

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Friday 23 June 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESSES

Associate Professor John Whitlam, Nephrologist and Medical Director of the Kidney Transplant Service, and

Professor Robert Jones, Liver Transplant Unit Director, Austin Health.

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's Inquiry into Increasing the number of registered organ and tissue donors.

I begin this morning by acknowledging the traditional owners of the land on which we are meeting, the Wurundjeri Woi Wurrung people of the Kulin nation. I pay my respects to their elders past, present and future and extend that respect to First Nations communities across Victoria. 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; Chris Crewther, the Member for Mornington; Gary Maas, the Member for Narre Warren South; and Cindy McLeish, the Member for Eildon. Committee Members Christine Couzens, the Parliamentary Secretary for First Peoples and Member for Geelong, and Meng Heang Tak, the Member for Clarinda, send their apologies.

Earlier this year the Legislative Assembly tasked the Legal and Social Issues Committee with the Inquiry into increasing the number of registered organ and tissue donors, and the Committee will report back no later than 31 March 2024.

Many valuable written submissions have been received to date and are available to viewed online on the Committee's website. On behalf of the Committee, I take this opportunity again to thank those who provided a submission, particularly the individuals and families who bravely shared their own personal stories of organ and tissue donation.

Today is the second day of two public hearings this week, and we will hear from witnesses representing a number of Victorian and Australian organisations and international organisations that work in organ and tissue donation. Today we will hear from Austin Health, the Organ and Tissue Authority, Deaf Victoria, Donor Tissue Bank of Victoria and the Victorian Institute of Forensic Medicine, Cool Australia, the Islamic Council of Victoria, the Multicultural Centre for Women's Health, and joining us from Spain, the Organización Nacional de Trasplantes. 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 phones please be turned to silent.

We will now commence public hearings with our first witnesses. I welcome from Austin Health Associate Professor John Whitlam, Nephrologist and Medical Director of the Kidney Transplant Service, and Professor Robert Jones, Liver Transplant Unit Director. I invite you to make an opening statement, and this will be followed by questions from Members. Thank you.

John WHITLAM: Good morning, and thank you for this opportunity to speak and for considering our written submission. Professor Jones and I are here as representatives of Austin Health, a transplant centre in north-east Melbourne. Austin Health is responsible for retrieving abdominal organs from donors across Victoria and Tasmania and delivers transplantation services spanning kidney, liver, intestine, bone marrow, paediatric and multiorgan transplantation. We are here today to discuss the critical importance of organ transplantation and the need for stronger measures to maximise the benefits of organ donation for the people of Victoria.

I want to begin by sharing a story. This is about James, a farmer from rural Victoria and a devoted father of two, whose life was transformed by organ transplantation. For years he was enslaved by the unyielding schedule of dialysis, an hour from his home. His once robust fitness and health crumbled, and he was unable to work and care for his family. Transplantation handed James a lifeline, liberating him from the shackles of

kidney failure and allowing him to resume the comforting rhythms of his farm life, his integral role in his community and the everyday joys that we often take for granted. Stories like these, where organ donors and their families profoundly transform the lives of strangers, are the reason why we are here today. So we want to begin by acknowledging organ donors and their families, thanking them and assuring them that their altruistic actions are recognised and valued amidst these deliberations.

Transplantation is not just a medical procedure; it is a life-saving medical marvel. For kidney failure, successful transplantation is associated with a five to tenfold reduction in death, substantially improved quality of life and freedom to recreate, work and travel. Transplantation is also dramatically cheaper for our healthcare system than dialysis, an artificial means of filtering the blood which can cost upwards of \$85,000 per person per year. To put this into perspective, the cost of haemodialysis for a single person over five years could buy a two-bedroom home in Craigieburn. Over the past two decades Australia has seen a more than doubling in the number of dialysis recipients, from around 11,000 to 27,000. As a result, dialysis has become the leading cause of hospitalisation in Australia, accounting for 14% of hospitalisations in 2020.

For someone living with end-stage liver disease or battling liver cancer, liver transplantation is the light at the end of a very dark tunnel. It means getting back to family, to work and to living life without the looming spectre of an imminent untimely death. Alarming, the prevalence of chronic liver disease and cirrhosis is on an upward trajectory in Australia, propelled by the rising incidence of diabetes and obesity. The gravity of this situation is further underscored by the fact that, unlike kidneys, there is no artificial support available for the liver, making it impossible to sustain patients awaiting liver transplantation for prolonged periods.

Delayed access to liver transplantation not only results in loss of lives but also takes an emotional toll on families as they watch their loved ones suffer from complications and frequent hospitalisations. Behind these facts are fathers, mothers, sons and daughters whose lives could also be immeasurably improved by the gift of organ transplantation. These are individuals who contribute to our communities in countless ways. Therefore through organ donation and transplantation we are not just saving lives but strengthening communities. As such, transplantation represents a beneficial intervention for individuals, society and the healthcare system, one worthy of our support.

However, our optimism is dampened by the longstanding disparity between organ availability and demand. Additionally, organ transplantation saw a substantial reduction during the COVID-19 pandemic. We have yet to recover from this in Victoria. In comparison with prepandemic levels, 2022 saw 7% fewer heart transplants, 11% fewer kidney transplants, 19% fewer liver transplants and 24% fewer lung transplants. The current year paints a bleaker picture. Organ donor numbers in Victoria are already down by 20%, a trend conspicuously absent in other states. We can only imagine how delayed access to kidney transplantation would have affected James, his family and his community.

This crisis calls for an urgent and dual-pronged approach. We advocate for boosted donor registrations and stimulation of family discussions about organ donation. Capitalising on milestone events such as drivers licence registrations, public awareness campaigns, simplifying registration and leveraging relevant events and social media could be beneficial, but these measures will take time to be implemented, and death supporting organ donation is a relatively rare occurrence, so seeing their impact on donation rates might also take time—time we do not have.

In the short term, it is critical that we optimise the utilisation of our existing donor pool. Historically, older donors and donors after circulatory death have been underutilised due to apprehensions about organ quality and vulnerability to ischaemia. Ischaemia refers to a period when an organ does not receive enough oxygen-rich blood. This occurs during donation after circulatory death and after an organ is removed from its donor. The longer the ischaemia, the higher the risk of organ damage.

In response to this challenge, machine perfusion has emerged as a technological solution. Ex vivo machine perfusion uses a machine to circulate blood or preservation fluid through an organ outside of the body, reducing ischaemia damage and giving us time to assess the organ's quality and function before transplantation.

At Austin Health, we have successfully integrated liver machine perfusion into our practice for the past four years, enabling us to transplant livers from donors previously thought to be non-viable. Machine perfusion would have been particularly beneficial for James, who needed time to travel from the country for his transplant

from an older donor. This year, with philanthropic support, we are introducing kidney machine perfusion as part of a comprehensive state-wide kidney machine perfusion program. However, to fully realise the benefits of these technologies, resourcing for consumables and technicians is required.

Normothermic regional perfusion is another strategy adopted in Europe, including Spain, to reduce ischaemic injury to vulnerable organs. In this technique, oxygenated blood is pumped through a group of organs—for example, the thoracic and abdominal organs—after the donor has died, but before they have been removed for transplantation. In our opinion adoption of normothermic regional perfusion in Australia faces legal and ethical hurdles that will require some time to carefully consider and address, limiting its role in the present crisis.

We additionally propose policy changes that permit withdrawal of life support in the operating theatre rather than the ICU. This practice, already routine in New South Wales, respects the donor family's privacy and reduces logistical complications that can occur when rushing donors from the intensive care unit to the theatre, reducing ischaemia time and supporting better outcomes from existing donors.

In closing, we ask the Committee to remember that the ultimate objective of organ donation is transplantation. Insights accrued from previous state and federal reviews provide invaluable recommendations that can be proposed by this inquiry to improve the entire trajectory from donation to transplantation.

Addressing the low rates of organ donation and the under-utilisation of organs from the existing donor pool is not just a healthcare priority, it is a moral and societal imperative. Every month that passes without action risks lives and threatens families and communities. With your support, Victoria has the potential to become a national leader in organ and tissue donation, retrieval and transplantation.

Considering the stakes involved, we call upon the Parliament to act decisively and implement not only initiatives to increase donor registrations but also initiatives that resource retrieval and transplant services to make better use of the existing donor pool via new technologies and refinements to medical practice. These initiatives are not just about saving lives, they are about enriching the quality of life for individuals like James and honouring the altruistic intentions of our donors by maximising their donation outcomes. Let us all collectively shoulder this responsibility and act now to leave a legacy that will transform and save lives for generations of Victorians to come.

Thank you once again for this opportunity to speak and for your consideration of this important topic.

The CHAIR: Thank you. Can I say thank you for that very comprehensive statement and also for your written submission. It has certainly given the Committee a significant amount of information about the work that you are doing and the challenges that you see and also the opportunities where we can do better in terms of organ and tissue donation. Particularly thank you for sharing that story about James. I think it is always incredibly powerful when we can hear stories of lived experience and how organ donation changes and saves lives. I will now hand over to Committee Members for some questions. Annabelle, would you like to start?

Annabelle CLEELAND: Thank you. I guess I wanted to start with—because you have been in this space and a leader in this space, experts—how many state and federal government inquiries have you contributed to in recent years?

John WHITLAM: There have been at least three in the last decade that I have been involved with.

Robert JONES: I have been involved in two federal, the EY and the Victorian inquires just in the last five or six years.

Annabelle CLEELAND: Do you feel there have been any benefits or change in this space from those inquiries?

John WHITLAM: I guess the first point to make, as we highlighted in our written submission, is that there was a federal reform that was introduced in relation to organ donation and transplantation about a decade ago that was incredibly effective and resulted in a substantial increase in deceased donor transplantation in Australia over the decade leading up to 2019. That federal reform focused primarily on the donation sector. It involved the establishment of the Organ and Tissue Authority and DonateLife, but it did not lead to substantial change in resourcing for retrieval and transplantation services. As a result of that incredible success, downstream services

were put under a substantial amount of pressure in the lead-up to COVID, and it was that success really that prompted both the state and federal reviews into organ donation and transplantation. However, neither of those reviews have resulted in any meaningful action arising.

Annabelle CLEELAND: That time line coincided with the registry moving from a Victorian VicRoads-led registration, I believe, to a national one. There seems to be data we cannot fully attribute to that, but do you feel like the registration, when it went from a Victorian-managed database to a national one, has had an impact on our extremely low population enlisted on the AODR?

John WHITLAM: I do not feel I have got the expertise to comment on that. I think that is a question for the donation sector.

Annabelle CLEELAND: Sure. I wanted to ask: you mentioned the Victorian Department of Health review into organ donation. Did you contribute to that report?

John WHITLAM: Yes. The entire sector contributed substantially to that report, but the report has not been made public.

Annabelle CLEELAND: Have you seen a version of the report?

John WHITLAM: The report has not been released to clinicians.

Annabelle CLEELAND: Right. Okay. I just want to speak about, I guess, that flow-on effect from the organ donations when it comes to hospital management and theatre management as well. When you send out a retrieval team, how do you manage the theatre for the day and what impact does that have on scheduled surgeries?

Robert JONES: Look, it is a great question. The whole field of transplantation is extraordinary, because it is probably the only service that truly is meant to be available 24 hours a day, seven days a week for the entire year. You really cannot minimise the service and just have a skeleton crew on. For example, if we are doing complex transplants, we may need three or four surgeons, or five or six surgeons, and they are available continually, around the clock. You cannot plan any of these procedures, so they are very short notice. For example, we are transplanting right at this very moment—just commenced a transplant—with an organ that was retrieved from a regional town from a marginal donor that we would otherwise might seriously have thought of not using. It was brought back to the Austin overnight. It has been sitting on one of these fancy perfusion machines. Despite us being very pessimistic, it has performed extraordinarily. There are lots of computer printouts to look at, but this is a beautiful graft. It is functioning beautifully, and it is about to be transplanted into someone who would otherwise not have received this graft. So it is a wonderful example. And the planning for that has been quite chaotic because it has disrupted someone else's operating list. We have had to cancel an operation, and the nursing staff are short at the moment, as you are aware, so these are very disruptive procedures. In a way you cannot just keep an operating room and staff available, because most of the time they would not be utilised, so the planning and management of these procedures requires integration and tremendous cooperation right across the board. We have to take a surgeon and say, 'Look, can we take your staff and your operating room, and you won't be operating today?' It requires tremendous goodwill from an institution to manage. This is across the board, really, for transplantation.

It is what really makes transplantation extremely difficult to manage and to actually function, and it is extraordinary that some of these programs—the heart and lung program and the liver program are particularly challenging, as these organs have a relatively short ischemic time and you cannot put them in a refrigerator and leave them for hours and hours. Kidneys are a little bit more flexible, and that is where machine perfusion comes in, where we can place them on a machine and say, 'Let's start tomorrow,' or where we do not get access to the operating room for 12 or 15 hours, we can actually keep the organ alive and reutilise it. It is a rather longwinded answer to your question.

Annabelle CLEELAND: The retrieval team that was sent, does that mean you have delayed the surgeries that were scheduled for today to prioritise the –

Robert JONES: To actually know the graft is working we have to leave it on the machine for 6 to 8 hours minimum. It went on the machine about 7 pm last night, so by midnight we knew that it was actually working

beautifully. We knew it was going to keep working beautifully, so we just left it till the morning so we did not have to start transplanting at midnight. We started at 6 this morning, and that graft would have been on that machine 12 to 15 hours. It will be taken from that machine. It is pink, it is warm, it is working and actually looks like a normal liver sitting in a bowl. It is a very pretty machine, very expensive to run.

Annabelle CLEELAND: It is very exciting, and your passion is contagious about organs, by the way.

Robert JONES: It is exciting.

Annabelle CLEELAND: How crucial is it to have the organ donor coordinators? We heard on Monday that there has been a reduction in Victoria by four in recent years. Does that have an impact on the conversation with the families and the flow of donors?

Robert JONES: That is a really good question, probably best handled by the DonateLife specialists, who I think will be presenting to you—but certainly from our perspective at our end, absolutely crucial as the first step.

John WHITLAM: Just to give you an idea of the landscape, so the donation and transplantation sector has a demarcation between the two, and transplantation clinicians typically are not involved in the care of organ donors to prevent perceived or actual conflicts of interest in relation to how organ donors are treated. There are also differing skill sets, I guess, between donation specialists and transplantation specialists. So we work very closely with our partners in the donation sector, but we are not intimately involved in the management or the operational elements of the donation side of things.

Robert JONES: It is an extraordinary event, because we retrieve most of the organs in Victoria through our program—this is adults and children who are donors. We go out to hospitals where there has been a catastrophe, particularly a child's unexpected death. You are taking an organ from that patient and bringing it back to the Austin, where there is hope for a new life and a new beginning. So the contrast with these is enormous. It is not unusual for us to actually meet the donor family, because the donor families want to meet the surgeon who will be operating on their son, rather than this being impersonal. They will often want music played that was the music that he liked to play, or she. So there is a strong connection. You can remove it from that, but it is a very extraordinary human process. The gift is just magnificent, and it saves lives. As a surgeon, when you see these organs, they are extraordinary. The liver is this beautiful organ, and within 20 to 30 minutes of your heart stopping, that organ is no longer viable. So just purely in practical, utilitarian terms it is sort of a terrible waste to not recycle it. Children often appeal—you know, recycling things is a big thing, and it is part of the green movement.

Annabelle CLEELAND: I was pretty alarmed by the figures around the dialysis and the value and the cost of that per person.

The CHAIR: Sorry, last question, thanks.

Annabelle CLEELAND: How many patients do you know are on dialysis in Victoria?

John WHITLAM: Over a thousand, at least.

Annabelle CLEELAND: And are there concerns that that is increasing annually?

John WHITLAM: The numbers have doubled in two decades.

Annabelle CLEELAND: Wow, okay. Thank you.

John WHITLAM: And to be clear, we have the largest number of people on our waiting list awaiting kidney transplantation that we have had in the last decade because of the slowdown in transplantation arising from the COVID pandemic, the persisting low donor rates and the fact that there is no off switch, so people progress to kidney failure continuously. We were struggling to keep up with demand even when transplantation rates were better than they are now, but we are substantially behind the eight ball. There is a sense sometimes, one might assume, 'Well, if donor rates are down, you aren't as busy as you were previously.' But in fact for us it is easier to transplant people and get them well than it is to keep them well with organ failure and ready to receive a transplant. So in fact this current state, where there are more people waiting for kidney transplants,

more people on dialysis, is actually more work for the healthcare system than getting them transplanted and well and independent of the healthcare system. It goes to this point about the healthcare cost of organ failure, and the fact that transplantation effectively shifts people from high-acuity, high-cost care required to support organ failure to lower cost, lower acuity care, which paradoxically is associated with substantially better outcomes. I think there are very few interventions in health care that are as cost-effective but also as beneficial to an individual as kidney transplantation is for kidney failure. You know, we spend tens of thousands of dollars on chemotherapy drugs that have a much smaller accrued benefit than kidney transplantation.

Annabelle CLEELAND: Thank you.

The CHAIR: Thank you. Gary, would you like to ask some questions?

Gary MAAS: I would. Thank you very much for your time and—I think I share the same sentiment in saying this—for your passion as well. I must submit I briefly thought there, ‘If only I did medicine.’ But it is never going to happen, trust me. A couple of things: thank you for your submission as well and for showing the practical connections between the optimisation of organ retention techniques and then connecting that to organ and tissue donating. There are a couple of recommendations that you have made there. I was going to home in on the machine perfusion technologies, but I think we have heard a fair bit about that today. How do we connect that to your recommendation of developing and implementing policies to support and encourage Victorians to register? How do we make that connection there?

Robert JONES: Again, we are probably not the experts –

Gary MAAS: It is part of your recommendations.

Robert JONES: Well, seriously, I have spent my whole career in transplantation and done a lot of talks in schools, and just rather anecdotally I have a story. I go into a school class of about 12-year-olds and ask simply, ‘Who would want to be a donor?’, and a few hands will go up, invariably in families that have discussed it. Then you ask, ‘Who’s got a brother or sister?’, and ‘If your brother or sister needed to have a transplant and was going to die of heart failure or lung failure or liver failure, who would want them to be transplanted?’, and virtually all the hands go up. The kids get that. So my wife suggested really what we should have is a card that says not, ‘Do you want to be a donor?’, but ‘Would you be an organ recipient?’, and in other words—you know, we want to have that available. My children or my grandchildren or my wife might need a transplant, particularly an urgent transplant—liver, lungs, you are going to die without those—and really for that to happen we all have to be in as part of this process of actually being a donor. So we tend to concentrate on donation, which is really unattractive because you have got to die to donate, but really, as John has said, what we are wanting to do is actually transplant. I think it is worth trying to remember that: that it is the transplantation that is important. I want the ability to have my family transplanted if needed, and that is only going to happen if we as a community are all involved in the process of donation.

John WHITLAM: Can I also address your point. The reason why we have included those two is that we are presently in an environment where families that wish to donate—who have that altruistic intent—are not able to donate because of retrieval and transplant services’ concern that the quality and resilience of their organs may not be sufficient to permit a safe and effective transplant. So what we are trying to do with machine perfusion is maximise the ability of existing donors—people who are registered on the Australian organ donor registry, or not, whose families consent to donation—to fulfil that altruistic intent through better capability to assess and preserve their organs for transplantation.

Gary MAAS: I just want to explore a little bit more this notion of consenting to receive an organ as opposed to assenting to donate an organ. Are you aware of any other jurisdictions that might do it that way, or is that just something that you and your partner were having a chat about?

Robert JONES: That is right; it is really more a conceptual idea. For example, we transplant and we are responsible for Victorian, Tasmanian and South Australian children’s transplants. Almost without exception there is not a single parent who does not want their child to be transplanted, because they going to die, these kids, often in very short—we can have children present who are going to die within five or seven days, so there can be quite some urgency about it. And that invariably brings up that virtually every parent wants to do something or actually present themselves to be a donor for that child, which is instinctive, of course. As John said, that places our program under extremes, because we are now operating on a parent who may have other

children—be the father of other children—and the risk when taking a chunk of an adult liver is quite substantial. Around the world a significant number of living donors, usually parents, have died as a consequence of this surgery. So we are operating on someone who does not need an operation to save the life of their child, and the risk to the adult, for example, is quite significant. And if there are other children—the man may never be able to work again or there may be all sorts of other implications even if he does not die. So having organ donors throughout the community—patients who have already died—takes that pressure off. It is a wonderful thing if we can say to a family, ‘Look, you don’t have to be a donor. You don’t have to take that risk.’ And of course families under that pressure are going to want to take that risk, and our program is then forced to sometimes go ahead with that because there is no other alternative.

Gary MAAS: Thank you. Following on from that then, how could hospitals better obtain family consent to organ donation through increasing the involvement of, I guess, donation specialist nurses or other training opportunities? Do you accept that premise in the first place, and then –

Robert JONES: I guess again we are probably not quite at the forefront of dealing with that interface. As John said, there is a separation mostly between the donor side of transplantation and the recipient side, and there has been a tremendous interest over the years in various social and advertising programs on how to handle that. It is interesting, I think, that the majority of families that we see are very pro donation, because they have someone in front of them and it is very clear cut. And families who have met someone else who has had a transplant are often very pro donation. So those sorts of community attitudes are very much engendered by your own experience—someone down the street or someone’s child has had a transplant and is now living normally. In fact I was talking to a family just a week ago and we were talking about transplantation and the outcomes, and they said, ‘Oh well, we know—our child is in a class with someone’, one of our other patients. We did not know that. So we did not actually have to talk about the risks of transplantation, because they actually knew this other child and knew the outcome at a personal level. So I think contact with someone who has transplantation is very important—being aware of it—and I think in the community being aware that ‘This is something that could hit my family tomorrow’.

It is not just a chronic disease that takes years in the planning—and it is a simplistic concept, isn’t it, to take an organ from someone and replace it. John and I were just talking about this over a coffee. I am sure in 20, 30, 50 years we will look back and say these were the medieval times, when you used to take an organ out of someone and replace it, and we will be able to do this with stem cells or something fancy and beautiful. It is still an extraordinary process. As John said, patients get better, and they get better dramatically and go back to living very, very normal lives. It is not usual in a hospital to have someone who has a terminal, end-stage disease and to be able to say, ‘Not only can we fix you, but you can go back to living pretty normally. If you want to go skydiving, go skydiving.’ If you want to go scuba diving—we try and talk them out of it, try and get the kids not to play football, but they can do all those things.

Gary MAAS: Did you wish to add anything to that?

John WHITLAM: No. I think it is something that is best put to the donation sector.

Gary MAAS: Yes. Okay. Thank you. I will leave that there. Thanks very much.

The CHAIR: Thanks, Gary. Cindy?

Cindy McLEISH: Thank you. Thank you for your presentation. It has been exceptionally interesting and stimulating already. Being in a family who have been through the dialysis situation, I understand that quite well. I want to talk first of all about kidney donation, which I imagine is less complex than liver transplants and donations—I am not sure. But how often do you use living donors rather than deceased?

John WHITLAM: This is an important point in kidney transplantation. The majority of humans have two kidneys, and healthy adults can survive with one kidney and can typically live a healthy, fulfilling life with one kidney. So, living donors are a pool of donors that could help address the organ shortage. At the Austin about a third of our transplants come from living donors, which is higher than the national average. Living kidney donation certainly has higher stakes, because as Professor Jones has pointed out, a living donor is undertaking risk and a surgery for no personal benefit. So it certainly is not something to be undertaken lightly, and it is something that benefits from a skilled team and a higher volume of activity. It also requires healthy donors, people who can afford to lose a kidney and people who can survive and experience an uncomplicated living

donor operation. For us, even though we enjoy proportionately substantially better access to living donors at Austin Health, it is unlikely in our experience that living donation will substantially replace the need for deceased donors, because many of our patients with kidney failure do not have suitably healthy living donors that can give them a kidney or do not have individuals offer to donate them a kidney.

Cindy McLEISH: When you said a third are living donors—you would rather that be less?

John WHITLAM: No. We seek to maximise living donation wherever possible, and the reason for this is that living donor kidneys, in the course of donation, are subject to less stress and damage than deceased donor kidneys. Living donor kidney transplantation is typically associated with better early and long-term outcomes compared to deceased donor transplantation. There are also advantages, because access to transplantation when a suitable living donor is available is much more rapid. We know that for people with kidney failure the sooner the transplantation can be achieved, ideally even before dialysis is needed, the better it is for the outcomes of that individual and the better it is for the outcomes of the transplant. Because of the substantial waiting times for deceased donor kidney transplantation, including the fact that many people who wait for a deceased donor kidney transplant never achieve a kidney transplant because it does not come in time, living donor transplantation offers a way around that congestion.

Cindy McLEISH: Of the, say, 1,000 patients that you said are on dialysis how many would be waiting for a kidney?

John WHITLAM: There are five kidney transplant centres in Victoria. Kidneys are far and away the most commonly transplanted organ in Australia—more than double that of any other solid organ. We have many transplant centres for kidneys in Victoria, and these kidney transplant centres have a number of KPIs that we are assessed against. One of these relates to access to transplantation, which the federal review certainly identified as highly variable across Australia and within state jurisdictions. One such KPI is the proportion of people with kidney failure below the age of 65 years who are active on the deceased donor transplant list or transplanted within six months of starting dialysis. At the Austin we perform in the top 10 of the jurisdictions in Australia, with about 42% of our dialysis cohort listed or transplanted within six months. Then if that time frame is increased to 1 to 1½ years, we would be well above 50%—so I think 55 to 60% probably.

Cindy McLEISH: If a potential donor is identified and the family has given consent, what are some of the reasons this would not proceed to a donation?

John WHITLAM: That is a very good question. In Australia this sort of cascade of utilisation is captured by a number of bodies. Just to give you some facts, I guess: if we consider one donor offers two kidneys, and we consider each kidney separately, in 2021 there were 809 kidneys consented for organ donation, and from those, 726 kidneys were retrieved. So you can see that for 83 kidneys, there was a decision made not to retrieve them from the donor. Then, of those 726 kidneys that were retrieved, there were 668 kidneys that were transplanted. So there were another 56 kidneys that were retrieved from a donor but did not ultimately find their way into a recipient.

There are many reasons why there is this attrition. Sometimes a decision is made that the kidneys are not medically suitable for transplantation because of irreparable reasons, and this might include finding a cancer in a kidney, or the kidney being damaged in the course of retrieval, or the kidney being unable to be perfused, for example, but sometimes these kidneys are not used because no transplant centre is willing to use them.

Just by way of proving our point, in the years between 2014 and 2019, in a study that looked specifically at kidneys retrieved from donors after circulatory death, 15% of those kidneys were not used in Australia, which is a substantial number. In conducting a statistical analysis of reasons for this, the two key factors that affected that decision not to use those kidneys were concerns regarding the function of the kidney and concerns regarding the ischaemia time. To our point about the potential utility of machine perfusion in maximising donation opportunities, this addresses those two primary concerns.

Cindy McLEISH: Just before I go into the second part of that question, how long can an organ stay on one of the machines that does perfusion?

John WHITLAM: That is a good question. The role of machine perfusion differs for each organ, and there are additionally two different types of machine perfusion technology that are used on kidneys as part of our kidney machine perfusion program.

When a kidney is retrieved from a donor, it is cooled, which effectively puts the kidney into hibernation. Our current strategy for what we call cold preservation in Australia is called static cold storage. Effectively the kidney is wrapped in sterile plastic bags and put into an esky—and in Victoria the eskies we use are not fancy eskies; they are just eskies that you get from the local department store basically—and they are shipped to the transplant centre from the donor site. This kidney is sitting on ice. Basically the time that it is sitting on ice is calculated, and it correlates with this issue of ischaemic damage and the likelihood that the kidney will work after transplantation. The longer that a kidney is in that esky, the more concerning it becomes. So, for example, one reason why kidneys may not be used is that transplant centres may not be happy with how long that kidney has been in that esky, particularly if it comes from an older, more vulnerable sort of donor.

Hypothermic machine perfusion is a cold type of machine perfusion, where rather than having the kidney sitting in an esky doing nothing, the kidney sits in a little bit more of a fancy esky but is being perfused with a fluid that is cool and has oxygen added to it, and that substantially increases the time that a kidney can sit on ice. It substantially, for any fixed time, increases the likelihood that the kidney will work after transplantation and work well.

To answer your question, that time in Australia that a kidney is on ice averages about 6 to 8 hours. Once the cold ischaemia time gets above 16 hours, I think people become increasingly reluctant to use the kidneys. What we have seen from international studies, particularly in the United States where ischaemia times are much longer, is that kidneys remain viable with hypothermic machine perfusion beyond 20 hours.

Cindy McLEISH: Yes, sure. Have you had to deny an organ transplant because of theatre and staffing problems?

Robert JONES: In the 25 or so years that I have been working at the Austin, it is exceptionally unusual. Perhaps once –

Cindy McLEISH: Everything happens.

Robert JONES: Well, everyone makes it a priority to make this happen. You can defer another operation that can be done another day, but it is really dependent on the enthusiasm.

Cindy McLEISH: It is priority one.

Robert JONES: Yes, priorities.

John WHITLAM: In relation to kidney transplantation, I would just flag that there are many sorts of uncaptured decisions that include assessment of multiple competing variables. Transplant centres may, for example, decline to use a kidney for their particular recipient if they anticipate that the cold ischaemia time is already long, they have got a recipient coming in from the country, and they are already doing two transplants. This type of decision does not necessarily mean that the kidney is not used at all, but it does mean that that kidney might go to someone else lower down on the list at another centre to sort of manage those competing risks.

Cindy McLEISH: Thank you.

The CHAIR: Chris, would you like to ask some questions?

Chris CREWETHER: Thank you, Chair. Firstly, thank you, Associate Professor Whitlam and Professor Jones, for your submissions, which are very comprehensive, and your time giving evidence today. I asked this of other witnesses in our public hearing the other day, but I am interested in Austin Health's view on having an opt-out system in Victoria and what your views are as to the potential success of that or problems and so on.

Robert JONES: Well, again, we are on the recipient side. Certainly this has been widely discussed internationally and, as you are probably aware, recently introduced in other countries. I think it is probably not mission critical in that I think there is not a huge amount of data to suggest that it makes a substantial

difference. I think underlying that of course is still that community information and knowledge that is required to make an informed decision about donation, whether it is opt-out or opt-in. I am not sure—at best it is a personal opinion as a recipient; nothing to do with any data—whether it would be worth the pain and effort of trying to introduce that to Australia. There are certainly a lot of conflicting opinions for and against I think within the transplant community and probably within the wider community as well.

John WHITLAM: The only point I would add is that the transplant community are dependent on and benefit greatly from the public's trust in our organ donation system, and so we would strongly encourage any consideration of policy change in relation to organ donation to be incredibly sensitive to that public trust and to be very carefully designed to maintain that public trust. There is the chance of throwing the baby out with the bathwater.

Chris CREWETHER: You talk about introducing kidney machine perfusion at Austin Health. Can you go further into the resources you may need? You talk about trained technicians and funding for consumables, but can you go into more detail about those needs and also, beyond kidney machine perfusion, the general need for retrieval and transport resources at Austin Health.

John WHITLAM: Just to focus on the kidney machine perfusion program, we commenced this program this year, leveraging the success and familiarity of our retrieval service using liver machine perfusion, and our kidney machine perfusion devices—two hypothermic, the cold machine perfusion; and one normothermic, the warm machine perfusion a bit like the liver machine perfusion device—were purchased using funds raised by the Diamond Valley opportunity shop, and this has dramatically changed our options in relation to retrieval and transplantation of kidneys.

The consumable costs for the hypothermic machine perfusion device are \$7,000 per case, and the consumable costs for the normothermic machine perfusion device are about \$10,000 per case. Generally speaking, when I speak to people about this cost, you can see in their eyes the surprise at the cost, but just to put that into perspective, the hypothermic device costs the equivalent of one month on dialysis and the machine perfusion device consumables cost the equivalent of six weeks on dialysis, so these machines are expensive and they are expensive to run, but compared to the alternative, they are cost saving.

In relation to technician support the hypothermic devices go out to the retrieval site with the retrieval service. They are about this big. Once a kidney is connected to that device and the device is running, it gets closed up and it gets handled like the esky. It will be shipped to the Royal Melbourne Hospital or Monash Medical Centre, and as part of this program we are intending to train up their surgeons to remove kidneys from these devices. In the course of transport, they do not need any dedicated monitoring, so they are sort of self-contained and sit on their own.

Our vision for that technology is to use that for the majority of deceased donor kidneys in Victoria, particularly donation after circulatory death donors, to support transplant centres' confidence to use those donor kidneys and to maximise the utility of our existing donor pool.

As I discussed earlier, that volume in Victoria is quite substantial in terms of kidneys. The normothermic device is a more complex undertaking. That is a device where, like the liver, the kidney is actually woken up from its hibernation and there is an opportunity to assess its function to see if it is making urine, to see how blood is flowing through it, to see how it looks, to perform a biopsy. So we propose to use this technology only in cases where we think it could salvage kidneys. Kidneys that were otherwise heading for non-utilisation could have this technology used to assess their performance and substantiate utilisation, and so the proportion of kidneys that we anticipate using this technology for is substantially smaller than the hypothermic technology.

All up, given the volumes and acknowledging the costs relative to dialysis, we estimate that a fully fledged program would be about \$4 million a year.

Chris CREWETHER: Thank you. You have had liver machine perfusion for around four years, as mentioned in your submission. What have been the changes that you have seen in terms of the success rates over that time, and have you also had a similar reduction in other costs and time spent on dialysis and other treatments because of this increasing success rate with liver machine perfusion?

Robert JONES: It has been restricted just to liver, so it really has not overlapped with renal perfusions, and of course it is more expensive because you have the additional costs of the machinery and the capital cost and the running costs, and someone has to babysit this.

Chris CREWETHER: You can tell I am not an expert.

Robert JONES: The trade-off is additional organs that can be transplanted, so that is the enormous benefit. I think with kidneys, John, it will presumably increase the availability of donations. There will be more renal transplants being done.

John WHITLAM: And more flexibility around operating times.

Chris CREWETHER: This is where we need Chris Couzens here to correct my pronunciation. The Ngamuru Advisory report that was done, do you have any ideas as to why that was not disclosed publicly or shared in the medical community, or have you garnered at least some understanding of what is in the report?

Robert JONES: I do not think we really know. It was done simultaneously with the EY—the national federal—report, which had about 50 recommendations. There would obviously be tremendous overlap, so I presume it may relate to the EY report. Simultaneously at the moment the Nationally Funded Centres Programs are being reviewed federally—there is lots of chopping and changing about that that affects some of the programs.

Chris CREWETHER: Have you garnered some understanding, though, through presentations or other means as to potential recommendations enclosed within that report?

Robert JONES: I guess if I was doing the Victorian report, I would certainly want to know what was in those other reports to see, so maybe that has been part of the delay.

Chris CREWETHER: It certainly would be handy for our inquiry to have a copy of that report in terms of looking at our own recommendations.

Robert JONES: It would, yes.

John WHITLAM: We are all incredibly interested to know what is in that report. We all spent a substantial amount of time as clinicians contributing to the report. The Department of Health have done a remarkable job at keeping a lid on that report, so there is no back channel communication regarding the contents of that report unfortunately.

Chris CREWETHER: What are your views on abolishing family assent for organ donors except perhaps in exceptional circumstances?

John WHITLAM: Look, I think we would maintain that that is a question probably best put to the donation sector and also maintain the view that public confidence in the donation process should be maintained as a key priority in whatever decision-making is made regarding policy around donation.

Chris CREWETHER: What is the sort of percentage of medical and logistic reasons for an organ donation not proceeding where there is an organ that can be transplanted and there is assent? What is the sort of percentage of medical and logistic reasons, and what are some of the main reasons that a transplant does not occur in those circumstances?

Robert JONES: I am involved in the retrieval side, the surgical retrieval side, and it is the prioritisation of retrieval. If you are a major teaching hospital, you have an enormous waiting list of operations, and retrieval for organ donation is sort of added in usually at very short notice and usually very inconveniently. If we are at a smaller hospital, we are suddenly going to consume an operating theatre for quite a substantial amount of time, and that is going to affect their theatre flow and operating. So prioritisation of organ retrieval certainly is something hospitals have to be conscious of, and you cannot really program it in because it is ad hoc. You may only find out at 6 pm or midnight that somebody wants to take one of your theatres, and you do not have a spare theatre at most hospitals. So perhaps hospitals prioritising retrieval and fitting that in or at least being conscious of the ad hoc nature of it.

Chris CREWOTHER: I am sure there are some circumstances where you cannot just put off an operation if it might put at risk the life of the person who is needing that operation.

Robert JONES: Absolutely. For example, with the Alfred—a big trauma centre—and the Royal Melbourne, you can be heading out there and plan to do something at 8 in the morning and be told, ‘Sorry, there was an accident,’ and you are going to be sitting there for many hours. So we have to be very flexible. But certainly incorporating into the hospital system at least the concept of prioritisation for organ donation would be very valuable.

John WHITLAM: Just to extend upon that as well—there is a little bit of flexibility in timing of organ donation that is also used, I guess, to manage logistical stressors. Certainly in the kidney space the vast majority of non-utilisation arises from concerns regarding medical suitability, donor quality, et cetera, as opposed to logistical barriers to donation.

Chris CREWOTHER: Thank you. I have more questions, but I had better finish up because of time.

The CHAIR: Unfortunately, we are a couple of minutes over time, but I do want to, if we can have a few more minutes, just go into living donors a little more if possible, just following on from some of Cindy’s questions. I wonder if you can provide me with some information that looks at who the living donors are. For example, are they mostly family members or are they friends of a recipient in the cases to your knowledge?

John WHITLAM: I think most living donation in Australia would concern the kidneys because of the spare kidney opportunity that we discussed earlier. And in my personal experience, the majority of living donors are family members or in some way related to the donor.

The CHAIR: How would a non-family member become a living donor?

John WHITLAM: Well, anyone can donate a kidney. We also have what are called ‘altruistic living donors’. These are people who have no-one that they know who has kidney failure, and because they are just incredible human beings, they put their hand up to donate a kidney to a stranger.

Typically, unrelated individuals donate via what is called the Australian and New Zealand Kidney Exchange Program. This is a mechanism that effectively performs the role of a transplant allocation system, except for living donors. What this program does, which is supported by DonateLife and the Organ and Tissue Authority, is it matches living donors with recipients so that others who are paired to that living donor can receive a kidney from a better matched donor. So, for example, when an altruistic living donor becomes available, they also donate to the kidney exchange, and they create what are called ‘chains’ of donation. One altruistic living donor, one fabulous person who gives a kidney with no intended recipient, can start a ‘chain reaction’ that leads to seven, eight, nine other individuals receiving kidney transplants through the kidney exchange program.

So there are mechanisms, to answer your question, to handle unrelated donors.

The CHAIR: Do you know how many people would want to come and register to be a part of that program?

John WHITLAM: No.

The CHAIR: No? Do you know who would be best placed to answer some of those questions about that? Would that be the Australia and New Zealand kidney exchange program?

John WHITLAM: Look, to be honest I do not know whether anyone would know, because I do not think there have been population studies evaluating willingness to participate in voluntary altruistic living donation. Certainly, the experience in living donation from altruistic donors—that is, people who just want to give up a kidney because they are great people—is that it is a rather complex process to navigate that involves psychiatric evaluation to understand whether the intent of donation is altruistic and genuinely free of coercion and other factors. So at the moment the number of altruistic living donors in Victoria and Australia is still proportionately very low compared to the demand, the contribution from living donors who are donating because they know someone who has kidney failure, and the deceased donor pool.

The CHAIR: Do you have any recommendations around how to increase the number of living donors?

John WHITLAM: Clearly living donation is a very unique situation, and I certainly do not think, for example, it is possible to translate learnings and understandings concerning the deceased donor pool to the living donor context. Certainly, living donors do face a number of challenges, because living donation surgery is not a small operation. It is a rather substantive operation; the kidneys are relatively inaccessible in the back of the abdomen. So one barrier to living donation is the implications that that has for the living donor in terms of time off work to attend evaluations for living donation, which involve a series of appointments, scans and tests at the living donor centre, and then there is also the issue of implications for income and sick leave following donation. So there have been a number of strategies over the last 10 to 15 years that have led to paid support for living donors who miss out on work as a result of living donation, and I think perhaps there is a sense—and Helen Opdam from the Organ and Tissue Authority may have a better grasp of this than me—that in Australia we could be doing more to support living donors, particularly in relation to the time and cost of being a living donor.

The CHAIR: And just noting what you have told us today about the rates of dialysis and the demand for kidneys, before we conclude today, do you have any further comments or suggestions around how we can increase Victoria's rate of kidney donation?

John WHITLAM: Nothing beyond our submission.

The CHAIR: Great. Thank you. Thank you very much for appearing before the Committee today and for your contribution to this inquiry. I think you have provided us with a remarkable submission and evidence, and in particular the information you provided around machine perfusion technologies is really fascinating and life changing. The Committee appreciates your time and effort that you have taken to prepare your evidence. I do not believe we had any questions for you that you took on notice, but we will be providing you with a transcript for you to verify. The Committee will now take a short break while we prepare for our next witness. Thank you.

Witnesses withdrew.