

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

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESSES *(via videoconference)*

Associate Professor Christopher Hogan, General Practitioner, Member of Victoria Faculty Council and Historian for the Royal Australian College of General Practitioners Victoria,

Dr Bindiya Sethi, Co-Deputy Chair, Victoria Faculty,

Dr Aadhil Aziz, Co-Deputy Chair, Victoria Faculty, and

Mr Kon Kakris, State Manager, Royal Australian College of General Practitioners.

The CHAIR: Good morning, everyone. We will now recommence the 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 the Chair of the Committee. I am joined today by Deputy Chair Annabelle Cleeland, Cindy McLeish, Chris Crewther and Meng Heang Tak.

I welcome from the Royal Australian College of General Practitioners Dr Christopher Hogan OAM, general practitioner; Dr Bindiya Sethi, Co-Deputy Chair, Victoria Faculty; Dr Aadhil Aziz, Co-Deputy Chair, Victoria faculty; and Kon Kakris, RACGP Victoria State Manager.

All evidence being 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 of this hearing may not be protected by this privilege.

I invite you now to make a brief opening statement of approximately 10 minutes, and this will be followed by questions from Members. Thank you.

Christopher HOGAN: Thank you. All right, with your permission, I will start off. As a GP, I have had multiple involvement with organ and tissue donation. When I was working in a hospital, I had to ask relatives to donate their loved ones' organs. During routine practice, I discussed organ donation at the same time I discussed preparing a will and enduring powers of attorney with my patients. I have seen patients who have benefited from organ donation, and I have seen patients who have confirmed their loved ones' gifts of life to others. Now it is personal, as my eldest son is on dialysis and awaiting a kidney transplant.

What are the barriers? The first barrier is the poor health literacy in the Australian community, which leads to multilevel ignorance, misperception and conspiracy theories about death, health and organ transplantation. Society-wide risk aversion and the terror of doing the wrong thing often leads to people doing nothing. The next issue we have is relatives who will override a donor's expressed wishes and refuse donation. And the other thing is cultural issues.

When it comes to health literacy, we are in a sad situation. The last estimate of health literacy was done in 2006, where less than 41 per cent of Australians aged 15 to 74 were assessed as having adequate or more than adequate health literacy skills, which means that 60 per cent did not.

What are the strategies? Well, the first strategy is the opt-out donation option: rather than seek a person's permission to donate, make it such that all people are donors when they gain a drivers licence unless they specifically refuse to be donors. Now, if that fails, the discussion generated by such legislation will significantly heighten community awareness about registering for organ and tissue donation. Also, education to encourage affordable, accessible first-aid training at the time of gaining a drivers licence for those who have not been educated in Australia, or even those who have and missed out, and support for health education and first-aid training in schools, as per the Australian Resuscitation Council's advice. The other thing would be community education and advertising programs for organ and tissue donation—there is a current program, but unfortunately it does not explain how much the community has to learn.

Finally, I would like to state that GPs' time is precious and their workload is significant but supporting organ and tissue donation is important to us all. Thank you. I think my other colleagues may have something to add.

The CHAIR: Thank you, Chris. We are happy to hear from your other colleagues too.

Bindiya SETHI: Hi, my name is Bindiya Sethi. As Chris has just mentioned, putting something on the driving licence—say, for example, when you get a driving licence for the first time, on the form, when they actually get the medical done by a GP to get the driving licence, there should be an option where they should tick. After discussing with the general practitioner they should actually tick whether they want to be an organ donor or not, and they can opt out at that point basically. This annotation should be printed at the back of the driving licence, and in case of emergency that is where we basically, you know, have the time to see whether the person is going to be an organ donor or not. A driving licence is the best opportunity basically. You flip it and see whether this person wants to donate organs or not, and I think that is the best way to go.

The CHAIR: Thank you.

Aadhil AZIZ: Hi, my name is Aadhil Aziz. I have a very similar experience to Dr Bindiya. I lived in America, in New York, for a long time. On the back of my drivers licence there was a tick box, and you could tick it by pen, or it could be printed by the drivers licence organisations. And, yes, that is a very effective way because you simply get to state then and there. Unfortunately, a lot of organs are harvested at a car accident. The patient is brain dead for whatever reason, but all their organs are alive. And when you have this tick box, then in America at least it is a call to action. There is this whole chain of events that happens: organ donation teams are activated, they fly there—they are there within, you know, like, minutes or half an hour at the most—salvage the organs, salvage the body, and they transfer the body to the nearest hospital. And that is in a 300 million population. This is certainly something we can easily do in Australia. We have the means, we have the technology, we have the funds and we have the ability and skill set to do it, and it is certainly something we should do.

On a personal note, I have been a GP for about 10 years. I have been a doctor for 22 years. In my first 10 years I used to be in surgery. I did neurosurgery and renal transplant surgery. In my country of origin I was on the first renal transplant team ever, and I assisted in over 50 transplant surgeries successfully. And it is a real struggle to find organs. I can speak very, very, very in detail about renal transplant, but of course I am talking about organs in general. It is a really hard, heartbreaking thing to see patients and family members just waiting, waiting, waiting because they do not have a family member that is a match. And sometimes they actually do not make it—their kidneys fail to the point where they actually pass away—and that is something that should not be happening in such a beautiful country as ours. Thank you.

The CHAIR: Thank you. Anything further with regard to your opening statement, or are you happy for Members to start asking questions of you?

Christopher HOGAN: Unless Kon has something to add, we are more than happy to answer any questions you might have.

Kon KAKRIS: I have nothing much further other than what has been indicated already, but, similarly, I have got a personal connection too. My wife, who is an ICU nurse, used to be an organ donor transplant coordinator for the states of Victoria and Tasmania. It was many years ago, but she speaks to the challenges she had convincing families to donate organs. And at that time—I mean, you said that is often a highly emotional, highly charged environment. It is not the right time to be having those conversations for the first time with grieving loved ones. Her advice, which she asked me to pass on, was that these conversations need to be had much, much earlier, and they need to be clear so that everybody knows and it takes the emotion away from the situation.

Bindiya SETHI: I would like to add something. As we discussed and as Chris mentioned also, and I think Aadhil covered a part of that as well, if there are any cultural barriers and if there are any cultural reasons, we would need to increase the health literacy and basically discuss those cultural reasons and the barriers and if there are any myths. So health literacy would need to be really very good in terms of whether we can actually cross those hurdles and the barriers.

The CHAIR: Thank you. Alright, so we will get started with some questions now, and I might start on behalf of the Committee. So thank you all for providing that information in your opening statements, and thank you as well for sharing your own personal stories and different connections to organ and tissue donations. Personal stories are always incredibly powerful in this space, and we are really appreciative that you have shared that with us.

We have heard a lot from other witnesses in this inquiry so far about the importance of conversations—those conversations between health professionals, whether it is a GP or an ICU nurse or a surgeon, having that conversation with the family members of the person involved. What do you think are the best ways for GPs to be having those conversations, noting, Chris, I think it was you in your statement, you mentioned that GPs are under pressure and there are a lot of time constraints to be very conscious of?

Christopher HOGAN: One of the techniques that I used to use was that I, for a long time, had a sign on my wall that says, 'Why take your organs to heaven? Heaven knows we need them here.' And people would laugh at that and would talk to me about it and then we would discuss it. And I like to incorporate it as part of the

routine. I think it is extremely important that people make preparations for their mortality or incapacity, so I have always been an advocate. Even as soon as people were employed I used to encourage them to have a will and to have an enduring power of attorney. I think that making it part of the routine is important. And the other thing too is that one of the things that I teach my students, and I am an Associate Professor, is that the important thing for a doctor to do is to first of all deal with the concept that they are not going to be here forever and that they will one day die. And once we get that out of our way and discuss it, then we can talk about it with other people. That is one of the things that we talk to our students and registrars about, to confront our own mortality, to accept our own mortality and to realise that we are here for a good time, not for a long time.

The CHAIR: That is good advice. And are there any supports in place for GPs to be having those conversations, for example, through the RACGP—you know, say, some suggestions about how GPs can approach that conversation?

Christopher HOGAN: Well, yes. A formal part of our training is how to have difficult conversations with patients, and there is no shortage of difficult situations. But I would think that one of the things is that there is a great push at the moment for enduring power of attorney for any of our patients who have undergone or are about to undergo serious health events, but also as a part of their routine.

A large proportion of general practice is devoted to preventive work, and the most important preventive work is to make sure that their families are supported should anything happen. We deal with families, and I have had people come in who have been the fifth generation of a family that I have seen. So the idea of spreading the message out to make it routine, to make it part of what we do—you know, sort of ‘What’s your name? What’s your address? Do you have any drug allergies? Have you made your will?’, that sort of business—is something that is important, and I think the opportunity to discuss it. Certainly we know that in the informal structure that general practice is, every time there is something of importance in the media, we are often asked to comment on it. I would think that that discussion is being held at the moment, so when I was talking about advertising and how the GPs would love to be able to support that sort of stuff, it is something very close, as I said, to my heart.

The CHAIR: Just to expand on that a little further, is there anything that can be done to improve the supports in place for GPs to have those conversations or anything that you think can be driven by the government in this space?

Aadhil AZIZ: If I may jump in here—I actually had my hand up—Chris is right. We do definitely have the skill set to have those conversations. We are well trained and we are able to have those tough conversations. The practical issue is time. We do have a lot on our plate. I am sure you guys have heard that after COVID we have got doctors who can retire retiring early because of lack of funds to general practice. We have shortages of young doctors choosing to become general practitioners, and this means the working doctors are getting squeezed for time. So as a way around this, my recommendation would be to have some kind of marketing campaign or an ad campaign going nationally which would encourage patients not to add this on at the end of a consult or not for doctors to have this in addition to the other 20 things we need to talk to a patient about or not to put the onus on the doctor to bring this up with their patient at the end of 15 other things they are here for, but an ad campaign explaining to patients that they can go make an appointment with their doctor to only talk about this singular point. When you have that time based for that consult, then you can really get into it and you can explain in very great detail its importance, its significance and how this helps all of us.

The CHAIR: Great, thank you. Would anybody else like to add anything to those questions before I hand over to my colleagues? Great. Annabelle, thank you.

Annabelle CLEELAND: Thank you. I am interested in honing in on your research from 2018 and the effectiveness of that. Did you review that research and see how many potential new people you encouraged onto the national donor registry, by any chance?

Christopher HOGAN: No. Like any GP, I have had multiple draws on my time, unfortunately, and have not had the opportunity to do that. That work that I was talking about is actually from the Australian Institute of Health and Welfare. It is a Commonwealth report, and if you wish I can send you the link to it.

Annabelle CLEELAND: Yes, we would appreciate that. Thank you. The information packs that were sent out to 3,600 practices—for that to occur again I guess I am interested to know: was it effective, and if so, what are the barriers to replicating that?

Christopher HOGAN: Well, some of my earliest research was to actually weigh the amount of correspondence that I got, and in the 1990s I was getting seven kilos of mail a month.

Annabelle CLEELAND: So we need to duplicate you, Dr Hogan. Is that what you were saying?

Christopher HOGAN: The trees will not thank you for it. The ability to contact and interest GPs is a skill for which I ran a research unit based in general practice for a while, and we looked at the strategies that we could use to contact GPs. It is actually extremely difficult to get their interest and to read their time, and I used to have a pile on my desk of the papers that had to be read at the first available opportunity. So I think basically the ad campaigns hit doctors as well, and they are aware of them. The multimedia access is a way of doing it, so I am sure that that is done. What the college have done in the past is to provide extra support to doctors who are interested in pursuing these things, but we find that if the GPs do not ask for the information, providing it to them is not helpful.

Kon KAKRIS: I would like to add to that further. As Chris indicated, the sheer weight of physical mail sometimes does not even get to a GP, because the practice manager quite rightly will sort through what they are getting and see what is of critical importance that a GP might need to see. Nowadays through technology I think we have far better options to be able to communicate important information like this, one of which is the potential embedding in various numbers of practice software prompts that GPs will need to acknowledge and recognise for the communication that they have received. I know there are some quite old-fashioned GPs that prefer to get their information in hard copy, but that number is decreasing over time. One of the ways we can better utilise technology nowadays is to do so through practice software that, to my knowledge, just about every GP has to use nowadays, to be able to pass that information on.

Annabelle CLEELAND: Sorry. I hope I am not interrupting anyone else's contribution. GPs as well as Lifeblood have come up a lot as the conduit of the conversation between organ donors and registration, so I am interested to know that time is the biggest barrier. Are there any other barriers for GPs playing a role similar to Lifeblood in having that conversation? It just came up this morning as well, the opportunity for cheek swabs for stem cells, which has got major barriers of registration as well.

Aadhil AZIZ: I think there are some cultural barriers, not necessarily from GPs but from certain communities. I know there are some Muslim communities where you cannot really, you know, desecrate the body, for lack of a better word, but I think it is just back to health literacy. If you explain to these cultures and communities from their point of view—like, let us say if it was themselves, a loved one, a family member or a really close friend, then what would they do—then they start to open their eyes. Maybe you might not get every single person to change their religious views or cultural views, but you could certainly change a vast number, enough to increase the number of organs available.

Annabelle CLEELAND: The major advocacy group DonateLife, have they been in touch with GPs to see what opportunities there could be for that sort of collaboration?

Kon KAKRIS: In the three-plus years that I have been with RACGP Victoria I can say no—not with me anyway.

Annabelle CLEELAND: Now, I think it was Dr Aziz who, I believe, raised the drivers licence.

Aadhil AZIZ: Yes.

Annabelle CLEELAND: Great. What about another opportunity with the Medicare card? I guess in Victoria we are looking at going to a digital licence, so that removes the physical, but we are still quite reliant on the physical Medicare card. Is there a similar sort of opportunity with that physical representation of consent?

Aadhil AZIZ: Absolutely. Dr Bindiya also mentioned the drivers licence, but I said the same thing. I was actually shocked. Actually, before this meeting I pulled my Aussie drivers licence out and had a look and made sure there was no actual organ donation thing on it. And I was like, 'Oh, there isn't one.' And that really shocked me, you know, because everywhere else I have lived—and I have lived all around the world—we do have that little tick box. So yes, it does not have to be a drivers licence. It does not have to be a physical card. A physical card does make it easy, because with face ID and phones being locked it may be a little bit harder to

access it unless the police or the ambulances have some kind of way to bypass the security on their device. But yes, whatever technology is available, that would be the way forward. I think you might have to, in this day and age, have a combination of technology and old-school just physical cards, and I do not think it is that expensive to have something printed on the back of your Medicare card or your drivers licence.

Annabelle CLEELAND: If no-one else—actually I have got two –

Bindiya SETHI: Sorry, yes, could I add something to it? I do not know if it already is, but if the database of organ donation was a central system which the emergency people can access, then the list of people who are potential donors could be accessible from the emergency services to the doctors who have to make the decision with the family—or without the family if the family is not around or if the person does not have a family—and whatever decision needs to be made can be made. So quickly checking on the central database and being able to find out whether this person is going to be an organ donor in, you know, a situation of emergency is another thing which can be incorporated potentially, I guess.

Annabelle CLEELAND: Dr Hogan, I am sorry to hear about your son. One thing that we learnt early in these public hearings was around the financial benefit of having more robust organ donor registration with the cost of dialysis per person. So from all of your expertise, what do you see as the financial benefits or the economic potential benefits of having more robust organ donor registration?

Christopher HOGAN: Quite simply put, it turns people from being a burden on our health system into positive contributors to the community. It is literally a gift of life, and it gives people back their lives not only from a financial point of view but also as an individual point of view. Before my son went onto dialysis, the basic function was all he could manage, and his ability to work was more an act of courage than anything else. Now that he has the dialysis, which he undertakes at home, effectively he can do anything he likes so long as he does not leave home for more than 48 hours. And to a person who was a traveller, that is fairly difficult, but for other people—I mean, I have seen friends of the family who have been incapacitated even by dialysis and have been able to return to a full and productive life for the time that they have left. It is transformative, and as I said, it is truly a gift of life.

Annabelle CLEELAND: Just on that, Dr Hogan, how long has your son been on a waitlist?

Christopher HOGAN: So from the day he started dialysis, which is getting onto eight months now.

Annabelle CLEELAND: Thank you for sharing that.

Aadhil AZIZ: Yes, I can speak to that as well, having had the pre- and post-transplant interactions with multiple patients over the years. It is life-changing. You are taking someone off a dependent situation where they are in hospital three to four times a week for three to four hours or four to five hours, depending on their need for dialysis, and literally returning them back to being a fully functioning human being. And none of these patients want to be sick. They just want to be healthy and live normal lives, and once they are able to live normal lives, they return to the workforce. So yes, like Chris correctly said, they stop being a burden—and that was your question—to the healthcare system, and they start contributing to the economy again, which is what, really, every human being wants to do.

Annabelle CLEELAND: Thanks, Ella.

The CHAIR: All done—great. Thanks. Heang.

Meng Heang TAK: Thank you. I thought my question would go to Dr Aziz. You have already touched a little bit on cultural background. When there are difficult conversations between GPs and patients about organ or tissue donation, do you think it would be a bit easier in terms of the conversation between a GP and a patient if they came from or shared a similar culture and background?

Aadhil AZIZ: Absolutely. I did a campaign for Cancer Council Victoria, and I would be happy to be involved with a campaign like this. We ran many campaigns for different cultures, like we had different languages, like people from different backgrounds speaking their own native language promoting things during COVID. And this is something that we could use similarly here, too, where we could target different communities by getting doctors from that culture speaking their language saying, ‘Hey, go visit your GP, make

a booking and have a conversation about this because this is something that could affect you or someone you love.' Yes, these are difficult conversations, but everybody thinks this is going to happen to somebody else until it happens to you or someone you love, and that is when you wake up and go, 'Oh, now we need assistance.' So just bringing this into the public's radar because with a lot of things we are just too busy with life and we forget about things. I do not think the target audience is the GP. I think the target audience here is the Australian citizen, and they have to make that appointment with their respective GPs. And correctly said, sir, that if you speak to a GP with your cultural background, you are probably going to get a better outcome.

Meng Heang TAK: Thank you. And would you share a similar—perhaps Dr Sethi even, if I can ask the same question?

Bindiya SETHI: Yes, I agree with what Dr Aziz said, that cultural barriers can be big barriers and if the patients could actually make an appointment with the GP and discuss that, and the way we can encourage those patients is with appropriate campaigning. I mean, as Australians we are a multicultural country, and then if we could campaign and encourage the people of various cultures to actually make that appointment and discuss those barriers and book the appointment with the GP, then I think we could do much better.

Meng Heang TAK: Okay. Thank you.

Kon KAKRIS: Further to what Drs Aziz and Sethi have indicated, what we learned through COVID in particular, particularly trying to encourage the uptake of vaccinations, is when we engaged community members to speak to general practitioners who were in their own community from the same cultural background, that made a significant impact in terms of the uptake of vaccinations in helping to dispel some of the myths and miscommunication that was out there in the community. So we have seen that in action. We have worked closely with the Department of Health on a number of different health campaigns where we have purposely targeted clinicians from certain cultural backgrounds to help address some of those challenges.

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

The CHAIR: Thank you.

Christopher HOGAN: I can add to that. I have an Italian ancestry as well. Being able to understand the Mediterranean mindset is particularly helpful, and I found it to be useful. Part of our training as GPs is in cultural sensitivity, and that applies not only to First Nations but it also applies to every other culture that we encounter.

The CHAIR: Thank you. Cindy.

Cindy McLEISH: Thank you, Ella. Thank you, everybody, for taking time out of your exceptionally busy practices today. Can I just ask first of all for a show of hands: who knew it was DonateLife Week this week? Okay, 50 per cent. And following on from Annabelle's questions before, I was quite surprised that it is DonateLife Week and I have seen in some places a lot of literature and advertising, and I thought that it would have been quite useful for you guys to be involved or understand that as well. Are you surprised that you have been left out of the loop here?

Aadhil AZIZ: I should clarify, I only knew it was life week because of this meeting. I probably would have missed it if I was –

Cindy McLEISH: Okay. We are down to 25 per cent.

Christopher HOGAN: I heard it on the radio this morning.

Cindy McLEISH: From my point of view—and probably that of the Committee Members—I would have thought that because you have so much interaction with patients at all different times of their lives and with their families, undergoing different treatments and circumstances and things like that, that you might have been good to be hooked in. Another quick show of hands: who works in country Victoria? No-one? Okay.

Christopher HOGAN: I used to. I am in Sunbury, and Sunbury used to be rural when I came here.

Cindy McLEISH: I will accept that. A couple of us here are country Members of Parliament, and I was just going to start, actually, with: all of you have an understanding of organ donation and that is why you are here today. How do you think that stacks up with the general GP population, and in particular country versus city? I will take anybody's comments.

Aadhil AZIZ: General practitioners are all trained to the same standard, so like Dr Chris correctly said, we can all have those difficult conversations. It is not just about organ donation, it can be about a million things—end of life, whatever it is, you know. So we are all trained the same, but you might have a doctor too that slightly has their own personal viewpoint, like with any health condition or any sensitive topic. But I would say in general everybody would have the same literacy—the doctors, I mean. Now we need to get the patients on board.

Cindy McLEISH: Yes. So even though the doctors might have that same literacy, I guess it is another thing to put it into practice.

Aadhil AZIZ: That is just time. We do not have the time to—like, every time a patient comes in here, I have so many things to go through. I mean, I will be lucky if I make it to their family history if they are a new patient, you know, on that first consult. So I am going to often get them in for a second consult and a third consult—and patients are busy, too, with their mortgages and their kids and whatnot. They do not have time to come to the doctor. If they are not bleeding and they are not having chest pain, they will push it off, especially guys.

Cindy McLEISH: Yes.

Bindiya SETHI: Also, when the patient is coming in for a general thing and suddenly you bring up the topic of organ donation, I think the patient feels like, 'What are we talking about here? I am here for something else.' So I think that an appointment really specified for this purpose or allocated for this purpose would be really good, so that the patient knows what the context is going to be and we are not just bringing up organ donation when you come in for flu or a cold or something.

Cindy McLEISH: Yes. A bit out of context.

Christopher HOGAN: Yes. I think it is extremely important that one of the things we look at is the way that people retain information during consultations. One of the things is that if they are not well, they are not going to remember a whole lot of what happened. I can still distinctly remember someone came in with asthma and it was complicated, so I went through 40 minutes and they went next door to the pharmacy, which my wife happened to be working at at the time, and she said, 'What did the doctor say to you?', and was greeted by a blank stare. She said, 'Well, did he give you anything?' She said, 'Oh yes, here is a handout', and my wife was then able to look through the handout. But people's recall about what happens during consultations is –

Cindy McLEISH: Limited.

Christopher HOGAN: variable.

Cindy McLEISH: Variable, that is probably a good point. One of the comments that came up earlier was about how difficult it is for families when they are put on the spot, if there has been an accident or something has happened and they have to have these conversations. If it has come out of the blue—but even ones that may not have come out of the blue, where people may know that somebody is going to die—what are the fears or the lack of understanding do you think that families have? Is it not knowing the wishes of the person who is dying, or is it other factors?

Aadhil AZIZ: Yes.

Christopher HOGAN: It is –

Aadhil AZIZ: Yes, go ahead.

Christopher HOGAN: We have what we call the universal medical answer, the answer to every question in medicine. It is two words: it varies.

Cindy McLEISH: Yes.

Aadhil AZIZ: I was just going to say this is primarily why if you have something on a Medicare card or drivers licence, then it takes out that guessing game—you can just show the family ‘This is what your loved one wanted, this was their wish, they did not make it on a whim, it was a choice.’ I do like Dr Chris’s idea of opt out, not for any other reason except that it would drive the conversation; you are going to get a lot of interest, just like we did with eHealth. We made people opt out, and a certain segment of the population got very angry and upset, but it drove the conversation. So if nothing else, that is probably good. Or even having a vote on whether we are going to opt out—that would drive the conversation. And that is what we really need here: we need the conversation to be driven.

Cindy McLEISH: We have had some evidence—sorry, Kon, have you got your hand up?

Kon KAKRIS: I was just going to add, as I touched on earlier, previously my wife was an organ donor transplant coordinator, but she was also an ICU nurse for over 30 years, and she has had many, many conversations with family members whose loved ones were on the verge of death and been brain dead and having that conversation. More often than not, she has related, is that when raised, the family—again, emotionally distressed and all the rest of it—did not know what the person’s wishes were; they had never had that conversation. And that is a very, very difficult thing for them to decide in that moment.

Cindy McLEISH: Yes, terribly stressful. We have also heard evidence that, despite knowing in some instances that their loved one wanted to be an organ donor, families have overridden that wish. Has anyone got an example of where that sort of thing has happened, and what were the key reasons?

Aadhil AZIZ: Yes. There is always going to be a handful of cases like that, but that is not the majority. The majority respect their loved ones’ wishes, and they go through with it. In this little handful of cases that make the media, I do not think that is really the objective here. I do not think we should focus on the few. This is maybe 2 to 3 per cent out of, like, 100 we are talking about.

Cindy McLEISH: Yes. Fair point.

Christopher HOGAN: Yes. I also used to have to ask for permission to perform autopsies when I was in hospitals. The main thing about it was I discovered that as soon as I adjusted my attitudes to it, as soon as I made the decision that I would like an autopsy after I die, I found it became a lot easier to ask other people to do it. The thing that also happens is they say, ‘Well, what do you do, why do you want to do it, and why do you do it?’ I think it was just the ability to have them in a situation where they felt they had control, because they could say no. They would say, ‘Well, what’s it going to do?’ And I used to say, ‘Well, the first benefit will be to the family.’ ‘What do you mean?’ ‘Well, one, if we know what happened to the person, that will be able to inform those people who were biologically related to them or those people who have been exposed to the same circumstances.’ I think that making it personal and saying that, you know, ‘It’s a gift of life and it will change lives’ and it is not just whether you cut up a body or you disfigure a body or whatever that is, because these days we refer to death as the last taboo. It is basically a matter of an open and gentle conversation, and saying, ‘You can do something.’

I still remember I had a very troublesome incident where I had a person under the age of 20 who was brain dead, and I asked—they were the same blood group as one of the patients that I knew, and I thought obviously it would be a nice opportunity to see if I could provide some assistance—and what happened was they said, ‘No, we just couldn’t. We failed him during life. We can’t fail him in death.’ I said, ‘Failed him?’ He said, ‘Well, we tried to teach him to protect himself, and we failed him because he didn’t look after himself.’ Being young and brash, I pushed a little harder, and they said, ‘Look, we really would feel uncomfortable.’ So the issue was not donation; the issue was the relationship with the deceased.

Cindy McLEISH: Yes, it varies.

Aadhil AZIZ: I also feel like it is about communicating that the remains will be culturally and respectfully handed over to the family after that organ is harvested—so, if we communicate that we are not just, you know, slicing and dicing a body and, you know, chucking it in the bin, which is obviously not what happens. People have misconceptions, and if you are very clear that it is respectfully done, it is respectfully harvested, the body is respectfully sewed up again and then handed back to the family for whichever funeral ritual they want to

continue on with, most people will be fine with that, especially if they know that on top of that they save a life, or two even. And whatever your beliefs are—some people believe that if you save a life, that is going to reward you in an afterlife, if you believe in an afterlife. There are lots of ways around it.

Cindy McLEISH: Terrific, thank you. Thank you, Ella. I am done.

The CHAIR: Thank you. Chris.

Chris CREWITHER: Thank you, Chair. Well, firstly, thank you again for your time giving evidence today. I was particularly interested in your comments, Dr Hogan, on an opt-out system—perhaps some of the strongest comments out of any submissions or evidence that has been given in favour of an opt-out system. I am interested in your further views on why you support such a system and also your view that it will inevitably potentially raise awareness, even if it fails.

Christopher HOGAN: Well, I think the most important thing that we need to do with people is to engage them, and one of the ways to engage people is to challenge them just a little bit and to put them in the situation where they have to make a choice. I think that when we have that, the opportunity for discussion then becomes extremely important. The benefit of transplantation is inestimable, and it is truly a gift of life. And I would think that having the opportunity to be able to calmly present this to people and say, ‘Well, this is what we want’, those people who are firmly against it will say no, but those people who are not firmly against this will say, ‘Why should I?’ And I think when you have the opportunity of saying ‘Why should I?’ you can then sit down and talk about it.

The other thing too is, as we are talking about cultural issues, I am well aware that during COVID one of the things that we did was to involve the religious leaders of a whole range of traditions. We were able to sit down with them and to say, ‘What happens? How do we do it?’ And it was being brought to my attention by colleagues who were involved in such things that they were able then, at these religious gatherings, to institute immunisations. So having the opportunity to have a conversation with people, and having that discussed in an open forum and then having their risks addressed, and even having, you know, the priest or the imam or the guide to advise them, they are in a situation where they can discover that there are a lot more facilitators than there are barriers towards helping your fellow man and woman.

Aadhil AZIZ: If I may add to that, it is very similar to the mandatory COVID vaccinations we had. You are always going to get a handful of people—let us call it 10 per cent, for the sake of argument—that do not get vaccinated, but that was never the objective. The objective was always to vaccinate the majority, and that was what we achieved. This is a very similar situation. You are not going to get everyone to donate their organs, and that is fine, so long as we can get the majority to agree to it. To have that conversation with their doctors, being respectful of their cultures and ethics and backgrounds—that is all we need here. We just need to drive the conversation forward, and I think that is very easily achievable.

Chris CREWITHER: Adding to that, do you think there should be an elimination of the ability of family members to override donors’ express wishes unless there are exceptional circumstances?

Christopher HOGAN: Look, that is a matter of law. I mean, I can have my opinion on that, but really I would think that it is a matter of law. And as far as I am concerned, the person who owns the body should have primacy over it, but you know, I am aware of the legal ramifications. I think if all else fails, the discussion would be just sufficient there, but I know of a lot of people who were quite insistent that their wishes not to be overridden.

Aadhil AZIZ: It is very similar—we do lots of end-of-life plans for patients, and their end-of-life plan cannot be overruled by anybody else. They can always change the end-of-life plan as many times as they wish to, but at the end of the day it is the patient’s prerogative to do what they want to do with their body after they are no longer around. But yes, as Dr Chris says, that is a legal thing, and if you asked 10 doctors, you would probably get 10 different opinions.

Chris CREWITHER: Thank you. Alfred Health in their submission and in their evidence have suggested there could be two steps or two levels of registration, the first being a simple registration to get people into the registry to start with, but then a subsequent follow-up or more binding form of registration that could result in a greater difficulty for a donor’s family to overcome. Would you support such a two-step registration system?

Aadhil AZIZ: Could you repeat the second step, sorry?

Chris CREWOTHER: So the second step was to have a more binding form of registration which could result in greater difficulty for the donor's family to overcome a donor's expressed wishes.

Aadhil AZIZ: I can only speak for myself here, because it is a personal view here. I think you are going to get lots of certain cultures that do not believe that their bodies should be desecrated, the same way people go and marry whoever they want, change religions or whatever. Personal choice is personal choice. But whether you want to have a fight in every waiting room or every hospital—and that goes on to the coroner, the poor registrar, the poor doctor, the first attendant, who has actually nothing to do with this, you know—I do not know if that is fair to that healthcare workforce. So I would be very careful about these laws because it is easy for you to make the laws, but you do not have to defend them in the hospital where this argument is going to happen. So I do not know. I think Dr Chris said it best: it is the conversation with the doctor and the family, and if everyone is on the same page, then you do not have to have that argument. Personally, I do not think that is a great way to go against the family. I think you want the family on board if at all possible. How we get there I do not know.

Chris CREWOTHER: Thank you. Final question: you talked about poor health literacy locally, and I guess in Victoria and Australia, including as it pertains to organ and tissue donations. How can we improve health literacy in Victoria, and what are the steps that you think are necessary in that regard?

Christopher HOGAN: I think it is a matter of community dialogue. I think the first thing we need to do is to realise that there is a problem, and the fact that just because we are surrounded with information does not mean that we have the ability to know it or to understand it. I mean, I have an interest as an educator, and one of the things that I have discovered is that there are a lot of people who do not have the health literacy to be able to understand what Dr Google is saying. In fact, I can still remember I had one patient quoting the National Asthma Council against me. When I pointed out to him that I actually had written that article, it made very little difference to his views.

The first thing is we have to recognise there is a problem. The second, I think, is that access to first aid training is a very good introduction to generating health literacy and health knowledge. I think there is also that involvement with the schools, so the schools actually involve not only the student but the rest of their family when it comes to a range of important objects. I am fairly experienced when it comes to teaching, having been involved in it for so long and having done the appropriate study for it, but I do think that it is something that is nonetheless extremely important. And one of the things that I did in times past when we had the divisions of general practice was we used to provide speakers for the children who went into the schools at the end of the year after the exams and before they left to be able to talk to them on a range of important health issues and health topics.

Chris CREWOTHER: Thank you.

The CHAIR: Great. Thank you.

Aadhil AZIZ: If I could just jump back for a second to the previous question, regarding the second submission, I would just suggest that you get a witness to sign, and that could be a family member or a friend. Then that way you have two people that are—maybe two witnesses, one could be a family member and one could be a friend, and that way you have already overcome that barrier.

A member: Yes. That is a good idea.

Bindiya SETHI: Also, if we are employing this, in the doctors having the discussion, it is a very difficult discussion for the family and the doctors involved in that. At the same time there are a lot of legal issues with the will and the family trying to override that, so for the legal representatives of the hospitals, them taking this discussion forward with the family, that is going to help even more because then the legal issues discussed by the legal professionals I think is going to make more sense to the family and they can deal with that better.

Chris CREWOTHER: Thank you.

The CHAIR: Okay. Well, thank you all very much for appearing before the Committee today and for your contributions to this inquiry. Thank you for taking some time out of your very busy days and also just for sharing with us the very important role that GPs have to play in terms of organ and tissue donation and those incredibly important conversations with your patients and with family members. You will be provided with a proof version of today's transcript to check, and verified transcripts will be published on the Committee's website.

The Committee will now take a 1-hour break. I declare this hearing adjourned.

Witnesses withdrew.