T R A N S C R I P T

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Monday 24 July 2023

MEMBERS

Ella George—Chair
Annabelle Cleeland—Deputy Chair
Chris Couzens
Chris Crewther
Gary Maas
Cindy McLeish
Meng Heang Tak

WITNESSES

Associate Professor William Silvester, Chair, Death and Organ Donation Committee,

Dr Gian Sberna, Chief Executive Officer, and

Dr Rohit D'Costa, Victorian Representative, Australian and New Zealand Intensive Care Society *(via videoconference)*.

The CHAIR: Good afternoon. We will now recommence the public hearings of the Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors. My name is Ella George, and I am the Chair of this Committee. I am joined today by Deputy Chair Annabelle Cleeland, Cindy McLeish, Chris Crewther and Meng Heang Tak.

So to our next witnesses: I welcome from the Australian and New Zealand Intensive Care Society Associate Professor Will Silvester, Chair of the Death and Organ Donation Committee; Gian Sberna, Chief Executive Officer; and we are joined online by Dr Rohit D'Costa—great to see you again. Thanks very much for joining us today.

I now invite you to make a brief 10-minute statement to the Committee, and that will be followed with questions from the Committee.

Just on the evidence given today, all evidence 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. Thank you.

William SILVESTER: Thank you very much for inviting us to come along, and we appreciate that you have found our 15-page submission useful. My original intention was not to make any additional comments right now, because I would assume that you have read our submission. However, subsequent to our written submission to the parliamentary inquiry, we have had the opportunity to meet with the Donor Tissue Bank of Victoria, because they approached us given our recommendations around that. So I wish to make the following supplementary comments, if I may.

The tissue banks of New South Wales, Queensland and WA receive rapid electronic notification of a person's death in their hospitals. This facilitates rapid assessment of electronic medical records and leads to timely discussions with next of kin so that tissues can be retrieved within an acceptable time limit. This process does not occur in Victoria, thereby missing many potential tissue donors. We recommend that the Victorian Government establish a method of electronic communication between the Department of Health and the Donor Tissue Bank of Victoria, or the DTBV, which is under the department of justice. Now, I am aware that they did bring this to your attention, but we would certainly support that contention. We would hope that there is some way around that.

We also recommend that the DTBV change its practice of only accepting tissue donation if interpreters meet with donor families face to face. Interpreters assisting with tissue donation conversations in other states conduct this by telephone. With the advent of COVID and other restrictions, the vast majority of interpreters who assist Victorian ICU doctors, which is very frequent, or organ donation staff in communication with families do this almost inevitably by telephone. To require this to be face to face is unnecessarily restrictive and obviously obstructs potential tissue donation.

Given the significant differences in practice between the tissue banks in each jurisdiction, we recommend that the DTBV proactively facilitate all tissue banks to achieve consensus amongst all tissue banks on inclusion and exclusion criteria, processing requirements, and how to maximise safe tissue donation and consequent transplantation. When we met with the DTBV on Friday, I pointed out that all tissue donation and transplantation in the UK is under one group. They have a population three times ours—of Australia—so therefore why is it we have so many different tissue banks that are all operating in a different way, even though they are all governed by the same requirements of the TGA? We do understand that there is a balance between optimising tissue availability and minimising risk and believe that much more should be done to share knowledge and understanding between the tissue banks to optimise the outcome, whether this be achieved through facilitation and support by the Australian tissue authority or through independent collaboration.

Finally, we highlight the fact that staff at the New South Wales and Queensland tissue banks travel out to the appropriate hospitals to retrieve tissues—this is both metropolitan and some regional centres—rather than expecting families to agree to their loved one's body being transported to the Coroners Court, which of course from my experience in dealing with families leads them to immediately wonder what is going on. And although you assure them that it is nothing to do with it being a coroner's case, nevertheless being transported from a hospital in Melbourne or from Bendigo or Ballarat, where I also work, is just not viewed in a positive way, and therefore they say no to tissue donation. This request is more often than not met with a 'No, he or she has been

through enough'. If the absence of this process is due to staffing resources, then we recommend that the Victorian Government increases the funding of the DTBV services in order to increase the retrieval and processing of suitable tissues. When we met with the DTBV I was certainly made aware of their resource restrictions, and I am aware that the resources available in New South Wales and Queensland are significantly greater and therefore facilitate being able to send staff out to hospitals to retrieve tissues.

I might just finally say that we are having ongoing engagement, even as of a few minutes ago, with the Donor Tissue Bank of Victoria in terms of looking at the issues about deceased and living donation. They have already heard from me and Rohit that we are very happy to support them in that, whether it be having clinicians on their steering Committee or giving other advice, because we are really all on the same team. Thank you.

The CHAIR: Thank you very much for that. We appreciate you providing those clarifying comments, and it would be wonderful if you could provide those comments in writing so that we can publish that on the Committee's website alongside your original submission.

William SILVESTER: Sure.

The CHAIR: That would be fantastic. Thank you. I will hand over to Committee Members for some questions now. Annabelle, would you like to start?

Annabelle CLEELAND: Great. Thank you. Have you presented to an inquiry of this nature before? There have been quite a few in the organ and donor tissue space in recent years. Have you presented?

William SILVESTER: No. The Victorian parliamentary inquiry I presented to previously was to do with end-of-life care and voluntary assisted dying in my capacity as a leader in advance care planning, but that was a few years ago.

Annabelle CLEELAND: Okay. I was just trying to catch up. You mentioned, obviously, your relationship with the Victorian tissue bank, and one thing that they raised when they spoke here was around the barriers, being under the department of justice. Do you see opportunities with maybe being under the Department of Health in resolving some of the barriers that you spoke about?

William SILVESTER: The only barrier that I am really referring to—because I am not a subject matter expert in their area—is the fact that there is an absence of electronic communication of a death. It currently does not occur. Whenever I speak to tissue banks interstate, they are very proud of the fact that they can—almost as soon as someone has died, whether in the ICU or in the ward there it gets typed in by the ward clerk. They get an instant communication. That then gives them time to look into the cause of death and whether there are any obstacles such as infection or cancer or whatever might be an obstacle. That gives them time to look at the electronic medical records, so then they can choose a timely moment to then contact the family and seek consent for tissue donation.

At the moment in Victoria we just do not have that, so often by the time they even hear about the death, let alone having an opportunity to look into it by making phone calls rather than looking at anything electronically, the 24-hour cut-off period is almost up. And then when you are approaching the family—so you are going to have to rush in and do whatever you do before 24 hours—really I would see it as an impediment. So whether that can only occur if they come under the health department jurisdiction or whether it can still stay under justice and have some way of sorting those electronic communications, I do not know.

Annabelle CLEELAND: Is there a model that you are looking at globally that works better, with that more electronic communication throughout the different jurisdictions?

William SILVESTER: Do you mean across different states?

Annabelle CLEELAND: Or between hospitals, between departments—everyone that is involved in organ and tissue retrieval.

William SILVESTER: Well, organ donation is quite different because of the way we become aware of people who are potential donors or will become donors. That is all done through DonateLife Victoria, for which Rohit is the medical director, as you would know from his previous presentation. But this is particularly around tissue donation. I am originally from WA, and I know that whichever hospital you go into in WA you have a

single medical record number. It is a very streamlined, easy thing to do, whereas here every hospital has its own medical records system and there is no communication between them.

Annabelle CLEELAND: I was pretty floored by your data around the organ donation rate increase versus the transplantation rates, and you have attributed it to the level of transplant surgeons. We have spoken about this with DonateLife around the logistics of managing a surgery when you have your retrieval teams leave for a day and what that looks like. What are your suggestions, other than increasing the number of surgeons? What can we do in this space to have those figures more in line?

William SILVESTER: Look, you may not want to hear it, but really it does come down to funding. Because people like Rohit and I, we are medical consultants for a week at a time where we supervise or provide oversight for any donation activity where it is not running according to plan, and we have all had experience where it is simply not possible to retrieve either any organs or particular organs because the surgeons are not available, either because they are currently doing an operation—a transplantation—or they have already done an organ retrieval. It is not because of absence of DonateLife staff or donation coordinators, it is not due to absence of theatre space, it is not due to the absence of anaesthetists; it is almost invariably due to the fact we just do not have enough transplant surgeons who also do the retrieval as well as the transplantation being available.

We might have two cases occurring in Melbourne—we might have one at Monash and one at the Austin—and we are wanting to get a retrieval team up to Bendigo Hospital, for example, and they are just simply not available because they are already flat strap, either because they are actually operating right now or they have been up all night or they might have been up for 24 hours and they just do not have that ability to provide that service. Every time a set of kidneys do not get retrieved or a liver does not get retrieved, then there is a recipient at the other end who may be dying on the transplant waiting list. So that is why even a single organ or a set of organs that are missed simply because we do not have the logistical support with surgeons or anything else has an immediate impact on potential recipients.

Annabelle CLEELAND: Are you aware of cases where an organ or tissue has not been able to be retrieved because of the –

William SILVESTER: Absence of surgeons? Absolutely.

Annabelle CLEELAND: How often would that occur?

William SILVESTER: Rohit, do you want to—you might have the stats available to you more quickly than me.

Rohit D'COSTA: Yes, I do not have the stats at hand. It does occur. It is less common since the pandemic as the donation numbers have gone down, but in our peak year there would have been a handful of instances where logistic factors—lack of surgical availability—were the limiting factor.

William SILVESTER: People who are waiting for a kidney transplant can stay on dialysis until it is available, but there are people every year in Victoria who are dying on the heart, lung and liver waiting lists. Sometimes that occurs because they have been waiting for a while, we have worked up a case, we are offering the liver, for example, to the Austin Hospital, where all the transplantation occurs, and they have said 'Yes, we are interested,' and then the case falls over because we simply cannot get surgeons to the hospital where they are waiting to be retrieved. Because you cannot get normal surgeons to do it, it is a very particular surgery to take out a whole liver and all the vessels around it, or a set of lungs, or a heart. You cannot ask anyone other than the transplant surgeons that stick them in; they are the ones who know how to take them out, because they know how much vessel to take and they know how to preserve the organ while it is going to be, as we say colloquially, 'on ice' until it gets to the other end, or to be connected up to a machine to be maintained on that machine until the other end.

So really our restriction is the availability of transplant surgeons. Some of them are surgeons who have been with us for many years, and then we have also got the registrars or the people who are getting trained up to do that, but for a certain period of time they have to be supervised as well. But really, that is a restrictive factor.

Annabelle CLEELAND: And with the technology advancements with—I cannot remember the term, but it is like, the box, prolonging the health of an organ—does that come with a particular toll on resources as well, like, do you require more staff or less staff to transport on your retrieval team?

William SILVESTER: That has actually helped. I will give you an example with livers. Now and in the past they sometimes had to turn livers down simply because if, say, they retrieved a liver at 4 o'clock in the afternoon, by the time they got it back to the Austin Hospital for a transplantation, it was going to be about midnight, and then they are going to be up all night having been up already for 12, 18, 24 hours. But now they can actually stick it onto the box that you are referring to, and they can then put it on hold, and that also gives them time to see how the liver is working, and then they can do the transplantation the next day.

Annabelle CLEELAND: Rohit.

Rohit D'COSTA: Yes, I just wanted to add to my previous response that the range of outcomes is either that the organ does not get transplanted, which is pretty uncommon, or what is more common is that there is juggling and negotiation between everyone involved to delay the organ retrieval procedure. Often this has an impact on the family who are already grieving, and sometimes it takes them to a point where they say, 'Look, we've been through so much, we can't wait any longer.' Those are the sorts of incidents where the organ donation procedure does not go ahead. Bill is completely correct about the fact that the stats will not tell how big the problem is because a lot of the time people make do. The system makes do because people are willing to be flexible and families are willing to be flexible in very difficult times.

With the organ retrieval system and the perfusion devices that we were talking about, they can help, but they also do require, particularly for the liver, for example, personnel to actually watch the graft, because a perfusionist needs to be with the graft, depending on the type of perfusion. So some of the cold perfusion for the kidneys does not require that, but the liver perfusion does. So that is also sometimes a limiting factor.

William SILVESTER: I have been involved in this since 1997 and had lots of times where, if our local teams could not retrieve, we would then offer it interstate. So you might end up having a heart or lung or liver team, including the surgeons, fly down by Learjet from Sydney. They come down—they are the ones that retrieve the organs because they have actually got the staff—and then they take them back to New South Wales, which is nice for New South Wales but a loss for Victoria. Rohit just reminded me of a case. I work in the ICU in Bendigo as well, and it was only earlier this year when we had a case where we were proceeding and then there was going to be a delay and the family finally said, 'We can't deal with this anymore.' As you can imagine, they are just emotionally distraught and exhausted and get to a point where they just cannot sustain it and they say, 'Look, sorry, we're going to pull out,' and then all those potential organs are lost.

Annabelle CLEELAND: With your close understanding about regional challenges in this area, are there any insights you want to give us in terms of some of the issues and potential resolutions to increase both organ donor registrations but also to improve the retrieval process?

William SILVESTER: I suppose in terms of talking about the limiting factor being the surgeons, it has more of an impact in the regions because they have to travel. For example, to go to Bendigo you have to get everything organised and it is two hours out and two hours back plus all the time. Whereas if it is the Austin team going to the Royal Melbourne Hospital, it is half an hour in the traffic. So that does have more of an impact.

In terms of regional, you might remember that in our submission we put in some comments. Well, the tissue donation comments already stand, but even with eye or corneal donation it is much harder for the Lions Eye bank staff to travel out regionally, so you have to work out the best bang for your buck or for your hours available. You are more likely to retrieve eyes within the metropolitan area. But I have been engaging with the Lions Eye bank, and we may well encourage the ophthalmologists up in Bendigo to retrieve eyes which can then be transported by the people called the blood bikers, who are people who volunteer their services to travel down by bike to take the eyes down to the Lions eye bank. We certainly know in New South Wales that not only do they get the ophthalmologists to do it, but they also have general surgical registrars retrieving eyes in the other hospitals, and they are either send through the written instructions or they are actually online talking them through what they need to do to retrieve those eyes. And again they can be transported back to the NSW tissue bank where they process the eyes. So there are lots of ways around this with a bit of collaboration.

Annabelle CLEELAND: I have more questions, but I have only got time for one. We heard from an advocacy group, a representation from Spain, around the review of donor age and history. Do you think that there is a space that we need to review our donor profile, I guess, or demographic background? Poorly worded, pardon, Rohit.

William SILVESTER: Do you want to comment on that, Rohit?

Rohit D'COSTA: Yes, unfortunately I did not get a chance to watch the submission from our Spanish colleagues, but I think I know what you are referring to. In Spain the demographic profile of donors is much wider, seeing that there are a number of older donors compared to the profile in Australia, and there are a couple of factors associated with that. Firstly, the effect of that is that they have sometimes more non-utilisation of grafts, so it changes some of the decision-making to after the organ has been retrieved. But it also means that Spain has one of the highest donation rates and transplantation rates in the world, so there is that trade-off. So yes, I think we do believe—and Bill, I am sure you will confirm this—that the system should always look at ways to broaden the donor pool, including broadening age acceptance criteria as well as looking at donors with potential medical comorbidities that we currently might be more conservative than Spain at pursuing and retrieving from.

William SILVESTER: We cannot really explain it, but we have noticed since the advent of COVID that in some ways the transplant units, particularly the renal transplant units, seem to have become more conservative with regard to the donors that they will accept. We have not really got an explanation for that, have we, Rohit?

Annabelle CLEELAND: Do you have statistics about that?

Rohit D'COSTA: There is some data looking at age, which I do not think is statistically different, but there is also data which OTA has perhaps shared, I am not sure, on the number of intended donors. These are donors where donation has been worked up but then does not proceed. And the number of intended donors has gone down in the pandemic relative to the number of donors as well, so that means, arguably, there is less pursuit of working up a donor case often where things are a little bit more marginal in terms of medical suitability and age criteria. But yes, it is a hard thing to actually measure. I am not sure what solid data to support that there is at the moment.

William SILVESTER: Initially there was a drop-off in kidney transplantation because they were concerned that to immunosuppress and then transplant a patient in the advent of COVID very early on when we did not know who was going to get it or where we were going to get it from might increase the risk of dying from COVID. In some ways the number of people who were waiting on dialysis had a higher incidence of mortality from COVID than the people who had been transplanted.

One of the things we have seen is that a certain proportion of patients when they have had a kidney transplant still require dialysis for a short time afterwards until the new kidney starts working. I have heard that the renal physicians have become more conservative about who they might want to transplant kidneys into because they simply do not have the dialysis chairs available to continue to dialyse someone afterwards because they have got so many other patients waiting to be on dialysis. So there is a real pressure on availability of dialysis, so therefore they think if this person is more likely to require dialysis for a period postoperatively, they are less likely to accept that kidney at that time. They will just leave those patients on dialysis.

Annabelle CLEELAND: Thank you.

The CHAIR: Thanks. Look, I would probably like to explore some of these, I guess, data or trends a little bit further in terms of decreased number of organ donations. I am just really curious. We have heard from other witnesses throughout this inquiry that there has been a decrease since COVID and there is no clear answer as to why that is, but the evidence that you have provided around being a bit more conservative about—is it correct to use the word 'quality' of the organs, or the functionality of the organs, is that accurate, would you say?

William SILVESTER: The use of that term 'quality', like, is it going to be a good organ to transplant? Yes.

The CHAIR: I do not think we have heard that yet in terms of, I suppose, transplant surgeons being more cautious in their approach. Are you able to go into that a little bit further?

William SILVESTER: I suppose you are wanting—I have not got any statistics, so –

The CHAIR: That is okay.

William SILVESTER: I suppose anecdotally, I would probably refer that to only to do with kidney donation. We are finding that—and I will be interested to see if Ro has any further comment on that—with heart, lungs and liver donation, I have not seen that they have become more conservative in what they are willing to accept. Rohit, in one set of organs, the donation or the retrieval rate actually went up during the COVID period?

Rohit D'COSTA: Yes, that is right. But you are right, kidneys are the bulk of the transplanted organs, so any trends are going to reflect, in great part, kidney donation. And kidney donation of course had to cease for very good reason during the COVID pandemic, because of the concerns about unknown risks of mortality from transmission and the risk of transmission within the hospital setting. I think there has been since then a need to reset back to normal and also continue to push boundaries. Like Bill, I do not know that we have got very solid evidence to back that up, but anecdotally that has been a barrier to overcome since the pandemic.

William SILVESTER: But I suppose we are all here talking about donation because we want to see transplantation rates go up. Keeping it in perspective, that area of a reduction, if there was one, of acceptability of organs—that pales into insignificance in terms of how to improve the transplantation rate by improving the identification of potential donors and improving the consent rate. I am sure you have heard this from others, but I just want to say that that is really where the money is. And part of the issue with consent through the COVID period has been that in the past we would always be having discussions with families face to face. Now even if we are face to face, we are doing it behind masks. For a long period of time we have not even been able to have the families in there; we are now starting to have the families in there. Even now there is restriction on the number of family members that can be there. In the past you might have been able to talk to a room of 10 relatives; now is down to only two or three because different intensive care units have restrictions on how many family members you can have in the hospital.

I am sure if any of you have tried to visit a hospital relative in hospital, you might be told, 'Well, it is you and one other person today, and it is another two the next day.' In that way, it is very restricted. And if you are trying to have a carefully nuanced, emotional discussion where you are going to be asking this family to put aside their grief in the midst of what is happening and consider and then agree to donation based on what their loved one's views would have been, that is a very hard discussion to have over the phone, particularly if they are already feeling aggrieved that not as many of them could come in when they wanted to and the hours have been restricted. I am not saying there is an antipathy, but there is not necessarily the same atmosphere in the room to be able to talk about something like donation. We think that has had an ongoing impact.

The CHAIR: Yes. That is fantastic, Bill, because you have completely pre-empted my next question, which was: from your experience how have those family conversations been going recently and how has that impacted a decrease? That is really valuable evidence for the Committee, so thank you for that. Just finally, I would like to touch on the donor registration process. Our inquiry is really focused on increasing the number of registered donors, and I understand that you provide a whole range of clinical advice, but do you ever look at strategies to increase the number of registered donors in Australia, or do you have any thoughts on how to increase the number of registered donors?

William SILVESTER: As you would have seen in our submission, ANZICS supports the contention that a drivers licence is a good way to go back to. That is how it used to be done in the past for a whole bunch of reasons, including the fact that it is brought up with people who are applying for their drivers licence for the first time. Not only do they talk about it between themselves but they go home and talk to their parents about it and their siblings. It raises a conversation, because we know that whatever is registered it is actually a conversation that occurs between family members. It is discussed and debated and concluded in the cool light of day. Then suddenly when the parents have heard that Johnny said, 'Yep, I'd want to be a donor', even if he has not filled out the registration, and he ends up in a car accident a week later, they say, 'Yep, that's exactly what Johnny would have wanted.' It is all about encouraging and highlighting that discussion. It is much more likely to happen at a time when you are doing your drivers licence or renewing it compared to people thinking about going onto the AODR, which is just one of many websites that are there. People think, 'Oh, yeah, I'll get around to it' but never quite do. We know in South Australia the registration rate is much higher than anywhere

else in Australia, and that is, we think and they think, because they have maintained the drivers licence system. You want to make sure the two marry rather than it being one or the other, but there are ways around that.

The CHAIR: Thank you. Cindy, would you like to continue with some questions?

Cindy McLEISH: I would. Thank you very much, Chair. I just want to talk about some of the recommendations that you have put in your submission. One of them is the first recommendation.

William SILVESTER: Do you have a page?

Cindy McLEISH: Part 1.1(iv), and it is about vigilance of the hospital-based health practitioners, page 6.

William SILVESTER: Yes, the vigilance of hospital-based health practitioners.

Cindy McLEISH: Yes. I probably want to talk about, or get you to explain a little bit more: on the floor of the hospitals, what is preventing this now? I know that when we had a hearing before the RACGP were here, and they talked about how all of the doctors are trained up to the same standard about having very difficult conversations, of which one of them is about organ donation. I wondered if you feel the staff in the hospitals have not had that sort of training, or is it quite specialised so that they need to be thinking about it separately, an additional type of training?

William SILVESTER: I think, because you referred to RACGP, there is a big difference between a GP saying to their patient who has come in to see them about their blood pressure or whatever, 'And also have you thought about donation?', and saying a little bit about it, 'And here's the AODR website'. There is a huge difference between that and then actually having the discussion with the family of the loved one who is in the ICU right now, who has either died or is very likely to die, to then explaining the whole situation, making sure they understand the precarious predicament this person is in and then how to bring up the whole issue of donation. They are chalk and cheese.

To be able to do that—I mean, we send our intensive care trainees along to a two-day course on how to do that, and even at the end of that that is really only the beginning. That is then the experience that you build. We also have our donor coordinators. They also not only get trained up on that, but then they have lots of experience at actually having the discussions. The statistics show that by having a trained person, whether it be a doctor or even more so a donation coordinator, who usually comes from an ICU nursing background, being trained to have those discussions, they are more likely to be able to adequately and appropriately inform the family, which then is more likely to lead to a yes. Now, we would never of course want it to be a coercive yes. We want it to be an informed yes, and a yes based on, 'Yep, we've thought about it. This is what Mum or Dad or my partner would have wanted.' It is so different to raising it in general practice.

Cindy McLEISH: My question is about what is happening now that prevents that on the floor of the hospital? Is it the training, or are they so busy that it is something that is not front of mind at the moment?

William SILVESTER: It is both. It does take time, and it is mainly the ICU doctors that we are concentrating on providing that training to. The ED doctors—some get training on that but not all, and certainly the doctors working out on the wards where there may be a deteriorating patient who could potentially be thought of as building up to being a potential donor, those doctors out there would have had no training on it whatsoever. That is why we were recommending that the profile of organ donation, how to have these discussions, should be raised throughout the whole hospital, not just in ICU or ED.

Cindy McLEISH: You have mentioned nurses as well in your submission.

William SILVESTER: Yes. Often families are turning to nurses and saying about this. We want the nurses to know how to respond to those questions and how to raise it. The worst thing is if, say, an ED doctor who has not been trained in this is dealing with someone who has just come in with a head injury from a motor vehicle accident and the ED doctor is saying to Mum and Dad, 'Look, Johnny is not going to—you know, this is a terrible, catastrophic injury. We think he is going to die. And by the way, can we have his organs?' I am being a bit extreme, but if it is put in a bad way where the family might then perceive a conflict of interest—'Oh, so you're not going to do anything for Johnny, but you want his organs'—again there is a possibility. Whereas it is a much more nuanced approach which has to be timed the correct way, when we know the family have come to

terms with the fact that Johnny is not going to survive, and then we bring it up. It takes two days of intensive training to know how to do this properly.

Cindy McLEISH: And this I guess goes to the nub of the question: how do you make that happen? You know, I understand, and we all understand, the nuance, the timing and the care that is required. But then how do you bring the standards up so that if they turn to the nurse—because they do because the nurse is the one that is there—the nurse now understands and knows. Where does the nurse get that sort of support or training from? I am trying to make it work.

William SILVESTER: No, I agree. Well, through OTA and through, for example in Victoria, DonateLife Victoria, we run these training courses. If we had the funding to be able to run more of these courses and the ability to bring it to the attention of the staff we want to train to attend the courses, that would help. And then the final thing that would help would be—I am careful about using the word 'mandating', but in intensive care, intensive care trainees have to do this course as part of their training. They do not pass their training as an intensive care specialist unless they have attended the course. And they now have to attend both, don't they, Rohit, the core and the –

Rohit D'COSTA: No, just the core.

William SILVESTER: Just the core, right. There is a core course for two days, and then there is another course which even further improves your ability to do this. But as I said, it is mandated with intensive care trainees –

Cindy McLEISH: Across the country.

William SILVESTER: across the country, yes. It is not mandated for emergency department doctors. A lot of them—because some of their ED training is done up in intensive care so they know how to look after critically ill patients in ED—while they are there we often say, 'Look, this course is available.' Just last month I said to my registrars in Bendigo, 'We've got some spare spaces in this course that's happening in July,' and they all put their hand up and said, 'Yeah, I'd love to go.' We need to raise its profile. And I also think that it would be ideal if doctors and nurses working on the wards and particularly working in ED were aware of this and attended the course because not only does it raise their awareness, they are thinking, 'That person's not doing well, are they a potential donor? I better ring DonateLife Victoria and explore that,' and if that is the case, then we either know how to talk to the family or we will even get one of their staff to contact and be part of the discussion with the family.

Cindy McLEISH: Have you got numbers of the people that have been through the courses by state?

William SILVESTER: I can take that as a question on notice. Are you happy with that, Rohit?

Cindy McLEISH: Would you mind? And doctors, nurses, any of those that have been through. The numbers would be really good for Victoria over the last, I do not know, five or 10 years, and interstate as well.

William SILVESTER: Yes, we could provide that so that you get a sense of how Victoria stands relative to other states. And if you like, maybe another question you would like to ask me is: what funding would be required to provide that extra training to doctors and nurses?

Cindy McLEISH: That is my next question, and I would love it if you can provide that information for us as well.

William SILVESTER: Sorry, same as you, I pre-empted the question.

The CHAIR: That would be fantastic if you could provide those.

Cindy McLEISH: Sorry, I know have taken a little bit of time. Also in your submission, you have talked about the Lions Eye Donation Service and Bloodbikes, and they are volunteer driven. How important are the volunteers in the organ donation sector?

William SILVESTER: I think crucial. Given we cannot fund everything, if the blood bikers are willing to transport eyes or tissues from one place to another as required, I think it is fantastic. Look, I do not know about

liability and reimbursement of their travel costs and so on. I do know anything about that, but I just think that the fact that this is something that got started in the US and has now been established in every jurisdiction in Australia is fantastic.

Cindy McLEISH: I know the Lions Club are particularly proud of their involvement with the eye donation work. Thanks, Ella.

The CHAIR: Thanks, Cindy. Heang.

Meng Heang TAK: Thank you, Chair. I guess many of my questions you have already answered, but I just thought that I would ask anyway. Apart from having that line to tick on the driving licence, would you think anything else would assist in terms of maximising or increasing the registration?

William SILVESTER: Rohit, you have recently been in the media because it is donation awareness week. You have probably had more time to think about other ways of raising awareness apart from through the media.

Rohit D'COSTA: I think any governmental interaction is a useful touchpoint, whether it is a drivers licence obviously, or whether it is electoral roll type interactions or other health, Medicare, interactions—anything that provides a seamless and reliable connection to the national register, because I think the efficacy of registration is pretty clear. If the family does not know what the loved one would have wanted and the loved one is not registered, the consent rate is currently at 40 per cent, and it doubles if they are registered and they know what they want. So if we could get the 80 per cent of Australians who say they support organ donation—and there are lots of surveys that reflect those sorts of numbers—instead of 7 million in Australia we would have 16 million, and in Victoria instead of the 23 per cent, we would have 80 per cent registered. That would go a long way towards increasing the overall consent rate and numbers.

William SILVESTER: Can I add—look, I am an intensivist, but I have been working in the end-of-life care side of intensive care for decades now and I am pretty familiar with the fact that talking about death and dying is very difficult for most people. And it has not been helped by the fact that we have taken on this ridiculous American term of passing on, passing over or passing, you know. It frustrates me greatly because we have stopped using the D word. And the reason why I am making that emphasis is because the more we normalise death as a part of living, the more people are going to be prepared to talk about this.

And there is no better time to talk about it than with young people who become familiar with it. So if you had some way of engaging with the education department to introduce talking about death and dying, particularly around organ donation, with schoolkids, that would be fantastic because not only do they think about it and they talk about between their peers, you know, 'What do you think, Johnny? Oh look, I think it is a fantastic idea,' and then they talk about it between themselves, but they all go home and talk about it with Mum and Dad. And the number of times I have heard mums and dads say, 'Look, Johnny came home and talked about this, and we think it is a fantastic idea. We also now know what he would want, but we have talked about it between ourselves.' They talk about it over Sunday dinner, then it becomes that conversation, and as I said before, even if they do not fill out the registration thing online, the fact that they have talked about it is actually the most important thing. So a way of introducing it through the education department into all schools as a subject that is discussed, maybe in year 11 or 12, I think would just be magical in terms of raising that awareness.

Meng Heang TAK: Thank you, Professor. Thank you.

The CHAIR: Thank you. Chris.

Chris CREWTHER: Thank you, Chair. Firstly, with my colleagues, thank you very much for your submission, which was a good read and very extensive, and your time giving evidence today. My first question is on the issue of transplant units and organ perfusion machines. There has been a lack of funding and a need for increased funding for both transplant units and organ perfusion machines to keep up with demand. Can you give some further thoughts on that, as to that need, and also are there other government systems and processes that are substandard or in need of increased funding at the moment as it relates to organ and tissue donations?

William SILVESTER: I hear from the transplant units. This is third hand, but what I hear from them is that not only do they need extra resources to be able to have those staff to do the retrievals, but they also need more

staff to be able to deal with the transplant recipients. As you would have heard from the previous submissions and as you would have seen from the graphs, our donation rate has increased significantly in recent years. I also understand that the resources for the transplant units that are dealing with all these extra transplants have not increased, so they are completely stretched. Their ability to be able to see transplant recipients postoperatively as much as they need to or to work them up preoperatively is greatly restricted. For example, if we have a potential donor who is of a certain height and certain size, the lungs therefore have to go into an appropriate recipient. Several times this year I have heard, 'No, the lungs can't be used because we don't have any suitable recipients,' simply because they are the wrong size. Now, if they are not getting enough funding to work up potential recipients who could have been the right size, then those lungs metaphorically go in the bin, and a potential recipient who is still being worked up misses out. I would just reiterate that if the donation rate and therefore the transplantation rate has gone up, but they have not got extra resources, then of course they are not going to be able to meet that demand. Rohit, do you have any further thoughts from a transplantation perspective about how we could help?

Rohit D'COSTA: No. I agree in principle with what you have just said, Bill. I do not have any other comments.

Chris CREWTHER: You mentioned the Ngamuru report—now, my pronunciation may be incorrect.

William SILVESTER: The which, sorry?

Chris CREWTHER: The Ngamuru report.

William SILVESTER: Yes.

Chris CREWTHER: Do you believe that the Victorian Government should release that report and consider implementing its recommendations? And secondly, is it possible to get a copy of your contribution to that report?

William SILVESTER: I was interviewed by Heather Wellington at that time, so I did not provide anything in writing. You know, the last thing I want to do is for this Committee to cause difficulties for the Victorian Government in terms of releasing reports, but we certainly think a lot of effort went into that. I can only speak on the side of people in the donation sector and how many people I know put a lot of effort into thinking about how to improve things, so I would absolutely applaud that report being released. In terms of transparency, let us look at what it says. If it cannot be justified, then do not proceed, but if it certainly indicates that it is going to improve donation and transplantation—I think what is often forgotten is that by increasing transplantation it actually saves money. Every kidney that gets donated and transplanted saves $80,000 a year because that person no longer needs dialysis. You know, dialysis is an incredibly costly exercise in terms of someone having to come in and connect up to a machine three times a week. All the equipment and the staff involved in that way of keeping someone alive is very costly. Every time two kidneys get transplanted we are saving the state health system $160,000 per year. It does not take long to work out the maths to see that providing a few extra staff to be able to facilitate donation and transplantation would actually, in my mind, save money.

Chris CREWTHER: Yes. My next question more relates to regional Victoria. You have made a number of comments that relate to regional Victoria in your submission. I have seen a number of instances where there has been a defunding or reduced funding for community transport services by which potential patients or people would be transported to specialist services. One example is the Centre for Participation in Horsham in western Victoria, which offered community transport services to go to specialist services in places such as Ballarat, Bendigo, Geelong and Warrnambool. Through reduced funding that has meant less people being able to access those services, and therefore you have, I guess, a reduced ability to access ICU when it is needed, or reduced conversations about organ and tissue donations and reduced ability to be a recipient or a donor. Do you think funding of community transport services therefore has a direct link to organ donation rates and the ability to access donations as a donor or as a recipient?

William SILVESTER: I am not in a position to comment on those general things. What I can say is that if a patient is critically ill and needs to be transported to a centre that has intensive care for that person, then ARV do a fantastic job under difficult conditions—and did particularly through the COVID period, when there was such a huge demand. They do a fantastic job of getting people to where they need to be. So in Bendigo, where I am running the ICU, we have patients coming from Echuca, Mildura, Swan Hill, Shepparton and Wangaratta,

and patients get transported as required, either by helicopter or by land ambulance, to our ICU. Of course if they have got a head injury or they are multi-trauma, then they are going to be taken down to Melbourne anyway. They would go to Rohit's hospital, the Royal Melbourne Hospital, or the Alfred, so they would bypass us anyway. It is, generally speaking, that people with catastrophic intracranial haemorrhages or strokes or head injuries—those sorts of people who are the main suppliers, to put it crudely, for potential organ donation—are going to be transported anyway, because at the time they are being transported we are working towards providing the best care possible for that person. It is only when we realise that they are not going to pull through that we then start the donation conversations and consideration. So I do not see that—I am not privy to what you are referring to about restriction in transport services, but from an intensive care perspective, I think ARV does a great job under the circumstances.

Chris CREWTHER: Thank you. Can you elaborate on the need to increase rates of FDCs, family donation conversations, and how government in particular can help to increase those rates?

William SILVESTER: Well, the FDCs, the family donation conversation, is exactly what I was talking about with Cindy, and we would certainly see that providing that more frequently to the staff who either want to do it but have not been able to or who do not even see that there is a need for it to be a part of their training, whether it be doctors or nurses, would certainly increase awareness and increase the likelihood of a nuanced, successful discussion being held.

Chris CREWTHER: Have I run out of time, Chair?

The CHAIR: We are running out of time, I am afraid.

Chris CREWTHER: All right.

William SILVESTER: Sorry, I am talking too much.

The CHAIR: Well, thank you very much for appearing before the Committee today and for your contribution to this very important inquiry. We have greatly appreciated the written submission that you have provided but also the work that you have done to prepare for today's hearing, so thank you very much for your attendance.

William SILVESTER: Can I just make one last comment?

The CHAIR: Please.

William SILVESTER: In discussions with the Donor Tissue Bank of Victoria, we understand that they felt that our representation of their level of service was misrepresented by us referring to table 1 in our submission, as against table 3, which is the representation of deceased donation of tissues as per the source document, which is the ANZOD document. I have certainly been looking at that with them, including over the weekend. We recognise that combining living donation and deceased donation might lead to us thinking that Victoria is not doing as well as other states, and I accept that. But even if we take out living donation, there is certainly room for improvement for deceased donation of particularly heart valves and other tissues in Victoria. I do not know whether Rohit wants to make any comment, but we met with them last Friday, and we look forward to continuing to work with them to see how tissue donation can be increased in Victoria.

The CHAIR: That is great. Thank you again for appearing before us today. You will be provided with a proof version of today's transcript to check, together with the questions that were taken on notice. Verified transcripts and responses to any questions taken on notice will be published on the Committee's website, and we would also like to publish your opening comments as well alongside your submission, so if you could send that through separately that would be greatly appreciated.

William SILVESTER: Will do.

The CHAIR: The Committee will now take a 5-minute break ahead of our next witness. I declare the hearing adjourned.

Witnesses withdrew.