

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

WITNESS

Mr Chris Thomas, Chief Executive Officer, Transplant Australia.

The CHAIR: We will now recommence the public hearings of the Legislative Assembly's Legal and Social Issues Committee's Inquiry into increasing the number of registered organ and tissue donors.

My name is Ella George, and I am the Chair of the Committee. I am joined today by the Deputy Chair Annabelle Cleeland, Gary Maas, Meng Heang Tak, Cindy McLeish and Chris Crewther.

I welcome our next witness, Chris Thomas, Chief Executive Officer of Transplant Australia. Thank you very much for joining us here today.

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.

I invite you to now make a brief opening statement of up to 10 minutes, and this will be followed by questions from Members. Thank you.

Chris THOMAS: Thank you very much, and thank you for the opportunity to speak with the Committee today. It is nice to meet every single one of you and lovely to be down here in beautiful Melbourne. My name is Chris Thomas. I am the Chief Executive Officer of Transplant Australia and actually have held that role for 16 years, so my knowledge I think goes back prior to the creation of the Organ and Tissue Authority, prior to the creation of the DonateLife network. I was actually on the national clinical taskforce which recommended the establishment of the authority, so I go back to a time when our donor rate was around 10 donors per million head of population. Through the national reform program we saw a doubling of that growth, significant growth and many more lives were saved. Success has many mothers and fathers, but Transplant Australia, as the national charity for organ donation and transplantation, was very proud to be part of the formation of our reform program in Australia and to see the tremendous growth that did occur.

Transplant Australia are an unusual beast. We are an event manager, we are a charity, we are a membership organisation and we are a health promotion agency. We have about 3000 members across Australia. They are transplant recipients, they are living donors, they are donor families and they are healthcare professionals. I would like to think that we are the professional community organisation, and the evidence that I will present today really comes from a 15-, 16-year monitoring of evidence, both here in Australia and overseas. I recently completed a voluntary role, which was the presidency of the World Transplant Games Federation. That enabled me to travel significantly and to speak at many international conferences. We are all learning in life, but I would like to say that I am reasonably versed in this subject.

I mean, transplantation—let us just put it into perspective—is the most significant surgical development of the last century. So much so that at the World Transplant Games in Perth, which we held in April, the transplant recipients from the 46 countries there represented more than 10,000 extra years of life lived because of organ donation, because of the gift of life and because of transplantation. One person to note in particular is Nigel Goldsworthy from Victoria. He was present at the games and was celebrating 48 years with a kidney transplant. We often talk about, 'Let's get someone a transplant,' but we do not think about the years on. It is the gift that keeps on giving. Often those people go on to have children of their own, and potentially grandchildren, and get to contribute to society. So the work that you are doing to try to improve donation rates here in Victoria is to be commended.

In the interests of time, I am going to get straight to what needs to change: the consent rate. It sits at 54%, as no doubt you are aware. That is 54% of families saying yes to potential donation. While we respect and cherish each decision of those donor families, we know that collectively that number is not good enough.

Our recommendations can be broken up into two areas: the clinical setting and the community setting. In the clinical setting all potential donors must be realised, and potential donor families must be supported through the process. There needs to be 100% routine referral to DonateLife of all planned end of life in the ICUs or emergency departments. That currently sits at 81% nationally. We can do better. There should be 100% checking of the Australian organ donor register for those potential donors. In not all occasions is the register checked prior to the discussion happening with the family. Yet the knowledge that that person had decided to become a donor—it was not their wish, it was their decision, which is an important distinction—is not always checked prior to the conversation. One hundred% of the donor conversations with families should have a

donation nurse specialist involved. It is currently 76%, but we know that the consent rate from families when specialist donation nurses are involved is significantly higher than, say, when the conversation is led by the intensive care unit specialist. I think we need to acknowledge that intensive care units are undoubtedly busy places, and the intensive care specialist is there to save lives and to manage an entire unit and now we have, through the DonateLife network, specialists in position, who can actually take those families on that journey and maximise the opportunity for donation.

I think we do need to encourage the sector to better understand the logistical and medical reasons that impact on the total number of donors achieved each year. 247 of the 701 consenting donors last year were actually ruled out because of medical or logistical reasons. Their families had said yes, but that person was not able to go on to donation. Transplant Australia would like to better understand from the Organ and Tissue Authority the breakdown of those 247 people. Was it all medical reasons, so potentially a cancer was discovered? Was it a logistical problem—that they could not get a flight to that potential donor in time? I think there needs to be a better breakdown of that.

I will not spend a lot of time on it today, but I think it is also important that there needs to be an updating and standardisation of the human tissue Acts in each state and territory. The one thing I will say about it is that if you have consented to donation and you present to an intensive care unit and your family are brought in to have a conversation, in all states and territories—because we have, I think, a defensive medicine philosophy—those families are asked to essentially re-consent and yet that person had already ticked the various parts of their body that they would like to donate when they signed up to be a donor. Donor families say to us that it is quite confronting that they are then asked to go back through that list and think about Billy's heart, lungs, liver, kidney, musculoskeletal tissue, corneas. When you are in that, you are in an extremely emotionally charged, grief-stricken stage: you have been out going about your business, you have been at work, you have received a phone call to say that a loved one has taken ill, and within 24 hours you are coming to grips with that person not coming back. Without going into any detail, that is the exact situation that happened to my mother when I was 23 years old, and we donated her corneas, so I have got a good understanding of the dynamic that occurs at that particular point in time. To actually ask those families to go back through and re-consent seems to be an area where potentially people then end up saying no, and the decision of that original donor, the person that is lying there, is not then respected.

In the community setting Transplant Australia would support the return of the yes option to the state-based drivers licence systems, with the data uploaded onto one national register. This will ensure that all Australians when first applying for a licence or renewing are able to commit to donation. Studies show that 80% of the population will support donation, yet only 36% nationally are registered. In Victoria that sits at 23%. It was phased out across Australia some 12 to 20 years ago, meaning now that there are almost two generations who have not had the opportunity when making that key, what we would call, life moment decision: 'I'm getting my licence!' We all probably remember how exciting that was. We were able to embed that decision around organ donation with that life decision of getting a drivers licence, and we actually gave it away. I am more than happy to speak in more detail about the rationale and why that was. But as I say, there are a couple of generations now where they have missed that opportunity.

The case for a mass registration platform is really compelling, and it is not a case of 'We put a link to the organ donor register on a website'; it is actually embedding it into the drivers licence system. That is the hallmark of the American system and it works so well. They have got some states where 70 to 80% of the population have signed up to organ donation through their drivers licence system. It is there not as a permanent record but as a record that people are able to update every five to 10 years. So you end up with a very compelling case. If that person was 45 years old and they signed up when they were 17 years old and every five, 10 years they recommitted to it, it is a pretty compelling case to say that they believed in organ donation and that person's decision should be respected.

I think the other point that is really important is—and there is a lady in America at the Commonwealth University in Virginia who has done a lot of research into this, Laura Siminoff—who benefits from that person making that decision and that decision being respected? I would argue that the person who made the decision, the bed donor, benefit because they get their decision respected. I am a firm believer in personal autonomy. If I want to be an organ donor, if I am eligible, there should be a really good reason why my family is able to overrule it. Obviously the transplant recipients who are potentially going to receive kidneys, liver, the hearts and lungs et cetera, they benefit. But the other group that is not particularly identified well that this professor

has done some research into is the donor families themselves, because the decision has already been made and they know with confidence that is what that person wanted. They do not have to grapple with, 'What were Billy's values? Did he ever talk about it?' The decision has been made. I think that is one of the reasons why we would like to see a return to a mass registration system, and the drivers licence is the key.

Education and communication—obviously through returning it, potentially as each state moves to digital licences, education and communication then needs to follow. In years gone by we used to go to those driver training forums. The forums are still happening but the organ donation component of that does not anymore. Overall, we need to at least double, or triple in this instance in Victoria, the rate of registered donors to match what has been achieved in South Australia where 73% of the adult population are on the donor register through the drivers licence. The consent rate there has been consistently higher across 10 years than in other states.

I am sure by now you have had a few public inquiries, a few meetings. There is a strong correlation between consent and registration. If a person is registered to be a donor, normally in nine out of 10 cases families will support that decision, although last year in Australia that did drop to around eight out of 10, which was concerning. But if you are not on the register, if you have not discussed it with your family, that drops down to about four out of 10. I did mention that donor registration through the drivers licence is also a hallmark of the American system. It was a world leader. The consent rate in America is now equalling what was achieved in Spain. There are other factors influencing that, which I will not go into. Suffice to say that opioid use, gun crime and things like that are having an impact on donation rates, and that is a tragedy in its own right. But these changes that we would be recommending should improve our consent rate to at least 75% of potential opportunities, and we feel that that is the game changer to donation.

If I may, I would just like to bring into the conversation the concept of opt-out to illustrate a key point in relation to drivers licences and expressed opt-in, which we have—an expressed opt-in system. In the UK where opt-out has been adopted over the last four years the numbers are still somewhat unknown due to COVID. The whole pandemic has influenced and impacted on hospital systems in ways that we previously had not envisaged. But I am certain that opt-out is not the panacea for the improvement that we would like to see.

The table I would like to—can I table a table? I suppose I can, on a table! Sorry. The table I would like to table compares consent rates by the type of consent from April 2020 to March 2021—and the table comes from the UK—in England, Scotland and Wales; Northern Ireland had not yet participated in the opt-out program. I just would like to take you through what the United Kingdom has moved to, actually what they call an 'opt-in and opt-out' system. I think that is a misnomer in Australia. People say, 'Oh, let's go to opt-out', but when you have got 7.6 million people already on the Australian Organ Donor Register, a third of the population, you are not going to just wipe the slate clean and move to an opt-out system; you are going to somehow respect those card-carrying members who have signed up and believe in your cause. So if we were to move to an opt-out system, it would actually be like the UK, where it would be opt-in and opt-out. Now, that presents some challenges to the population, because 'Do I need to do anything, don't I need to do anything' becomes quite confusing.

But if we look at the statistics—as I say, I will table this—they have ended up with four groups of population. First of all, I will just deal with the group which they call their—and please excuse my terminology, it is UK terminology, not ours—black, minority, ethnic, their BME audiences. So they actually excluded some people from the opt-out system, people that maybe had lower health literacy levels and people who had come from different cultures and so on. Over this 12-month period, acknowledging that it was during COVID, the consent rate from that group of people was 54.8%, so about what the current consent rate is from the general Australian population. The consent rate from those who had opted out was, not surprisingly, zero percent; they had opted out. The deemed consent pool—so those people who had not opted in, were not excluded, but just did nothing, so they were now presumed to have opted out—the consent rate for that group of people was 66.7%. So potentially you say, 'Okay, we've gone from 54.8% of that other group to 66.7. There's an increase there.' But from the expressed opt-in group, the people who had actually said, 'Yes, I believe in organ donation and I have signed up for it', the consent rate was 92.8%. So to Transplant Australia, the simple solution is not revolution, it is just to do better with what we have currently got, and to treat organ donation as this most magnificent gift, to value it as this gift and to get as many people to opt in to donation as possible. And the results, at least from this table, show that the conversion rate, if you like, is far significantly higher from those who have opted in.

Why is all of this important? As I am sure you know, too many Australians are waiting for a transplant. Waiting lists are growing and there are inequities in our systems impacting diverse and Indigenous communities, and we can speak more about that if you wish.

Finally, just a word about respect: Transplant Australia would like to see a greater respect for a person's decision to donate. While potential donor families must be considered at every step of the donation process and their support sought and obtained, at a macro level it really should be society's expectation that, if you register to donate, this should be respected by all concerned. A family consent rate of 82% last year in Australia where the person has registered I do not believe is in the community's expectations. This means almost one-in-five families are overriding their loved one's decision—'No, it's not for us.' There will always be cases where—no organisation such as Transplant Australia, no government, wants to impose themselves on that intensive care unit with that one discussion. Surrounding organ donation is always emotion, death, the very difficult challenges that families face, but holistically we need to respect people's decision to donate.

Transplant Australia is the nationally respected charity in donation and transplantation. I think essentially we are a charity of storytellers, people whose lives have been saved by donation. We tell these stories through our communications programs, including the Australian Transplant Games. These stories bring a tangible focus to the benefits of donation and show the success of those whose lives have been saved. We also help people on the transplant journey and provide education and support to help with their rehabilitation. The World Transplant Games in Perth were an outstanding success and helped focus Australia on the living proof of donation, and we would be eager to explore the staging of another Australian Transplant Games in Victoria. The last was in Melbourne in 2014.

In conclusion, Transplant Australia is committed to helping improve donation in Australia. It is in our DNA. We want to see reform universally approached. We believe that organ donation is a gift we leave behind, and there is great merit in the concept of personal autonomy: 'It's my decision and it should be respected.' We are committed to working closely with the authorities to instil confidence in our donation system. Ultimately we need to ensure that organ donation becomes a fundamental human responsibility.

I would like to thank the Committee for its focus on our donation systems. As legislators you have the power to lay the building blocks for an improved donation system both here and in the rest of Australia. That is my opening statement.

The CHAIR: Thank you very much, Chris. That was an excellent opening statement. Through that and your submission I think you have given the Committee a lot to think about. I know I have got a couple of questions, and I would say the other Committee Members do as well. I would like to start it off, if I may. I think one thing we are hearing about as we progress this inquiry is some of those inequities in the system, particularly when it comes to experiences for Australia's First Nations populations. Earlier today we did hear from some Aboriginal liaison officers working in the Northern Territory about some of the barriers to learning about organ and tissue donation and some of the different challenges that First Nations communities face. I would like to delve into that a little bit further with you. From your perspective, what are some of those key barriers in terms of increasing the number of registered donors who are from a First Nations background?

Chris THOMAS: We had the privilege of presenting to the Western Australian inquiry into organ donation a couple of months ago, and I had the opportunity to ask an Indigenous mother from Kununurra Rowena Alexander to present with us. She tragically lost her daughter to self-harm and her daughter became an organ donor. She spoke to that inquiry and I think I can repeat the messages here: there has been little education of our Indigenous populations. We need to make sure that they have a better understanding of the benefits of donation and transplantation, but not through the voices of people such as me—Rowena can tell that story much better.

As I said, we are a charity of storytellers, and we would like to be able to harness those voices much more—to be able to have the Indigenous Australians who have actually agreed to donation and who have received a transplant to be able to talk to their own communities in their language. We all know that word of mouth is perhaps the most important form of advertising, so that word of mouth is really important. We would certainly welcome working with the Victorian Government more closely to enable those stories to be better told.

It is terribly concerning that Indigenous Australians face renal disease at a far greater rate than non-Indigenous Australians, yet they have about a quarter of a chance of actually getting a transplant. I think that is what is really quite challenging. I know that the federal government, through the then Honourable Ken Wyatt, had a task force to look into kidney transplantation across Australia for Indigenous Australians. We cannot solve the clinical issues. We can highlight the issues and we can talk about the lack of access to transplantation for Indigenous Australians. I think our role as a charity of the community is to, as I say, harness those voices and tell them in a much more powerful and structured way.

The CHAIR: Great. I note you do say in your submission that:

Transplant Australia can play a role in increasing the role of Indigenous transplant recipients ...

I am wondering if you can point to some examples of maybe how you have done that previously or how you think you can work with government to do that in the future.

Chris THOMAS: Rowena Alexander, once again, is a wonderful example—the stories that we were able to generate in Western Australia in a really sensitive and compassionate way, because you are dealing with the death of a daughter. Also, there are quite a number of Indigenous Australians who have received transplants. Ken Farmer is a wonderful Western Australian man who has received a heart transplant. He was able, through our storytelling associated with the World Transplant Games, to share the success of his life and the fact that he has been able to go on to be an artist of some acclaim. There are these people dotted throughout the world—throughout Australia—who have benefited, and I think that we need to be able to work with the transplant units to identify them, to be able to encourage them to share their stories. It is not always easy. Organ donation is something which is not particularly embraced by our Indigenous communities.

Transplant Australia is also concerned about our diverse communities as well. I went to an organ donation conference on multicultural communities in Los Angeles about seven or eight years ago, and all the evidence there showed that migrants actually bring their organ donation rate with them from the country where they have come from and it takes at least two or three generations to start to break down those barriers. OneLegacy, which is an organ procurement agency in California, embedded a Mandarin-speaking person into the Chinese communities in San Francisco, and for 10 years nothing happened. It takes generations to be able to change attitudes. That is why we applaud the work of the Organ and Tissue Authority to actually drive education programs into the 18- to 29-year-olds through university education and so on. We are probably not going to change grandma who came out from Eastern Europe or came out from somewhere in Asia—we may not be able to change her attitudes—but over time we will be able to influence those communities to embrace donation more.

The CHAIR: Thank you. Annabelle.

Annabelle CLEELAND: Thank you, Chris. I am just interested to know how many inquiries and reports in this space you have contributed to in recent years.

Chris THOMAS: Well, the last inquiry that I came along to the Victorian Parliament was probably, I want to say, 12 years ago—I made a presentation to an inquiry that was done in Victoria. One of the recommendations of that inquiry was to hold a transplant games in Victoria. I would love to see a repeat of that here. It is an easy win, because Victoria is—I was going to say the sporting capital. Melbourne has a history of wonderful sporting events, of which all Australians can be proud.

We obviously spoke to the national clinical task force back in 2008–09. There has been a Tasmanian inquiry. There is the current Western Australian one, a previous Victorian one, a previous New South Wales one and one in Queensland. So yes, most states and territories over my 16-year tenure as CEO of Transplant Australia have held inquiries. I think the most significant change was a national clinical task force at the Commonwealth level which reformed the organ donation program. What it did not reform was the transplant program, which is still the domain of the transplant units in the state hospitals. I think there has been significant progress. The COVID pandemic has impacted upon donation rates, but maybe that is another point you were leading to.

Annabelle CLEELAND: We will no doubt get there or try to. The 2009 changes coincided with the shift from the drivers licence database in Victoria to a national registration. Give me the background from your perspective: what happened there? And do you believe there was data lost in that transfer from the number of registered donors in Victoria?

Chris THOMAS: The national clinical task force recommended the establishment of a national register—that all data be moved to a national register. I think the first major campaign to actually promote that was the David Hookes Foundation, after his tragic death. In New South Wales—I will just speak of that for a moment—it was both a ‘yes’ register and a ‘no’ register. About 30% of the population were actually going into the motor registry, waiting in line for their ticket and then looking at that question and ticking ‘no’. It was a legal document, so the doctors and nurses were unable to ask that family if that person would like to become a donor because they had formally opted out by ticking ‘no’ on the drivers licence. So a ‘no’ was a ‘no’, and a ‘yes’ on the drivers licence was a ‘maybe’ if the family were in agreement.

The consensus—with a voice disagreeing, because I was the only community member on that clinical task force—was to phase out the drivers licence system and move to a national register. I made the point many times that we should not give up that one sacred life-decision moment and that there were many health causes out there that would jump over everyone else to get that if they possibly could. I do recall a radio interview I did with 2UE in Sydney when this decision was made—New South Wales phased it out, and Transplant Australia went along for the greater good and agreed to it. I did an interview to explain it; the Minister for Health in New South Wales asked me to do that.

I had a phone call from the researcher from the radio program afterwards to say that, ‘The CEO of the NRMA would like to talk to you.’ So I telephoned him back, and I will not repeat what he said in that conversation for Hansard here, but he basically said, ‘You guys are crazy—here you had your one cause on the drivers licence, and you took it away.’ Essentially, he was right. I think there was a problem, the ticking of the ‘no’ box at 30%, but we came up with the wrong solution. In America, conversely, where they had both a yes and a no, they actually withdrew it and reintroduced it as a yes-only register; you know: ‘In the event of your death, would you like to save others through the gift of organ donation?’ and turned it into a positive.

I know there were about a million registrations in New South Wales that were not uploaded from the drivers licence system into the Medicare system because the then privacy commissioner Chris Puplick in New South Wales actually said, ‘Hang on, people have opted in to a state system; that is data which is private to the state system. You can’t then upload that into the national system.’ I am not aware that that occurred in Victoria, and if you like I would be happy to take that question on notice and do a little bit more digging. It would seem from your numbers, sitting at 23% rather than, say, New South Wales sitting at, I am going to say 33%, you cannot lose that many people unless there was a problem with uploading the data, as you have identified.

Annabelle CLEELAND: We will take that on notice, if that is okay. I am just conscious that we all want to ask some questions and we have only got about 15 minutes.

The CHAIR: Sorry, Annabelle, we will have to move on now.

Chris THOMAS: Okay. Sorry.

The CHAIR: All right. Thanks.

Annabelle CLEELAND: Can I just ask one quickly –

The CHAIR: Can we come back to you at the end?

Annabelle CLEELAND: it is about that, just a quick input—at the end. Thank you.

The CHAIR: Gary.

Gary MAAS: Thank you. Further on drivers licence registration, you said you wanted to make some more comment on that, so I am basically giving you some free rein now to go there.

Chris THOMAS: Well, thank you, and I will keep it short. Look, essentially, I think moving to a digital licence, there is an opportunity to place the option to become a donor back onto that, and for it to be a yes-only option. People still have the right to go to the Australian Organ Donor Register where there is a ‘no’ option, but I think the numbers—way less than one percent of people actually go onto the national register to opt out and say no, whereas in the New South Wales example it was around 30%. So I would strongly urge the Committee to look at a yes-only option. If it became a ‘no’ option as well, then it seems to overinflate those numbers, and we have often asked, or the authorities have asked, the families and they have said, ‘Oh, no. Billy was always

very positive towards donation, but at some point in time he ticked that ‘no’ box through the drivers licence.’ So I would strongly urge a yes-only option, which is very similar to what they have in the United States.

Gary MAAS: You spoke about physical licences and what that used to be like a few decades back. Well, electronic licensing is coming in here, drivers licences. How would you see that that might work?

Chris THOMAS: Perhaps this answers the Deputy Chair’s questions as well; you need to make sure that there is a seamless transition of that data. It is not hard on a digital licence to add an extra question: ‘Organ donation is important. In the event of your passing or of your death’—we do not need to nuance the words today—‘would you like to save others through organ donation?’ That is fairly much what they have done in the United States. Then maybe there could be some drop-down boxes. Most people are happy just to give the tick to the gift of life, but there should be an option, obviously, to drop-down to the various organs. People may be more inclined to give their liver, kidneys or heart. For some reason some people have troubles with corneas, for example. But then we need to make sure that that data can be uploaded into the national organ donor register, and that was one of the problems that we had previously. The Commonwealth through social security, Centrelink, whatever it was called at that particular point in time—Human Services—were saying that it would cost \$1 million to actually be able to implement a system to upload. Well, I am sure it would not have. But even if it did cost that it, it would be money well worth it because we are just losing too many people, and I think I have demonstrated that the consent rates from those who have registered are significantly higher. It is money well spent and would help in bringing up our donation rate immeasurably.

Gary MAAS: Thank you. The human tissue Acts: you spoke about the differences between the states. What advantages would there be to having individual state Acts regulated consistently across all jurisdictions?

Chris THOMAS: Well, most of the human tissue Acts go back to the 80s and have not been updated since. So there is a significant changing of technologies, especially in the tissue donation space. Tissue is treated differently; it is almost a product in some instances. There are quite a number of inefficiencies in the system and in the Acts and inconsistencies. For example, in the ACT, South Australia and Western Australia there is a bizarre aspect of the human tissue Acts where after someone’s death no-one can actually reveal the identity of the donor. Now, the intent of that was to say that we should not be passing the details of the donor onto the recipients and in fact vice versa, the recipients to the donors. But in those Acts it actually became that they were not able to reveal the identity of the donor publicly. There has been this strange legal case going on, mainly in Western Australia, where some donor families have felt that they are not able to actually talk about their loved one who became a donor, so Rowena, who I mentioned before, talking about Macaiah until the health minister there issued an order. It was not part of the legislation change—that will come—but an order issued to say that ‘Well, yes, of course donor families should be able to talk about their loved one.’ There is no interest in prosecuting someone who talks about their loved one who has become an organ donor. That is one example of some of the inconsistencies.

We are mainly concerned, with the human tissue Acts, about the questions that those potential donor families are put through at time of potential donation, because it is just another inhibitor, if you like, to families saying yes. The number one reason why families actually decline is not cultural reasons and it is not religious reasons. Essentially it is—and DonateLife would be able to confirm this—the amount of time it takes to go through the process. It can be, like, 30 hours from when you started to have that conversation till the donation actually takes place, and it is an extremely emotionally draining period of time. We need to make it easier for those donor families, and hence our interest in the human tissue Acts in that sense.

Gary MAAS: Thank you.

The CHAIR: Thanks. Cindy.

Cindy McLEISH: Thank you. I am just going to continue on the line of donor families for the moment. One of our previous witnesses said that there was a link, they felt, between the experience in the hospital that that family had with the hospital in the hospital setting and consent. Do you get that sense? So, if you had a positive experience—the staff were all respectful and gave you the time—that you were more likely to say yes, whereas if you have perhaps moved rooms a few times or different things have happened and the experience has not been so great that it has impacted on consent?

Chris THOMAS: Yes, most definitely, and we do know that we have got great confidence in what the organ and tissue donation authority has done. They have introduced the Gift of Life training workshop, which has come out of Philadelphia, and all of the donation nurse specialists have actually undertaken that program. Ten years ago we might have said, ‘Are we asking those families at the right time?’ The one thing that we learned in the early days is that you do not bring up the idea of donation until the family have come to the realisation that their loved one has died, because there is nothing more final about death than wanting to remove someone’s organs. So the whole education process that DonateLife have undertaken with the donation nurse specialists has resulted in significant improvements. Hospitals are real places. They are under strain, they are under pressure, and I can imagine that there will always be a less-than-optimal experience. There will always be a donor family that are disappointed with—let us face it, the outcome is always a difficult outcome. They are losing a loved one. The fact that anyone actually says yes in that instance and agrees to donation is to be cherished, after what they have just been through. But we have hundreds of donor families who share the stories that they knew that their loved one was not coming back but they were able to make a decision which will actually impact upon other families in the hospital system who are actually going through almost exactly the same scenario. There can be someone else in that hospital who is waiting on life support for a transplant, and those families are able to make a positive decision to impact those other families and they go on to tell those stories, and we are very proud of their contribution.

Cindy McLEISH: Just a final question. Just to take you back a little bit to when we were talking about the Indigenous communities and the renal disease and you mentioned how prevalent it was, is that hereditary? Is having a kidney donor from within the community an option, or are we looking at usually an option from a different ethnicity?

Chris THOMAS: One of the difficulties of the national reform program was indeed that it focused on deceased donation, and our deceased donation rates went up immeasurably—doubled, you know, in the 10 years to 2019—but our living donation rates actually fell back somewhat. Our living donation rate in Australia is half that now of New Zealand, which was totally different, as I say, 10 years ago. We do need more focus on living donation, and I say that because it has the potential to impact our Indigenous and diverse populations much more—to benefit them much more. In kidney transplantation there is a correlation between your ethnicity and your DNA, your genetic make-up, so if you are from, say, a Maltese background living in Australia and no-one from a Maltese background is donating you probably will never rise to the top of the list. It is always the person who is in most need who is the best match. If you are never going to get the best match, then you are going to wait for years on a waiting list, and that is why we need more Indigenous Australians to say yes to donation. But part of the solution also must be in the living donation space because there will be occasions where someone will not be able to or is unlikely to receive a deceased transplant, but living donation may well be something for them.

Cindy McLEISH: Thank you.

The CHAIR: Heang.

Meng Heang TAK: Thank you. I think the question I am about to ask is within that remit in terms of family consent. How do we maximise or encourage having more members of the family, like in the case of Maltese, where they have come from the same family or the same community?

Chris THOMAS: I think if we can embed it into the younger populations within those families, if they can gently share their beliefs about why organ donation is a good thing, we can tell the stories of those communities. I know people from all cultural backgrounds that have had a transplant. Many of them are prepared to share their stories, and Transplant Australia is well positioned to be able to do that. So I think the most important thing for families of multicultural communities is actually the sharing of those stories amongst their own communities, so they can better understand the benefits of transplantation and donation.

Meng Heang TAK: Has there been a specific campaign or a best practice example that you know of?

Chris THOMAS: The Organ and Tissue Authority did some good work about eight years ago where they had faith leaders from all different faiths sign on to a memorandum—it is probably not the exact word I am looking for—and I think that helped address what are perceived to be religious barriers. We know that the vast majority of religions actually support donation, but there are some religions where people need to be buried

within 24 hours and things like that, but that does not preclude donation. So I think there has been some work done in that space, but there needs to be much more, especially in states such as Victoria and New South Wales with predominant multicultural communities. We celebrate that and we love that, but if we want every Australian to be able to access transplantation, every Australian needs to understand the benefits of donation.

Meng Heang TAK: Thank you.

The CHAIR: Thank you. Chris.

Chris CREWITHER: Thank you, and thank you for your time giving evidence and your submission. My question is in relation to a yes-only driver licence option, and perhaps it is a computational question: do you think it should be a box that one has to untick as opposed to a yes box that one has to tick, particularly given that if there is only one optional option, a person may otherwise just click past the page? So should it be a yes box that is automatically ticked that the person has to untick or should it be a yes box that a person has to actively tick to be on the register?

Chris THOMAS: It is a good question. Certainly it should be a compulsory question—‘mandatory’ I think is the word I am looking for. So you should not be able to pass it without—no, sorry, let me think through that.

Chris CREWITHER: The issue is that if there is only one option, it is very hard to make it a compulsory question, because –

Chris THOMAS: Yes, I am just thinking.

Chris CREWITHER: otherwise you would just move past that page and it would be an optional option, unless you could have an alternative option that says ‘unsure’ or ‘not at this time’ or something like that, that is an alternative to a no.

Chris THOMAS: It is a very good point, Chris, if you do not mind. I have seen it in a number of jurisdictions where it is a ‘yes’ or ‘I will leave it to my family to decide’, and either of those are the options. In America it is mainly just an optional yes, tick a box, and if you do not tick it, then it is still up to the family to be able to make a decision. So I think our preference would be a yes-only option to tick. I am not certain that our society wants to have a system on the drivers licence where it is already ticked for them and they have to untick it. From Transplant Australia’s point of view, I would love it, but I think our society is—things have changed a little bit following the COVID pandemic and governments are perceived to be forcing decisions on people. We, from Transplant Australia’s point of view, think it is the ultimate gift that you can leave behind, and we would like people to actively participate in that. So I think my considered view, having heard the question, is that it should be something that people opt in to, or either way after that it is left to the family to make a decision.

Chris CREWITHER: Could it be potentially an option where the box is ticked to start with, but if the box is ticked to start with there is a prompt to say, well, ‘Are you sure that you want to proceed with that?’ Then it actually will prompt the person to untick it if they want to.

Chris THOMAS: Speaking on behalf of Transplant Australia and not maybe as an Australian who wonders about the acceptance of those programs, I would certainly encourage that to be explored to see if that was something the community would accept, and if the community would accept it, we would be supportive.

Chris CREWITHER: And elaborating on my further part before about your comments that have perhaps been in favour of a box you need to tick, would you then be supportive potentially of having those two options of a ‘yes’ and a ‘not at this time’ or ‘it’s something I will consider later’ or something like that to ensure that you do have a prompt?

Chris THOMAS: We are supportive. Transplant Australia would be supportive of any system where the option to become an organ donor is reintroduced onto the digital drivers licence in Victoria. The various permutations that you have presented would be acceptable within the overall society’s expectations and how the Committee decides. The only area that we would seriously caution against is once again, as I have said a number of times, a ‘no’ option on the drivers licence. Any of the other options that you have mentioned are a

significant improvement to what we have currently got, and we would welcome and work with you to ensure that the Victorian public embraced it.

Chris CREWETHER: Thank you. Over time, I think.

The CHAIR: Thank you. We are a little bit over time. Chris, thank you so much for appearing before the Committee today and for your contribution to this inquiry, both your written submission and in preparation for today. The Committee very much appreciates the time and effort you have taken to present your evidence.

You will be provided with a proof version of today's transcript to check together with the question taken on notice. Verified transcripts and responses to any questions taken on notice will then be published on the Committee's website.

The Committee will now take a short break before our next witness, and I declare this hearing adjourned. Thank you.

Witness withdrew.