

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Monday 19 June 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESSES

Mr Tony Holland, General Manager, and

Dr Rohit D’Costa, State Medical Director, DonateLife Victoria.

The CHAIR: Good morning. My name is Ella George, and I am the Chair of the Legislative Assembly Legal and Social Issues Committee. I declare open this public hearing of the Legislative Assembly Legal and Social Issues Committee Inquiry into Increasing the Number of Registered Organ and Tissue Donors.

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

I also acknowledge my colleagues participating today: Deputy Chair Annabelle Cleeland, the Member for Euroa; Christine Couzens, Parliamentary Secretary for First Peoples and Member for Geelong; Chris Crewther, the Member for Mornington; Gary Maas, the Member for Narre Warren South; Cindy McLeish, the Member for Eildon; and Meng Heang Tak, the Member for Clarinda.

Earlier this year the Legislative Assembly tasked the Legal and Social Issues Committee with an Inquiry into Increasing the Number of Registered Organ and Tissue Donors. The Committee will report back no later than 31 March 2024.

In calling for public submissions the Committee noted that it was particularly interested to hear from the Victorian community about the effectiveness of the current model for registering to be an organ donor or a tissue donor in Victoria, issues impacting organ and tissue donation rates in Victoria, opportunities to improve organ and tissue donation rates in Victoria and national and international models for registering to be an organ and tissue donor. The Committee has received a number of valuable submissions today, and these are all available to be viewed online on the Committee's website. On behalf of the Committee, I would like to take this opportunity to thank those who have provided a written submission, particularly the individuals and families who have bravely shared their own personal stories of organ and tissue donation.

Today is the first day of two public hearings this week, and we will hear from witnesses representing a number of Victorian and Australian organisations that work in organ and tissue donation. Today we will hear from DonateLife Victoria, Alfred Health, the Lions Eye Donation Service Melbourne, Lifeblood, the Leukaemia Foundation and researchers from La Trobe University. I thank all the witnesses for their time and interest in participating in this important inquiry.

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

Witnesses will be provided with a proof version of the transcript to check. Verified transcripts and other documents provided to the Committee during the hearing will be published on the Committee's website.

I ask that all mobile telephones please be turned to silent, and we will now commence public hearings with our first witness.

I welcome DonateLife Victoria, represented here today by Tony Holland, General Manager, and Dr Rohit D'Costa, State Medical Director. Thank you for your attendance today. I invite you to make a brief opening statement of around 5 to 10 minutes, and this will be followed by questions from Members. Thank you.

Tony HOLLAND: Good morning, and thank you very much for the invitation to speak today and for your interest in improving organ registration rates in Victoria. Before we go any further, we would like to actually formally thank donor families for their generosity in times of extreme sadness for every family and for the life-saving opportunities that come from organ donors each year.

DonateLife Victoria are the state-based network of health professionals who make organ and tissue donation possible. We have an agency team employed by Lifeblood and clinical teams based at 14 health services across the state. We work as part of a national program federally funded through the Organ and Tissue Authority. Our remit is deceased organ donation, and we work with our colleagues from the Lions Eye Donation Service and the Donor Tissue Bank of Victoria to facilitate tissue donation as well. Importantly, we also run a community engagement program to raise awareness of organ and tissue donation.

We are incredibly proud of the organ donation space and program in Victoria, and almost every year Victoria has the most organ donors of any state in Australia. There is always more that can be done, and one of the biggest opportunities that we see to save more lives is to improve registration rates so that more people can receive a life-saving transplant. Registration in Australia is recorded on the Australian Organ Donor Register owned by Services Australia or Medicare. This is where you record your intent to donate your organs—that is, heart, lungs, liver, kidneys, pancreas and intestines—and tissues, which include eyes, skin, tendons and bone.

Registration is important. The trend over the past 10 years shows that nine in 10 families say yes to organ donation when their loved one was registered and they had discussed it. This drops to four in 10 when families do not know their loved ones' intent, in Victoria. A 2020–21 survey of more than 60,000 Australians showed that 81% Australians would be somewhat or very likely to donate when they die, yet in Victoria only 23% have registered their decision to be an organ donor. This is the second-lowest rate in the country and below the national average of 36%. The reasons first for this are historical. At one point Victorians could sign up through a register managed by VicRoads when they received their drivers licence. We are not confident that these registrations were all carried over when the AODR was created in 2000. South Australia is the only state in Australia who continues to have a drivers licence system, and their registration rate is 73%. Anecdotally our communications team know that the community still associates registration with being on the licence. In fact many people in their 30s, who in Victoria have never had access to the system, will tell our team that they signed up when they got their licence. This natural association, along with evidence of the system working in South Australia, makes us believe that introducing this system is the best long-term strategy to improve registration. That is why we believe, in summary, that the best approach is (1) a drivers licence system of registration and (2) a mass communications and education campaign for the conversation, because it is also very important to have the conversation along with the registration to convey what your wishes are to your family.

Unfortunately our colleague Dr Sam Radford is unavailable today, but my colleague Dr Rohit D'Costa works as an intensive care specialist at some of Victoria's leading hospitals and also is medical director of DonateLife Victoria. Rohit has had many discussions with families about donation and is well placed to comment on the importance that prior knowledge of one's view on donation can have at end of life. Our recommendations for improving registration and family conversations are clearly outlined in our submission, but we know that there are other opportunities in this space that could also increase donation numbers. I will throw over to Rohit to continue. Thanks, Rohit.

Rohit D'COSTA: Thank you, Tony, and I thank the Committee for the opportunity to present to you today. I am going to focus on some of the more clinical matters but also return to some of the issues Tony has discussed in summary. I think it is really important to stress that organ donation is genuinely a rare opportunity in the community. There is an inverted pyramid diagram that I have presented to the Committee—it is also available on the DonateLife website—which shows that within the nation there were 170,000 deaths in 2022, half of which occurred in hospital. If we consider those 80,000 deaths that occurred in hospital, only 1400 occurred in circumstances where organ donation was medically possible. So we are really talking about a small subset of deaths where this is even considered. In most of these instances the family was approached, and from those 1300 instances last year where family was approached, 700 families consented to organ donation and 454 actual donors donated organs or tissue. The gap between the 700 and 450 is due largely to medical reasons in the workup process that meant that the 700 consented individuals could not donate. Really it is quite genuinely a rare opportunity that people can donate organs, so it is really important that we try and maximise the donor pool, and there are many ways that we can think about doing this.

Firstly, there are ways upstream of the donation conversation, and Tony has alluded to registration and some of the community activities and education processes that are going to be useful for that. Within the donation conversation itself, DonateLife has been doing a lot of work on conversation training to ensure that families are in the best possible position to make a decision that would support what their loved one would have wanted. Ideally, knowing what their loved one would have wanted is the best possible position. This is through registration but also through conversations that individuals have during life about their donation wishes. We want to encourage both to happen.

The next area we can be influential is after the actual donation conversation in the donation workup process, so making sure that logistical barriers within hospitals—again, DonateLife, together with our partners, has done a lot of work to ensure that the hospital systems are well set up to promote and support organ donation processes

wherever this is possible—and also making sure retrieval services and transplantation acceptance of donors, by that I mean medical acceptance criteria, are as broad as possible. So really it requires a whole-of-health-care investment—right from the community aspect of it to the hospital and then aftercare.

Returning back to registration and its impact on consent, Tony has already talked about how important registration is. We collect very detailed data on the consent rate within each subset of the population when we actually request donation. We have graded these in terms of difficulty, for want of a better term. The best situation is where we speak to the family and their loved one is registered and they have had a conversation, so they know what their loved one would have wanted. In those instances consent is almost always given. On the other hand, the situation which we have termed grade 4 is the situation where we speak to the family and their loved one is not registered and they cannot recall having the conversation with them about donation. Unfortunately in Victoria at the moment this is the most common scenario when we have a conversation with a loved one. On the worst possible day for them, when they are losing someone that they love dearly, making this decision is perhaps more challenging than it would be if they knew what their loved one would have wanted. So we really want to support two things—that is, getting people registered and having them have the conversation, so people know what their loved one would have wanted.

Of course we focus on how we have those conversations in that so-called grade 4 group. We know unfortunately since COVID that the consent rate in that group has gone down, and because they are the largest group the overall consent rate in Victoria has gone down, as you can see from the graphs in front of you. Prior to COVID it was about 50%—and I know we talk about COVID as an event. We are not sure what the factors were that relate to this decrease in consent, but it has been a trend that we have seen across the nation and indeed internationally.

In terms of registration there are things we are suggesting. Tony has already talked about drivers licence, but also we would suggest looking at other avenues to synergise interaction with people with government and other community services, such as seniors cards, Ambulance Victoria, proof-of-age cards and Victorian Electoral Commission enrolment—and also in concert with education programs. There may be other ways to do this through non-governmental partnerships; for example, through private health insurance or tech. A novel system used overseas in the United States was people registering through the Apple Health app—which in the United States translates to the National Donate Life Registry which is run by Donate Life America—and this has resulted in a great number of registrations in the United States.

The other specific focus that we would recommend is that on retrieval and transplant. We know that at our busiest time—and this was 2019 when we had the largest numbers of donors and transplant recipients in Victoria—it was sometimes a challenge to ensure that retrieval services were always available due to theatre availability space and retrieval team availability. This is less of a challenge as the donor numbers have reduced, but we know that it is not just about staffing but the use of novel technologies such as perfusion after retrieval. We know there is a lot of exciting work that is going on in kidney perfusion and liver perfusion. This is where organs can be retrieved and can be conditioned and assessed on systems outside the body to ensure that the transplant procedure occurs at the most opportune time.

That is all I have to say about the overall process, and we are happy to take any questions.

The CHAIR: Firstly, can I say thank you for that very informative opening statement. We will now start with questions from Committee Members. Annabelle, would you like to begin with questions?

Annabelle CLEELAND: Thank you. I guess my questions are focused a bit on funding and your goals around that distribution as well as the retrieval logistics. I just wanted to note, though, and ask why Lucinda Barry and Helen were not able to attend our inquiry?

Rohit D’COSTA: They are.

Annabelle CLEELAND: Oh, okay.

Rohit D’COSTA: So we represent DonateLife Victoria; Helen and Lucinda represent the Organ and Tissue Authority, which is a national –

Annabelle CLEELAND: So we will be seeing them.

Tony HOLLAND: So they are, I think on Friday –

Rohit D’COSTA: Friday.

Annabelle CLEELAND: Okay. Wonderful. Good. I saw their presentation at the Perth hearing, so I was keen to do some follow-up questions. So in terms of the funding arrangement, can you break down your annual funding commitments and where they come from? And I have a supplementary question.

Tony HOLLAND: Sure. All of the funding that we receive comes from the Department of Health, Victoria. From a governance perspective we are slightly different to the rest of the country. DonateLife agency staff are employed by Lifeblood, and we have got an opportunity this afternoon for Lifeblood—my executive director and I will come this afternoon. But the funding is through Lifeblood, so all of the DonateLife Victoria funding for the agency is funded through Lifeblood.

However, the funding for the hospitals—because all of our doctors and nurses are actually employed by the health services, so it is quite an unusual governance relationship. Our staff who actually are on the ground at the coalface work in the health services, which is where they need to work, obviously, because that is where donation occurs. But the majority of funding comes from the Organ and Tissue Authority—the Department of Health, effectually—through the state government and then through to Lifeblood for us, and then through to the health services for the doctors and nurses who are employed in each of the health services across Victoria. We have two types of nurses employed: we have donation specialist nurse coordinators, who work in the major metropolitan hospitals, and nurse donation specialists, who work predominantly in the regional and outer-metro hospitals. And then we have our medical donation specialists, who work in predominantly the metro area, and I think that is all metro, yes.

Annabelle CLEELAND: And annual funding—what do you receive?

Tony HOLLAND: Off the top of my head—it is a bit complicated because it goes in many different buckets, but I think it is about \$10 million a year across the system.

Annabelle CLEELAND: And that is Victorian.

Tony HOLLAND: Yes, that is Victoria only.

Annabelle CLEELAND: And with your coordinators, both metro and regionally, what is the breakdown? How many staff do you have employed in Victoria?

Tony HOLLAND: We have 34 nurses and 14 doctors.

Rohit D’COSTA: Yes.

Tony HOLLAND: Fourteen doctors. Plus our agency team, which is about 15 or 16 people, which includes comms and marketing and our senior nurses, our clinical nurse managers and our director of nursing as well as our state medical directors and myself.

Annabelle CLEELAND: With your donor coordinators, how many are based at metro hospitals and how many are based at regional hospitals?

Tony HOLLAND: Well, all of the DSNCs are in the metro area, that is 27, and there are seven in the outer metro and the regional, because the bulk of the activity happens in the big hospitals. Probably about 75 to 80% of our activity happens within the Melbourne metro area, and then 25 to 30% is in regional and out of metropolitan Melbourne.

Annabelle CLEELAND: And what regional hospitals are they based at?

Tony HOLLAND: We work in any hospital. Our staff are not employed in every hospital. We have got staff in Albury, Ballarat, Bendigo, Geelong, Northern Hospital and peninsula. I think I have got them all. Yes. They are the regional and outer-metropolitan hospitals, and obviously it is Monash, Melbourne—all the big ones. And also the Children’s is classified as an NDS hospital as well.

Annabelle CLEELAND: The donor coordinator breakdown from regional Victoria to metro, has that fluctuated in recent years?

Tony HOLLAND: Yes, it has, based on activity. I think two years ago we removed four NDS positions at four of the regional hospitals. Obviously it is a difficult decision to make those changes to staffing, but that was based on activity in those locations, because we need to put our resources where there is the greatest amount of opportunity for activity.

Annabelle CLEELAND: So does that mean four increased at metro hospitals?

Tony HOLLAND: No. There was a reduction in overall staffing. Sorry, no—actually that is not true. We have increased our total staffing. It is very difficult to get nurses in Victoria—in fact anywhere—and over the years we have struggled to keep a full roster. But for the first time in I think living history we now have a full roster of nurses, subject to maternity leave and leave opportunities. But yes, we have slightly increased our total number of people to 34. Probably three years ago we would have had about 27 or 28 people on the roster, but now we have 34.

Rohit D’COSTA: I think the locations people are based in are a little bit artificial, because people travel across the state. So a donor coordinator who was based at the Royal Melbourne, for example, might travel to regional Victoria to coordinate a case as the needs require. So there is never any impact on the actual coordination of a case. However, we acknowledge that of course having someone on site is better than not having someone on site in a particular hospital in terms of building culture and improving donation knowledge and services in general within the hospital—but never in relation to the workup of a particular donor.

Tony HOLLAND: And we actually believe that we are appropriately staffed for the roles that we need to undertake for the demand that we have in Victoria. We believe that the current staffing levels are adequate.

Annabelle CLEELAND: Just going to your graph here, the 701 consents to 454 donors—that was an eye-opener for me. What are the major barriers? And when managing the theatres and the logistics of a retrieval team, have you had to deny an organ donation because of the theatre pressures?

Rohit D’COSTA: The short answer is yes. Fortunately it is a rare occurrence, but it does occur. Most of the drop from 700 to 400-odd is due to—there are two categories. Firstly, it is someone who is worked up to be a circulatory death donor. So this is someone who is dying—and deceased donation occurs after intensive care supports, typically, are withdrawn—their heart stops, and then they are rushed to theatre to be a donor. The challenge is that this has to happen within a particular amount of time to enable the organs to still be medically viable. So if someone has intensive care supports withdrawn and then they die many, many hours later, that process of dying renders the organs unsuitable for transplant. There is a thing we call warm ischaemia. The warm ischaemia time—the longer it is, the worse it is for transplant outcomes. Typically we say two hours is a rough guide for kidneys, for example. So if someone dies outside this tight window, even though they would have wanted to be a donor and the family consents, if they unfortunately do not die within those two hours, then they cannot be a donor. That is a large proportion of that drop-off.

Another proportion is where a person in good faith has registered and wants to be a donor. Medical histories and comorbidities are getting more complex as time goes on—which is great, because there are more treatments available to people—and then some of these medical facts are only able to be determined during the workup process. For example, it might be uncovered that someone had a distant history of a cancer that might preclude donation or some other factor. So there is a proportion of individuals for whom we work this out only after consent for donation has occurred and the workup process for donation has occurred. Those are the two main categories. The smaller categories are logistics or, for example, the coroner determining that they cannot in a particular circumstance give authority for donation to proceed, but those are rare instances.

Annabelle CLEELAND: So can you explain to me, with the management of a theatre, say, at the Alfred, how many operations are planned in a day? And if there was a heart that became available, say, in Mildura, what impact to the theatre management would that have? Do you understand –

Rohit D’COSTA: Yes, I do understand what you are saying. I guess you are asking in terms of donation theatre. I would imagine the Alfred, for example, would have a number of theatres to navigate and juggle, and we do get a sense that any hospital in Victoria is going to prioritise an organ donation procedure. Although that

is not a formal arrangement, it is an understanding that works the vast majority of times. When things are more challenging and there is lots of activity within the hospital and say, for example, multiple donors, particularly at the same hospital, that does become challenging, and what happens then is we typically have to speak to families and explain this in full transparency and say that perhaps a donation procedure has to be delayed. For some families this is completely acceptable; for some families it is not. And in rare instances we do have families say, 'Well, this is not acceptable to us, this delay,' and therefore we have to, with respect, say that we are not going to support donation in this instance.

Annabelle CLEELAND: Okay. I guess I am just trying to understand. I have been researching more specific donor hospital set-ups and understanding what that would mean from an investment perspective. In Victoria we have hospitals which are business as usual, so when a donor becomes available my understanding is that you probably have multiple surgeries, and to manage that in Victoria at the moment is a logistical challenge. But how is that being navigated at the moment? Because of the waitlists around surgeries, you are not just operating on donors at the time.

Rohit D'COSTA: Probably a hospital team would be better placed to make those decisions. From our perspective we know that there is a lot of wrangling to try and work out the appropriate priority, and usually it works out. Well, always it works out. It is just a matter of whether it works out that we get a theatre space within the time that is acceptable for the family. It usually is; sometimes it is not.

There is a broader question and side to this as well, in that if we have multiple donors who are all potentially going to theatre in different hospitals on the same day, there is a rate-limiting step of the number of retrieval teams that can retrieve. For example, the perfusion technologies that I mentioned have now enabled more than one liver retrieval to occur on the same day, and therefore the retrieval team can separate the transplants. I know the Austin team is going to speak to you later in the week, and they will be able to provide more detail about this. Previously it would have been more challenging to have two liver transplants performed on the same day, just due to the length of the procedure and the availability of expert teams to actually do the procedure. Now that is more feasible.

For kidney transplantations there are multiple transplant surgeons that can do it, so we are limited sometimes by retrieval surgeon availability because we do not have a dedicated team of retrieval surgeons on call to be able to do this. They all have other roles within hospitals, so they do juggle and, I must say, in general do accommodate us and do prioritise us in terms of retrieval procedures to enable these life-saving transplants to occur. With the heart unit there is one and with the lung unit there is one unit at the Alfred, so those retrieval logistics are controlled by them. It is sometimes challenging to have two retrievals on the same day, although it is possible, particularly when this is also factored in with the number of transplant procedures, which all would occur at the Alfred. That not only relates to Victorian donors but also to interstate donors whose organs become available for transplant to Victorian recipients. But again I note that Greg Snell and the Alfred team are speaking to you later in the week and will be able to provide more detail then.

Annabelle CLEELAND: I have got more questions, but I will share around. Thank you for your time.

The CHAIR: Thanks, Annabelle. We will come back to you at the end if we have time. Christine, would you like to ask some questions?

Chris COUZENS: Yes, thank you. Thank you both for your valuable time today—we really appreciate it—and your comprehensive submission as well. You talked about possibly having AEC and ID applications and those sorts of things as part of increasing the register. Is there any work around the Aboriginal community, and if there is, what are you putting in place? You talked about the community engagement and education programs. Is there anything specific? And you could say that about the multicultural communities as well. Is there anything in place in those areas?

Rohit D'COSTA: Yes. The short answer is yes. With the First Nations communities, for example, we have got a First Nations engagement group, which is a national group of DonateLife staff within each of the jurisdictions within Australia, so we have got two representatives here in Victoria. We are working with Abstarr, which is an organisation which is helping us learn in this space. We have got quite a lot to learn, and we are open to that process. There is a lot of work we realise we need to do in that space. What the First

Nations engagement group is currently doing is trying to set up a framework which will be then rolled out with jurisdictional specificity across the country.

Chris COUZENS: So there is nothing in place now?

Tony HOLLAND: No, there are factors in place. We obviously have been working as closely as we can with, for example, Aboriginal liaison officers in each of the hospitals. In a number of circumstances I am aware of there have been smoking ceremonies and other things to accommodate cultural requirements. You talked about non-English speaking—we do the same things with people from many faith backgrounds, like Jewish, Muslim, Hindu and others, to try and facilitate involvement with their spiritual leaders and so on. Certainly we are proactive in this space.

I think the current circumstances are that about two years ago we made a concerted effort to try and engage with the right Indigenous agencies within Victoria, and we actually found it very difficult to know who to engage with. One of the things that Abstarr is going to do with us is try and find the best collaborations that we can, because we need to do this in partnership. We need to bring the right people to the table and have the right conversations. It is certainly not through lack of trying; it is just about understanding the right approach to take and the right groups to approach. So it is not that nothing has been done, it is just it is a respectful and slow process. One of the things that Abstarr has done is cultural safety awareness training for our staff. Certainly our senior staff and many of our coordinators have been through cultural safety training as well, but it is ongoing work in progress.

Chris COUZENS: So you would see your education program as building that donor list for First Nations people?

Tony HOLLAND: Yes, absolutely. We are well and truly on the journey. We probably need to do a lot more with non-English-speaking groups—it is a hard demographic because there are many more groups. With our community engagement programs we would love to get more volunteers, particularly from non-English-speaking backgrounds, to work within their communities, but we have a very small team and an incredibly tiny budget. Of course you can only do what you can do with the wood you have. We cannot be in all places for all circumstances, but we are acutely aware of the importance of trying to build collaboration relationships with the right groups within the community.

Rohit D’COSTA: And some of them have been very successful. We note, for example, this Committee is going to hear from the Islamic Council of Victoria as well as the women’s multicultural group. These are both organisations we have had partnerships with through community awareness grants. These are exciting steps in the right direction. I am sure at the same time we can always do more, and we do need to always do more. It is something that we recognise the importance of.

Chris COUZENS: And will that branch out into the regional areas?

Tony HOLLAND: Yes.

Chris COUZENS: There are the Aboriginal health organisations and there are multicultural organisations in most regions, so will that spread out into the regions?

Tony HOLLAND: Absolutely—that is the goal. But again, it is down to resourcing—how many people and dollars and opportunities we can use. We are trying to facilitate a much broader base of volunteers across the whole state, because we just do not have staff in every environment to work in local communities. And once we have a clearer understanding of the best approach to take—we know the best approach is collaborative and is consultative, and once we know who the groups are that we need to engage with, we will then put in place a process. No, it is not just Melbourne based—absolutely not.

Rohit D’COSTA: I think that is really important and a very good question. I work in a city hospital. The patients come from all across Victoria. Particularly working at a trauma hospital—all major trauma in Victoria comes to the Alfred or the Royal Melbourne. A number of our donors, whilst they occur within metropolitan hospitals, are people from the regions. The messages they have heard in their communities about donation are really, really important and powerful when it comes to actually either making a decision themselves or their families confirming or affirming a decision that they have made.

Chris COUZENS: We have heard a lot about people not disclosing their information and that that can be a difficulty in getting people to register as donors—not just in the Aboriginal community or the multicultural community but we have seen that particularly over the last couple of years. What do you see as the solution to that—if you have got one?

Tony HOLLAND: One of the things we think is a partial solution to the registration process is to avoid a two-step process. In our submission we talked about a data bridge. There needs to be an API so that when you click a link on any government website, automatically you register with Medicare. It cannot be: click a link, open up a webpage and get your Medicare card out. We lose lots and lots and lots and lots of people who want to register. We think one of the biggest problems is that it becomes a two-step process, and people with good intent do not follow through because they need another bit of information—‘I’ll come back to that,’ and of course they do not. We think that that is really imperative. You cannot build a clunky, paper-based system. It has got to be a seamless, automatic, tick the box there—‘Yes, I’ve made my decision’—and bang, it happens.

Chris COUZENS: Do you have a breakdown of data on who is actually registered? Would you know how many Aboriginal people are registered or how many people from multicultural communities? Is there a question in that that can help you identify who is registered?

Tony HOLLAND: Not in the registration process, but we certainly have some demographic data, which I could find and have sent through to you if you like.

Chris COUZENS: Yes, that would be great. Thank you.

Rohit D’COSTA: I know we have postcode data, but I am not sure about other demographics.

Chris COUZENS: So that would identify the regions, for example.

Tony HOLLAND: Yes.

Rohit D’COSTA: It would identify the regions, absolutely, yes.

Chris COUZENS: Great. Thank you.

Tony HOLLAND: No worries.

The CHAIR: Thank you, Christine. Cindy, would you like ask any questions of our witnesses.

Cindy McLEISH: Thank you. I will just ask one quick one: with the advertising campaigns—which are often pretty crucial to getting the word out, because it is not so much a word of mouth—can you measure the effectiveness of these, and what do you think have been the best ones that have been run to date? Or are there ones in other states that have been really good?

Tony HOLLAND: Obviously it is hard with things like bus advertising or billboards. It is very hard to measure efficacy for spending money on those things. It is more general awareness. We can measure click-through rates on things where there are QR codes. One of the most successful things that happened in the last couple of years is the coffee cup campaign. I think this year they are planning to distribute a million stickers across Australia to go to coffee shops so they can stick them on their cups. That has had the highest rate of click through of any program we have had. Convenience—public toilets—advertising has been reasonably effective.

We obviously measure the effectiveness of events because we have got a QR code and we actually count how many people register or check the registration and events. For example, we were at the Melbourne show. This shows you the amount of effort that goes in. How long does the Melbourne show go? Eight or nine days or thereabouts. We have two people morning and afternoon every day for the whole show, and we had less than 1000 registrations for the whole show. A lot of effort and energy goes into that. There may be others that sort of see the signs and say, ‘Well, I’ll go and do it later.’ But you cannot not do things—you need to keep doing things. We are doing something different this year. We going to do a letterbox campaign—go back to old school and see how effective that is. But we think that this will pale into insignificance when it comes to an API and automatically click rate. It is not going to be the panacea, by the way; we are not going to have a million registrations in a year. It is going to take a generation or two before there is any real change, because people do not register and then become a donor in six months, particularly if they are 18 or 19 when they are registering—

hopefully. It is going to take years, but you have got to start somewhere. It never changes if you do not do something.

Cindy McLEISH: But surely with the registrations, if your advertising campaigns are successful and you have billboards—for example, you have the Melbourne show—you should see a spike in registrations. That is not decades or generations; that should be immediate.

Tony HOLLAND: Unfortunately it is not. It does not appear to matter what we do. The year when it made the most difference—the only year when it made a difference—was when people had to check their COVID status on Medicare, and registrations went through the roof. It was still not ridiculously high, but they went through the roof, because they went onto Medicare, checked their registration, saw organ donation and registered immediately. That is what we need. We need to get them to the Medicare page. When we put a QR code on anything that we produce, it goes through to the DonateLife registration page, where you put your name, your details and your Medicare number in and then click ‘I want to register,’ and then that is transferred to Medicare. The time that it actually increased registrations across Australia, but particularly in Victoria, was when they had to check their COVID certificate on Medicare. Our registrations increased by nearly double.

Cindy McLEISH: Do you think it is a bit clunky?

Tony HOLLAND: Currently it is very clunky. If we had an automatic link, it would be much less clunky. It is very clunky now, yes.

Cindy McLEISH: How do you get that automatic link?

Tony HOLLAND: We would have to talk to some IT people, but it is not impossible. You know, there are ways of verifying security and identity automatically. It could be done. It can be done in other states, so there is no reason it cannot be done in Victoria. That is why we are suggesting that licences are the best, but there should also be other opportunities—you know, Ambulance Victoria, ID checks, rental bond boards or whatever it is. Anywhere that you need to verify your identity in a state government database should ask, ‘Would you like to be an organ donor? Yes?’, and then, bang, you are on the register. That is not clunky at all.

Rohit D’COSTA: I think part of the issue, historically, was that when AHMAC set up the register as a national register back in 2000 there was this sense that there were two levels of registration. There was consent, where someone had actually signed something on a piece of paper, and typically at that time that was people going to their Medicare office, getting a form, signing it and sending it in. That was consent. But if you did not do that and did it through a driver’s licence or some other way that was already in existence, that would be counted as intent. So still to this day the national register has two levels of registration. The implication of that potentially is that if you have consented, your family do not need to confirm that. In reality it is not practised that way. We would always ask the family. In fact if you look at any country which operates either under an opt-in or an opt-out system, with very rare exceptions, families are always asked to confirm the final decision. I think philosophically we have considered this distinction between consent and intent to be irrelevant and have now looked at ways to actually just make it easier for people to have their intent known, because I do not think what we are seeking is a standard of informed consent out there in the community. I do not think that is realistic. At the same time, we know that people want their wishes and decisions to be respected, so the best way to do that is an intent to be reflected in some way. We just need to make it very seamless.

Cindy McLEISH: Thanks, Ella.

The CHAIR: Thank you, Cindy. Gary.

Gary MAAS: Thanks, Ella. Thank you both for your attendance today, for your presentation and also for your advocacy in this space. I too want to pick up on where we were moving in terms of the how. Some of us remember the glory days of the 1980s. When you received your licence, with your licence you received this little flip pack and a little red sticker to whack on the back of your licence. What that did was spur on conversations with your family, and as an 18-year-old kid—new adult—you would have those conversations. It seemed that everybody was clear what was happening there. In Victoria, after decades, we are about to move to a digital wallet system finally with our licences. I just want to explore this ‘how’ a little bit more, and I think, Tony, you were alluding to ways that we can do that. Within a drivers licensing system—and certainly your

submission, in comparing Victoria to South Australia, shows the power of having something like that—how would you see this potentially working?

Tony HOLLAND: Something we did not put in our submission which we think is also extremely important—it covers off in the education component—is that I have actually been invited to go to South Australia in September to go to I think it is called the party program. All young people, before they get their licence, I think around the age of 16 or 17, have an event—there might be other things as well, but I am going to an event. It is something like 17,000 young people who attend this event at an oval, and they have presentations from a whole lot of people about driver safety and so on, but also about organ donation. It is education at the base level so that people are aware, and those kids go home and talk to their parents about it.

There are two parts to the registration: family-raised registered is level 1. ‘Family raised’ means there has been a conversation. We think the conversation is equally as important as the registration. The education is really important. As good as billboards and placards and all of those things are, I think it is about targeted education programs as much as we possibly can, within the constraints of the education system. It is very hard to get access within the curriculum because the curriculum is so tight, but somehow educating young people, particularly young people. Obviously there are programs for other people as well, but that is number one. Number two is that it is seamless. It has got to be easy so that when you make your decision you do it on the spot. When your registration comes, when your licence comes, when your ambulance renewal comes, when your rental bond board comes for renewal, whatever it is, ‘Have you considered being an organ donor? Click here to register.’ It has got to be that easy. Stop the two-step process, because it actually kills the registrations. I do not have the exact numbers in the top of my head, but a fraction—it is about 12% or something—of people who click through will actually register. They get stopped in that middle ground, that wilderness zone.

Gary MAAS: The important part of the process for me, reflecting on those days, was the conversations that it spurred on. Cybersecurity to one side for the moment—and I do want to go back there—how do you see these kinds of conversations taking place? As I said, I am reflecting on the glory days, but you used to have conversations with the people who ultimately will be making a decision should the worst happen. I am just struggling. The conversation is important—if we accept that as a premise—and then we know that the education that goes around that is important. Given the kind of world that we are in, I guess I am trying to tease out how we make this occur.

Tony HOLLAND: The national campaign is run through the OTAs, so every state and territory delivers the same messaging across Australia. There is a consistency across every state and territory. They have just launched their new campaign this year, and it is about taking a minute—it only takes a minute to both register and it also takes a minute to have the conversation. We very heavily promote the concept of conversation in everything we do. How you do that at mass level—I am not a communications expert, so I struggle to understand exactly how to do it. But I think if there were some way of incorporating it into some sort of transition from teenage to adulthood, in there, because I think realistically that is the core group that we want to grab if we can, because there are many, many, many, many years of growth and development that are going to come. Obviously there are other facets of the community that need to be educated as well, and we have got programs, we do go to events and we try and reach as many with a very, very tiny budget. We have a really small budget for communications and advertising. But I think if I was going to put my bang into something, it would be into young people, particularly focusing on specific areas of young people—Indigenous, non-English speaking. Target the young people but get to the young people. I think if there was going to be money spent, that would probably be where the best bang for buck would be.

Gary MAAS: The thing that occurs to me about your drivers licence—you are targeting young people at that age and, as I said before, it spurs on conversations. Our multiculturalism in this state has gone through the roof over the last few decades. Yet again, a drivers licence is a thing that tends to cut across CALD communities, Aboriginal communities and every other community. It seems to be, for me, the link between all of the groups in society, and particularly because you are speaking about a young demographic. Do you want to share your views around that perhaps?

Tony HOLLAND: Well, absolutely. That is one of the reasons we are suggesting licences. It seems to be the easiest starting point. Again, I just want to highlight, this is not the panacea. This is not the silver bullet. It is not going to change things in five minutes. But it is a really good start, and it means that we can reach young

people who often have no or virtually no understanding of organ donation at all, because it is the furthest thing in your brain when you are 18 to think about organ donation.

Gary MAAS: Well, you are invincible of course.

Tony HOLLAND: Absolutely. But also the brain is malleable and open, and there seems to be a change to the way young people think these days. They seem to be much more open and altruistic in their thinking about the world as we know it. So it is probably a good place to start, and it is just how we get the message across. I think the party program that they run in South Australia is very, very impressive.

Rohit D’COSTA: It is run in Victoria but in different ways.

Tony HOLLAND: In a different way. It is not as, I suppose, comprehensive as what they do. Obviously the numbers of children, young people, are much less, and the general geographic zones that they move across are smaller.

Rohit D’COSTA: I think, as you alluded to, it is key to leverage these opportunities. I heard an interesting statistic the other day—and I am not sure which jurisdiction it refers to, but it could be any jurisdiction—that the whole of government expenditure on health promotion is dwarfed by soft drink companies by 10 times. So soft drink companies spend 10 times as much money on advertising as the whole of government on all of health promotion expenditure. And, you know, perhaps that is as it should be, because there are different priorities for government to spend money on.

I do not think that it is possible to adequately permeate everyone that needs—well, most people need to get a drivers licence, most people need to register their car. I think there are a lot more touchpoints, and education would be part of that touchpoint, because absolutely it is key. You cannot just tell people to register. They need to know what they are registering for and what that means. So synergising those opportunities is absolutely the way to go.

Tony HOLLAND: And making it normal—I think that is the thing that will actually happen. When it becomes part of the process of registration, ambulance renewal, rental bond or whatever it is—‘Oh, okay, look’—and that will generate conversations as well. And why is it so important? Just going back to those statistics: if you are registered and you have had the conversation with your family, there is between an eight and nine out of 10 chance of you being a donor if you are able to be. If you are not registered and you have not had the conversation, it is between three and four. So it makes our team’s job so much easier as well, and it actually means that there are going to be better outcomes.

Gary MAAS: I have two more questions. Is that okay?

The CHAIR: I am just conscious of time. We have got about half an hour left, so that should be okay.

Gary MAAS: Okay. I will keep this general then. You have already made a contribution towards your views on cybersecurity. Is there anything else you would like to add to that?

Tony HOLLAND: With cybersecurity.

Gary MAAS: Yes.

Tony HOLLAND: Again, we are not experts on cybersecurity, but my understanding is this happens regularly across government departments, and we are talking from government to government here. This is not in private hands. No private organisation is going to have anything to do with this. It is a link between the Victorian state government and Medicare, so I would have thought that would have been about as secure as you could possibly get. I will leave that to the experts.

Gary MAAS: Thank you. Final question: in terms of the registrations that exist, is there any differential around organs that would be donated? Is it a blanket people say yes to organ donation and that is it, or are there actually people who might specify that they may not want to donate their corneas or something, for example?

Rohit D’COSTA: Historically and even presently you can make a nuanced direction in that way, so particularly when it was considered a consent, you could write ‘I consent to all organs and tissues except’ for

example, my heart or eyes or as the case may be. As we have made it more streamlined and tried to make it easier, the default is just you are in or out. However, there is still that opportunity for people to use the other steps where you get a form or download a form and you kind of –

Gary MAAS: Are there any stats on that?

Rohit D’COSTA: I would have to take that on notice. There may well be, but I have not got them at hand.

Gary MAAS: Okay. Thank you. No further questions, thanks, Ella.

The CHAIR: Thank you, Gary. Chris.

Chris CREWITHER: Thank you. First, thank you very much for your submission and your evidence today. I agree with your suggestion of the need for multiple and seamless avenues of registration and multiple different government touchpoints, whether it is through the VEC, seniors card, proof of age, drivers licence and so on. You note in your submission that when the VicRoads data was transferred to the Australian Organ Donor Register, AODR, the VicRoads donor register was decommissioned and now Victoria is rated at 23%. You also note that South Australia is now the only state where you can register through the driver licence system and they have a registration currently of 72%. A few questions on this: what was the Victorian registration rate when the VicRoads system was in place before 2009, if you are aware of that?

Tony HOLLAND: I think we will take that on notice. I think we can get that for you.

Chris CREWITHER: Or at least from memory, how did it compare roughly with what it is looking like now?

Tony HOLLAND: My understanding is we were still well behind.

Chris CREWITHER: Do you know why an effort was not made, like in South Australia, either at the time or since, to link the VicRoads registration system directly with the AODR?

Tony HOLLAND: The only thing I could think of would be cost.

Chris CREWITHER: And you say that linking the VicRoads system is the single thing that will make the most significant impact to registration over time, noting that 81% of Victorians support donation versus the 23% registration rate. What do you predict the growth rate might be with the implementation of a VicRoads direct link to AODR like in South Australia?

Tony HOLLAND: Well, that is –

Rohit D’COSTA: It is hard—there are a number of factors. Firstly, it will take some time. If that was the only way, when you renew your drivers licence, say, every 10 years, there is going to be a significant lag time. The second question is—and this is something that needs to be considered—whether you make it a mandated choice policy, and this is controversial whether that happens, because then you force everyone through some step. This has occurred in jurisdictions, including, for example, in New South Wales in the past. That policy was withdrawn because it was felt that people put ‘no’ without necessarily giving it adequate thought. And then in the New South Wales *Human Tissue Act*, this prohibited any—this ‘no’ was not defeasible, so no meant no, whereas in Victoria the legislation allows for some discretion in those sorts of situations. These are complicated things that need to be considered, whether you mandate it or whether you just encourage it or how much you encourage it. Undoubtedly it will increase the registration rate, but the rate of how it does that is—we do not have any solid models of prediction on that.

Tony HOLLAND: One of the things that is currently the case is we are not even keeping up with population growth. Even though we are getting sort of around 40 000 to 60,000 registrations a year, it is not even at general population growth. Every year the figure hovers the same, and what we would hope is that at least that would start to increase. What the rate of increase will be, who knows, but we want to try and go ahead rather than just barely hover.

Chris CREWETHER: Do you think that, in addition to a public awareness campaign, that direct letter writing from the government to each resident of Victoria would be helpful, or indeed for each MP across Victoria, when they do touch base with their constituents, to write about the need to register?

Tony HOLLAND: Well, it could not hurt.

Chris CREWETHER: And going onto the comments that were made before: do you think that printing on cards—whether it is a Medicare card or a drivers licence or anything else—whether you are a donor or not and a link to donations or a QR code, whether it is on a digital licence or a hard copy licence, would be a mechanism that would help to increase donations as well?

Rohit D’COSTA: I think it would, anecdotally. At hospital I have to get my flu shot. I get a nice, shiny, silver sticker to put on my hospital badge. I think everyone does that, and it kind of creates that sense of a community of people who have been vaccinated against the flu within the hospital, so it may make a difference. I am speaking purely personally and anecdotally. There is probably data on the effect of public signals.

Tony HOLLAND: One of the triggers when you do register is you do get an organ donation card sent to you in the post. That is an acknowledgement. But with the introduction of electronic licences in Victoria, there is not going to be any opportunity to put a sticker on. On the electronic licence, though, there could be a little badge or something that says ‘I’m an organ donor.’ It does not actually mean anything when it comes to end of life because it is still the same process, but again it is another thing that promotes it. So when people look at their licence it reminds them and triggers conversation potentially. So, yes, it will not hurt.

Chris CREWETHER: Yes. Last question: what is your general view on an opt-out system? And if we were to have an opt-out system, what would be the touchpoints, in your view, when you could nominate to opt out?

Rohit D’COSTA: Opt out is a very good question. I guess we have kind of been agnostic on the issue. We have looked at international data, and there have been a couple of very good recent reviews on it. They have looked at rates of organ donation and consent in opt-out countries versus opt-in countries. It is really hard to tease out the effect of actual policy versus other things such as education campaigns. For example, in Spain, which is typically thought of as an opt-out country, they had mandated sort of presumed consent. There is no register as such. You cannot opt out in Spain; there is presumed consent. Legislation was enacted in 1988, and then it took 10 years for organ donation rates to increase in Spain. That was felt to be largely due to organisation within the sector—some of things that we have already started to do through the national program in Victoria and other parts of the country. The literature suggests that there is no direct effect.

If we look at countries that have recently moved—Wales, for example, enacted legislation in 2013. It came into force in 2015 after quite a large public campaign, and in 2015 things did not change straightaway. They started to creep. More recent data suggests that when compared to England, for example—Wales is a much smaller population, so it is hard for this to reach statistical significance, but there is some signal that the Wales consent rate and organ donation rates are higher. So to answer the question, we are not sure. I think the key thing if we did consider opt out would be that it has to be associated with a significant campaign of education. It has to consider that we are a pluralist society and to reach everyone to give them a fair chance to opt out. It might be different to the kind of situation in Wales, for example. And it is not going to change things instantly.

Chris CREWETHER: Thank you.

The CHAIR: Thank you, Chris. Just a couple of questions from me and then I will hand back to Annabelle, because I think you have still got some to go. And you have got one too, Chris? Great.

We have spoken a lot today and we have heard from you a lot about the importance of family conversations and having that conversation. I reflected on my own experience of registering to be an organ donor. I did it online and I ticked all the boxes, but I do not recall seeing anything about how you should go and tell your loved ones that you have decided to become an organ donor and ‘This is the sort of conversation you might want to have with them to explain that these are your wishes, should you find yourself in that circumstance.’ I guess I am just wondering: are there resources available for registered organ donors, or is there an opportunity to look at how we can better equip organ donors or registered donors to have those conversations with their loved ones?

Rohit D’COSTA: Yes, that is an interesting point you raise. I am not sure what we have. I would have to go to our website to look at what is the latest. But that is a very good suggestion, because I think it is really important to provide some guidance about how to have these conversations. Important conversations are difficult sometimes, and it is useful to have some sort of guidance on how to have that conversation with your loved ones.

Tony HOLLAND: I agree. That is a very, very good point, and I am not aware either. I think it is something we could potentially talk to the Organ and Tissue Authority about, whether or not there could be, I do not know—we are working with Medicare here; it is a big organisation—some way of getting some sort of link to resources when people register. It might, I do not know, click them through to a site or whatever, but I think that is an excellent idea so I will definitely follow that up.

The CHAIR: Great. You mentioned conversation training earlier, which I think was with regard to your nursing staff having those conversations with families, but I was wondering if you could take us through that in a bit more detail, what that involves.

Rohit D’COSTA: Sure. We run what is called a family donation conversation program for the people having the conversation—primarily nurses but also doctors, allied health professionals and others who might be involved in the conversation. There is a two-day workshop which is run across all jurisdictions. In Victoria, for example, we hold a number of these a year where our nurses come. What is discussed are communication skills in general and then how to support families at times of intense grief. The particular focus of the conversation training is getting people to make an informed and enduring decision, recognising that these are some of the times when people have experienced a position where they feel they have lost their autonomy, they have not been able to make any decisions and their loved one is dying. Really it is an unfair thing to happen to people that their loved one is dying in an intensive care unit, typically, and there is nothing that can save them. To then have that lead to a conversation where they are able to make a proper informed decision—that is what we want to support. We say that we want them to make a decision that they would make ‘on an ordinary day’, recognising that this is of course the most extraordinary day that they have probably experienced and the saddest day that they have probably experienced in their life. So that is the focus of the training—how to actually support families and how to actually raise it respectfully and enable the family to make a meaningful decision.

Tony HOLLAND: In addition to that we also then have a half-day practical workshop, where people come and do practice. We also have web coaching for our staff on the conversation. The conversation side of the role is really very, very important, and we put a lot of energy into training our nursing staff and our medical staff to be the best that they can possibly be. So there are a lot of resources nationally put into the conversation process.

The CHAIR: Great. With regard to the graph that you have provided about the family donation conversation breakdown over the past five years with grade 1 conversations, grade 2, grade 3 and grade 4, are you able to provide a bit of a definition around what each of those grades looks like and what type of conversation is taking place there?

Rohit D’COSTA: Yes. This data comes from an analysis we did of the types of conversations and the consent rate within them. Grades 1, 2 and 3 are conversations where there is some degree of previous knowledge that the person might have wanted to be a donor. In a grade 1 category these are people that have registered and have had a conversation, typically, with their family, so the family raise donation and say, ‘Look, my loved one has registered,’ typically. So in that instance they almost always consent. There might be very rare occasions where certain circumstances mean that they say, ‘We can’t consent in these situations.’ Grade 2 is where the family raise it but the person has not registered. So they have had a conversation, but the family say, ‘Look, we know our loved one supported organ donation; they might not have registered.’ Sorry, I might be getting slightly confused: grade 2 is where they have registered—what I just described is grade 3, where they have had the conversation but have not registered. Grade 2 is where they have registered and not had a conversation. But if we kind of put them all together, there is some prior knowledge, either through registration or conversation, or both, that the person supported organ donation and would have wanted to be a donor. Grade 4 is the largest group, where the family does not know what the wishes would have been and there is no registration. So therefore the family are making a decision based on their intimate knowledge of that person, which is very legitimate of course, but it is not as good as this knowledge being supplemented with what the person would have actually wanted.

The CHAIR: Okay. Thank you. Annabelle.

Annabelle CLEELAND: Thank you. Following up from Chris's comments around the 21% average donor registration in Victoria compared to the 36% national average—I hope those figures are right—would you assume that one of the major changes to registration is that changeover from a state to a national register?

Tony HOLLAND: I think there would have been a hit at the time. We do not know exactly what the circumstances were. But if you look at the current number of registrations, they are still very low. We still have less registrations every year than New South Wales, for example; they are a slightly bigger state. This is many years ago; this is like 13 years ago when the change was made. But over the last 13 years—other than 2021, I think, when people had to check their status on Medicare, when we went close to 100,000 registrations, off the top of my head—we have averaged around 40,000 to 60,000, somewhere around there, and it has not changed much. So registrations have increased. When we got a comms team, they went up significantly, so obviously our marketing and promotions have made a difference. We need 300,000, 400,000 registrations a year to really make a difference. It has not changed pretty much over the last five years.

Annabelle CLEELAND: What is your comms and advertising budget annually?

Tony HOLLAND: \$160,000.

Annabelle CLEELAND: What were the barriers to get in the curriculum?

Tony HOLLAND: It needs to be a government-to-government approach. An independent organisation going to a government department and saying, 'We would really love to do this in schools' is nearly impossible. Getting anything into a curriculum is hard because the curriculum is so jam-packed full. Everyone wants to be in there, every cause wants to be in there, and rightly so. You want to raise awareness about driver safety and so on. So the only way it is probably going to happen is for the Department of Health to talk to the Department of Education, saying, 'We need to do something together, boys and girls.'

Annabelle CLEELAND: Documenting this with the Parliament listening, would you think that that is something you would encourage—that it get into the curriculum?

Tony HOLLAND: Absolutely, yes.

Annabelle CLEELAND: Can I just ask: of the 1900 on a waitlist nationally, I believe, what portion do you believe would die waiting for an organ?

Rohit D'COSTA: I will have to take that on notice. There is some data from, I think, 2015 on what we call the ebb and flow, because as you suggested, it is a dynamic phenomenon. People get waitlisted. Some people would actually get removed from the waitlist before they die. So I think the actual portion that die on the waitlist is small, but this does not reflect the whole picture, because some people would get too sick to be able to still qualify for receiving a transplant safely and would get delisted. That would particularly occur within the kidney list, for example, but also sometimes perhaps with the heart, lung and liver waitlists. So I would say it is small—less than 5%, I would say—but I can get an update.

Annabelle CLEELAND: I would be keen for that number, to know who has been delisted because they are no longer well enough to receive an organ, to be considered in that detail. What is the age barrier for receiving an organ? What is the benchmark where you are too old to receive an organ?

Rohit D'COSTA: The short answer is there is no official age barrier, particularly for kidneys. Again, some of the other witnesses speaking to you representing transplant units would be better able to answer this, but I can provide a broad answer. Typically for kidneys there is a life-saving benefit regardless of age to receiving a transplant versus dialysis. It is an individual decision, and a person's age, to my understanding, is not a huge barrier. With the heart, we look at people below 65, and with lungs, below 75. Again, these are broad age limits, because there would be other factors not relating to age that would rule someone in or out. To get a more detailed and nuanced answer, other witnesses from some of those transplant units would be better able to provide that.

Annabelle CLEELAND: But there is an understanding that for the heart it could be that at around 65 you are too old. Is there pressure to increase that?

Rohit D’COSTA: Again, I am not really able to answer that.

Annabelle CLEELAND: If I can ask one more, Tony, with your comms and advertising budget, what is required for a state to achieve that 300,000?

Tony HOLLAND: If we had a million dollars a year, I think we would give it a crack. I would have to do some analysis, but obviously \$160,000 is a pretty small amount of money. That is on top of, though, by the way, all of the development costs borne by the OTA. The OTA actually does all of the development of the graphics and so on, so we do not have to bear that cost. But specific Victorian spends—television advertising, for example, is quite a successful campaign in regional Victoria. I am going to go off the top of my head here. I think Ballarat or Bendigo has one of the highest rates of registration in Australia. I will be corrected if I am wrong with that. We have had a number of years of really strong television campaigns with WIN Television in those areas. Any amount of increase would be helpful, particularly if it was to accommodate or go along with a change to the process of how to register, because that is a state-specific thing. If we were able to implement a data bridge through government agencies, definitely we would need to do a fairly concerted effort. It would be more nuanced than the back of buses, I think. The idea of you all going out today and telling all of your colleagues to write to your constituents to become organ donors is a great idea. Put a QR code on it, and we will track it for you, if you like. So yes, anything is good.

The CHAIR: I just have a very quick follow-up to Annabelle’s question around funding for advertising. I understand the OTA develops the creative content that you do, but do they do any advertising in Victoria to complement your work?

Tony HOLLAND: For example, we have a partnership with the Melbourne Storm and the Western Bulldogs. That is a national partnership, because the AFL and rugby league are both national games. So that is a program that is funded directly through the OTA, that partnership program. There are also grants that the OTA provides each year, community grants, and a number of Victorian organisations have been successful in obtaining funding. That is in addition to the \$160,000 that we have spent, yes.

Rohit D’COSTA: If I may add something to that as well, the creative content is through the Organ and Tissue Authority. Our local communications agency based at DonateLife Victoria just uses all this content to promote within Victoria. There is a specific requirement within the *Human Tissue Act* that there is ministerial approval for advertising, and that sometimes can be perceived to be a barrier for us because by law in Victoria we need to seek ministerial approval for any advertising that occurs. If it is OTA advertising, that bypasses that requirement in a sense, but it is just a little bit unclear within the framework of the current legislation. That sometimes is a little bit of a challenge for us because obviously the process of seeking ministerial approval is not necessarily pragmatic for each and every piece of advertising.

The CHAIR: Thank you. Christine.

Chris COUZENS: Thank you. That has been a great discussion, and you have raised a number of areas for improvement, obviously: the licence, the advertising and the awareness campaign. In terms of resources, though, are there any other—and I do not expect you to put a dollar figure on it—key areas where further resources are required to assist in educating our community?

Rohit D’COSTA: The two things we have highlighted, I think, firstly, in terms of a broad, sweeping ability to actually register through various avenues—including the drivers licence, which we have focused on, but other ways. That would require resourcing, together with a quantum of funds for an advertising campaign. I do not think an advertising campaign by itself will work, because that will require a lot of money, and I do not think that is feasible or necessary. The other thing is resourcing, as we have discussed, within the hospitals. We are very well organised now, we think, within the donation sector, and that is through the national reform which has informed the way that the jurisdictions have collaborated with each other and have set up processes internally. Someone was remarking that it is actually a wonderful area of government, in that the states and the Commonwealth have got together and set up this program, and it has worked well, where we have some synergy in the way we operate—and necessarily so, because organ donation and transportation, while it is a Victorian thing for Victorians, there is cross-border sharing not just of knowledge, information, but also, vitally, of organs for transplant and tissues for transplant. So it is really important that we all work together. But by design, transplant units work within hospitals and they are governed by hospitals. The reach is cross border.

The world-class lung unit at the Alfred, for example, transplant people from South Australia, they transplant people from Tasmania, so it has got a broad reach. However, the system is not necessarily set up the way that we are, and I am not suggesting it is a simple matter of just organising them like us. But work needs to be looked at, to see how the benefits that we have seen in the donation sector can be leveraged within the transplantation sector to enable things like retrieval to be more seamless and to make sure that we do not ever miss a donation opportunity because a theatre spot is not available or a retrieval team is not available. These are rare instances, but really I think there is an opportunity to make them ‘never’ instances.

Chris COUZENS: Would you see community engagement as a big part of all of that? That is different to advertising, obviously. To get into those communities we spoke earlier about—Aboriginal communities, multicultural communities—would you see that as being one of the key factors?

Rohit D’COSTA: Yes, and thank you for making that distinction. You are absolutely right. It is not just about advertising. It is about actually really connecting with communities. We have come part of the way to trying to do that, but we really need to strengthen that, and some of the things we have already put in place will help do that.

Chris COUZENS: Thank you.

The CHAIR: Chris, did you have a final question?

Chris CREWITHER: I think we have run out of time, so all good.

The CHAIR: Okay, great. Thank you very much for appearing before the Committee today and for your contribution to this inquiry. I think it has been a very informative discussion this morning, and the Committee really appreciates the time and effort that you have taken to appear before us and prepare your evidence and your submission. Responses to any questions taken on notice are requested within two weeks, and you will be provided with the questions on notice along with transcripts from today. The Committee will now take a 15-minute break, and I declare this hearing adjourned.

Witnesses withdrew.