TRANSCRIPT

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

WITNESSES

Dr Bernadette Hickey, Senior Intensivist and Medical Donation Specialist, Intensive Care Unit, and

Dr Yvette O'Brien, Intensivist and Medical Donation Specialist and Deputy Director, Intensive Care Unit, Organ and Tissue Donation Team, St Vincent's Hospital Melbourne.

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

I welcome our next witnesses, from St Vincent's Hospital Melbourne's Organ and Tissue Donation Team: Dr Bernadette Hickey, Senior Intensivist and Medical Donation Specialist from the Intensive Care Unit; and Dr Yvette O'Brien, Intensivist and Medical Donation Specialist and Deputy Director of the Intensive Care Unit. Thank you so much for attending today.

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

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

Bernadette HICKEY: Thank you. Thanks for inviting us to make a presentation today. Our document that we submitted has got a slightly wider remit than the actual terms of reference of the Committee. But I think the experience of the organ and tissue donation sector in general, especially families' and patients' experience of it, influences the community's respect, understanding and trust of the system, and that therefore also influences registration rates. So while some of the issues that we will discuss are not directly related to increasing registration, I think they are indirectly related.

One of the three areas that we wanted to highlight from our presentation is looking at trying to understand what is currently driving a decrease in hospital consent rates, and I think that information will already have been presented to you by other witnesses. We also then wanted to look at some of the issues about optimising the logistics of the organ and tissue donation process as it is experienced both by staff and by potential donor families, because there have been changes over time but also changes during the COVID period that may well have an impact on the experience of families and also the potential consent rates. And the third element that we wanted to highlight was the development and investment in sustainable donation and transplant teams, because that is something that you have already just heard from a prior witness—how people have concerns about it—and we will develop that idea I think under direct question.

We think all these are really important elements to focus on and to improve before as a community we start looking at some of the less established ideas about improving both consent rates and donation rates. In that heading I would include legislative changes for the opt-in, opt-out concept—which I am happy to discuss in more detail, but I am sure you have had people talk to you about the varied experience in legislative change alone in the international field—but also some of the clinical processes that are increasingly being trialled and discussed as ways of improving donation rates, such as warm perfusion rigs. And while they may have a role in the future it is our view that there is a much greater capacity for us to take the community with us by addressing some of these more mainstream issues.

The CHAIR: Great.

Bernadette HICKEY: That is my statement.

The CHAIR: Thank you very much. All right.

Yvette O'BRIEN: Well done.

The CHAIR: Thank you. I will start out with some questions. I understand in 2015 you undertook some research around organ donation consent rates in Victorian hospitals. I wonder if you could tell us a bit more about that.

Bernadette HICKEY: Sure. This is a section of research that we coordinated but other hospitals in Victoria participated in, particularly the Royal Melbourne, the Western Hospital and DonateLife, and it looked at a combination of qualitative and semiquantitative measures of the opinions of families—families who had agreed to donation and also some families who had refused the donation opportunity in our intensive care units in the preceding couple of years. It was included in a suite of additional research that we did looking at the attitudes, understanding and knowledge of clinicians—emergency department clinicians and intensive care clinicians—for the donation sector in general, but I think the thing that has relevance for this Committee is the work around why people said yes and why people said no to organ and tissue donation. And it was quite varied. We pulled out a number of themes; trust is one of them and understanding is one of them. We did not have a very large patient population. It was somewhat difficult to recruit to, and we had a limited time frame, but I think we did understand some of the social and the clinical and the hospital variables that affected people's decision about whether to agree or not to agree to donation.

It was built on work that had been done in the United States earlier in the 2000s, and we found things that correlated with the findings from the United States about families' understanding of their loved ones' wishes being strong predictors of the likelihood to agree to donation but also that their in-hospital experience—whether they felt valued, whether they felt rushed or whether they had a good global measure of the in-hospital experience—also correlated with their likelihood of saying yes to donation. I think that observation has led us to wonder whether one of the problems that we are experiencing during the COVID years and in the tail from the COVID years, where our consent rates are not as high as they were in 2019, is that there has been a general deterioration in families' trust in the health service and trust perhaps in community health messaging in general. But also there has been a limitation in the ability for families to spend time at the bedside over the COVID period, and it is really only just starting to return to normal. But there are still limitations on families' ability to spend time with a loved one in hospital. Our suspicion is that that is contributing to families' lack of desire to consent to organ and tissue donation.

The sector has a lot of theories around what might be contributing to the decrease in consent rates, but based on our experience of doing that research in the mid-2010s, I think the only way we would really know what is happening is by repeating some quantitative and semi-qualitative evaluation of what people are using to inform their decisions. And the only other thing I will say before I finish is one of the things that being involved in the donation sector for a long time has taught me is that it is quite difficult to make generalisations. People have a variety of reasons and reasoning about why they entertain one decision or another, and it is often emotionally driven as much as it is intellectually or substantively evidence driven.

The CHAIR: That is great. I have two follow-up questions, which I will just go through, relating to that. Are you aware of any current research being undertaken that looks at family consent rates and why consent is changing?

Bernadette HICKEY: DonateLife Australia or OTA has done the family follow-up studies. They have an acronym that currently evades me. That is research that is funded by OTA, and that has been conducted by an independent agency, I think based in New South Wales. There are three waves, I believe, of that study. The first was done prior to COVID. There is one being undertaken at the moment. Whether it addresses the same questions and what its substantive work structure is, I do not know.

The CHAIR: Okay. And then my second follow-up question: was your 2015 research made public?

Bernadette HICKEY: It is published. There are about seven or eight articles that were published from it. I think I referenced one in the submission that I made, which was on understanding Australian families' organ and tissue donation decisions. There are a number of others, but they were a combination of the issues influencing decisions but also the work around understanding emergency department clinicians' attitudes and understanding of organ and tissue donation knowledge, for want of a better word.

There have been suggestions the past that one of the barriers to widespread acceptance of organ and tissue donation as a concept in health communities is lack of knowledge or biases on one of a number of fronts. Religious belief is obviously one that people are concerned about—patients or people from culturally and linguistically diverse backgrounds not having either support or understanding of the process. And some of the other work looked at trying to identify whether clinicians or people who worked in the health sector felt that they had adequate understanding of the process, whether it correlated with their training and their years of training and if they were happy to identify with a cultural or a religious affiliation. Except for knowledge, we did not really find a lot else in the communities that we surveyed. But it was a set of descriptive work about people's knowledge and understanding.

The CHAIR: Okay, great. Those published articles, would you be able to provide us with copies?

Bernadette HICKEY: Sure. When I access them from Medline, yes, I can provide you with a copy of those.

The CHAIR: That would be greatly appreciated. Thank you. I will hand over to Chris now. Thank you.

Chris CREWTHER: Thank you, Chair. And thank you, doctors, for your submission and your time today. My first question is: can you elaborate further on revisiting the dead donor rule and consideration of normothermic regional perfusion, as mentioned in your submission?

Yvette O'BRIEN: Is that me?

Bernadette HICKEY: One of the –

Yvette O'BRIEN: You are on a roll.

Bernadette HICKEY: I am on a roll. I mentioned that in this submission because one of the suggestions for us to make a submission to the Committee was based on an observation from a colleague that there would be a request to revisit the dead donor rule in Victoria at some point. The dead donor rule is a slightly harsh descriptor of an underlying ethical principle in donation that extends from the 1968 President's Commission looking at the ethical basis for and definition of brain death, that you had to be dead before you could donate your organs. It then led to a description of the clinical situation in which brain death could be certified, and that informed the law reform commission's recommendations that then informed the Act in Victoria. And so the ethical idea is that you do need to actually be dead before organ donation is appropriate.

There was some publicity in one of the Victorian newspapers earlier this year, I believe of a mother whose son had been suitable for donation after circulatory death but did not die in the time frame, and the comments were made from that mother that she felt it was disappointing there was not an opportunity for her son to be a donor, given that he was going to be—it was an unsurvivable injury and he would die regardless. And I could understand that mother's opinion with regard to it being a waste, that otherwise organs that might have really helped someone else were not available for donation and therefore transplantation. But in my view, breaching the dead donor rule would be just a very substantial change in the way we consider the ethical basis of donation, and it would be, I want to say, very brave like Sir Humphrey to think that we might delve into that space. It may come that that is the community's view at some point, and if that were the case it would require a lot of work, thought and planning on how to do that, but I included it in this submission because it was one of the ideas that was proposed to us as a point for making a submission, and I think there is just so much else that we could do to improve the donation rate in the sector before we even need to start stepping into areas that are potentially quite controversial.

The normothermic perfusion is—you will have heard, I think, Dr Silvester talking about rigs and perfusion rigs—an evolving area of research where organs can be supported for a period of time on a perfused apparatus, and you can use that time to make a decision as to whether or not the organ is transplantable. I think that will be very valuable to increasing the number of organs that are potentially transplantable but at the moment are discarded because the concern is they will not function in the recipient. Normothermic perfusion is when you take somebody who has had an out-of-hospital cardiac arrest and restart their—so they are certified dead from out-of-hospital cardiac arrest because their heart has ceased for the period of time, but the circulation is restored using extra corporeal perfusion to perfuse the heart, kidneys and the liver in preparation for transplantation. I think personally that is a concept that many people would find confronting. It is happening in Spain, but I think it is something that many people would find confronting, that we have certified this person as dead on the basis that their heartbeat stopped, but we can now restart their heart and re-establish circulation and perfuse the organs with a view to transplanting them to another recipient.

I could make a longer discussion of it if you would like, but I include it in this document because I think if we go to that sort of length to try to improve the organs available for transplantation it will be creating a very big need for education and taking the community with us, and I am not sure that both the community or even a lot of the health sector would be comfortable with that as an intervention at the moment—albeit, it is happening in Spain. And at the recent conference the Spanish organ donor management organisation woman that dialled in said that she felt it was happening in Spain because they did not have the funding for rigs that is being made available in Australia. So they really do not have the capacity to do cold or donor organ perfusion, so they are being somewhat forced down a normothermic perfusion pathway.

Chris CREWTHER: Thank you, that was very informative. My second question is: when discussing donation specialist nurse coordinators you state:

> Victoria would benefit from a program to monitor and subsequently modify work practices contributing to staff loss.

I wonder if you can elaborate on that.

Bernadette HICKEY: Nurse donor coordinators do not report to me, but we do have one and two in our unit that are part of our team. It is a fact that there has been quite a lot of turnover in the sector in the last few years both prior to COVID and then during COVID, and every time an experienced nurse donor coordinator is lost to the sector, you lose a very large amount of investment and skill. I am sure you have been told in previous submissions how important that skill set is to the effective function of our system, so I think we always need to be mindful about whether the job is meeting the needs of the people who are doing it. Those needs will vary, but it is a time-intensive job. It is a difficult job for people with children and families to commit to because there is a lot of on-call and there is travel. So there has been a lot of turnover in the sector. It is more stable now, and the current DonateLife Victoria HR practices I think are working, but it is an area we need to be continually mindful of because when we lose skilled people, we lose more than just one person.

Chris CREWTHER: If I have time, Chair, my last question is: you talked about the optimal situation being 24-hour emergency theatre availability and said that staff shortages are one factor that influences that availability, but also you mentioned the funding model favouring elective surgery. I wonder, on that second part, if you can elaborate on this funding model and on how this funding model could be improved to better enable such 24-hour emergency theatre availability, from your perspective.

Bernadette HICKEY: Well, I am not an expert on emergency surgery funding, but I believe that there is an imbalance in the NWA model between the value that is placed on emergency surgery versus the value that is placed on elective surgery. It is not my area of expertise, but I believe that it is therefore financially less attractive to be doing emergency surgery than to be doing elective surgery and that that is a feature of the NWA funding model. I do have to say I am not an expert on the NWA funding model.

With the COVID and post-COVID staff changes, many hospitals have found it difficult to staff 24-hour surgery availability and to have elective or emergency surgery availability in the standard working hours. I think it is fair to say that it has not always been the case that there would be an immediate emergency surgery available in teaching hospitals, but over time that was a goal that was being worked towards, and it certainly assists the transplantation process when there is an emergency theatre available at all times. It is more expensive. You will have periods of time when there may be a fully staffed theatre that is under-utilised. But speaking solely from facilitating the transplant process, when that sort of theatre exists, it allows much more flexibility in the timing of the donor operation. It also means that when we want to time a donor procedure we are not bumping a booked elective procedure.

Chris CREWTHER: Thank you. Thank you, Chair.

The CHAIR: Great. Thank you. Cindy.

Cindy McLEISH: Thank you. We have heard that the consent rates have been dropping from 68 per cent—the family consent rates—in 2018 to 52 in Victoria in 2022. How does that compare to other states? Do we know?

Bernadette HICKEY: I do know, but I cannot provide you with the absolute numbers. I can tell you that when you see the graph, everybody is down, but we are down just a tiny bit more.

Cindy McLEISH: Okay, so it is all on a similar trajectory.

Bernadette HICKEY: Everybody except for South Australia—which is unfortunate. Everybody is down.

Cindy McLEISH: And unfortunate because –

Bernadette HICKEY: Oh well, South Australia always like to pretend that they are somehow better than everybody else.

Yvette O'BRIEN: It is a bit different though, really.

Bernadette HICKEY: They have got a different structure, and they have much more centralised provision of major health care. They do not have the major regional centres in the same way that Victoria does, so there are some differences that have made coordination and delivery of optimal transplant processes, we would think, easier than in Victoria. But they have for some time done well on the metrics around donation.

Cindy McLEISH: With the register, when you register to become an organ donor is there information that you think, as practitioners, could be there that is not there—things that could be included to perhaps make some of those discussions easier to get families over the line and consent?

Bernadette HICKEY: I have to be honest and say I have not looked at the MyGov registration page for some time. But if I were to go and look at it, the things I would be interested in seeing are whether or not there are adequate resources for people from culturally and linguistically diverse backgrounds, because increasingly the people that we have more need for discussion with are people that come from non-English-speaking backgrounds and from cultural backgrounds where we have less understanding of the way decision-making is structured within a family or the way that religious and cultural observances are important to a family. So I would be looking to make sure there were plenty of resources in that regard.

We have had very interesting education at DonateLife over the years from people from a whole range of spiritual and faith backgrounds talking about how that faith group supports donation, and I would have thought that a website would give a lot of opportunity for there to be audiovisual resources to support people who might be indeterminate about their decisions—that they could then help them confirm their decision. And the other thing that I would be looking for is some structure about how they involve their family in their decision, because I think one of the difficulties is that young people often are quite altruistic and they register to be a donor, but they do not carry their family with them. And although the registered decision to donate is often the thing that is most influential in the family discussion, if the family have substantial objections, then that can lead to a registered donor but the family not providing consent. So I would like to see on that website some practical instruction about how you take your family with you, and then that would probably also resort back to this idea about the resources that might be available to a person who registers, on how they would do that.

Cindy McLEISH: What about a tick box? 'Have you discussed this with your family? Yes or no. If yes, who? Mum, Dad or whoever.'

Bernadette HICKEY: I think there was at one stage a recommendation that—you know, it sounds slightly macabre—on an anniversary date, maybe your birthday, maybe New Year's Eve, you reinforce that decision and you re-describe it so that it is actually something that is then embedded in continual family discussions.

Cindy McLEISH: Can I just ask about the research you conducted eight years ago. How was this funded, and how quickly did you put it together?

Yvette O'BRIEN: The funding was St Vincent's, wasn't it?

Bernadette HICKEY: We were fortunate that we managed to convince St Vincent's to utilise some of the organ and tissue donation funding. When a registered donor goes through to complete donation, the federal government grant provides a moiety of funding to the organisation. It is not payment for the transplant, but it is an idea of some recompense that might backfill any additional expenditure that the organisation has had to make to allow that donation to continue. For example, if we had purchased a private intensive care bed for a day because we needed an intensive care bed or we had employed an agency nurse because we needed an extra nurse to facilitate the ICU bed, that would be the sort of funding backfill that the federal government money could be used for. We were fortunate in convincing the hospital that a section of that money could be used to fund the research, but then we were not successful in that continuing. It was partly because the guidelines of what that money can be used for were opaque, and there was a decision made that it was not suitable to be used for research. So we were not able to roll over continuing to use it from a research perspective. There could be a lot of reasons why we were not able to roll it over for a research perspective, but that was the one that was given.

Cindy McLEISH: Dr O'Brien, just in your experience, what has been the biggest barrier, do you think, to donation?

Yvette O'BRIEN: In terms of consent rates?

Cindy McLEISH: Yes.

Yvette O'BRIEN: Look, I have been doing this for a shorter period of time than Bernadette. I suppose most of my experience has been really through COVID, and I think many parts of our ICU experience have changed through COVID and have remained different since COVID. I speak particularly about ICU because that is where really the vast majority of donation occurs, but our acuity, our resources, our staffing and everything have changed and have remained different. As Bernadette elucidated, I think the relationships with our patients and families have changed over that period of time. I think it is largely because of that lack of time that we spend together nursing, building rapport, getting to know the patients and families and building a relationship of trust. I think that has changed both within our immediate environment and more largely throughout the community. Our workforce and what we are asking of our workforce have changed significantly. We have a tired, a stretched and a less well-resourced workforce. We have lost a lot of senior experienced staff, and I think we are rebuilding that capacity in a general sense in ICU as well as in the organ donation section. They are sectors that overlap and work together, and I think we are in a challenging position where we are trying to rebuild both of those aspects, which I think has flowed on to our capacity to have those really important conversations with families that might enable us to help a family come to a decision where they consent when they might be on the fence. So I think those are probably the biggest things.

Cindy McLEISH: Thank you very much. Thank you, Chair. I am done.

The CHAIR: Great. Annabelle.

Annabelle CLEELAND: Thank you so much for your time and contribution. Have you contributed to an inquiry or a report of this nature in recent years on this topic?

Yvette O'BRIEN: I have not.

Bernadette HICKEY: No.

Annabelle CLEELAND: Right. Sorry, I am jumping around a bit. I am trying to fill gaps I heard with questions without making you repeat yourselves. One thing about optimising logistics of the donation process I am particularly interested in. I guess I have been a bit surprised about the ways in which it is communicated when an organ or tissue becomes available. Do you see IT as playing a role? How can you streamline, improve and modernise the communication processes between hospitals, between retrieval teams, between the donor registration and the whole hog?

Yvette O'BRIEN: We had better not speak about the St Vincent's side of things. We are still trying to get a cohesive EMR within our hospital.

Annabelle CLEELAND: Please do.

Yvette O'BRIEN: So that would be, from our perspective, part of it.

Bernadette HICKEY: In 'Optimising the logistics of the donation process' in our submission, I think we looked very much at the front door of the hospital through the ICU experience and then the donation conversation and the donation procedure. So we have talked more about staff, staff training, staff retention and the availability and sustainability of transplant surgeons. The process more broadly sitting behind that, which does also influence the hospital experience, is the matching process. It does seem a little less than satisfactory that in the 21st century the organ donor coordinator is standing in a back corridor with two mobile phones and waiting on hold for someone to answer. I think there is the potential for IT to improve that, but it would have to be a whole-of-system process. In health care we have not been very successful at delivering whole-of-system IT initiatives, and I am not sure that, in trying to develop a whole-of-system IT initiative in attempting to streamline the matching process, the investment that would be required would match the outcome. My suspicion is that the donor coordinator who develops a relationship with the donor group in the Alfred, the Royal Prince Alfred in Sydney or the Auckland group and rings up and says, 'Hi, I've got this,' and they have got a personal relationship and they sort that out—even though it seems quite cumbersome when you watch it—may well be the best system that we have for some time.

I think the electronic donor record has made a difference. That was a piece of work that OTA designed and delivered. I think it went live just before COVID. So all of the information about the donor now goes into an electronic record, and it is available to anyone in all of the transplant sectors around Australasia, and I think that has made a difference. But for want of a better word, the argy-bargy around, 'Do you want this kidney or don't you,' and 'If you don't want it, have you got someone? If you haven't, I am going to go onto the next offer,' would be a process quite difficult to replace with an IT system. And the sort of system that would do it efficiently I think would be very expensive, and I am not sure personally that it would be a good return on investment.

Yvette O'BRIEN: Perhaps a more feasible sort of approach would be—I think what Bernadette is describing is that there is a lack of agreement, consistency and transparency amongst the transplantation groups, who all probably act in a very individual way around what investigations they want to aid in their decision-making, whether they will or will not accept a particular organ, and there is probably a lack of conformity across –

Bernadette HICKEY: There has been a commitment from the Transplantation Society to unify and make a standard approach to, for example, the assessment of an extended criteria kidney so that that evaluation will be uniform across the country. But we have not as yet got that uniformity, and if there was a uniform practice, that would certainly improve the efficiency of the donation and the organ suitability and the organ allocation process.

Annabelle CLEELAND: As an example of that IT barrier, the tissue bank of Victoria raised that their email, being under the department of justice, sometimes goes to spam—so they are kind of communicating that a tissue retrieval has had some issues. How does that conversation through St Vincent's occur with the tissue authority, separate from organ retrieval?

Bernadette HICKEY: The tissue bank would like automatic referral. They would like anyone who dies in the hospital to be automatically referred to the tissue bank so that they can then contact them and follow up whether or not they would be a suitable donor. We have not revisited that process at St Vincent's in the recent past, but the last time we revisited it the organisation had concerns about an unrelated party, the tissue bank, contacting a bereaved family immediately after the death of their loved one. I know that the tissue bank have experience with that, but they have experienced it through the coronial process, so families already know that their loved one is in the coronial process. When they receive a phone call from the tissue bank of Victoria, it is not that much of a shock because they know their family member is in the coronial process. The decision was made at St Vincent's that if a phone call was going to occur, it should occur from a hospital person, not a tissue bank of Victoria employee. We have tried to institute processes that allow us to do that, but we do not automatically disclose all deaths immediately to the tissue bank, which I think is what they would prefer. I mean, it may be timely for us to review that decision at an organisational level, but that is our current process.

It is actually not that many people that die in hospital that are not part of the coronial process or ordinary organ donation assessment, where tissue donation would be evaluated as a part of that, that would be suitable for tissue donation. There are a lot more exclusions to be a tissue donor, and there are not many people who die in the general hospital that would be suitable.

Annabelle CLEELAND: I am going to skip all over the place, so I am testing your mental agility at the moment—at this time of the day as well. In 2009, I believe, when we moved from a licence-based registration to a national registration of donors, did you feel like there were any changes in the registration and your access to that information in that period?

Bernadette HICKEY: I probably was—do you want me to answer that?

Yvette O'BRIEN: Yes. Look, I was not doing that in 2009, sorry.

Bernadette HICKEY: My simple answer is no, but my more extensive answer is I really was not part of accessing the registry prior to 2009. I came on board as part of the national reform agenda, and as part of that we then got access to the national registry. I do not have any problem accessing the national registry now—

although I do not do it myself; I ask one of the organ donation nurse specialists to do it. We do need to be mindful that you are meant to access the registry prior to death. It is not authorised to access it after death, but ordinarily if we are accessing the registry in an appropriate manner, it is prior to the certification of death. I do not really notice any difference, but I did not notice a burst of registrations either. I did not notice that many people who I was having conversations with suddenly had registered as part of the new arrangement.

Annabelle CLEELAND: Sure. Do you believe the age and acceptance criteria of donors should be reviewed? And my supplement to that is: just prior to you presenting, there has been anecdotal reporting that maybe since COVID it has been more conservative, on the retrieval of organs.

Bernadette HICKEY: Look, I think my approach to what is a suitable organ to donate is: is there a transplant unit that will transplant it? So the decision about suitability of organs for donation is really a question about suitability of organs for a unit to transplant, and I think there is probably a lot of assessment that goes into that. People are in the transplant business to do functioning transplants, but it is very difficult when you transplant something that fails. And so the three-dimensional cognitive and Gestalt assessment of whether or not an organ is suitable for transplantation is a pretty specialised skill.

I know there has been discussion in the United States that there are less extended-criteria organs being donated because there are now financial penalties within their health funding for failed donation, so if you put a penalty into a health system, people respond to that penalty quite efficiently. We do not have that in Australia, but there is a professional penalty that it is not a happy circumstance to have transplanted an organ that fails. So I think your question needs to be directed to a transplant centre about whether they are feeling that there are additional barriers or performance metrics being placed upon them that are influencing their decision about which organs to accept and which not to accept?

Annabelle CLEELAND: I will sound so intelligent if I articulate it like that as well. If you do not have anything to contribute, Dr O’Brien, to that question, at St Vincent’s are there any continuing COVID restrictions that exist when you are having that conversation with families around organ donations with a deceased loved one?

Yvette O’BRIEN: No. I think largely—and even during COVID—I suppose we would try to, you know, be flexible and arrange the circumstances where we would loosen visitation and so on. At the moment the restrictions have been lifted—we are able to have our families spend a lot more time in the unit—but I suppose what we are probably describing is a longer-term change in terms of patients and families and their attitudes.

Bernadette HICKEY: We still do have some visitor restrictions, though. Not for the unit –

Yvette O’BRIEN: Not for the ICU.

Bernadette HICKEY: but for the hospital.

Yvette O’BRIEN: Sorry, I think I was being very specific to the unit.

Bernadette HICKEY: So if someone, for example, was in hospital for another reason and they have a catastrophic stroke in hospital and they end up with us, the family may have experienced some limitation of visitation in the earlier part of their hospital admission. The work that was done in the United States in the early 2000s suggested that it was people’s whole hospital experience that contributed to their trust, distrust or their desire to donate, not just the care they received in that last period of time around a crisis. So I think there is potentially still some overlay, but we are working towards it being nothing and we certainly do not experience it in the ICU.

Annabelle CLEELAND: Sorry to add homework, but could you share that report with us or send us in the direction to get that US research?

Bernadette HICKEY: The Smirnoff report? Yes, I can.

Annabelle CLEELAND: Finally, because I have gone and exceeded my time—sorry –

Bernadette HICKEY: No, that is fine.

Annabelle CLEELAND: just with the surgeon availability comment in your submission, are you aware of a donated organ that has not been able to be utilised because of surgeon availability?

Bernadette HICKEY: Yes.

Annabelle CLEELAND: How frequently is that occurring at the moment?

Bernadette HICKEY: It is infrequent, but I think when you look at the fact that we have relatively low numbers, full stop, even infrequent events become important. I think training time for a transplant surgeon is probably 15 years, so you cannot just sort of decide, ‘We would like another couple next month’, you need to have a process in place of recruiting and training people for a long time. It is not a field that lends itself to combining well with other types of private practice, for example, so it is a specialised person that is going to be the transplant surgeon. Victoria particularly has operated on a model of what I would almost call sainthood, where people have been the sole person and taken call and done amazing amounts of work. But the current generation of trainees is not going to take up that model of employment, and we need to have a model that is sustainable, on call consistent with having a family life and work-life balance, and that will require significant planning and investment in transplant surgeons.

Annabelle CLEELAND: What is your view—and this might be a personal view, to both of you—on a dedicated organ transplant hospital, and managing those? Would that ease the logistical burden?

Yvette O’BRIEN: I have got a view; I do not know if you do.

Bernadette HICKEY: Yes, share your view.

Yvette O’BRIEN: I think you are still going to have patients that present to many hospitals that may be potential donors, and I think taking expertise and skills—you know, there is the retrieval side and then the transplantation side, and I think a transplantation hospital might be better resourced to have a full-time transportation team and that sort of comes back to one of Bernadette’s thoughts around: do we fund a full-time team of surgeons or a full-time team that can be deployed 24 hours to be able to facilitate donation rather than relying on a few people who might have other commitments, I suppose. But does that take expertise out of other centres? I am not sure what you –

Bernadette HICKEY: I do not think we are big enough. I mean, to some extent we have heart, lung, liver and kidney designated units at the moment, and the additional infrastructure support that is required for a hospital to support the work of a transplant unit is not inconsiderable. To have a hospital that both supports a transplant unit and delivers a transplant of every conceivable option would be a very large organisation, and my personal view is that I am not sure the effort and investment required to deliver that sort of a standalone organisation would be warranted. I think that we have a skeleton at the moment of a very highly efficient and functional transplant system in Victoria; we just need to make sure that we have got appropriate forward planning for it to be sustainable.

Annabelle CLEELAND: Thank you so much. Are there any questions that we have not asked that you would love to respond to?

Cindy McLEISH: Meng has not asked. Did you want to –

Meng Heang TAK: No, no, thank you.

The CHAIR: I have got a couple more –

Meng Heang TAK: I just thought that your comment about the multicultural, diverse, CALD background, is very important, and the interface is also very important, in terms of education and promoting awareness.

Bernadette HICKEY: Yes. Look, it is a huge topic and one that I am sure we could do better.

Meng Heang TAK: Yes. Thank you, Chair.

The CHAIR: One thing I just would like to touch on before we finish is obviously our inquiry is really about increasing the number of registered donors. I am just interested from a clinical perspective in, say you have a patient who is in your hospital and you are looking at end-of-life planning and, for example, that patient is not currently a registered donor, whether you would consider that an opportunity for them to get on the registry, or are the time frames not suitable for that to take place? Does that make sense?

Yvette O'BRIEN: For that patient?

The CHAIR: Yes.

Yvette O'BRIEN: I think probably that we would see the time frame for that individual, and we would be having conversations if they were someone that was potentially a donor. We would then just have those collaborative conversations to provide –

Bernadette HICKEY: I also do not think they would be capable of registering because they would not be able to make health decisions. My understanding of the registry at the moment is your health medical treatment decision-maker is not able to register you on your behalf. But I do not think it impairs our usual processes. We would just go through the usual processes. We have a fairly standard opening, which is: 'Your loved one is not registered.' That is not an uncommon situation. Many people in the community support organ and tissue donation but have not got around to being registered. In fact in my experience that is the more common family conversation I am having, rather than going into a family conversation saying, 'Your loved one is registered and this is what that means.'

Yvette O'BRIEN: I think doing those processes well, though, would be an opportunity for the families and their friends and their community to know more about donation. I think the flow-on effect is if we do that part of the conversation well with a patient who is not registered, that informs their family and potentially their community. I suppose them having a positive experience potentially has a flow-on effect to raise awareness within their community, and I think that is particularly important in communities that are under-represented already on the register and in this field. We were talking a little bit more before we came about opportunities, apart from all the online resources, but reaching out into those communities that have been under-represented—and they often are culturally, linguistically and spiritually diverse communities—having more champions and people that they can relate to and trust working within those communities, embedded within those communities and providing positive reinforcement of donation and transplantation, perhaps highlighting the benefits of donation on one side in terms of the transplantation effects that it has on a patient, families and communities. It is a bigger investment but maybe one that might be more effective.

The CHAIR: On that, who do you think would be best placed to go into those communities—I guess from having that health and clinical expertise—as an expert in organ and tissue donations?

Yvette O'BRIEN: We did not workshop that part. We had the idea.

Bernadette HICKEY: My answer to that is the people who need the transplants, people who are on the list, people who have received an effective transplant, to go and say why it is so important. Over my time in the sector we have gone from wanting to be very aware of not being coercive about people's decision-making, and so really not disclosing too much up-front—that if your loved one is a donor, it could influence and improve the health outcomes of 15-plus people—because that was sort of seen as a bit coercive. We have now come to a point of being much more balanced in the information that we provide. It is important people understand what a life-transforming activity being able to be an organ donor is. I think the answer to your question is you can use a whole range of media, but the best messenger is that person who has benefited from donation as a successful transplant recipient. There is a reason that all those DonateLife posters have smiling children who have received livers on them. There are not many things in our work that transform people's lives, but a successful organ does. I think we need to get that message out into communities that have not had experience with advanced western medicine, where successful transplantation is not something that they are particularly aware of.

Yvette O'BRIEN: I think the donor family sometimes could also tell a powerful story. Certainly your work and the work of DonateLife and OTA is that donation families often talk about the positive impact that it can have, knowing that they have done something for the good of others in a really difficult and tragic time for their family.

Bernadette HICKEY: Time is up, but one of the things that people talk about is recognition of donors and if there is a way to do some sort of appropriate recognition of donors. It has gone from some sort of financial moiety through to some token of acknowledgement. I do remember a lady who was trying to get a petition signed outside South Melbourne Market a number of years ago simply to have organ donation acknowledged on someone's death certificate. But there are a whole range of ways that being a donor can be acknowledged beyond having your name on the piece of paper at DonateLife or at the tissue bank, and I think revisiting some of those might also be worthwhile. I do not necessarily think we should be paying for peoples' funerals, but I think there are other ways of acknowledging that people have been generous enough to donate in an emotionally difficult time.

The CHAIR: We had a witness earlier from Monash Bioethics Centre talk about some of those options for recognition and some of the ethical challenges around that as well, so that is a really timely comment from you. Thank you.

Yvette O'BRIEN: That might be a good place to stop.

The CHAIR: Thank you very much for appearing before the Committee today and for your contribution to this inquiry, both the written submission that you have provided and the time taken to prepare for today. It is greatly appreciated. You will be provided with a proof version of today's transcript to check together with the questions taken on notice. Verified transcripts and responses to questions taken on notice will be published on the Committee's website. I thank all the witnesses who have given evidence to the Committee today as well as Hansard, the Committee Secretariat and the security team here. The Committee will continue its public hearings for this inquiry tomorrow, Tuesday 25 July 2023. I declare this hearing adjourned.

Committee adjourned.