) information about accessing VAD". It also sets out the series of initiatives dedicated to facilitating regional access. While the Access Standard does include initiatives dedicated

Any awareness-raising initiative introduced should appropriately engage diverse populations including those who may have lower levels of health literacy. Initiatives should also be culturally appropriate and informed by consultation with relevant groups. The strategy, and any associated initiatives, should acknowledge the important role of health practitioners in raising community awareness and the need to improve existing resources. The authors have made a specific recommendation about patient-focused resources later in this Report (see Recommendation 9).

Recommendation 1
Develop and implement a public communication and engagement strategy to increase public awareness of VAD.

2. Health Practitioner Awareness

Regardless of whether a health practitioner is able (or willing) to actively participate in the VAD process, it is important that they have some understanding of the VAD system given it is now an end-of-life option for eligible Western Australians. This level of understanding is important because the *WA VAD Act* prescribes a series of obligations, and sets out a series of offences, which are relevant to all health practitioners regardless of whether they are accredited VAD practitioners. Patients also depend on health practitioners for accessing health information. Hence, it is important that health practitioners have sufficient knowledge of VAD so they can pass on appropriate information to patients and raise it as a potential end-of-life option with them where appropriate (and when they are comfortable doing so).

Participants' Submissions and Evidence

Participants reported that awareness of VAD among health professions was generally poor, with many health practitioners either unaware that VAD is a lawful end-of-life option or knew very little about the process other than that it was lawful.[26] This lack of understanding, particularly among the medical profession, meant health practitioners were unaware of their legal obligations under the *WA VAD Act*, particularly in response to the first request process (discussed later in Part IIIB2):

> I think of concern is still the lack of awareness amongst some of the medical fraternity in particular. Who some of them still don't even know it's law, let alone what their obligations are. We've certainly had patients and families raise it with doctors. [Participant 5]

Another common area of uncertainty among health practitioners related to whether they were able to raise VAD or engage in conversations about VAD with patients:

> I've just had two cases in the last week where the consultants have said, "It's just such a shame that we couldn't raise this with the patient". Then I've said, "Well actually you can, that our legislation allows for that" … There's a lot of stuff that, even in people who are happy to refer their patients, they're not aware of what they can and can't say sometimes, which is a challenge … especially considering that it's going to be three years in July since the legislation was enacted. [Participant 7]

Participants acknowledged that there had been efforts to educate health professions including through community forums, webinars and resources produced by the DoH, the VAD Board (eg Quality Practice Series) and by various workplaces.[27] While participants identified that there are a range of VAD resources available, there was a sense that there was a lack of buy-in or that the resources were not necessarily well-targeted or apt for health practitioners who were unaware of the process:

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to facilitating access to information VAD, it does not include provision for broad scale community awareness. See DoH, *Voluntary Assisted Dying Act 2019 Access Standard* (Government of Western Australia, 2020) 2 <https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/Access-Standard.pdf> (*Access Standard*).

[26] For similar findings see J Rutherford, "Doctors and the Voluntary. Assisted Dying Act 2017 (Vic): Knowledge and General Perspectives" (2020) 27 *Journal of Law and Medicine* 952; White, Jeanneret and Willmott, n 20, 2700.

[27] See, eg, DoH, *Voluntary Assisted Dying* (Government of Western Australia) <https://www.health.wa.gov.au/Articles/U_Z/Voluntary-assisted-dying>. For the WA VAD Board's Quality Practice Series, see WA VAD Board, *Practitioner Quality Practice Series* <https://www.health.wa.gov.au/Articles/U_Z/Voluntary-Assisted-Dying-Board>.

> There are all these little bits of good quality information out there, but we don't know what's mandatory, how often it's accessed, who is actually using it and if it's having the intended effect that we would like it to have. [Participant 18]

Participants expressed support for bite-sized information and shorter education modules. Additionally, participants identified the value of one-on-one training and mentorship for some of the more clinical aspects of the process:

> I think given the length of time that the training takes, I'm fairly OK with people having shorter and more accessible general resources available to any practitioner, like around modules etc. and then people can go … "this is an area of interest to me, and I'm going to go and commit the 8 hours or whatever it is to do the training". [Participant 19]

> The Community of Practice is looking at trying to offer some more formalised mentorship … I certainly don't think … that the training to become credentialed needs to be changed because I do think it's a separate element. I think if you added too much more, it's already quite overwhelming. I think we're talking about that practical side … The idea of that watch one, do one, teach one. [Participant 11]

Participants also supported greater integration of VAD within existing medical curriculum including at a tertiary level (whether as part of the core curriculum or as a guest lecture) or in speciality training. The need for VAD to be covered in other health professions' curriculum such as nursing and pharmacy was also identified:

> I think we can make some inroads there whether that be targeted education sessions through colleges … Similarly to that as well, other jurisdictions are moving into education in the undergraduate degree for the medical space. But equally that should probably be a key theme for other applicable disciplines as well. Whether that [just] be [a] brief mention of what [the] roles and responsibilities are. [Participant 10]

Significantly, participants noted that the development of resources or provision of information alone was unlikely to raise awareness. Multiple participants identified a need for an overarching strategy which set out various actions and supported ongoing education and reinforcement, and engagement with appropriate channels to ensure that it was filtering down to the workforce:

> [T]here's a lot of education things that are out there, but the biggest thing [I] found in my experience in promotion and prevention was the repetition. [Education] had to be part of our core business and it always had to be repeated. [Participant 21]

Issues Identified

Many health practitioners currently have insufficient knowledge about VAD. Education of health practitioners is needed to promote compliance with legal and system requirements, and to help support access to VAD by ensuring patients are provided with correct information about VAD, where relevant.

Recommended Responses

The authors support the development of a strategy encompassing a range of initiatives that will help build health practitioner awareness of VAD and their obligations. Such initiatives should include consideration of how existing resources can be improved and identify gaps for additional resources. An example given by participants was a short online education module available to all practitioners.[28] Training initiatives should be appropriate for their target audience, acknowledging that different health practitioners will have varying levels of involvement in the VAD process due to the nature of their profession, qualifications and beliefs about VAD. Providing further opportunities for mentoring and in-person training might also be considered. Given the important role of health practitioners in responding to patient enquiries about VAD, the DoH may wish to consider including commitments to improve health practitioners' knowledge in the Access Standard.

[28] In Queensland, such a form of training exists (education module for healthcare workers) see Queensland Health, *Voluntary Assisted Dying* <https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/voluntary-assisted-dying>.

Recommendation 2
Develop and implement a strategy to increase health practitioners' awareness of VAD and their obligations.

B. Accessing and Navigating the VAD System

The number of people accessing VAD in WA has exceeded initial estimates.[29] There is also evidence that a diverse cohort of people across a range of cultural backgrounds and various levels of education have been able to access VAD in WA.[30] The Access Standard (and the initiatives it provides for) and other strategies have been implemented to provide access to this choice, particularly with respect to regional access.[31] Despite this, a number of barriers were found to affect the ability of a person to access VAD such as the limits on raising VAD, the current first request process, individual conscientious objection, institutional objection, telehealth restrictions and current patient-focused resources. These barriers can affect the ability of a person to connect to the VAD system and navigate the system once they are connected to it.

1. Limits on Raising VAD

Section 10 of the *WA VAD Act* permits medical and nurse practitioners to initiate a discussion about or suggest VAD to a patient provided, at the same time, the practitioner informs the patient about other treatment and palliative care options, and the likely outcomes of such care and treatment.[32] Any other health care worker (registered health practitioner or person who provides health or professional care services to the patient)[33] is prohibited from raising (or suggesting) VAD, although they can engage in a discussion or provide information about VAD at the patient's request.[34] Restricting a health care worker's ability to discuss VAD with patients has the potential to create access barriers.[35]

Participants' Submissions and Evidence

Participants considered that the ability of medical (and nurse) practitioners to raise VAD with patients played a significant role in building awareness and facilitating access. The WA approach is preferable to that taken in some other States (Victoria and South Australia) where health practitioners are prohibited from raising VAD with the patient, which has been found to create access challenges.[36]

However, the WA law governing how medical and nurse practitioners may discuss VAD has still been identified as problematic. One issue is that treating VAD differently from other end-of-life choices can constrain open discussions about these decisions and give rise to possible stigma.[37] Another concern stems from the complexity of the law. Section 10 of the *WA VAD Act* creates a blanket prohibition on all health care workers initiating a discussion about VAD or suggesting it, and then creates the above exception for medical and nurse practitioners provided certain information is given to the patient. The complexity

[29] S Blackwell, "Voluntary Assisted Dying in WA: The People's Choice" (2022) 62(1) *Medicus* 32; Haining, Willmott and White, n 1, 732–733; *WA VADB 2021-2022 Report*, n 12.

[30] *WA VADB 2021-2022 Report*, n 12, 18–19; *WA VADB 2022-2023 Report*, n 12, 24–25.

[31] See *Access Standard*, n 25. For further discussion of the Access Standard see Haining, Willmott and White, n 1; CM Haining, L Willmott and BP White, "Accessing Voluntary Assisted Dying in Regional Western Australia: Early Reflections from Key Stakeholders" (2023) 23(4) *Rural and Remote Health* 8024; L Willmott, CM Haining, BP White, "Facilitating Regional and Remote Access to Voluntary Assisted Dying in Western Australia: Targeted Initiatives During the Law-Making and Implementation Stages of Reform" (2023) 23(1) *Rural and Remote Health* 7522.

[32] *Voluntary Assisted Dying Act 2019* (WA) s 10(2)–(3).

[33] *Voluntary Assisted Dying Act 2019* (WA) s 10(1).

[34] *Voluntary Assisted Dying Act 2019* (WA) ss 10(2),(4).

[35] See n 23.

[36] *Voluntary Assisted Dying Act 2017* (Vic) s 8; *Voluntary Assisted Dying Act 2021* (SA) s 12. See also Haining, Willmott and White, n 1, 733–734.

[37] White, Jeanneret and Willmott, n 20, 2702.

of the current law, and limitations imposed on some health practitioners, has led to uncertainty about the extent to which health practitioners can lawfully engage in VAD conversations.[38] This has meant that some health practitioners have found it difficult to navigate VAD conversations in practice and, in some cases, has made them more anxious to engage in end-of-life discussions more broadly.[39]

Participants also considered that the prohibitions placed on other health care workers were unnecessarily restrictive and created access barriers. This is particularly so because patients often spend little time with medical and nurse practitioners compared to other care providers such as nurses (who are not nurse practitioners) and social workers. Participants expressed a desire to permit other care providers to raise VAD where appropriate:[40]

> Doctors generally spend the smallest amount of time of all health professionals with a patient. Being wholly and solely sometimes dependent on a single provider to know what VAD is. To know that they're able to talk about it and then to feel comfortable raising it with a patient is a very small, very tiny window, considering the amount of time that senior nursing staff spend with patients, that social work spend with patients and sometimes that power imbalance that patients have with doctors about being comfortable raising it. There's a whole lot of factors there that impact an ability for a person to understand their options and also to have a frank and honest conversation about it to explore them. [Participant 3]

Identified Issues

There is uncertainty and confusion within the health professions about whether VAD can be raised with patients, by whom, and subject to what limits. This means that some medical and nurse practitioners do not feel able to raise VAD, despite it being lawful to do so. Section 10 of the *WA VAD Act* also prohibits other health care workers from raising VAD which further adversely affects the ability of patients to know about VAD.

Recommended Responses

Allowing medical and nurse practitioners to raise VAD with patients is preferable to the position in some other States. However, s 10 of the *WA VAD Act* remains problematic. The authors consider the optimal approach to addressing this would be to amend the legislation to remove s 10. This would result in health practitioners being able to discuss VAD in the same way as all other end-of-life choices. Removing complexity in this aspect of the law and the resulting confusion for health practitioners will promote optimal conversations at the end of life.

A further benefit of removing s 10 is that it removes the distinction between medical and nurse practitioners and other health care workers. Participants identified that a range of health care workers, such as nurses and social workers, can be an appropriate source of information about VAD for patients, so it is important that they can have frank and open conversations about all available end-of-life options. Removing s 10 would not affect existing duties that health practitioners have in relation to informed consent, and the professional obligation to provide patients with all the necessary information they need to make informed decisions. Removing this section would also not affect duties health practitioners have to act within their scope of practice. Health practitioners should only raise VAD where this is appropriate and within their scope of practice and, if this occurs, they would also need to provide information about the spectrum of end-of-life options relevant to a patient, including palliative care.

Additional non-legislative strategies will help address the issues identified. Education of medical and nurse practitioners would support them to know that they can raise VAD with patients provided they do so in accordance with the law (which requires them to also raise other treatment and care options).

[38] Such findings are consistent with previous reports see Haining, Willmott and White, n 1, 734.

[39] Previous research found that the current restrictions on raising VAD in WA has meant that some health practitioners (eg nurses) have expressed concerns about engaging in end-of-life discussions in case VAD is raised see Haining, Willmott and White, n 1, 734.

[40] The desire to permit other health care workers to raise VAD with patients in WA has been reported elsewhere see Haining, Willmott and White, n 1, 734; F Carberry, "When Psychologists are Unable to Discuss Voluntary Assisted Dying, Patients Suffer", *Croakey*, 14 June 2023 <https://www.croakey.org/when-psychologists-are-unable-to-discuss-voluntary-assisted-dying-patients-suffer/>.

A useful tool may be the recently developed "Guiding Principles for Health Professionals" which suggest that "when the law permits this, health professionals *should* inform people about VAD if this could be an option for them".[41] The creation of other resources such as conversation guides to help health practitioners navigate these conversations should also be considered.[42]

Health care workers who are not able to raise VAD with patients should also be made aware of lawful strategies to ensure their patients are aware of VAD where appropriate. This may include encouraging patients to ask their medical or nurse practitioner to discuss all end-of-life options with them or, where applicable, speaking with medical or nurse practitioners responsible for the patient's care to indicate that raising VAD with a particular patient may be appropriate.

Recommendation 3

Consider appropriate legislative and policy changes and education strategies to ensure health care workers can best navigate conversations about VAD, including raising VAD (where appropriate and permissible) with patients.

2. First Request

Under the *WA VAD Act*, to begin the VAD process, a person must make a first request for VAD to a medical practitioner.[43] The request must be clear and unambiguous, and made during a medical consultation.[44] Merely seeking information or expressing curiosity about VAD is not considered to be a first request.[45] When a patient makes a first request to a medical practitioner, the medical practitioner must accept or refuse the patient's first request within two business days (or immediately in the case of conscientious objection).[46] A medical practitioner can refuse a patient's first request if they have a conscientious objection to VAD or is otherwise unwilling or unable (eg due to availability or inability to act as a coordinating practitioner).[47] A medical practitioner who may be eligible to be a coordinating practitioner but has not yet completed the training, may accept a first request. However, they cannot proceed to a first assessment until the training is completed.[48]

The medical practitioner is required to record the first request in the patient's medical record and whether it has been accepted or refused.[49] At that time, the medical practitioner must provide the patient with information approved by the CEO (Approved Information).[50] The practitioner must also notify the VAD Board of the request within two business days, via the completion of the First Request Form which is

[41] See *Guiding Principles for Health Professionals – Voluntary Assisted Dying in Advance Care Planning Conversations*: Australian Centre for Health Law Research and Advance Care Planning Australia, *Navigating the Topic of Voluntary Assisted Dying in Advance Care Planning Conversations* (2024) <https://www.advancecareplanning.org.au/about-us/available-support-materials> (emphasis added).

[42] For an example of conversation guides see Queensland Health, *Conversation Guides for GPs: Voluntary Assisted Dying* (Queensland Government, 2023) <https://www.health.qld.gov.au/__data/assets/pdf_file/0034/1195675/Conversation-guide-on-voluntary-assisted-dying-for-GPs.pdf>.

[43] *Voluntary Assisted Dying Act 2019* (WA) s 18.

[44] *Voluntary Assisted Dying Act 2019* (WA) s 18(2).

[45] DoH, Voluntary Assisted Dying Guidelines (Western Australian Government, 2021) 29 <https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-guidelines.pdf> (*WA VAD Guidelines*).

[46] *Voluntary Assisted Dying Act 2019* (WA) ss 20(4)–(5).

[47] *Voluntary Assisted Dying Act 2019* (WA) s 20(2).

[48] *WA VAD Guidelines*, n 45, 30.

[49] *Voluntary Assisted Dying Act 2019* (WA) s 21.

[50] DoH, *Information about Voluntary Assisted Dying (VAD)* (Western Australian Government, 2024) <https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/Approved-information-booklet.pdf>; *Voluntary Assisted Dying Act* (WA) ss 20(4)–(5).

submitted to the VAD Board Secretariat through the VAD-IMS (or fax).[51] Recording a first request serves the purpose of notifying the VAD Board of the outcome of a patient's first request. It does not generate a referral or pass on the patient's details to a VAD practitioner or the SWCNS.

Participants' Submissions and Evidence

Issues with the first request process and connecting with the system were observed across all participant groups and have been identified previously including by the WA VAD Board in its Annual Report.[52] Indeed, the WA VAD Board noted that the first request process was an area that should be considered as part of this Review.[53]

Participants noted that many non-VAD practitioners were unaware of how the process worked and/or the nature of their obligations when they receive a first request from a patient. The current terminology used and the nature of the first request process was a significant source of confusion. Indeed, participants reported that many medical practitioners did not understand the difference between a first request and a request for information, and in the case of the former, that they are required to log the request on the VAD-IMS and provide the patient with the Approved Information. Similarly, participants noted that some medical practitioners were unaware that they had to both log a first request and provide a patient with the Approved Information regardless of whether they were a VAD practitioner (and registered with the VAD-IMS) and in a position to accept the first request:

> People struggle with … the first request. This is very confusing for clinicians because there's the first request which most of them have to decline … I have clinicians saying to me, "I don't need to log that with VAD-IMS because I'm not able to accept a first request. So, as far as I'm concerned, I've given them the information and passed that on". There's still that even though [they] are meant to log that as a first request. A lot of the time they'll say, "Well no, I just referred them for a discussion about the process. So, I haven't had anything to do with the first request". [Participant 7]

Moreover, even in cases where medical practitioners were aware of their obligation to log a first request on the system, participants reported that there was confusion among medical practitioners about how to do so. Participants reported that some medical practitioners were uncertain about the function of a first request and that it served merely as a notification to the VAD Board and did not generate a referral (eg to a VAD practitioner or the SWCNS):

> It's not rocket science but apparently it is. Likewise, it's the language, it's the process. It's people can't understand that nothing is happening when, [they] had to go through a whole rigmarole to fill out the form and figure out how to upload it. And doctors have called me like, "But I can't get into VAD-IMS … it won't let me register to VAD-IMS". You don't have to register, you just upload it … but doctors can't get that either. [Participant 6]

The lack of referral and connection with the system upon lodging a first request was criticised by some participants. The current system meant that patients would be waiting for someone to contact them as they incorrectly believed they had already started the process by making the first request. Some participants conceded that part of the issue was that practitioners were not necessarily passing on the details of the SWCNS (via the Approved Information) or making it clear to patients what their options were when their first request was refused. In some cases, this was the result of the medical practitioner being unaware of the process themselves. This in turn often led to delays in being connected with the system, which sometimes had adverse consequences for patients. Indeed, some participants reported that there have been cases where patients have deteriorated rapidly while waiting to be assessed. When this occurred, some participants reported greater pressure to progress the patient through the process to avoid them missing out on VAD. This pressure placed additional stress on both the family and health practitioners involved:

> [Patients often think] that they've already started the process and you have to explain actually, "No, nothing's happened yet. Now we start". And the frustration that they feel. Sometimes in that two months

[51] *Voluntary Assisted Dying Act 2019* (WA) s 22; *WA VAD Guidelines*, n 45, 30.

[52] *WA VADB 2022-2023 Report*, n 12, 55.

[53] *WA VADB 2022-2023 Report*, n 12, 55.

> they've deteriorated quite significantly and then it's the pressure on them and their family and it all starts. [Participant 4]

Participants also identified broader issues in relation to terminology. When a practitioner is unable to fulfil a role under the Act because they are not a VAD practitioner or do not have the capacity to take on the patient, they are required to "refuse" a first request. However, participants indicated that the term "refuse" in relation to the first request was "loaded". It was particularly challenging for some practitioners, for example, who had a long-standing therapeutic relationship with the patient, and did not want to be seen to be abandoning them during a vulnerable time because they were "refusing" their request:

> The word "refuse" as well … which goes back to that referral question … that patients of practitioners who are refusing aren't necessarily saying, "No I don't want anything to do with this". They are actually just saying, "I'm not able to" … So, the word "refusal" is a bit loaded for some of them. [Participant 20]

Participants also reported that there were cases where a non-VAD practitioner would "accept" the patient's first request under the misconception that in doing so they were showing support for the patient's choice and/or indicating their potential eligibility, not realising that the process would not proceed unless they were acting as the patient's coordinating practitioner:

> We often hear with acceptors "No, I am accepting that my patient should be able to access that"
>
> … "Well, that's great, but this request is about you accepting the role of being their coordinating practitioner". [Participant 21]

The ability of non-qualified VAD practitioners to accept a first request was perceived to complicate the process. The policy justification for allowing a non-qualified practitioner to "accept" a request was to accommodate "trigger" or "catalyst" patients (ie patients requesting VAD who would trigger the practitioner's participation in VAD).[54] However, in practice, trigger patients were thought to be rare. Indeed, practitioners were advised against accepting first requests without completing the training due to the time it takes to do the training and do the necessary referral checks:[55]

> So it could be that [X is] my patient, I've seen her … I've known her for 20 years and she … makes a first request to me and I say, "Yes, I'm going to accept this because I'm going to go on and become your coordinating practitioner, haven't done the training yet [X], so it'll be a bit of a gap"… So, the process for winding up someone and doing the training and doing referee checks and doing all the rest of it, as much as there is intention of streamlining that … there are necessary steps that have to happen and the time that it takes to do that is well longer than the time that it takes for the average person to move through the system. [Participant 19]

Participants observed that it was difficult to measure the extent to which patient access was affected by the first request problems. Awareness that problems exist are only known through patient accounts, and these come from individuals who were then able to connect with the system. Little was known about patients who made a first request, but nothing further occurred:

> I think because we do have cases of people who tell us that they've [made attempts] – [but these are] people who eventually find a way. So, because of those people and they tell us that they were told that they weren't eligible and nothing was done, and [the Board] didn't receive a notification of a first request we know that that's happening. But we don't know how many [people this is] happening [to] that don't then find a way, that's our problem. [Participant 23]

Part of the rationale for the current first request process was to assist with the Board's monitoring function. But many participants observed that this policy goal was not being realised because not all first requests were being lodged, and hence there are significant data gaps:

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[54] Such patients typically include those who may tick all of the boxes for eligibility, long-standing patients or patients who are so adamant in their request that they serve to crystallise a practitioner's involvement in VAD. See Rutherford, Willmott and White, n 23, 1074.

[55] Such sentiments are reflected in guidance issued by the DoH. See DoH, *Voluntary Assisted Dying First Request* (Government of Western Australia, 2024) <https://www.health.wa.gov.au/voluntaryassisteddyingfirstrequest>.

> We know that the system isn't working perfectly. Maybe … we didn't come up with a very good system to start with. But what we have in place [is] not doing everything we wanted it to do, or it should do … the whole thing maybe needs rethinking. [Participant 22]

Some participants criticised the first request lodgement requirement on policy, rather than practical, grounds. They noted that having a designated notification process seemed to undermine attempts to normalise VAD and integrate it within end-of-life care as other options do not have notification requirements:

> How much value is the recording of a first request if it doesn't go any further … the Board often talk about the normalisation of this as a medical procedure. And I'm not sure there's anything else that happens in medicine that requires a form to be deposited somewhere to say, "I've had a request but I'm not doing anything". It just doesn't make any sense to me. [Participant 24]

Participants noted that problems with the first request process had been previously identified, and attempts had been made to remedy confusion. For example, participants referred to efforts by the WA VAD Board to educate on this issue and that the Secretariat had modified its practices so that once a practitioner lodges a first request, the Secretariat would notify the practitioner that the lodgement of the first request was for notification purposes only, and the Secretariat would not be making any further contact with the patient. However, it was suggested that such initiatives have been largely ineffective:

> Even though I know the Board have been trying really hard with supporting emails and sending them things, people just don't understand that nothing happens automatically. They don't get it, can't get it and I don't know what the magic fix for that is. [Participant 3]

Despite such challenges, some participants still favoured retaining the notification obligation associated with the first request but identified a need for further steps to improve the current approach. Strategies identified included introducing a referral system and further educative efforts:

> I think a change to capture the referral form process has always been my biggest ticket item … complete all of these details, submit your form to the Board. Would you like to refer your patient to the Care Navigator? … No obligation to do it but an option … There [are also] many different points of education. So … for me it would be one of those things that there is not just one golden solution that will fix everything, it's little pieces altogether that would contribute towards that. [Participant 21]

Issues Identified

Requiring medical practitioners to lodge first requests is an important data source for the VAD Board. If accurately reported, such information will notify the Board of when patients begin the VAD process and will facilitate collection of information about the participation of practitioners in VAD in WA.[56] This in turn can assist the VAD Board's understanding of the demand for the service, the extent to which practitioners are refusing first requests, and information about the length of a patient's VAD journey. However, evidence suggests that the first request process is currently poorly understood, and medical practitioners are not always complying with their obligations. Accordingly, the desired information from the first request process is not being captured in practice.

This also has downstream effects. As patients (and their loved ones) are commonly not given the Approved Information, nor receive clarification about the first request process, they often mistakenly believe they have commenced the process or have been connected with the system, when this is not the case. This has led to delays and, in some cases, patients have deteriorated to a point where they are no longer eligible for VAD.

Recommended Responses

Although there were differences in participants' views about the utility and workability of the first request process, on balance, the authors consider it should be retained. However, to achieve its intended objectives, the current difficulties with how the first request process is operating in practice should be addressed. A multifaceted approach is required. Specific training and education about medical practitioners' obligations on receiving a first request are needed. This should address issues such as

[56] Explanatory Memorandum, *Voluntary Assisted Dying Bill 2019* (WA) cl 21.

the nature of a first request, legal reporting duties, obligations to provide information to the patient and terminology. This training and education should be directed at the medical profession as a whole given this knowledge needs to penetrate beyond existing VAD providers.

The authors also recommend that revisions to the existing system design should be implemented to support effective connections of the patient to the system after a first request has been made. This could include an optional referral to the SWCNS, whereby the practitioner receiving the first request asks whether the patient is willing for their contact details to be passed onto the SWCNS. Consideration should also be given to whether legislative change might be needed to facilitate this, in addition to any changes to consent policies and processes to enable this to occur.

Recommendation 4

Through training and education, improve medical practitioner awareness of the first request process and how to respond appropriately.

Recommendation 5

Improve system design so that a patient who makes a first request is connected with the VAD system.

3. Individual Conscientious Objection

The *WA VAD Act* offers protections to individual health practitioners who have a conscientious objection to VAD. It permits them to refuse to participate in the request and assessment process; prescribe, supply or administer the VAD substance; and be present at the time of administration of the VAD substance.[57] However, as discussed above, medical practitioners who refuse a first request are required to notify the patient of their refusal and provide them with the Approved Information immediately.[58] Similarly, if medical practitioners receive a referral for a consulting assessment from a VAD coordinating practitioner, they must refuse the referral and notify the coordinating practitioner and the patient of their refusal immediately.[59] Professional obligations in relation to conscientious objection are set out in relevant health professions' codes of conducts,[60] and various guidance documents developed by the DoH, which indicate that those claiming a conscientious objection must not "unduly delay a patient's access to VAD"[61] or "inhibit a person's access to [VAD]".[62]

The need to respect all persons' culture, religion, beliefs, values and personal characteristics is one of the guiding principles of the *WA VAD Act*.[63] While it is widely recognised that some form of protection of conscientious objection is important, in the absence of obligations or systems to facilitate patient access, or in the event of non-compliance with such obligations, patients' access to VAD can be unduly and inappropriately compromised.

[57] *Voluntary Assisted Dying Act 2019* (WA) s 9(1).

[58] *Voluntary Assisted Dying Act 2019* (WA) s 20(5).

[59] *Voluntary Assisted Dying Act 2019* (WA) s 31(5).

[60] See, eg, Medical Board of Australia, *Good Medical Practice: A Code of Conduct for Doctors in Australia* (Australian Health Practitioner Regulatory Agency, 2020) s 3.4 <https://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>; Nursing and Midwifery Board of Australia, *Code of Conduct for Nurses* (Australian Health Practitioner Regulatory Agency, 2018) s 4.4 <https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines- Statements.aspx>; Pharmaceutical Society of Australia, *Code of Ethics for Pharmacists* (2017) care principle 2 <https://www.psa.org.au/practice-support-industry/ethics/>.

[61] *WA VAD Guidelines*, n 45, 31, 45.

[62] DoH, *Providing Voluntary Assisted Dying in Western Australia: Health Professional Participation* (Western Australian Government, 2022) 3 <https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/Health-Professional-Participation.pdf>.

[63] *Voluntary Assisted Dying Act 2019* (WA) s 4(1)(k).

Participants' Submissions and Evidence

Conscientious objection and health practitioners' willingness to participate in aspects of the VAD process exists across a spectrum.[64] Some participants identified cases where conscientious objectors to VAD still supported their patients. Indeed, participants described cases where health practitioners with a conscientious objection were directly referring their patients to VAD providers (despite having no legal obligation to do so). In some cases, conscientious objectors were still willing to offer forms of moral support to their patients notwithstanding their decision to access VAD:

> [Our] GP, was very supportive, but he didn't like the idea of [VAD because of his] religious faith … but he didn't allow that to influence [the patient]. He just said to [the patient] … "There could be other ways" … "We won't let you be in pain", all of that sort of thing … [The GP] gave us the [SWCNS] number to ring. And we were in very close contact with him. As I said, although he's not a personal friend, he was visiting on weekends just because he liked [the patient], he liked talking about all sorts of things with him and it always came up in discussion. [Participant 34]

Participants across multiple stakeholder groups identified instances where conscientious objectors were obstructing access (overtly or covertly).[65] The absence of requirements on conscientious objectors to provide information about VAD (except for when a patient makes a first request) and/or refer them on to another colleague without a conscientious objection or health service that provides VAD has potential to impact access.[66] While the absence of such obligations could affect access, the mere presence of obligations does not guarantee compliance. Indeed, participants observed that the legal and professional obligations that are already in place (described above) were not always being complied with in practice. Indeed, participants observed that some conscientious objectors were shutting conversations down and failing to provide the Approved Information (when required), which made it difficult for patients to connect with the system:

> We then went to Mum's doctor, and her doctor refused to talk to her about it because of his religion and his beliefs. He didn't give her … and I only found out afterwards … that doctors were supposed to give them information. Mum wasn't given anything. [Participant 8]

Participants also observed cases where conscientious objectors exhibited varying levels of hostility towards patients for choosing VAD. This manifested variously including withdrawing forms of care, attempting to persuade people out of pursuing VAD, displaying unsupportive attitudes and making negative comments:

> [Some doctors are] ferociously backing away from the patient and saying, "I no longer care for them if they want to explore this". [Participant 3]
>
> One of the palliative care nurses … [who was] a conscientious objector to VAD, came in rudely and abruptly to doublecheck. And [the patient] informed her very clearly that [he], "Absolutely [wanted to access VAD, why] won't you listen to me?" … so that put her in her place and off she went, but yeah, she had a bad attitude. [Participant 35]
>
> After a fall, he did have a head scan [that] showed that there was a bit of a bleed. And the doctor kind of said flippantly, "If you're going down VAD, there's no point really doing any treatment, like why don't you just stop the Warfarin?" I don't think the doctor understood that we don't actually want him to die from a brain bleed … like he wants to go on his own terms … I think just because the oncologist specialises in chemotherapy, and once that chemotherapy was withdrawn, he kind of washed his hands of the care. [Participant 2][67]

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[64] CM Haining and LA Keogh, "'I Haven't Had to Bare My Soul, But Now I Kind of Have To': Describing How Voluntary Assisted Dying Conscientious Objectors Anticipated Approaching Conversations with Patients in Victoria, Australia" (2021) 22 *BMC Medical Ethics* 149; Rutherford, Willmott and White, n 23, 1073.

[65] The impacts of individual conscientious objection have been observed elsewhere see Rutherford, Willmott and White, n 23, 1068–1069.

[66] I Kerridge et al, "Conscientious Objection and Institutional Objection to Voluntary Assistance in Dying: An Ethico-Legal Critique" (2023) 30 JLM 806; R McDougall and B Pratt, "Too Much Safety? Safeguards and Equal Access in the Context of Voluntary Assisted Dying Legislation" (2020) 21 *BMC Medical Ethics* 21; Rutherford, n 26; Rutherford, Willmott and White, n 23, 1072–1073.

[67] Warfarin = Medication used to prevent blood clots.

Participants also reported challenges with some non-participating medical practitioners commenting on a patient's prospective eligibility. In some cases, this resulted in delays to access, particularly if the practitioner suggested that the patient was unlikely to meet the eligibility criteria (eg because they were unlikely to die within the required timeframe). Participants noted that while, in some cases, this may have been done with good intentions (eg to manage expectations), there were cases when participants perceived that conscientious objectors intended to subvert the process and steer people away from VAD:

> Often, I will meet patients or family … who've been told by a non-VAD participating practitioner that they're not eligible … Sometimes that's valid, but obviously not the law. Sometimes it's just not valid … [and] whether it is or isn't intended, [it] has a knock-on effect of delaying the process and delaying a person's access to assessment. [Participant 5]

Participants also reported cases where medical practitioners refused to provide, or delayed, access to clinical information. While VAD practitioners are sometimes able to make VAD assessments without seeking additional clinical information, this is not always possible. Access to clinical information is important in cases where the practitioner does not have a pre-existing therapeutic relationship with the patient (which is often the case in practice), is not familiar with the patient's disease, in complex cases where specialist input is needed, or in cases where the patient's medical records are not up-to-date or are incomplete. While in some instances, participants suggested that delays accessing information were for administrative reasons and not intentional, participants also identified cases where practitioners would refuse to provide clinical information on the basis that it would be used to inform a VAD assessment. This was particularly challenging in regional settings due to the dearth of available specialists:

> Access to clinical information full stop. We know that there are providers who no matter who asks them, they will not provide medical information in relation to their patient. [Participant 3]

This unwillingness to provide clinical information was also reported as particularly difficult in complex clinical cases (eg when the patient had a rare disease or an unclear prognosis). In such cases, VAD practitioners could be left in a vulnerable position if they found a patient to be eligible without accessing such information. Participants reported that, over time, there has been an increasing number of instances where medical practitioners, unsupportive of VAD, would not provide clinical information (despite discussions about patient trajectory being customary in multidisciplinary teams in the health service setting), but then seek to challenge eligibility assessments made by VAD practitioners on the basis that such assessments were made in the absence of necessary clinical information:

> [If the VAD practitioner] know[s] the person's treating specialist or the organisation that they work for is not supportive of VAD, it leaves that doctor very vulnerable if they find them to be eligible, when the specialist knows they haven't given them anything … when the specialist is clear in the fact that they don't support VAD. We have certainly had people indicate that a patient's prognosis is unlikely to be within the window. Often with very strong language around that, [and] practitioners don't feel comfortable making an alternative finding. [Participant 3]

Participants observed that some of the issues with conscientious objection related to the lack of recourse available to patients, and perceived lack of consequences for the conscientious objector in cases of non-compliance:

> I think there's a lot of comments that get made to patients in those settings that are totally inappropriate but have no recourse. If your [community-based] nurse tells you that you shouldn't be doing VAD because that's not where you are, what do you do about that? You just pretend you didn't hear it. [Participant 6]

Some participants supported greater enforcement of sanctions, while others supported a softer educative approach to achieve a cultural shift:

> So, there are soft tricks that you can do. Like when I tell my GPs that I'm going to be possibly doing this, I send them a card in the mail, not an email from a hospital… But we could, as these quiet, gentle, sneaky death doctors, transform and make people be more [acceptive of VAD] … and not beat them with the stick … [and] threaten them with legal stuff. [Participant 32]

Participants also noted that, in practice, conscientious objection was not only being claimed by health practitioners but also by administrative and executive staff, which had downstream effects:

> [Conscientious objection is also there] in terms of people … within health settings that may not have any direct interface with voluntary assisted dying … they're not a practitioner and they were not receiving requests. [Participant 19]

Issues Identified

The authors support legislative protection of individuals who conscientiously object to participating in the VAD process. However, the above evidence suggests that the conduct of some conscientious objectors has resulted in barriers to reasonable and timely patient access to VAD. There is also evidence that some conscientious objectors, upon hearing of the patient's desire to access VAD, have engaged in conduct that may be deemed as unprofessional when interacting with patients (and their loved ones) as well as members of the VAD workforce. These behaviours range from attempts to actively dissuade people from seeking VAD, withdrawal of other forms of care, to hostile encounters.

Recommended Responses

While conscientious objectors should not be expected to directly participate in the assessment, dispensing and administration aspects of the VAD process, conscientious objectors should not interfere with the ability of other health practitioners to do so. A conscientious objector should also not deprive a patient or another health practitioner of information that is necessary for the patient to access VAD.

To address these concerns, the authors make two recommendations. First, when a patient asks a medical practitioner for information about VAD, the authors believe that medical practitioners should provide such information to the patient. This information already exists in the form of Approved Information discussed above. This duty currently exists in relation to first requests made to medical practitioners, so this recommendation proposes a limited extension to that existing duty. This helps ensure that patients asking about VAD will be connected with the system.

The second recommendation is that medical practitioners should also be obliged to provide to other medical practitioners, on their request (and with the patient's consent), relevant clinical information to facilitate VAD eligibility assessments. The transmission of clinical information about a patient is a reasonable requirement to ensure a patient's eligibility for VAD can be assessed accurately and in a timely manner.

The optimal response to address both issues is to make minor amendments to the *WA VAD Act* to impose obligations on medical practitioners to:

- provide Approved Information about VAD if the patient seeks such information (not just in cases of a first request); and
- provide clinical information about the patient or access to the patient's medical records, as soon as practicable, upon receiving a request by a medical practitioner assessing a patient's eligibility for VAD (and with the patient's consent).

However, there are also a range of other strategies to address these issues, one of which is to draw on existing ethical duties. As mentioned above, medical practitioners are currently required by their medical codes of conduct not to impede or delay patient access to a service because that service conflicts with their own conscience. Education about how these and other ethical duties apply in the context of VAD is likely to assist in addressing these issues. Such education should also include the emerging evidence (as outlined above) of the harm caused to patients when their access to VAD is hindered. Given medical practitioners' commitment to patient-centred care, deeper understanding of these harms should assist in shifting practice.

Guidance by the DoH in relation to conscientious objection (discussed above) should be strengthened so, in addition to reminding health practitioners of their obligations not to impede access, health practitioners are actively encouraged to provide general information about VAD to patients who request it. In addition, DoH should develop additional standardised resources providing general information about the VAD process which could be made available to patients (eg in waiting rooms via a short pamphlet or an information card with the contact details of the SWCNS as used in other jurisdictions). DoH guidance

should also encourage health practitioners to provide relevant clinical information about the patient to medical practitioners for the purpose of a VAD eligibility assessment.

Recommendation 6

Develop strategies to ensure medical practitioners provide Approved Information about VAD to a patient who asks for information about VAD (and not just in cases of a first request).

Recommendation 7

Develop strategies to ensure medical practitioners provide, as soon as practicable, clinical information about the patient or access to the patient's medical records (with the patient's consent) to a medical practitioner assessing their eligibility for VAD.

4. Institutional Objection

The *WA VAD Act* is silent on the participation of institutions (such as health services, hospices, aged care facilities and community nursing organisations) in VAD. The WA VAD Guidelines acknowledge that entities may have different levels of participation in VAD due to the organisation's views on VAD or other reasons (eg resourcing).[68] The Guidelines stipulate that entities should ensure that their staff are aware of the *WA VAD Act* (and their obligations under it), the VAD process itself, VAD statewide services, and have access to information that will support them to respond to a patient who raises VAD. In the case of WA health system entities, the *Managing Voluntary Assisted Dying Policy*[69] requires them to have local policies and procedures in place to manage VAD processes. Outside of this, however, no further obligations are placed on entities to facilitate access to VAD. This is different in South Australia, Queensland, New South Wales and the Australian Capital Territory where their legislation imposes certain obligations on objecting institutions.[70]

Participants' Submissions and Evidence

There have been multiple reports of institutional objection to VAD in WA.[71] Objection to VAD has occurred in health services, hospices, aged care and community care settings. Institutions have varied with respect to their level of support for VAD as well as the nature of the limitations they place on VAD activities that are permissible on site.

Unsurprisingly, participants reported that some institutions prevented institutional staff from being involved in the VAD process. However, many also reported restrictions on the ability of external health practitioners to visit patients or residents in these institutions to provide VAD services. Some commented that this prohibition on participation also extended to information provision or counselling. In the view

[68] *WA VAD Guidelines*, n 45, 12.

[69] DoH, *Managing Voluntary Assisted Dying Policy (MP 0154/21)* (Government of Western Australia, 2021) <https://www.health.wa.gov.au/~/media/Corp/Policy-Frameworks/Clinical-Governance-Safety-and-Quality/Managing-Voluntary-Assisted-Dying-Policy/managing-voluntary-assisted-dying-policy.pdf> (*Managing VAD Policy*). WA health system entities include Health Service Providers established under s 32(1)(b) of the *Health Services Act 2016* (WA) and the DoH as an administrative division of the State of WA pursuant to section 35 of the *Public Sector Management Act 1994* (WA). Contracted health entities are not considered WA health system entities.

[70] See *Voluntary Assisted Dying Act 2021* (Qld) Pt 6 Div 2; *Voluntary Assisted Dying Act 2021* (SA) Pt 2; *Voluntary Assisted Dying Act 2022* (NSW) Pt 5; *Voluntary Assisted Dying Act 2024* (ACT) Pt 7. See also K Waller et al, "Voluntary Assisted Dying in Australia: A Comparative And Critical Analysis of State Laws" (2023) 46(4) *UNSW Law Journal* 1421, 1455–1462.

[71] See, eg, Haining, Willmott and White, n 1, 737–738; *WA VADB 2022-2023 Report*, n 12, 53; G Adshead, "Perth Man's Battle to Die with Dignity Despite Being Approved Under Voluntary Assisted Dying Laws" (6PR Perth, 3 September 2021) <https://omny.fm/shows/6pr-mornings/perth-mans-battle-to-die-withdignity-despite-bein>; A Brennan, "Concerns Raised About Access to Voluntary Assisted Dying in Western Australia", *NCA NewsWire*, 29 November 2023 <https://www.news.com.au/lifestyle/health/concerns-raised-about-access-to-voluntary-assisted-dying-in-western-australia/news-story/9c3e61e5b1c06b52f0ea6242e89e1079>; J Dietsch, "Voluntary Assisted Dying Board Chair Scott Blackwell Says Some Hospitals Blocking Access to Procedure", *The West Australian*, 29 November 2023 <https://thewest.com.au/news/health/voluntary-assisted-dying-board-chair-scottblackwell-says-religious-hospitals-blocking-access-to-procedure-c-12563909>.

of one participant, institutional objection had a greater potential to affect VAD access than an individual conscientious objector:

> [The conscientious objector] was a horrible nuisance, but it was mainly the total hospital's policy statement that worried me more because that was just a solid brick wall. [Participant 35]

Participants observed that institutional objection can create significant barriers to access and worsen family caregivers' grief in some cases.[72] Participants described that institutional objection often meant patients needed to be transported or transferred out of the institution for aspects of the process. In some cases, institutional objection necessitated workarounds, requiring aspects of the VAD process to occur behind closed doors within the objecting institution, in gardens, carparks and local schools. However, in cases where the family could not afford a taxi to move to a new facility or the patient's condition deteriorated significantly, transfers and workarounds were not possible. These patients were denied the ability to access VAD and would be required to pursue care and treatment options they perceived to be less favourable:

> I was very concerned about moving [the patient] … he was really immobile, which was why there was no way he could ever come home. I was really concerned as to how I was going to get him off the hospital grounds and I said that to [the VAD Statewide Care Navigator] … even though his mind is [good] … he's not physically. The ambulance transfer financially … would have been about $1,100 to get him there and back and we had to do that four times. That would have been the only way … [t]hat really wasn't financially an option for us to do that. [Participant 35]

In addition to the logistical challenges, participants reported that due to an institutional objection (or opposition within a particular health service unit), patients who raised VAD were often met with hostility or had their conversations concerning VAD shut down. This was reported to disrupt continuity of care and damage therapeutic relationships:

> I am almost in tears just remembering all the cases, all the people that have suffered at the hands of [Religious Institution X]. And it's not good … it is terrible … I've had patients, one particular woman with a terrible fungating cancer … in a terrible state. She tried to raise VAD when she was an inpatient … and just got short-shift and was so scared of raising it again with anyone … it all came out how awful they were to her because she'd raised that. I've had other patients also who have gone into [particular institutions] with symptom control have come out again, come and seen me … and [told] me just the most awful [things] – they're just cut off and shut up, shut off. [Participant 28]

Participants were also critical about the fact that institutions were not transparent about their degree of participation in the VAD process. Some institutions provided no (or minimal) insight into the degree to which VAD activities were permitted onsite. It was reported that some institutions would adopt a broader faith-based position and not provide detail about how this had been operationalised in the institution. There was even a suggestion that some institutions were still yet to form a position on VAD.

One participant criticised an institution's position statement that suggested it was supportive of VAD on the basis that such support was not reflected in practice, citing examples of the institution's staff exhibiting hostility towards patients wishing to access VAD and withdrawing other forms of care:

> I accept at the end of the day [religious health services are] not authorised to help in any way, shape or form, but they should still nevertheless be pleasant to the patient … [T]hey shouldn't withdraw any of their normal palliative services to the patient. They shouldn't in any way penalise the patient just because they are aware that person is seeking VAD. The Code of Conduct reads absolutely stunningly beautifully, for an institution that's actually totally opposed to VAD. Unfortunately, [it] doesn't always happen on the ground like that. [Participant 13]

Participants observed that the lack of transparency by some institutions had made it difficult for patients to make informed choices about their care options prior to admission.[73] Consultation undertaken by

[72] The impact of institutional objection has been discussed elsewhere see, eg, Haining, Willmott and White, n 1, 737–738; White et al, n 23, 212–214; BP White et al, "The Impact on Patients of Objections by Institutions to Assisted Dying: A Qualitative Study of Family Caregivers' Perceptions" (2023) 24 *BMC Medical Ethics* 22; White, Jeanneret and Willmott, n 20, 2702.

[73] Such sentiments have been reported elsewhere see E Close et al, "Institutional Objection to Voluntary Assisted Dying in Victoria, Australia: An Analysis of Publicly Available Policies" (2023) 20(3) *Journal of Bioethical Inquiry* 467, 478; White et al, n 72, 4–5,11; *WA VADB 2022-2023 Report*, n 12, 53.

the statewide services in the early stages of the regime provided an indication of the limitations of some institutions. However, information about the level of participation of institutions was not publicly available or easily ascertained, given institutions were not always transparent about the extent to which they permitted VAD activities on site (if at all). Participants suggested that there had been efforts made by advocacy organisations to try and map out institutions and their position on VAD in WA, but the lack of input by institutions to inform this map has presented difficulties:[74]

> It is a serious problem, I think. And the fact that the Statewide Care Navigator Service won't publish a list of the institutions that are not VAD friendly, if I can put it like that, also makes it very difficult for people to make a decision about where they want to go if they have to move to an institution. That should be public information on everybody's website, and freely available as part of the package that goes to GPs' offices. [Participant 15]

Participants also reflected that there was currently limited scope for recourse. One option noted was for patients to complain to the institution itself. However, such recourse was considered suboptimal as not everyone would feel comfortable to do so or know how to make a complaint. Participants also suggested that some families thought that complaining about an institution once their loved one had died was futile. Others felt a complaint would be ineffective to change the institution's stance on VAD. Nevertheless, participants cited examples where families had gone to media (or threatened to do so), which resulted in some success. They also gave other examples of cases that were escalated with no success:

> Despite one of my patient's relatives escalating a complaint through all the appropriate channels … nothing's been done about it and it's disgusting, and ultimately should be changed. [Participant 33]

> Because when the CEO made it clear that they had world's best practice in palliative care and wouldn't interfere with a patient coming in and out, there was no point. If the head honcho said that a doctor's not going to visit, well, there was no point in having any further consultation or requests. [Participant 35]

Participants noted that patients often had limited choices when it came to institutions, because many facilities were faith-based and not supportive of VAD. This left patients who were unable to access VAD within the community with limited options:

> Accommodation is something that comes up for us all the time. "I want to die. I can't die at home". Getting access to a bed in a public hospital is a nightmare. Most of our hospices are faith-based. Where can I go and how can I access it? [Participant 3]

Some participants expressed frustration that publicly funded institutions were able to opt out of delivering a lawful medical service. Many participants considered reform of how institutional participation is currently regulated necessary. When expressing such views, participants often referred to legislative models in other Australian States as preferable to WA's current regulatory approach. In particular, the Queensland model was favoured among participants. Many participants expressed a desire for greater transparency from institutions about what VAD activities would be permitted onsite, and a requirement for institutions to allow access to VAD (acknowledging that its own staff would not be required to participate in the process):

> My view is if you get Government funding, you implement the Government policy and you implement the Government legislation …. That's the simple thing for me is that you – yes, they're going to use religious whatever, I get that. But I don't know, it doesn't sit well with me that they get funding to deliver a service, but they're not prepared to deliver this service. So, I think the Government has an opportunity to put it into their contracts. [Participant 25]

> Institutional conscientious objection … it's a big one. It's easily addressed in a way, noting that I think it's South Australia, Queensland and New South Wales that have included in their legislation quite comprehensive provisions detailing what are the obligations of particularly of aged care facilities that are not hospitals … [S]ome or a combination of those types of provisions should be adopted and added to our Act … the Queensland provisions may be the best. [Participant 14]

[74] Efforts to map out levels of participation of aged care facilities in VAD has been done in Victoria. See Dying with Dignity Victoria, *VAD and Aged Care Facilities* <https://www.dwdv.org.au/our-services/vad-and-aged-care-facilities/>.

Issues Identified

Participants identified institutional objection as a significant access barrier to VAD and the cause of suboptimal care and experiences for patients and their loved ones. These views accord with Australian evidence about the harms of institutional objection, in settings where institutional objection is regulated by policy alone.[75] They are also consistent with views of the WA VAD Board.[76] WA's current policy approach to regulating institutions has not been effective in addressing these concerns.

Recommended Responses

A new approach to regulating institutional objection is needed in WA. The *WA VAD Act* should be amended to impose obligations on institutions to facilitate better patient access to VAD. The stronger force that is associated with legislative mandate rather than policy direction is needed to shift institutional behaviour on this issue.[77] Having legal obligations imposed on an institution, as opposed to guidance in a non-binding Government policy, can assist an individual to advocate for their choice and, to an extent, address power and resource imbalances between large institutions and terminally ill individuals. The force of law may also be needed to direct institutions with deeply-held views including those stemming from religious faith, to act in particular ways.[78]

A legislative model should balance competing interests and aim to ensure that patients who want VAD can have access to VAD, but not require institutions or their staff to directly participate in VAD. Similar to the views of some participants, the authors favour a modified Queensland approach. To provide some context, under Queensland legislation, entities[79] (and their staff) are not obliged to actively participate in the VAD request, assessment or administration process. However, obligations are placed on entities to facilitate access, at least to some extent. These obligations vary depending on whether the facility is residential or non-residential (and in cases of residential facilities whether the person is a permanent or non-permanent resident). All entities must disclose publicly if they do not provide VAD services.[80] They must also allow relevant health practitioners to visit residents who request information about VAD and permit them (with eligible witnesses) to make VAD requests (including first, second and final requests).[81] In the case of residential settings (including aged care facilities and nursing homes), if the person is a permanent resident, the facility must allow access to relevant health practitioners onsite so eligibility assessments (including referral of determinations) and the administration decision can take place, or facilitate transfer if a practitioner is unable to attend.[82] Administration of the VAD substance must also be permitted onsite.[83] In cases of non-permanent residents, the facility must facilitate a transfer to a place where VAD assessments, the administration decision and administration can take place.[84] If transfer is not reasonable, then the facility must allow relevant health practitioners to come on site to carry out such activities.[85] Obligations in relation to non-residential facilities (eg public and private hospitals and hospices) mirror the obligations placed on residential facilities with respect to non-permanent residents.

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[75] BP White et al, "Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia" (2021) 3 *UNSW Law Journal Forum* 1 <https://www.unswlawjournal.unsw.edu.au/wp-content/uploads/2021/05/2021-3-White-et-al.pdf>; Haining, Willmott and White, n 1, 737–738; White et al, n 72; White et al, n 23, 212–213.

[76] *WA VADB 2022-2023 Report*, n 12, 53.

[77] White et al, n 75; Close et al, n 73, 480.

[78] Close et al, n 73, 480; White et al, n 75.

[79] Entities are defined as entities other than an individual that provides a relevant service (including health service, residential aged care service and personal care service) see *Voluntary Assisted Dying Act 2021* (Qld) ss 87–88.

[80] *Voluntary Assisted Dying Act 2021* (Qld) s 98.

[81] *Voluntary Assisted Dying Act 2021* (Qld) ss 90, 92, 93.

[82] *Voluntary Assisted Dying Act 2021* (Qld) ss 94(2), 95(2), 96(2).

[83] *Voluntary Assisted Dying Act 2021* (Qld) s 97(2).

[84] *Voluntary Assisted Dying Act 2021* (Qld) ss 94(3), 95(3), 96(3), 97(3).

[85] *Voluntary Assisted Dying Act 2021* (Qld) ss 94(4), 95(4), 96(4), 97(4). When assessing reasonableness consideration is given to whether transfer will cause serious harm to the person or transfer would likely adversely affect the person's access to VAD.

The authors are of the view that the Queensland provisions that govern the ability of a permanent resident to access VAD in an objecting institution should apply across the board to all individuals seeking VAD, regardless of the nature of the institution or whether the person seeking VAD is a permanent resident. In other words, WA should amend its legislation to require all institutions to follow the position in Queensland for permanent residents. Such an approach better balances the competing interests of a person seeking VAD and the right of an institution and its staff not to provide VAD services.

Non-legislative approaches to address institutional objection should also be vigorously pursued and the authors note that some of these initiatives are capable of prompt implementation. For example, the current *Managing Voluntary Assisted Dying Policy*[86] which applies to WA health system entities should be amended to introduce more prescriptive requirements such as requiring a VAD service to be provided on the premises. In relation to non-WA health system entities, engagement by the DoH or the WA VAD Board is needed to consult (or further consult) with such entities about their approach to managing VAD. All entities should be made aware of evidence of significant harm that institutional objection causes, and be requested to review and, if necessary, amend local policies to address such harm. Consideration should also be given to developing a publicly available guide that outlines which entities provide VAD services or allow them to be provided on their premises. This would enable patients to make informed decisions about their care. Finally, efforts to manage institutional objection and facilitate access to VAD should be included in the Access Standard.[87]

Recommendation 8

Impose obligations on all entities providing health, aged, residential and other care to facilitate access to VAD.

5. Telehealth

The Commonwealth Criminal Code makes it an offence to use a "carriage service" (such as telephone, videoconference, email or other forms of electronic transmission) to distribute material that counsels or incites committing or attempting to commit suicide.[88] A Federal Court decision handed down in November 2023 found that the term "suicide" can extend to VAD.[89] In practice, this means that certain aspects of the VAD process cannot be carried out via electronic communication such as telehealth and/or email.

The *WA VAD Act* permits certain aspects of the VAD process to be carried out using audiovisual communication, provided such communication is not contrary or inconsistent with Commonwealth law.[90] The WA VAD Guidelines provide guidance regarding which VAD activities may occur via audio-visual communication.[91] The Guidelines state that:

> As a general rule, any information that relates specifically to the act of administering a voluntary assisted dying substance or provides details or instructions about the act of administering a voluntary assisted dying substance must not be discussed or shared by phone, fax, email, videoconference, internet and the like.[92]

Concerns about the barriers that the Commonwealth Criminal Code creates in relation to VAD provision have been raised by the WA VAD Board with the Minister for Health, Attorney General, and Chief

[86] *Managing VAD Policy*, n 69.

[87] The Access Standard does not currently account for institutional objection in any detail other than to "encourag[e] health providers and health services to be ready to receive enquires for information from people and their families and be able to respond in a patient-centred manner" see *Access Standard*, n 25, 2.

[88] *Criminal Code Act 1995* (Cth) ss 474.29A, 474.29B.

[89] *Carr v Attorney-General* (Cth) (2023) 300 FCR 562; [2023] FCA 1500, [74].

[90] *Voluntary Assisted Dying Act 2019* (WA) s 158.

[91] *WA VAD Guidelines*, n 45, 26–27.

[92] *WA VAD Guidelines*, n 45, 8, 26.

Executive Officer of the DoH.[93] In 2024, Kate Chaney MP introduced a Bill into Federal Parliament to amend the Commonwealth Criminal Code to remove lawful VAD activity from the definition of suicide. If passed, this amendment would remove potential liability arising from VAD services being provided via telehealth.[94]

Participants' Submissions and Evidence

Participants expressed frustration about the impact of the Commonwealth Criminal Code on the practice of VAD, particularly in relation to regional patients.[95] Participants were also aware that only the Commonwealth Parliament could amend the Commonwealth Criminal Code and supported the lobbying efforts for legislative change by those within the WA system and Government.

However, some participants suggested that there was scope for the DoH to provide more clarity in their Guidelines about which VAD activities are permitted:

> Telehealth is outside the control of the state. But what is within the state's control is how they word the Guidelines to doctors to work around Telehealth … I just think that the Department needs to do a much better job in its Guidelines of helping explain to doctors how to work their way around the system. [Participant 13]

Issues Identified

It is clear from participants' views as well as other evidence that the Commonwealth Criminal Code creates unjustifiable challenges for access to VAD, particularly for regional patients.

Recommended Responses

The authors (along with other colleagues) have previously called for the Commonwealth law to be amended.[96]The authors support and recommend ongoing efforts by the WA Government and those in the VAD system to advocate for this change at a federal level.

6. Patient-Focused Resources

As discussed in Part IIIA1, access to information about VAD is necessary for awareness-raising. However, given the complexity of the VAD process, access to detailed information is also critical for patients to connect with the system and then navigate the various aspects of the VAD process.[97] Such information is particularly important for patients who are unable to access VAD through their usual treating doctor or from within their treating facility. Information and resources need to be readily available when sought and accessible to WA's diverse population.

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[93] *WA VADB 2021-2022 Report*, n 12, 37.

[94] *Criminal Code Amendment (Telecommunications Offences for Suicide Related Material—Exception for Lawful Voluntary Assisted Dying) Bill 2024* (Cth).

[95] For commentary about the Commonwealth Criminal Code, including its harms, see, eg, E Close et al, "Voluntary Assisted Dying and Telehealth: Commonwealth Carriage Service Laws Are Putting Clinicians at Risk" (2021) 215(9) *Medical Journal of Australia* 406; K Del Villar et al, "Voluntary Assisted Dying and the Legality of Using a Telephone or Internet Service: The Impact of Commonwealth 'Carriage Service' Offences" (2022) 47(1) *Monash Law Review* 125; K Del Villar et al, "Voluntary Assisted Dying By Practitioner Administration Is Not Suicide: A Way Past the Commonwealth Criminal Code?" (2022) 29(1) *Journal of Law and Medicine* 129; K Furness et al, "The Commonwealth Criminal Code Restricts the Use of Carriage Services to Access Voluntary Assisted Dying in Victoria: A Perspective" (2022) 47(1) *Australian Health Review* 64; Haining, Willmott and White, n 31; Haining, Willmott and White, n 1, 738–739; RSW Lugg, "Voluntary Assisted Dying and Telehealth: Commonwealth Carriage Service Laws are Putting Clinicians at Risk" (2022) 216(4) *Medical Journal of Australia* 210.

[96] Close et al, n 95; Del Villar et al, "Voluntary Assisted Dying and the Legality of Using a Telephone or Internet Service: The Impact of Commonwealth 'Carriage Service' Offences", n 95; Del Villar et al, "Voluntary Assisted Dying by Practitioner Administration is Not Suicide: A Way Past the Commonwealth Criminal Code?", n 95.

[97] White, Jeanneret and Willmott, n 20.

Participants' Submissions and Evidence

Participants acknowledged that there were a wide range of VAD resources available, many of which were developed by the DoH.[98] However, participants were of the view that resources were difficult to locate. Indeed, participants perceived that sometimes relevant information was buried within copious online resources and was couched in language that was not easily understood. Participants speculated that many documents developed by the DoH were framed to manage potential legal risk and this resulted in documents that were unnecessarily detailed and hard to understand by those needing the information:

> The resources that we have available significantly impact on people being able to understand what VAD is and how to access it. All of the documents the Department of Health provide are incredibly challenging to read and understand for people, particularly from different cultural backgrounds where English is not their first language, where they're not particularly health literate. Even the public facing website you have to know to click on an accordion to see the list of about a bazillion information sheets. All of which you're just clicking and hoping you land on the right one in most cases. Even [VAD staff] that use them every day often are like, "I don't know which one to give them. There's too much stuff". None of them really target the information that we hear from patients they actually want. Like what does this actually mean for me and my person? How do I help support them? How do I help plan for what this could look like? Where can I take the substance? What happens after I die? … The information isn't accessible. It's only available audibly or in the written fact sheet. There's no infographic that's useful or videos. [Participant 3]

Participants had mixed views about the utility of the Approved Information that is required to be provided to a patient who makes a first request.[99] Some participants commented that the Approved Information document was useful and assisted patients connect with the system by providing details of the SWCNS. Although some thought that the document could be more succinct, participants felt that it effectively distilled the key steps of the process. This document, together with the guidance provided by VAD staff (eg VAD practitioner, SWCNS, SWPS and VAD Coordinator), helped patients to navigate the system:

> They did have a document – I think at that time your head is in such a place that you just need something really simple. You know pages and pages of information are probably not very useful – well I didn't find. But [the document] laid out what the steps are … [the] checklist was really helpful so that we knew what was coming next. And also being told what was coming up by the people that were helping you navigate that process. [Participant 9]

Despite some positive feedback about the Approved Information document, participants noted that its utility relied on patients receiving it. As noted earlier, participants expressed concern that medical practitioners were not always providing it to patients, despite their legal obligation to do so. Participants also considered the document was difficult to locate through usual online searches:

> I just found the Approved Information, and of course the first thing on page 1 is the phone number for the Care Navigators and [their] email. [It would be helpful if] that was made significantly more easily searchable … I mean you can find this if you know where to search on the DoH website, but it does take multiple clicks along some very unfriendly looking links … [you need a] button like, "Are you interested in information on assisted dying? Click here". Bang, done – searchable by everyone, including patients and GPs. [Participant 33]

Participants offered several concrete suggestions to improve current resources. In addition to simplifying the content, participants suggested that resources should be available online and widely available in print form (eg within health services):

> [There is a need for] clarity of information … If there was a one page document, rather than a 16 page document. And if it had, "The Care Navigator's phone number is dot, dot, dot. If you're in hospital, ask to see a VAD Coordinator. This is what VAD is". And just really, really short and to the point I think would be really helpful. Because I go to that website to find a Navigator's phone number quite often and I struggle to find it. I know it's there, but it should be front, centre and right at the top. [Participant 6]

[98] For information about VAD specifically directed at the community see DoH, *End of Life Care* (Government of Western Australia) <https://www.healthywa.wa.gov.au/Articles/A_E/End-of-life-care>.

[99] Such sentiments reflect previous findings see Haining, Willmott and White, n 1, 737.

> The information brochures [medical practitioners are] supposed to hand [to] patients who make enquiries about VAD … the Department has to make sure that those brochures are replenished so that there are always a few of them available in any practice. [Participant 13]

Issues Identified

Access to accurate and accessible information about the VAD process is critical for empowering patients (and their loved ones) to access and navigate the VAD process. The evidence suggests that, in their current form, patient-focused resources are not adequately achieving these objectives.

Recommended Responses

The authors recommend that existing resources be reviewed and revised to improve accessibility of content. Steps should also be taken to improve availability of resources. Consideration should be given to

- ensuring resources are:
  - available in a variety of formats;
  - culturally appropriate (informed by consultation with the communities they are intended for);
  - suitable for varying levels of health literacy;
- improving search engine optimisation and mapping of websites so online resources are easily locatable; and
- ensuring that print resources are widely available across various care settings (e.g. hospitals, GP clinics).

While there are a series of commitments to facilitate access to information about VAD within the current Access Standard, revision may be helpful to highlight the need for resources to be appropriately tailored to suit a wide range of audiences. Consideration may also be given to include commitments within the Access Standard with respect to the dissemination of such information (beyond the current position of having the SWCNS as the point of contact for information).[100]

Recommendation 9

Review and revise the content, format and accessibility of consumer VAD resources.

C. Eligibility Assessments

Participants who participated in interviews and focus groups for the purpose of this Review were aware (and reminded at the beginning of the interview or focus group) of the Panel's terms of reference and that the Panel was not seeking views on eligibility criteria. However, in order to provide insight into the operation and effectiveness of the Act, participants were asked to provide general views on the eligibility assessment stages of the VAD process, and challenges they identified in practice. This section provides an overview of these reflections, as well as participants' views about the existing eligibility criteria.

Participants' Submissions and Evidence

1. General Reflections

Some participants expressed concerns about the inflexible framing of the eligibility criteria. Reference was made by some to legislation in some other States that allowed applications for exemption if the person did not satisfy the eligibility criteria relating to the person's medical condition (Tasmania)[101]

[100] For current commitments to facilitate access to information about VAD see *Access Standard*, n 25, 2.

[101] Section 6(3) of the *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) permits the VAD Commission (similar body to the WA VAD Board), on application of the person, to provide an exemption if they do not have a disease, illness, injury or medical condition that is expected to cause death within six months, or 12 months if neurodegenerative.

or citizenship or residence (Queensland,[102] New South Wales[103] and Australian Capital Territory[104]):

> Tasmania has an exemption process, and I would love an exemption option because I think that's probably what our legislation doesn't have. [Participant 6]

Another challenge participants noted was in relation to managing changes in eligibility once a person was assessed as being eligible for VAD. This typically arose when patients subsequently lost decision-making capacity or, less frequently, when they were no longer expected to die within the prognosis window. These situations were especially concerning for practitioners if the patient was already in possession of the VAD substance.[105] The lack of guidance regarding what should be done in such cases was reported to be a source of distress for VAD practitioners, loved ones of the patient and others involved in the patient's care (eg hospital treating team and community nursing staff):

> [In relation to] management of change in eligibility … I think our practitioners are very, very vulnerable in that space. Because there is nothing in our Act that speaks to assessment of changing eligibility or how that could be managed. So, it's up to the individual provider to make their own determination about what they do, which is really, really difficult. [Participant 3]

Participants also identified that there was some confusion in relation to the reporting obligations placed on VAD practitioners when seeking input from others to determine eligibility and the referral for determination process. The *WA VAD Act* requires VAD practitioners to make a referral for determination when they are unable to determine a patient's decision-making capacity, prognosis, or whether they are acting voluntarily and without coercion.[106] The referral must be made to an individual with the appropriate skills and training to make that determination.[107] The requisite forms which the coordinating and consulting practitioners need to fill out (ie First Assessment Report Form and Consulting Assessment Report Form respectively) require the practitioners to document whether a referral for determination was made when assessing the patient's eligibility. In practice, the ways in which VAD practitioners were seeking information from other medical practitioners varied, ranging from proactively seeking specialist information to help inform eligibility to cases where specialist input was sought due to uncertainty. Participants reported that medical practitioners had a poor understanding of what constituted a referral for determination under the *WA VAD Act* and what needed to be documented. Some participants surmised that this poor understanding of this process meant that, in some cases, VAD practitioners were not documenting specialist input which would constitute a formal referral for determination because they mistakenly believed that it was not such a referral:

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[102] In Queensland, a person may apply to the chief executive for an exemption for Australian residency and local residency requirements. The chief executive must grant an exemption if satisfied that the person has a substantial connection to Queensland and there are compassionate grounds for granting an exemption: *Voluntary Assisted Dying Act 2021* (Qld) s 12.

[103] In New South Wales, a person can apply for an exemption in relation to the requirement to be ordinarily resident in New South Wales for 12 months. The New South Wales VAD Board must provide an exemption if satisfied that the person has a substantial connection to New South Wales and if there are compassionate grounds: *Voluntary Assisted Dying Act 2022* (NSW) s 17.

[104] In the Australian Capital Territory (ACT), when the Act comes into force, the director-general must grant an individual an exemption from the eligibility requirement that requires an individual to have lived in the ACT for the previous 12 months if the individual is found to have had a substantial connection to ACT. See *Voluntary Assisted Dying Act 2024* (ACT) s 11(1)(f), 154.

[105] Similar concerns have been raised in Tasmania where the legislation is silent: Tasmanian Voluntary Assisted Dying Commission, *Report on the End-of-Life Choices (Voluntary Assisted Dying) Act 2021's Operation in Its First Six Months* (2023) 21 <https://www.health.tas.gov.au/sites/default/files/2023-09/Voluntary-Assisted-Dying-Six-Month-Report-of-Operations-June-2023.pdf>; Tasmanian Voluntary Assisted Dying Commission, *Voluntary Assisted Dying Commission Annual Report 2022-2023* (2023) 28 <https://www.health.tas.gov.au/sites/default/files/2023-11/voluntary_assisted_dying_commission_annual_report_2022-23.pdf>.

[106] *Voluntary Assisted Dying Act 2019* (WA) ss 26, 37.

[107] *Voluntary Assisted Dying Act 2019* (WA) ss 26, 37. In cases of a referral for prognosis and decision-making capacity the referral must be to a registered health practitioner. In cases of a referral for determination for the purposes of assessing voluntariness, this may be made to any person with the appropriate skills and training and including, for example, social workers and police officers. See *WA VAD Guidelines*, n 45, 42.

> I know that there's some different ways that the processes work in terms of practitioners gathering information in order to have a background on a patient and undertake a first assessment, which they will then come to a decision on versus practitioners who will undertake a first assessment, and then go out and seek a referral to another practitioner for a determination in relation to criteria
>
> … I say this just because we don't have specialists involved in the process … but we are aware that practitioners are seeking specialist opinions around prognosis … I think that's happening more than we are aware in the sense that not all of that's being documented as a referral for determination. [Participant 19]

2. Reflections on Specific Eligibility Criterion

Prognosis

Under the *WA VAD Act*, a person is required to have a disease, illness or medical condition that will, on the balance of probabilities, cause death within six months or 12 months if neurodegenerative.[108] Participants raised several issues relating to assessing prognosis.

Difficulty of Prognostication

First, participants observed the difficulty of prognostication, particularly for patients who do not have a clear disease trajectory. Participants noted that prognostication was very much an art not a science, and it can be hard to do with any level of certainty.[109] Participants identified prognostication was challenging for conditions such as chronic obstructive pulmonary disease and neurodegenerative diseases. Challenges in prognostication were compounded for conditions where it was difficult to find a specialist (due to prevalence of conscientious objection among some specialities or due to appointment availability):

> Prognosis is a … nightmare to determine … particularly with patients with neurodegenerative conditions that don't have a clear trajectory. The practitioners struggle with it, particularly when they're not specialists in the area. [Participant 3]

Time Period Too Short

Participants identified that the presence of a time-based prognosis requirement of six or 12 months (in the case of neurodegenerative diseases) created challenges in practice.[110] Uncertainties in relation to prognosis, or prognoses that were outside the prescribed window, often meant that patients needed to sustain further suffering for an arbitrary period of time, which seemed to undermine the guiding principles of the Act.

Some participants also observed that, in many cases, patients would experience anticipatory forms of suffering for the later stages of their disease, and by the time they reached that level of undesired deterioration they would be ineligible for VAD. It was noted that the ability of patients to be able to access VAD in a timely manner, before their health significantly deteriorated would provide them with great comfort and would mean they could enjoy the final weeks of life, rather than enduring further stress through the assessment process:

> I think sometimes it leaves the patient feeling that they have to wait to get to a point in their health that they're trying to avoid in accessing VAD. They have to wait till they're that severely deteriorated in a

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[108] *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(ii).

[109] Challenges with prognosticating for the purposes of a VAD assessment have been observed elsewhere. For instance, in the WA VAD Board's Quality Practice Series the difficulties with existing clinical tools such as SPICT (Supportive and Palliative Care Indicators Tool) and Gold Standard's Framework PIG (Proactive Identification Guidance) were noted. Such tools have been developed to identify people who would benefit from end-of-life care planning, rather than provide a specific timeframe to death: WA VAD Board, *Quality Practice Series #5* (Western Australian Government: DoH, 2023) 1 <https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VADBoardQualityPracticeSeries5.pdf> (*Quality Practice Series #5*).

[110] For further observations about difficulties of assessing prognosis for the purposes of a VAD assessment and the current prognostication timeframes see Rutherford, Willmott and White, n 23, 1071; M Sellars et al, "Medical Practitioners' Views and Experiences of Being Involved in Assisted Dying in Victoria, Australia: A Qualitative Interview Study among Participating Doctors" (2021) 292 *Social Science and Medicine* <https://doi.org/10.1016/j.socscimed.2021.114568>.

> position they didn't want to be. Which is really distressing for all of us. We can really see they're unwell, but the prognosis is just not supporting. [Participant 4]

Participants reflected that the ability for patients to access VAD before they severely deteriorated would likely decrease the likelihood of a patient missing out on accessing VAD and could alleviate some of the pressure on clinicians and the SWPS when presented with urgent cases. Having a more permissive prognostication window such as 12 months for all diseases, removing the prognostication window entirely and changing the criterion to something such as foreseeable death, or permitting an exemption were identified by participants as possible solutions.[111]

Variability in Approach

Concerns were also raised about the variability among practitioners with respect to their approach to prognostication. Some participants noted there was a lack of standardisation in terms of how eligibility was assessed among practitioners. For instance, participants observed that there appears to be uncertainty and divergent views among the medical community about whether a patient's decision to stop treatment or nutrition should be accounted for when making a prognosis.[112] The variability of approaches among practitioners was perceived to create a type of lottery in the sense that a patient's ability to access VAD was contingent upon which doctor was assessing them for VAD:

> I have concerns around some of the standardisation across the state. We've started talking about it from a [health service provider] level that we do things very differently. But even just from a practitioner standpoint around prognosis and some of those aspects. That different practitioners have very different understandings of the legislation and the Guidelines, and that actually comes out in the way that they do their work. [Participant 6]

Despite this, some participants indicated that variability in approaches to assessing patients was inevitable in medicine, and overall, there did appear to be concordance between coordinating and consulting assessments. There was also suggestion that this indicated that the eligibility criteria were being applied consistently.

Referrals within a Small Pool of Assessing Practitioners

One participant opined that VAD practitioners, particularly within a health service setting, tended to refer between the same pool of VAD practitioners who tended to think the same way and approached VAD assessments similarly.[113] However, while this could be perceived as a risk, due to the small pool of VAD practitioners, this was also thought to be necessary:

> We tend to refer between one another … That's a good thing in a way because we're all like-minded professionals. But there is a thought that that could be perceived as an element of risk in that we're all like the same sort of person, think about it the same way … always referring patients only between one another … because there's a very small pool of practitioners and because mostly, I practice within a hospital setting. [Participant 33]

Citizenship

Under the *WA VAD Act*, a person accessing VAD must be an Australian citizen or permanent resident. Participants identified two concerns about this eligibility criterion. First, as evidenced by the literature, from a legal and practical perspective there are challenges in determining whether a person is an Australian citizen or permanent resident.[114] Participants echoed the practical challenges associated with a determination and noted the limited guidance to support practitioners on this issue.

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[111] For the purposes of comparison, the ACT's new law will not have a prognosis limit and Queensland's law provides a prognosis limit of 12 months for all diseases. See *Voluntary Assisted Dying Act 2024* (ACT) s 11 and *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(ii).

[112] This scenario was identified by the *Quality Practice Series #5*, n 109, 1.

[113] Concerns about referring between the small pool of VAD providers has previously been raised see Haining, Willmott and White, n 31.

[114] K Del Villar, L Willmott and BP White, "The Exclusion of Long-Term Australian Residents from Access to Voluntary Assisted Dying: A Critique of the 'Permanent Resident' Eligibility Criterion" (2023) 49(2) *Monash Law Review* 1; Willmott et al, n 23, 127.

> Citizenship is incredibly difficult. There's no recourse for people to have a decision reviewed in that space … There's no guidance for the practitioners in that space. They are essentially required to be immigration lawyers in many cases which is incredibly difficult. I never want to know anything else about Special Class Visas. It's a bloody nightmare. There's no support for the practitioners … when they make that determination … We've had doctors write to the Department of Home Affairs trying to clarify things and still none the wiser. [Participant 3]

The second concern was that some individuals who had been living in WA for an extended time could not satisfy this criterion. One participant suggested that the current citizenship requirements raised concerns from an equity point of view, noting that the WA community was very diverse, and some members of the community who were on different Visa categories and had different residential statuses would not satisfy the criterion:

> Not all people have the same access and equity in terms of Visa categories and residential status … because we're a migrant settler society our Visa categories are so complex. We haven't actually dealt with any of those cases, but I wouldn't want those [people] to be ignored because there are people who've been here just as long and are still waiting for Visas or recognition … it's not just the Ten Pound Poms, it's other people as well. [Participant 25]

These sentiments are consistent with those of the WA VAD Board which has previously recommended expanding "access to [VAD] for long-term Australian residents who are not an Australian citizen or permanent resident".[115]

Residency

Under the *WA VAD Act*, a person must be ordinarily resident in WA for at least 12 months to be eligible to make a first request for VAD. Many participants criticised this requirement, and suggested it was somewhat redundant now that every State has legalised VAD. Recognising the mobility of the Australian population, participants observed there would always be cases where individuals would live in other States for certain periods, and that depriving VAD on that basis was unnecessarily limiting:[116]

> Now that VAD is across Australia, or soon will be when the territories come on board … we've got to have consideration around not only the fluidity of the assessments across the states, but also we've had reports where family members who have gone through a process in other states want to come spend their last few days with their family members in WA and vice versa, and it seems to me that we can facilitate that better. [Participant 24]

Participants identified practical difficulties in assessing the residency requirements.[117] However, the recent series of Western Australian State Administrative Tribunal (WASAT) decisions[118] were thought to be positive in terms of giving further guidance to practitioners. Participants spoke favourably of the WASAT, and the fact that VAD cases were being considered by the Tribunal on an urgent basis. However, they also noted that WASAT ultimately had limited jurisdiction which was interpreting the existing criterion of "ordinarily resident". Participants expressed a desire for a more flexible approach and suggested that individuals should be able to be granted a residency exemption (as is available in some other jurisdictions), if there were a sufficient connection to WA.[119] The WA Board has also previously called for "an exemption pathway" in relation to the residency requirements:[120]

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[115] *WA VADB 2022-2023 Report*, n 12, 55.

[116] For critique on residency requirements see, eg, K Del Villar and Amelia Simpson, "Voluntary Assisted Dying for (Some) Residents Only: Have States Infringed S 117 of the *Constitution?*" (2022) 45(3) *Melbourne University Law Review* (advance); Waller, n 70, 1435.

[117] This has previously been observed see Willmott et al, n 23, 127.

[118] *AB and CD* (2024) 112 SR (WA) 281; [2024] WASAT 6; *BMR, MTH and CG and the Co-ordinating Practitioner for MTH* (2024) 114 SR (WA) 257; [2024] WASAT 44; *EF, GH AND IJ and KL* (2024) 113 SR (WA) 324; [2024] WASAT 18; *HM and The Co-ordinating Practitioner for HM* (2024) 113 SR (WA) 314; [2024] WASAT 2.

[119] For comparative purposes see *Voluntary Assisted Dying Act 2021* (Qld) s 12; *Voluntary Assisted Dying Act 2022* (NSW) s 17; *Voluntary Assisted Dying Act 2024* (ACT) ss 11(1)(f), 154.

[120] The WA VADB recommended the *Voluntary Assisted Dying Act 2019* (WA) be amended to "provide an exemption pathway to the ordinary residency requirements for people who have a substantial connection to [WA] or have been found eligible in another Australian jurisdiction". See *WA VADB 2022-2023 Report*, n 12, 55.

> We've had quite a few patients who have got residency and have travelled and moved interstate. And that really has become an issue. I believe other states have put something where at least they have a tribunal where it can be appealed. Whereas we can question the definition, but we can't appeal it. Even if the criteria didn't change but there was some capacity for appeal. [Participant 19]

Disease Expected to Cause Death

Under the *WA VAD Act*, a person is required to have "at least [one] disease, illness, or medical condition".[121] Participants identified that, in practice, the framing of this criterion could create challenges. Cases that were especially challenging for practitioners were patients who did not have a single condition expected to cause death but were frail and had a combination of co-morbidities and were likely to die within the necessary timeframe. Such scenarios were perceived to lead to a degree of uncertainty for doctors and place them at medicolegal risk if they did not document the "right disease" for reporting and documentation purposes. Risk was felt to be greater for medical practitioners working within multidisciplinary settings (such as a health service or aged care facility) who were perceived to be under constant scrutiny:

> We … very often have patients present with an unrecognised diagnosis of frailty in our country. You're pulling all the co-morbidities together. Everybody knows that this person is dying. They're referred to palliative care. Sometimes they're planned to go to a hospice, but they don't have a thing that somebody can pin it on. [Participant 5]

Capacity

Under the *WA VAD Act*, a person is required to have decision-making capacity throughout the process. While assessing capacity was unproblematic in many cases, there were circumstances which proved challenging. For instance, one area of challenge identified was the impact of a Guardianship Order on a capacity assessment.[122] Participants also identified challenges, and expressed a degree of frustration, with respect to cases where a patient may have decision-making capacity at the time of an eligibility assessment, but subsequently lose capacity before completing the process, rendering them no longer eligible for VAD. This could happen for a range of reasons including from medical treatment received to manage pain or other symptoms:

> So, we have had a report where a participant of VAD, his plan was to undertake VAD, but he deteriorated quite rapidly … And then his medical needs were such that he was sedated past the point where he could give consent to his VAD administration … So, for him, his death was prolonged, and that wasn't what his wishes were. [Participant 9]

There was also evidence of patients who were so concerned about the effect of pain-relieving medication on their decision-making capacity (and hence their ability to access VAD), that they opted to scale back opioid analgesic medications.

Many participants across a range of stakeholder groups talked about dementia and the inability of a person to receive VAD on the basis of this condition alone. Some participants have suggested that some form of advanced consent (such as through an advance health directive)[123] could be a potential option. However, there was ambivalence about whether VAD should be extended to dementia patients and, if so, how this would be best regulated.[124] Regardless of the position taken, however, participants suggested

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[121] *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c).

[122] This was a previous area of focus in the Quality Practice Series see WA VAD Board, *Quality Practice Series #7* (Western Australian Government: DoH, 2023) 2 <https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/ VADBoardQualityPracticeSeries5.pdf>.

[123] Under current WA laws VAD cannot be formally consented to via an advance health directive see *Guardianship and Administration Act 1990* (WA) s 3B. This is not to suggest that VAD cannot be discussed during advance care planning see BP White et al, "Implications of Voluntary Assisted Dying for Advance Care Planning" (2024) 220(3) *Medical Journal of Australia* 129.

[124] Mixed views on this issue have also been reported elsewhere see, eg, PA Komesaroff et al, "Should Voluntary Assisted Dying in Victoria be Extended to Encompass People with Dementia?" (2024) 220(9) *Medical Journal of Australia* 452; Sellars et al, n

that this is an issue that cannot be ignored and there is a need for further consideration, discussion and research:

> Dementia is – and the fear of it – is what everyone raises with us all the time … it is the big-ticket item. It's not easily addressed, but we need to engage in that discussion. [Participant 13]

Voluntary and Enduring Request

Under the *WA VAD Act*, to be eligible for VAD a person must be acting voluntarily and without coercion, and the person's request for accessing VAD must be enduring.[125] Participants did not indicate that these two eligibility criteria posed any significant issues in practice. In fact, participants observed that coercion tends to operate the other way, where people (including the patient's loved ones and treating teams) tried to coerce people out of accessing VAD:

> There [were] concerns about coercion towards VAD. We probably see more of that negative coercion. People being either not offered it as an option or being told that they have still plenty of options available. [Participant 11]

One way the enduring nature of the request is tested is through the mandatory waiting period. Ordinarily there must be a nine day period from the first request until the final request, and one day from the consulting assessment until the final request.[126] The intention behind the provision was to ensure that the process is not rushed and to give people enough time to consider all information and contemplate the effect of their decision.[127] The process can be expedited if the patient is likely to die or lose decision-making capacity before the end of the designated period.[128]

Participants reported that the waiting period presented some practical challenges. While understanding that the policy intent behind the waiting period was to ensure that the person's request for VAD was enduring, participants noted that in many cases individuals had been seeking VAD for a long period but, for reasons beyond their control, the first request was only recently made. In such a case, some practitioners regarded the nine day waiting period to be punitive. Some also expressed concern that expediting the period exposed practitioners to some kind of medicolegal risk:

> There needs to be agreement between the two practitioners … about the risk of somebody dying or losing capacity. [This] feels a little bit, or sometimes a lot, punitive in terms of the patient who may have been requesting this for months and not been responded to. We're now saying, "Now that we've heard your request, you still have to wait effectively at least a week and a half when you've already waited two months and you've been asking people all over the place" … I think we're much more experienced by and large, particularly those experienced practitioners, in determining that somebody clearly has an enduring request. We don't need to test that for nine days. [The current process] puts practitioners in a place of medicolegal vulnerability, for them to agree on expediting a process by finding the possibility of something, just to make it happen. [Participant 5]

Issues Identified

Given eligibility criteria for VAD are outside this current Review, the authors did not specifically seek input on this issue in the interviews and focus groups specifically conducted for the purpose of the

110, 4; R Le May, "Roger Cook Flags Expanding Voluntary Assisted Dying Laws to Dementia Patients, Leaves Door Open to Teens", *The West Australian*, 2 August 2023 <https://thewest.com.au/politics/state-politics/roger-cook-flags-expanding-voluntary-assisted-dying-laws-to-dementia-patients-leaves-door-open-to-teens-c-11462717>; BP White et al, "People with Dementia Aren't Currently Eligible for Voluntary Assisted Dying. Should They Be?", *The Conversation*, 21 May 2024 <https://theconversation.com/people-with-dementia-arent-currently-eligible-for-voluntary-assisted-dying-should-they-be-224075>; T Wong-See, "Husband Calls for Voluntary Assisted Dying Access for WA Dementia Patients After Wife's Tragic Death", *ABC Great Southern*, 22 August 2023 <https://www.abc.net.au/news/2023-08-22/calls-for-voluntary-assisted-dying-access-dementia-patients-wa/102755336>; J Zimmerman, "Voluntary Assisted Dying: Mark McGowan Supports Dementia Sufferers Accessing VAD And Larger Telehealth Role", *The West Australian*, 28 February 2023.

[125] *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(e)–(f).

[126] *Voluntary Assisted Dying Act 2019* (WA) s 48.

[127] Explanatory Memorandum, *Voluntary Assisted Dying Bill 2019* (WA) cl 47.

[128] *Voluntary Assisted Dying Act 2019* (WA) s 48(3).

Review. Nevertheless, participants made a range of comments about the appropriateness of the existing eligibility criteria and the lack of mechanism for an individual seeking VAD to apply for an exemption. Participants also raised practical challenges in applying the current eligibility criteria and expressed concerns about the uncertainties surrounding prognostication and the lack of guidance where there was legislative silence (eg in cases where patients had the VAD substance dispensed but then lost decision-making capacity). The current timeframe of six or 12 months until death was repeatedly identified as challenging for practitioners as well as for their patients (eg due to the potential need for patients to endure additional suffering). Participants also identified that the issue of whether VAD should be available to those with dementia was an area that needed further examination.

Recommended Responses

The authors consider there is merit to many of the issues raised by the participants. With respect to the challenges associated with applying current eligibility criteria (eg due to legislative silence or current uncertainties with respect to certain clinical presentations), the DoH or WA VAD Board should consider whether further support or guidance may be beneficial for VAD practitioners. This could occur, for example, though further guidance, educational sessions, the Quality Practice Series, the information hub on the VAD-IMS, or discussions in the Community of Practice.

With respect to the nature of the current eligibility criteria, although they are outside the scope of this Review, it would be prudent for these issues to be examined in future reviews. Some of these issues were debated extensively at the time of passing the WA law. However, some of the issues raised should be reassessed in light of growing evidence of how VAD is operating in WA and other Australian States (as well as drawing on international evidence, where relevant), in addition to current community views. In particular, given the frequency with which they were raised by participants, the current prognostication timeframes and potential access of individuals with dementia should be considered in subsequent reviews.

Recommendation 10

Future reviews of the WA VAD Act should consider current eligibility criteria for VAD.

D. Prescription, Administration, Disposal and Post-death

This section considers the processes that occur for the patient (and their loved ones) after the patient has been assessed as eligible for VAD and the VAD substance has been prescribed. It considers the prescription delivery process, the transportation of the VAD substance, the administration process, and the disposal of the VAD substance. It also considers after death components including the role of the contact person, certification of death and grief and bereavement supports.

1. Prescription Delivery

Under s 70(6) of the *WA VAD Act*, "the coordinating practitioner must give the prescription directly to an authorised supplier". In practice, this requirement has been interpreted narrowly to mean that only the practitioner can deliver the prescription directly (or do so via registered post or an authorised courier) to the SWPS (the authorised supplier).[129] As a consequence, in practice, other personnel who may be well-placed to deliver the prescription (such as the SWCNS, institutional VAD Coordinators or pharmacy technicians) are unable to pick up the prescription from the VAD practitioner and deliver it to the SWPS. This was also an area that the WA VAD Board has recommended to be reformed.[130]

[129] *WA VAD Guidelines*, n 45, 58.

[130] *WA VADB 2022-2023 Report*, n 12, 55.

Participants' Submissions and Evidence

Participants perceived s 70(6), and the way in which it has been interpreted, placed unfair burdens on VAD practitioners in terms of time and associated cost to either travel to the pharmacy or organise a courier service or postage. In addition, it was observed that such steps inevitably resulted in delays. Participants observed that such practices were practically unnecessary as, on occasions, personnel from the SWCNS or institutional VAD Coordinators had been available to deliver the script. It was also noted that while pharmacists from the SWPS had sometimes driven out to collect scripts from medical practitioners in an attempt to save them time, this was also unnecessarily creating burdens on the SWPS:

> Accessibility... as far as having it available … especially regional areas again [and just] getting script to pharmacy and the barriers to that and that having to be the practitioner themselves, or a courier or post … so [practitioners] have to organise a courier sometimes from five hours away, when [the Care Navigator is] right there with the practitioner and could actually bring up the script to Perth to give the pharmacy. So that causes definite delays. [Participant 4]

Participants also considered that the inability to use electronic prescriptions was unnecessarily limiting. While it was identified that the Commonwealth Criminal Code currently precluded the use of electronic prescriptions, participants emphasised that even if the law were changed, the current legal framework would not support electronic prescriptions. Multiple participants expressed desire for some form of electronic prescribing infrastructure, with different models proposed, including the use of digital image prescriptions:[131]

> The WA legislation is not set up to cater for an environment for us to do electronic prescribing tomorrow. Let's say [the Commonwealth Criminal Code changes], we're not ready to go. [Participant 10]

Issues Identified

As s 70(6) in the *WA VAD Act* is currently interpreted, there are limited avenues for the coordinating practitioner to deliver the prescription to the authorised supplier. The current practice imposes unnecessary and unfair burdens on VAD practitioners. These unnecessary logistical barriers also create barriers for patients accessing VAD, particularly patients living regionally.

The authors note that the *WA VAD Act* currently allows an "agent" to collect and deliver the actual VAD substance.[132] Logically, it is not justifiable to more tightly control delivery of a prescription.

Recommended Responses

The category of individuals permitted to transport the prescription from the coordinating practitioner to the authorised supplier should be broadened. Staff from the SWCNS, VAD Coordinators and SWPS technicians would all be suitable for this task and allowing them to do so would not affect the safety of the process.

This issue could be addressed by amending the *WA VAD Act* to explicitly authorise delivery of the prescription by a broader category of individuals. An alternative strategy is that the DoH could revisit the current narrow interpretation of the legislation in the WA VAD Guidelines. A broader interpretation of section 70(6) may be more consistent with some of the guiding principles of the *WA VAD Act* and the Government's commitments to facilitating access, including those set out in the Access Standard.[133]

Recommendation 11
Broaden the category of individuals who are authorised to deliver a prescription to an authorised supplier.

[131] An example of instrument that permitted digital image prescriptions temporarily during the COVID-19 pandemic is *Authorisation (No 6) to Supply or Prescribe a Poison* (WA). This instrument was made pursuant to the *Public Health Act 2016* (WA) and is no longer in force. The WA VAD Board has also shown support for use of electronic prescribing in relation to VAD see *WA VADB 2022-2023 Report*, n 12, 55.

[132] *Voluntary Assisted Dying Act 2019* (WA) s 58.

[133] *Access Standard*, n 25, 2.

2. Transporting Substance

The *WA VAD Act* currently prohibits any person apart from the patient from transporting the VAD substance once it has been supplied to the patient. The agent or contact person can only possess the substance for the purposes of supplying it to the patient.[134] This creates difficulty in cases where a patient transitions between care settings (eg between a residential aged care facility and a hospital). The current framing of the law precludes another person from bringing the substance to the patient in the new facility.

Participants believed the current restrictions on transporting the VAD substance put people at unnecessary medicolegal risk. Participants suggested that the patient's loved ones, in practice, would on occasion transport the substance to the patient's new care location (hence contravening the law). Alternatively, the patient may be encouraged to take the substance with them whenever they travel to a new care setting, which was believed to create undesirable risks:

> There's a bit of an issue [in] when [the medication is supplied] to a patient, the patient is the person who is now in possession of the VAD substance and no one else can be in possession of it. If the patient then goes to hospital and they didn't take the kit, which we really don't want them taking the kit just because they're going in for something non-life threatening, but then they decide they want the VAD substance kit, in theory, no one can bring it to them because no one else is allowed to be in possession of it. I think that is something that needs to be written into the law. [Participant 11]

Issues Identified

Lack of legal authority for someone, other than the patient, to transfer the VAD substance between care settings has undesirable outcomes: the patient may not be able to access the VAD substance in the new care setting, as they desire; or the patient may need to transport the VAD substance wherever they go, creating unnecessary medication safety risk.

Recommended Responses

A person should be allowed to transport the VAD substance across care settings on behalf of a patient. Amending the *WA VAD Act* to explicitly authorise a person to transfer the VAD substance on the patient's behalf would be the most effective and appropriate solution. Failure to do so would put that person at legal risk.

Until legislative amendment can occur, patients should be encouraged to take the VAD substance with them when they transition across care settings if they believe they may wish to use it at the new location. To promote safety, entities should also ensure that a safe place to store the VAD substance is available upon transfer.

Recommendation 12

When a patient transitions between care settings, facilitate the transport of the VAD substance to the new care setting by another person authorised by the patient to do so.

3. Administration

Under the *WA VAD Act*, administration can occur via self-administration or practitioner administration. Patients are required to make an administration decision with, and on the advice of, their coordinating practitioner.[135] If the original administration decision is no longer appropriate, the patient must formally revoke the administration decision and make a new decision.[136] In cases of self-administration there is no requirement for a health practitioner to be present. However, often in practice, a VAD practitioner and/or a member from the SWCNS or VAD Coordinator would be present for administration to support the patient, their loved ones and the administering practitioner.

[134] *Voluntary Assisted Dying Act 2019* (WA) ss 58(7), 67(1).

[135] *Voluntary Assisted Dying Act 2019* (WA) s 56.

[136] *Voluntary Assisted Dying Act 2019* (WA) s 57.

Participants' Submissions and Evidence

Proportion of Practitioner Administration

One surprising feature of the WA system has been the high proportion of practitioner-administered deaths compared to self-administration. Some participants suggested that the manner in which VAD practitioners approached administration decision conversations may have contributed to this. Indeed, some participants suggested that some VAD practitioners conveyed (even if unintentionally) a preference for practitioner administration, which was thought to influence patients' decisions.

To further promote informed patient choice, some participants suggested it would be useful to develop resources setting out the advantages and disadvantages of each administration option. It was noted that currently practitioners are required only to provide written information on the administration route that is chosen:[137]

> I think you want a lot of patient ability to make that decision. I think that's got to be the key message. You really want some sort of informed consent, for want of a better word, process in terms of pros and cons to go through it … I do think our practitioners overly push the practitioner admin because that's just become part of the culture. [Participant 10]

Participants suggested some patients were opting for IV administration, due to reservations about the bitterness of the VAD substance or because they perceived that IV deaths were quicker and offered greater certainty. Participants also suggested that some patients opt for practitioner administration (or at least practitioner presence) due to a desire for continuity of support:

> [It's] understood that the medication's very bitter and there's a worry about vomiting and not being able to go through the process I suppose. And we've also speculated that perhaps there's a comfort that there's a medical practitioner present. So, if you're getting practitioner assistance, well there's a doctor there, at least one medical practitioner there plus or minus a nurse, to help with the aftermath of the death. [Participant 26]

Prohibition on Assisting the Person to Self-Administer

Participants frequently discussed the current prohibition on assisting the patient to prepare the VAD substance. Among participants there was speculation about whether this influences patients to choose practitioner administration. The authors note that this prohibition has previously been identified as an issue of concern by the WA VAD Board.[138] Participants suggested the law should be reformed to permit such assistance, although views were mixed about whether that support should be available from family and friends:

> The fact that no one else can help [patients] prepare [the substance] is challenging and I don't know that Victoria's legislation is necessarily correct either. I think when we entered into this, I thought it was really prohibitive that people couldn't have someone help support them prepare the medication. Now I'm not entirely sure that that would be a positive thing to have available in all cases. I think it puts a lot of pressure on family and support people to facilitate access to VAD … But I would be very keen to see there be capacity for an appropriate health professional to support someone to do it, who doesn't have to be a doctor or a nurse practitioner who's done the training. So that the person and their family aren't alone. [Participant 3]

Simplifying Process to Change the Administration Decision

In cases where the original selected administration pathway is no longer appropriate for the patient, the current processes require the original decision to be revoked, a new prescription to be provided, and new kit dispensed. This inevitably results in delays. Participants described the process as burdensome and expressed a preference for a more streamlined approach. Some participants suggested permitting multiple kits to be dispensed and allowing practitioners to move between protocols if needed would be beneficial and would assist with streamlining. However, there were also reservations expressed in

[137] *Voluntary Assisted Dying Act 2019* (WA) s 69.

[138] *WA VADB 2021-2022 Report*, n 12, 39.

relation to dispensing multiple kits due to the associated wastage which would result from such an approach:

> No capacity for multiple options to be dispensed … is an acute care issue for patients. We've had a number of cases where IV access has not been obtainable where that was the person's wish but not a requirement … so changing to oral administration revolves around a massive trip back to pharmacy … Similarly, where a practitioner arrives to a patient with the intent of doing oral or feeding tube administration and then that's no longer possible. Then again, the same trip happens to get access to an intravenous option. It's incredibly distressing for everyone. [Participant 3]

> I know in other countries overseas that they sometimes take two kits. So, if something goes wrong, they've got another option. That's something practitioners have proposed but it would lead to a lot of wastage because [the SWPS] don't take medications back once they've left [their] site. [Participant 11]

Simplify the Process for Transferring Between Administering Practitioners

Participants also identified that the current process for transferring the administering role to another practitioner (whether a medical or a nurse practitioner) was unnecessarily complex. Participants reported that difficulties commonly arose when the coordinating practitioner was no longer available to administer (eg due to a lack of capacity or being on leave). In such cases, a new administering practitioner could be assigned. However, participants noted that the current processes can be administratively burdensome. Indeed, such cases required the originally assigned administering practitioner to log on to the VAD-IMS to facilitate the transfer. This was considered impractical and challenging at times, particularly in cases when they did not have access to the VAD-IMS when the transfer needed to occur. Similarly, due to the absence of a streamlined transfer process, participants described that difficulties also arose in cases when a transfer of administrating practitioner was made (eg because the patient was expected to take the substance while the original administering practitioner was on leave) but circumstances changed and the original administering practitioner was now able to carry out the administration (eg because they returned from leave).

Participants expressed a preference to simplify and streamline this process. Participants suggested this could be achieved by permitting the nomination of multiple administering practitioners so if the originally intended administering practitioner is unavailable, one of the other listed administering practitioners could step in:

> When a practitioner is no longer available, usually they're on leave. You go on leave, your patients are stable. Do you transfer them to another practitioner? Transfer the medications? Because if you have the possession of the medications and you don't transfer them, the patient would have no option to administer until they return. If they had to go back to the start, they'd have to have a new administration decision made, a new coordinating practitioner allocated. It's a really big gap. If you transfer the patient to a new administering practitioner and you come back, and they didn't need it then you've got to transfer them back to yourself. [Participant 11]

Permitting Practitioner Administration for "Failed" Administration

VAD deaths (particularly via the oral route) can vary from patient-to-patient.[139] Participants reflected on the issue of "failed" administrations such as when there were longer than expected time intervals between administration and death due to the patient's medical condition (and inability to absorb the substance) or because a patient vomited some of the VAD substance. Such "failures" were observed to be challenging for those present at the patient's death. Some participants suggested that consideration should be given to allowing an attending practitioner to provide practitioner IV administration, as is currently possible in Tasmania,[140] without the need to formally change the administration method:

> It would be great to have flexibility, wouldn't it, for the potential case … of a self-administration where it goes wrong. It's not working. It's not getting the job done. Is the person throwing up or whatever? I don't know. And if a doctor is present – whether the consulting practitioner or another – should they not be permitted to intervene to really take it over and provide practitioner administration? [Participant 13]

[139] Sellars et al, n 110, 5.

[140] *End of Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 88.

Issues Identified

Several issues associated with administration were identified by participants:

- the proportion of practitioner *v* self-administered VAD deaths in WA;
- the inability to assist a patient prepare the VAD substance in cases of self-administration;
- the administrative complexities with changing the administration decision and changing administering practitioners; and
- difficulties associated with 'failed' administrations.

Recommended Responses

The Proportion of Practitioner v Self-Administered VAD Deaths in WA

Informed decisions about methods of administration of VAD are needed to facilitate patient choice. Practitioners discussing administration decisions with patients should ensure that they are fully informed and aware of the relative merits of each option. The development of standardised resources that cover such content may help facilitate those discussions. Different proportions of administration methods have been observed by the WA VAD Board, and the DoH may wish to monitor trends over time.[141]

The Inability to Assist a Patient Prepare the VAD Substance in Cases of Self-Administration

It is desirable for a patient to be permitted to receive assistance to prepare the VAD substance if this help is wanted. This is allowed in other jurisdictions and there is no evidence that this kind of assistance compromises the voluntariness of the patient's choice to take the VAD substance. This is best addressed by amendment to the *WA VAD Act* to permit this assistance. Pending legislative reform, the DoH should also consider whether alternative strategies may help address this issue such as clarifying what constitutes prohibited assistance and whether there are any steps that others may lawfully do which would not be considered preparation of a VAD substance.

The Administrative Complexities Around Changing the Administration Decision and Changing Administering Practitioners

Changing the administration decision and transferring to another administering practitioner are two processes that commonly occur during the VAD process, and there is a need to simplify both processes. Some of the current complexities are the product of how the legislation is framed in terms of the requirements for formal revocation, and restrictions placed on the number of administering practitioners that can be appointed. Legislative amendment would be the most effective way to address these complexities; however, changes to existing system design may also help streamline these processes and should also be considered.

Difficulties Associated with "Failed" Administrations

The authors recommend consideration be given in future reviews to permitting practitioner administration for "failed" self-administrations (where a patient consents to this in advance). Although there is little evidence of complications of self-administration, evidence suggests that, when this occurs, it can be distressing for the patient's loved ones.[142] Evidence from the Tasmanian experience (where this is permitted) should inform these future deliberations.

Recommendation 13

Allow assistance to be provided to the patient, if requested, to prepare their VAD substance.

Recommendation 14

Simplify the process for changing the method of administration including in cases where self-administration is no longer appropriate.

[141] *WA VADB 2022-2023 Report*, n 12, 33.

[142] Sellars et al, n 110, 5.

Recommendation 15
Simplify the process for transferring the role of administering practitioner.

Recommendation 16
Future reviews should consider amending legislation to permit practitioner administration if self-administration "fails".

4. Storage and Disposal

Under the *WA VAD Act*, an authorised disposer can receive any unused or remaining VAD substance for the purposes of disposal. The Act requires disposal to occur "as soon as practicable after receiving it" but does not provide a specific time within which this should occur.[143] Clarity is also not provided in the DoH's Guidelines. Upon disposal, the authorised disposer must immediately complete the Authorised Disposal Form and provide a copy to the VAD Board via the VAD-IMS within two business days of disposing of the substance.[144]

Participants' Submissions and Evidence

Lack of Specific Timeframe for Disposal

Participants identified that the current lack of legislative clarity about explicit timeframes for disposal created practical difficulties. Participants reported that, on occasions, because of the lack of a specific timeframe, it had taken months for disposal to occur. The lack of timeframe has also made it hard to track the VAD substance. This meant, in some cases, it was not clear whether the substance was still with the contact person or had been given to the authorised disposer. On occasions, this has led to unnecessary follow up with the contact person:

> An authorised disposer needs to dispose of the substance, I think it says something in it as soon as is practical. We've had that be months … until the authorised disposer does the disposal, it still looks like the kit sits with the contact person. The VAD Board may be calling the contact person saying, "Why haven't you taken it to a Pharmacy yet?" But they may have done. The pharmacy's just sitting there and haven't done anything with it. It's a bit of a loophole which potentially puts the contact person in an awkward position. [Participant 11]

Storage And Disposal of Residual VAD Substance

Administering practitioners will collect the VAD substance prior to administration (sometimes well in advance). Additionally, in some cases, the administering practitioner may have residual VAD substance in their possession following patient administration. Some participants raised concerns about both of these stages.

First, it was noted that VAD practitioners would sometimes keep the VAD substance at their premises prior to a scheduled administration. Participants observed that this was not consistent with good practice for medication storage:

> It's working OK it's just … [there are occasions where the SWPS] may be supplying to a practitioner living in a shared house. Where [are they] meant to store it? We are putting a bit of onus back on those practitioners to manage and own that. They may end up with multiple four, five kits stored in their house. It's really not the intention and not good storage practice. [Participant 11]

Second, concerns were raised about aspects of disposal practices. Some suggested that the disposal process may be more uniform (and safer) if legislation required practitioner disposal to be witnessed. Practical barriers to such a requirement, however, were also noted. Participants also identified that the current framing of the *WA VAD Act* puts practitioners at medicolegal risk in some circumstances, which

[143] *Voluntary Assisted Dying Act 2019* (WA) s 75(3).

[144] *Voluntary Assisted Dying Act 2019* (WA) ss 76(1), 76(3).

has also previously been identified by the Board.[145] Currently, s 77 of the *WA VAD Act* only permits the administering practitioner to possess and dispose of the VAD substance in cases where the patient has revoked the practitioner administration decision or if the patient has died (whether or not from the VAD substance). This means that in cases that a patient no longer meets the eligibility criteria (eg loses capacity), the legislation does not provide authorisation for the practitioner to lawfully possess and dispose the VAD substance:

> I think there's a few practitioners who feel a bit uncomfortable that any disposal isn't witnessed so that's just up to them. But it's a bit of an awkward one that you might be out in the middle of nowhere. [Participant 11]
>
> The legislation is flawed in relation to the disposal and possession of substance. So, it needs to be changed. Because if a practitioner rocks up to see a patient and they've got the kit with them and they are unable to do their administration because the person's lost capacity, that practitioner [is] not authorised to possess the substance for the purpose of disposal. [Participant 19]

Issues Identified

Community safety requires sound systems to manage safe custody and disposal of VAD substances. Two main issues were identified in relation to current practice. The first was the lack of timeframe within which an authorised disposer must dispose of the substance. It is preferable for a disposer to have clarity about their obligations. Also, a lack of timeframe for disposal makes it difficult to track where the substance might be and can lead to unnecessarily reaching out to the contact person.

The second issue is the potential medicolegal risk for administering practitioners who are in possession of the VAD substance in the absence of express legal authority.

Recommended Responses

These issues are most effectively addressed by legislative amendment to the *WA VAD Act*. The Act could impose a timeframe in which an authorised disposer should dispose of the substance and provide legal authority for an administering practitioner to possess the VAD substance if the patient is no longer eligible. However, non-legislative responses may also assist in addressing these issues and should be explored. One option is for current disposal forms (which are approved by the CEO) to recognise additional reasons for disposal or specify a timeframe within which disposal can occur. Another option is to provide further guidance (eg in the VAD Guidelines).

Recommendation 17
Make changes to legislation, forms, and/or current guidance to:
- establish or advise on a specific timeframe for the authorised disposal to occur; and
- permit the administering practitioner to possess and dispose of the VAD substance to accommodate all cases where the practitioner is appropriately in possession of the substance.

5. Grief and Bereavement

Participants described that people found journeying with and supporting someone through the VAD process to be a largely positive experience. However, it was generally acknowledged by participants that this process can be emotionally challenging for people, even if they morally supported the person's choice to access VAD. The WA VAD Board in its most recent report identified the need for more VAD-specific grief and bereavement resources, practitioner guidance and referral pathways.[146]

Participants' Submissions and Evidence

Participants identified that there are some aspects of the VAD grief and bereavement experience that are different from non-VAD deaths. While some people were heartened by the VAD process and death and took pride that their loved one could end their life on their own terms, they still reported

[145] *WA VADB 2021-2022 Report*, n 12, 38.

[146] *WA VADB 2022-2023 Report*, n 12, 57.

experiencing complex forms of grief. Grief experiences were variable and included anticipatory grief, forms of complicity grief associated with supporting a patient through a process that ultimately resulted in death, feeling guilty and unsettled by the fact that they have coped well with their loved ones' death. Participants reported that some people found the uniqueness of the VAD grief isolating. Grief was not only experienced by the patient's loved ones, but also some of the personnel directly involved in the person's VAD care, as well as those related to other aspects of the patients' care (such as community nursing staff and interpreters):

> [I] found it very isolating. You don't know people who have gone through this journey. It's an incredibly confronting thing to be knowing that you've got a ticking clock waiting for that loved one to die. Even though it's what they want and you're supporting them very much with their wishes, it's just something that the human condition isn't … we're primed to keep people alive and to support people. [Participant 9]

> What people, particularly in the palliative care space, have found is that it is a bit different … people … because of their work, they really don't have issues with people dying in the service. They have found that they have had some issues when the person that you're looking after essentially farewells you because they then say, "Well, I'm dying tomorrow because that's when I'm going to take the substance", and people have found that really confronting in ways that they didn't even expect. [Participant 38]

Participants largely felt that VAD-specific grief and bereavement services were under resourced, and while general grief and bereavement services were available, they were often not appropriate or tailored to meet people's needs. Participants suggested some people might be reluctant to engage general bereavement supports due to uncertainty about how a VAD death might be judged. The need to engage with people unfamiliar with the VAD system also necessitated the person repeating their story over again. Support provided by people familiar with the VAD journey was suggested to mitigate this:

> The concern in engaging with different health professionals or different entities is that you have to tell your story over again and you don't know whether you're going to cop a conscientious objector. You don't know if you're going to cop someone that has very goodwill towards you, but has no knowledge of voluntary assisted dying. And so, if someone's grieving that they're like, "Well at least they got to have the death they want". You know the … at least … type of sympathy, not empathy people. [Participant 19]

The absence of dedicated supports has meant other people in the system have taken it upon themselves to provide support.[147] Participants spoke of VAD practitioners, the SWCNS and VAD Coordinators stepping up to provide support given their close connection with the patient. While this level of support was welcomed, and participants praised their efforts, it was noted that such personnel were not necessarily trained, nor had the capacity to offer grief and bereavement support to everyone who needed it. Some participants praised the Queensland approach of a more integrated support service which includes follow-up support in addition to navigation support:[148]

> I think in Queensland having that alongside … while they're going through the process of VAD… to have that support right from the get-go … I think would be tremendously beneficial. [The SWCNS] check in [and] build beautiful rapports with … patients and families, but I think [to have that] support alongside them with bereavement counsellors that can really do that work with them [while the SWCNS] are caught up with other work … I think that would be an amazing thing to have. [Participant 4]

The emergence of Willow was viewed positively by stakeholders. Willow is a peer support group that offers support through provision of information, private online group meetings for people with lived experience of VAD, and regular in-person catch ups.[149] The SWCNS and some VAD practitioners were referring patients' loved ones to the service as a potential support avenue. However, given the service is unfunded and the network is currently small, it is naturally limited in terms of the level of support it can provide and currently does not extend to providing dedicated grief and bereavement supports:

> The community support group, Willow, that we've got now … that's just such a relief now that we can offer that to patients and that they know that's there. We're getting a little bit more specific with what we

[147] Sellars et al, n 110, 5.

[148] In Queensland, there is a VAD support service known as QVAD-Support. The service is supported by Care Coordinators (similar to WA's SWCNS), who, in addition to fulfilling a care navigation role, provide follow-up care and support.

[149] See *Willow – Community and Family Support Through Voluntary Assisted Dying (Facebook)* <https://www.facebook.com/people/Willow-Community-andfamily-support-through-Voluntary-Assisted-Dying/100095063409905/?locale=hi_IN>.

> can offer. Whereas I know when we started it was very general … Lifeline, Beyond Blue. When I used to give [out those services' details] I didn't really feel that it's a wonderful tool for them. [Participant 4]

Some participants also shared reflections on the WA VAD memorial service,[150] which was viewed positively among participants:

> I found it was very important for people to hear a story and be able to connect with a story that they weren't alone. And I think the service last year was even bigger than the one before. And there were some beautiful families, and people on the journey, people who'd been through the journey. So, I found that service was invaluable. [Participant 8]

Participants also spoke of efforts in organisations such as Grief Australia to upskill people to deliver appropriate VAD support.[151] However, participants urged that more work in this area was needed, and some participants also called for greater research in this space.

Some participants suggested that the current need for dedicated supports reflects the fact that VAD is still a relatively new practice. As the system matures and VAD is normalised and integrated more within end-of-life and palliative care, dedicated supports may no longer be necessary:

> I think it's something that would need to be explored with a view of what [is already available in] the current system and with a view toward building capacity in the system and with due regard to sustainability. You know I think we need to really look at the issue in depth, look at a bit more research and work out a policy solution that's going to be best from a system-wide policy perspective … The SWCNS is not a grief and bereavement service, however, it does have a role in education and building capacity in the system more generally. The SWCNS has partnered with Grief Australia to build capacity in the grief and bereavement workforce and to create a referral pathway. I think there needs to be more of these kinds of initiatives. From a broader policy perspective, any new grief and bereavement initiative must also not be considered inequitable for other non-VAD patients in terms of the level of service provision such as palliative care patients. Although VAD is new now, eventually it will be normalised. [Participant 17]

Issues Identified

Appropriate grief and bereavement support is needed for people whose loved ones have gone through the VAD process. While grief and bereavement are an expected and natural part of death, the specific nature of VAD (and the fact it is a new end-of-life choice) means people may need dedicated support that is sensitive to the VAD context.

Recommended Responses

In Recommendation 21, the authors specifically address this issue in the context of the wider VAD workforce, namely that statewide services should be resourced to provide grief and bereavement support to family and carers. However, the authors recognise that people will seek this support from a range of settings, including from general grief and bereavement support services. The DoH, in conjunction with the SWCNS (given its experience), may wish to consider whether it can provide resources and/or advice about VAD to these other services so that their support can be sensitive to the context of VAD (eg understanding how issues such as anticipatory grief can arise with VAD deaths).

Recommendation 18

Review existing grief and bereavement supports currently available to assess suitability and availability to support individuals affected by a VAD death.

6. Contact person

Under the *WA VAD Act*, a patient must appoint a contact person.[152] The contact person can be any person aged over 18.[153] The Board is required to provide information to the contact person that explains

[150] The first VAD Memorial Service was held in September 2022 to mark the first year of VAD.

[151] For example, Grief Australia has held webinars and workshops about the VAD grief experience and possible interventions.

[152] *Voluntary Assisted Dying Act 2019* (WA) s 65.

[153] *Voluntary Assisted Dying Act 2019* (WA) s 65(2).

their obligations.[154] Other than providing that information, there is limited engagement by the VAD system with the contact person either to check in or to provide an opportunity for the contact person to clarify any points of concern. Formal follow up is only likely to occur if the contact person is at risk of breaching their obligations to dispose of the substance.[155]

Participants' Submissions and Evidence

Participants expressed concern about the nature of the contact person role and the burden placed on them. Participants noted that the role was often misunderstood, and that some people did not necessarily appreciate the level of responsibility and the nature of obligations associated with that role. Participants advised that the SWPS commonly tried to do some education with the contact person about their role, but this was not part of the formal VAD process.

The limited follow-up with the contact person (outside the contact by the VAD Board Secretariat in relation to the return of the VAD substance, if needed) was also criticised. Participants suggested that outside the informal support from the SWPS, current processes meant that the contact person was largely unsupported, despite the significance of their role. This was perceived to be particularly problematic if the contact person was the patient's loved one:

> I think the contact person role is really, really challenging. I don't think there is enough recognition about the load that that puts on the person who is doing the contact person role. There's no formal requirement for follow up in any way, shape or form, with that person outside of the legal responsibilities … I think we leave them out to dry and we don't often make space for them to have their own conversation, about what that means for them before they accept the role and in the time afterwards … So, they don't often have access to the kind of support that they often need when they're providing that kind of care and support for the person. [Participant 3]

Issues Identified

The contact person plays an important role in the WA VAD system. Participants raised several issues regarding the burdens placed on them, and whether they are adequately supported in their role.

Recommended Responses

The authors endorse calls for education of persons fulfilling the contact person role to ensure they are aware of their legal obligations, as well as the need for them to be supported. The authors acknowledge the efforts by the SWPS to educate the contact person, but note this is not the core business of the SWPS. The DoH may wish to consider whether current practices should be more formalised, including whether (and when) contact persons should be contacted after a VAD death. Some of the issues raised by participants relate to wider support needs for contact persons which are also addressed by observations and recommendations above in relation to grief and bereavement (see Recommendation 18).

7. Death Certification

Section 44 of the *Births, Deaths and Marriages Registration Act 1998* (WA) requires a Medical Certificate[156] of Cause of Death (MCCD) to be completed by a medical practitioner who is responsible for the person's care immediately before death or has examined the deceased body.[157] In cases where a nurse practitioner or registered nurse are present for the patient's death, they can certify life extinct, but a medical practitioner must complete the MCCD.[158] The MCCD must not include any reference to VAD,

[154] *Voluntary Assisted Dying Act 2019* (WA) s 149.

[155] For examples of the contact person's obligations see *Voluntary Assisted Dying Act 2019* (WA) ss 67, 105.

[156] The authors note the difference between a Medical Certificate of Cause of Death which is completed by a medical practitioner and the death certificate which is issued by the Registry or the Courthouse. However, participants used the term death certificate as an umbrella term to refer to both documents.

[157] Unless the death is reportable to the coroner. See s 44(5) of the *Births, Deaths and Marriages Registration Act 1998* (WA).

[158] *Quality Practice Series #5*, n 109, 3; *WA VAD Guidelines*, n 45, 65.

even if the death resulted from the VAD substance.[159] The policy intention behind this restriction is to protect the person's privacy and reflect that the person died from their underlying illness.

Participants' Submissions and Evidence

Some participants advised that there had been barriers to getting the MCCD completed following a VAD death.[160] This typically occurred in cases where a nurse practitioner was taking on the role of the administering practitioner, and the coordinating or consulting practitioners were not available to certify the death. While in such cases, contacting the patient's GP was an option, if the GP had a conscientious objection to VAD or were not confident about the cause of the patient's death, they may be reluctant to complete the certificate.[161] One solution offered by participants was to permit nurse practitioners to complete the death certificate, particularly if they were the administering practitioner:

> There are issues for nurse practitioners in organising a death certificate for the patient … A nurse practitioner … can't complete a death certificate … [they can] complete a Life Extinct form which goes with the patient to the funeral home. But if … your coordinating practitioner is not in the country, so is not able to do the death certificate for you, and then your only other person is the GP who is a conscientious objector, or refuses to do the death certificate, you're stuck because you then don't have a death certificate for the patient. And so, the funeral home then, in a couple of cases, have put pressure on the family going, "Well we can't organise this person's funeral until we've got this death certificate". And it's just unnecessarily holding up the process. [Participant 29]

Moreover, participants reported that mixed views have been expressed about whether reference to VAD on the patient's death certification documentation should be permitted:

> Death certificates hurt us as well … we are hearing from patients repeatedly that they want voluntary assisted dying on their death certificate, they feel very strongly about it that they don't want the disease to be listed as the thing that kills them. But then correspondingly we have patients who are so relieved to know that it's not on their death certificate. And practitioners that fall on both side of the fence … I think that is really challenging and it needs a lot more care and consideration. It's given a lot of debate in Parliament, but I think our understanding of the impact of that has changed significantly. [Participant 3]

Issues Identified

Participants identified that logistical challenges sometimes arose in finding a medical practitioner to certify a VAD patient's death, particularly in cases where the administration was performed by a nurse practitioner. There was also ambivalence about whether death certification documentation should include mention of VAD.

Recommended Responses

The DoH should consider addressing some of the logistical issues raised in relation to delays associated with certification of death, due to the inability (or unwillingness) of some medical practitioners to certify patients' deaths in cases where they accessed VAD.

Whether VAD should be recorded on death certification documentation was extensively considered when the law was designed and debated. In the absence of a clear consensus on the best approach, the authors are not making a recommendation on this issue. However, it may be an issue for future consideration should a settled preference within the WA community emerge. If ambivalence about this issue continues, consideration could be given to providing people with the option, depending on personal preference, for death certification to include a reference to VAD.

E. VAD Workforce

Safe and effective delivery of VAD is reliant on a VAD workforce comprising VAD practitioners, the SWCNS, the SWPS, VAD Board and Secretariat and institutional VAD supports (eg VAD Coordinators).

[159] *Voluntary Assisted Dying Act 2019* (WA) s 82(6).

[160] *Quality Practice Series #5*, n 109, 3.

[161] Refusal to complete death certification in cases of VAD deaths have been previously reported see White et al, n 72.

The current WA VAD workforce has consistently been commended for their commitment to VAD and person-centred care, as well as their compassion.[162] The demand for VAD in WA has been higher than anticipated and is likely to increase over time as awareness of VAD grows in the community.[163] There is also a higher-than-expected number of practitioner-administered deaths which places greater demand on the workforce.[164] For patients to continue to have this end-of-life option available to them, it is important that there is a sufficient workforce to meet community demand, and that the workforce is appropriately supported to carry out this work. This section explores both of these issues.

1. Expand the VAD Workforce, Including in Regional Areas

According to the most recent VAD Board Report, 68 medical practitioners and 1 nurse practitioner have participated in the VAD process as either a coordinating, consulting or administering practitioner. Most practitioners are likely to have acted as a coordinating, consulting or administering practitioner for between 2 and 10 patients.[165] This distribution of provision places a high burden on a small number of practitioners, and efforts are needed to increase the VAD workforce including in regional areas. The need to expand the workforce has previously been identified by the WA VAD Board.[166]

Participants' Submissions and Evidence

An important barrier to the involvement of medical practitioners in the VAD workforce is the lack of remuneration. Currently, there is little financial incentive for practitioners to undertake the mandatory training and to act as VAD practitioners.[167] Although not in effect at the time of data collection, participants noted the DoH's plan to establish remuneration packages for VAD practitioners, scheduled to take effect in July 2024.[168] This was viewed positively by participants, although many suggested that this would only offer a short-term solution, and changes at the federal level were necessary. Significantly, participants suggested that until there was financial incentive to do this work, there was unlikely to be a further increase in number of VAD practitioners:

> [GPs] can't spend 12 hours per patient for two hours remuneration … we're not going to get new providers in until that's addressed. [Participant 30]

The dearth of VAD practitioners in WA creates challenges for the timely delivery of VAD particularly in regional areas.[169] Regional access to VAD has been facilitated, to some extent, through the regional

[162] See n 13.

[163] Blackwell, n 29; Haining, Willmott and White, n 1, 732–733; *WA VADB 2021-2022 Report*, n 12; C Elton, "Voluntary Assisted Dying Demand Three Times Greater than Expected, VAD Board Reveal", *The West Australian*, 10 February 2022 <https://thewest.com.au/business/health/voluntary-assisted-dying-demand-three-timesgreater-than-expected-vad-board-reveals--c-5642082>; P Lundie, "Slow Start for Voluntary Assisted Dying" (Western Independent, 8 November 2021) <https://westernindependent.com.au/2021/11/08/slow-start-for-voluntary-assisted-dying/>; K Bourke, "WA's Voluntary Assisted Dying Laws Have Been in Place for a Year. Have they Served their Purpose?", *ABC News*, 1 July 2022 <https://www.abc.net.au/news/2022-07-01/doctors-reflect-on-wa-voluntary-assisted-dying-scheme-a-year-on/101194566>.

[164] CM Haining et al, "Access to Voluntary Assisted Dying Requires Fair Remuneration for Medical Practitioners" (2023) 218(1) *Medical Journal of Australia* 8; S Towler, "It Has Been a Privilege to Have Alleviated Significant Suffering" 62(1) *Medicus* 33

[165] *WA VADB 2022-2023 Report*, n 12, 14.

[166] *WA VADB 2021-2022 Report*, n 12, 37.

[167] Rutherford, Willmott and White, n 23, 1070; Sellars et al, n 110, 6.

[168] WA VAD Board, *Quality Practice Series #8* (Western Australian Government: Department of Health, 2024) <https://www.enudgecom.au/email-share-link.php?ca=llQd3fP9Q2sVSvNMK1OnkQ%3D%3D&cl=PzzsVLE3SKY9iDbfoMJRoQ%3D%3D> (*Quality Practice Series #8*).

[169] The dearth of the WA VAD workforce has previously been identified see Haining, Willmott and White, n 31; *WA VADB 2021-2023 Report*, n 12, 37; *WA VADB 2022-2023 Report*, n 12, 4; Cox, n 19; P Law, "Voluntary Euthanasia: Alarming Number of VAD-Trained Doctors In WA Revealed", *The West Australian*, 1 July 2021 <https://thewest.com.au/news/health/voluntary-euthanasia-alarming-number-of-vad-trained-doctors-in-wa-revealed-ng-b881917671z>; Lundie, n 163; T Robinson, "Goldfields GPs Yet to Get on Board with Voluntary Assisted Dying Program", *Kalgoorlie Miner*, 3 July 2021 <https://www.kalminer.com.au/news/kalgoorlie-miner/goldfields-gps-yet-to-get-on-board-with-voluntary-assisted-dying-program-ng-b881918247z>.

access support scheme (RASS).[170] However, it is not always feasible for metropolitan practitioners to travel regionally, and hence increasing local providers is considered preferable for sustainability.[171] Participants also noted that there are some limitations of the scheme. For example, it would not fund the travel of a specialist who may be needed to help inform a prognosis but was not conducting their own eligibility assessment, nor would it fund practitioner travel if videoconferencing could be used (despite practitioner preference to see patients face to face for aspects of the process):

> [Regional Town X] got a bit short of practitioners, or the Navigators don't know all the practitioners in [Regional Town X]. So, I've been getting asked to go there, which is 78 Ks [kilometres] for me … I get paid for my mileage and I've been paid reasonably promptly. So that's been very good, but I've been told, "If you could do it by video conference, you should be doing it by video conference and they shouldn't allow you to claim the RASS" … I prefer to see them in person, I'd rather not get paid that way … I prefer that I just see my local community. I just occasionally help out if I've got capacity. [Participant 32]

Participants also showed support for expanding the roles of other health practitioners in the VAD process.[172] First, participants were of the view that authorised nurse practitioners were more likely to be involved as administering practitioners if they were involved in more of the VAD process. Participants suggested that expecting a nurse practitioner to step in at the "pointy end" of the process was unreasonable, unethical and emotionally challenging. Participants noted that in some cases efforts were made to involve the nurse practitioner earlier in the process (eg sitting in on consults) to provide them an opportunity to form a relationship with the patient and the family.

Participants also expressed support for nurse practitioners to have a greater role in the process (namely assessing eligibility), given their level of expertise and experience:

> I think nurse practitioners probably … wanted more of a role within VAD, which hasn't happened
>
> … but, I think, yes, a lot of the nurse practitioners aren't involved because, yes, they don't want to be there right at the end where they haven't had contact with the patient before. [Participant 29]

Furthermore, some participants suggested that senior registered nurses should be able to act as administering practitioners, as occurs elsewhere in Australia:[173]

> I know that in other states it's possible for other senior nursing staff to fill administering roles particularly which I think is worth a conversation for us. [Participant 3]

A final issue about expanding the VAD workforce raised by participants related to the current CEO practitioner requirements. The CEO requirements[174] for participating practitioners include the minimal number of clinical hours per registration period, the need for two professional referees to ascertain suitability, and the requirement not to have notifications, conditions, undertakings or reprimands on one's registration record. Additional requirements apply for overseas-practitioners. The authors note this issue falls outside the scope of the Panel's Review, but report on participants' views for completeness.

Participants had mixed views about these requirements.[175] Some participants suggested that the CEO requirements had a deterrent effect on practitioners being involved. There was also a degree of frustration surrounding the way the CEO requirements were conceived, including the view that the Director General had an unfettered discretion to assess suitability of practitioners to participate in VAD. Conversely, other participants endorsed the CEO requirements because they introduced a level of safety within the system.

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[170] Haining, Willmott and White, n 31.

[171] Haining, Willmott and White, n 31.

[172] Previous research among WA stakeholders demonstrated support for expanding the role of health practitioners see Haining, Willmott and White, n 1, 734–735.

[173] In Queensland and Tasmania, registered nurses can act in administering practitioners if they have completed the mandatory training and have at least five years' experience. See *Voluntary Assisted Dying Act 2021* (Qld) s 83 and *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) ss 62–63.

[174] DoH, *Voluntary Assisted Dying Act 2019 (WA): CEO Practitioner Eligibility Requirements* (Western Australian Government, 2024) <https://ww2.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/CEO-Practitioner-Eligibility-Requirements.pdf>.

[175] Mixed views around current accreditation requirements have been reported see A Miller, "Support the Community and your Colleagues" (2022) 62(1) *Medicus* 32; Haining, Willmott and White, n 1, 735–736; Lundie, n 163.

In particular, participants noted that the WA Government does not control access to VAD through a state-issued permit like some other Australian States and considered that these CEO requirements served as a safeguard about who was providing VAD in lieu of that.

Issues Identified

The demand for VAD in WA has been higher than expected. This has had a significant impact on the workloads of VAD practitioners, especially participating practitioners who are often completing this work alongside other clinical commitments. The VAD workforce needs to be expanded including in regional areas to meet current and future patient demand for VAD.

Recommended Responses

The authors acknowledge the actions to date by the DoH to encourage and incentivise the provision of VAD, for example, through roadshows and community forums to raise awareness and through establishing new remuneration packages as well as remunerating practitioners via the RASS.[176] The authors support such ongoing efforts, but also recommend DoH develop additional strategies to increase the number of VAD practitioners.

The authors acknowledge potential limits on the scope of the Panel's Review, but recommend future reviews consider extending the roles for both nurse practitioners and nurses. Models adopted in other States such as permitting senior nurses to act as administering practitioners and, most recently, permitting nurse practitioners to assess for eligibility in the Australian Capital Territory would be worthy of consideration.[177]

Recommendation 19

Develop strategies and explore opportunities to increase the VAD workforce including:
- adequate workload recognition or remuneration for medical practitioners providing VAD; and
- payment to complete the mandatory VAD training.

Recommendation 20

Future reviews of the WA VAD Act should explore the feasibility of expanding the roles of other health practitioners in relation to VAD such as:
- nurse practitioners to assess eligibility; and
- senior nurses to act as administering practitioners.

2. Supporting and Sustaining the VAD Workforce

As well as expanding the VAD workforce, it is critical to ensure that the existing VAD workforce is supported to continue its VAD work. The workforce here refers to all health practitioners working to deliver VAD as an end-of-life option to individuals who choose it. Failure to appropriately support the existing workforce may lead to attrition and result in an unsustainable VAD service. While many practitioners observe that the nature of the work is rewarding, it is also recognised that the provision of VAD is resource intensive and can take an emotional toll.[178] A failure to adequately support practitioners and service delivery can also put sustainability of the VAD system at risk. Two important issues were

[176] Haining, Willmott and White, n 31; *Quality Practice Series #8*, n 168. The range of initiatives to incentivise provision were also canvassed in the Government's Response to recommendations from the WA VAD's Board's 2021–2022 Annual Report see A-J Sanderson, *Government Response to the Recommendations of the Voluntary Assisted Dying Board Annual Report 2021-2022*. <https://www.parliament.wa.gov.au/publications/tabledpapers.nsf/displaypaper/4111939aaecbf9255f8ca898482589aa002918d8/$file/tp+1939+(2023)+sanderson+-+bms+-+tabled+paper+-+government+response+to+the+v oluntary+assisted+dying+board%E2%80%99s+annual+report+-+final.pdf>.

[177] In Queensland and Tasmania, registered nurses can act in administering practitioners see n 173. In the ACT, one of the practitioners who assess eligibility can be a nurse practitioner see *Voluntary Assisted Dying Act 2024* (ACT) s 89.

[178] Such sentiments are consistent with what has been expressed elsewhere see, eg, Rutherford, Willmott and White, n 23, 1070; Sellars et al, n 110, 6–7; Bourke, n 163; Lundie, n 163.

raised by participants relevant to the sustainability of the VAD workforce: the need to provide the VAD workforce with emotional and practical supports; and the need for VAD practitioners to be adequately remunerated and their work valued.

Participants' Submissions and Evidence

Need for Emotional and Practical Supports

Many participants identified that the level of support currently offered was inadequate. Participants observed that people in the VAD system were commonly going above and beyond to support a patient's VAD journey (including being present during administration, visiting patients and their loved ones on multiple occasions and providing grief and bereavement support). Although the efforts of individuals involved in the delivery of VAD were pivotal in supporting a patient and family to navigate the VAD process, these efforts took an emotional toll on those individuals. This is exacerbated by the long hours, many of which are not remunerated, that are worked by many, and the absence of adequate supports:

> I don't think we do grief and support counselling very well for anybody in the system. [Participant 25]

The need to support VAD practitioners, in particular, was widely observed by participants. It was acknowledged that medical practitioners invest heavily in the process and, given the dearth of providers, some practitioners were taking on high patient loads to ensure demand was being met. Participants noted that high workloads posed a risk of burnout and attrition. This will also affect the ability to meet patient demand:

> We know that some of the participating practitioners do take time out. They tell the Statewide Care Navigator Service, "I need a break". And the Care Navigator Service are also very aware of the individual practitioners, and they can see where burnout [is] beginning to appear in some of them. It's a great worry for us because we've had a smaller cohort of very active practitioners. And then a larger cohort where people have participated with one, two or three cases or so. And when we lose one or two of the very active practitioners who've done 10, 20, 30 cases that's a worry because they're [our] most experienced practitioners. [Participant 26]

It was noted by some participants that the statewide services and institutional VAD staff offer support to practitioners where possible.[179] For instance, it was noted that staff from the SWCNS would often attend practitioner administration to help support the practitioner by managing the patient's family. This provided the space for the practitioner to focus on the patient and the administration process. Similarly, the SWPS were seen as a form of peer support. They would discuss with the practitioner potential strategies and avenues for support and self-care, and commonly make follow-up calls after administration with the aim to ascertain feedback about the SWPS service, which also provided medical practitioners with an opportunity to debrief:

> Because [WA] have such a high proportion of practitioner administration [the Pharmacy] definitely see that as a big role from [their] perspective, because [they are] often the ones who saw [the practitioner] immediately before they left. [The Pharmacy] offer feedback forms and offer phone calls afterwards. [The Pharmacy] … will [ask] practitioners … what are you going to do after the admin to look after yourself? [The Pharmacy provide] some suggestions about what other practitioners do [and] about maybe putting some time aside … when a practitioner calls about their next patient. [The Pharmacy] often ask about how things went with the last patient. [The Pharmacy] have practitioners dropping in most days and so [they] really do see [themselves] as a good resource for that, whether or not [they are] well equipped and well trained to do that. [Participant 11]

The Community of Practice was also identified as a critical form of support for VAD practitioners. Participants spoke favourably of the Community of Practice and how it has evolved over time to be inclusive of those within the VAD system (eg SWCNS and SWPS), rather than limiting its membership to medical practitioners:[180]

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[179] For discussion of supports available to VAD practitioners see Western Australia, *Parliamentary Debates*, Legislative Council, 14 February 2023, 88 (Hon Sue Ellery) <https://www.parliament.wa.gov.au/Hansard/hansard.nsf/0/9E9E729F5742B8FE48258975001F9B38/$file/C41%20S1%20 20230214%20All.pdf>.

[180] This is consistent with other evidence see Haining, Willmott and White, n 1, 740.

> [The Community of Practice meetings] we have every month … They're getting bigger and bigger because more people just love coming, it's great networking for us all … I think it's really supportive and we can always … we've got a little sub-group off that which we sort of meet every couple of months at one of the doctors' houses … I think it's a fantastic group. We all get on really well and would not have the hesitancy in flinging a message or whatever if you're wanting support or help from one of your other colleagues. [Participant 29]

While these forms of support were highly regarded by practitioners, participants identified that there is disparate resourcing of support networks for the workforce.[181] Indeed, participants acknowledged that not all practitioners were necessarily linked into such supports. Participation in the Community of Practice is not mandatory, nor is connection with the SWCNS. Hence, practitioners who were not accessing these forms of support could feel isolated. Similarly, it was noted that while some practitioners who are associated with health service providers may have access to generic forms of employee assistance program supports, not all practitioners, including those working in general practice, will have access to them. There was also suggestion that regional practitioners could feel isolated due to their lack of connection:

> I mean I feel this is a calling. And I feel very connected to the other people. But I am very lonely down here [in Regional Town X]. [Participant 32]

Need for Practitioners to be Adequately Remunerated and Their Work Valued

The lack of appropriate remuneration for the VAD workforce has been repeatedly criticised.[182] Participants reinforced frustrations about the lack of formal recognition for VAD practitioners' efforts, both in terms of the value of their work and in the form of remuneration. The workforce devotes a significant amount of time carrying out VAD-related work. The most recent WA VAD Board Report estimated that VAD practitioners were committing a minimum of 8.5 hours per patient (including contact and non-contact activities) when completing the request, assessment and administration process.[183] Failure to properly pay VAD practitioners for their work has meant that many carry out this service altruistically. Many VAD practitioners also carry out their VAD work over and above their usual work allocation. For regional patients for whom a local provider is not available, the time commitment to travel to these patients (in cases where videoconferencing is not appropriate) is significant and not always feasible.[184]

These practices have led practitioners to question whether their VAD work is sufficiently valued. Participants suggested this toll over time has led some practitioners to cut back their participation in VAD, leading to significant attrition among an already small pool of trained doctors. The lack of remuneration has also led to a two-tiered system for patients: greater access for those who can afford a fee-paying doctor; and less access for those who cannot.[185]

Participants acknowledged that the WA Government has attempted to address this problem by establishing remuneration packages (to take effect from July 2024),[186] but expressed concern that this would likely only be a temporary or partial solution. Indeed, multiple participants highlighted that ultimately Federal recognition through the inclusion of a dedicated Medicare Benefits Schedule item number was needed:

> Practitioners' sustainability tension is to be our primary point of concern. I know that our Department is working on renumeration packages for practitioners that we hope to see available shortly. But the complete absence of recognition of the worth of the work that they do has been incredibly challenging and has definitely seen some significant attrition of these amazing doctors who do this work. And the capacity to continue to provide this care without anyone saying, "Yes, your time is worthwhile, and you

[181] Such sentiments have previously been expressed in the context of Victoria for example, Rutherford, Willmott and White, n 23, 1070; Sellars et al, n 110, 6–7.

[182] The lack of appropriate remuneration for the VAD workforce has been repeatedly criticised. See, for example, Haining et al, n 164; *WA VADB 2021-2022 Report*, n 12, 37; *WA VADB 2022-2023 Report*, n 12, 56; Bourke, n 163; Brennan, n 71.

[183] *WA VADB 2022-2023 Report*, n 12, 56.

[184] Haining, Willmott and White, n 31.

[185] *WA VADB 2022-2023 Report*, n 12, 56.

[186] *Quality Practice Series #8*, n 168.

> are required to have specialist skills and experience to do this work and you do it well", is really difficult. That has led to a bit of a two-tiered access system now that we're continuing to see emerge where various people who can afford to pay a fee [for a VAD] doctor … because doctors need to charge fees to be able to pay their mortgage, and patients who can't afford a fee-paying doctor, so then wait longer for access, can't get access. [Participant 3]

It was also identified that while the VAD system appears to be operating smoothly now, this was the product of the exceptional quality of the personnel currently within the VAD system and their current willingness to undertake this volume of work. These individuals included health practitioners, statewide staff, VAD Coordinators within institutions, VAD Board Secretariat and VAD Board Staff. However, participants identified that there is a risk when the system's sustainability is dependent on individuals going above and beyond in performing their roles.

Issues Identified

The deep commitment of the VAD workforce to support VAD in WA and carry out VAD work is striking. However, more is needed to support these individuals. This is not only to ensure their wellbeing but also to ensure system sustainability as, without them, the VAD system cannot operate.

Recommended Responses

A system review is needed to address the two issues identified above: emotional and practical supports to address VAD workforce wellbeing; and adequate remuneration and recognition of the VAD work undertaken. Some of this work has begun with the new DoH remuneration scheme for VAD practitioners. Part of this recommendation also relates to the resourcing of statewide services to provide the grief and bereavement support discussed earlier in the Report.

Recommendation 21

Review current VAD practices and workload of existing VAD workforce (including VAD providers and those who have a role in VAD such as statewide services and VAD Coordinators) to ensure:

- participating practitioners are provided with adequate workload recognition or remuneration for providing VAD;
- statewide services are resourced sufficiently to provide required services including statewide travel and grief and bereavement support to family and carers; and
- access of the VAD workforce to services to support their self-care and wellbeing.

F. VAD System Design

Participants offered reflections on the VAD system as a whole and on some of the structures in place that make VAD possible both within the community or within an institutional setting. This included reflections on the structure and location of statewide services, management of VAD within a health setting, information-sharing and privacy constraints, integrating VAD within health care and palliative care and the relationships and interaction between the VAD Board, its Secretariat and the DoH.

1. Structure and Location of Statewide Services

In WA, the VAD system is supported by two statewide services, the SWCNS and the SWPS. The statewide services are managed by two metropolitan health service providers, the South Metropolitan Health Service and the North Metropolitan Health Service respectively. These services are designed to operate only during business hours,[187] and they service the entire State. There are Regional VAD leads in each of the regions, but there are no designated regional Statewide Care Navigators, nor regional Statewide Pharmacy hubs.[188]

[187] Although, it is noted that sometimes regional travel and flight availability has necessitated that these services operate outside of hours.

[188] Haining, Willmott and White, n 31.

Participants' Submissions and Evidence

As noted above, there was universal high praise from participants for the statewide services, and the professionalism and compassion of staff within those services.[189] However, several suggestions were made for how the services might be improved.

Merging the Statewide Services

Participants had mixed views on the structural arrangement of the statewide services. Some participants suggested that the co-location and merging of the statewide services would help streamline operations. Some participants referred to the Queensland model as worth considering.[190] But other participants were of the view that now that the structures supporting VAD in WA had already been established, it would be impractical to merge the services:

> I think definitely the Queensland model is much more advanced in that way than ours … there's so much duality between [the SWCNS and SWPS] roles that it would allow for a little bit more scope when one team is busy or the other team is busy. [The SWPS] do sometimes still do joint visits with the [SWCNS] and work in collaboration. [The services] have weekly meetings. [There have been attempts to try] to set up the patient information system to speak between [the two services] so there's a little bit more collaboration. [Participant 11]

> If we were going to do it again, I'd say combine it generally. But … it's very, very hard to do changes like this once they're in. Because you've got infrastructure problems; you've got budget problems; you've got personality elements around it. This will not get changed unless it's significantly broken … I do think that there's advantages to a point with our model relative to others. With our model you'll get hyperfocus from a Chief Pharmacist who's very aware of navigating complex medicines problems because they come under that portfolio. But you would never want a Chief Pharmacist managing a Care Navigator Service because that's well outside their scope … I think if you've got that sequestered under a Care Nav role, there might not be the organisational knowledge or the ability to do a lot of complex change management as it relates to VAD medicines. [Participant 10]

Centralised or Decentralised Statewide Services

Participants also offered reflections on the centralised nature of the statewide services. They did not consider the centralisation of the SWPS was necessarily acting as a barrier to timely access to VAD substances. However, some conceded that there were some logistical barriers because of travel constraints of individual practitioners and flight availability. One participant suggested that utilising private providers for flights may help to address some of these issues:

> Where we come into trouble … is when Qantas is striking and there's no other option … whether or not there are some other airlines that [could be considered] that are being used currently in a private capacity. [Participant 11]

The possibility of alternative models, such as the hub-and-spoke model, were raised by participants, but there was not universal support for change.[191] For those supporting no change to the current structure, some pointed to perceived feasibility issues and resourcing constraints, as well as the absence of steady demand in particular regions. However, other participants could see the benefit of permitting storage of prepared kits in regions with higher demands (eg Great Southern region). This approach would have the added advantage of limiting the need to store the substance in a practitioner's home (and mitigate some of the concerns with respect to storage practices discussed in Part IIID4), in cases where the substance was dispensed early to facilitate access to the substance if the patient deteriorated quickly:

> I think one of the things at the moment is for a start we don't have enough regular supplies to any one region. We'll have a peak in one area and then we don't have any supplies there for two months. So, supporting someone to work in that region, having medication supplied in that region and managing the

[189] The pivotal role of the statewide services has previously been acknowledged see Sellars et al, n 110, 7; White et al, n 23, 214–215; Willmott et al, n 23, 127.

[190] In Queensland, QVAD-Support (SWCNS equivalent) and QVAD-Pharmacy service are both operated out of the same health service provider, Metro South Health.

[191] Such reflections are consistent with previous evidence see Haining, Willmott and White, n 31.

> expiries, supporting that person from a debrief and a grief and bereavement from a staff member point of view I think would be really difficult … Whether or not there's some other options for supporting storage of a kit that [has] already supplied somewhere external to the practitioner's home. For instance, we have some lockers like the Australia Post lockers that we currently use for practitioners to drop off prescriptions. [Participant 11]

One participant suggested that the medications used for VAD, especially those used in the practitioner IV protocol, were not unusual and could appropriately be dispensed by a local pharmacy in regional areas:

> I mean it's certainly not efficient to me, that two human beings spend six hours in a car to come to me when the IV drugs are next door in my theatre, or they're in my [Emergency Department]. So, for the IVs, delivering to me, who's done lots now … it seems ridiculous to me that they have to come and give me the drugs when I could get them from next door. [Participant 32]

Some expressed a desire for VAD Care Navigators to be located in some of the regions. In one of the regions there were a growing number of VAD practitioners who were not known to the SWCNS (because they did not provide consent for their details to be released to the SWCNS). Hence, when VAD enquiries were coming through the SWCNS, the RASS was being used to service this region instead of these local practitioners. This was regarded as a waste of time and resources. In other cases, where VAD requests were coming from the community in a particular regional area, there was a reliance on particular VAD practitioners to coordinate appointments and link patients up with other practitioners, which meant they were unofficially fulfilling a Navigator type role unfunded:

> I get quite a few where no Navigators are involved, then I end up doing the Navigator role, I guess down here... Because sometimes involving the Navs just is an added layer of complexity to me. So then I'm organising the day – I'm having to negotiate with both the patient and the Navigator and it makes my job harder, not easier. If there was a local Navigator, they would be doing that job. [Participant 32]

Resourcing Levels

There was an overwhelming call for greater resourcing of the statewide services (also noted earlier in recommendations to provide supports for the wider VAD workforce).[192] While both services were currently able to meet demand, there was little, if any, time to devote to quality improvement initiatives, training and upskilling. Some participants observed that they needed to deprioritise some activities (such as follow-up checks and grief and bereavement support) because of a lack of time.

Some suggested initiatives to support statewide service staffing during periods of high-demand or when staffing levels were down. One solution posed by a participant was to employ health service VAD Coordinators as part of the SWCNS:

> We have health service [VAD] Coordinators and Statewide Care Navigators. Each health service [VAD] Coordinator is like one person in a hospital. I think that the [VAD] Coordinators should be part of the Care Navigator Service that work on rotation in the various hospitals, but ultimately from the perspective of being able to provide you know backfill leave management, training support etc. should be part of the Care Navigators. [Participant 19]

Need for Out of Hours Support

Multiple participants also expressed a desire for the statewide services to operate outside of business hours. It was acknowledged that while the system goal is for VAD not to be seen as an emergency service, in practice it sometimes is:

> One of the big drawbacks [of the statewide services] is they are not available outside office hours
>
> … that is, having someone on roster who's on duty with a phone afterhours. And surely that could be done and surely it should be done. And it won't be very expensive … [VAD] is an emergency service, and it's really important. [Participant 14]

[192] The need for additional resources was identified by the WA VAD Board see *WA VADB 2021-2022 Report*, n 12, 38.

Issues Identified

The statewide services play a critical role in the effective functioning of WA's VAD system and are highly regarded by participants. However, some participants did raise for consideration structural questions about whether the services should be merged and whether they should be decentralised to provide a greater regional presence.

Recommended Responses

While it may be premature to review current structures now, future reviews should consider the current structure, processes, and resources of the statewide services to ensure they are delivering care optimally, and in a sustainable manner. Examination of other Australian models, and emerging evidence about such models, should inform any future review.

Importantly, while the authors are suggesting that these issues should formally be considered as part of future reviews, some of these suggestions could be implemented at an earlier time, if deemed appropriate. Indeed, some issues such as regional spokes could be implemented now and are already contemplated in the current Access Standard.[193]

Recommendation 22

Future reviews should consider whether the current structure, processes and resources of the statewide services are optimal for service delivery, including:
- whether greater integration of statewide services is desirable;
- whether Statewide Care Navigators should be located in regions with high VAD activity;
- whether regional hubs should be established to dispense medication; and
- whether out of hours support should be provided by the statewide services.

2. Managing VAD within a Health Service

The implementation of VAD within institutional settings often requires several policy decisions to be made including the level of participation in VAD and what institutional structures and policies are needed to facilitate service delivery. These decisions are generally made at the executive level (sometimes with input from staff or community).[194] In the context of large health services, significant resourcing is often needed to develop the necessary structures and policies to deliver VAD.[195]

As noted in Part IIIB4, in the case of WA health system entities, the *Managing Voluntary Assisted Dying Policy*[196] requires them to have local policies and procedures in place to manage VAD processes. Outside this, however, health service providers do have discretion as to how they approach the management of VAD at a local level.

Participants' Submissions and Evidence

Participants identified that across the main health service providers there was variation in processes and funding, which impacted care delivery. This extended to different staffing models and funded staff allocations, as well as support for different VAD activities:

> Although processes were set up at the start of the legislation, how things have transpired and worked in real time probably doesn't really fit with what was anticipated. I think there's some of the gaps that we all know that are there … [We] probably need to look at some of those policies and procedures and guidelines

[193] The Access Standard provides for the development of a VAD Pharmacy Service which is required to provide services statewide "either directly from the metropolitan service or via an Authorised Supplier network of regional spoke services" see *Access Standard*, n 25, 2.

[194] K Auret, T Pikora and K Gersbach, "Being a Safe Place: A Qualitative Study Exploring Perceptions as to How a Rural Community Hospice Could Respond to the Enactment of Voluntary Assisted Dying Legislation" (2022) 21 *BMC Palliative Care* 2.

[195] Rutherford, Willmott and White, n 23, 1070.

[196] *Managing VAD Policy*, n 69.

> that we have. Especially when there are multiple health sites involved and each health site … has their own way of doing things and their own way that they want things to function. [Participant 7]

Furthermore, participants observed that credentialing has proven to be difficult within some settings due to different approaches taken by health service providers. While some health service providers were able to expedite credentialing for practitioners for the purposes of VAD, this was not widespread and very much depended on the executive:

> It's so … hard to get GPs credentialed to come into hospital to offer this care. I mean I feel like I've literally been climbing mountains trying to get this messaging across. [Participant 33]

Issues Identified

There will always be some degree of variability with respect to how health service providers deliver care. Since the legalisation of VAD in WA, each health service provider has determined their own model of care for VAD, based on a range of considerations including the resourcing available to them. This has resulted in variability of service provision, and access difficulties for some patients.

Recommended Responses

To enhance consistency in how VAD is provided, the DoH should consider whether further guidance should be provided about managing VAD within health services. Such guidance would ideally extend to credentialing to help promote consistency of approach.

3. VAD-IMS and Mandated Forms

There are several reporting requirements imposed on practitioners who participate in the VAD process. They are required to complete forms that are provided to the VAD Board via an online information management system (VAD-IMS). Only VAD practitioners who have completed the WA VAD Approved Training are provided with a VAD-IMS account.

Participants' Submissions and Evidence

Participants largely spoke positively about the VAD-IMS.[197] Indeed, despite the administrative burden and occasional technological glitches, participants suggested that the VAD-IMS provided a sense of comfort to practitioners. Specifically, participants observed that the VAD-IMS assists practitioners to step through the process and complete the necessary steps and documentation in the correct order. This acts as assurance that they are complying with their legislative requirements:[198]

> The request for the assessment process works. It works very well because we have VAD-IMS. And the confidence of the Secretariat and the Board's confidence of the request and assessment process as well comes from the forced functions that exist in VAD-IMS. [Participant 21]

Participants also identified that support provided by the VAD Board Secretariat was readily available when they encountered difficulties. However, practitioners did not always know who they should be contacting for support on different issues, and hence were, in some cases, seeking help from the wrong team (particularly in relation to VAD-IMS matters):

> I think there is confusion from clinicians around who's who in the zoo in the roles. Because they'll [contact the Secretariat and say] I need my statement of completion to give to [my] health care service and it's like, "Oh no, no that's End of Life Care", and then they'll ask the End of Life Care team for something and then they'll ring up the Care Navigators and say, "Why can't I access VAD-IMS?" [Participant 16]

Participants also identified other areas for improvement. In particular, participants expressed frustration with some of the forms, and highlighted that the forms had not been reviewed since the scheme began. Participants identified that some of the forms contained legalese and identified that they were challenging to navigate and complete. The layout of some of the forms resulted in some sections (such as signing)

[197] Positive sentiments about the WA VAD-IMS system have been reported elsewhere see Haining, Willmott and White, n 1, 739.

[198] Sentiments about the VAD-IMS ensuring compliance have been expressed elsewhere see BP White et al, "Prospective Oversight and Approval of Assisted Dying Cases in Victoria, Australia: A Qualitative Study of Doctors' Perspectives" (2024) 14 *BMJ Supportive and Palliative Care* e1462.

being wrongly completed, or not completed at all. Participants also suggested that some of the forms (such as the Contact Person Appointment Form) would ideally be signed earlier in the VAD process:

> There's quite a number of issues with some of the forms. Particularly that consent form which three years down the track, I now feel like I can mostly sign it in the correct spots each time. But it does my head in every time … Some of the forms [the issues are] just around the processes of practicality. It would be really helpful for someone to be able to print out the consent form with the filled in documentation prior to the second assessment … So that if you're going to someone's house for the second assessment, then you can also witness the consent form on the same day without needing to find a printer at whatever time that is after that meeting. And similar with the contact person form, it'd be great to have the contact person form available before you've done some of the other stuff. [Participant 6]

Issues Identified

Although the VAD-IMS is generally operating well, practitioners are still encountering some difficulties in completing forms correctly. Participants also identified some system design features which could benefit from being more streamlined (eg availability of particular forms at different times of the process).

Recommended Responses

The DoH should continue to review current reporting systems and update them as appropriate. The DoH should ensure practitioners are aware of appropriate contacts to provide support when they encounter system issues. The DoH should also consider a review of the forms to enhance useability and to reduce technical errors.

4. Information-sharing and Privacy Constraints

Sections 106 and 151 of the *WA VAD Act* restrict disclosure of personal information and information about the VAD system more generally. These restrictions aim to protect privacy and promote confidentiality with respect to a patient's medical condition and end-of-life choices. However, restrictions on information-sharing can create practical challenges. In practice, appropriate information-sharing optimises patient experience, promotes continuity of care and ensures safety. In the VAD context, restrictions placed on certain personnel accessing the VAD-IMS have the potential to disrupt patient care management.

Section 106 provides that "[A] person must not, directly or indirectly, record, use or disclose information obtained by the person because of a function that the person has, or at any time had, under this Act". This provision applies to personal information,[199] but does not apply in certain cases including when the disclosure of information is "for the purpose of performing a function under [the] Act",[200] or where written consent is obtained.[201] Failure to comply with this requirement constitutes a criminal offence. Section 151, on the other hand, limits the extent to which the WA VAD Board can disclose information. Specifically, this section permits the disclosure of information (other than personal information) to specified persons or entities[202] on request.

Participants' Submissions and Evidence

Information-sharing and access to clinical information in the context of VAD is important to ensure the VAD process runs smoothly. This is particularly so because people responsible for the patient's care, whether they be VAD practitioners, VAD Coordinators or statewide services' staff, often do not have a pre-existing therapeutic relationship with the patient. Also, in many VAD cases, there is a need for care co-ordination within a particular care setting, and sometimes between care settings (eg if a patient is transferred from a residential facility to a hospital setting). Access to information about VAD is also important in the context of quality improvement and targeted education.

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[199] *Voluntary Assisted Dying Act 2019* (WA) s 106(3).

[200] The *Voluntary Assisted Dying Act 2019* (WA) does not include detail about who is considered a person performing a function under the Act. At the time of writing, no specific guidance on this or s 106 in general is available on the WA DoH website.

[201] *Voluntary Assisted Dying Act 2019* (WA) ss 106(2)(a), 106(2)(f). The authors note that s 106(2) also lists other exceptions.

[202] This includes a public authority as defined in s 6 of the *Health Services Act 2016* (WA), or a person or body for the purposes of education or research.

Restrictions on VAD-IMS Access

Some participants whose role was to support a patient to access VAD experienced challenges accessing relevant information. In particular, participants identified the inability of the SWCNS and VAD Coordinators to access information in the VAD-IMS.[203] Participants advised that such access would have been useful, for example, to contact individuals who lodged a first request (and who may require further support in connecting to a VAD practitioner), or more generally to assist a patient with their VAD care co-ordination. Some participants suggested that the inability to access the VAD-IMS was due to certain personnel not being explicitly recognised under the *WA VAD Act*. Some noted that other jurisdictions (eg Queensland) permitted their equivalent care co-ordination staff to access their online portal:

> We have the Care Navigator service that plays … probably besides from an individual VAD practitioner the most pivotal role in the process, and they are an entity that cannot be replicated… [but they] that don't have a function under our legislation. The Board … can share information that they access through their performance of their functions under the Act for the purpose of performing a function … [The way] VAD-IMS was established was that information is only shared with people through our VAD-IMS for people that are performing functions … [So] having a system that [recognises their role] … would facilitate improved information sharing... There could be changes to the way that the legislation is actually written, that actually would support the Board in transferring … mandatory movement of personal information without having to seek consent. [Participant 19]

It was also noted that the SWCNS and VAD Coordinators were often the first port of call to support practitioners needing assistance with the VAD-IMS. The inability to access the system restricted their ability to provide practitioners with troubleshooting support:

> [The SWCNS and VAD Coordinators] are often the point of first call from practitioners who are struggling, particularly new practitioners or those that don't see patients often. So, [practitioners] forget that [the SWCNS and VAD Coordinators] don't actually have access to the IMS system to know how to navigate it and guide them. [Participant 5]

Frustration was also expressed by participants in relation to the inability of nurse practitioners, who were acting as administering practitioners, to access the VAD-IMS for purposes of accessing clinical information about their patients (including previous VAD assessments):

> [The nurse practitioner role is limited to] the very end and it can be where a practitioner is overseas or not available to do the admin and then [the nurse practitioner] get[s] asked the day before or two days before, "Quick, this person needs admin in two days' time, or tomorrow can you do it?" [Without] getting a handover, knowing what's wrong with the patient. [They] might be told the person's got breast cancer, but … know nothing else about that patient … it would be helpful [for] nurse practitioners just to be able to see those assessments and just get a bit of background information on the patient. [Participant 29]

One participant, while conceding these challenges, did emphasise that the VAD-IMS was designed to promote compliance with the Act rather than serve as a digital medical record:

> The Act is very prescriptive, and the steps of VAD-IMS follow that. But the expectation from clinicians is it's actually part of a medical record … That wasn't the intention when it was set up, but I think that's how clinicians see it. They see it as the patient's medical record for VAD. [Participant 16]

Challenges of Managing VAD Patients within a Care Setting Due to Disclosure and Documentation Restrictions

Section 106 was also thought to raise challenges for documentation practices and information-sharing within particular settings. Some participants suggested there was a degree of uncertainty about whether information about VAD could be lawfully included within a medical record. This lack of clarity was thought to introduce a degree of vulnerability and anxiety for those working in the field and was considered particularly impractical within the health service provider setting:

[203] The WA VAD Board has identified a need to permit information to be shared with people who are critical to the delivery of VAD such as the SWCNS and VAD Coordinators. The Board recommended for the *Voluntary Assisted Dying Act 2019* (WA) to be amended so such personnel were designated a function under the Act, see *WA VADB 2022-2023 Report*, n 12, 56.

> The absolute opposing situation of a tertiary multidisciplinary setting where practitioners and those of us that are having conversations that are required to document something and not allowed to give away any information about it. It's nonsensical and has been difficult to get clarity from the Department and legal people … We know in every other sphere of medicine that good collaborative multidisciplinary care keeps people safe and delivers better outcomes. I think there needs to be some clarification around that. [Participant 5]

Participants noted that the restrictions did not apply when the patient provided written consent. However, they commented on the impracticality of routinely seeking patient's written consent to record clinical information:

> And that amongst us all we can ask, "Are you involved with this? What have you done so far? Where are things up to?" Sometimes when a patient – I can't get access to the patient to get that written consent to then have the conversation. It just gets in the way of smooth, streamlined care. [Participant 5]

Participants also identified as challenging the inability to share information with certain personnel directly involved in caring for the patient:

> In regards to … Section 106 … we have been so working hard at integration into the hospital system … How does that work in a hospital ward setting when this is stuff that the rest of the ward needs to know? But I'm technically not supposed to share, but also, we're trying to make this part of usual care. … We used to joke about it that we would – especially early days – it'd be like secret squirrel, no one knows anything about it. It's totally confidential. Then the patient [is] in Room 3 and every time the cleaner goes in or the person [is] asking [them] what they want for dinner, the first thing the patient says is, "I don't need dinner because I'm doing VAD tomorrow". [Participant 6]

Complexities were also observed regarding the lack of knowledge about the patient's decision to access VAD by some staff not directly involved in the patient's medical care. However, restriction on information-sharing in relation to these personnel seemed to be more palatable to participants:

> Staff were really challenged by, "There's something going on here and I don't know about it, and I can see a group of my teammates crying", on the day when the administration occurred. So that was a challenge around then having conversations with the staff who didn't know to say, "Look, something has occurred, and yes, people are upset, but they are being supported and for reasons of privacy, I can't and won't be telling you what's going on". [Participant 37]

Restrictions Placed on the Ability of the WA VAD Board to Proactively Release Information

A final and specific issue raised by participants relates to the restrictions imposed by s 151. This provision allows the WA VAD Board to release information for the purpose of education or research. However, release of information is only allowed "on request". This provision was thought to limit the ability of the Board to proactively release information when it considered it appropriate to do so:

> The Board currently can release information for education and research on request … this creates some issues where the Board is the holder of all information, and they might also then identify … education needs … I think they would very much like to be able to proactively use the information that they hold to educate... if they're going to undertake their monitoring function and go and meet with people to make sure the Act is running OK … In reality, there might be an educative component to that as well … [I]t's just stupid to say, "We're coming to see you and you want the Board to come and talk to you, can you request this information we'd like to tell you about?" [Participant 19]

Issues Identified

Current practices and restrictions in relation to information-sharing have negatively affected the ability of VAD practitioners and other VAD staff (eg the SWCNS and VAD Coordinators) to deliver appropriate care to patients.

Current restrictions also have the potential to make information sharing by the Board, in the process of carrying out its functions, unnecessarily complex.

Recommended Responses

System modification is needed to ensure those who have a direct role in supporting VAD access for a patient can carry out their functions effectively. This could be achieved through legislative amendment

or through clearer guidance on what is currently permissible and ways in which information-sharing practices can become more streamlined.

To effectively and efficiently carry out its functions, the Board should have the ability to disclose relevant information without first receiving a specific request to do so. Changes to legislation and/or practice should be considered to facilitate this.

Recommendation 23

Consider strategies such as legislative amendment or modification of system design to permit individuals who are fulfilling a role under the Act to have access to the information needed to undertake that role.
This would include:
- access to clinical information and medical records (which may include information about VAD) needed to assess eligibility or support a patient's VAD process; and
- access (including for the SWCNS, VAD Coordinators and nurse practitioners acting as administering practitioners) to the VAD-IMS as needed to support a patient's VAD application.

Recommendation 24

Consider changes needed to legislation and/or practice to ensure the WA VAD Board can use information it receives to effectively and efficiently carry out its functions.

5. Relationship between VAD and Palliative Care

VAD is a new end-of-life choice. To date, the extent to which VAD has been integrated within end-of-life care and palliative care varies across the State. Some in the palliative care community remain opposed to VAD on the basis that VAD is incompatible with palliative care philosophies.[204] But others in the palliative care workforce support VAD choice and advocate for both forms of care to co-exist. There are also mixed views about whether VAD should be formally incorporated within palliative care or remain distinct.[205] The WA Board's reports indicate that most people electing to access VAD also access palliative care concurrently.[206] However, participants noted that very few palliative care specialists were trained VAD practitioners.

Participants' Submissions and Evidence

Participants shared mixed experiences regarding interaction with palliative care. On the positive side, there were reports of VAD and palliative care services in some institutions operating in parallel. Some palliative care staff supported patients accessing VAD even if they personally (or their institution) did not support VAD in principle. Such experiences provided comfort to patients and facilitated continuity of care. VAD practitioners also felt that the support from palliative care colleagues was critical to their ability to carry out their work:

> I think that they co-exist well. I think that what needs to happen is very clear communication between the patient and their doctor and the clinical team about what the expectations are in terms of timelines … But,

[204] For reflections on the current tensions between palliative care and VAD and calls for it to be more streamlined see, eg, CJ McLaren and G Mewett, "Update on Voluntary Assisted Dying in Australia" (2021) 215(3) *Medical Journal of Australia* 115; Rutherford, Willmott and White, n 23, 1069.

[205] For different views about the relationship between VAD and palliative care see, eg, K Auret et al, "'Respecting Our Patients' Choices': Making the Organizational Decision to Participate in Voluntary Assisted Provision: Findings from Semi-structured Interviews with a Rural Community Hospice Board of Management" (2022) 21 *BMC Palliative Care* <https://doi.org/10.1186/s12904-022-01051-x>; SM Blaschke et al, Common Dedication to Facilitating Good Dying Experiences: Qualitative Study of End-of-Life Care Professionals' Attitudes Towards Voluntary Assisted Dying" (2019) 33(6) *Palliative Medicine* 562; CM Haining, LA Keogh and LH Gillam, "Understanding the Reasons Behind Healthcare Providers' Conscientious Objection to Voluntary Assisted Dying in Victoria, Australia" (2021) 18 *Journal of Bioethical Inquiry* 277; J Phillip, "Palliative Care Physicians' Preparation and Planning for the Implementation of the Voluntary Assisted Dying Act in Victoria" (2021) 51(10) *Internal Medicine Journal* 1559; Rutherford, n 26; Rutherford, Willmott and White, n 23, 1069; E Waran and L William, "Navigating the Complexities of Voluntary Assisted Dying in Palliative Care" (2020) 213(5) *Medical Journal of* Australia 204.

[206] *WA VADB 2021-2022 Report*, n 12, 20; *WA VADB 2022-2023 Report*, n 12, 23.

> really, what I would say about palliative care and VAD is that conversations about symptom control are imperative and keep going all the way along the VAD journey. [Participant 36]
>
> I was actually thinking what's working well is the relationships are better than I expected them to be three years down the track. From a hospital perspective, palliative care generally it hasn't all fallen apart … I think that real sense of trying to build respect and relationships has been a good approach. [Participant 6]

However, negative encounters were also experienced by stakeholders, with participants commenting that the absence of support from palliative care staff made the delivery of VAD challenging. Many participants observed the inability of patients to access VAD if they were receiving palliative care in religiously-affiliated institutions. Further, participants commented that there were many strong personalities in palliative care and their staunch opposition to VAD has led to hostile encounters between palliative care and VAD staff, as well as hostile behaviours towards patients and their families. Participants reported conduct including abandoning patients, withdrawing palliative treatment, condemnation and rudeness to patients seeking VAD. It has also resulted in VAD practitioners' eligibility assessments being challenged, and refusal of hospice care:

> I think it's an institution by institution thing, and an individual by individual thing … I have had pushback by... [palliative care] colleagues in the state … I can only talk for hospitals in my region, but the big hospital in my area is run by a service that is so fearful of VAD that it rolls over into their professionalism. It's no longer patient-centred. It's their centred. And it is extremely bad, is all I can say … [T]hat palliative care service has impacted the delivery, even the rolling out of FTE which finally came. And they're impacting clinics being set up because they don't [do VAD] under the palliative care tier of clinics. [Participant 28]

In other cases, opposition to VAD manifested more subtly. For example, participants reported that palliative care staff provided false hope and promises that the patient's suffering would be alleviated once medication is re-titrated to deter patients from pursuing VAD. In some cases, patients decided to abandon the VAD process, because they perceived they would receive sub-optimal care if transferred to another institution (eg public hospital) to receive VAD:

> I think they did like make a few false promises... And I think there was a lot of time wasted with [Specialist Palliative Care Service] promising once we change this or re-titrate this medication things would be better. And like, it never got better. [Participant 2]
>
> [The patient's] three nights in [the Public Metropolitan Hospital] was so horrendous in a group room of four people, there's no way I wanted him back at that Public Hospital. It wasn't an acceptable place to be, except for a consultation … And it's not their fault, the public system is overloaded. He wouldn't have got even the care that he did get … Going to [the Public Metropolitan Hospital], was an option for VAD to occur, but it wasn't an option for [the patient]'s quality of life to go back to a ward there. [Participant 35]

Issues Identified

Despite some pockets where VAD and palliative care practitioners are working well together, there is evidence that, in some settings in WA, this is not occurring, and this can affect the quality of patient care.

Recommended Responses

While there is some evidence internationally that, over time, VAD can successfully exist in tandem with palliative care,[207] the DoH may wish to consider steps to engage leaders in the palliative care and VAD fields to collaboratively expedite this cultural change.

6. Structure and Interaction between DoH, VAD Board and VAD Board Secretariat

The WA VAD Board is an independent body created by the *WA VAD Act*.[208] It has a range of functions set out in the legislation including monitoring the operation of VAD within WA.[209] The Board is supported

[207] See, eg, SM Gerson et al, "The Relationship of Palliative Care with Assisted Dying is Lawful: A Systematic Scoping Review of the Literature" (2020) 59(6) *Journal of Pain and Symptom Management* 1287. Similarly, a Palliative Care Australia Report noted that, "[i]f anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced" see Palliative Care Australia, *Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care: Final Report* (Aspex Consulting, 28 October 2018) 5.

[208] *Voluntary Assisted Dying Act 2019* (WA) s 116.

[209] *Voluntary Assisted Dying Act 2019* (WA) s 118.

in its functions by a Secretariat which is staffed by DoH employees. The DoH's End of Life Care Program also has carriage of the delivery of VAD (eg through managing the practitioner verification process, developing resources, contract management for statewide services and the WA VAD Approved Training).[210] All of these bodies work together to deliver VAD in WA.

Participants' Submissions and Evidence

Only a limited number of participants raised existing structure as an issue to be addressed. Participants noted complexities in the current structure of the VAD Board, the Secretariat, and the DoH's End of Life Care Program team. Participants also questioned whether the Board could carry out its functions effectively and independently when supported by a Secretariat that is staffed by employees from the DoH and emphasised the need for the Secretariat to work in a confidential environment:

> [Having the] Secretariat in the confidential environment within the Health Department is critical – is really important … it [has been] about those relationships. And this whole notion that [you] have to build relationships with these people, I get it, but that's not the reality of the bureaucracy. So how does the bureaucracy work to support an independent Board and a Secretariat and all the other components that [are] operating within? [Participant 25]

Some participants also raised concerns about the ability of the Board to carry out its functions without a dedicated budget (that was subject to its control) or independent advice:

> The Board is independent … [but] they get their support through the Department … I think realistically the Board would probably prefer the independent legal advice to the Department, because … [the] legal advice [they get] from the Department is protecting the Department, not necessarily protecting voluntary assisted dying. [Participant 19]

However, a subset of participants considered that despite potential structural issues, in practice, the current approach was working. Many of these participants thought this was due to the specific personnel currently in these roles and the relationships fostered. Participants surmised that any changes to such personnel in the future had the potential to create risk that the system might not function in the same positive way.

Issue Identified

The ability for the VAD Board to maintain independence and carry out its legislative functions is a critical safeguard of the WA VAD system. Yet the current structure creates potential tensions for this independence.

Recommended Response

The authors recommend, for future consideration, that the current VAD oversight structure (Board, Secretariat and DoH) be reviewed to determine whether this is the optimal oversight structure to enable the Board to perform its legislative functions.

Recommendation 25
Future reviews should consider the optimal VAD oversight structure, including that which supports the VAD Board to operate independently and carry out its functions.

IV. Conclusion

This Report has identified that while the WA VAD system is generally operating well, there are several opportunities for improvement. The authors have offered a series of evidence-based recommendations to inform the inaugural review of the *WA VAD Act*, however, ongoing review remains critical. Future reviews should consider issues beyond the current terms of reference and any future reform should also be evidence-based.

[210] *WA VADB 2022-2023 Report*, n 12, 42.

SUPPLEMENTARY MATERIAL 1 – ADDITIONAL QUOTES

Sub-theme		Quote
Community awareness	Increasing level of awareness of the community	We almost celebrate at the moment, even if it's negative press, [because] at least people are becoming more aware of VAD as an option. So, it's definitely an area that needs growth. [Participant 11]
		I think there is increasing community awareness now that we're seeing people who are referring to – well, I know that my friend's aunt did VAD … that just friend of a friend … But at the same time, I think there is a lot of misinformation and just lack of information. [Participant 6]
Health Practitioner awareness	Perceptions of current awareness	Doctors probably know that it's there, but they choose not to become very familiar with it unless it gets close enough to them that they sort of have to. [Participant 23]
	Current resources not necessarily targeted or apt	The Guidelines are a fantastic resource, but the people that we're dealing with haven't read the Guidelines. Or they've read the Guidelines very superficially because they've gone, "Someone's just asked me about voluntary assisted dying and I'm a baby doctor, what do I do?" [Participant 19]
	Need for an overarching strategy	I think the issue is that whilst … [a] training module … can sit on [a] website, if we don't have that sort of ability to be engaging with different organisations and feeding it out … it's going to be less value. [Participant 19]
Limits on raising VAD		I think that the inability of particular health professional groups to raise voluntary assisted dying proactively with people, mean the type of people that are likely to be delivering ongoing care and having ongoing relationships with people towards end of life … aren't able to be proactive. So, combine that lack of general knowledge and the inability to actually be given information in the context of a consultation or your care being provided by a non-medical practitioner or a nurse practitioner, I think that that is probably the big issue that we have there in terms of awareness and access. [Participant 19]
First Request	How to lodge a first request	There is confusion by doctors knowing that even if they … [refuse] a first request [on the VAD- IMS], they often think that is a referral. [Participant 32]

Individual Conscientious Objection	Spectrum of conscientious objection	So, in our hospital in [Regional Town] we had a lot of referrals from conscientious objectors [to one of the VAD practitioners and VAD Regional Lead]. [Participant 31]
	Conscientious objectors steering people away from VAD	[Some doctors say to patients] "You won't be eligible [for VAD] anyway, there's no point", and a whole host of permutations of those conversations. Sometimes done with good intention, sometimes not. [Participant 3]
	Deny access to clinical information	I just want to say rural areas – the issue I have with prognostication is you've got a very limited pool of specialists, and you may need a specialist to give the prognosis. And if your regional specialist is a conscientious objector, it makes it quite difficult … A lot of specialists don't want to see a patient if it's only about prognostication for VAD. I had this issue early on with a neurological case. I got turned down by four different neurologists in Perth, and my regional neurologist was a conscientious objector. [Participant 31]
	Lack of recourse for breach of conscientious objection obligations	There's no teeth in this; there is no one to monitor it. [Participant 30]
	Support for educative approaches to achieve cultural shift	I think there's potentially a lot of on the ground work that could be done to promote those kind of culture champions. Because I think even one of our practitioners gave us example … that at one of our public hospitals we have a number of [practitioners from speciality X] that are trained, but at the other metropolitan public hospital – which is only however many kilometres down the road – they have no [practitioners from speciality X] that are trained because the head of the department is a conscientious objector. So, if there was a culture champion in both of those settings would we see that kind of representation from both of them? [Participant 21]
Patient-facing resources		The information as well that they can access, the majority of this is on the internet. Many of our patients, elderly, don't have internet access so there's no other way for them to really access the information apart from a GP [or] specialist. [Participant 4]
		The documents have been crafted to minimise risk to the Department of Health, not to minimise risk of the voluntary assisted dying process not working effectively … [I]f they were there to ensure that the legislation actually worked as it was intended, they would be crafted very differently. There is no such thing as six page fact sheet, and there is like no fact sheet that is under six pages because it's all full of legalese. [Participant 19]
Prescription delivery	Restrictions on who can transport the VAD substance prescription	A rando courier or Australia Post is fine, but the people that are walking through the process and employed to do the role are not OK to be hand-delivering a sensitive document. [Participant 5]
Administration	Proportion of practitioner administration	[During] the admin decision the practitioner must give written information but it's on the route that's chosen; it's not necessarily on all the options. [Participant 11]
	Permitting practitioner administration for 'failed' administration	It took about four hours for him – four-and-a-quarter hours between drinking the substance and… biologically just took a bit longer to get where it needed to go. But yes, it was an interesting experience to have it take that long. In hindsight, I think it was positive for myself to be able to say goodbye over that length of time. But my brother found it very difficult … the doctor and the Care Navigator were there the entire time. And I'm eternally, eternally grateful for their presence. [Participant 9]

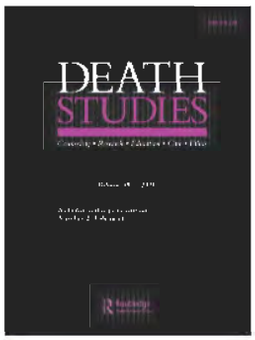
Storage and disposal		To have all this [medication] sitting around that they then are supposed to dispose of distresses them. And while I sort of say that I think that they are careful not to leave anything behind that could be misused by other people, I have to say that it doesn't all get back to the disposer. Probably a lot of it goes down the sink. I mean why would you track it all back to the disposer? I mean it's just ridiculous. [Participant 13]
Contact Person		There's nothing in the VAD Act discussing the need to do education for the contact person. Again, pharmacy have taken that role on but whether or not that's something that should be formalised. [Participant 11]
		In WA we don't follow up with the contact person unless they are at risk of breaching their obligations under the Act, in that we are aware that their substance has not been consumed …. And the mitigation is that the volume of substance is considered to be low enough that the person is consuming it all in one shot, and so there would not be leftovers … I know then that in other jurisdictions they ring every contact person after a death. And that has been a source of useful information and potential risk mitigation. But it's also been something that is traumatic often for [the] contact person and [the] Secretariat … calling someone so soon after the death of a loved one too. [Participant 19]
Supporting and sustaining the workforce	Need for emotional and practical support	We've really almost left it to [doctors to] sort of provide their own self-support arrangements really. And I think we're very fortunate that we have good quality people in the Care Navigator Service and in the leadership of the Community of Practice that sort of do enable that to a reasonable degree. But we don't really have a measure of how well our doctors are supported in this sense … to my mind there isn't enough coordinated support. [Participant 23]
Structure and location of Statewide Services	Need for out of hours support	We need to talk about at some point, this perception that there are no emergencies in VAD because of course there are. [Participant 30]

SUPPLEMENTARY MATERIAL 2 - SUMMARY OF RECOMMENDATIONS

Theme	Sub-theme		Recommendation
Awareness of VAD	Community awareness	1	Develop and implement a public communication and engagement strategy to increase public awareness of VAD.
	Health practitioner awareness	2	Develop and implement a strategy to increase health practitioners' awareness of VAD and their obligations.
Accessing and navigating the VAD system	Limits on raising VAD	3	Consider appropriate legislative and policy changes and education strategies to ensure health care workers can best navigate conversations about VAD, including raising VAD (where appropriate and permissible) with patients.
	First request	4	Through training and education, improve medical practitioner awareness of the first request process and how to respond appropriately.
		5	Improve system design so that a patient who makes a first request is connected with the VAD system.

	Individual conscientious objection	6	Develop strategies to ensure medical practitioners provide Approved Information about VAD to a patient who asks for information about VAD (and not just in cases of a first request).
		7	Develop strategies to ensure medical practitioners provide, as soon as practicable, clinical information about the patient or access to the patient's medical records (with the patient's consent) to a medical practitioner assessing their eligibility for VAD.
	Institutional objection	8	Impose obligations on all entities providing health, aged, residential and other care to facilitate access to VAD.
	Patient-focused resources	9	Review and revise the content, format and accessibility of consumer VAD resources.
Eligibility assessment		10	Future reviews of the WA VAD Act should consider current eligibility criteria for VAD.
Prescription, administration, disposal and post-death	Prescription delivery	11	Broaden the category of individuals who are authorised to deliver a prescription to an authorised supplier.
	Transporting substance	12	When a patient transitions between care settings, facilitate the transport of the VAD substance to the new care setting by another person authorised by the patient to do so.
	Administration	13	Allow assistance to be provided to the patient, if requested, to prepare their VAD substance.
		14	Simplify the process for changing the method of administration including in cases where self-administration is no longer appropriate.
		15	Simplify the process of transferring the role of administering practitioner.
		16	Future reviews should consider amending legislation to permit practitioner administration if self-administration 'fails'.
	Storage and disposal	17	Make changes to legislation, forms, and/or current guidance to: • establish or advise on a specific timeframe for the authorised disposal to occur; and • permit the administering practitioner to possess and dispose of the VAD substance to accommodate all cases where the practitioner is appropriately in possession of the substance.
	Grief and bereavement	18	• Review existing grief and bereavement supports currently available to assess suitability and availability to support individuals affected by a VAD death.

VAD workforce	Expand the VAD workforce including in regional areas	19	Develop strategies and explore opportunities to increase the VAD workforce including: • adequate workload recognition or remuneration for medical practitioners providing VAD; and • payment to complete the mandatory VAD training.
		20	Future reviews of the WA VAD Act should explore the feasibility of expanding the roles of other health practitioners in relation to VAD such as: • nurse practitioners to assess eligibility; and • senior nurses to act as administering practitioners.
	Supporting and sustaining the VAD workforce	21	Review current VAD practices and workload of existing VAD workforce (including VAD providers and those who have a role in VAD such as statewide services and VAD Coordinators) to ensure: • participating practitioners are provided with adequate workload recognition or remuneration for providing VAD; • statewide services are resourced sufficiently to provide required services including statewide travel and grief and bereavement support to family and carers; and • access of the VAD workforce to services to support their self-care and wellbeing.
VAD system design	Structure and location of the statewide services	22	Future reviews should consider whether the current structure, processes and resources of the statewide services are optimal for service delivery, including: • whether greater integration of statewide services is desirable; • whether Statewide Care Navigators should be located in regions with high VAD activity; • whether regional hubs should be established to dispense medication; and • whether out of hours support should be provided by the statewide services
	Information- sharing and privacy constraints	23	Consider strategies such as legislative amendment or modification of system design to permit individuals who are fulfilling a role under the Act to have access to the information needed to undertake that role. This would include: • access to clinical information and medical records (which may include information about VAD) needed to assess eligibility or support a patient's VAD process; and • access (including for the Statewide Care Navigator Service [SWCNS], VAD Coordinators and nurse practitioners acting as administering practitioners) to the VAD Information Management System [VAD-IMS] as needed to support a patient's VAD application.
		24	Consider changes needed to legislation and/or practice to ensure the WA VAD Board can use information it receives to effectively and efficiently carry out its functions.
	Structure and interaction between the Department, Board and Secretariat	25	Future reviews should consider the optimal VAD oversight structure, including that which supports the VAD Board to operate independently and carry out its functions.



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Community knowledge of voluntary assisted dying: a cross-sectional survey of the public in Queensland, Australia

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ABSTRACT

This research, undertaken in Queensland, Australia aimed to explore community members' knowledge of voluntary assisted dying (VAD) 17 months after it became a lawful option. Adults living in Queensland ($n=1000$) completed an online survey about knowledge of VAD as a legal option and awareness of how to access VAD and information about it. Quotas were set for age, gender and geographical region within Queensland. Only 33% ($n=329$) of community members correctly identified that VAD is legal and fewer (26%, $n=257$) reported that they would know how to access VAD if they wished to. Most community members (86%, $n=858$) reported they would access information on VAD online, typically via search engines, and from health and medical practitioners, primarily doctors. Since lack of awareness and understanding are major barriers to seeking and accessing VAD, proactive measures are needed to increase awareness of VAD in the community and among potentially eligible patients.

Introduction

Health literacy is a longstanding barrier to accessing healthcare, with individuals possessing lower levels of health literacy facing greater challenges than those with higher health literacy (Levy & Janke, 2016). Although some contest voluntary assisted dying (VAD) as a form of healthcare, "VAD literacy" has been identified as a significant barrier to access (Voluntary Assisted Dying Review Board, 2023a; White, Jeanneret, & Willmott, 2023). In most Australian jurisdictions, VAD laws now allow a competent adult with a terminal illness to request and receive medication from an authorized health practitioner to end their life, either through self-administration or practitioner administration. However, a recent study of caregivers of patients seeking VAD in Victoria, Australia found multiple "point of access" barriers as access cumulatively depended on: "knowing VAD exists as a legal option; knowing they might be eligible for it; identifying and successfully taking the next steps to connect with the VAD system; and successfully raising and discussing VAD with a doctor" (White, Jeanneret, & Willmott, 2023, p. 2703). A key part of "VAD literacy" is awareness that VAD is a legal option. However, limited research has explored this.

Length of experience with VAD in a jurisdiction appears to improve community awareness. For example, in the Netherlands, where VAD has been lawful for over two decades, the public is now regarded as "reasonably well informed" about VAD (van der Heide, 2023, p. 27). By contrast, after VAD had been available for two years in Oregon, a study of outpatients attending selected primary care sites found only 23% of those surveyed knew it was legal (Silveira et al., 2000).

System design and implementation also influence VAD awareness (White, Jeanneret, & Willmott, 2023). A study comparing Canada and California, where VAD has been legal in both jurisdictions since 2016, found that 67% of Canadians over 60 knew it was legally available, compared to 25% of Californians over 60 (Byram & Reiner, 2024). This disparity was linked to Canada having six times more VAD practitioners and institutional support for accessing VAD (Byram & Reiner, 2024). Other studies have examined VAD knowledge in Canada (actual knowledge and perception of their knowledge), but did not test the threshold issue of whether people knew it was lawful or not (Choi et al., 2024; Oczkowski et al., 2021; Wilson et al., 2019).

Beyond knowing VAD is legal, understanding how to access it is crucial. The Victorian study highlighted

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earlier (White, Jeanneret, & Willmott, 2023), and studies from Canada, report access challenges including lack of clarity around processes (Hales et al., 2019) (Brown et al., 2020) and difficulties in initiating the VAD process (Crumley et al., 2021). The Canada-California study also revealed that only a third of respondents in both jurisdictions felt confident in knowing how to access VAD (Byram & Reiner, 2024).

This literature underscores the need for more research into community-level knowledge about VAD as a legal option as well as access navigation (White, Jeanneret, & Willmott, 2023). This is especially crucial in Australia, where laws restrict whether and how health practitioners can initiate VAD discussions with patients (a unique feature in the states of Victoria and South Australia is that all health practitioners are prohibited from initiating VAD discussions with patients) (White, Archer, et al., 2024). Restricting conversations about VAD has a major impact on public awareness and engagement with the VAD system (White, Jeanneret, & Willmott, 2023). This study reports on a community survey in Queensland, Australia aimed at understanding awareness of VAD legality and how people are likely to access information about it.

Context

Queensland's Voluntary Assisted Dying Act 2021 passed on September 16, 2021. The legalization of VAD was widely publicized through a parliamentary inquiry, public consultations, and media coverage, alongside advocacy campaigns from both supporters and opponents. The Act commenced operation on January 1, 2023, after a 15-month implementation period to create oversight systems, train health practitioners, and establish safe, accessible, and well-communicated VAD request and assessment processes.

A person is eligible for VAD if they:

- Are aged 18 or over;
- Have a disease, illness, or medical condition that is:
  - Advanced, progressive, and will cause death;
  - Expected to cause their death within 12 months;
- Are suffering intolerably because of the disease, illness, or medical condition;
- Have decision-making capacity in relation to VAD, meaning the person is capable of
  - Understanding the nature and effect of decisions about access to VAD,
  - Freely and voluntarily making decisions about access to VAD, and
  - Communicating decisions about VAD in some way;
- Are acting voluntarily and without coercion;
- Are an Australian citizen, permanent resident of Australia, have been ordinarily resident in Australia for at least 3 years prior to making the first request, or they are granted an Australian residency exemption; and
- Have been ordinarily resident in Queensland for 12 months before making a first request, or they are granted a Queensland residency exemption.

Residency exemptions may be granted for individuals with a substantial connection to Queensland on compassionate grounds. Disability or mental illness alone does not make a person eligible for VAD; they must also have a terminal condition and meet all other criteria.

The process of seeking VAD involves multiple steps, including voluntary requests and independent medical assessments, with the option for self- or practitioner-administered medication. Oversight is provided by the Voluntary Assisted Dying Review Board to ensure system compliance. Health practitioners can conscientiously object but in some circumstances are required to at least provide information to requesting patients about the state VAD care navigator service.

Materials and methods

This study explored community members' knowledge of VAD in Queensland, one of Australia's six states, 17 months after it became a lawful option (and a little under three years after the law was passed). Data were collected through an online survey, developed by the researchers with input from the Queensland Health VAD Program Unit, Queensland VAD Review Board and Queensland VAD Support and Pharmacy Service. A draft online survey was piloted on a community sample ($n = 15$) of mixed age and gender between 1–9 May 2024, resulting in minor adjustments: reformatting one question, revising the wording and answer type for another, splitting one question into two, adding a response option to a question, defining technical terms, expanding text box sizes for free-text responses, and improving mobile optimization.

The sample cohort comprised all Queensland residents aged 18 years and over who were included in the Octopus Group database, an online survey provider, at the time the survey was launched ($n = 7362$). To ensure sample proportions accurately reflected the broader population, we set quotas for age, gender and

geographical region within Queensland based on Australian Bureau of Statistics population estimates (Australian Bureau of Statistics, 2021a, 2021b).

The online survey was made available on the Qualtrics survey platform. A survey link was provided to Octopus for distribution. Community members were identified through the Octopus database and invited via email plus app and website notification. Data collection commenced on 29 May 2024. Two follow-up reminders were sent to non-responders and the survey was closed on 11 June 2024 once the target sample of 1,000 completed surveys was achieved.

The project was approved by the Queensland University of Technology Human Research Ethics Committee (approval 8421). Informed consent was obtained from all participants. Participants were provided with a participant information sheet to assist in the process of achieving informed consent. Submitting an online survey was accepted as an indication of consent to participate in the research project.

Measures

The final survey (see Supplementary Material 1) contained 24 questions, and took an average of 7 minutes to complete. Section 1 contained nine standard demographic questions plus a question on relevant professional experience (whether the participant was a professional in health, law or another discipline that might provide any knowledge and experience in this area).

Section 2 contained 14 questions about VAD. Participants were presented with the following definition of VAD developed by the authors: "the practice whereby a person suffering from a terminal illness (that is expected to result in their death) has the right to request a lethal drug from a doctor to end their life." They were then asked, "Do you think that VAD is legal in Queensland?" with response options of yes; no; I don't know. Participants who responded yes were then asked how they knew this with a list of response options including from "other sources" and "can't recall." Multiple response options were available and for each response option selected, participants were asked to provide further details by entering free text, ensuring we gathered specific information related to each choice. Participants were also asked whether they supported or were opposed to VAD being lawful in Queensland (five point scale: strongly support to strongly oppose), prior to the survey informing them that VAD was legal in Queensland. Participants were then asked how likely they would be to personally consider VAD as an option for themselves if they were suffering from a terminal illness (five point scale: extremely likely to extremely unlikely). Following this, participants were asked questions about whether they would know how to access VAD if they wished to and, if they wanted to know more about VAD, where they would look and who they would ask (multiple response options available).

Statistical analysis

Data were imported into SPSS Statistics 29 for analysis. $p \leq 0.05$ was used to indicate statistical significance. Preliminary analyses used descriptive statistics to assess sample representativeness and explore:

- Community awareness of VAD legality and sources of this knowledge.
- Whether participants believed they would be able to access VAD, if desired, and the steps they would take to learn more.

Open-ended responses to individual survey questions and at the end of the survey were qualitatively analyzed to better understand responses and to identify common themes and insights regarding community knowledge of VAD.

Bivariate associations between VAD knowledge and potential predictors (demographics and VAD support) were examined using either chi-squared tests or Fisher's exact tests, depending on the size of the cell counts. Significant variables were then included in two binomial logistic regression models predicting awareness of VAD being legal. Model 1 was run on the full sample. Model 2 excluded health practitioners so we could examine potential unique effects or trends within the health practitioner sub-sample. This approach was taken based on the hypothesis that health practitioners, more so than those in law or other relevant disciplines, are likely to have additional knowledge of VAD_ partly due to specialized training and education—which may not align with the general community's understanding. Using the conditional backward elimination model, we investigated if demographics and VAD support predicted awareness of VAD legality. At each step, variables were chosen based on p-values; a threshold of 0.05 was used to limit the variables included in the final models.

Results

Demographic characteristics of the sample (see Table 1) were broadly representative of all variables except for primary education, which was underrepresented (1% vs 8% in the population). Due to this broad representativeness, survey data was not weighted. Also, health

Table 1. Demographic characteristics of the sample.

Variable	Sample %	Population estimate (census data for Qld) %
Gender		
Female	50	50
Male	50	50
Non-binaiya	0.3	0.2
Age group (years)		
18–24	11	11
25–34	18	18
3 5-44	17	17
45–54	17	17
5 5-64	15	15
65–74	13	13
75 years and over	9	9
Location		
Major city	65	65
Regional and rural	35	35
Countiy of birth		
Australia	77	76
New Zealand	5	4
England	4	6
Other	14	14
Main language spoken at home		
English	91	87
Aboriginal and/or Torres Strait Islander origin		
Yes	2	5
Highest level of educationb		
Primary school	1	8c
Year 10	12	18
Year 12	17	17
TAFE/Technical Certificate/Diploma	34	32
Bachelor degree	24	17
Postgraduate qualification	13	8
No educational attainment	0	1
Relationship statusd		
Never married	23	23
Married	47	45
Separated but not divorced	3	4
De facto relationship	16	13
Divorced	7	10
Widowed	3	5

Note: $N = 1000$. Rounded to nearest per cent.
[a]Census data is for the Australian population.
[b]Census data is for people aged 15 years and over. Population estimate excludes 464,063 persons where educational attainment was not stated/inadequately described.
[c]Significantly different from the population estimate ($p < 0.05$).
[d]Census data is for people aged 15 years and over.

practitioners made up 9% of the sample (12% of participants aged 18–64), compared to 5% of the working Queensland population (Queensland Government Statistician's Office, 2024).

Knowledge of VAD as a legal option

Only 33% ($n = 329$) of community members correctly identified that VAD is legal in Queensland; this figure was 62% for participants who were health practitioners (participants were classified as health practitioners based on their response to the question on relevant professional experience). The largest group of participants (41%, $n = 411$) reported thinking VAD is not legal. Around a quarter (26%, $n = 260$) reported not knowing if VAD is legal in Queensland. The most common response to the question of where people found out that VAD is legal was media or social media (36%). When asked to provide details, the majority of these participants specified that they found out via news reporting. Participants who knew that VAD is legal also found this out through knowledge or experience of family or friend/knowing someone who was interested in VAD (19%, with qualitative comments indicating this was primarily knowing people/knowing of people who had accessed or looked into VAD); and/or own professional knowledge (13%). All other response options were identified by fewer than ten per cent of participants and 22% could not recall how they found out that VAD is legal (see Figure 1).

In bivariate analyses, there was a significant positive association between education level and knowing that VAD is legal ($\chi 2(5, N = 1000) = 18.05$, $p = 0.002$). Knowledge levels were lowest among those with primary school education only and highest among those with university (bachelor or postgraduate) education. There was also a significant positive association between being a professional in health, law or another relevant discipline and knowing that VAD is legal ($\chi 2(1, N = 1000) = 42.650$, $p \leq 0.001$). No other demographic variables were significantly associated with knowing that VAD is legal. There was also a significant positive association between strongly supporting VAD being legal and knowing that VAD is legal ($\chi 2(4, N = 1000) = 39.910$, $p \leq 0.001$).

In multivariable analyses, the final model run on the full sample (Model 1) indicated that being a professional in health, law or another relevant discipline and level of support for VAD were both significant predictors of knowing that VAD is legal (education level was not a significant predictor) (see Table 2). Professionals in health, law or another relevant discipline were 2.7 times more likely to know that VAD is legal than other participants ($p \leq 0.001$). Compared to participants who strongly opposed VAD being legal, participants who strongly supported VAD were 3.1 times more likely to know that VAD is legal ($p = 0.006$). The Cox and Snell pseudo r-square was .086, suggesting that there are other factors not captured by the model that predict awareness of VAD legality. The model was much better at predicting a lack of knowledge about VAD being legal (95.4% accuracy) compared to predicting knowledge of its legality (16.4% accuracy).

The model which excluded health practitioners (Model 2) contained only level of support for VAD (for this sub-sample there were no significant associations between demographic variables and knowing that VAD

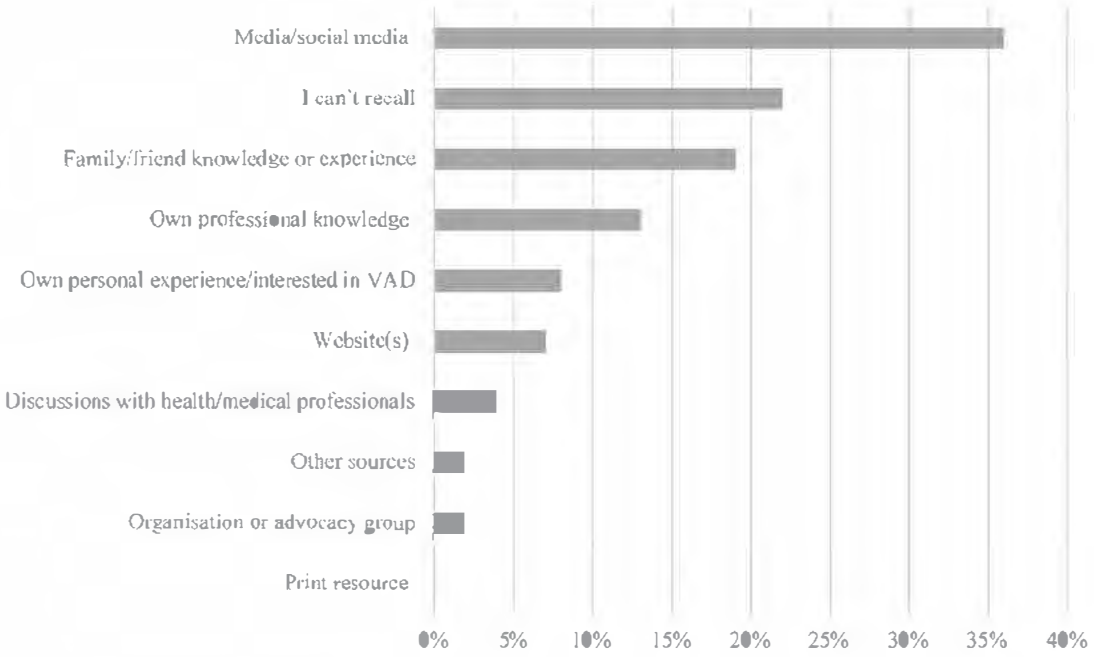

Figure 1. Sources of knowledge about VAD being legal ($n = 329$).

Table 2. Results of binomial logistic regression analysis predicting awareness of VAD being legal.

Predictor	B	SE	p	OR
Professional in health, law or other relevant discipline	1.010	.220	< 0.001	2.745
Support of VAD being lawful				
Strongly support	1.142	.416	0.006	3.133
Somewhat support	.408	.433	0.347	1.503
I don't know/ undecided	.212	.469	0.650	1.237
Somewhat oppose	−.475	.747	0.525	.622
Strongly oppose			< 0.001	
Constant	−4.22	.090	0.998	.015

Table 3. Results of binomial logistic regression analysis predicting awareness of VAD being legal excluding health practitioners.

Predictor	B	SE	p	OR
Support of VAD being lawful				
Strongly support	1.625	.537	0.002	5.077
Somewhat support	.806	.552	0.145	2.238
I don't know/ undecided	.782	.581	0.178	2.187
Somewhat oppose	.213	.815	0.794	1.237
Strongly oppose			< 0.001	
Constant	−2.110	.529	< 0.001	.121

is legal in bivariate analyses) (see Table 3). Level of support for VAD was a significant predictor of knowing that VAD is legal. Compared to participants who strongly opposed VAD being legal, participants who strongly supported VAD were 5.1 times more likely to know that VAD is legal ($p = 0.002$). These findings were consistent with results from the model run on the full sample, suggesting that there were no unique effects or trends within the health practitioner sub-sample (and that overall results were not skewed by the relatively large number of health practitioners in the sample).

Knowledge of how to access VAD

Only around a quarter of participants (26%, $n = 257$) reported that they would know how to access VAD if they wished to (72% did not, 2% preferred not to answer). When asked where they would look for information about VAD, most community members (86%) reported they would access information online, typically via Google or other search engines (see Figure 2). A small number of participants identified specific websites such as Queensland Health or the Queensland Government. When asked who they would approach for information about VAD, 79% of participants reported that they would seek information from health and medical professionals, primarily doctors, or at hospitals (see Figure 3). Twenty-seven per cent of participants would ask family or friends. All other response options were identified by fewer than ten per cent of participants.

In open-ended responses at the end of the survey, several participants felt there was a need for more awareness and information/education on VAD. Some proposed disseminating information via the Centrelink website, medical/health clinics, social media and advertising campaigns.

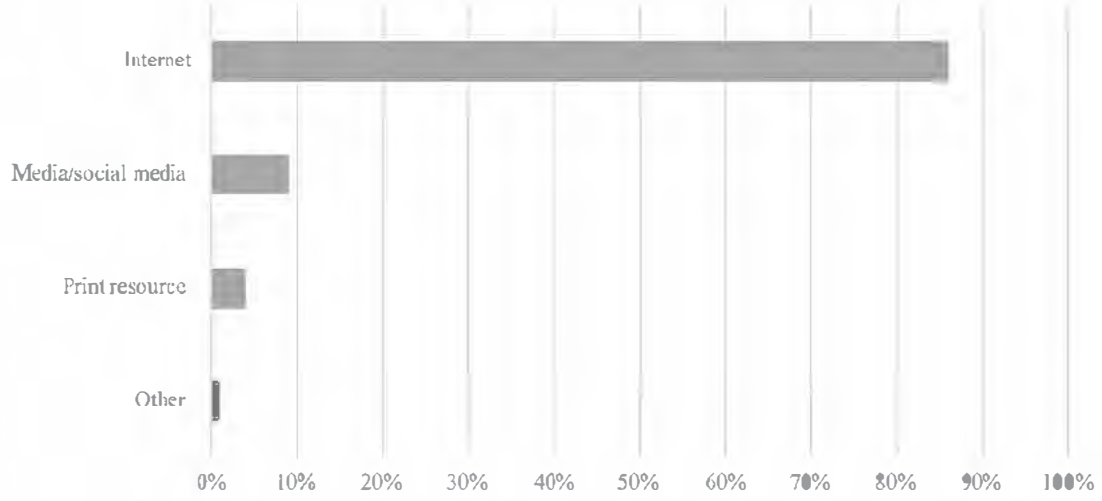

Figure 2. Sources of information about VAD – where to look ($n = 1000$).

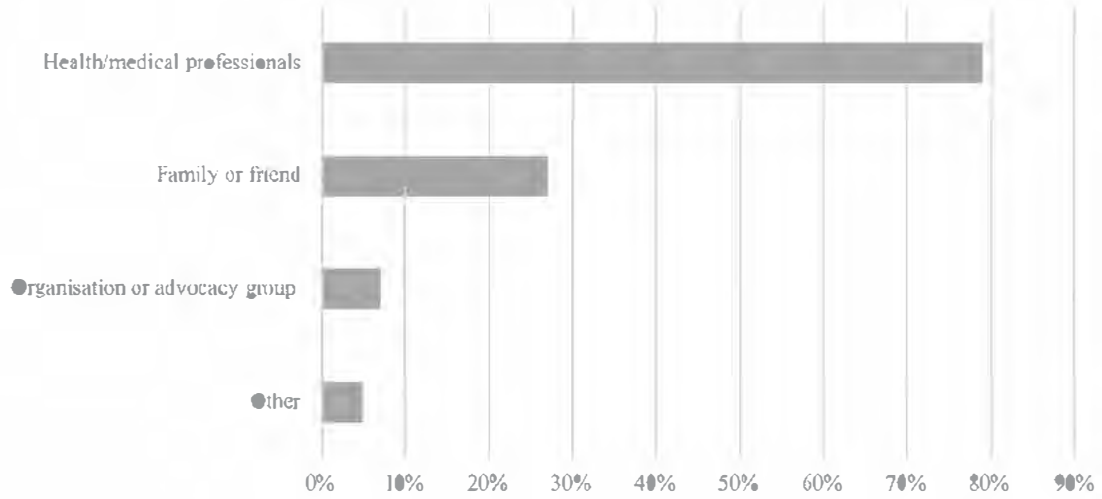

Figure 3. Sources of information about VAD – who to ask ($n = 1000$).

Discussion

This is the first study of community knowledge about VAD in Australia, and one of very few studies internationally. Despite VAD being lawful in Queensland for over 17 months, only 33% of participants knew it was legally available, although this rose to 62% for health practitioners in the sample. The statistical models could not reliably predict whether someone would know VAD is legal, suggesting other personal and/or system-level factors might be involved. Personal factors, such as an individual's religious identification, experience with death and dying care and education or work experience in palliative care, can all influence knowledge of end-of-life options including VAD (Silveira et al., 2000). Previous Australian research on community knowledge of end-of-life decision-making laws found that being a decision-maker for medical treatment at the end of life was associated with higher levels of legal knowledge (Tilse et al., 2019), highlighting the potential role of personal experience in shaping understanding of this topic. System-level factors influencing knowledge of the legal status of VAD are under studied; however, we hypothesize that jurisdictional differences in legislation and health policies, as well as the impact of public campaigns and media representation, may impact community knowledge.

Consistent with earlier research, most participants here learned about VAD through media/social media or personal/professional connections, suggesting passive acquisition of knowledge rather than active pursuit of this information. Challenges for access appear likely with only 26% of participants reported thinking they would know how to access VAD if desired. These findings suggest poor VAD literacy both in terms of knowing this a legal option and, once aware, people's confidence in finding out how to access VAD.

Rates of awareness reported here are similar to those reported in research in Oregon and California (23% and 25% respectively), but much lower than in Canada (67%) (Byram & Reiner, 2024; Silveira et al., 2000). Participants here also reported slightly lower levels of confidence in their ability to access VAD compared to California and Canada (32% and 33% respectively) (Byram & Reiner, 2024). Study samples and periods of VAD experience vary across studies and this may impact results. For example, the Oregon study surveyed patients (not the general public) two years post-legalization, and the California-Canada study focused on adults aged 60 and over and was conducted seven years post-legalization (Byram & Reiner, 2024; Silveira et al., 2000), whereas our study surveyed the general community 17 months after the legalization of VAD.

Community knowledge is important for access to VAD (Byram & Reiner, 2024; White, Jeanneret, Close, et al., 2023; White, Jeanneret, & Willmott, 2023). A contrary position could be advanced namely that, as for other healthcare choices, people do not need to know about VAD until they might be eligible and want it. However, there is a case for treating VAD differently for at least three reasons. First, in Australia (and New Zealand), VAD laws place limits on how and when VAD may be raised with patients by health practitioners (White, Archer, et al., 2024). Indeed in the states of Victoria and South Australia, raising VAD with a patient first is specifically prohibited (White, Archer, et al., 2024). Second, VAD is a practice for which conscientious objection is more likely to arise so some health practitioners will choose not to tell patients about VAD. Third, even when a health practitioner may not be a conscientious objector and is legally allowed to raise VAD, there can still be reluctance to tell patients about this option, perhaps partly because of stigma attached by some to VAD (White et al., 2023). Hence if patients are unaware of VAD being legally available and health practitioners do not inform them (or are legally prohibited from doing so), they will not know the option exists. While Queensland law allows medical and nurse practitioners to raise VAD with patients as part of a discussion about other palliative care or end-of-life options, restrictions still apply, and those with conscientious objections may choose not to raise VAD and can refuse to provide VAD information, except as required by law when a patient makes a formal "first request" for VAD to a medical practitioner.

Prior research suggests that community knowledge of VAD is an evolving process that may require considerable time to develop, for example, as people in the community have loved ones and friends who seek this choice (Byram & Reiner, 2024). Here, 19% of participants who knew VAD was legal reported learning this through personal experience or from family and friends (often knowing individuals who had sought or explored VAD). However, relying solely on the natural spread of knowledge through personal experiences and word-of-mouth—what could be described as education by osmosis—is insufficient. Such an organic approach is also likely to lead to uneven awareness and understanding, leaving some community members more likely to be uninformed.

To address knowledge gaps, proactive measures are needed to increase awareness of VAD in the community and among potentially eligible patients. In terms of community awareness, the study highlighted earlier on patient and caregiver experiences in Victoria called for initiatives to ensure basic VAD literacy within the community (White et al., 2023). The Queensland VAD Review Board has also emphasized the importance of enhancing community awareness of VAD (Voluntary Assisted Dying Review Board, 2023b). Some participants in the Victorian study suggested that education was needed and that the internet, media/social media, and health practitioners are key channels for raising awareness (White et al., 2023). As community members commonly use search engines to identify information online, information must be user-friendly, tagged with everyday language, and optimized for search engines (White et al., 2018). Inclusivity is vital, requiring community engagement and adaptable, accessible communication for diverse groups (White et al., 2023). Educational material should also be factual and balanced, providing information without bias, and respecting the diversity of views about VAD.

In terms of more targeted education, some individuals will need this, particularly patients who now or in the future may be eligible for VAD. If potentially interested in VAD, these patients should have sufficient understanding of the eligibility criteria for accessing VAD to recognize if VAD may be an option for them (White et al., 2023). They should also know the required steps to access VAD, or at least who to contact about VAD (and how).

VAD system design and implementation have a role in influencing community knowledge of VAD, as evidenced by the previous comparative research on California and Canada (Byram & Reiner, 2024). Implementation of VAD within the Queensland and other Australian health systems more closely reflects the system design in Canada (which has high public awareness of VAD). However there are some notable differences (e.g. restrictions in Australian states on

discussing VAD and providing VAD information) which have implications for information transparency and accessibility. Addressing system design and implementation is crucial for improving public awareness and ensuring equitable access to VAD information and services. Broader health system design is also likely to be relevant. For example, both the Australian and Canadian health systems aim to provide universal coverage whereas the United States does not have universal healthcare; this can significantly impact access to healthcare (Weaver et al., 2021).

Community members in this study reported they would seek information about VAD from health and medical practitioners, particularly general practitioners (GPs). Given knowledge gaps within this group reported here, health and medical practitioners, particularly GPs and others working in end-of-life care, would benefit from targeted education and training. They should be supported to ensure they can provide patients and families with appropriate information on VAD, feel comfortable having these discussions and understand their legal rights and obligations in relation to discussing VAD and providing VAD information (including when and how they can initiate VAD discussions in Australia).

Limitations

This research has limitations. First, community members with an interest in VAD may have been more likely to respond. Second, our sample had a lower proportion of people with only primary school education. It is possible that reliance on an online survey with recruitment via email and notifications may have reduced participation by individuals with only primary school education, who can face challenges related to general and/or digital literacy (and may also have lower levels of health literacy). Our sample was otherwise representative with respect to education level and all other demographic characteristics examined. Third, 9% of participants were health practitioners, which was a surprisingly high proportion for a general community sample. Health practitioners had higher levels of awareness of VAD being a legal option. Collectively these limitations suggest our sample may be more legally knowledgeable than the wider community and that the relatively low level of knowledge that VAD is legal might actually be understated. Finally, the survey did not include questions on participants' personal experience with VAD (beyond how they learned about its legalization), their own or their family members' health status, or system-level factors that may have influenced their legal knowledge.

Conclusion

The first Australian research on community knowledge of VAD shows low levels of VAD literacy. Seventeen months after the commencement of VAD in Queensland only 33% of adult community members correctly identified that VAD is legal in the state and only 26% reported that they would know how to access VAD if they wished to. These are significant findings given that several key barriers to seeking VAD stem from a lack of awareness of and understanding about it. Community awareness initiatives are therefore needed to increase VAD literacy among the general public. The internet, media/social media and health and medical practitioners are likely to be appropriate avenues for education as community members have or would seek information on VAD from these sources. The education of health and medical practitioners (particularly GPs) is also critical. Future research may benefit from using accessible recruitment methods (e.g. disseminating study information via radio and television) and adopting multimodal data collection strategies (e.g. offering paper-based surveys) to help mitigate barriers and foster inclusion of people with more diverse educational backgrounds. Another area for further investigation is how community awareness initiatives could be used as a tool to promote equitable access to VAD, ensuring that all individuals, regardless of their background or circumstances, have the information and support they need to make informed decisions about their end-of-life care.

Disclosure statement

Ben P White and Lindy Willmott were engaged by the Victorian, Western Australian and Queensland governments to provide the legislatively required training for doctors (and nurses and nurse practitioners where relevant) involved in voluntary assisted dying. Ben P White and Lindy Willmott were engaged by the Western Australian Government to be involved in the statutory review of the Voluntary Assisted Dying Act 2019 (WA). Lindy Willmott is also a member of the Queensland Voluntary Assisted Dying Review Board. Rachel Feeney was previously engaged as a clinical consultant for the Voluntary Assisted Dying Training Education Module for Healthcare Workers in Queensland.

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References

Australian Bureau of Statistics. (2021a). *Census of Population and Housing: Household and Families Data Summary*. ABS.

Australian Bureau of Statistics. (2021b). *General Community Profile Queensland, G04 Age by sex*. ABS.

Brown, J., Goodridge, D., Harrison, A., Kemp, J., Thorpe, L., & Weiler, R. (2020). Medical assistance in dying: Patients', families', and health care providers' perspectives on access and care delivery. *Journal of Palliative Medicine, 23*(11), 1468–1477. https://doi.org/10.1089/jpm.2019.0509

Byram, A. C., & Reiner, P. B. (2024). Disparities in public awareness, practitioner availability, and institutional support contribute to differential rates of MAiD utilization: A natural experiment comparing California and Canada. *Mortality, 2024*, 1–21. https://doi.org/10.1080/13576275.2024.2328627

Choi, W. J., Astrachan, I. M., Sinaii, N., & Kim, S. Y. H. (2024). When medical assistance in dying is not a last resort option: Survey of the Canadian public. *BMJ Open, 14*(6), e087736. https://doi.org/10.1136/bmjopen-2024-087736

Crumley, E. T., Kelly, S., Young, J., Phinney, N., McCarthy, J., & Gubitz, G. (2021). How is the medical assistance in dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study. *BMJ Open, 11*(7), e048698. https://doi.org/10.1136/bmjopen-2021-048698

Hales, B. M., Bean, S., Isenberg-Grzeda, E., Ford, B., & Selby, D. (2019). Improving the medical assistance in dying (MAID) process: A qualitative study of family caregiver perspectives. *Palliative & Supportive Care, 17*(5), 590–595. https://doi.org/10.1017/S147895151900004X

Levy, H., & Janke, A. (2016). Health literacy and access to care. *Journal of Health Communication, 21*(Suppl), 43–50. https://doi.org/10.1080/10810730.2015.1131776

Oczkowski, S. J. W., Crawshaw, D. E., Austin, P., Versluis, D., Kalles-Chan, G., Kekewich, M., Curran, D., Miller, P., Kelly, M., Wiebe, E., & Frolic, A. (2021). How can we improve the experiences of patients and families who request medical assistance in dying? A multi-centre qualitative study. *BMC Palliative Care, 20*(1), 185. https://doi.org/10.1186/s12904-021-00882-4

Queensland Government Statistician's Office. (2024). *Queensland regional profiles: Workforce profile for Queensland*. Queensland Treasury.

Silveira, M. J., DiPiero, A., Gerrity, M. S., & Feudtner, C. (2000). Patients' knowledge of options at the end of life: Ignorance in the face of death. *JAMA, 284*(19), 2483–2488. https://doi.org/10.1001/jama.284.19.2483

Tilse, C., Wilson, J., White, B., Willmott, L., Lawson, D., Dunn, J., Aitken, J. F., Pearce, A., & Ferguson, M. (2019). Community knowledge of law on end-of-life decision-making: An Australian telephone survey. *Journal of Law and Medicine, 27*(2), 399–414.

van der Heide, A. L., Johan; Onwuteaka-Philipsen, B., Bosma, F., van Delden, H., Mevis, P., Mink, K., Pasman, R., Postma, L., Renckens, S., van Thiel, G., & van de Vathorst, S. (2023). *Fourth Evaluation of the (Dutch) Termination of Life on Request and Assisted Suicide (Review Procedures) Act (Wtl)*. ZonMw.

Voluntary Assisted Dying Review Board. (2023a). *Annual report July 2022 to June 2023* Safer Care Victoria.

Voluntary Assisted Dying Review Board. (2023b). *The Queensland Voluntary Assisted Dying Review Board Annual Report 20222023* Voluntary Assisted Dying Review Board.

Weaver, M. R., Nandakumar, V., Joffe, J., Barber, R. M., Fullman, N., Singh, A., Sparks, G. W., Yearwood, J., Lozano, R., Murray, C. J. L., & Ngo, D. (2021). Variation in health care access and quality among US states and high-income countries with universal health insurance coverage. *JAMA Network Open, 4*(6), e2114730. https://doi.org/10.1001/jamanetworkopen.2021.14730

White, B., Archer, M., Haining, C., & Willmott, L. (2024). Implications of voluntary assisted dying for advance care planning. *Medical Journal of Australia, 220*(3), 129–133. https://doi.org/10.5694/mja2.52183

White, B., Jeanneret, R., Close, E., & Willmott, L. (2023). Access to voluntary assisted dying in Victoria: A qualitative study of family caregivers' perceptions of barriers and facilitators. *The Medical Journal of Australia, 219*(5), 211–217. https://doi.org/10.5694/mja2.52004

White, B., Jeanneret, R., & Willmott, L. (2023). Barriers to connecting with the voluntary assisted dying system in Victoria, Australia: A qualitative mixed method study. *Health Expectations, 26*(6), 2695–2708. https://doi.org/10.1111/hex.13867

White, B., Willmott, L., Tilse, C., Wilson, J., Lawson, D., Pearce, A., Dunn, J., Aitken, J. F., Feeney, R., & Jowett, S. (2018). Community knowledge of law at the end of life: Availability and accessibility of web-based resources. *Australian Health Review, 42*(3), 266–271. https://doi.org/10.1071/AH16234

Wilson, D. M., Triscott, J. A., Cohen, J., & MacLeod, R. (2019). Educational needs of healthcare professionals and members of the general public in Alberta Canada, 2 years after the implementation of medical assistance in dying. *Health & Social Care in the Community, 27*(5), 1295–1302. https://doi.org/10.1111/hsc.12766

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How best to regulate voluntary assisted dying: a qualitative study of perceptions of Australian doctors and regulators

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ABSTRACT

It is widely accepted that voluntary assisted dying (VAD) should be regulated but little is known about the most effective way to regulate doctors in this setting. This article reports on empirical research conducted in two Australian states where VAD is lawful (Victoria and Western Australia). Interviews were conducted with 92 participants: one group comprised doctors providing VAD and the other group was regulators in this field. Participants were asked about how best to regulate doctors providing this service. Strikingly, both regulator and doctor participant groups were consistent with each other in their views on what constituted effective regulation. The nature of VAD was perceived by participants to require special regulation, although some felt this was overdone in these states. Reported features of effective regulation included regulators taking an educative approach, regulation being perceived as acceptable by doctors, and it being responsive and nimble to provide the guidance that doctors need. Participants also considered a range of regulatory tools were required to regulate VAD effectively, and some identified a need for these tools to be employed together in a holistic way. This article concludes with a set of principles for effective regulation of VAD, discerned from the views of participants.

I. INTRODUCTION

Effective regulation design is a long-standing challenge across all fields of human endeavour. Challenges include ensuring the regulatory regime achieves its stated policy goals and the standards for behaviour it sets out are understood and applied in a way that reflects such goals.[1] Regulating the field of medicine itself creates additional challenges. Guiding

[1] Karen Yeung, 'Regulating Assisted Dying' (2012) 23 King's Law J 163.

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behaviour in a field with clinical complexity and developing generalized rules or norms where individual situations are highly variable is difficult. Compounding this is the fact that doctors have traditionally been recognized as a difficult cohort to regulate. While society has shifted away from the culture of medical dominance characterized by paternalism and self-regulation, some doctors remain reluctant to accept direction that could impinge on professional autonomy or conflict with professional norms.[2] Indeed, many view regulation as an 'intrusive and inefficient interference by external authorities that distracts from the importance of clinical care'.[3]

In this article, we focus on Voluntary Assisted Dying (VAD),[4] an area of health care where regulation has been extensively considered and debated. This is not surprising given the gravity of the decisions involved. VAD involves intentionally taking steps to end a person's life, and so it is argued that social control of the practice through regulation is needed.[5] While not all jurisdictions globally have VAD laws, there is an increasing number of jurisdictions that are passing such laws.[6] In recent times, VAD laws have been passed in jurisdictions including Spain, New Zealand, and Australia,[7] and jurisdictions such as Scotland, Ireland, and England and Wales, are actively considering laws.[8] Conversely, other jurisdictions have a long-standing history of the practice such as the Netherlands, Belgium, and Oregon.

A feature of all VAD laws, and associated debates, is the critical role of regulation. All jurisdictions where VAD is lawful have established systems of regulation to govern VAD. Likewise, all jurisdictions contemplating reform have outlined models of VAD that include specific consideration of its regulation. In most jurisdictions, this regulation includes a statute that makes VAD lawful and outlines how the system will operate.[9] The legislative models internationally often operate within a medicalized framework,[10] although individual doctors can choose not to participate.[11] Such medicalized models require at least two doctors to assess whether a patient meets defined eligibility criteria. Those criteria can include unbearable suffering that cannot be relieved (no terminal illness requirement); being expected to die

[2] Judith Allsop, 'Medical Dominance in a Changing World: The UK Case' (2006) 15 Health Sociol Rev 444; Judith Healy, 'Regulating the Health Professions' in *Improving Health Care Safety and Quality: Reluctant Regulators* (Routledge 2011); Chris Dent, 'The Role of Law in the Treatment Decisions of Doctors' (2022) 48 Mon Law Rev 94.

[3] Eirini Oikonomou and others, 'Patient Safety Regulation in the NHS: Mapping the Regulatory Landscape of Healthcare' (2019) 9 BMJ Open <https://bmjopen.bmj.com/content/bmjopen/9/7/e028663.full.pdf> accessed 27 February 2024.

[4] VAD refers to where a person voluntarily accesses a medication provided by a health practitioner which will end their life which the person either takes themselves (self-administration) or has it administered (practitioner administration). Different terms are used in different jurisdictions such as medical assistance in dying or euthanasia.

[5] Yeung (n 1).

[6] Sarah Mroz and others, 'Assisted Dying around the World: A Status Quaestionis' (2021) 10 Ann Palliat Med 3540.

[7] ibid. Katherine Waller and others, 'Voluntary Assisted Dying in Australia: A Comparative and Critical Analysis of State Laws' (2023) 46 UNSWLJ 1421. We also note that VAD was briefly lawful in Australia in the Northern Territory following the passing of the *Rights of the Terminally Ill Act 1995* (NT). However, in 1997, soon after the law was in effect, the Commonwealth Government removed the territory's power to legislate on euthanasia: *Euthanasia Laws Act 1997* (Cth). This Act was repealed in 2022 by the *Restoring Territory Rights Act 2022* (Cth).

[8] The Assisted Dying for Terminally Ill Adults (Scotland) Bill was introduced in the Scottish Parliament in March 2024, the Voluntary Assisted Dying Bill 2024 was introduced in the Irish Parliament in June 2024, and the Assisted Dying for Terminally Ill Adults Bill 2024 was introduced in the UK House of Lords in July 2024.

[9] We note there are also different models of regulation such as those based on not criminalizing some aspects of VAD (Switzerland) or permitting VAD through court decisions (eg Germany, Italy, and Colombia). For further discussion of various international VAD regulatory models, see Ben P White (ed), *Research Handbook on Voluntary Assisted Dying Law, Regulation and Practice* (Edward Elgar 2025).

[10] We note for completeness that some argue against a medicalized model including on the basis that doctors become the ultimate arbiters and administrators of one's death: see, eg Lucy Thomas, 'Demedicalisation: Radically Reforming the Assisted Dying Debate' (2020) 371 BMJ m2919. However, not all commentators believe de- medicalization in this context is possible: see, eg Suzanne Ost, 'The De-medicalisation of Assisted Dying: Is a Less Medicalised Model the Way Forward? (2010) 18 Med L Rev 497; Evelien Delbeke, 'The Way Assisted Suicide Is Legalised: Balancing a Medical Framework Against a Demedicalised Model' (2011) 18 Eur J Health Law 149.

[11] Emily Jackson, 'Legalizing Assisted Dying: Cross Purposes and Unintended Consequences' (2018) 41 Dalhousie LJ 59.

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within a specific time period, such as six months (and not requiring suffering); or requiring both a terminal illness and suffering.[12] VAD systems also generally require the completion of forms or paperwork that attest to the person's eligibility, which is submitted to an oversight body. While this varies across jurisdictions, some form of oversight has generally been deemed necessary to provide public confidence in the system.[13] The regulation also governs what type of assistance to die is lawful. This could be via self-administration (patient receives the medication and takes it themselves) or practitioner administration (medication is administered to a patient by a health practitioner).

While legal reform is generally needed to permit VAD (which could otherwise constitute crimes such as murder, manslaughter, or assisting a suicide), regulation in this space goes beyond law and includes a range of other instruments, such as policies, guidelines, ethical codes, training, and funding (including resourcing to enable health services to provide VAD as well as remuneration for individual VAD providers).[14] In recognition of this, it has elsewhere been argued that regulation of end-of-life care requires a 'holistic approach' because it is not possible to understand the regulatory impact of single instruments in isolation.[15] For example, while law may permit VAD, there may be ethical guidelines or policies that play a prohibitive role such that, in practice, access to VAD is limited or even not possible in particular circumstances or settings. Other regulatory instruments could also play a facilitative role in law. For example, where a VAD law simply grants permission for VAD to occur in certain circumstances but says little about how the provision of VAD should be operationalized in practice, regulatory guidance about these matters may need to come from local guidelines or training.

This article takes a holistic approach to examining VAD regulation and considers the question of how best to regulate doctors. Very little attention has been given to the most effective way to regulate doctors in VAD systems, which is surprising given their central role.[16] This article reports on the findings of an empirical study of Australian VAD regulation, where VAD is permitted through legislation in all but one jurisdiction, each of which has a slightly different law.[17] This research focuses on the two states that have the longest experience with VAD in Australia, namely Victoria and Western Australia. These jurisdictions' laws commenced operation in 2019 and 2021, respectively. This study, the first of its kind in Australia, draws on semi-structured interviews with both the creators of regulation

[12] Mroz and others (n 6).

[13] For commentary on oversight see Sean Riley, 'Watching the Watchmen: Changing Tides in the Oversight of Medical Assistance in Dying' (2023) 49 JME 453. For judicial consideration of the importance of effective regulation and oversight, particularly where oversight is subject to retrospective review, see *Mortier v Belgium* [2022] ECHR 764. In this case, the court considered that the current Belgian legislative framework was capable of protecting a patient's right to life and provided the necessary safeguards [155], but also emphasized the importance of strict, impartial, and effective oversight and scrutiny for ensuring public confidence and support.

[14] For a typology of different regulatory sources used in Belgian VAD regulation, see Madeleine Archer and others, 'Mapping Sources of Assisted Dying Regulation in Belgium: A Scoping Review of the Literature' [2023] OMEGA (forthcoming) <https://doi.org/10.1177/00302228231210146> accessed 27 February 2024.

[15] Ben P White, Lindy Willmott and Eliana Close, 'Better Regulation of End-Of-Life Care: A Call for a Holistic Approach' (2022) 19 JBI 683.

[16] While doctors are the primary target of regulation, we acknowledge that there are others including other health practitioners and healthcare institutions.

[17] Voluntary Assisted Dying Act 2017 (Vic) ('Vic VAD Act'); Voluntary Assisted Dying Act 2019 (WA) ('WA VAD Act'); Voluntary Assisted Dying Act 2021 (Qld); Voluntary Assisted Dying Act 2021 (SA); End-of-Life Choices (Voluntary Assisted Dying) Act 2021 (Tas); Voluntary Assisted Dying Act 2022 (NSW). The Australian Capital Territory has just passed its Voluntary Assisted Dying Act 2024 (ACT), but it will not be operational until 3 November 2025. The Northern Territory is the only Australian jurisdiction that does not have VAD laws but a report into developing a framework for VAD has been released which details recommendations for the government to consider and inform draft legislation for VAD in the Northern Territory if supported. See 'Voluntary Assisted Dying' (*Northern Territory Government*, 2024) <https://cmc.nt.gov.au/project-management-office/voluntary-assisted-dying> accessed 4 October 2024.

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('regulators') and their primary regulatory target (doctors providing VAD), exploring how both groups conceptualized optimal regulation[18] of VAD.

Finally, while we recognize that there are different views on whether VAD should be permitted, this article steps past these debates, recognizing that VAD is now lawful in these two states. The focus of this research is on reporting and analysing participants' perspectives on how best to regulate doctors within these now-established VAD systems.

A. An overview of VAD regulation in Victoria and WA

Before turning to the method of this study, we briefly outline how VAD is regulated in these two Australian states. Both states adopt 'the Australian model of VAD', whereby access to VAD is limited to terminally ill adults[19] with decision-making capacity[20] who satisfy strict eligibility criteria as assessed by two specially trained and qualified doctors.[21] In these two states, eligibility criteria include that the person must be experiencing suffering from a disease, illness, or medical condition that is advanced, progressive, and expected to cause death within 6 months (or 12 months for neurodegenerative conditions).[22] There are ongoing reporting requirements for doctors involved in assessing eligibility, with dedicated state statutory bodies (the VAD Review Board in Victoria and the VAD Board in WA) charged with system oversight.[23] By international standards, the Australian model of VAD is comparatively highly regulated and very prescriptive in its control of the process.[24]

While the Victorian and WA regimes are broadly similar, there are some points of difference. WA predominately departed from the Victorian model in response to early learnings from the Victorian experience and to accommodate WA's vast geography and diverse population.[25] Both regimes are regulated by a series of regulatory tools and actors. Tables 1 and 2 provide a brief overview of the most significant tools and regulatory actors involved in VAD regulation.

II. METHOD

This article reports on the findings of semi-structured interviews with two broad categories of participants, namely doctors who provide VAD and regulators. Drawing on Black's

[18] For the purposes of this article we conceptualise regulation broadly and adopt Julia Black's widely-used definition: 'regulation is the sustained and focused attempt to alter the behaviour of others according to defined standards or purposes with the intention of producing a broadly identified outcome or outcomes, which may involve mechanisms of standard-setting, information-gathering and behaviour-modification'. This definition recognises that regulation is decentralised and pluralistic and, therefore, can occur by both State actors (eg governments, courts, statutory bodies) and non-State actors (eg advocacy organisations, medical defence organisations, colleges) and through a variety of instruments (law, policies, guidelines, ethical codes, training, and funding programs). Such an approach broadens traditional 'command and control' conceptions of regulation, which narrowly focus on law enforced by the State. Julia Black, 'Critical Reflections on Regulation' (2001) Aust J Leg Philos 1, 26.

[19] Adult refers to a person aged 18 years and over in Australian jurisdictions. See Vic VAD Act s 9(1)(a); WA VAD Act s 16(1)(a).

[20] In Australia, a person must have decision-making capacity during the process before being granted access to the VAD medication (in the case of self-administration) or at the time of having the practitioner administer the medication (in the case of practitioner administration).

[21] Waller and others (n 7).

[22] Vic VAD Act s 9; WA VAD Act s 16.

[23] Vic VAD Act s 93; WA VAD Act s 118.

[24] Waller and others (n 7).

[25] Some of the key differences between the Victorian and Western Australian VAD systems relate to: the ability of certain health practitioners to raise VAD; the ability to use telehealth (within the constraints of the Commonwealth Criminal Code); the approach to facilitating regional access; requirements for being a VAD practitioner; permissibility of nurses being involved as administering practitioners; circumstances in which practitioner administration is permitted; obligations placed on conscientious objectors; and whether a state-authorized VAD permit is needed. For a discussion of these differences, see Casey M Haining, Lindy Willmott and Ben P White, 'Comparing Voluntary Assisted Dying Laws in Victoria and Western Australia: Western Australian Stakeholders' Perspectives' (2023) 30 JLM 716.

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Table 1. Overview of VAD regulatory tools

Regulatory tool		Description
Law[a]	Legislation	Dedicated state VAD legislation that establishes the VAD system (including the statutory review Board) and regulates access to VAD in the relevant jurisdiction.[b]
		Other legislation at the state and federal level also indirectly impacts the regulation of VAD. For example, federal criminal legislation that prohibits the use of telehealth, email, and other electronic means to communicate about 'suicide'[c] has been held to be capable of applying to VAD, so may prohibit some VAD communications.[d]
	Delegated VAD legislation	Statutory rules made under the primary VAD legislation that set out some of the procedural aspects of the system.[e]
	Case law	Court and tribunal decisions that have emerged since VAD laws commenced operation, providing interpretative guidance.[f]
Policy and guidelines[g]	Government-issued policies	Policies that aim to provide high-quality care for those who seek VAD, including providing support and guidance to health professionals and institutions.[h]
	Professional organization-issued policies	Policies which generally seek to support their diverse membership, making them aware of their professional obligations and best practices for their patients.[h]
	Institutional[i] issued policies	Policies that generally aim to control (or limit) access to VAD and staff conduct within the institution (or under its operations).[j]
Education and training	Legislatively mandated training	Training formally approved by the government,[k] which must be completed by participating health practitioners.
	Local education	Education developed at the institutional level.
	General end-of-life training	Broad end-of-life training and education where VAD may feature.[l]
System design and architecture	VAD Information Management System (IMS) or Portal	An online system or portal in which mandatory forms are submitted at various steps during the VAD process, monitored by the Secretariat of the statutory review Board.[m]
	Community of practice	A forum for practitioners involved in VAD to share experiences and provide peer support.[n]
Funding[o]	Federal government funding	There is limited scope for doctors to bill under Medicare (federal government program to fund health care) for VAD activities due to the absence of a dedicated billing code. Some VAD-related activities may be able to be claimed under general consultation billing codes, but this is limited and does not extend to the administration of the VAD medication.[p]

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Table 1. (continued)

Regulatory tool		Description
	State government funding	Practitioners travelling regionally have been able to access some compensation for associated travel costs from state-based funding (the availability of which varies between the two states).[q]
	Other billing	Practitioners may be able to use salaried clinical time for VAD-related activities. Some practitioners may opt to bill privately.[p]

[a] For a comprehensive overview of laws relevant to VAD regulation in Victoria, see Ben P White and others, 'Mapping the Legal Regulation of Voluntary Assisted Dying in Victoria: The Coherence of a New Practice within the Wider Legal System' (2022) 29 JLM 783.

[b] Vic VAD Act; WA VAD Act.

[c] Australian Criminal Code Act 1995 (Cth) sections 474.29A, 474.29B. For a detailed account of the federal law and prohibition of telehealth, see Del Villar and others (note 38).

[d] Carr v Attorney-General (Cth) [2023] FCA 1500.

[e] Voluntary Assisted Dying Regulations 2018 (Vic). The WA VAD Act permits the Director General of the Department of Health to set out requirements and/or standards such as an Access Standard (which details how the State intends to facilitate access: section 156) and requirements for participating practitioners: sections 17, 54.

[f] Ben P White and others, 'Mapping the Legal Regulation of Voluntary Assisted Dying in Victoria: The Coherence of a New Practice within the Wider Legal System' (2022) 29 JLM 783, 787; NTJ v NTJ [2020] VCAT 547; YSB v YSB [2020] VCAT 1396; Medical Board of Australia v Carr (Review and Regulation) [2023] VCAT 945; Carr v Attorney-General (Cth) [2023] FCA 1500; AB and CD [2024] WASAT 6; EF, GH AND IJ and KL [2024] WASAT 18; HM and the Co-ordinating Practitioner for HM [2024] WASAT 23; BMR, MTH and CJG and the Co-ordinating Practitioner for MTH [2024] WASAT 44.

[g] For the purpose of classification, we have adopted a broad construction of policy, which includes any document that aims to 'steer the flow of events or behaviour through providing information; issuing guidance; or advancing vision, outcome or standard', see Close, Willmott and White (note 43) 1457. We note from this analysis that there is a diverse regulatory landscape when it comes to policies regulating VAD. While not exhaustive, the taxonomy adopted here is informed by the primary policy-makers identified by the authors.

[h] Close, Willmott and White (note 43).

[i] Healthcare institutional policymakers may include health services/hospitals, community nursing services, standalone palliative units and aged care facilities.

[j] Close, Willmott and White (note 43); Eliana Close and others, 'Institutional objection to voluntary assisted dying, Australia: An analysis of publicly available policies' (2023) 20 JBI 467.

[k] Vic VAD Act sections 17, 26, 114; WA VAD Act sections 25, 36, 160.

[l] For examples of end-of-life/palliative care education and palliative care training that features VAD, see 'Palliative Care Education' (Palliative Care Education and Training Collaborative) <https://palliativecareeducation.com.au/?tenant=ELLC> accessed 27 February 2024.

[m] See White and others (note 46).

[n] Haining, Willmott and White (note 25).

[o] The Australian health system is funded by federal and state and territory governments and non-government funders including private health insurers and individuals. See 'Health System Overview' (Australian Institute of Health and Welfare, 7 July 2022) <https://www.aihw.gov.au/reports/australias-health/health-system-overview> accessed 13 December 2023.

[p] Casey M Haining and others, 'Access to Voluntary Assisted Dying in Australia Requires Fair Remuneration for Medical Practitioners' (2023) 218 MJA 8.

[q] ibid; Casey M Haining, Lindy Willmott and Ben P White, 'Accessing Voluntary Assisted Dying in Regional Western Australia: Early Reflections from Key Stakeholders' (2023) 23 RRH 8024 <https://www.rrh.org.au/journal/article/8024> accessed 6 April 2024.

definition above,[26] we define 'regulators' as those whose role involves 'altering behaviour' in this field, which extends to both State and non-State actors (see Table 2 for some examples of regulatory actors). For the purposes of reporting this study (while also ensuring the confidentiality of participants), we break down these regulators further into two main categories:

[26] See Black (n 18).

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Table 2. Key Regulatory Actors

Type of actor	Name of actor	Description
Actors who are part of the State	Parliaments	Each state parliament passed laws that permit VAD. In Victoria and Western Australia, these followed parliamentary inquiries into end-of-life care which recommended, *inter alia*, the enactment of VAD legislation.[a] Potential oversight through the requirement that the VAD Board produce periodic reports for Parliament[b] as well as the mandated review of the law's operation, which also results in a report that must be tabled in Parliament.[c]
	Court and tribunals	Courts and tribunals may issue decisions that have precedential value based on matters that come before them (eg in cases of non-compliance or interpretative issues). Tribunals also have jurisdiction to review certain VAD decisions.[d] Coronial courts may also have a role in cases where a VAD death is a reportable death and may be subject to investigation. However, where a VAD death occurs in accordance with legislation it will not be a reportable death.[e]
	Governments and their departments	An End-of-Life Care Team within the Department of Health in each state has the main carriage for VAD. Each team coordinates the mandatory VAD training, issues policy and guidance, and manages the contracts of the VAD Statewide services.[f] Other Government departments also have a role, eg Births, Deaths and Marriages, through its register.
	VAD Board (statutory body)	The Board monitors and reports on activity to ensure compliance with the law. It retrospectively reviews VAD cases.[g]
	VAD Board Secretariat	An administrative body that supports the Board by providing day-to-day operational support.[f]

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Table 2. (continued)

Type of actor	Name of actor	Description	
	Australian Health Practitioner Regulation Agency (Ahpra) and state complaints commissioners[h]	Manage complaints[i] received in relation to VAD directly from the complainant or via referral (eg via the VAD Board). These organizations may also issue advice or decisions to educate and promote transparency. Ahpra also has a role in accrediting and registering health practitioners.[j]	
	Statewide services	State-wide Pharmacy Service	Statewide service that dispenses the VAD medication (and collects any unused medication). It provides support and information to people accessing VAD, their loved ones and doctors.[f]
		Statewide VAD Care Navigation Service	Statewide service that provides information and support to the community, health practitioners and health services.[f]
Non-State actors	Patient advocacy organizations[k]	Organizations that may issue information about VAD provide a range of support services and advocate for improvements. This is often informed by research they have conducted and/or stories they have received.	

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Table 2. (continued)

Type of actor	Name of actor	Description
	Professional organizations (including professional associations, medical defence organizations, colleges, and unions)	Organizations with a dedicated membership, which support members via a variety of means depending on the nature of the organization. Examples include issuing standards and guidelines, and delivering education and training.
	Healthcare institutions (health services, community services)	Organizations which may have patients within their care who request VAD and have local responses to managing such requests. In some cases, this may include dedicated policies and procedures in response to VAD and/or a dedicated VAD liaison (ie an individual who is responsible for VAD requests within the organization).[l]

[a] In Victoria and WA, following recommendations from the parliamentary committees to enact VAD legislation, independent expert panels were appointed in each state to advise on the law's content. Bills were then introduced into each Parliament, and following extensive parliamentary debate, VAD was legalized. For an analysis of this reform process in Victoria, the first Australian state to pass VAD laws, see Lindy Willmott and Ben P White, 'The Challenging Path to Voluntary Assisted Dying Law Reform in Australia: Victoria as a Successful Case Study' in Ben P White and Lindy Willmott (eds), *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (CUP 2021). See also Haining, Willmott and White (note 25) for a brief description of the reform process in WA.

[b] Vic VAD Act sections 93, 107, 108; WA VAD Act sections 118, 155. In both states, the relevant VAD (Review) Board must produce an annual report that contains prescribed information, including statistical information about the people accessing VAD, recommendations and details about Board referrals to the relevant bodies. Victoria now has annual reporting requirements, but biannual reporting was initially required. See Vic VAD Act (Vic) section 112.

[c] Vic VAD Act section 116; WA VAD Act (WA) section 164. The mandated reviews in both states assess the 'operation' (and effectiveness in WA) of the Act.

[d] Vic VAD Act section 68; WA VAD Act section 84.

[e] Coroners Act 2008 (Vic) section 4(3); Coroners Act 1996 (WA) section 3A.

[f] Victorian Voluntary Assisted Dying Review Board, 'Voluntary Assisted Dying Report of Operations June to December 2019' (Safer Care Victoria 2020) <https://www.safercare.vic.gov.au/reportsand-publications/voluntary-assisted-dying-review-board-annual-reports-2018-to-2023#goto-2018to-2019> 4, accessed 27 February 2024; Western Australian Voluntary Assisted Dying Board (note 31) 29–31, 34–35.

[g] Vic VAD Act section 93; WA VAD Act section 118.

[h] In Victoria, this is the Health Complaints Commissioner. In WA, this is the Health and Disability Complaints Office.

[i] In the case of Ahpra, this is done in conjunction with profession specific boards.

[j] 'Australian Health Practitioner Regulation Agency' (Ahpra) <www.ahpra.gov.au> accessed 6 April 2024.

[k] There is also some evidence that patients and their family caregivers can themselves act as regulatory actors, see Ruthie Jeanneret and others, '"Regulatory Action" By Patients and Family Caregivers to Overcome Barriers to Accessing Voluntary Assisted Dying: A Qualitative Study in Victoria, Australia' (2024) 47(3) UNSWLJ 705 <https://doi.org/10.53637/XYWL2133>

[l] This may be a specific role or a responsibility a person acquires as part of another role they have.

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(i) regulators who are part of the State and those who occupy official VAD system roles[27] and (ii) health and professional organization representatives.[28]

A. Sampling and recruitment

Recruitment occurred in four stages (with some overlap), and different strategies were employed depending on participant type and jurisdiction (see Table 3).[29] We adopted a purposive sampling approach to aim for diversity in our sample, including obtaining representation across several specialities/regulatory roles and metropolitan/regional representation. Snowball sampling was utilized during each recruitment period to extend the sample.

B. Data collection

Data were collected across four periods (see Table 3). Interviews were carried out with 1–3 participants over the phone or via Zoom by 1–3 interviewers (BPW, CMH, LW, RJ, MS), with one interviewer taking the lead during each interview. The interviews were semi-structured, and interview guides were crafted to suit the participant type. In the case of regulators, each interview guide was tailored to the individual's regulatory role. While individual interview guides did vary, they generally covered the same domains, including reflections on the VAD regime and how it was operating in practice, the ability of the VAD legislation to meet its broad policy goals (ie providing a choice for eligible patients that is reasonably accessible while ensuring safety so access is limited to those who are eligible), and VAD regulation more broadly (including questions that explored participants' perspectives on how best to regulate).

Interviews were recorded and transcribed verbatim by a professional transcription service. Transcripts were de-identified and checked for accuracy. Participants were sent their de-identified transcript prior to analysis to provide them with the opportunity to revise their transcript.

C. Data analysis

Transcripts were imported into NVivo 12 and analysed using thematic analysis.[30] CMH first familiarized herself with the data by reading through each transcript. CMH then developed a broad coding framework that would capture data relating to regulating doctors in the context of VAD, including sentiments expressed about how to best regulate this cohort. The coding framework was guided by CMH's familiarization with the data, and a research journal and article plan that BPW and CMH developed during the data collection stage. CMH coded the data, revising the coding framework, as necessary. While most of the coded data relevant to this article was in response to specific questions about how to best regulate doctors, each transcript was analysed entirely by CMH, who employed an open approach to ensure that any potentially relevant data were coded and data were not missed. BPW re-engaged with all of the data and refined the coding framework to define themes (and sub-themes). These themes were then discussed and revised in consultation with CMH, and then further refined by LW based on her recollection of the interviews and expertise in the area. All authors agreed upon the themes defined and reported in this article.

[27] Individuals that shape the regulation of VAD (either across the entire state or within a particular health service network) include those overseeing it, regulating it (or end of life more broadly) and providing education about it.

[28] This includes individuals who belong to a particular organisation including healthcare organisations (eg community nursing or aged care organizations) or professional organizations (eg advocacy organizations).

[29] The WA data was collected as part of a small pilot study, and hence the overall sample size is smaller: Table 4.

[30] Virginia Braun and Victoria Clarke, 'Using Thematic Analysis in Psychology' (2006) 3 Qual Res Psychol 77.

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Table 3. Summary of data collection

Participant type	Data collection periods	Primary recruitment strategies	Ethical approval ID[a]
Victorian doctors who had provided VAD	April to July 2020	• Contacting medical practitioners who completed the mandatory training and provided consent to be contacted for future research[b]	2000000033
Victorian and National regulators[c]	September 2022 to July 2023	• Drawing on professional networks • Directly contacting prospective participants via publicly available details	20000002700
Western Australian doctors who had provided VAD	March 2022 to May 2022	• Drawing on professional networks • Directly contacting prospective participants via publicly available details • Advertising the study through social media[d]	20000002700
Western Australian regulators	June 2022 to September 2022	• Drawing on professional networks • Directly contacting prospective participants via publicly available details[d]	20000002700

We note due to different periods of data collection and the progressive nature of this research project, we have previously published other work using some of this data. See Marcus Sellars and others, 'Medical Practitioners' Views and Experiences of Being Involved in Assisted Dying in Victoria, Australia: A Qualitative Interview Study among Participating Doctors' (2022) 292 Soc Sci Med 114568; White and others (note 46); Lindy Willmott and others, 'Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study' (2021) 215 MJA 125; Haining, Willmott and White (note 25); Casey M Haining, Lindy Willmott and Ben P White, 'Accessing Voluntary Assisted Dying in Regional Western Australia: Early Reflections from Key Stakeholders' (2023) 23 RRH 8024 <https://www.rrh.org.au/journal/article/8024> accessed 6 April 2024.

[a] This study was approved by the Queensland University of Technology Human Research Ethics Committee.

[b] This process of seeking consent to contact about future research was sought through the mandatory training all doctors wishing to provide VAD must do. For more information on this sample, see Lindy Willmott and others, 'Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study' (2021) 215 MJA 125.

[c] National regulators are used to describe regulators that operate nationally or across multiple states (and hence are not necessarily based in Victoria or WA, but may be), which have a role in regulating VAD.

[d] For more details about recruitment method, see Haining, Willmott and White (note 25).

III. RESULTS

Eighty-four interviews were conducted with 93 participants, ranging between 33 and 152 minutes. One participant's interview was conducted in two parts, two participants participated in multiple interviews (due to different roles), and one participant withdrew their data prior to analysis. The final sample of 92 participants comprised 39 doctors who had provided VAD and 55 regulators (see Table 4 for demographics). [31]

[31] It is not possible to ascertain the exact number of doctors at any point of time participating in VAD, and hence determine the exact proportions; however, a rough estimate can be obtained based on figures contained in the Boards' reports. In Victoria, the relevant report indicated that there were 125 active practitioners as of 30 June 2020 (where recruitment ceased in July 2020), so those interviewed represent approximately 25.6%: Victorian Voluntary Assisted Dying Review Board, 'Voluntary Assisted Dying Report of Operations January to June 2020' (Safer Care Victoria 2020) <https://www.health.vic.gov.au/voluntary-assisted-dying/voluntary-assisted-dying-review-board> accessed 21 October 2024. For the WA sample, the total number of doctors participating in the first year was 74, so those interviewed represent approximately 9.5%: Western Australian Voluntary Assisted Dying Board, 'Voluntary Assisted Dying Board Western Australia Annual Report 2021-22' (Western Australian Government Department of Health 2022) < www.health.wa.gov.au/~/media/Corp/Documents/

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Table 4. Participant Demographics ($n = 92$)

Participant type[a]	Doctor (D)	39
	Regulator (R)[b]	55
Gender Identity	Female	48
	Male	44
Age	30–39	12
	40–49	20
	50–59	26
	60–69	26
	≥ 70	8
Regulator-specific demographics[c]		
Location	National[d] (N)	15
	Victoria (V)	33
	Western Australia (WA)	18
Regulator Type	State Regulator and VAD System Role	29
	Health and Professional Organization Role	37
Doctor-specific demographics		
State	Victoria	32
	Western Australia	7
Main speciality	General practice	15
	Oncology	12
	General medicine	3
	Anaesthetics	2
	Palliative care	1
	Intensive care	1
	Haematology	1
	Nephrology	1
	Emergency medicine	1
	Surgery	1
	Rural generalist	1

[a] Two participants were classified as both a doctor and a regulator.
[b] For the purposes of this classification, a person was classed as a regulator if they had at least one regulatory role.
[c] Regulators can operate nationally or confine their regulation to a state. Many participants had multiple regulatory roles; the numbers reported here account for all the regulators' roles and exceed the total number of regulator participants.
[d] For the purposes of classification, the category 'national' recognizes both regulators who have an influence at a national level or influence across multiple states.

Thematic analysis led to the description of five themes. The first reports on participants' views about the special nature of VAD and why they (generally) felt it required specific regulation. The remaining four themes examine participants' observations about how to regulate VAD most effectively. Figure 1 provides a thematic schema of the themes identified. Significantly, when comparing the views of regulators as a group with the views of doctors, there was striking consistency in the data between both groups across all themes. Where there were points of difference, they are noted below.

A. The special and specific nature of VAD regulation

This theme explored participants' observations about the nature of VAD regulation with two sub-themes.

Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2021-22.pdf> 29, accessed 27 February 2024. It is impossible to determine the proportion of regulators interviewed because of the broad definition of regulator. However, the sample was diverse and comprised a breadth of different regulators, both at the state and national level. Our sample included those in State-sponsored roles and non-State actors (including advocacy organizations, institutional representatives and peak bodies).

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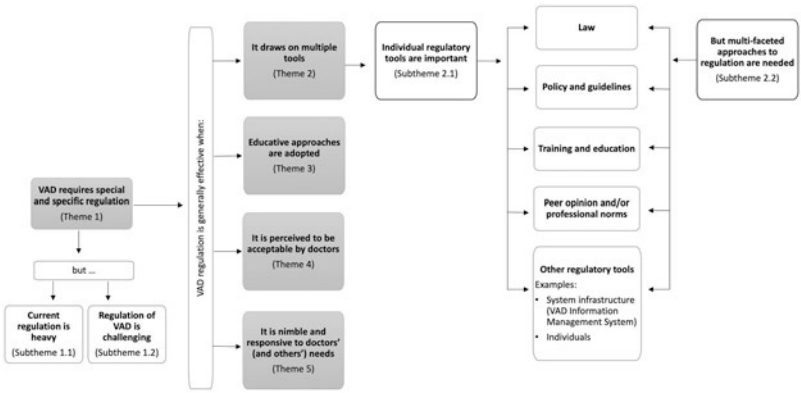

Figure 1. Thematic Schema

1. Specific regulation of VAD is needed, but current regulation is heavy

There was global recognition from participants that VAD warranted specific regulation, namely, its own distinctive regulation that specifically governed VAD and this regulation should be stricter than for other areas of medicine. The nature and gravity of a choice to seek VAD informed this assessment. Many participants perceived VAD to be different from other areas of medicine, hence requiring additional control and oversight.

> This is a niche case … a unique thing in medicine. Traditionally medicine has been set up to stop people from dying … This is a big difference … you can't undo it … this is an intervention that … is actively killing patients. So, I think you need that oversight for it and [a] legal approach more than you'd need for other areas of medicine.(#23, VD)

Some participants also identified that having some regulatory framework in place was useful, as it helped to remove ethical complexities and meant that conduct could be assessed according to prescribed rules.

> Having the governments [determine] what the standards are and how practitioners should conduct themselves and deal with the situation of assisting others to die ... makes it a lot easier … [because you] don't have those same ethical conundrums to deal with … [regulators can] look at the nature of the conduct and how that aligns with the statutory requirements.(#53, VR)

However, some thought that the chosen level of regulation of VAD was excessive and its enforcement was 'pedantic'. This was expressed more often in relation to the Victorian system and more often by doctors than regulators. The current approach to regulation was seen as having an adverse impact on the system, including potentially deterring doctors from participating. For others, this level of regulation was perceived to increase participation amongst doctors. Indeed, some participants perceived that the current approach to regulation meant that doctors were protected and, therefore, felt safer being involved.

> The more tick boxes that you have and the more that it's prescribed, to a certain extent, the easier it is to get people involved. Because they know that if they do A, B and C, that they're not going to be in trouble.(#32, VD)

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Some regulators also regarded this as a positive and, indeed, had intentionally chosen to regulate in a vigorous manner, despite potentially making the VAD process more challenging for doctors (and patients) as a consequence. These participants perceived this was justified to ensure there were no mistakes. A critical consideration underpinning this approach was the need to 'protect the system' and retain public trust in the system. Some participants suggested that any perceived problems would make the system vulnerable to attack and compromise public confidence.

> My lens is what's the risk I need to consider and how do I manage that particular risk … to protect the programme? The other thing I should say protect the doctor … if they do the wrong thing, they're accountable for a hell of a lot … (#68, VR)

Such sentiments partly reflected the gravity of VAD but also the fact that it is new in Australia, so mistakes or problems with the system in its early days could jeopardize its future.

> [Victoria] were [the] first in the country, so [they] were … deliberately trying to put in safeguards that no one could argue against, and that's what we've done over the last … three and-a-half years … if something went wrong on the first ten cases, it would have closed down everything for a decade.(#33, VR)

There was little doubt that the degree of regulation of VAD was unique or at least very rare in medicine: 'there is no activity in health care, other than a few very small things, that has this degree of oversight and regulation.' (#91, WAR)

2. There are particular challenges regulating VAD

Participants recognized that while regulating medicine in general is challenging, it is particularly challenging for VAD. Both states have long and complex Acts that make VAD legal, but 'translating that law, that framework into practice is where … the challenge really lies.'(#43, VR)

Both regulators and doctors noted tension between strict rules that tightly control the process to ensure VAD is done safely and consistently, with the need for the regulatory system to allow for flexibility and discretion to make appropriate judgments for the particular clinical context.

> If doctors feel that this regulation is so tough and tight that they are worried about making a mistake or … the wrong thing, then that … might deter them from wanting to get involved. So, I think [good] regulation [is] where they understand the parameters within which they're expected to work, but … it still respects, to some extent, their autonomy as professionals and gives them scope to look after their patients safely.(#38, NR)

> … the law just makes it easier to punish those people because they've clearly broken a rule. I'd prefer a VAD system based more on … guidelines, … policies and procedures … with maybe some more autonomy and independence and wriggle room.(#29, VD)

B. Effective VAD regulation draws on multiple tools

In addition to acknowledging the need to regulate VAD, many participants expressed views about the most appropriate way to do so, including what regulatory tool(s) to use.

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Participants identified a wide array of tools needed for effective regulation of VAD and considered their strengths and weaknesses. Most commonly mentioned were law, policies and guidelines, training and education, and peers (including communities of practice).

1. Reflections on individual regulatory tools

a. Law

Many participants discussed the role of law in regulating VAD. This was generally the VAD Act, but sometimes subordinate legal instruments or rules were mentioned, such as health or aged care standards, which are required to be complied with for the purposes of accreditation.

Law was often seen as necessary to set the boundaries for what is possible, establishing a broad framework for VAD.

> I think [for] something as serious as this, it probably has to be legislated. I think there has to be a sense of this is a legal requirement.(#27, VD)

Participants rarely reported law directly driving specific behaviour in a particular way but rather as operating at a higher or more abstract level to motivate compliance. Many participants suggested that doctors are keen to follow the law when stakes are high (such as VAD), suggesting 'the more serious the topic gets, the more law abiding [doctors] become'. (#24, VD)

The adverse consequences of not following the law were seen as significant in promoting compliance by doctors. This included the prospect of sanctions (including public sanctions).

> If you want to get doctors to do something, the law is pretty tight. Other than that, doctors think they know better and can do whatever they want.(#28, VD)

> My experience with dealing directly with clinicians … is a genuine willingness to be compliant because they don't want to breach the Act … even just that sentence, 'If you do not do this, it is a breach of the Act,' … is very motivating in getting people to do what needs to be done.(#76, WAR)

> There's law that you have to abide by, and there's regulations that you have to follow, or Ahpra will be on your case, or you'll have complaints, and before you know it, you'll be in the civil court, or in the coroner's box. So that stuff is a pretty powerful motivator for doctors … (#46, VR)

However, participants acknowledged limitations on the law's ability to regulate. First, it cannot assist in promoting good practice; rather, it can only prescribe a 'minimum standard or a lowest common denominator'(#66, VR). Furthermore, as noted above, the law was perceived to have limited effectiveness in helping doctors understand the steps they should take. Indeed, the law *requires* translation into clinical practice, and this falls to other regulatory tools such as policy or training (see below). Finally, some participants expressed reservations that the rigidity and prescriptiveness of law constrained professional autonomy in clinical practice, while others queried whether the law should be able to compel doctors to take certain actions (particularly if they are conscientious objectors). Indeed, one suggested 'you just can't force somebody to do [something], even if it's the law … you can just encourage them.' (#49, NR)

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b. Policy and guidelines

Participants identified a broad spectrum of documents within this category (see Table 1 for an overview of regulatory tools including policy and guidelines). At one end of this spectrum were high-level positional statements, including those from medical bodies such as the Australian Medical Association (AMA)[32] or medical colleges, and high-level care pathways or decision-making frameworks in relation to VAD (often issued by governments and health-care institutions). At the other end of the spectrum were more detailed policies and procedures about the practice of VAD, typically issued at the local level (ie institutional level).

In terms of types of policies that were more likely to guide behaviour, both groups of participants identified that policies or guidelines that related specifically to clinical practice and gave concrete direction about how VAD would be operationalized and what processes or actions are needed were of most utility to doctors. Specifically, guidelines that would help doctors answer the question: 'What can I do for my patient today?'(#84, WAR) were deemed most useful.

Such documents were often perceived as key to translating the law into practice, especially when couched in language that doctors were familiar with (ie in medical terms and/or consistent with clinical and professional standards), as opposed to the law which doctors are less familiar with.

> Doctors aren't good at law … there are some advantages in a professional practice document because it starts to set the professional standards as different to the rules. (#91, WAR)

Examples of effective clinical policies or guidelines included Health Pathways,[33] documents with clinically relevant case studies, checklists, flowcharts, and decision-making trees (ie documents that specify required procedural steps).

> Those sorts of guidelines and the decision-making tree are probably the thing[s] that the GPs will follow. So that's probably the most important thing in terms of compliance. (#57, NR)

Some participants also identified that local policies and processes were particularly important in the context of VAD, as they were needed to create permission for things to occur.

> I like to just do what I want, but a lot of what I do I can't do unless everybody's happy with me doing that … [It] comes with this kind of subtle herding … there might not be a written guideline about that, but it's just what everyone does so that's what you do. So, if a person comes into a ward with a medication you need to have some sort of hospital [process].(#88, WAD)

Policies perceived as having less direct relevance to clinical practice were generally considered less powerful in steering behaviour (and in contrast to the law, which, although seen as

[32] The AMA is the peak professional body for doctors in Australia with federal and state-based organizations. It operates on a voluntary membership. See 'Australian Medical Association' (*Australian Medical Association*, 19 February 2020) <www.ama.com.au> accessed 6 April 2024.

[33] Health Pathways is an online resource which provides clinicians with access to clinical referral pathways and resources, within designated regions. 'Primary Health Networks and Pathways' (*Victorian State Government Department of Health*, 2021) <www.health.vic.gov.au/preventive-health/primary-health-networks-and-health-pathways> accessed 2 April 2024; 'Health Pathways' (*Western Australia Primary Health Alliance*, 2024) <www.wapha.org.au/health-professionals/healthpathways/> (2024) accessed 2 April 2024.

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remote, is backed by coercive force). Examples of less influential regulatory tools included position statements of medical organizations and colleges.

> This is my personal opinion, but I don't think the [organisation by stating they] believe doctors should not be involved, is going to change somebody's individual opinion on the ground.(#49, NR)

While such documents were less likely to directly guide behaviour, making an organization's position clear was still considered useful by some participants, as it enables the organization's constituents to assess what lens it uses when issuing advice, which may influence whether the doctor would follow such guidance.

> [If the organisation] tried to say anything practical —and [they] didn't say anything about where [they] stood on the topic–that would always be begging the question … 'We're getting advice, but what position is this coming from? Is this coming from a 'for' position or an 'against' position?' I mean, I guess you could read between the lines, but I think you're obliged to say what your position is.(#41, NR)

c. Training and education

Training and education were identified as important parts of VAD regulation. This may have been shaped by both states having legislatively mandated training that participating health practitioners need to complete (see Table 1), which was the subject of most of the discussion on this topic. The mandatory training is delivered online.[34] The VAD Care Navigators and some health services have hosted in-person training sessions where clinicians were invited to attend to complete the training with other practitioners.

There was a spectrum of views on the utility of this mandatory training. Most felt it equipped doctors with knowledge of the VAD law and their responsibilities under it, and endorsed its role as a safeguard.

> I mean the way it's set up it's made pretty clear—the training is good, and it's made quite explicit what are the ironclad rules, law regarding this.(#23, VD)

Other participants from both cohorts were more critical, suggesting the training was too legalistic and long, and a potential barrier to VAD participation. There were mixed views on the assessment component: some perceived it as too hard, while others considered it necessary to ensure careful engagement with the training. Some participants suggested having the opportunity to undertake the online training in person and with peers (as opposed to doing the training alone) was likely to enhance engagement with the material, and willingness to undertake the training.

> The very legalistic focus of the training, in the beginning, was probably not well received by doctors. And the 90% pass rate with rather esoteric legal questions wasn't taken well. But getting [health practitioners] to do training in groups is collegiately good; being together and talking about things is really good. And the pass rate has gone right up as a result.(#48, VR)

[34] Ben P White and others, 'Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration' (2021) 36 J Palliat Care 162.

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There was also a desire for more training about the practice of VAD (rather than the legal framework), whether that was in the mandatory training or generally: 'It's doing it practically that is useful. It's filling in the forms the first time.'(#21, VD) Some participants reflected that some softer process skills (eg communication skills), that were not necessarily VAD-specific and transferable to other aspects of medicine, could be embedded within other forms of education (eg tertiary education and continuing professional development).

> The training requirements for this could pretty much fall within the usual approach that we have for professional development in the medical sphere … digging down to what that looks like … well, the universal in health is the communication skills.(#41, NR)

d. Peer opinion and/or professional norms

Perhaps the most striking finding was the frequency with which peer opinion and/or professional norms were mentioned in response to questions about how best to regulate. It is significant that they are not traditionally regarded as 'regulatory tools' in the same way as the preceding tools (perhaps a formal community of practice is the closest to being 'formal regulation'). Yet, both doctors and regulators identified peer opinion and professional norms as powerful factors guiding doctors' practice.

Some noted this normative power came from a desire to conform to peer opinion as no one wants to be the 'only person marching out of step' (#42, NR). Another was that doctors recognize this professional consensus or peer opinion is how clinical practice is regulated generally and resembles how learning usually occurs in medicine.

> Everything [doctors] do is peer learning, so we need to adapt that framework to fit into the model that already exists, and that is the primary way that we conduct and learn about medicine.(#1, VR)

A few participants specifically acknowledged the influence not just of peers but of a mentor whose experience or seniority gives credibility. Sentiments also reflected the importance of 'on-tap' support when needed(#66, VR), as opposed to training, which is often only done at one point in time.

> What you also need is a mentor. So, I personally think, having been through it, that it would have been really great if I had had someone with me the first time who'd done it before.(#21, VD)

The communities of practice formally established in both Victoria and Western Australia and informal communities established by doctors themselves were identified as important sources of VAD regulation. Such communities crystallize a repository of VAD knowledge in an accessible forum which allows doctors to 'calibrate [conduct] amongst our peers' (#88, WAD) and, in doing so, provides 'subtle herding' (#88, WAD) of doctors towards safe and consistent practice. Doctor participants valued the opportunity to test their thinking generally and in relation to particular cases to support their decision-making. This benefit was also observed by regulator participants.

> I think there's a great value in having those professional communities and networks … being able to engage around practices and learn together in such a new and evolving scheme,

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to be able to say, 'What does this education tell us, and what have we learnt from that?' or, 'I've had this situation'.(#52, NR)

e. Other regulatory tools

Although the above four regulatory sources were most commonly identified when discussing effective regulation, participants also discussed other regulatory tools. A significant one was the online information management system (or portal) through which forms are submitted (generally by doctors) during the VAD process. Some doctors were critical of this infrastructure, particularly with respect to the time and administrative burden it placed on them. Some participants also criticized the rigidity and useability of this system (especially in Victoria and in the early days before a system upgrade).

However, both doctors and regulators saw the regulatory benefits of the system. First, this infrastructure prompted doctors of the next step in the process, which helped guide them through the correct stages of the complex VAD assessment and approval procedure. Furthermore, the periodic submission of forms during the process allowed for scrutiny of these documents, providing an opportunity to monitor decisions being made informally. This scrutiny of each submitted form meant that potential mistakes or issues could be identified before VAD was provided.

> The portal … like it's a bit foolproof … going through each step. I think that that's useful, because it means that you're not sort of going on and thinking, have I stuffed this up … along the way … I guess … [you need] legislation and then technology that means that we can't deviate from the legislation.(#18, VD)

> To help enforce a particular process, you need something that helps guide [health practitioners'] decision-making but also guides automated accountability. And I think the (information management system) … [has] an aspect of guided accountability … in terms of the notification process, the prompts, the underlying education … the reinforcement … I think that's the key thing, in the absence of sort of any other stronger control, in terms of ensuring compliance to legislation.(#85, WAR)

A second significant form of regulation perceived to be effective was the role that key individuals play in guiding behaviour. This is linked with peer opinion above, as this individual was often a health practitioner but is narrower because the guidance was not grounded in wider professional norms but rather came from the concentrated expertise of specific individuals. The most common example was VAD Care Navigators. Their experience with the system meant they were able to guide doctors through the process (and therefore within the law), advise on how Boards and Secretariats require the forms to be completed, and were generally often sought out as trusted sources of reliable information about VAD. Another example participants gave was a lead VAD clinician for a facility or organization.

Other forms of effective regulation participants identified include contracts with health services (which can include conditions that guide behaviour such as a requirement to develop local policies and procedures to manage VAD processes),[35] meetings and relationships with health professionals and service providers (as a chance to influence their practice), and research (which can be used to generate evidence to help guide policy and practice).

[35] See example: 'Managing Voluntary Assisted Dying Policy' (*Western Australia Government Department of Health*, 2021) <www.health.wa.gov.au/About-us/Policy-frameworks/Clinical-Governance-Safety-and-Quality/Mandatory-requirements/Managing-Voluntary-Assisted-Dying-Policy> accessed 27 February 2024.

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Financial resourcing was also mentioned as a way to increase the participation of doctors in VAD (along with the linked issue of releasing clinicians from existing clinical duties to undertake VAD work accounted for in local policies, discussed above).

Accessible resources and readily available information also helped to regulate the practice of VAD. Public debate (including through the media) and information-sharing forums (eg webinars, conferences) about VAD have also shaped practice, with personal stories about an individual's VAD experience found to be particularly compelling. Indeed, publicity around suboptimal practice was perceived to encourage compliance with regulation, shape VAD practice or serve as an advocacy tool to help guide future reform. In a different vein, exposure to personal stories was also found to encourage practitioner involvement with VAD.

2. Multi-faceted approaches to regulation are needed

The foregoing discussion shows that participants collectively identified a wide range of regulatory tools when discussing what made for effective regulation of VAD. However, some participants went further and made the specific point that effective regulation of VAD depends on using multiple tools of regulation *together*.

> You need a mix of approaches. I don't think there's a single way of regulating behaviour that is likely to capture all eventualities and to work for all types of practitioners or all types of people … different people are motivated by different things. (#77, WAR)

Other participants demonstrated this view by talking about more than one regulatory tool being needed. Many participants identified that regulation in the form of law was important but should be supplemented with at least one further form of regulation. In particular, and as noted above, this was commonly framed as the law establishing a framework or process that needs translation into clinical practice or guidance, the latter being achieved by other regulatory tools.

C. Educative approaches to VAD regulation are generally more effective

Both doctor and regulator participants generally preferred an educative approach over a punitive approach for a minor error or non-serious breach. Although this theme was present in views from both states, it was particularly so in WA. This difference likely reflects that the fact the WA VAD Board has been recognized to take an educative approach to regulation, compared to the approach by the Victorian VAD Review Board in its early days of operation which has been perceived to be more punitive.[36] An educative approach was seen as more effective in guiding practice: it is better to be 'gently herding' rather than 'shaming people' (#88, WAD). Some participants emphasized the importance of dealing with issues in a constructive and proportional manner.

> … things might be a breach of the Act, but then they get notified to the DG [Director-General of the Health Department]. But it's not like … that's automatic notification to the police. The DG will have a look at it and say 'what does this actually mean? … Is there something else that needs to be done here? Or is this just evidence of part of the process that we need to improve? In which case, let's improve that part of the process.'(#76, WAR)

[36] Haining, Willmott and White (n 25) 739.

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An educative approach was seen as appropriate because doctors want to comply with the VAD system, so mistakes or failures generally reflected a lack of understanding, as opposed to a deliberate breach.

> I think education is the key … if practitioners fully understand what their obligations are and what steps they need to take to comply, I expect that 99 percent of them will comply … It doesn't mean there won't be slipups, and … mistakes … But I genuinely think that if they're properly educated and they understand their requirements, then they'll do it.(#53, NR)

Indeed, some regulators identified that it would be inappropriate for them to take action for non-compliance, without first educating their constituents.

> [Regulators would] be criticised if [they] hadn't done [their] bit to try and educate the profession so they know what the requirements are before [they] jump in and start disciplining them.(#52, NR)

Adopting an educative approach was also perceived to be conducive to fostering relationships between regulators and doctors. Maintaining such relationships was particularly important for State-based regulators. From their perspective, educational approaches provided a mechanism to softly correct behaviour without being antagonistic and risk discouraging doctors from continued participation in providing VAD. This was considered imperative to the system's overall sustainability.

> It is about those informal links and relationships … the Board emphasising that they have an educative approach and that if [the Secretariat does] ring a practitioner and tell them they made an error in the form, [they are] not quoting the Act at them, 'under section blah, blah, blah,' and 'if you don't do this, you could be fined.' It's about approaching people with sensitivity, and working with practitioners and if they have made a mistake or an error.(#70, WAR)

Despite the preference for non-punitive approaches, the ability to implement punitive measures was seen as necessary and appropriate in some (exceptional) cases: 'For the one percenters, deterrence is going to have to be important, and that means that [regulator] will have to take appropriate action'(#53, NR). Punitive measures included risk to medical registration and/or financial sanctions. Furthermore, a more vigorous approach to regulation was also perceived by some regulators to be needed if action was required to 'protect the system' (as noted above, given the specific nature of VAD).

D. VAD regulation is effective when it is perceived by doctors as acceptable

This theme explores why doctors might accept or respect VAD regulation as appropriate and choose to follow it. It goes beyond the special nature of VAD warranting particular regulation (theme 1) and how different tools of regulation may be effective, for example, how the law's coercive power may be effective to promote compliance by doctors with the system's rules (theme 2). Instead, this theme focuses on how the nature or design of that regulation contributes to doctors perceiving that regulation as legitimate and appropriate in the VAD field and, therefore, worthy of compliance. One participant spoke about the need for such regulation to reach people's 'hearts and minds'(#57, NR).

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Some participants (both doctors and regulators) noted that doctors are generally not easy to regulate: 'doctors like to be able to just do what we think is the right thing to do' (#88, WAD); 'We're [an un]ruly bunch, we don't like rules really'(#27, VD); and 'a lot of doctors just don't like being told how to practise medicine'(#49, VR).

Participants suggested that for regulation to be effective, doctors generally needed to recognize (and appreciate) its purpose.

> Rules for the sake of rules they're often very frustrating for doctors who are trying to be very practical … if there's a clear, logical explanation behind something, then we'll follow that.(#31, VD)

> I hate when somebody tells me that I have to do things in a certain way … I'll stick to what I think is a sensible guideline … (#88, WAD)

> I think sometimes doctors are cut[37] more when something seems really much more bureaucratic, but they can't see the logic behind it. Which I don't think is in the case of VAD. (#24, VD)

The special nature of VAD (theme 1) was identified by some participants as helping make this case, but this was not sufficient, demonstrating that some laws are perceived differently on paper than they are in clinical practice. An example given by several doctors was that state VAD laws made sense and were understandable (particularly the need for eligibility criteria), but federal limits on telehealth[38] were not reasonable and, therefore, were less persuasive.

Factors participants identified as contributing to a perception of VAD regulation being justifiable and therefore legitimate included that regulation was of benefit or useful for patients, the public or community, or doctors themselves (eg legal protection).

> [Doctors] only care about something if it impacts their patients generally or is going to make them not able to practise medicine anymore.(#84, WAR)

> When there's a lot of bureaucracy and things don't make sense to doctors, then they're probably, as a group, more willing to push boundaries because … their priority is … their patients' care rather than bureaucracy.(#24, VD)

> … to get medical staff to want to participate in anything there's got to be a bit of what's in it for me? … [that] lever is helpful.(#61, VR)

Some participants also pointed out that regulation was more likely to be perceived by doctors as appropriate if it was based on evidence.

> I think for medical practitioners, where we try and base most of our decisions on evidence … the rules have to have [a] good rationale behind them, and … be logical. So, I think that if you're designing a system where [you] want people to do this … it either has to be practical or have a strong degree of evidence there.(#61, VR)

[37] 'Cut' is an Australian colloquialism which means upset or angry.

[38] For a detailed account of the federal law and prohibition of telehealth, see Katrine Del Villar and others, 'Voluntary Assisted Dying and the Legality of Using a Telephone or Internet Service: The Impact of Commonwealth "Carriage Service" Offences' (2022) 47 Mon L Rev 125.

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The resonance or 'fit' of regulation with clinical practice also had an impact on perceived legitimacy. When regulation is practical and aligns with how doctors understand and practise medicine, it is more likely to be viewed positively. For instance, limiting telehealth for VAD (which is now routinely used in medicine, including end-of-life care) was an example of an impractical law with potentially limited normative force.

> One issue I've had with the regulation is the whole idea of the telephone conversations or email conversations … The guidance we've had is just don't do it, which is impractical … Whereas when it comes to the state law around it, it's quite clear what the guidance is, and we know what to do … having that framework, and having it somewhat practical as well, is probably the two things that I'd say to getting doctors, or anybody, to comply with the regulation.(#22, VD)

The process that went into developing the form of regulation also influenced its perceived acceptability. This included who was involved in its development and delivery, with positive observations when key medical leaders were involved. Regulation developed in consultation with doctors and others involved in the system was also seen as having greater legitimacy.

> People feel willing to contribute and participate if they feel some sense of co-design or autonomy and it's not unilateral … There's no point in just saying, 'All emergency doctors have to do blah, blah, blah. Here's your directive memo from the general manager, end of story.' It's about sitting down with them and saying, 'OK, these are the things we're trying to achieve. What's your role in that and how?'(#60, NR)

This process of participation and inclusion in decision-making was perceived as being especially important for regulators who depend on their medical (and/or broader health) membership for support. Policies or position statements had to juggle reflecting the views (or breadth of views) of members and being representative, while also recognizing the possibility that such statements may go beyond existing views of members and attempt to create leadership in policy directions preferred by specific personnel within those organizations. Support of members for regulatory tools was also perceived to be needed for them to have any weight.

A final observation about the acceptability of VAD regulation related to whether VAD should be conceptualized as different from usual health care or not. Theme 1 identified VAD as warranting special regulation and identified particular challenges with its regulation. This has implications for the legitimacy of VAD regulation, including, as noted above in this theme, providing a rationale for regulation that doctors understood as justified and, therefore, respected. However, by contrast, some regulator participants argued regulation of VAD is more likely to be effective and seen as legitimate if it is treated consistently with how regulation of health care generally occurs.

> VAD is being implemented within an existing system where you already have kind of established purposes and relationships … I've really tried to ensure that we achieve with VAD is that, wherever possible, we just line up with how [we] normally [do] business. [We]'ve tried really hard not to have an approach that is different and outside of that if we can possibly avoid it.(#77, WAR)

Another regulator participant expressed similar sentiments and even proposed conceptualizing VAD regulation in a way that resonates with how doctors approach clinical work.

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> The way to approach it is to see if you could frame this as simply being another form of medical treatment, and how would they approach that … In other words, to try and present this as not being something that is, at the moment, seen as this technical legal thing, but more just as another form of treatment and approach it in the same way, and recognising that there are some formal requirements of going through the [eligibility] criteria, but that's a bit like symptoms. There are some formal requirements for forms, but you'd have to do that if you wanted to prescribe methadone or whatever. So, to try and make it less unfamiliar to them and less seen in a legal framework.(#40, VR)

E. VAD regulation is effective when it is nimble and responsive to doctors' (and others') needs

The final theme was that regulation is more effective when it is nimble and able to respond to what doctors need to participate in VAD. This included recognition that the introduction of VAD meant that doctors had to receive and process a large volume of information initially (eg mandatory training) but that ongoing guidance is needed.

> I think it's unreasonable to expect that … a very, very busy clinician who's got a full normal clinical load, is doing VAD quite literally in their own spare time, who's done the training … could be expected to memorise the legislation … VAD guidelines, et cetera, and know all those off by heart. We have to have a level of decision-making support, guidance … prompt automation to ensure compliance.(#85, WAR)

Key aspects of effective regulation were right-sizing the volume of information, having it available in the right form, and making it available at the right time.

> I think it's about recognising the need for that ongoing resource support and that there will be need for ongoing questions and … reinforcement. And providing that in a chunky way that makes it not so overwhelming and huge, but is accessible … They want to know: what can I do for my patient today? So, providing the information in a way that's chunked up, that supports that decision making at the right time … is [what doctors] generally need.(#84, WAR)

This includes doctors who might not yet be involved in VAD but nevertheless must respond when it is raised (even if they do not directly participate).

> If you think of a GP down at [a regional town], and someone walked in off the street and raised assisted dying with them, it's going to be the first time they've ever turned their mind to it. They're not going to be sure about what the legislative obligations are. They're not expected to. So, they really have to know, 'Who do I speak to now to try and sort out what do I do next?'(#53, NR)

Participants noted it can be challenging to find that information. But some spoke about the vital role that people—as opposed to the system itself or published information—played in guiding people to the right resources or providing advice to assist and being available to troubleshoot where applicable.

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> One of the things that we've tried to achieve is the clear and strict process that needs to be followed, but also the human communication and assistance that can help practitioners to follow that process.(#88, WAR)

> … support comes from the Care Navigators, it comes from the Pharmacy, it comes from the Board and it comes from [the Secretariat]. You know, 'If you need help, give us a phone call. If we don't know the answer, we'll find the right person.'(#86, WAR)
> I think it's about remembering that doing the training is a particular point in time. So, they get it when they do it, and then they'll come back to us multiple times with questions: 'Can I do this? Can I not do this? What does this say? What do you think?' And we will refer them back to the right bits and bobs. (#84, WAR)

Some participants reported this human support as missing, with one participant responding, when asked what might help them:

> Easier technology, the ability to talk with a human. This [online] portal is just bizarre, and you're not talking to a human. I don't know why you can't have a human at the end. (#4, VD)

The layering or multi-faceted nature of the VAD regulation was considered an important feature of nimble and adaptive regulation. These layers of regulation emerge clearly from the above quotes in this theme. They are also reflected in the earlier themes, for example, recognition of the utility of training, but the need to supplement this with mentoring to practically deliver VAD (theme 2).

In addition to responding to individual doctors' needs at any given point in time, participants also saw the benefit of the system as a whole being responsive to the needs of doctors providing VAD. This included system changes in response to feedback (eg upgrades to the information management system) and issuing generalized advice (eg in the forms of newsletters or practice notes) in response to learnings from the system. This system responsiveness was seen as particularly important because VAD was new and hence required regulators to actively reflect on this evolving practice and initiate timely adjustments.

Participants also gave counter-examples of where regulation, in their view, failed to be nimble and responsive, and so was not effective. One was in relation to the early days of the Victorian system, where the process of reviewing and approving the forms that must be submitted by doctors was slow and 'pedantic'. Another was where health services organizations failed to develop policies and processes to respond to VAD promptly, resulting in a regulatory vacuum leading to confusion and inaction.

IV. DISCUSSION

This article reported on perspectives about how best to regulate VAD from both doctors who have provided VAD and the regulators who guide this practice (Fig. 1). Strikingly, both regulator and doctor participant groups were consistent with each other in their views on what constituted effective regulation.

The nature of VAD was perceived by participants to require special regulation, although some felt this was overdone in these two Australian states. Reported features of effective regulation included regulators taking an educative approach, regulation being perceived as acceptable by doctors, and it being responsive and nimble to provide the guidance that doctors need. Participants also considered a range of regulatory tools were required to

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regulate VAD effectively, and some identified a need for these tools to be employed together in a holistic way.

A. Holistic and layered approaches to VAD regulation

Our findings which identify the need for a holistic approach to VAD regulation align with wider regulatory scholarship. As noted above, modern regulatory theory generally recognizes that regulation is decentralized and hence a range of regulatory tools exist, requiring holistic approaches to understanding how behaviour is guided.[39] These findings may be unsurprising given how we defined regulation and our purposive approach to sampling, which targeted different regulator types who employed different types of regulatory tools (See Tables 1 and 2). However, the need for multiple regulatory tools, and for them to be used in an integrated way was independently identified by the participants themselves (theme 2). Such findings are congruent with previous calls for holistic approaches to regulating end-of-life care.[40] Failure to appreciate the interdependence of regulators and their regulatory tools can lead to a 'mosaic of regulatory arrangements' which are highly fragmented and result in duplication.[41]

Participants' holistic approaches were also layered in that they generally reported a graduated conception of regulation that begins with a general legal framework which then progresses to increasingly specific guidance at the clinical coalface where actual decision-making about VAD occurs. There was recognition that law was required to permit VAD to occur and establish the boundaries of the regulatory framework. But legal rules, reflecting the challenges of regulation more generally,[42] are inherently indeterminate in that they can never completely capture the circumstances law and policymakers intend them to be used for, due to their anticipatory nature and their reliance on others to interpret. Further regulatory work is needed to translate those laws into safe and compliant clinical decision-making, and, as is commonly the case in medicine,[43] this generally fell to tools such as training, policy, and guidelines. We also note repeated calls from participants, as part of the 'nimble' regulation theme, for a further layer of regulation at the coalface, such as 'on-tap support' to troubleshoot where necessary, often involving access to a specific person who could advise.

Significantly, participants identified two tools as being prominent in guiding behaviour, beyond what might ordinarily be anticipated in an evaluation of VAD regulation. The first was the State-run online information management system that is used for the submission and management of the forms that doctors (and others) must submit during the VAD approval process. Although information technology is a recognized tool in wider regulatory scholarship,[44] it was not part of the legislation that established VAD, nor was it one of the considered safeguards.[45] Rather, an information management system was only conceived of during the implementation phase of the legislation.

[39] Black (n 18).

[40] White, Willmott and Close (n 15).

[41] Oikonomou (n 3) 2.

[42] Yeung (n 1) 169–70.

[43] Eliana Close, Lindy Willmott and Ben P White, 'Regulating Voluntary Assisted Dying Practice: A Policy Analysis from Victoria, Australia' (2021) 125 Health Policy 1455, 1457; Joke Lemiengre and others, 'Impact of Written Ethics Policy on Euthanasia from the Perspective of Physicians and Nurses: A Multiple Case Study in Hospitals' (2010) 1 AJOB 49.

[44] Karen Yeung and Mary Dixon-Woods, 'Design-Based Regulation and Patient Safety: A Regulatory Studies Perspective' (2010) 71 Soc Sci Med 502.

[45] See, eg Ministerial Advisory Panel on Voluntary Assisted Dying, 'Ministerial Advisory Panel on Voluntary Assisted Dying Final Report' (Victorian Government Department of Health and Human Services July 2017) <https://content.health.vic.gov.au/sites/default/files/migrated/files/collections/research-and-reports/m/ministerial-advisory-panel-on-voluntary-assisted-dying-final-report-pdf.pdf?> accessed 27 February 2024; Ministerial Expert Panel on Voluntary Assisted Dying, 'Ministerial Expert Panel on Voluntary Assisted Dying Final Report (Western Australia Government Department of Health

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Yet participants, consistent with other literature drawing on some of these interviews,[46] report that this information technology infrastructure exercises very significant practical control over the VAD approval process. This is particularly the case in Victoria, where VAD cannot be accessed until a senior public servant in the Health Department authorizes VAD via a 'permit'. This permit can only be issued after reviewing all of the submitted online forms for compliance, and hence, this additional final step in Victoria facilitates a gatekeeping function through the information management system.[47] While the focus of VAD regulation tends to be on tools such as law, policy, and training, this research demonstrates that information technology can exert powerful regulatory control and its potential role needs to be considered in the holistic design of VAD regulation.

A second regulatory tool worthy of specific comment is peer opinion and/or professional norms. It was striking that both doctors and regulators identified how significant these were for guiding behaviour in the VAD field (as well as medicine more generally). While this might be anticipated in the discipline of medicine, which has a long recognition of the power of peer opinion and professional norms in guiding practice, it does sit somewhat awkwardly with the conception of 'regulation' proffered by Julia Black. Black's conception refers to a 'sustained and focused attempt to alter behaviour' and does not extend to the operation of market forces, social norms and culture.[48] In Black's view, such factors might influence how regulatory systems operate, and regulatory systems might seek to harness and alter them, but they are not in themselves forms of regulation.[49]

Despite this, our participants consistently identified peer opinion and/or professional norms as a critical part of effective regulation of VAD. There is also a link to more formal regulation in that, in both Victoria and WA, the State sought to utilize these forces in regulating VAD through their intentional 'seeding' of VAD communities of practice (ie regular meetings of doctors providing VAD).[50] Resources and infrastructure were initially provided to establish such forums, and some of this State support continues today. Early evidence shows these communities of practice have been valuable in providing a forum for collective expertise, fostering camaraderie, and permitting information-sharing and the development of consistent VAD practice (some of which we would regard as regulation).[51]

Regardless of whether peer opinion and/or professional norms can be conceptually regarded as a regulatory tool, their significance for both sets of participants suggests they are a powerful way to guide behaviour in the provision of VAD and should be harnessed, or at least their influence accounted for, when the State is considering its overarching approach to VAD regulation. One issue to monitor is the risk that norms of the medical profession may not align with the intended policy goals of VAD regulation (eg norms which prioritize doctor discretion over compliance with system safeguards). This may require greater State intervention via other regulatory tools to constrain professional norms affecting VAD practice in this way.

2019) <www.health.wa.gov.au/~/media/Files/Corporate/general-documents/Voluntary-assisted-dying/PDF/voluntary-assisted-dying-final-report.pdf> accessed 27 February 2024.

[46] Ben P White and others, 'Prospective Oversight and Approval of Assisted Dying Cases in Victoria, Australia: A Qualitative Study of Doctors' Perspectives' (2024) 14 BMJ Support Palliat Care e1462-1471 <https://spcare.bmj.com/content/early/2021/05/24/bmjspcare-2021-002972> accessed 27 February 2024.

[47] ibid.

[48] Black (n 18) 26.

[49] ibid.

[50] 'Western Australian Voluntary Assisted Dying Guidelines' (Government of Western Australia Department of Health, 2021) <www.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-guidelines.pdf> 84, accessed 27 February 2024; Victorian Voluntary Assisted Dying Review Board (n 31) 9.

[51] Haining, Willmott and White (n 25).

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B. Why doctors choose to comply with VAD regulation

Other significant findings in this research related to participants' observations about a regulatory system's legitimacy, again reflecting wider debates in the regulatory literature.[52] Many participants believed VAD required regulation due to its 'special nature', with some doctors observing this served to protect doctors (as well as patients). This resonates with what has been observed internationally.[53] However, beyond acceptance of a threshold point of the need to regulate, the challenge is designing and implementing a regime that commands widespread acceptance.[54] As identified during the implementation period in Victoria, concerns have been raised by doctors about the inability of a legislative approach to capture the nuances of a clinical environment.[55] Doctors' compliance with rules are largely shaped by their values and views on the laws they are governed by, and to what extent they perceive them to be legitimate.[56] This in turn informs the way in which they resolve tensions in professional obligations.[57] Participants observed that doctors were more likely to see regulation as legitimate and comply with it when they could appreciate its rationale. This points to the importance of communicating the 'why' of VAD regulation to doctors.

Also important for perceptions of legitimacy can be the 'how' of regulation in terms of its development. While regulation from the State may be able to depend on enforcement through coercion (which in itself can bring some legitimacy),[58] non-State actors and tools of regulation may need to construct legitimacy for their regulatory influence to be acknowledged.[59] Good process in developing regulation can help with this. Participants suggested that regulation was more likely to be acceptable if it was developed through a process that was based on evidence, was consistent with clinical practice, and if doctors (or perceived 'credible' or 'authoritative' sources) were involved in the design. Although not specifically commented on by participants, this would include legitimacy attached to the original VAD laws due to the credible and inclusive process of developing and passing them.[60] This resonates with what has been observed internationally. For instance, one study carried out amongst VAD providers in Canada during the COVID-19 pandemic found that in cases of tensions between VAD laws and COVID-19 public health rules, many clinicians appeared to prioritize VAD laws, perceiving them to be more legitimate.[61] The authors surmised that this may be a product of the time, research, debate, and deliberation which lead to their formation.[62]

A final observation about compliance is to note that regulation is a human enterprise, and decision-making and conduct of individuals were shaped by several 'motivators'.[63] For doctors, this included risk motivators that were either reputational (eg being out of step with

[52] Yeung (n 1); Tom R Tyler, *Why People Obey the Law* (Princeton University Press 2006).

[53] Eric Byrnes, Alasdair Iain Ross and Mike Murphy, 'A Systematic Review of Barriers and Facilitators to Implementing Assisted Dying: A Qualitative Evidence Synthesis of Professionals' Perspectives' (2025) 90 OMEGA 1137 <https://journals.sagepub.com/doi/10.1177/00302228221116697?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed302228221116697> accessed 27 February 2024.

[54] Julia Black, 'Constructing and Contesting Legitimacy and Accountability in Polycentric Regulatory Regimes' (2008) 2 Regul Gov 137; Yeung (n 1).

[55] Rosalind McDougall, Bridget Pratt and Marcus Sellars, 'Ethical Diversity and Practical Uncertainty: A Qualitative Interview Study of Clinicians' Experiences in the Implementation Period Prior to Voluntary Assisted Dying Becoming Available in their Hospital in Victoria, Australia' (2023) 20 JBI 71, 82–84.

[56] Sabrina Tremblay-Huet and others, 'The Impact of the COVID-19 Pandemic on Medical Assistance in Dying in Canada and the Relationship of Public Health Laws to Private Understandings of Legal Order' (2020) 7 J Law Biosci Isaa08 <https://doi.org/10.1093/jlb/lsaa087>

[57] ibid.

[58] ibid.

[59] ibid.

[60] See above Table 1 ('Parliament') in relation to the development of Australia's VAD laws.

[61] Tremblay-Huet and others (n 56).

[62] ibid.

[63] Dent (n 2).

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colleagues) or professional (eg non-compliance leading to loss of registration and/or financial sanction). In a similar vein, motivators also informed regulators' approaches to regulation, including preserving the sustainability of the workforce (eg adopting educational approaches to preserve relationships) and protecting the system as a whole (eg by regulating vigorously to protect patient safety and public confidence in the system).

C. A regulatory pyramid for VAD

A widely recognized approach to promoting compliance with regulation is the idea of a regulatory pyramid.[64] At the bottom of the pyramid, regulators seek to secure compliance with a regulatory framework through persuasion but they have the capacity to progressively escalate up the pyramid to more serious responses should previous approaches not be successful. This includes, at the top of the pyramid, utilizing the coercive power of the State to punish non-compliance.

This reflects the broad approach to regulation preferred by participants. They favoured an educative approach to VAD regulation (sometimes expressly contrasted with a punitive approach) but with scope for punitive measures to be used if needed. Generally, participants considered that in the context of VAD regulation, educative approaches would be sufficient. Perhaps this is because of the significant regulation that surrounds VAD, which already guides behaviour towards compliance with the framework.

There has been, however, one instance in Victoria where the oversight Board has opted for a punitive approach and referred a VAD provider to the Medical Board (a disciplinary body for the medical profession) in relation to a failure to observe legislative procedural requirements (unrelated to patient eligibility).[65] The practitioner was reprimanded and fined for their conduct.[66] According to the judgment, the sanction was appropriate for the purposes of deterrence (both general and specific) and to maintain public confidence in the VAD regime.[67]

A specific challenge relevant to regulating doctors providing VAD is that the effective functioning of the VAD system (and its sustainability) depends on having doctors who are willing to participate. In other words, access to VAD is only possible if there are sufficient doctors who will provide this option for patients.[68] Yet, the limited pool of participating doctors is a known challenge in both states.[69] This further supports the preference for an educative approach that helps doctors comply with the VAD framework rather than a punitive approach (unless required for system safety), which may drive them away.

[64] Ian Ayres and John Braithwaite, *Responsive Regulation: Transcending the Deregulation Debate* (OUP 1992). For a specific application of a regulatory pyramid in the context of health, see Judith Healy and John Braithwaite, 'Designing Safer Health Care through Responsive Regulation' (2006) 184 MJA S56. The notion of the regulatory pyramid features in several regulatory strategies, including (in the order in which they appear in the original source): voluntarism, market mechanism, self-regulation, meta-regulation and command and control. The less coercive measures appear at the base of the pyramid (starting with voluntarism). The most coercive measures (command and control) appear at the pyramid's apex.

[65] *Medical Board of Australia v Carr (Review and Regulation)* [2023] VCAT 945. This case involved review of a practitioner for 'providing false and misleading declarations, albeit not deliberately' that the mandatory forms had been submitted in accordance with the legislative requirements, when they in fact had not been as the witnessing requirements were not strictly complied with. Failure to comply with this procedural aspect was found to amount to professional misconduct. However, the court noted, 'there [was] no suggestion that the patient was ineligible to participate in VAD, or that any of the strict statutory requirements relating to the patient's eligibility or voluntary participation in the process were not satisfied': [9].

[66] ibid.

[67] ibid [41]–[65].

[68] Jodhi Rutherford, 'Conscientious Participants and the Ethical Dimensions of Physician Support for Legalised Voluntary Assisted Dying' (2021) 47 JME e11.

[69] See, eg Ben P White and others, 'Access to Voluntary Assisted Dying in Victoria: A Qualitative Study of Family Caregivers' Perceptions of Barriers and Facilitators' (2023) 219 MJA 211; Jodhi Rutherford and others, 'What the Doctor Would Prescribe: Physician Experiences of Providing Voluntary Assisted Dying in Victoria' (2023) 87 OMEGA 1063.

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D. Exceptionalism of VAD regulation?

The preceding discussion identifies a tension: participants clearly considered that VAD was different and required special regulation, yet they also suggested that part of effective regulation of VAD was to treat it like other aspects of medical practice. Theme 1, which concerned 'the special and specific nature of VAD regulation', reflected the commonly held sentiment amongst both doctor and regulator participants that VAD is different. This is what justifies its specific regulatory approach: very detailed and prescriptive legislation with a suite of other tools such as policies and legislatively mandated training for providing doctors. This is also reflected in theme 2's discussion about the need for multiple tools of regulation and in theme 4, which explained that one reason why doctors accept this high level of regulation in VAD is because it is different from other areas of medicine.

However, participants also made observations suggesting that part of effective regulation of VAD meant not treating it differently from other parts of medicine. For example, some regulators noted that they aimed to use tools of regulation (theme 4) and approaches to regulation (theme 3) that are usually applied in medicine because they are more likely to be acceptable to doctors. A similar point was made in relation to regulation being more effective when the content of regulation aligns with existing clinical practice (theme 4), which may be applicable beyond the empirical research reported on. Indeed, as the above discussion notes, many of the issues and challenges of VAD regulation are not unique and observed in both the regulation of medicine in general as well as other regulatory domains.

We do not seek to resolve this wider conceptual point here. We note that internationally, at least to date, VAD has been treated as an exceptional case in terms of regulation. Even in countries like the Netherlands and Belgium which have over two decades of experience with VAD, and high cultural acceptance of the practice, specific and different regulation governs it.[70] But further thought is needed about whether VAD is exceptional in requiring special and specific regulation, and, if so, why. Regardless of one's view on that, we do consider that where possible, as our participants also noted, the benefits of regulating VAD like other fields of medicine should be harnessed. This means that where there are lessons to be learned from the regulation of medicine (or regulation generally), they should be applied and considered in VAD. The converse point can also be made: studies of VAD regulation can inform how to optimally regulate medicine, and perhaps also inform thinking about regulation in other 'high-stake' settings.

E. Strengths and Limitations

A strength of this empirical study is that we were able to interview a large number of doctors (as the primary target of regulation) and a wide and comprehensive range of VAD regulators, who regulated VAD directly or indirectly, across two Australian states (as well as national/multi-state regulators) about their views on how best to regulate VAD. The consistency across the views of regulators and doctors gives credence to our findings. A further and linked strength was that some regulators had (or previously had) clinical roles, which means that their insights were informed by first-hand clinical experience, including what might constitute effective regulation.

One study limitation is that interviews with different cohorts were conducted at different points in time (see Table 3), and regulation may have evolved over time. However, the impact of this is partly mitigated by the fact that interviews in Victoria were conducted in both early (doctors) and later (regulators) stages of system development.

[70] Agnes van de Heide and others, 'Fourth evaluation of the Dutch Euthanasia law' (ZonMw, 30 May 2023) <www.rijksoverheid.nl/documenten/rapporten/2023/05/30/pg-1048101-b-vierde-evaluatie-wet-toetsing-levensbeeindiging-op-verzoek-en-hulp-bij-zelfdoding> accessed 5 April 2024; Archer and others (n 14).

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Another limitation is that this research is conducted in relation to the Australian model of VAD, which is highly regulated. While findings are likely to have direct relevance for other Australian jurisdictions, or international models which take a similar approach to regulating VAD, including because they have drawn on the Australian model when designing their own system, the findings may be less generalizable to other international models. However, some findings are not directly related to the specific nature of the Australian VAD system, such as findings about the effectiveness of peer regulation and professional norms, and the role of system design in regulating doctors in the context of VAD. As such, these more generic findings may be transferable to other jurisdictions even though they regulate VAD differently from Australia.

V. CONCLUDING REFLECTIONS: EFFECTIVE REGULATION OF VAD

We conclude this article with some reflections, drawing on our participants' observations, about how best to regulate VAD. Box 1 sets out proposed principles for effective VAD

Box 1. Principles for effective regulation of VAD

1) VAD regulation should be approached holistically.
   a) VAD regulation is likely to be carried out by State and non-State actors who use a diverse set of regulatory tools. The impact of some regulatory sources may not be readily apparent or obvious such as peer opinion and/or professional norms, and information management systems. The role and interaction of all actors and tools must be accounted for in understanding VAD regulation holistically.
   b) This holistic regulation should recognize appropriate roles for different types of regulation, which generally has been:
      i) Permission to lawfully perform VAD in defined circumstances—generally provided by the law which establishes a permissive framework in broad terms; through to
      ii) Clinical operationalization of that permission, which is appropriate for local settings, and is generally provided by other regulatory tools such as policies, guidelines, and training.
   c) Holistic approaches should avoid duplication, fragmentation, and inconsistency in regulation where possible. Where this is not possible, there should be support for those being regulated to navigate these issues.
2) VAD regulation should be clear and provide confidence that doctors providing VAD within the law and other regulation are protected.
3) VAD regulation should prefer educative approaches to support doctors providing VAD in complying with regulation. However, punitive measures should be available (and be seen to be available) when necessary (eg serious and/or repeated breaches).

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4) VAD regulation should be nimble and responsive to doctors' (and others') needs. This may require more regulation to be in a form other than legislation (which is difficult to amend so less nimble and responsive to needs). To be nimble and responsive, regulation should be clinically relevant and available to guide those it is regulating in an ongoing way, for example:
   a) Readily available guidance and information which is accessible when needed (eg a patient request), in the right form and 'right-sized' in terms of the volume and detail provided.
   b) 'On-tap support' when needed from a person who is able to provide appropriate information and impartial advice.
   c) Clinical mentors and designated personnel with expertise in VAD (eg Care Navigators) who are available to provide support and troubleshoot.
   d) Sufficiently detailed clinical guidance to enable doctors to safely provide VAD in practice.
   e) Prompt responsiveness by the system upon receiving feedback about possible system issues; this is particularly important in the early days of a new VAD system.
   f) Regulating the clinical aspects of VAD using regulatory tools that can be easily adapted to respond to new evidence and learnings from practice (eg policy, practice guidelines).
5) To promote the acceptability and legitimacy of VAD regulation, it should:
   a) Be based on justifiable purposes that are transparently communicated to doctors (eg benefit to patients, community or doctors).
   b) Be developed through a co-design process in consultation with reputable sources (ie members of the profession) and driven by evidence.
   c) Align with how medicine is regulated generally unless there is a basis for regulating VAD differently.
6) Selected features of effective VAD regulation include:
   a) A dedicated system to regulate VAD that provides oversight external to the medical profession (eg by a VAD Board).
   b) Training and education that includes information about the practical elements of the VAD process (with the provision for in-person training) and an opportunity to seek ongoing mentorship.
   c) Forums that promote collegiality and permit information-sharing (eg community of practices) to drive best practice.
   d) User-friendly information management systems that guide VAD practice to compliance with regulation.

regulation. These principles focus on how regulation should be designed and implemented rather than the content of that regulation; for example, they consider how regulatory tools should be employed rather than what eligibility criteria for VAD should be. These principles also accept as a starting point the current position (expressed by our participants and reflected in Australian and international practice) that VAD warrants specific regulation.

As noted above, we recognize that regulation is a local endeavour that is informed by a range of domestic and contextual factors, and so the utility of these principles may vary for other jurisdictions. Nevertheless, given the paucity of work on effective regulation of VAD

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to date, we hope the above findings and these principles may contribute to deeper thinking about how this practice is best regulated. As such, this research should be considered when VAD systems are reviewed, for example in the mandatory reviews in Australia and the five-yearly evaluations in the Netherlands. This research also should be considered by jurisdictions that are contemplating legalizing VAD or are implementing their VAD systems. In addition, we note the potential (as mentioned above) for this research about VAD to inform wider debates about the regulation of medicine more generally.

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ETHICS

This research was approved by the Queensland University of Technology Human Research Ethics Committee (approval numbers 2000000033 (26 March 2020) and 20000002700 (13 July 2020)).

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CONFLICTS OF INTEREST

Ben P. White and Lindy Willmott were engaged by the Victorian, Western Australian, and Queensland governments to provide the legislatively required training for doctors (and nurses and nurse practitioners where relevant) involved in voluntary assisted dying. Casey M. Haining was employed as a legal writer on the Queensland training project. Ben P. White and Lindy Willmott were engaged by the Western Australian Government to be involved in the statutory review of the Voluntary Assisted Dying Act 2019 (WA), and Casey M. Haining was appointed as the research fellow on that project. Lindy Willmott is also a member of the Queensland Voluntary Assisted Dying Review Board.

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