INQUIRY INTO VOLUNTARY ASSISTED DYING
Aboriginal Engagement and Strategy Unit – Alice Springs Hospital

CHAIR – Dr Tanzil RAHMAN: Hello all the members of parliament. I am the Chair of the Committee here today. Are we getting started?

Members: Yes.

CHAIR – Dr Tanzil RAHMAN: Katie are you going to serve out those documents?
I actually need my glasses.

Look, before we say anything we want to as a committee, we want to acknowledge the traditional owners of this country, we want to pay respect to elders past, present and emerging. We are very grateful to be here, grateful to be able to have conversations with people and to be able to hear from all of you.

So thank you very much for coming and talking to us today, we appreciate you taking the time.

So as I was saying; my name is Tanzil Rahman I am the Member for Fong Lim one of Darwin's city seat, my colleague Matthew Kerle Member for Blain out Palmerston way, Oly Carlson Member for Wanguri.

We are here today to talk about voluntary assisted dying, and we know that it is difficult to talk about for a lot of people so we always tell people at the beginning; if anybody needs a break or feels upset just let us know we can do that, because a lot of times people do want that. We also have support services available which the parliamentary staff can also help with.

We are recording this meeting as you can see; and would like to use the recording as part of our evidence for our report, but if you say anything that you want off the record you want kept private, just let us know and then we will make sure to exclude that from our testimony essentially, we will redact that side of things. This is formal proceeding of the Legal and Constitutional Affairs Committee of the parliament and so all the protections of parliamentary privilege applies as well.

So could we start by, could I just get all of your names and your job title for the record?

Patrick Torres: Patrick Torres. I am the actually cultural coordinator here at the Alice Springs Hospital.

CHAIR – Dr Tanzil RAHMAN: Thanks Patrick.

Curtis Haines: Curtis Haines ------2:09 sponsor, language is --------2:12

Linda Bray: My name is Linda Bray. I am the liaison officer here at the hospital and I am an interpreter for Pitjantjatjara people that covers South Australia as well.

CHAIR – Dr Tanzil RAHMAN: Fantastic! Surprised they haven't got you already. So covering the field at every interpreter we can get.
And sorry, I also should have mentioned we have got Caroline, Georgia and Katie from parliamentary staff who are supporting us to do the inquiry.
There are a couple of other members of the panel as well, unfortunately they couldn't be here today; Kat McNamara the Member for Nightcliff, Dheeran Young the Member for Daly they are also on this as well but today they had to be elsewhere.

So I will just give you a little bit of background before we hear from you guys a bit.
So in 1995 some of you might remember there was a Euthanasia Law for the Northern Territory; it only lasted for one year before the Federal Government overturned the capacity for the Northern Territory to make laws about voluntary assisted dying. Then in 2022 the Federal Government finally allowed the A.C.T and the Northern Territory to make laws in the territories. In the meantime every state and territory across Australia has introduced a euthanasia law; starting with Victoria in 2017 through to the A.C.T most recently, and so the Northern Territory is the only place that doesn't have one.

So last year the former government had commissioned an independent expert group made up of; doctors, lawyers, community people, health care practitioners, all sorts to make this report. So this report was the 2024 Independent Expert Report on Voluntary Assisted Dying.
Our job basically, we were asked by the Attorney-General as a committee to look into this report and to look into the model that they suggested for how voluntary assisted dying might work in the Northern Territory; we are going to talk about this model in a bit.

So what we have done in the meantime is look at that, produce our own consultation paper about what we think is important to look at in this. We presented a report in parliament recently about where we are going, what our plan has been so far, so written submissions have been coming into our committee for the last two three weeks, they have still got a couple more weeks until the end of the month to be collected. We have been going out into remote communities particularly and that is because our Terms of Reference basically asked us to; 1. Produce these consultation documents 2. To go out bush and particularly ask people in remote communities how they felt about voluntary assisted dying, because there was a recognition that maybe there had not been enough consultation done in those places. Then from that, if we could figure out what kind of voluntary assisted dying law might work in the Northern Territory because we know that the Northern Territory is different, we know that the health care needs are different, we know that the population is different.

And then if that all checks out then we have a legal team that we are getting to work with us to help make drafting instructions for a bill, for a law.
So we are not going to make a law; just to be clear, we are going to write a report, we are going to get it back to parliament that will happen by the end of this year and then the government will have to decide how it wants to go forward, basically.
If that all sort of clear? So far, yes?

So in general terms it might be useful to just hear from all three of you first, about how you feel about the voluntary assisted dying stuff. If you have any general thoughts, we might start with that.

Matthew KERLE: Sorry. Just before we get to that is it possible for you to explain; I know you're Aboriginal liaison officers but on a day-to-day basis what sort of stuff do you do in the hospital, just so that we understand where you are coming from? Is that Ok? And then we will move on with all that. Do you want to start?

Linda Bray: We do a lot of family meetings, procedures; like, we will have a meeting if there is a surgery we will have a meeting with the family and explain everything in our language what that is.

Oly CARLSON: Can I ask question about the family? Is it generally family members that are there to help them make decisions as well? Support people.

Linda Bray: Yes. Just like before they go to palliative care we sit down and have a meeting and explain if they can go home, finished up in country or they can go over there to the palliative care house and spend it there.

CHAIR – Dr Tanzil RAHMAN: We will have a lot of questions about that, so let's come back to talk about it in detail.

Linda Bray: Alright.

Curtis Haines: Could we also make it, talk about surgery, amputation.

Matthew KERLE: I am really curious, so you would have to translate medical terminology to traditional people from community?

Oly CARLSON: How difficult is that?

Linda Bray: Oh, it's not easy…

Curtis Haines: We will try our best to make them safe.

Linda Bray:…like, we did have some training in medical terminology.

Oly CARLSON: You said it's taken a long time for you to become familiar with medical terms and then…

Linda Bray: Yes. We explain to them in simple words.

Matthew KERLE: Just one last thing; what kind of accreditation do you need to have in order to do what you do, to be a translator.

Linda Bray: We have got to sit for a test; NAADI certified liaison officers.

Patrick Torres: So just as like your French interpreter here in Australia, they do the same test but with their language, it's a national accreditation.

Matthew KERLE: So, is it just; you have to do the test and then you're good to go? Or do you have to do a course?

Patrick Torres: There is pre-trained, with a test yes.

Matthew KERLE: Alright.

CHAIR – Dr Tanzil RAHMAN: That's fine. I mean all of these things are exactly the kind of things we want to talk about in more detail. It is just good to get a general sweep first. Patrick?

Patrick Torres: Our hospital services somewhere around a minimum 15 different languages throughout central Australia. We try to cover most of them we have got 11 ALO positions here. And those positions can only be filled by language speakers and there may be accreditation some of them are very fortunate that they come to us already with the qualifications, it is then we also encourage them to do the accreditation while they are here as well.

At the moment the ALO's are going through doing the annual health worker course, as well. And we are putting them through that, they are not going to be clinical, but it gives them a medical background. Like Linda is probably the longest ALO here?

Curtis Haines: Yes.

Patrick Torres: So she is most experienced. And you look at some of the work they do; it is just "WOW". They can handle it!

We have also got a -------------------------------- 9:17 Some of the complex issues we come in and help the ALO's with. ------------------------- 9:28 for instance quite a few prisoners or ex-prisoners come through the system here and them they will be palliative care, so we sort of support them with that journey.

CHAIR – Dr Tanzil RAHMAN: Alright we have got about half an hour to dig under the hood for all of that, so I think with this group we can probably dive deep. Just before we start though…

Penny Stewart: Thank you very much, I was late.

CHAIR – Dr Tanzil RAHMAN: No apologies required. I am Tanzil I am the Chair of the committee Matthew and Oly are…

Matthew KERLE: I am the Member for Blain. Oly is the Member for Wanguri.

CHAIR – Dr Tanzil RAHMAN: Do you want to introduce yourself, just for the record?

Penny Stewart: Yes. So I am Penny Stewart I am the medical advisor for safety and psychology and I am ----- 10:15 Care Specialist as well and what I am particularly interested in from a safety and quality point of view; our Aboriginal workforce is key and actually ensuring their safety, ensuring better doctors better

communication and listening to their voices is absolutely key to everything that we do. Because if you look at all of the problems around the hospital; like readmissions, take your own leave, lack of trust, it is all because of miscommunication and no relationship.

CHAIR – Dr Tanzil RAHMAN: So as we have been doing consultations particularly out bush, ------------- 11:13 is very specific in some ways which has sort of made this report think about bad models. But in saying that we are also aware that there are about three or four things that intersect very strongly with that, that come up over and over again.
One of them is to do with interpreters and language another one is to do with palliative care another one is to do with aged care services another is to do with general provision of health care staff (nurses and doctors and the like).

So if you can give us a sense of what services are available at the moment or where the deficits might be, that would be very helpful for the record.
Any of you want to contribute on that?

Patrick Torres: One of the things that is certainly lacking, lacking throughout the Northern Territory is the actual health practitioners.
We have 250 positions here in the Northern Territory, we only have 185 registered, so there is a big gap there and those positions are vacant. Certainly, if you look back to the 1980's and 1990's we had Aboriginal Health workers throughout the Territory. The region where I come from Utopia, we had 14 of them which is one for every outstation that we have there and now we have zero.

So those are the types of roles that certainly educate our mob in Central Australia on the health issues and try and support the medical staff in regard to that, but we have just let it lapse probably over the last 25 years, unfortunately.

CHAIR – Dr Tanzil RAHMAN: Yes.

Matthew KERLE: So you say that health provision is sort of more centralised in the major regional centres from the remote communities?

Patrick Torres: Yes. It has changed a bit; we are a normal clinic with our two nurses plus maybe two actual health workers and that is no longer the case. We are such a fly-in fly-out group especially in regard to nursing, and one of the biggest things for us is cultural awareness especially here in Central Australia. If you look at Central Australia we have colonised 100 years after everyone else, so we are still learning to grow into the Australian systems we have got a lot of catching up to do but unfortunately everything is just yeah…

CHAIR – Dr Tanzil RAHMAN: So we have to be clear to not promise anything with our promise. All we can do; us as a panel of five is write a report which will go back to the government.
But we are very, very mindful at other jurisdictions around the country when the pass the VAD law the increase in palliative care demand goes through the roof as well. So we have to understand where we are up to with palliative care right now.
Could you give us an indication of what services you are providing, whether there are deficits in that space?

Penny Stewart: Sure. Can I add one thing to the Aboriginal Health Practitioner Model?

CHAIR – Dr Tanzil RAHMAN: Absolutely!

Penny Stewart: One of the other things that there is a big deficit in, is the ability to do good TeleMeds and conferencing.

Because one of the things is that all of the Aboriginal Health Practitioner Models in the past have been linked with nursing staff rather than actually hearing medical knowledge and translating medical instructions and all of those kinds of things.

So one of the things that we think is really important is to link Aboriginal workforce with both medical knowledge as well nursing duties, so that if people are needing with telemedicine in the future we will have an ability to be able to help with that translation and that support after, as well as helping people understand those medical instructions.

Because if you look at that 80% of the life expectancy gap is in chronic disease, accelerating fast and it is because they are not taking; people are not fully able to enact the medical instructions because either they didn't understand or it is not possible and they are not able to negotiate with doctors to change that or to make sure that is done.
So I think that Aboriginal Health Practitioner role is key but it almost means an expanded kind of… would you agree with that Patrick?

Patrick Torres: Yes. I mean if you look at the statistics coming out of Darwin I believe as well, we talk about the toll taking your own leave and we are up around 12%. The national average for any hospital is .8%. So you can see the vast difference.

Matthew KERLE: Sorry. Taking your leave; is that when someone self discharges and walks out?

Patrick Torres: Yes.

Matthew KERLE: Against the medical advice?

Penny Stewart: No. They don't give you a chance to get medical advice, they just take their own leave.

Matthew KERLE: Ok.

Patrick Torres: And that is just something that is occurring here, but I understand it is happening up North as well.

The other step which is really horrific is the fact that after the fifth toll, there is no sixth, the person passes.

Unfortunately their medical condition deteriorates to the point where the fifth time they toll and they never return because they have passed on.

Penny Stewart: And the re-admission. So both the incomplete so that people not taking those medical stories and doing the things that you need to do because they are not trusting the system and going, leads to incomplete care and a much higher rate of people passing. And the other thing is, even if people aren't taking their own leave there is a group of people that are not understanding the instructions or the instructions are not related to the context in which they are going, and so they are re-admitting straight away and getting worse. Would that be reasonable?

CHAIR – Dr Tanzil RAHMAN: -----------17:40 … you know that once upon a time there was a large number of translators and language officers and Aboriginal health workers, those numbers have fallen over a period of time; can you give us any indication as to why that might be the case?

Patrick Torres: If you have got somebody that is bilingual why would you work as an AO3?

Matthew KERLE: Ok. That is important so an ALO is at an AO3 which is effectively entry level. Is there career provision available?

Patrick Torres: Fortunately within this hospital we are working towards that. So we are changing the structure so ALO's can progress from being trained interpreters AO4 and AO5's but then of course the leadership team positions as well, so they can progress into them.
Matthew KERLE: Is there any way for an ALO to progress to a medical stream, like some sort of health…

Patrick Torres: They are in the process at the moment. So while you have only got a minimum of staff here talking to you guys, it is because the rest of them are either doing the Aboriginal Health Worker Program, which is a 12-month long course. And there is hope that if they want to progress they will become non-clinical Aboriginal health practitioners as well, which is a three to four year course. So there is a lot of training going on with our ALO's but once again they are sitting at an AO3 form wage, which is, they are worth a lot more than that.

Matthew KERLE: So the accreditation standards for interpreters, we know change about a decade ago or thereabouts and we are told the bar was raised and that may have resulted in us losing capacity in terms of people who could function into that space, is that something you can verify for us as well?

Patrick Torres: Fortunately ------------------19:41 will be from Aboriginal Interpreter Services.

CHAIR – Dr Tanzil RAHMAN: Yes.

Patrick Torres: A lot of our interpreters, fortunately with our staff they are getting a permanent wage but when you look at the interpreters they actually get paid for the job, for the exact work they do. So if we get an interpreter from the AIS to come to the hospital; so they may travel from out at Larapinta pay their own taxi fare into town go up and do a 15 to 30 minutes job and only get paid for that…

Penny Stewart: Oh no way!

Patrick Torres: …they don't get reimbursed for the tax fares, so why would you work in that field. I mean if you look at the other side of it, and then hence why we lost a lot of the interpreters in the AIS. But the only jobs that they do have are a four hour day in the courts, or a four hour day at Centrelink, so it is not beneficial to be an interpreter getting an AO3 wage when you are only getting paid for the exact time you are interpreting.

CHAIR – Dr Tanzil RAHMAN: So out in remote communities we have got a mixed set of responses on everything, some things are good some things are bad of course. Telehealth is another one where some places people have said it is constructive they use it; other places they have suggested to us the technology is not good enough to make it happen. But the biggest common sort of thing we hear is that even when it does happen there is usually not an interpreter there.

Penny Stewart: The support.

CHAIR – Dr Tanzil RAHMAN: Yes. The support. So again, this report and in the VAD space leads heavily on the fact that Telehealth might be part of the solution in the future; we are not so sure about that but we would be curious to know whether you think Telehealth could help in palliative care spaces or in the VAD space.

Penny Stewart: I think that Telehealth could really help in all spaces. I think that you need to separate people who are looking after different types of aspects of why people get confused. People, and the biggest thing for and Curtis and Linda and Patrick; tell me if I'm saying the wrong thing… but the real thing is people want to stay on country and stay well and everything that helps people understand what they need to do and that communication can be supported and also, their carers can understand and the family can understand what is going on.
That really helps, but the PATS system (Patient Assisted Travel Scheme) which has an outpatient appointment here is a big impost on particularly people when they are frail, because travelling on the bush bus when you're pretty frail is pretty tricky! and often people who are really unwell fear going home to country because they think that they won't get support and so they are sort of left in limbo in Alice Springs. Is that correct? Am I saying the right thing?

Linda Bray: Yes. You are saying the right thing.

Penny Stewart: And so it has to high quality and it has to be supported and there has to be mechanisms of, like as you get more frail and as you have more complex disease and as the stories and the medical things become more complex, the ability to actually hear and make sure that it is the right advice in your context and for all your diseases is much harder and much more important and having navigators to help people in that space, and being able to deliver that more at home would be incredibly important. And on that point in the palliative care space we sort of have been piloting a program for next year, which is not just about palliative care but it is about the longer and extreme the more chronic disease people that either have got a bit frailty, kidney disease and re-admitting a lot of times, or have cancer, to do supports with a hopefully an Aboriginal navigator practitioner worker working alongside a junior doctor so that we learn how to support that group more and the community supports more.

CHAIR – Dr Tanzil RAHMAN: So in the interests of time, we are going to try and focus a little bit of this towards the VAD stuff specifically to see if we can get some thoughts from you about that.

There is a model that was proposed in this last report which was a bit like this, which is basically; 'if somebody is terminally ill and has control of their senses still they go to a first doctor who can say "Yes I will sign off on this" and then there is a waiting period of a couple of weeks the second doctor does the same sort of thing, waiting period again, then a written consent and then finally it goes a medical team to be able to assist with that process.

Now, we are trying to establish the extent to which that model might or might not work here. One interesting thing is that this report was also interested in having a stand-alone VAD service but then we were hearing from the Health Department where everyone wears multiple hats, it is very difficult to compartmentalise it completely.
So the submission that came from the Alice Springs Hospital, where any of you guys involved in contributing to that?

Penny Stewart: I was.

CHAIR – Dr Tanzil RAHMAN: You were?

Patrick Torres: No. I wasn't.

CHAIR – Dr Tanzil RAHMAN: No? So there are some very specific things that I mention there; so of which are consistent with this, inconsistent with this, do you want to speak too?

Penny Stewart: I'll get these guys to speak.

CHAIR – Dr Tanzil RAHMAN: Anything to do with the VAD model or your thoughts generally, I think.

A lot of people frankly are not familiar with the entirety of it.

Patrick Torres: There is a lot to it.

CHAIR – Dr Tanzil RAHMAN: Yes. And there is a time to it.
So what we have tired to learn to some extent going out bush, is a lot of people have said to us; "maybe not for us but we don't mind if other people have it", which is different than what a lot of people thought initially, let's just give it out to ------- 26:25. So that has been interesting.
The other thing that we have learnt out there is a lot of people; the phrase that has cut through is when you talk to people about health and choice to finish up. Then a lot of people say; "Yes if you could help us" then more people would come out of the country to finish up with some help, then that would we be something that we would be interested in.

We get a lot of concern about people arrive in Katherine Hospital Alice Springs Hospital Darwin Hospital not being able to get back to country in time. So this is the chance for us to find out about that story from this side, if you like rather than from the patient or the community side. Do people get to discharge themselves without adequate time or with adequate support to be able to organise care plans to be able to go back home?

Patrick Torres: Unfortunately, with a lot of our patients we get them at the very bad stages towards the end of life anyway.

CHAIR – Dr Tanzil RAHMAN: Yes.

Patrick Torres: So it is sort of taken out of our hands; the only thing they can do is go to Palliative Care.

Penny Stewart: That is what we heard at Papunya, yesterday.

Patrick Torres: So that is the tendency, that we are not getting them early enough and that is the major problem. Usually those type of people are the ones that are tolling.

And like I said, we have got 11 positions here as ALO's but it is really hard to keep and to cover all of the different languages that are here in Central Australia. But then I suppose the ALO's certainly have a hard time when you have family meetings; people are coming from remote areas six and 10 hour drives to get to Alice Springs, and the Telehealth system not up to parr at this stage.

We have had so many meetings in regards to people here at the hospital through the Teams System or whatever you want to call it.

Matthew KERLE: The video one.

Patrick Torres: Yes. The video link-up. And if all remote communities could have that video link up it would work for health, justice, and all the other government areas as well for the people to get in touch.

Penny Stewart: The other thing that will be here a lot from an ICU point of view, is that no one is ever told the relatives, no one has ever told us that the person was that sick before hand. We were ready for it.
So often, people are coming in and not quite ready for ---------------------22:19 would that be right on Linda?
Linda Bray: Yes. Sometimes they get lone??29:27 death.

Penny Stewart: And then sometimes you don't enough time to make sure that everyone realises that it is just because there is a sickness and everyone has come in to have the discussions, and there is an agreement that it is because of the sickness not because of any blame, and that time means that by the time everyone gets that understanding the person is probably too sick to go back, or go back in a comfortable way.

And the other thing is the infrastructure of how to support people out in the remote communities, because it might be that if someone dies in a house that everyone has to leave that house and if they die in the clinic people might fear going into that clinic. So it is around the unintended consequences.

Matthew KERLE: Because there is a whole lot of cultural things that have to happen when someone passes away.

Penny Stewart: That's right. So those places when people go back to the community, that has to be thought about carefully. Is that correct?

Linda Bray: Yes.

Matthew KERLE: Are there issues with; say if someone is really sick and in the medical opinion the clinician they probably have a limited amount of time before they pass are issues being able to tell… because in our system there is a next-of-kin and you either disclose to them medical information, but Indigenous structures of kinship are a lot more extended than western structures so they have cousin-brothers and cousin-sisters and all the people who have cultural authority over the person who would be involved in the decision. Are there limits where you are not allowed to tell those people how sick someone is because of, you know, the legislation?

Penny Stewart: Disclosing medical information?

Matthew KERLE: Yes.

Patrick Torres: Not when you bring family together, it is more the social workers that tend to organise that and our ALO's support that.

Matthew KERLE: So that is once the groups are together, but if they are all out on community and you say; "this person has only got a couple of weeks left" so you have got to ring people and tell them.

Penny Stewart: This is why the ALO position at AO3 is ridiculous because there is a huge complex with cultural knowledge and negotiation that comes into the position. So they will help organise the appropriate family and decision makers so that people aren't blamed and we would be making huge mistakes all of the time if the ALO's were not involved in these decisions.

Patrick Torres: You will get some of the families coming in from remote communities, but they are not necessarily the decision makers but these are the ones were able to make. So this is where the -------------32:50 in this room here and you could have a full house here, but the main decision makers may not be in the room, and that is a major issue.
And I believe that this is where Telehealth link-ups will support us a lot better.

We had a lady here and each time they had a meeting with the family, there were three decision makers who were involved with it. So if ever we go away they tried to follow up on that and we couldn't move the old lady out of this hospital because, we didn't involve the three decision makers.

Matthew KERLE: I am just trying to think; councils would probably have Teams link-up, but that could be on an outstation or something like that?

Patrick Torres: Maybe not outstation but the main clinics should have it.

Matthew KERLE: So not all communities have clinics, or not all clinics or communities have a good Teams link-up.

Patrick Torres: Most communities have good mobile towers and stuff; the infrastructure is there to able to have Tele link-ups, it is just a matter of having infrastructure installed.

I suppose one of the things; you don't want to sit in the clinic, you don't want to sit in an area where other users are there.

Penny Stewart: Yes, privacy.

Patrick Torres: It should be ---------------------34:20 and that literally can be used for the courts, it could be used for the…

Penny Stewart: I was going to say, for Telemedicine outpatient, all of those kinds of things.

CHAIR – Dr Tanzil RAHMAN: Linda, can I ask you a question specifically as sort of the super senior ALO; would you feel comfortable discussing Voluntary Assisted Dying stuff with people out in communities.

Linda Bray: No I wouldn't. It is against their law.

CHAIR – Dr Tanzil RAHMAN: Ok.

Linda Bray: We'd get speared, it's not my place, anyway it is the families they have got to talk about it and they don't do that.

CHAIR – Dr Tanzil RAHMAN: We have found people were very generous from other communities talk to us about death, dying, ceremony, a lot of things around that, but we also hear that people don't want to talk about it all the time.
We know from the Alice Springs Hospital submission, for example; in some states and territories there is a law that doesn't allow medical professionals to discuss with patients about it, in other places you are allowed to talk about it when you're ready.

Linda Bray: As an option.

CHAIR – Dr Tanzil RAHMAN: To initiate discussions, yes. Depending on what stage you are at. The Alice Springs Hospital position was that they would like for practitioners to be able to have those discussions, and that might be nurses at doctor level staff. Again, you have to go through people like yourselves to interpret to do that kind of work.

If you were in that position what kind of training might you need, or what kind of help might you need, or could you just not do it?

Linda Bray: Talk about dying?

CHAIR – Dr Tanzil RAHMAN: Yes.

Linda Bray: No. I wouldn't do that.

CHAIR – Dr Tanzil RAHMAN: Ok.

Linda Bray: Maybe the health workers I don't know, but I just…

CHAIR – Dr Tanzil RAHMAN: There's a communication thing here we have got to address as well…

Patrick Torres: Some of the belief is that you start talking about an illness or something or talking about voluntary dying or moving across to palliative care, a lot of them mob still think you are cursing them!

Linda Bray: Yes.

CHAIR – Dr Tanzil RAHMAN: Yeah! we get that.

Patrick Torres: That is the tendency. And like I said; we are 100 years behind everyone else when it comes to compensation, so even my mob the elder people we are traditional, as all the other 50 language groups.

Matthew KERLE: Are people afraid to come to the hospital because they fear that if they come here that they will die? Even though this is where you get treated for your illness?

Patrick Torres: Yes. That is a big 'yes'.

And we are trying to change that way of thinking, you know. We are trying to advertise it and portray it as a healing centre not a hospital somewhere you come to die...

CHAIR – Dr Tanzil RAHMAN: So that is consistent… sorry Patrick, carry on.

Patrick Torres: So that is what we're hoping to work towards but we have certainly got some hurdles to get there.

CHAIR – Dr Tanzil RAHMAN: So what I was going to say, the Alice Springs Hospital admission is quite unique amongst a lot of things and a lot of places around the country where; it is actively saying; "we don't want VAD services to happen on our hospital site".

Linda Bray: Yes.

CHAIR – Dr Tanzil RAHMAN: Because it will only add to the confusion and complication of; is this a healing centre or a place where you come to die, essentially.

Patrick Torres: The thing was the infrastructure to support people would be 'return back to country' that would be a lot better.
When people come in from the community they have got to tolerate all the alcohol involved and all the other stuff that is involved; so it is trauma on them double! Whereas as if you return to country have some big thing, a lot of the family will be around that person during that time but once again it goes back the other way.
So if they are placed in a house where a family member lives; especially my mob they will vacate that house, so we get a lot of empty houses out here in Utopia when family members pass away. But in our tradition we have got to give every away as well; so we give out clothes, our cars or we swap the cars without other family groups because that deceased has been involved in that vehicle or involved in that house, so yes.

And it's only deaths within Central Australia, families are just you know having a high turn over of car swapping.

CHAIR – Dr Tanzil RAHMAN: Yes. So again, we know from this report and from other things that have happened outside of this inquiry, that there is probably more than 51% support in the Northern Territory for some sort of VAD legislation; maybe not 99% but somewhere that is a majority number. But what we are trying to work out is if this was to turn into a law how could we make sure that it was available to any Indigenous person who might want it but also that it doesn't affect them or affect their health care situation or compromise a hospital setting for example. So can you give us any indication about what safeguards we might need in order to make that the case?

Penny Stewart: One of the problems is that it is so easy to say the wrong and miscommunicate and get misunderstood because a lot of our medical language is outside the world view of our patients. So you know you have to make sure that they can understand it within their world view, to put it to function and things like that.

But there is also things like if you say; “we think you have only got six months to live” or something like that, people will think that six months no matter what you do, so they might just say; “Ok it is time to party now I am going to drink a whole lot and do all of those kinds of things”. That would be right, wouldn’t it?

Linda Bray: Yeah, little bit, yeah.

Penny Stewart: But there are messages that can be easily interpreted in different ways and that leads to things that make people sicker, quicker. Am I right there?

Linda Bray: For some people.

CHAIR – Dr Tanzil RAHMAN: Linda, tell us more about that. You seem like…

Linda Bray: Pardon?

CHAIR – Dr Tanzil RAHMAN: Tell us more about that…

Linda Bray: About what?
CHAIR – Dr Tanzil RAHMAN: From your perspective, what we were just discussing.

Penny Stewart: If someone was to be told by a specialist that they may not…

Linda Bray: That they are really sick, they would probably go home. They would go home and sit down with family. I’m talking about Pitjantjatjara mob, because different tribes there.
Our family would go sit down home and talk about it, yes. That is family you know, when they know you’re really sick.

CHAIR – Dr Tanzil RAHMAN: Then on that let’s just say that you go home; aged care services health care services once they are out there, we know that why Patrick is laughing.

Patrick Torres: Non existent.

CHAIR – Dr Tanzil RAHMAN: So non-existent is what we hear in some places. If they are existent can you guys ever get involved out there in being able to help with end of life care?

Linda Bray: Yes, we have got clinics there and aged care and that is where they will go and sit down. Because it gets too much at home for families, there might be too many kids.
So they will go to aged care and sit down there and people go there and sit down wait until she’s passed away.

Patrick Torres: Yes. There are probably aged cares around; Docker River…

Linda Bray: Docker River --------------------41:47

Patrick Torres: Yes. There are none out in my region, so they just send them over
------------41:53 not out that way.

CHAIR – Dr Tanzil RAHMAN: We have seen a couple here and there.

Patrick Torres: Yes.

CHAIR – Dr Tanzil RAHMAN: But we know obviously they are not everywhere. Some places have a got a great school but not a great clinic, some places have got a great clinic but not enough translators; so on and so forth, it is hard to find one place with enough of everything.

Patrick Torres: Yes.

CHAIR – Dr Tanzil RAHMAN: Now listen guys we know we have got another team coming through soon, of doctors and nurses to talk about the next lot and palliative care, whatever. Is there any more that you want to get on the record in and around all of this to help us understand this better, for my report.

Patrick Torres: I suppose if people, if they choose to end their life; to have the infrastructure to return home to community rather than being in town. Not only that, if you look at the cost of housing you know it's a million dollars to put a house in a remote community and it is certainly a waste if a person passes away in there all of a sudden you get a vacant house with multiple other family members can…

Matthew KERLE: Can you have temporary housing where they pass away there, so then you sort of, disassemble it and you don't have those expenses.

Linda Bray: No. Those people just swap houses. Clean it.

Patrick Torres: Yes, they swap houses. But certainly if you had a unit where somebody could be comfortable next to a clinic for the medical staff to at least over-see it all. We don't have anything up at ---------------43:24 but certainly nothing for a pensioner. Utopia is sort of a little bit more convenient to have the service there.

Matthew KERLE: Linda, you said before VAD is against Indigenous law; you said if you suggested it you might get speared, so that is pretty much saying that Indigenous people probably wouldn't be likely to take it up themselves.
In your experience or for who you can speak for; which is probably yourself in you experience, do you think people would be opposed if other people used it?
So if this became a law and white people or non-Aboriginal…

Linda Bray: They don't like killing themselves, if they're sick they would like to go naturally.
They don't want to end it quick because they have got families and grandkids they want to spend some time with.

Matthew KERLE: But if it was voluntary, so no Indigenous people had to use it but then…

Patrick Torres: If it's painful, yes some people would choose it. If it's been long drawn out, painful.

Linda Bray: -----------------44:39 you can pull all that home.

Matthew KERLE: But would it cause harm of distress to Indigenous people if non-Indigenous people used it?

Say if my neighbour in Palmerston who is not Indigenous, if they wanted to use it would that cause harm or distress to any of the people you know?

Linda Bray: No. That's white fellas way, they choose it that way and they will leave that way. Us we have got our different way.

Matthew KERLE: Thank you.

Penny Stewart: But if say; for instance if I was a doctor in ICU and I was looking after Aboriginal people and I had been known to use VAD on other people, would that stop me from being trusted looking after Aboriginal people?

Linda Bray: Yes, maybe.

Matthew KERLE: Ok.

Penny Stewart: And that would be what I would be really worried about, is that trust is so important and it is very easy to lose trust, we lose it all the time anyway. But if we get a really bad name for any reason, if we are seen to be promoting something.

Linda Bray: Like last year or a couple of years ago we had a yarn about organ donor; our people don't like giving organs away and it is alright for them to receive kidney, but our people don't. Someone was in car accident and the white fella needed his organ, we will say; "Nah", it stays with him and he takes it. Half cast people, alright they understand they educated they will do that ---------------- 46:33

CHAIR – Dr Tanzil RAHMAN: Alright guys I think we are going to have to wrap up because we have to got to get to the next group.

Matthew KERLE: Thank you so much.

CHAIR – Dr Tanzil RAHMAN: But can I just say on behalf of all of us thank you for coming, thanks for your time and sharing with us every conversation.

Penny Stewart: For us to be stop trusted and therefore they can't support us would be really bad from the hospital. Would you agree with that?

Linda Bray: Yes.

CHAIR – Dr Tanzil RAHMAN: Alright guys, thank you so much. We really appreciate the time.

Penny Stewart: Thanks very much.