

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Friday 23 June 2023

MEMBERS

Ella George—Chair

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WITNESSES

Ms Lucinda Barry AM, Chief Executive Officer,

Associate Professor Helen Opdam, National Medical Director,

Mr Mark McDonald, National Manager, Analytics and Technology, and

Ms Brianna Elms, National Manager, Communications and Engagement, Australian Organ and Tissue Authority.

The CHAIR: Good morning. We will now recommence public hearings of the Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors. I welcome from the Organ and Tissue Authority Lucinda Barry AM, Chief Executive Officer; Associate Professor Helen Opdam, National Medical Director; Mark McDonald, National Manager, Analytics and Technology; and Brianna Elms, National Manager, Communications and Engagement. Thank you for joining us today.

All evidence given today is being recorded by Hansard and will be 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.

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I invite you now to make a brief opening statement of around 10 minutes. This will be followed by questions from Members. Thank you.

Lucinda BARRY: Thank you for the opportunity to appear before you today. The Australian Government's Organ and Tissue Authority, also known as the OTA, leads the national program to increase organ and tissue donation so that more Australians can receive a life-changing transplant. The program is delivered in collaboration with all governments, the clinical sector and the community. The OTA thanks all organ and tissue donors, who have transformed the lives of people needing a transplant through donation. We also acknowledge the dedication and commitment of donation specialist staff, transplant teams, community advocates and supporters. Transplantation is only possible through the donation of organs and tissues, and its life-changing benefits would not be possible without this shared commitment.

I would like to take a few minutes to outline the current operating environment for donation and transplantation in Australia and key focus areas to drive best practice and increase registration rates across the national program, including in Victoria.

Globally there will never be enough organs available to meet the demands of those needing a transplant. Australia's program is aimed at optimising all donation and transplant opportunities so more people can access a life-changing transplant. In 2008 the Australian government announced a national reform program. Key to the success of this program was the establishment in 2009 of a national coordinating organisation, the OTA; a DonateLife network, which includes an agency in each state and territory and dedicated donation specialist staff in hospitals funded by the Australian government; embedding best practice in hospitals, including routine referral at the end of life in intensive care units and emergency departments and a collaborative approach to offering organ and tissue donation to families within the hospital; and a national community education and engagement program to build support for donation and tools for measuring this performance and reporting on it. There is a clear division of government responsibilities under the national program. The Australian government through the OTA provides leadership and funding to drive, implement and monitor the national approach to donation and works in partnership with the DonateLife network. Services Australia administers the Australian Organ Donor Register on behalf of the Commonwealth Department of Health and Aged Care, who have policy responsibility for organ and tissue donation. Downstream, state and territory governments are responsible for the delivery of the donation, retrieval and transplant programs.

The implementation of the national program saw 10 years of growth from 2009 through to 2019. Donation rates had more than doubled from an average of 200 donors per year prior to 2009 to 548 donors in 2019. This resulted in the number of Australians receiving a transplant significantly increasing by over 80% from an average of 680 per year prior to 2009 to 1,444 in 2019. In 2018 Victoria reached 30.1 donors per million population, with the national program embedded in Victorian hospitals to great success. At the time, Victoria was considered in the top 10 globally for donation rates. This high level of donation activity placed pressure on the transplant services, sparking reviews into retrieval and transplantation, including a Victorian government review in 2019.

However, the COVID-19 pandemic has created significant pressures over the past three years, with impacts to the health system, the health workforce and the community. At the end of 2021 the number of organ donors and people who have received a transplant had dropped by 25% compared to 2019. While there was some recovery

last year, we remain at about 15% down from pre-COVID levels. I would like to table 'Figure 1: Deceased organ donation and transplant recipients 2000–2022', which outlines the trend information for you. The experience in Victoria is consistent with the national data picture, although we acknowledge the significant and enduring impact of COVID-19 for both your community and health systems.

Although it will take time, the focus nationally is returning donation rates to pre-pandemic activity. Beyond this, a strong end-to-end system working together across donation, retrieval and transplantation is vital to increasing the number of Australians who receive a life-saving transplant. The OTA and the clinical sector await the release of the Victorian review into donation and transplantation.

And finally, there is opportunity with the draft *National Strategy for Organ Donation, Retrieval and Transplantation* and the *National Eye and Tissue Sector Framework* being led by the Commonwealth Department of Health and Aged Care in collaboration with state and territory governments. The draft strategy sets out the high-level future direction of the Australian organ donation, retrieval and transplantation system and works in collaboration with the OTA's five-year strategy.

The OTA strategy to return donation and transplantation activity to pre-pandemic levels and to drive further improvements has three clear goals. Goal one: building support across the community. There are three objectives: (1) increase the number of Australians registered on the AODR, (2) increase awareness about organ and tissue donation, and (3) encourage family discussion. Goal two: optimising opportunities in the clinical sector. The three objectives are (1) identify donors and increase consent, (2) drive excellence in donation services, and (3) increase safe and equitable transplantation. Goal three, enhancing systems to enable quality outcomes, with three objectives: (1) continue to monitor, collect, analyse and report on national performance; (2) advance quality, safety and efficiency of the system; and (3) sustain specialist resources.

As the scope of your inquiry is on increasing the number of registered organ and tissue donors, and in the interests of time, I would like to focus today on the importance of building support for donation and the impact of registration on consent rates. If we can increase the consent rate or the number of families who say yes to donation in the hospital, we will increase the overall number of donors and ultimately the number of life-saving transplants available for transplantation. Many people do not know that to be considered for organ donation you need to die in a hospital setting, because your organs need to be functioning well to be considered for transplant.

I would now like to table figure 2, 'Australia's potential deceased organ donor population and transplantation outcomes', for your reference. The pyramid shows that only around 2% of people who die in hospital die in a way in which organ donation can be considered. Increasing the consent rate within this small pool of potential donors, which was only around 1,400 people in 2022, is critical to further growth in donation. Being a registered donor has a direct impact on families consenting to donation in the hospital. Data trends show that around 90% of families consent to donation when their family is a registered donor, 60% of families consent when their family knows they want- to be a donor and, finally, this consent rate drops to around 40% when they are not registered and the family is unaware of their wishes. Australia's national consent rate at the end of 2022 was 54%—down from 59% in 2019, largely due to the impacts of COVID-19. A consent rate of 70% would move Australia to be one of the world's leading donation countries, and critically, it would mean around 300 more transplants a year. For around 1,800 Australians currently on the organ transplant waitlist, it can be a matter of life and death. There are also 14,000 people in Australia on dialysis, and many may benefit from a kidney transplant.

Australians have the option to record their intent to donate their organs and tissue on the Australian Organ Donor Register. The AODR was established in 2002 as a national register. It is administered, as I said before, by Services Australia. Prior to this most state and territory drivers licence registries included a box to tick to indicate a person's willingness to be an organ and tissue donor. However, by 2012 all jurisdictions except South Australia had closed this registration channel. Australians can currently register on the AODR through the DonateLife website, their Medicare account, the printed registration form and, in South Australia, their drivers licence. The process for registration is simple. It takes less than a minute with your Medicare card at donatelife.gov.au or just three taps on your Medicare app. While we know from community surveys that four in five Australians support organ and tissue donation, only one in three, or 36%, of the eligible population are registered. As a result of the drivers licence system in South Australia, 72% of the adult population is registered. South Australia's consent rate in 2021 was 73%. In contrast, 23% of Victorian adults aged 16 and

over are registered on the AODR, and in 2021 the consent rate was 55%. The national performance targets are to have 50% of the eligible population on the AODR and a consent rate of 70%.

The Organ and Tissue Authority leads the national communication and engagement program in collaboration with the DonateLife network across Australia. Every year in July we hold DonateLife Week. It is our biggest national awareness initiative, encouraging Australians to register as an organ and tissue donor and tell their family they want to be a donor. DonateLife Week is delivered within a small budget and includes digital marketing activities, community events, PR and media promotion. DonateLife Week accounts for around 30% of new registrations on the AODR annually, and last year we saw around 210,000 Australians registering, of which 48,000 were Victorians.

Modelling data shows that registration needs to occur on a mass scale to make a difference, with 1 million registrations converting to approximately 11 donors. Building on success seen during DonateLife Week, investment in mass public awareness and advertising campaigns that educates the Australian public about organ and tissue donation would encourage registration and awareness at a greater scale. Additionally, making the registration process easy and direct, like ticking a box, encourages more people to register. This was demonstrated by the 87% increase in new registrations in 2021, largely due to people ticking a box to register as they were downloading their COVID-19 vaccination certificates on the Medicare app.

Just in finishing, collaboration is key to increasing donation and transplantation rates. There is no silver bullet. State and territory governments, the organ donation and transplantation sectors, eye and tissue banks, hospitals, community organisations and the public are critical partners in the national program's success. International and Australian experience has shown that a coordinated and consistent national approach across the hospital system with sustained public awareness leads to increases in donation and transplantation rates. Australia has the right foundations in place and Victoria has the right foundations in place. In Victoria, a continued focus on lifting consent rates supported by increasing the number of Victorians registered would contribute to increasing donation rates. In addition, a focus on optimising the end-to-end clinical system is required. This would build on the investment made into the national donation program to include retrieval and transplantation. Thank you, and I welcome your questions.

The CHAIR: Thank you, Lucinda, for that excellent opening statement, and again thank you to you and your team for providing a very substantial written submission to our inquiry. It has been most helpful. I will start with a few questions. I would initially like to start on some questions around your funding for the Organ and Tissue Authority. Are you able to provide an overview of the funding that you receive from the Commonwealth government?

Lucinda BARRY: As we said, we were set up in 2009, so in total the Organ and Tissue Authority's annual funding is around \$54 million, noting that around \$48 million of this is funding that we provide through grants, with the majority of that to state and territory governments for the DonateLife Network as well as organ donation hospital support funding that goes into that. So in 2022–23, Victoria, noting this inquiry, received \$9,347,559.

The CHAIR: So just to clarify, that is just over \$9 million out of \$48 million that is distributed through grants programs?

Lucinda BARRY: Yes, noting that the organ donation hospital support funding is activity based. It is a payment for jurisdictions on donation for intended donors and donors to help support the extra care required for donation to proceed.

The CHAIR: How does the Organ and Tissue Authority decide which programs to fund through the grants programs?

Lucinda BARRY: I just need to clarify which grant program we are talking about, because we have numerous.

The CHAIR: Yes, look, I am happy for you to clarify. So there is \$48 million worth of grants; over \$9 million has been allocated to Victoria. So it is about understanding how decisions are made between how much funding is allocated to each state, and then, say within that \$9 million that goes to Victoria, how decisions are made to allocate to different programs in Victoria.

Lucinda BARRY: Definitely. The funding for states and territories was originally based on population, with that split across the states and territories. We are now working towards activity-based funding, so there is a number of factors that are included in how that funding works. Taking into account the number of intended donors and donors within that state tells us the activity that the state is working at. There is also the number of hospitals and the location of the state, noting our states are quite varying and some of our bigger states have hospitals that are hours and hours away. There is a formula that is worked out underneath that for funding, and that is around their funding for the DonateLife network—and I will give you some details on Victoria's network. As I said, the ODHSF, or the organ donation hospital support funding, is purely activity based, so depending on the number of intended donors and donors within the state, they will receive money on that activity. That does change throughout jurisdictions on what they receive with that.

Just to clarify, how the jurisdictions then use that money through their DonateLife agency and their funding for their staff for the DonateLife network is normally determined by the state based on their hospitals and where their activity is occurring. Part of that funding does fund a DonateLife agency in each state and territory, which includes a DonateLife agency manager, a state medical director which is a fractional position in that state. It includes specialist nursing staff that are funded, and we also fund positions for donor family support, education, community awareness programs and data analytics through that. In Victoria in the agreement that is currently in place they are funded for 38.8 FTE for the DonateLife network

The CHAIR: Great. Regarding historical funding, I am very happy if you want to take this on notice, but it would be good to get a snapshot of funding since 2009. If you could just detail the funding that has been provided to the Organ and Tissue Authority and how that has been broken down to different states.

Lucinda BARRY: We are able to provide that.

The CHAIR: Thank you. That would be great. Just one more question regarding funding: do you have any processes in place around reporting on outcomes by state?

Lucinda BARRY: Absolutely.

The CHAIR: Yes. Are you able to talk us through those?

Lucinda BARRY: Yes. There is a key funding agreement with key performance indicators that states and territories sign up to in addition to reporting on what they are doing with staff, where staff are located and what positions are being filled, which they do on a six-monthly basis with their staff. They also need to report on activity within their jurisdiction and their hospitals. I might hand over to Mark, who does our data and all the analytics to do with that, and he can explain what reporting states need to do and what we do with that.

Mark McDONALD: Thanks, Lucinda. In terms of the actual and intended donor metrics, there is a national organ donor register that is based out of SAHMRI in South Australia. They collate the information around our intended and actual donors, and that drives the payment of organ donation hospital support funding. From a qualitative perspective, we run an audit of all deaths that occur across the DonateLife Network Hospitals, of which there are more than 90 around Australia, and that captures all of the information necessary to determine what our potential donor pool is as well as providing information such as consent rates. For each patient, we know whether they were assessed as feasible for organ donation, we know whether donation was discussed with the family and, if the family declined, what the reasons for decline were. And then we know from the patients that consent whether they progress to become an organ donor.

We also capture detailed information around our key metrics, one of which is referral to the DonateLife agency of all patients at end of life. We capture that at a hospital level, and the data is captured a month behind the actual case, so it is a fairly contemporary dataset. We capture information around who is involved in discussing donation with the family, which is another of our key metrics. The evidence overwhelmingly shows that when a family is supported by a donation specialist nurse they are more favourably looking towards donation, and so in terms of the activity from that system we can capture how many discussions are had with family and what the nature of those discussions were, and that again feeds into our resourcing models.

Lucinda BARRY: And we do provide on a monthly basis, to what we would call the biggest-volume 30 hospitals, a dashboard through the DonateLife agency in each state and territory on how their performance is tracking.

The CHAIR: Great. Changing tack a little bit, we heard from DonateLife Victoria on Monday, and they mentioned that they run their awareness and marketing campaigns based on national messaging, which I understand is provided through the Organ and Tissue Authority. Do you have any messaging that specifically is about speaking to First Nations communities, and if so, could you take us through that?

Lucinda BARRY: I will ask Brianna to talk us through, who is the National Manager of our communications program.

Brianna ELMS: Ella, would it be okay if I went back to the beginning and just told you about how the communication and engagement team works –

The CHAIR: Absolutely.

Brianna ELMS: just to be really clear about how we operate outside and within that framework that Lucinda has outlined. I have a team of 5.6 FTE that work nationally for the Organ and Tissue Authority in the communications and engagement space. Then we also have a manager over the top and me within that team too. We have that small budget, which Lucinda indicated at the beginning, and we do top-down, focused marketing and communications activities for national benefit. So we do things like: we set the strategy nationally; we develop and manage digital and brand; we look after partnerships and marketing and grants, which is maybe where your question was earlier, which I can talk about too; we look after media and public relations; and we oversee the running of community engagement, which is the majority focus of states and territories.

Locally the funding that goes to states and territories does include a small amount for communications and engagement activities, and we work collaboratively with that group of people. There are around seven of them across Australia, and the Commonwealth funds two positions in Victoria. Those two positions are community engagement and media and communications, and we consider ourselves, as a comms cohort, the DonateLife communications team. We do work much more collaboratively than the clinical program because of the sheer size of our program—it is really small.

Locally in the community engagement space what the states and territories deliver for us is they deliver local implementation of our strategy. They manage the relationships with hospitals, with transplant recipients and with donor families and build that storytelling capacity that is kind of the centrepiece of our marketing, and they do local stakeholder engagement too. So that is the picture of how we operate.

In regard to First Nations, we have a really strong strategy for the program. First Nations are an integral part of our strategy and an identified target audience group. Messaging will always change depending on who you are talking to, what you are talking to them about and what outcomes and deliverables you want to achieve. We really strongly lean in to a partnership approach in the First Nations space, and we work with organisations who are much better placed or much more local than we operate to make sure that we achieve outcomes. For the most part we do that by administering grants.

So we have a partnerships program that is a four-year budget commitment from the Commonwealth. One of those partnerships is with Tonic Health Media. Tonic Health Media are in Aboriginal-controlled health centres, and they are also in CALD GP clinics. There are a whole number of grants that we administer on an annual basis that support that cause too, and we will target messaging according to whatever sort of tactic that we are implementing on the ground. I will say that for First Nations audience groups a heavy registration drive, which you may see in a lot of our mass media activities, does not work and is not as effective. In fact really explaining that end-to-end story about health care, about donation, all the way through to the benefits of transplantation is really important. We have been working collaboratively on making sure that that messaging is effective. We certainly value evaluation as a big part of our activity too.

The CHAIR: Great. Thank you. Just a follow-up question to that: could the Organ and Tissue Authority provide a list of organisations that have received community awareness related grants like you mentioned since the OTA's inception. Is that possible?

Lucinda BARRY: Look, it is possible. When the OTA was first established, there were a significant number of grants. Some of them may have been \$1,000. So we will provide –

Cindy McLEISH: A list of 100,000, you reckon?

Lucinda BARRY: But we definitely do have records and we publish them each year with that. But, yes, we will attempt to give you the best tables that we can.

The CHAIR: That would be greatly appreciated. Thank you.

Brianna ELMS: The origins of this program that we run is community engagement, and it was based on awarding a lot of community grants into community for them to advocate on behalf of organ and tissue donation. As marketing and as audience preferences change, we have developed the program to be much more marketing focused although still making sure that we are integrating community engagement activities into that program. So what we set to achieve with grants has changed over time a little bit too.

The CHAIR: And just one last question regarding grants, do you have reporting requirements for your grant recipients?

Brianna ELMS: Yes, we do. All grants are awarded through a competitive procurement round and the guidelines are published, and in accordance with the Commonwealth guidelines they are assessed independently. They are approved by a delegate, and they are required to provide evaluation reports against the milestones outlined in their agreement.

The CHAIR: Great. Thank you. That is all from me for now. Cindy.

Cindy McLEISH: Thank you, Chair. Thank you for coming in today. Have you had to travel?

Lucinda BARRY: Two of us have travelled and two are located here.

Cindy McLEISH: Very much grateful for you coming down. I just want to have a look at some of the issues around the register itself and when you were established. You mentioned that the actual registry was established in 2002; you guys were established 2009. When the register was first put in place, I imagine that there was a whole lot of systems that had to be rolled into that. Did you lose all that data?

Mark McDONALD: We know from the numbers of registrations on the AODR, and we can see the registration numbers going back right to the inception of the national database—it is clear that there were varying numbers of registrations from state-based licensing systems that were uploaded into the central AODR database, but that did vary across jurisdictions. So we are aware that there are some states that imported, in the case of New South Wales, in the vicinity of 2 million records. However, that has varied across the states.

Cindy McLEISH: So if New South Wales was so good, how did we do?

Mark McDONALD: I cannot tell you exactly how many were uploaded. I can tell you how many we can see now, because Services Australia do curate the datasets, so some of the registrations that initially moved across may no longer be active. However, at the moment I would estimate somewhere between 300,000 and 320,000 registrations were migrated from Victorian licence-based systems into the AODR database.

Cindy McLEISH: Compared to 2 million in New South Wales?

Mark McDONALD: Yes.

Cindy McLEISH: Wow. That is really quite a stark difference, isn't it? If somebody is put down on the register at birth and they are now an adult, how do they get notified?

Mark McDONALD: You cannot join the register until you are 16 years of age.

Cindy McLEISH: I put my daughter down at birth.

Lucinda BARRY: Previously parents could register their children as an intent on the register—I am aware of that. I would need to take on notice when that actually changed, but the register as it stands now you have to be 16 or over to register. I would need to –

Cindy McLEISH: So a parent can no longer put a child on the register?

Lucinda BARRY: No. However, as we know, if faced with the decision with donation, the parent would be the person agreeing or not agreeing to donation in the hospital at that time.

Cindy McLEISH: Is there any marketing that is done to kids as they turn 16?

Lucinda BARRY: Yes. The program we have—which I will ask Brianna to talk about in more detail—there is a schools program that has been established. As well, individual states and territories contribute to what is called, normally, the PARTY program in the state, and that is targeted at 15- and 16-year-olds in states. I would need to confirm Victoria's contribution to that, because it is done through the DonateLife agency here. In South Australia every student goes to their PARTY program. They have 8,000 over two days go into a stadium, and as a part of that program they are educated around driving, drugs and alcohol, and it is scenario based. I have attended it; it is very, very well done. As a part of that, there is a scenario where unfortunately a person dies and an actual mum of a boy who became a donor talks to the stadium and talks about organ donation, and our state medical director presents to that. So they are educated about organ donation prior to getting their drivers licence.

Cindy McLEISH: So do you see a spike in registrations from young people following that? It sounds like a pretty amazing activity.

Lucinda BARRY: As I said, in South Australia they have got a registration rate of 73%.

Cindy McLEISH: And you think you could attribute that to part of it?

Lucinda BARRY: I do believe that people going—I think it is because –

Cindy McLEISH: So it is opt-out?

Lucinda BARRY: No, so they tick the box on their drivers licence. It has been in South Australia for that entire time, so it is quite a cultural—and in fact a number of Australians believe that it is still on their drivers licence, even if they are not in South Australia.

Cindy McLEISH: So other states are doing things that we are not, but what else can you call on to explain the low rates of registration in Victoria?

Lucinda BARRY: I do believe in today's society that unless it is exceptionally quick and easy for people to register, whilst they support it, they are not taking the next step to register, and we do have some research on that that we have done with some youth. I might hand over to Brianna just on that.

Brianna ELMS: Young people are a target cohort for our activities that we run in the program. In fact they are a group that is very under represented on the AODR. There is only 18% of young people across Australia registered. South Australia's registration rate in that cohort is high, and as Lucinda mentioned, that PARTY program is particularly advantageous in terms of timing because it happens at an age just before they go and get their drivers licence, so anecdotally we believe that that program then leads to an informed decision that they make when they are getting their drivers licence. It is varied across states and territories about what other activities happen. I know in Queensland, for example, DonateLife runs their own in-schools education, so they go to assemblies, they go to health classes or whatever that may be. They use their nursing cohort to do that, and often they will take recipients with them to share that kind of personal story. Essentially, I guess the problem across all of Australia in the community space is that we are asking them for behaviour change, and that is a significant marketing challenge.

The bit that we try and tackle—I guess, in marketing speak, you want to take people through a bit of a funnel. You want to start with awareness. You want to then move into interest and support—and remember that we know that publicly four out of five Australians do support donations, so in a lot of ways we are kind of already there—then we want to turn them into acquisitions, so we want them to convert. We want them to take action. We want them to talk to their family or to register, and then beyond that we want retention. We want advocacy, really, in an ideal world, which we try and do quite heavily in our space with our volunteers and the stories that we share that are just really powerful.

In 2021 we did a project with the behavioural economics unit in the Department of the Prime Minister and Cabinet in Canberra, and they did a project looking into registration rates in young people, 18 to 25, which is probably

worthwhile having a look at. It is very clear in that cohort, from that research, that there is that intention–action gap—that bit in the middle; the bit that says they support donation but they have not got around to taking action. And the main reason for that is, and this will change over time but at the moment the research is telling us, that they think that it is overly complex to register, and they just have not got around to it. This is particularly why we use messaging like ‘It only takes a minute’, ‘It’s really simple and easy’ and ‘You can save a life in less than a minute’. Those sorts of messages actually work really well for young people, and we do use them in our marketing campaigns.

Cindy McLEISH: Gary has got a supplementary question.

Gary MAAS: Yes, just on that, you talked about the ease to register as being a barrier, and then you talked about engagement with the youth cohort. Does that apply to other cohorts equally, or does that apply to other cohorts as well?

Brianna ELMS: Yes, it does. That intention–action challenge is the biggest sort of challenge that we face as marketing professionals. It is easy to register in that it does take less than a minute. You do need to have your Medicare card, so that is an extra step—if you do not have it with you, you cannot do it immediately. You might need more information, and that takes you back to the awareness area of finding out more about organ and tissue donation. But I guess with our marketing activities we know that we will never necessarily achieve a registration with one impression about us or about organ and tissue donation—it will take multiple impressions to build that story in someone’s mind—and that every impression about us as DonateLife or about organ and tissue donation does matter and does count.

Gary MAAS: Thank you.

Cindy McLEISH: I am all good too. Thanks, Ella.

The CHAIR: Great. Thank you, Cindy. Gary, would you like to continue?

Gary MAAS: Oh, excellent. Yes. Thank you. And I will also throw in at this time: thank you very much for making the effort to be here today and for your very comprehensive submission as well. It is greatly appreciated by the Committee.

I will keep going down this line of barriers to people registering. You have already identified ease to register, complexity and the like. What is your view on this notion of trust, of people trusting a system, particularly with cybersecurity breaches and the like—not to plant ideas in your head or lead you in any way with this evidence? What about this notion of trust as a barrier?

Lucinda BARRY: I personally believe it is really important that people have trust in the health system. I am very happy if anyone can also give us a survey that tells us where people’s trust is at the moment, particularly following COVID and, I think, the pressures on the health system and the delays in the system. We do have feedback through having done five waves of a donor family study, which is where we have had over 1400 families since 2013 give feedback about their experience with donation. Some of the quotes and feedback in that are that quite often that if the system is not working well—that is, there is a delay even in the ambulance or the ambulance getting to them—by the time they get to the hospital, their trust in the health system is not that great. They can be quite upset with that, and I think we would all understand that. Look, I think it is really important that that trust is established. The Organ and Tissue Authority—we do see ourselves as basically the centre of truth to try and build that trust. I also think myth busting, because—I am leading down another path, but we do know that some people have indicated in –

Gary MAAS: Is that like a fake news kind of thing, is it?

Lucinda BARRY: Yes. But particularly, as we know, organ donation can be quite complex and there can be a number of myths around it—that is, ‘If I am a donor, the medical staff are not going to try and save me.’ That is absolutely not true, because donation is not even considered until it is determined that somebody is not going to survive. However, that indicates that there can be some distrust there. So we try and do that as well through our community education and awareness program to have, you know, a myth-busting Monday where we try and push this out to say that these are myths. I think it goes down to making sure that families, when they are approached about donation—noting that that is very few families, really, out of the number of people that die in

Australia—do have trust in the system. I think since 2009 through the DonateLife network and having specialist donation staff and in particular nurses being able to be supernumerary and have that time with families and answer all of their questions—because many families have a lot of questions about it; they may support donation but not really understand what that is—has been critical to building the trust in the donation system within a hospital. That is the feedback we get from having specialist staff in the hospital at that point in time, where people do have to make that decision about donation.

Gary MAAS: Thank you. You also said something about the notion of culture and history playing a role. And look, I have been around long enough to put the sticker on the back of my licence, and I remember the tremendous conversations I had with my family at that time, which to me, looking back on it as an old man, is the value, actually—the conversation that is had.

Lucinda BARRY: Absolutely.

Gary MAAS: Given that we have so many new communities, you know, since the glory days of the 1980s, and if a recommendation came out of this Committee that licensing would be something—how are we connecting with those communities?

Brianna ELMS: The first thing, I guess, to say here is that our budget that we spend on communications and engagement out of the OTA is around \$2 million. Of that \$2 million, around \$1.6 million is awarded into grants—so those partnerships that I mentioned as well as the community grants. That does not leave a lot of money to spend on promotional activities. I think that we have done an amazing job of optimising the reach that we can achieve through the scope of spend that we have in terms of being able to reach them. We can always do more, we can always do better. I think, like First Nations and youth, the third focus area for us in terms of strategic audiences are our culturally and linguistically diverse communities. We have a similar strategy in terms of how we reach them; it is, for the most part, a partnership strategy. I would say that if we were to move to any change, like the implementation of a drivers licence system, it would require some mass awareness activity to lift that awareness in those communities. So an investment would be required to make sure that we are delivering targeted messaging that is nuanced for them. That would be a piece of a bigger sort of mass campaign that would be needed.

Gary MAAS: Thank you. My last question is just around all the different stakeholders in this. We obviously have the donor, we have the recipient, and I guess the intermediary in there is the hospital. Is there any work that is being done with the sort of role that hospitals could play in terms of trying to increase registration of donors?

Brianna ELMS: We have this really unique subject area in that it is so story rich. In fact the stories that we are able to tell—those personal stories about donation and about that life-saving gift of transplantation—are the stuff that resonates well. It does not matter how old you are or where you are from, if you see someone that looks like you or is in a similar circumstance in life that has gone through this experience, there is nothing more powerful in terms of being able to convince people to register or to talk about donation.

Hospitals play a really important part for us in the communications space, because we do not have that governance over the transplant sector, so we are reliant on transplant units and hospitals to make sure that we get really good access to those amazing transplant stories. We will often use transplant stories and those success stories, I guess, for lack of a better word, in the media. We do work closely. We absolutely have advocacy as a backbone of all of our campaign work, and we try and extend the reach as best we possibly can or encourage support of DonateLife Week and other activities that we do throughout lots of different sectors, including hospitals.

Gary MAAS: Is there any direct link with the hospitals with those programs?

Brianna ELMS: For transplant?

Gary MAAS: Yes.

Brianna ELMS: Hospitals will run their own transplant communications activities, but luckily for us we do tend to have working relationships. So if they are doing that, we will know about them through transplant surgeons, who will know about them.

Gary MAAS: So the messaging is consistent?

Brianna ELMS: Yes.

Gary MAAS: Yes.

Brianna ELMS: And that is a really important part of our program. You asked before about trust; trust in our brand representing organ and tissue donation is really important. If someone has had a good experience with our brand or with organ and tissue donation and they have heard about it before they go into hospital, they are much more likely, obviously, to say yes, so that is one of the metrics we measure.

Gary MAAS: Thank you. I have no further questions. Thanks, Chair.

The CHAIR: Thanks, Gary. Annabelle.

Annabelle CLEELAND: Thank you. In the past few years, how many state or federal inquiries have you contributed to into organ and tissue donation?

Lucinda BARRY: Would you like me to outline which ones? I can run through them. Particularly I have been in my position now for five years, so during that time the Organ and Tissue Authority has contributed to the EY review into retrieval and transplantation, which was 2018–19, which I mentioned was on the back of the increased—doubling of—donation rates in Australia. We have also contributed to the PwC review into tissue donation. And we have just presented to the parliamentary inquiry in Western Australia, as they are doing one as well. The Organ and Tissue Authority did provide input, not through me but through one member of our staff, into the Victorian review into retrieval and transplantation that was done in 2018–19.

Annabelle CLEELAND: And of any of these government-led inquiries and investigations, have you not received the report from them?

Lucinda BARRY: The Victorian retrieval and transplant review has not been shared with the Organ and Tissue Authority. I think it may have been shared with one member, who was asked to sign a confidentiality agreement, so it was not able to be shared with me as the leader of the authority. And that person is no longer with the Organ and Tissue Authority.

Annabelle CLEELAND: Would you like to see that report?

Lucinda BARRY: Absolutely. We have requested to see that report, as has DonateLife Victoria, but we have not been able to see it as yet.

Annabelle CLEELAND: And what was your contribution to that review? What was the level of inquiry? I am just wondering: why do you believe it would not be released publicly?

Lucinda BARRY: I literally have not seen any of it. Did we provide any data, Mark?

Mark McDONALD: Loads of data into it, yes.

Lucinda BARRY: And Helen –

Helen OPDAM: I was interviewed.

Lucinda BARRY: who is our National Medical Director, will be able to give you a little bit more information.

Helen OPDAM: Only to say I was interviewed and provided information—but yes, we of course have not seen the report.

Annabelle CLEELAND: Okay. Strange. We just heard earlier this week about a reduction in donor coordinators in Victoria.

The CHAIR: Sorry, just to clarify, I do not believe we heard about a reduction in the nurses. I believe we heard that some nurses have been increased in metropolitan sites. I do not believe it was a statewide reduction.

Annabelle CLEELAND: Can we check? I thought he said there were four donor specialist nurse reductions in regional Vic.

Cindy McLEISH: We will clarify.

The CHAIR: Yes, we can clarify that.

Annabelle CLEELAND: We might clarify this.

Lucinda BARRY: Okay. I can confirm that the Organ and Tissue Authority's funding for donation specialist staff has been maintained. So yes, I am interested to clarify what that statement actually was as well from Victoria.

Annabelle CLEELAND: Okay. So on the number of donor coordinators in Victoria, are you aware that that has been maintained over the last few years?

Lucinda BARRY: We fund the funding for the FTE for the donor coordinators, but it is the state that determines where they are and what level of positions there are with that. I am unaware that there has been a reduction in the number of nurses. It may well be that they have reallocated where nursing staff are, based on volume within the state.

The CHAIR: That is my recollection of the evidence—that there was a reallocation of nursing staffing.

Annabelle CLEELAND: I thought he said it was activity based. I said, 'Does that mean there was an increase in metro areas?', and he said, 'No, there wasn't.' We will check the Hansard.

I might have some supplementary questions on notice if that is okay, just based on the evidence.

Lucinda BARRY: Yes. What the Organ and Tissue Authority can provide is the funding that goes in, but any further discussions around where the staff have been allocated would need to go back to DonateLife Victoria—to Tony Holland.

Annabelle CLEELAND: Okay. My questions are random because I am kind of following up from other things, so just bear with me. There is no order to this. Of the 1800 people on the current waitlist, do we know how many are First Nations people?

Lucinda BARRY: The waitlist is not –

Annabelle CLEELAND: The transplant waitlist, pardon me.

Lucinda BARRY: The transplant waitlist is not held by the Organ and Tissue Authority, so I would have to seek further information about the breakdown on the waitlist.

Annabelle CLEELAND: Who would be responsible for that?

Helen OPDAM: I think that information would possibly be available from ANZDATA. There is publicly available information, but there could be an inquiry through to the Australia and New Zealand Dialysis and Transplant Registry, which is run out of South Australia. There are publicly shared reports and breakdowns. I am not sure if they break down waiting list candidates by cultural background, but they may collect that information, and you could inquire.

Mark McDONALD: The historical reports certainly do, so I think they would be able to.

Annabelle CLEELAND: Okay. I guess my questions are around the percentage of people on the waitlist but also the donor registration of First Nations as well. If there is any gap there that needs investment in awareness to ensure that available donors would be—I am interested in that space, not that you can answer!

Lucinda BARRY: One area that we can talk about—and I might ask Bri, who is on the committee, to talk further about it—is how we are working with our network, as we do, particularly around communications. The Northern Territory DonateLife agency is leading a group, which is the First Nations engagement group, looking into how we can better engage with First Nations people. A lot of the work that they do in the Northern

Territory, as you would imagine, is working with Aboriginal and Torres Strait Islander communities, and there are engagement processes with that. But we do know that registration has been lower for Aboriginal and Torres Strait Islander Australians.

Annabelle CLEELAND: Okay. Now, I know this is also not necessarily your responsibility, but I will ask it anyway. When we looked at the transfer of the licence-based system to the AODR, we saw that sort of really significant reduction in Victoria's transfer of data. How did that occur? Who was responsible for that exactly? Was it quite manual?

Lucinda BARRY: I think that you would need to refer that to the Victorian government around how they chose—it was their drivers licence registry owned by Victoria—who was transferred and who was not transferred in on that. So I really think that that would be best placed to go to them.

Annabelle CLEELAND: I could be giving you a lot of questions about your responsibilities. So continuing on –

Lucinda BARRY: No, no, we are more than happy to answer what we can or hopefully direct you to where you can get your answers.

Annabelle CLEELAND: With the information from Cindy around the paediatric consent for parents and donor registration, when did that occur? And who was responsible for that decision? And was it a legislative reason or was it –

Lucinda BARRY: I will have to take that on notice.

Annabelle CLEELAND: And my supplement to that question on notice would be whether families were notified of that change. As an example with Cindy, her daughter—was her family notified that her daughter, who assumed she was on the register, is no longer on that register?

Lucinda BARRY: That would need to be directed to Services Australia, who have the register. That question—I am just trying to work out the process, whether we reach out to them, or it might be best to contact Services Australia and ask your questions around that transfer and the paediatric side of it.

Annabelle CLEELAND: That is okay. Thank you. I was looking at the launch in 2009 and your contribution to WA. You have been extensively questioned, so I appreciate all your time. I really appreciate your time. In 2009 when DonateLife launched, there was a target of I think 10 or 11% with the goal to increase donor registration thereabouts. Have you ever been able to achieve that target?

Lucinda BARRY: Yes. The KPI for us has been a 10% increase on the number of new registrations from the year before. I am just going to go straight off to start with—in 2021 we achieved that goal.

Brianna ELMS: Yes, there has been a steady growth in new registrations to the AODR. There has not been a big investment in mass media in the last 10 years, so that growth has been slow. We saw about a 2 or 3% increase, and in 2021, which was a bit of an abnormally good year for a lot of reasons, we saw a 5% growth in registrations.

Annabelle CLEELAND: And with that percentage increase, how much was that around conversations had with family who were not able to because of the COVID pandemic regulations, where the interaction with family was not there?

Brianna ELMS: There was a number of factors that happened. So firstly, the campaign, because of COVID, was very digitally focused, so we were able to probably scale it up a little bit more than previous years where community engagement was the focus of DonateLife Week. So we did see impact from mass awareness activities that we did into targeted cohorts. In addition to that, our campaign was fully informed by that research piece that we did with the behavioural economics unit, and our primary audience in that campaign was youth.

Another reason was we had developed a 30-minute documentary with WIN TV. It aired in the lead-up to DonateLife Week, and we were really fortunate to be able to secure community service announcement spots. I think we got more than 6000 ads running across the month of June 2021, noting that DonateLife Week is from July. So we had some really good saturation that we had not had for a very long time about organ and tissue

donation on the TV and saw an impact there too. So we had a really good lead-in, and we were trying something different because we were almost forced to because of the COVID restrictions in community and making sure that we were keeping people safe. And in addition to that, sort of the trifecta on top of that is the sheer volume of people that had to access their Medicare app, download their Medicare app, because they needed their vaccination certificates, and front and centre on that app, as simple as one, two, three, is registering as an organ and tissue donor.

Annabelle CLEELAND: Just two more questions—I am conscious of time—if possible. With the COVID pandemic hospital regulations, what impact did that have on organ donors?

Lucinda BARRY: Helen is also an intensivist at the Austin Hospital as well as our National Medical Director. She has experienced that firsthand, so I am going to ask Helen.

Helen OPDAM: Clearly you have understood, listening to everyone's evidence, that donation and transplantation are very complex health activities, and I think everyone is aware of the impact COVID has had generally on the health system. So it is no surprise donation and transplantation have been impacted. I think we would say consent rates have been impacted, whether that is through just some general sort of sentiment in the community that has led to a bit of a lack of generosity. But I think also particularly of the experience of families whose loved ones became potential donors during the heart of the pandemic, when families could not attend the hospitals and go through the end-of-life journey with their family member because of visitor restrictions. I mean, having a chance to build rapport with families, explain that survival of their family member is not possible and then at an appropriate time move on to raising the possibility of donation—without that direct relationship and trying to raise it over the telephone or a video teleconference, or if people were able to visit in person it was one or two family members and everyone was decked out in masks and PPE, clearly I think that impacted consent rates.

Annabelle CLEELAND: Sorry, my supplement to that is: would you have data on the number of deaths and how that compared to the number of donors out of the hospital during the pandemic?

Helen OPDAM: We collect all of that information through our audit of people dying in hospitals, which Mark was talking about, so we have quite detailed information. We are always trying to understand where there are missed opportunities or opportunities to adjust our clinical practice within hospitals to try to optimise donor identification and the way we care for families and communicate with families around the opportunity for donation.

I think the other big impact that COVID had on donation and transplantation was that there were a lot of unknowns, particularly early on in the pandemic, in terms of the risk to people who would need to come into hospital in order to receive a transplant and through that process receive very heavy immunosuppressive drugs and their risk of exposure to COVID. In fact early on in the pandemic that led to transplant units suspending activity, particularly kidney transplant units. The living donation kidney programs suspended activity for a period of time and I think then for a long time afterwards were more selective in terms of the decision to proceed. I think you have heard previously from others, perhaps from John Whitlam and Bob Jones, some of the complexity in deciding whether to proceed in transplanting a less than ideal organ. When you start putting in the factors of the added risk to individuals of becoming exposed to COVID, it led to, I think, a dampening down of that decision to proceed in those more marginal opportunities.

Annabelle CLEELAND: We have received information on the 1800 people on the organ transplant waitlist. How many fall off that waitlist or become too old to be considered? I guess there are two tiers to that that I am quite interested to know: how many people will die waiting for an organ, and how many people would fall off that list because their health deteriorates? Would you be able to provide that information?

Helen OPDAM: Yes, that information is collected. I think the thing that is really just sort of obvious, though, is the reduced number of donors. The terms are not ideal, but with an extended criteria donor, maybe their organs are not perfect and you need to be more selective into whom you transplant the organs. If there is a decision not to proceed with that donation, you never get those organs back again. There is someone who does not receive a transplant. And the reduction in the number of donors and the reduction in the number of people receiving transplants—that is just people who have missed out forever. The number of people active on the waitlist is fluctuant; there are new people coming onto it all of the time. There is some degree of artificial

control to that. There is no point waitlisting thousands and thousands of people who will never get a chance to receive an organ, because it is a lot of work to waitlist people, and you do not want to build up false expectation.

I think you are going to interview Beatriz Domínguez-Gil, from Spain. These systems need to gear up gradually. There are many interdependencies, and in order to continue to grow donation and transplantation, you continually need to work on all the limitations in the system and expand practice. That is what they have done more than any other country in the world—Spain. They proceed with much older donors than what we do. In Spain, for example, 57% of their donors are aged over 60; 28% are aged over 70. In Australia only 30% of our donors are aged over 60.

Annabelle CLEELAND: Why?

Helen OPDAM: Because there is more selectivity here, and there are also capacity issues, and there is some lack of technology, such as the machine perfusion that provides the added assurance and information to transplanters to know it is safe to proceed with transplanting, for example, these older kidneys into a person who is suitable. All of this takes time to build and grow. Spain is ahead of us; they started earlier. We have, I think, potential. We doubled our deceased donor number. We could get back to where we were pre pandemic and then continue to grow, but it does require investment. I think a lot of the recommendations that came out of the Ernst & Young review were targeted at those retrieval and transplantation limitations in the system, and it is those sorts of things that need to be implemented which fall under a draft national strategy that is being developed and yet has not been agreed, nor a clear plan regarding its implementation. It is moving forward with those things that is necessary if we are going to continue to grow donation and transplantation.

Annabelle CLEELAND: Thank you.

The CHAIR: Chris.

Chris CREWITHER: Thank you. I will try to keep my questions short, given we –

The CHAIR: We have got a few extra minutes at the end.

Chris CREWITHER: Well, firstly, thank you for your comprehensive submission and for all four of you giving evidence here today. It is good to see you again, Ms Barry—at both the federal parliamentary level and the state parliamentary level. I just want to ask, firstly: previous witnesses and those who have given evidence have said that—well, Alfred Health in particular have said that—there potentially could be two levels of registration and that while talking about the need for, I guess, a more simple registration system, there is also the need for a more complex system at the same time, and perhaps that there could be a simple registration to start with followed by a more complex follow-up registration. They refer to things like advance care directives. In particular Alfred Health talk about the need to do so to try and override family members who might not give assent to a person's wish to be an organ donor. What are your views on that simple versus complex registration system and perhaps having two tiers and a follow-up after a simple registration and so on?

Lucinda BARRY: As we have talked about before, as soon as it becomes complex, people do not register, so we have tried to keep our strategy at a national level and down to the states very simple, with the call to action to register and talk to your family. I think as well, as the data shows us, if we have somebody who is registered, nine in 10 times the family will say yes to donation. That is the trend of 90%. I will acknowledge that last year that was closer to eight in 10 families with consent, and we do know that even if they have only just had the conversation, 60% of families will still say yes. I think advance care directives are fantastic. We have talked to GPs about making sure that they are doing that. One of our partners with Tonic Health Media sent out packs to 7000 GP clinics to educate GPs a little bit more about organ donation, because quite often it is the GP that is doing that document around the advance care directive. But also we have to remember that quite often if it is a will or an advance care directive, sometimes that is not accessed within the time frame in the intensive care as we are trying to do that. I think the more we can, as we talked about, have a mass-registration channel combined with a very significant community campaign, we would lift that discussion with people, which is important—having that discussion with their family—because we do know the majority of families will say yes if they know what you want.

Chris CREWITHER: After a simple registration, though, is there an opportunity for a follow-up—for a person who has registered to then get, say, a survey that they fill out and go through that then can be read as a more complex directive to assist in overriding family not giving assent and so on?

Lucinda BARRY: At the moment when you do register, Services Australia will come back with a form for you to fill out where you can actually fill out what you would like to donate and what you may not want to donate, and that is checked—the register is checked at that detail in the hospital. But ultimately in Australia, families will always be the key to the conversation. Helen can probably say this, but I have got a background working in emergency and major trauma. I can tell you that no medical or nursing staff will walk off with a patient out of ICU with a family behind them saying, ‘You can’t do this.’ So we need to go back to that step, and it does not matter what consent system there is, even in countries that have opt-out, it is soft opt-out. Families can still object to donation, and it will not proceed. The key to remember is families will always be involved, and it is better to take families on that journey, but what we do know is if the family knows or the person is registered, in the majority of times families say yes.

Chris CREWITHER: Is there a potential mechanism for autonotification of family members, say, in the registration or post-registration phase, where a person might enter their family members’ email address or addresses or next of kin contact details and so on? Is that a system that is currently in place or could be implemented?

Brianna ELMS: I can take that.

Lucinda BARRY: Thanks, Bri.

Brianna ELMS: Because Services Australia administer the AODR, they are responsible for the sending out of information post registration. So people do get a donor registration card in the mail. ‘Is there opportunity?’—I think that is probably a question best directed at Services Australia. I do know that if someone is not registered, they get a letter into their MyGov inbox every five years reminding them of the importance, and that is just one of those activities that they do. On our registration channel, the donatelifegov.au website, which is connected to the AODR, we do provide a thankyou and acknowledgement and next steps, although it is not as formal as you are suggesting.

Chris CREWITHER: Do you think there should be an ability for parents to place their kids on the register or for kids to put their own names down, with parental knowledge, below the age of 16?

Helen OPDAM: One of the challenges I think sitting behind some of the questions is: how big a problem are some of these things and what is the cost of implementing some of these potential strategies to address it? I think being able to have children register would be really great, because I think it normalises both for adults and children the ability for people to express a willingness to donation. But in practice, if a child dies and can be a potential donor, the family will always be approached. There is not a requirement for someone to be registered for that to be offered and explored. So whether in any particular instance it is actually going to make a difference, I think the inclusion of children is just a good part of a general approach to allowing everyone to express a positive view about donation. But practically I am not sure if it would particularly change things.

Chris CREWITHER: We have got statistics showing, for example, a 23% registration rate in Victoria versus, say, 72% in South Australia. Do we have a breakdown within Victoria as well by area and reasons it is higher or lower in particular areas—say, in Bendigo or Mornington or elsewhere?

Lucinda BARRY: I might throw to Mark. You are talking postcode data, really, on the register?

Chris CREWITHER: Yes, SA1 data, postcode data or area.

Mark McDONALD: Postcode is captured as part of the registration process, so obviously you can roll that to SA1 –

Chris CREWITHER: Or LGA as well.

Mark McDONALD: or LGA. And yes, we do see some variation from some LGAs to the other. When you look at some of the socio-economic demographics that play out in those LGAs, then we do see lower rates of

registration, and we also see that in terms of lower consent for donation when the opportunity exists in the hospital environment.

Chris CREWOTHER: Thank you. You talked about the involvement of donation specialist nurses to increase consent. Can you elaborate on that a bit more and what you think the Victorian government in particular needs to do to assist in that regard?

Helen OPDAM: It is a key focus of the clinical program and our best practices that we want to see delivered in hospitals. Currently we know that if a nurse is involved along with the treating doctor in communicating with families at end of life about donation, six out of 10 families agree. If there is no nurse involved, then only two out of 10 agree. We think it is good practice, because having a donation specialist nurse who is able to answer any questions that families have about donation in a way that would not be possible without someone with that detailed knowledge present leads families to be more informed and view donation more favourably, leading to those higher consent rates. We measure the presence of nurses in our DonateLife audit. We feed it back to hospitals. We actively work using our DonateLife staff to embed practices to ensure through that early routine referral that nurses have the opportunity to attend. In 2021 on 77% of occasions where there were discussions with families about donation, nurses were involved. In 2022 that was up to 80%. We are seeking to grow that. Sometimes it is just not possible to get a nurse there in a regional or remote hospital or according to the time of day or the weekend. Sometimes families raise donation and sometimes treating staff do, which is a practice we do not encourage.

Chris CREWOTHER: Yes. One more question, if that is okay, Chair. I am just asking all the witnesses this question: what is your view of an opt-out system in Victoria and/or Australia?

Helen OPDAM: I can speak to that.

Lucinda BARRY: I will just start off. As you are aware, we are an opt-in system in Australia, and any change to that consent system is actually a government decision and not the OTA's decision. Just to clarify, no matter which system it is, families are still critical in the discussion and around consent for donation, because in basically every country in the world, even if they have opt-out, if a family objects donation will not proceed.

Helen OPDAM: I think people who support donation often think it is a quick fix, and there is this idea, which is not true, that if you had opt-out, it would just mean everyone would be a donor. That is not how it works practically anywhere in the world that has opt-out. People have looked at the data of the countries with it and countries that have moved to opt-out, and it is really not clear. I know we have got limited time, but we could share a lot more detail about that. Spain, for example, is notionally opt-out, but it actually functions like an opt-in system. There is no register for people to opt-out of, and I am sure if you ask Beatriz Domínguez-Gil, she will say it is not really relevant to their high rates at all.

Chris CREWOTHER: Yes. I am sure that is something that perhaps you could share. If you wanted to share further information, that could be passed on after the hearing as well.

Lucinda BARRY: And I think in particular we are closely working with our colleagues in the United Kingdom, because of course their countries are going to opt-out—and I think their last, Northern Ireland, has just gone this month—to see what the evidence has been around consent with that. The clear message out of the UK as well has been, as I said before, there is no silver bullet. With their move to opt-out, they have had mass community engagement down to the ground because it is a legislative change. They have had a significant input into their funding, particularly to the retrieval and transplant side, and they have also had a significant education program that has gone through hospitals. With COVID, they were tracking that quite well, but as you know, they have been significantly impacted as well with COVID. Overall the UK, up until the end of 2022, had seen a 9% drop in its consent rate as well. We are working with them, and we will continue to monitor that.

Helen OPDAM: I think just a further point—people often say that Wales was the first country in the UK to move to opt-out. It has got 3 million people, and the vast majority identify as white. I think Australia is a very complex country—it is vastly multicultural, far more multicultural than the UK, in terms of the breadth of our demographics. We have got some survey information. I think people from culturally diverse backgrounds and non-English-language-speaking backgrounds, as a first language, are less supportive of the idea of opt-out. I think we would need to think carefully as a country or a state towards moving to opt-out, because I think there would be some risk. For example, people thought that just changing the legislation per se would have a positive

effect—it could have a backlash, a negative effect. The concern out there—the myth—is that if it is opt-out, people are just going to proceed with donation and not listen to the family. Of course that does not happen, but any change to opt-out would need a lot of investment in terms of appropriate community messaging. In Australia that would be complex because of our cultural diversity.

Chris CREWITHER: Yes.

Lucinda BARRY: And if I can just clarify, the consent system, when we talk opt-in and opt-out, only relates to that potential donor pool. There are statements that say we will have thousands more donors; we will not have thousands more donors. There were only 1400 people in Australia who had the chance to become an organ donor. It only comes into play at that level.

Chris CREWITHER: Thank you.

Lucinda BARRY: Thank you.

The CHAIR: I believe we have one quick question from Annabelle, and then I have got one quick one.

Annabelle CLEELAND: We are meeting with Deaf Victoria next, and they have produced an awareness video in Auslan. One of their barriers, I understand, is that they have not been able to share this with you or the OTA website. Have you been able to reach hearing-impaired people through your awareness and communications?

Brianna ELMS: I would have to take that one on notice. I am not sure of the background of Deaf Australia, but I assume that they were awarded a grant in previous years.

Annabelle CLEELAND: Deaf Victoria, pardon. Sorry.

Brianna ELMS: Deaf Victoria, sorry, yes.

Annabelle CLEELAND: Yes. So they have produced it, but they are struggling to spread the awareness, and believe that they could collaborate with OTA's website.

Brianna ELMS: Yes, I encourage them to reach out.

Lucinda BARRY: It would be very good if they reached out to us.

Cindy McLEISH: It says they actually published it—you published it—in June 2018. It seems to be missing.

The CHAIR: OTA published a video on YouTube?

Brianna ELMS: Just get in touch; that is not a problem.

Annabelle CLEELAND: We will take that, yes. Thanks.

The CHAIR: Just very quickly, and I am very happy for you to take this on notice: is the OTA aware of any research being undertaken into some current barriers to registering to become a donor?

Brianna ELMS: Yes. We have got some in the market at the moment.

Lucinda BARRY: It is our research.

The CHAIR: Your own research that you have commissioned? Fantastic.

Lucinda BARRY: We have funded research nationally to look at that, definitely.

The CHAIR: Is that something you can share with the Committee when it is completed?

Brianna ELMS: Yes, once it is done—absolutely.

The CHAIR: Great. And if there is any other research that you are aware of that would be beneficial to the inquiry, the Committee would really appreciate seeing that too.

Lucinda BARRY: I will send you some links.

The CHAIR: That would be fantastic. Thank you. And just very quickly: in your view how will greater recognition for organ donors—for example, recognising an organ donor on their death certificate—help raise awareness and increase registration?

Lucinda BARRY: There are differing views on how donors should be recognised. From the Organ and Tissue Authority's national program, what we do is work directly with donor families through the DonateLife agency. We have got a family support coordinator in each state and territory that donor families are able to work with post the donation, and with that the OTA also has a program to recognise donors. We have a Thank You Day once a year for donors. We acknowledge publicly donation, and their many donor family stories are told through our community education and awareness program. But as I said, having donation recognised on death certificates is not a part of our national strategy that we have released. There are differing views from families on that, so that is probably what I would say. Individual people like to be recognised in individual ways. You just need to make sure, if that is occurring, that it is not in contradiction of the *Human Tissue Act* in privacy.

The CHAIR: Great. Thank you. Thank you very much for appearing before the Committee today and for your contribution to the inquiry. The Committee greatly appreciates the time and effort that you have taken to prepare your evidence, both your written submission and coming and presenting today. Any responses to questions taken on notice are requested within two weeks, and you will be provided with questions on notice along with the transcript. The Committee will now take a short break before the next witness. Thank you.

Witnesses withdrew.