

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Tuesday 25 July 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESSES *(via videoconference)*

Dr Paul Secombe, Senior Specialist Clinician, Intensive Care Unit, Central Australia Health Service;

Ms Chrissie Davis, Aboriginal Liaison Officer,

Ms Donna Lemon, Aboriginal Liaison Officer,

Ms Linda Bray, Aboriginal Liaison Officer,

Ms Christine Spencer, Aboriginal Liaison Officer,

Ms Sally Sena, Aboriginal Liaison Officer,

Ms Jennifer Armstrong, Aboriginal Liaison Officer,

Mr Curtis Haines, Aboriginal Liaison Officer,

Mr Anthony Davis, Aboriginal Liaison Officer, and

Ms Justine Swan-Castine, Acting Leader, Aboriginal Partnership and Strategy Unit, Alice Springs Hospital; and

Dr Rosalind Beadle, Research Fellow, College of Medicine and Public Health, Flinders University.

The CHAIR: Good morning. My name is Ella George, and I am the Chair of the Legislative Assembly's Legal and Social Issues Committee. I declare open this public hearing of the Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors.

I begin by acknowledging the traditional owners of the land on which we are meeting, the Wurundjeri Woiwurrung people of the Kulin nation. I pay my respects to their elders past, present and future, and extend that respect to First Nations people across Australia. I thank our First Nations people for their many thousands of years of care for their country.

I also acknowledge my colleagues who are participating today: Deputy Chair Annabelle Cleeland, Chris Crewther, Meng Heang Tak and Gary Maas.

Today is the second day of public hearings this week, and on behalf of the Committee, I would like to take this opportunity to thank all of those who provided a written submission or are appearing before the Committee for a public hearing.

Today we will be hearing from the Central Australia Health Service; Gregory Snell, Medical Head at the Lung Transplant Service at Alfred Hospital; Transplant Australia; Zaidee's Rainbow Foundation; and National Health Service Blood and Transplant in the United Kingdom. I thank all of the witnesses for their time and interest in participating in this important inquiry.

All evidence given today is being recorded by Hansard and broadcast live. While all evidence taken by the Committee is protected by parliamentary privilege, comments repeated outside this hearing may not be protected by this privilege.

We will now commence hearings with our first witness. I welcome from Central Australia Health Service Dr Paul Secombe, Dr Rosalind Beadle and some Aboriginal liaison officers who are part of the health service. Thank you so much for being here with us today. If you would like to introduce yourselves or make a brief opening statement, please do so, and then that will be followed by questions from Members. Thank you.

Paul SECOMBE: Thank you, Ella. Perhaps I will start. My name is Dr Paul Secombe. I am head of department in intensive care at Alice Springs Hospital. I have been living in Mparntwe, on the land of the Arrernte people, for the best part of a decade and have worked closely, and increasingly closely, with this remarkable group of people with whom I now share the room.

What we might do from our end is quickly just do some introductions—name, maybe country and language group—and then I might speak a little bit more. We can go to Ros, who can introduce herself and who has been a key part of the team that has produced the findings that we would like to talk about today.

You will of course excuse us—all the ALOs and I are on clinical duty at the moment, so there may be some interruptions with pressing clinical needs, and I apologise for that in advance. Perhaps, Linda, would you like to –

Linda BRAY: My name is Linda Bray. I am a Pitjantjatjara woman. I have worked in the hospital here for, I do not know, 30-something years.

Christine SPENCER: Christine Spencer, originally from Yuendumu, Warlpiri ALO. I have worked here for 14 years.

Chrissie DAVIS: Chrissie Davis. I speak Yarli, and I am new.

Justine SWAN-CASTINE: My name is Justine. I am the acting leader for the Aboriginal Partnership and Strategy Unit. I am Southern Arrernte—Pertame. I was and born and raised in Mparntwe. I have been in this role for now probably about eight months.

Donna LEMON: I am Donna Lemon, manager for the Aboriginal Support Services Unit, a local Warramunga Arrernte woman with an English-speaking background.

Sally SENA: Hi, everyone. My name is Sally. I am originally from Hermannsburg, and I speak Western Arrernte.

Jennifer ARMSTRONG: Hi, everyone. I am Jennifer. I have worked here for nearly 14 years now, and I speak Southern Arrernte and Western Arrernte.

Curtis HAINES: Hi, I am Curtis Haines, and I am originally from Ti Tree and I speak Anmatyerre.

Anthony DAVIS: I am Anthony and I am from Willowra, and I speak Anmatyerre.

The CHAIR: Thank you very much. It is great to meet you all.

Paul SECOMBE: I am not sure if you can unmute Ros and let her introduce herself.

Rosalind BEADLE: Hello, everyone. Thank you very much for having me as part of this meeting today. My name is Rosalind Beadle, and I am calling in from Yolngu country, Galiwin'ku, in East Arnhem Land. I have been here for 18 months, but prior to that I was living in Mparntwe for eight years and had the privilege of working with the team that we are discussing this with together today. Just in a nutshell, my background is that I am very passionate about ensuring that any research done alongside Indigenous people is done in a culturally safe way and that it is done not for the sake of just doing research but to make sure that action comes out of research. I think this particular project that we have all been working on together for the last 2½ years is a really fantastic example of that. So we really appreciate being able to share some of the findings with you, which I feel are really grounded in community values and community needs. Thank you.

The CHAIR: Thank you. Paul, Rosalind or anybody else, would you like to make an opening statement for the Committee? For example, you might like to highlight some of the key points from your research.

Paul SECOMBE: Are you mob happy if I talk to that? Yes. Firstly, let me thank the Committee for expressing an interest in the work that we have done here. Let me in part apologise for the fact that it is not yet quite complete. I think you have had shared with you some copies of some slides that Benedict Stevens and I presented at a recent conference in Melbourne, which go through the key findings. But the manuscript that is the result from this research is currently in peer review with a major medical journal, and therefore it is a little difficult to share until it has been through that process.

The other thing that is worth saying to put this research into context is that Aboriginal and Torres Strait Islander people make up 30% of the Northern Territory population but find themselves disproportionately admitted to intensive care. That is true in the territory as well as nationally. Certainly for Alice Springs somewhere between 65 and 70% of our work is with Aboriginal patients who require critical care services. Anybody admitted to intensive care with a critical illness has a higher risk of mortality.

I will very quickly use the word 'dying' and acknowledge that our research highlighted that words like that are inappropriate in our context. If I now use euphemisms, you will understand what I mean.

Nationally, 7.5% of people who enter intensive care will finish up as part of their hospital admission. I am pleased to say that in Alice Springs that figure is slightly lower, but nevertheless we deal disproportionately with end of life and with patients and families who are finishing up. That places intensive care in a unique position when it comes to identifying organ donors and being involved in organ donation conversations.

I will also perhaps highlight in passing that Aboriginal people have a lot to gain from organ donation. Alice Springs has the largest haemodialysis unit in the Southern Hemisphere. We have rates of dialysis-dependent kidney disease that are certainly the highest in Australia and possibly the highest in the world. The only way to get off the dialysis is usually with a renal transplant. We were nevertheless intrigued, in the decade that I have been here, that the consent rate—which is to say the proportion of people who proceed to consent to organ donation divided by the number of people who would potentially be organ donors—is lower for Aboriginal people than it is for non-Aboriginal people, and it typically sits somewhere between half to two-thirds of the consent rate of non-Indigenous people. There would seem to be lots of possible reasons for that, and certainly at the senior clinician level across a range of hospitals in the top end of Australia—Alice Springs, Townsville, Cairns and Darwin—we have wondered why that might be but, I guess to my personal embarrassment, have never really sat down and formally talked about it in a group setting, which is what this research was all about.

We were successful in winning a very small grant from the Flinders Foundation so that we could fund some focus groups. Given my absence of experience in qualitative research, we were lucky enough to involve Ros Beadle in the process, and we were also fortunate enough to have working in intensive care at that time an Aboriginal health practitioner by the name of Emslie Lankin, who has, sadly, left Alice Springs now but who acted as both a cultural broker as well as a participant in those focus groups. I will also say with considerable personal humility and embarrassment that it was the first time in the five or six years I had been working in this hospital to that point that I had sat down with this remarkable group of people and truly just listened to what they had to say about a whole host of issues, not just about organ donation but about the way that we Western-trained clinicians have perhaps been conducting our communications and also about the role of country and the role of family in the consenting process. I am happy to take you through a few of the slides that have the key points from that. I believe, and correct me if I am wrong, that the Committee has copies of those slides. I will be guided by the Committee then about how we proceed from here—whether we go through those slides in more detail or whether you would just like some broader brushstrokes. And then perhaps you could ask some questions of this very generous and talented group that is in the room with me now, all of whom, you will have noted, speak not just English very well but often multiple languages.

The CHAIR: Thank you, Paul. We did receive those slides, so Committee Members do have those in front of them. I think from my perspective the first question that I would have is in regard to some of your findings from that research, so if you want to use those slides to talk through the findings, that would be perfectly fine with me.

Paul SECOMBE: Sure. I do not know whether I can share the screen or whether we will just bring the slides up and I will talk predominately through the results screen—although the methodology is, I think, equally important, because the methodology provided the space to sit down and for there to be an opportunity for two-way learning about the process. I think, and please correct me if I am wrong, that the ALOs as a group learned as much about organ donation and the process as we learned about how wrongly we were doing it in the process. There are nods in the room, if not a positive yes.

Let me quickly then go through the main findings, and I will use the slides here. The four primary themes that emerged were that organ donation, for central Australian Aboriginal people at least, is a very new topic, certainly not something that has been discussed at community level and certainly initially was considered to be culturally taboo to talk about. Despite that acknowledgement that it is culturally taboo, it was equally acknowledged that it is a really important topic and one that Aboriginal people, certainly in central Australia, potentially have certain gains to be made from in terms of getting family members off dialysis. It is also remarkable, I think, that when we sat down with the ALOs, every ALO in the room had a family member, either direct or indirect family member, who was on dialysis or who had received a transplant. I think that in itself is truly remarkable, and I do not think that would occur in any other part of Australia—where you could sit down with a group of disparate people and everybody knows somebody who is dialysis dependent or has been.

I will just quickly highlight the other three main topics, and then I might drill down on each topic individually. The other three main topics were that the conversations that occur in intensive care, particularly towards the end of life or as patients are finishing up or have finished up, as is the case for potential organ donors, are very confronting and that the language that we have been using at times has been inappropriate, and that is something that goes back to the way medical education occurs.

The third main topic was that education forms the cornerstone of everything that needs to happen going forward. That education needs to occur for both clinicians in terms of the way they approach families and the concept of organ donation, but also there needs to be public education at community level, and I will talk a little bit more about that in a moment.

The fourth—I always struggle with this one a little bit. It astounded me, the depth of mistrust in the healthcare system that we unearthed, and there were a number of quotes that were reasonably confronting. I am really grateful to the ALOs for highlighting this as an issue. I will talk a little bit more about that in detail subsequently.

If I can return to the first main topic, which was that it is new and culturally taboo, we uncovered several themes that I guess have been highlighted in the international literature, particularly for Canadian Inuit people,

but also in a research project that some WA researchers conducted nearly a decade ago in far northern WA. Some of those themes were that there is an importance of returning to country to be buried and that there is an immutable connection between the person and country that for Western-trained clinicians was probably underappreciated. There is also an importance in returning to country and being buried whole. There was an anecdote given by one of the ALOs of a man he was talking to on the surgical ward who had had an amputation of his lower leg. He wanted the leg so that he could take the leg back to country to bury so that when he eventually did finish up in the years to come, he would go back to the same country and his leg would be already on country waiting for him.

There were some very powerful metaphors talked about. There was one that dying off country is like removing a book from a bookshelf and never putting it back—there would always be a hole there that could never be filled. They are really important concepts and something that we need to be thinking about when we talk about organ donation. It is interesting, and there is more work to be done in this space on drilling down onto that concept of returning to country and being buried whole. When you think about some of the operations that people have where an appendix is removed, for example, or a gall bladder, is it important for those organs to be returned to country? Because mostly they go off to the pathology lab for further examination. I guess that provides an area of further exploration that will be undertaken and in fact is referred to in some of the educational resources that will come out of this process. Is there anything that you mob would like to add to that? Have I done that justice?

The CHAIR: Thank you.

Paul SECOMBE: The second major topic was around conversations that occur, and you will see that there is some overlap between these topics. There is a feeling that there is systemic racism built into the system, and we need to do a lot of work to eliminate that and to make the services that we offer as culturally and linguistically safe as possible. Moving away from this slightly, there is some question as to whether informed consent for anything that we do is in fact entirely informed if an ALO or interpreter has not been intrinsically involved in that process.

We discovered that the words that we are traditionally taught in both medical school and vocational training that are considered important in conveying bad news and in talking about the finishing-up process are now offensive to Aboriginal people. You will excuse me again if I use terrible words, but we are trained to use non-euphemistic terms, to be as clear and unambiguous as possible. Certainly in my training I was told if I have not used the words ‘dead’, ‘death’ and ‘dying’ multiple times in the first 5 minutes of a conversation about finishing up, then I am not doing my job properly, and that is an experience shared by many of my colleagues. As it transpires, that is not the way we should be communicating with Aboriginal people, and the use of euphemistic terms is entirely understood and far more appropriate. Terms like ‘finishing up’ are understood. Terms like ‘We have done all that we can do with the medicine that we have’ are also understood far more.

There was perhaps an acknowledgement that we as clinicians are not offering enough time and space at that end-of-life process for some sorrow time and that perhaps some of our organ donation colleagues are seen as hanging around in the background—I think the word ‘vultures’ was used in one session. I guess in a very small place like Alice Springs people are also very aware of the roles that people have, so you cannot just be an anonymous person hovering in the background—everybody knows exactly what you are there for. Providing some more time and a bit more space is important.

Having the right family present is also very, very important, and the western legalistic and healthcare models of next of kin are not appropriate. We all know that the model is that a partner—husband—is the primary next of kin for an adult, then it falls to the children. There is a very prescriptive list of the order of next of kin. That is vastly inappropriate in our setting. In fact a partner is the wrong person to be speaking to, mostly. There are other family members who are far more important and who become the decision-makers for the patient. In most cases that would fall to the patient’s mother’s brother, so an uncle, as the primary decision-maker for that person, with input from both sides of the family, so the mother’s side and the father’s side. Having all of those family members present and involved in the decision-making process is important, and how we go about rejigging the legal aspects of that I think is something that the Committee can consider.

The final thing that emerged with a lot of the conversations was a reminder that for health care workers, we come to work, we do our job, we go home and we mostly leave our work in the workspace. It was good to hear

from the ALOs and be reminded of the fact that for them there is less distinction between work and home. There were a number of stories around ALOs having patients or their families knocking on doors once they were home, sometimes to find out a bit more about what has been going on, but sometimes also for food, for accommodation, for other pieces of advice. It was a reminder that with the ALOs we sometimes put them in untenable positions—not deliberately—and that for the ALOs work is part of life. It is intrinsically part of a circle, so to speak, that they never actually—‘escape’ is the wrong word to use—escape from.

The third major theme is around education. You can see the overlap there. Clearly there needs to be education of clinicians about the most appropriate approaches to be making and how that should be done. There was also lots of talk that the first time the concept of organ donation is raised with families should not be at the bedside of a loved family member who is at or past end of life. That education needs to occur at a community level, it needs to be led by community members and it needs to be culturally and linguistically appropriate.

One of the very positive offshoots of this project has been that we were successful in winning a small amount of money from the Organ and Tissue Authority to produce a local resource that the ALOs have all driven and been intrinsically involved in the scripting of, involved in what the animation looks like and finally have actually involved in narrating the video. Although it is not yet quite finished, I am happy to share with the Committee, with the ALOs’ permission, a very early draft of that video shortly if you would like.

The CHAIR: That would be great. Thank you.

Paul SECOMBE: It came down to education, education, education, and it has to be at community level so that people have heard of the concept of organ donation well before that terminal or pre-terminal admission to hospital. Sorry, I interrupted you. Was that you, Ella?

The CHAIR: I was just saying that would be great with regard to the video. Thank you.

Paul SECOMBE: Please be aware that it is not yet the finished product.

Finally, the hardest topic for me to talk about was the one of mistrust. There are some really telling quotes that you will see on your handouts there in front of you that highlighted to me that we are dealing with the ramifications of 200-plus years of policies that have continued to marginalise the people who were living and managing this country well before we as colonisers arrived. Yet despite that level of mistrust and despite all that has been done, that this group was prepared to sit down and talk to us in such an honest and transparent fashion and to continue to educate us in ways to provide health care in a better way was in fact really truly humbling.

They are the four key themes. I guess the strengths of our study are that it truly inserts an Aboriginal voice into the process of improving health care. I think it is a framework that can be lifted from central Australia and reimplemented or re-used almost anywhere else if the right people are there. I think we were lucky to have somebody like Ros whose PhD work has been community based and who could offer the passion around ensuring that community voices are present. We were lucky to have somebody like Emslie—who is an Aboriginal health practitioner who had worked in intensive care, who understood a lot of the processes—offering some further cultural brokerage and, finally, a very generous group who were prepared to share their time and their expertise in such a way.

The disadvantages obviously were that we were probably talking to one of the most health literate groups of Aboriginal people in central Australia. It would be interesting to repeat that process with perhaps people who are not as health literate as this group are to see if the same themes emerge, although I was considerably reassured that many of the themes that we uncovered mirrored some of the research that has occurred in far north WA, which makes me think that some of these are maybe universal for certainly the Top End of Australia. Whether it is true for the southern parts of Australia I guess is something that the Committee may choose to explore in other ways.

The CHAIR: Great. Thank you, Paul.

Paul SECOMBE: I have done a lot of talking there. And there have been some nods in the room, but not many. I have done too much talking.

The CHAIR: Great. No, that was a fantastic overview of your research that you have completed, so thank you for that. Before we move on to other questions from Members, would anybody else like to make any comments about the research or some of those findings?

Rosalind BEADLE: I think I would, just briefly, Ella. I guess, just going back to a little bit of a background about this research, that although there are of course many benefits of increasing the number of organ donors in central Australia, I want to emphasise that that was not what this research was about. It set out to understand Aboriginal perspectives and existing knowledge about organ donation. It was very, very open—and this came up multiple times in the focus groups—of whether that question should even be asked at the bedside, and then moving on to find out about the most appropriate ways it should be asked if the family are happy to enter into that conversation and alongside culturally appropriate [Zoom drop out] and linguistic resources. I think Paul has done a really great job of summarising all the findings.

Obviously the most important voices are there in the room in Mparntwe. I do not want to shame anybody here, but all of these fabulous ALOs have contributed so much to this conversation, and I just wondered, maybe everybody, if you would feel comfortable or some of you would feel comfortable in commenting on why it was important to you to be part of this project. Or what were some of the key things that surprised you, being part of this research? It would just be really lovely to hear some of your feedback about—we have done this work now for 2½ years, we have got this fantastic paper, and now we have got this incredible video, which is so deeply embedded with all of your contributions. I am sorry; I know that I am not in the room with you, and it makes it a little bit harder, but maybe we could hear from some of you about why you thought that having these regular conversations was good for changing things in central Australia.

Christine SPENCER: It was good to learn about organ donation so we can talk to our mob when it comes to them making that sort of a decision, to know about organ donation so you can educate them too.

Rosalind BEADLE: That is lovely feedback, Christine. I think that was a really important part of the process, that we were actually all learning together. I came in with very little knowledge. You were able to teach me what was happening in the hospital, and together we were able to learn about an area that—you know, it has been happening for a long time. People have been asked to donate their organs, but often people do not even understand what that entails, so that was lovely to learn that together. Anyone else?

Donna LEMON: If I can add something, I have only been in this position—this is my fourth week, so I have hit the ground running. Having come over the top of some of the information that exists around the research project, what I will say is that it is a real work in progress. This is something that will get taken forward into the future. This project has enabled a really strong foundation for education across a number of platforms. I think that the existing resources that have been developed to complement the work that has been done around this area are really worthwhile. Many of us also have family members who have registered to become organ donors, and I think it is that thing of being able to educate people around the life-saving component of it as well. I am really excited to move forward with the ALO team and find out where this goes. Thank you for having us as part of the team.

Rosalind BEADLE: Yes. Thank you, Donna. I think that is really important. As Paul mentioned, we learned so much through the methodology of this project, and we were quite fortuitous in the way that we did not have to rush too much. We actually were able to use COVID to our advantage in that way, because we got to spread the focus groups over quite a long period of time. We had factored in funding for a number of focus groups, which enabled us all to go away in between discussions and really think about some of the questions and topics, speak to family and community and then come back and continue to add to the conversation. I think as Emslie and I particularly were looking through the transcripts from the focus groups, we could see that as we moved forward in these conversations there was an increase in trust and an increase in transparency about what we could share. And we had the opportunity too to veer away from organ donation to the big picture of what is happening in Alice Springs Hospital—many of the topics that Paul just brought up about what non-Indigenous staff can learn in terms of culturally safe practices. Linda, did you have anything else that you wanted to add?

Linda BRAY: Still thinking. For us Aboriginal people, it was really hard to educate our people on organ donation. They did not know that. To say to Aboriginal people, ‘Would you like to donate an organ?’—that was really bad for me, to ask those things. I think a little bit of education is coming on now. We need to start in the community.

Rosalind BEADLE: That is a really important point, Linda, and I think you have raised something else that can maybe complement what Paul was saying. As Aboriginal staff in the hospital, it was really confrontational for you to be expected to be part of these conversations because it was not culturally appropriate to even have these conversations, but then it was undertaken by the non-Indigenous staff, which almost made things worse. We have now been able to bring out some rich discussion about that whole process of how liaison is done in a really safe way about organ donation but also about other things that are going on in the hospital. The fact is we have been able to then follow through with creating a resource that can hopefully minimise the shame in having that conversation and that difficulty, and as Indigenous staff and non-Indigenous staff you will be able to use that resource to help that conversation. I can totally understand that, having been in central Australia for many years, to have any conversations about passing can be difficult with families and we need to do it in the most culturally safe way possible. Does this remind you of any other parts of the conversation we had? I know some of it feels like a long time ago now. Curtis? Anthony? All good? Okay.

The CHAIR: Thank you. We might throw to Committee Members now to ask a few more questions. Did you want to start, Annabelle?

Annabelle CLEELAND: I just appreciate all of your contributions. This has come up several times, around making sure that First Nations and Indigenous Australians are well represented in our inquiry. I am just keen to understand an example, maybe from an Aboriginal liaison officer, of where it was a successful story. Can you maybe—if anyone was in that position—share with us when the conversation was had, how it was had and any anecdotes that we could document, so that in other parts of Australia that is recorded. Is there someone that feels comfortable, maybe, who had that conversation with a family and knows what family was present as well?

Christine SPENCER: I spoke to someone from Yuendumu yesterday that came back from Adelaide and who had a kidney transplant, and he was really happy about it because he gets to go home and be with his family and be in the community.

Annabelle CLEELAND: Wow.

Paul SECOMBE: Some context there that the Committee may not be aware of is that most dialysis services are offered in Alice Springs, which for people who are dialysis dependent often means relocating from community into Alice. That connection to country that we have talked about is obviously very strong, so to come off dialysis and to be able to return to community is a very, very important part of the process. The other thing you might have been alluding to was perhaps some anecdotes around a successful donor process for an Aboriginal person in Alice Springs; it has not occurred.

Annabelle CLEELAND: Okay. I am conscious of time, so I just have one question for the ALOs. Do you have a suggestion that could support culturally sensitive and appropriate conversations when it comes to organ donations using storytelling?

Christine SPENCER: Give them resources like the video for storytelling –

Paul SECOMBE: Like the video, yes.

Christine SPENCER: and maybe books.

Paul SECOMBE: The big thing for me about the story is that it has been produced by local people. It has the voices of people who are living in the community in the story, which has formed the story, and it has been approved by those people. So I think –

Christine SPENCER: If you take them videos like that, it will make them understand what is expected of them.

The CHAIR: Great.

Annabelle CLEELAND: I will have questions at the end, but I will just make sure that everyone gets a go.

The CHAIR: Thanks. Heang.

Meng Heang TAK: Thank you, Chair. Thank you very much. It has been very informative, especially coming from such a culturally appropriate way of speaking. From Linda, I understand that it would be very difficult to talk about this topic, but is there an incentive? What could be the incentive that could encourage community members to talk about or to think about this process? Would you think a certificate of some sort or recognition of some sort could help?

Christine SPENCER: A big community barbecue out in the community with resources out and things like that.

Paul SECOMBE: So a community event around which organ donation education could be co-presented.

Christine SPENCER: Yes, that is right—with schools and families invited and things like that, so that everyone in the community can get involved.

Paul SECOMBE: So that is about being proactive with education and making the education attractive for people to come along and attend.

Christine SPENCER: Yes.

Meng Heang TAK: But also perhaps some supplementary recognition of those who are donors, in terms of a community plaque or something like that in the home—something that could be displayed—is that something that you think could be an incentive?

Paul SECOMBE: You are talking about some sort of public acknowledgement of somebody becoming a donor. Do you think that would be appropriate, or do you think using the name might be a little bit difficult?

Christine SPENCER: Some people would like it, yes.

Rosalind BEADLE: Can I just make a quick comment. I think that Christine just shared that lovely story about somebody going down and having a transplant and coming back and feeling really healthy and happy that their life has been extended. I think with these educational materials that is going to be a big incentive: linking having a transplant and having a higher quality of life to where those organs came from. That is what we really identified in these focus groups, that people were having kidney transplants and coming back and feeling happy and healthy, but they did not really have a good understanding of where those new kidneys—and we realised this was part of the poor terminology—were coming from to enable them to have that transplant. So we have been very mindful of that and woven that into the video and other resources we tend to make. Would that be fair, everyone? ALOs?

Christine SPENCER: Yes.

The CHAIR: Chris?

Chris CREWITHER: Thank you all for your time to talk with us today. It is really appreciated. My question is: you talked about the Alice Springs Hospital receiving a community awareness grant from the Organ and Tissue Authority to produce videos on organ and tissue donations in Indigenous languages. I would be interested in hearing from any of the Aboriginal liaison officers who were involved in the project and any positive outcomes that you would want to share with us.

Paul SECOMBE: Did you enjoy the process of putting the video together and being involved in the video? I know there are at least two people in the room whose hands feature in the video. There are voices in the video that belong to you mob too. What was that process –

Christine SPENCER: It was good, ay. Anyone else? Yes, it was good. We enjoyed it.

Paul SECOMBE: Did it contribute to a feeling of ownership of that resource?

Christine SPENCER: Yes.

Paul SECOMBE: That is your resource, and I think—and correct me if I am wrong—that will make it easier to use, knowing that it is a resource that has come from you guys.

Christine SPENCER: They can recognise the voices, yes.

Rosalind BEADLE: I think we are still yet to see the fruition of what is going to come out of that. And something that we do not yet have funding for is to really try to lock in a strong evaluation process when we share it initially with community groups and families and to be able to get feedback from audiences to see what kind of impacts it is going to have. That will be from community groups, school groups—I know there is the intention of maybe sharing it with a group from Purple House this week—and obviously the Indigenous staff themselves in Alice Springs Hospital. It is going to be so important that we capture that feedback, to be able to measure some of the outcomes of having such a resource that has really, really come from community.

Chris CREWITHER: Thanks. And just a last question, noting the time: I would be interested in also hearing from one or a couple of the Aboriginal liaison officers here today in relation to what you do in your role to encourage organ and tissue donations on a day-to-day basis. And are there any learnings that we can learn from you about what we could do with the Indigenous community here in Victoria, from your experience?

Christine SPENCER: They normally tell us their story about their transplant and how they are feeling. They do not like being in the city. They have got to be in the city for about six to eight weeks, and then after getting that transplant it is good for them to go back home and be with family. And yes, being back in the community will help with their recovery and all that healing.

Paul SECOMBE: In the day-to-day stuff you guys are exposed to everything, transplants often actually a fair bit really, aren't they? What have we got, 60 or 80 transplants kicking around central Australia now?

Christine SPENCER: They get really healthy, and then they get to go back home.

Paul SECOMBE: It is almost a daily, constant reminder of what organ donation can lead to.

Christine SPENCER: Yes.

Chris CREWITHER: And is there anything on that second part of that question, anything that we can learn from you about what we can do with our Indigenous community here in Victoria, from your experience?

Christine SPENCER: Listening, mainly—listening to patients. That is what we do—listen—and they tell us their story.

Paul SECOMBE: It is about clinicians listening too, isn't it, and understanding that it is going to be a bit different.

Christine SPENCER: Yes, and asking questions too, you know—asking questions and listening to people.

Linda BRAY: It is hard for us. Our people here, they all speak languages. They are not really educated like the Victorians—they are educated people, Victorian Aboriginals. They expect that from renal—organ donors. But our people are really still –

Christine SPENCER: We have got to explain what organs are in our language –

Linda BRAY: It is hard for us.

Christine SPENCER: because English is like a second or third language to them.

Linda BRAY: You will have no problems in Victoria talking about organs. Our people are full-blooded Aboriginal people and they do not like taking organs –

Christine SPENCER: Or giving organs to people, and they live remotely.

Linda BRAY: Yes.

Chris CREWITHER: Thank you very much.

The CHAIR: Great, thanks. Gary.

Gary MAAS: Thank you. And thank you, everyone, for your contribution today. I have two questions. First question is to the ALOs. We have seen the success of the work that you are doing and potentially how that can go towards increasing the number of registered organ and tissue donors. What could be done to further strengthen the roles that you are performing in this way? Is it just a matter of resources to assist you, or is there anything else that could help strengthen the role that you play?

Paul SECOMBE: I am very aware that I am not an Indigenous person, but can I perhaps answer that question?

Gary MAAS: Of course.

Paul SECOMBE: I would observe that our ALOs are actually underappreciated by those that determine remuneration. I would observe that they are often overworked, and I would observe that there are often not enough of them at any one time. I would observe that most clinical teams do their rounds without having an embedded ALO or Aboriginal health practitioner as part of the included clinical team that is seen to be directly delivering care to the patient. And although it may be slightly different in Victoria, in our hospital, where 70 to 80% of our inpatients are Indigenous people, I would have thought that an Aboriginal person should be a core member of every clinical team when they see every patient.

Gary MAAS: Thank you.

Rosalind BEADLE: If I can just comment on that quickly, I think that is exacerbated by the fact that in a hospital like Alice Springs there is a high dependence on locum staff and short-term staff, and many of them are coming from backgrounds and have such little idea of the context of many of their patients. Cultural awareness training and understanding needs to be massively improved, and, as Paul noted, the ALOs are the experts in this environment. They are the experts of their country, their families, their communities, and that rarely gets acknowledged in the way that it should by non-Indigenous staff. And I know that things are changing a little, but there need to be more forums to educate the incoming staff of what the expertise is that ALOs can offer. I know that some of the feedback during the focus groups was that sometimes they get just get treated as interpreters, with not all of the other rich information they can bring to inform a patient–clinician relationship and improve that and ultimately to have positive outcomes for the patient’s health.

Gary MAAS: Thanks very much. Paul and Ros, this one is probably for you. It is more to do with the data that has been referred to—that, Paul in particular, you have referred to in your presentation. It is data about consent rates for organ donation in various categories of general ethnic groups, which used to be published in the *Australian Donation and Transplantation Activity Report*, but it is no longer publicly available. I was just wondering if you are aware if that data is still collected, and if so, why it is no longer published.

Paul SECOMBE: It is still collected. It was shown at the conference that Benedict and I went to in April, May, so it is still collected. I cannot speak to why it is no longer publicly available. I could postulate that perhaps the categories that are used to capture that ethnic data are potentially inappropriate. I think that would be a question you would need to put to DonateLife staff.

Gary MAAS: Thanks very much for that. Ros, did you have anything to add to that?

Rosalind BEADLE: No. That is not so much my area, so I think Paul has probably filled us in as much as possible.

Gary MAAS: Terrific. Thanks very much.

The CHAIR: Thanks. Annabelle, you just had one more question.

Annabelle CLEELAND: This is a bit of an imagination question, I guess. We would love to hear if you have some suggestions—from the ALOs—around maybe speaking with your family—you know, how these conversations might be had and some suggestions. I would love to learn from you, and I know it is a difficult one, so if you have some ideas now, I would love to hear them. Otherwise if you are thinking about it and these conversations arise, we would love you to take them on notice and you can provide it to the Committee at a later date, just to understand when the conversation should be had and who should be present—from the family, the patient and the hospital. So we have kind of really looked at that across the country from that organ donor

coordinator, and we just would love to understand that from our Aboriginal and First Nations people—how that might look in your communities. If you have some suggestions now, we would love to listen. Otherwise if you want to talk at a later date and let us know, we would be more than –

Justine SWAN-CASTINE: Sorry, Justine here. That conversation is mostly uncomfortable for us when it is someone on their deathbed, on the bedside. I think that conversation is covered when they are visiting their GP, because we have got our Aboriginal community controlled centres here in Alice Springs. You know, the conversation should be done with everyone, not just in the hospital setting. It should be out there when they are visiting their GPs, their clinics—just you know, ‘Do you know about being a donor?’ It is just having those conversations so that when they get to the hospital, they are informed a little bit about it. Even when, say, if there’s a video completed and then it is shown around in the communities. If we see it on TV, we can have the conversation with our friends and say, ‘Hey, I’m an organ donor. Have you ever thought about doing that?’—after having watched that video. It just makes it a little bit easier after watching, I think, that resource and having those conversations, or having that shown in the clinics or in the waiting rooms here at the hospital. While they are there in the hospital sitting down there watching that video, the ALO can have a conversation then, if that is appropriate, if it feels comfortable. But a lot of the time having that conversation in the hospital setting, I think, here in the hospital, just makes it really uncomfortable. But if we can get that done prior and they come into the hospital, having those education sessions or even that conversation at home, at the clinic, at community centres, out bush, it just makes it a lot easier by the time they get to that point where you want to be asking, ‘Have you heard about this, being an organ donor?’ And then they are like, ‘Oh, yes, actually I’ve seen something on TV at home about that.’ It makes a lot easier, I think, if we have that.

Paul SECOMBE: It just makes it easier if the story has been heard before, such that the first time you hear that story is not in a highly stressful –

Justine SWAN-CASTINE: Yes, the first [inaudible] shock—‘Oh, my God!’—you know.

Rosalind BEADLE: Another barrier that was noted in the focus groups is that one of the reasons organ donation has not, or another inhibitor for this being a topic of conversation, was that—you know, my first experience of considering organ donation was when I first got a drivers licence and I had to tick the box to be an organ donor. It has been noted many times that that is not a requirement of getting a drivers licence in the Northern Territory. To register as an organ donor you have to specifically get onto the website, and there is no default way, I suppose. I suspect if that was incorporated into licensing, maybe that would just be another little reminder that this is an opportunity for people and then an opportunity for a further conversation about what that means. And then of course we have got this fantastic resource. And, yes, exactly what we have been saying. Assuming that we get community approval for this video, the intention is we spread the resource far and wide. We will have it in clinic waiting rooms, have it in schools and have it on social media et cetera, and that will help give people a foundation.

Just another point too that I think we have not mentioned is, assuming we can get some more funding, this is intended to be the first of three different videos. This is a very foundational video to give people an overview of what is organ donation and what happens. The next set of resources are for families at the hospital bed. Then if that family was to say, ‘Yes, I approve’, the next video would be the details of how the whole process happens. We set out to do one big video, and it turned out, because we were only working with 2½ minutes, that we had to pare it down, and this was the most important one to start with.

The CHAIR: Great. Thank you. We are reaching the end of the session, but before I wrap up, would anyone like to add anything further to the conversation today?

Rosalind BEADLE: Have we got time to share the video?

The CHAIR: We were not able to see the slides before, so I am not sure that the screen sharing is working.

Paul SECOMBE: I do not have the option to share the screen from this end. I am happy to forward that link to your Secretariat if you like.

The CHAIR: That would be great. Thank you very much. We are really looking forward to seeing the video. All right. Thank you very much for appearing before the Committee today and for your contribution to this inquiry. The Committee greatly appreciates not only your time but also the trust that you have placed in us

to hear your experiences and to hear your stories about organ and tissue donation and the role that ALOs play. We are incredibly grateful that you have been able to share your experiences with us today.

You will be provided with a proof version of today's transcript to check. Verified transcripts will then be published on the Committee's website.

The Committee will now take a short break before the next witness. I declare this hearing adjourned.

Witnesses withdrew.