

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Monday 19 June 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

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WITNESSES

Mr Stuart Chesneau, Executive Director, Strategy and Growth, Lifeblood; and

Mr Tony Holland, General Manager, DonateLife Victoria.

The CHAIR: Good afternoon. I declare open this public hearing of the Legislative Assembly Legal and Social Issues Committee's Inquiry into Increasing the Number of Registered Organ and Tissue Donors.

Thank you to our next witnesses for joining us. We are here today with witnesses from Lifeblood. Thank you to Stuart Chesneau, Executive Director, Strategy and Growth, and to Tony Holland, General Manager, DonateLife Victoria, for reappearing.

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

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

I invite you now to make a brief opening statement of approximately 5 to 10 minutes, and then this will be followed by questions from Members. Thank you.

Stuart CHESNEAU: Okay, I will go. Thank you for the invite. As you say, I am the Executive Director of Strategy and Growth at Lifeblood. I thought what I would do is give you an overview of Lifeblood and our relationship with DonateLife and then a little bit more about how we recruit donors. Potentially that could lead to the opportunity for further discussion, as I understand it—by the way, I have just been invited to this; I do not really have a huge amount of background—as to how we might increase organ donation or people on the organ donor registry.

Lifeblood—we are a branch of the Red Cross and a national organisation. There are about 3700 staff, and we operate in every state and territory, funded by the Commonwealth and states. Largely we are known for the blood supply, so the safe and secure blood supply across the country, which I am sure you knew, but in the last 12 months there have been about 1.6 million donations for blood and plasma. But that is not all we do. We do a range of other biological products, largely working with voluntary donors to do that. We have a milk program as well, so that is donated human breast milk, which goes from mothers who have had full-term babies. We collect the milk, process and test it, and then send it on to neonatal intensive care units for treatment of extremely premature babies. We do that in most states now, and we are currently in conversation with the Mercy here in Victoria to expand and support that activity. We also do faecal microbiota transplants—so effectively poo. So it is poo donation and it is essentially transplanted to treat a certain gut condition. That is centred over in WA, but the supply of that poo is national. We have supplied here into the Alfred as well before. They are relatively new.

Areas that we have worked in for decades now are around solid organ and tissue. We have been involved in that for a while directly, and slightly more indirectly, and I will get to that, but the more direct piece is around the blood testing that supports the matching of organs. So there is quite a complex piece that matches recipient to donor, and we have got four labs around the country, including one here over in West Melbourne, that do that and do that for around 80% of the country as well. So that is around the testing side of things, and there is some other stuff that we do, but I will probably go on to our relationship with DLV.

DLV is slightly different, though. I am sure Tony in his own inimitable way went through this in more detail this morning, so I will not go into what DLV is but more our relationship with DLV. We are very proud of having DLV within Lifeblood as part of the family and very proud of what they do in coordinating the end-to-end organ donation program here in Victoria, but it is a slightly separate entity. It is not a direct line in the way that most of the other things I have just discussed are. DLV is part of the national network of DonateLife agencies and is funded a little bit by the Commonwealth through OTA and a bit via the state. Strategic direction is provided by OTA and in some areas by the state. In this state, VicHealth have decided that they will outsource the day-to-day management of the agency, so that largely is around shared services. That is things like people and culture, ICT and finance, with some management oversight, which is largely through me working with Tony and his leadership team. In essence it is really to make sure that it functions okay, but strategic direction does not necessarily come from Lifeblood—just to set that clear—and really we are just trying to make sure it works within the funding envelope that is provided, that people are well looked after and the day-to-day management of the agency makes sense, but largely we leave them to do what they do.

As to the specifics, as I understand them, for this hearing around increasing organ registrations in Victoria, maybe if I speak about our presence in Victoria, that might lead on to other questions and where the conversation hopefully will go. We have exactly 19 fixed donor centres across Victoria. They are bricks and mortar, so where people come in to donate blood—and a few other things but largely blood. They are focused largely in CBD and metro, but it is the four corners of the state as well, so up in Mildura, down in Warrnambool, over in Wangaratta or Shepparton and then down to Traralgon. The largest amount is CBD, but we do cover most of the state. We also have a couple of mobile units. They are like buses that people can donate on. One is based in Traralgon, one is in Ballarat, and they cover areas that are not serviced well by the fixed network, and also we do provide opportunities to just bring donation equipment in and go to like a town hall or an office—that kind of thing. So really anywhere where there is within a certain radius around 8000 people we probably visit for at least a few days in any given year across the state.

There are 155,000 recurrent blood donors in Victoria, and they have donated about 460,000 donations in the last 12 months. That is a phenomenal success story. So Victoria is the strongest blood donation state in the country proportionately, which I think is worth mentioning. Altruism does seem to run quite hard through Victoria, so we are very impressed by the way that Victoria supports a lot of other states as well when it comes to the blood supply. We do export a lot of blood from this state up to other states. It is about 30% of the nation, actually. Those 155,000 donors, there is quite a split demographically, and certainly by age—so between regional, rural and CBD. About a quarter are under the age of 30, about 40% are 30 to 50 and the rest are over 50, so it is quite a well-spread panel. We do recruit younger donors as well. Even though 155,000 does not sound like a lot, it is about 3% of the age-eligible population. It is quite a dynamic donor panel, so you lose donors each year. People for whatever circumstances—maybe they get deferred medically or they are just too busy or they just do not like it—stop donating, new donors come in. We get 20 to 30% churn every year. So over the course of say 5 to 10 years—and I have not gone back and done this, because it is a bit of work and I did not see the point—we might see in terms of Victoria well over 1 million donors that would have engaged directly with Lifeblood over the last 5 to 10 years easily, and then beyond that it would be a larger number.

Now, being a blood donor is different to being on the organ donor registry. As I say, we are looking to engage people to donate blood and keep donating blood. So we are constantly in contact with them. They can fall in and out of blood donation. We call ‘active donors’ donors who have donated in the last 12 months. Once they fall out of that, they are a ‘lapsed donor’, and that changes the relationship and the amount that we will contact them, whereas the organ donor registry is about getting someone onto it once so it is a different situation. We do not know the overlap between the panels, and nor can we, because there is data privacy here. If a person in the street says they want to become a blood donor, they consent for the use of their information when it comes to blood donation; they do not consent for us to contact them about any other type of donation. So for even the programs within Lifeblood, we cannot contact them and say, ‘Well, have you thought about being a milk or a poo donor?’ We can do general awareness through our centres. General awareness is part of our campaign. Our brand is well set up; donation is an overall kind of thing. But we cannot SMS or email them and say, ‘Do you want to become a donor?’ for anything else or wash those two datasets together to see where the overlap is. It would be reasonable, I believe, to think that there is an overlap. It is all about altruism, and the kind of people who would consent to be blood donors probably would consent to be organ donors as well, so I imagine there is a bit of overlap.

In terms of the opportunity, what we have done and what we are working on now and where you want to take this, if you want to discuss generally our approach to recruitment of donors and how that might be mimicked by the likes of DonateLife or the specifics of how Lifeblood is working with DonateLife, we can do either, but there have been a few conversations, particularly with Tony’s appointment into the role in the last few years and with Alana in marketing. We are getting some digital marketing boards within our donor centres which will feature DonateLife and the opportunity to become an organ donor. During organ donor week there is some collateral in our donor centres to help promote it, but it is not necessarily that targeted. We will be putting the link into our app. Each year there are about 2.3 million donations that get booked largely through digital channels, whether that be through our app or through the website so that is a lot of traffic that goes through there. We are going to put a button on there that links back out to the opportunity to then register as an organ donor. The likelihood of that going through we do not know. In terms of how many people then complete the process, you do not know until you do it, but you only need to get them to do it once as well, I suppose, would be the thinking.

We can do more, maybe, but it needs to be adjacent. So if we are in market or if we have got a donor centre in the area, we potentially can help to generally promote organ donor registration, but direct is more tricky and also it is not funded. The funding that we get to provide that kind of day-to-day management for the service is for specific activities; it does not cover any of the marketing costs. We are not funded to do that with DonateLife, although we are very, very happy to support. It is slightly different because we do need to get, as I say, donors to come in and to keep coming in and to come back, and if they have not come back for a while, to remind them, and they come back in. So we have a very high market presence, and that does come at a cost. We do spend quite a lot on marketing through Lifeblood. Some are below the line, but a lot are above the line as well just generally raising awareness. We are in campaigns quite regularly. We do go to media. We are on TV and radio quite a lot as well. It does cost money to remind people to be altruistic, would be my advice. So I would think something like an above-the-line campaign—which would not need to be so intensive as it is for Lifeblood and would not need to be so regular, but something that would raise awareness to increase the donation rate, which I understand is at about 27% now—would make sense to us from the experience that we have got over a number of years of building a very healthy donor panel. We have got about 550,000 donors across the country currently, and I suppose that would be—there were a lot of stats in there. It was a bit heavy. But anyway, I will stop there, and over to you.

The CHAIR: Great. Thank you, Stuart. That was a fantastic presentation. We will now begin with some questions from the Committee. So just to go back to what you just said, was it 550,000 blood donors across the country?

Stuart CHESNEAU: Across the country.

The CHAIR: Great. That is a lot.

Stuart CHESNEAU: Yes.

The CHAIR: I am one of them, and I get quite a few phone calls from your marketing team to remind me to book in to donate. So I will be jumping on the app after we have finished and booking in for some whole blood, and then some plasma. With Victoria being the highest blood donor state in the country, I think you would expect to see some of that altruism throughout other opportunities, including organ and tissue donation. In some ways I would expect that donating blood is a bit of a harder ask, because it is a regular thing and you are asking people to come back more than one time. I know sometimes from my plasma donations I could be there for an hour and a half, because it is a lengthy process. So with that in mind, I am just wondering if either you, Stuart, or Tony have any reflections as to whether blood donation is a higher ask on the community, and then, if that is the case, why we are not seeing those same numbers come through in organ and tissue registered donors.

Stuart CHESNEAU: I can start on my personal opinion. As to the process of registration, that may be more for Tony. I would tend to agree with you; I think it is a higher ask, because we do ask people to come in and have a needle put in their arm. There is lots of fear around that; we have done lots of research. And as much as you can do with the environment, there are certain regulations. It always feels a little bit like a hospital environment, as best we can do with it—although we do provide party pies, which go down quite well. But it is quite an ask, and you do get—and I am a donor and I get bombarded with phone calls as well. I get made to feel guilty whenever I see an advert, so it is quite an ongoing ask as well. So I think the bar is high. Whether that then is—I do not know. I will pass to Tony, really. It is a different bar that you set, though, I would imagine, when you are asking someone to become an organ donor. There is a different consideration, conversations with family—it is more of a change in mindset. And as for the process of registration, I am not sure how easy that is. I did it once; it was not that easy. But over to you.

Tony HOLLAND: I think absolutely, first of all, the process of blood donation is immediate. You know, you need to do it now because the blood supply is required now. I agree that the registration process we talked about this morning is convoluted and we miss a lot of people because it is not systematic, it is not seamless. Whereas if you want to be a blood donor, it is very easy to register; you get the app and it is done. We do not have an organ donation app; we do not have anything like that. It is also a very different mechanism. Our process is first-person consent—sorry, blood is first-person consent. Organ donation is first-person intent and senior next-of-kin consent. So it again changes the dynamic. You do not have to—unless you are under, whatever it is, 18 or 16, for blood donation. I do not think you can—what is the minimum age?

Stuart CHESNEAU: It is 18 to 75.

Tony HOLLAND: Eighteen, yes. So you do not have to ask your wife's advice or your wife's support to actually give blood or vice versa. You go in and do it yourself; it is your decision. So I think there are a lot of differences. Even though the altruism is the same, there are a lot of differences in the process.

The CHAIR: Just picking up on what you were saying, Tony, about the urgency, and urgency driving people to commit to a blood donation—I have definitely seen a lot of advertising around long weekends and holiday periods and people needing urgent blood supply. Do you have any research that points to some of those drivers as to why someone might donate blood, and is there any research that could be potentially applicable to this space of organ and tissue donation?

Stuart CHESNEAU: Yes, there is some around the urgency message as well. The long weekend we generally will remark it more because I think we have gotten better at managing the imagery. Because some of our products have a short shelf life—so it is from the point of donation; they expire within five days—for long weekends it makes it quite difficult. But I think we have managed to sort out some of our process around that. It is more the urgency. We went to appeal the week before last. I did a few radio interviews and some TV work, and it is interesting because we do see a 25 to 40% surge in appointments being made within the next week. There has been some research—and I do look after the research area for our organisation as well, so I might be able to lay some hands on it, but it is around that 'You need the extra push.' I am a donor. Lots of people consider themselves a donor. This is the thought process: they may not have donated for two years—and we did some research on this—but they still consider themselves to be a donor, even though they are not donating. They just want to be told that there really is a need for it, so when they hear that message then they will go that extra final bit, which is, 'Well, I'll donate.'

The one thing that we have done that kind of connects that dot closer on a more regular basis is we tell people where their blood has gone and when it has gone. So if you donate today, you might get a text in three days which connects to 'Well, it's gone out to the Alfred' or it has gone wherever—to Monash. It is just connecting it to the patient, which is the most important thing. That is where the research is, and that is why we get recipients into donor centres to talk to the donors as well. There is research on it that shows that it can be very powerful when there is a connection to a patient and when there is an urgent need. I do not know how that would necessarily translate for you.

Tony HOLLAND: Lived experience I think is the closest comparison, really. We do work with a lot of donor families and a lot of recipients. All of our advertising is based on real people, so it is somebody's picture with their finger up saying, 'Only one minute,' whether it be somebody who has obtained a heart or whether it be a donor family who have lost a child. We had a very, very powerful presentation at the Lifeblood strategic planning day a few weeks ago by three lived-experience recipients. One was an organ donor recipient, one was the mother of a little boy who required blood products and the other one was a fellow who had cancer and obtained blood products. It is very, very powerful. When you hear the stories and you can see the direct result of the generosity of other people it is hard not to be moved to action. But there is a factor with us as an agency—we have got to be a little bit careful about how we go about this sort of stuff, because whilst we promote organ donation, it is very much a personal choice, and we cannot coerce people into the decision. It has got to be a free-will decision for the senior next of kin, again understanding the wishes of their family. But I think lived experience is a very powerful tool, and we use that a lot in our advertising. In fact pretty much all of our advertising is based on that.

The CHAIR: Great. Thank you. I have got another question, but I will come back to it if we have time. I will hand over to Annabelle.

Annabelle CLEELAND: Thank you. Stuart, you mentioned we can do more. What more can you do to help to help donor registration in Victoria?

Stuart CHESNEAU: I think because we have got such traffic throughout donor centres we could do more to promote. We do promote things like becoming a poo donor over in WA. We have not done enough of that. We do it at a couple of pointy times during the year, once for organ donor week, but that is only recent and that is with a bit of nudging from Tony. With the contacts we have got, as long as we do not breach any of our data privacy rules and it is general awareness, we can do it through the app and we can do it through some of our

marketing. We are looking at this whole idea and concept of how it is not about being a blood donor, it is about being a general donor. Donation is a broad spectrum because we have got so many more biological products. Organ donation could be just as much a part of that as well. There is a bit more we can do that will not necessarily find us cross-subsidising, because we have got quite strict funding requirements, largely from the Commonwealth, as to what we can spend the money that is destined for the blood program on. But if it is partner adjacent, we can do more like that. There is a bit more that we could do.

Tony HOLLAND: The new strategic direction that Lifeblood has taken is not just about blood, it is about donation for life. As Stuart said, the tissue-typing service is part of the organ donation program. It is actually administered by Lifeblood. Also there is another program called OrganMatch, which does the organ-matching process. That is also administered by Lifeblood. Lifeblood is a very big back-of-house process with organ donation nationally, and the new strategic direction for Lifeblood is much bigger picture. Organ donation is mentioned in it as well.

Stuart CHESNEAU: Yes, we are calling it a movement of donors. As Tony said, what we do currently is more back of house. There is no need to promote that you are testing blood for compatibility, because we are not looking to get more blood in to test. That all comes through as it comes through; you just do what you get given. But telling the whole story of organ donation and the need for more donors and, I think, promoting the fact—the states are very competitive—that Victoria is at 27% compared to other states would certainly engender a response. You just need to be able to go out and send a message. We do have access to donors and we have a high presence in markets, so we could use that more to promote organ donor registration, I think.

Annabelle CLEELAND: Is it safe to say that one of the biggest barriers to doing more together or to promote through Lifeblood is funding?

Stuart CHESNEAU: Funding is part—yes. Certainly above-the-line stuff for overall awareness requires funding. As I said before, it costs money to remind people to be altruistic. There is that. There is the data privacy issue, which I do not think we can work around, because that is appropriate. We cannot risk being seen as untrustworthy in the way that we handle information with our donors, so we have to be careful there. But we can work around that with more generalities. Previously we have had some reservations around talking about end of life in donor centres when people come in, because people come in with some fears anyway about getting a needle in their arm et cetera. But we tested that and realised that there was not any credibility to it. People were not that concerned about talking about other ways of supporting the community, so that one has been kind of taken off the table. But funding is, I think, an issue if you are going to raise real awareness to the number of organ donor registrations that you want in Vic.

Annabelle CLEELAND: Can I ask what your marketing budget is, for comparison, a year?

Stuart CHESNEAU: You can. It does vary from year to year, but nationally it is \$10 million to \$14 million.

Annabelle CLEELAND: Nationally?

Stuart CHESNEAU: Nationally.

Annabelle CLEELAND: And would you know statewide?

Stuart CHESNEAU: I would suggest it would be about 30% of that, but I do not know, so I would say \$3 million to \$3.5 million. Some of those national campaigns we do not split necessarily by state. The way that the blood service is funded is coordinated through the National Blood Authority in Canberra, and it is a set proportion that the states contribute as well, so there is no state budget. We do not go back and speak to—we do for tissue typing and we do for milk, and we do for blood where we work with the individual state health departments and we run through the P and L. We do not do that for blood, so I do not know exactly what the marketing spend for Vic would be, but as a proportion it is probably about \$3.5 million.

Annabelle CLEELAND: I did get a text last week to say that St Vincent's were using my blood, which I loved—or my ego loved anyway. I think that there is a lot of opportunity with that and the personal benefit that, you know, makes you feel good. When doing this and trying to promote the inquiry to get a variety of submissions, the media have been reluctant to cover organ donor awareness unless they have got the whole—

you know, they have got the family that have supported the donation and the person that has received it. What are the barriers there in terms of that promotion of awareness through storytelling and connecting?

Tony HOLLAND: We have a really strong relationship with donor families and with recipients. As part of our comms team, one of our comms officers is directly responsible for all the development of media stories. Obviously we do it very carefully and very sensitively for both sides, and there is an absolute prohibition on us in any way revealing the details of either a donor or a recipient in a way that would allow their details to be matched. People do find out, but not through us. We are prohibited under law from disclosing the details of donor families. There are all sorts of reasons why that may be a good thing, but also there are reasons why it may be a bad thing. We are ambivalent about the process; that is just what we have to do. But we do use people's stories a lot, and we pitch people's stories to media a lot and get a lot of media. There is no lack of interest in the media in us generally.

In DonateLife Week we have—I cannot remember off the top of my head—lots of stories. And you can even see the bump. I am just looking at the table now. In 2015 there were about 25,000 registrations a year, and in 2016 when our comms team came on it went up to nearly 50,000—45,000—and now it is sitting at about 50,000. So raising awareness certainly works. There is no issue with us getting access to people, but we still have to do it very sensitively, because for recipients there is sometimes the guilt of living when somebody else has died and for donor families obviously there is the sorrow of the loss of their loved one. Some people want to really get out there and promote it, and others really just want to move on and not think about it too much, and we have to respect both opportunities.

Annabelle CLEELAND: Can I just ask about the OrganMatch program. Is that a paid service? Who pays for that? How does that work? Just explain that OrganMatch.

Stuart CHESNEAU: It is funded largely by the Commonwealth, by the Organ and Tissue Authority. Largely we are talking about an organ match system, which is a national system that houses all the information of those who are on the waitlist and then helps with the matching process when we do get a deceased or living donor through the program. It is a national system as well.

Annabelle CLEELAND: Is there opportunity to expand that from another element of that registration by any chance?

Tony HOLLAND: Not really, no. It is totally, totally different. It is an amazing system if it is done right. It has been going for about four years, five years?

Stuart CHESNEAU: Yes. We built it four years ago.

Tony HOLLAND: It is growing, so obviously it goes through iterations of how it is used. I remember hearing a story about a year ago where there was a person who was on the waiting list for 17 years waiting for a kidney. Stuart talked about crossmatching—neither of us are scientists but there is a thing called HLA crossmatching. One of our colleagues did a talk once and she told us about how many different types of HLA matches there are—over 33,000 and growing. You have got blood typing and blood matching, but there is also HLA. I do not even know what HLA is, but it is part of the testing. This fellow got a kidney after OrganMatch was implemented because it was so much more nuanced; it could go into the detail much better than people's calculations. So it has saved lives in its own right. But no, there is no link between OrganMatch and the registration process at all. I cannot even look at OrganMatch. We do not get access to it.

Stuart CHESNEAU: It is for the clinical community –

Tony HOLLAND: Yes, it is a clinical –

Stuart CHESNEAU: the testing communities really. It is human leukocyte antigen, just so you know.

Tony HOLLAND: Thank you.

Stuart CHESNEAU: There you go.

Annabelle CLEELAND: I am conscious of my time that I have taken up. Just finally, with your presence in regional Victoria, do you see any sort of opportunity for, or even barriers, I guess, to raising awareness for organ donations?

Stuart CHESNEAU: I think the opportunities—again, just being visible, whether it is with a mobile or one of the fixed centres or one of those pop-ups that I talked about. As we do with some other forms of donation—and for the stem cell registry we do that in centre as well—we do talk to people about the potential to cross over into that program. We could do that, and there is no difference I see or barrier between regional and metro. In fact in regional we find, particularly with frequency rates for donation, they are always higher in regional. There is certainly a greater commitment to that community feel—so no barrier.

Tony HOLLAND: And we already have a close relationship with the people at Lifeblood who actually manage all the digital marketing and engagement strategies. They have actually invited us to be part of that program in the pilot form in Victoria, and as it grows nationally I expect that that will continue.

Stuart CHESNEAU: Yes, and we will be national. I know we are running out of time, but going back to your earlier question around budget—and I gave you some numbers there, and they sound quite big. Again, going back, that \$3 million or however many million that might be apportioned out to Victoria, that is for the whole year to keep people engaged. We are spending a lot of money at the moment because there is a massive amount of cold, flu and COVID going around. We are seeing about 25,000 appointments being cancelled every week. People are self-cancelling—for the right reasons: if you do not feel well, do not come in to donate—but we need to fill those appointments up. It is a very intense process; that is why it will cost a lot. I do not think it would cost as much for an awareness campaign for organ donation registration at all. You could do it much cheaper than that. I am not pitching for Tony here. You can make your own decisions.

The CHAIR: Thanks, Annabelle. Christine.

Chris COUZENS: Thank you both for your time today. We really appreciate it. It is great to hear what you have got to say at this inquiry. My question is around—the Red Cross is a real icon. I mean, everybody knows who the Red Cross is and go and donate blood. So obviously, by the sound of it, Lifeblood is doing pretty well in terms of donations.

Stuart CHESNEAU: Yes.

Chris COUZENS: So using that success, how would you turn that around? You did mention that you cannot promote or talk to people about other donations. I would like to know why you say you cannot, and secondly, how we look at changing that.

Stuart CHESNEAU: Okay. If I can just be clear, the bit we cannot do is we cannot take an individual's details and then use them to contact them directly for something outside of what they have consented to do. So the consent form that they sign when they donate and when they sign up to be a donor is quite clear. It is a legal document. So we cannot then—in the same way you cannot pass information on to advertisers, I know this is a much –

Chris COUZENS: But you could change that form.

Stuart CHESNEAU: We could. If we said, 'Would you consent for us to contact you about organ donation?', we could. That would be quite a tricky thing to do.

Chris COUZENS: Is that something that would be considered?

Stuart CHESNEAU: No, because we would need to gazette that in every state parliament because that is a gazetted document that needs to be considered and changed. Changes to that questionnaire and the consent form that sits part of the questionnaire are quite complicated things to do. But that does not mean we cannot speak to people, and we do. So we do now get people onto stem cell registration, get people to become milk donors and get people to become poo donors. We do quite a bit. We have done that a bit with organ donation, although they are quite well looked after with their own marketing department, but we could do more is what I am saying, and we do have so much contact. We just cannot do that contact thing very easily.

The other thing I would say is, if you ask me more generally, there is our success and how that might be translated. We spend a lot of time explaining the need and what it is to be an organ donor. This is just a personal opinion: I spoke to a couple of people when I found out I was coming to an inquiry—which was quite a surprise—about being organ donors. I am not from Australia originally, but the few that I did speak to still felt that they were organ donors because it just happened anyway through VicRoads, which is still a complete misnomer and a misunderstanding.

We explain over and over what it is to be a blood donor and what the benefit of being a blood donor is. We go through this one stat that we mention all the time: one in three people will need a blood product in their lifetime. So if it is not you, it is going to be your sister, your brother or your friend. So we go through that constantly. I do not think people understand the need for organ donation or the process at all well at the moment, as a personal opinion. And you might correct me on that one. So I think that is where we have been very successful and where perhaps this program could be more successful. But we can help.

Tony HOLLAND: There is a small subset to that. We do get a fair bit of confusion about people who cannot be blood donors who think they cannot be organ donors.

Stuart CHESNEAU: Yes, yes.

Chris COUZENS: Oh, okay.

Tony HOLLAND: Like with the mad cow disease issue with English people, they can now be blood donors in Australia—fantastic. And I spoke to a number of people at an event, and they said, ‘Oh, okay, now we can be an organ donor.’ And I said, ‘Well, yes, absolutely, but it was not linked anyway.’ They are totally different sort of criteria. There is a lot of lack of understanding, but it is: how much detail do you put into advertising campaigns about nuanced issues like that? Really what we want to do is just encourage people to get on the register. But that is another potential issue that might be out there in people’s minds, I do not know. But the VicRoads one is a big one.

Chris COUZENS: Yes, yes. Okay. And do you have any suggestions in terms of engagement with First Nations people, with CALD communities, those sorts of groups that, you know, we really need to be engaging with? Are you doing anything in that space, and if so, what is it? And if not, what do you think it is worthwhile doing?

Stuart CHESNEAU: I am not well placed to say, when it comes to organ donation. I am not an expert on organ donation, so I do not think I can comment on that. We are doing some work with First Nations people, but that is quite recent, to be quite honest. And looking at our presence in regional areas and particularly access for First Nations people to donate, we have done work with some elders to understand the barriers to donation as well, and we are still working some of those out. I imagine something like that would be quite useful as well for organ donation. I do not actually even know what the position might be for First Nations people on that. But we are doing that now. Will that bring us a lot of blood donations? I do not know. I imagine not. We have got a very strong inclusivity project. We are working a lot at the moment with trying to get more same-sex couples or men who have sex with men to come in and donate and to remove other barriers for donation, and that is one of them. So we do not have a great penetration in that area either.

Chris COUZENS: Okay. But you have started working in that area?

Stuart CHESNEAU: Yes, talking with elders and trying to work out whether it is a presence thing or an understanding of some of the cultural barriers, but we do not have great numbers.

Chris COUZENS: Okay. And what do you think the overall challenges are in terms of getting people to register as donors?

Stuart CHESNEAU: Understanding the process. Understanding—as Tony has told me, and from my work with them—is that secondary piece of having a conversation with your family. I think it is just an awareness thing. As I said before at the beginning, Victoria is a state that really looks after each other. I think people would sign up. I think there is no reason why the rate would be this low if it was not for the fact that people just do not understand the need, the fact that it is that low and the process. Making the process easier, dispelling myths like the one for DLV and spending a little bit of money would be my advice, just to do that program. I

see no reason why that would not be very successful. I do not think there are any major barriers to fixing this problem, personally.

Chris COUZENS: Great. Thank you.

Stuart CHESNEAU: Pleasure.

The CHAIR: Thank you, Chris, and over to the other Chris. Thank you.

Chris CREWITHER: Too many Chrises. Firstly, thank you for your evidence before our Committee. It is greatly appreciated. Chris was talking before about the questionnaire and so forth, and our previous witness had said the organ and tissue donation should be included in Lifeblood's questionnaire. I know that you said it is quite complicated to change these things. Do you agree, though, that such a question should be in the questionnaire, whether it is easy or hard to change it?

Stuart CHESNEAU: I think there is great potential for that, yes. I do not think it is a bad idea. Having tried to change a couple of questions in one state and going through that process, I fear for the complexity of doing it, but it is not something that should be dismissed. We need to take a look at that as well. But they are complicated, and when they are multijurisdictional, as they need to be, that is a lot of effort and lobbying to get these things prioritised, changed and agreed. But I do not think it is a bad idea at all.

Chris CREWITHER: Given you mentioned that Victorians are quite generous with blood donations, but when you look at organ donations the rate is a 23% registration rate as against 72% in South Australia, do you have any advice for the field of organ donations from your experience in Lifeblood that could be replicated across in the organ sector?

Stuart CHESNEAU: I do, and I think those two numbers explain it well: make it easy. We have invested a lot in our digital presence, so there is the ability to make an appointment, cancel an appointment, do it on your phone, find where your nearest donor centre is, see which ones are free and even look at some predicted wait times. Make it easy and people will then generously give their time. If you make it complicated, that altruism just moves down the list a bit in terms of priorities in your life if it is just too hard. South Australia, from what I understand, make it easy. There is obviously a lot of work in the background, but it is not the work that the individual does. They can sign up quite easily, because again it is linked into something—I think it is through the South Australian agency like VicRoads. So I think that would be the advice. Find a way of simplifying the process and working with the channels that people want to work with.

Tony HOLLAND: I think that is absolutely right. Our app would be a single process—click the button, one registration process straight to Medicare. That is our booking app. We cannot have an app, obviously—do not need an app—but it has got to be seamless. That is the biggest answer. And it has made a big difference in Lifeblood, hasn't it, the online booking process?

Stuart CHESNEAU: Yes. So I have got an appointment in the system to donate. Between here and walking to the station I can just find and cancel that, rebook it, and then I will get a text saying, 'You're rebooked. Don't forget to hydrate,' and it is all done. It is simple. It took a bit of time, but it is not groundbreaking technology; it is everywhere. I am not saying you need that technology for this, but it is the simplicity argument that I think needs to be looked at.

Chris CREWITHER: This question is more for Tony. In terms of organ donations, do you currently tell people exactly who their organs have gone to, or do you generally tell them that it has gone to a male in their 50s or a female in their 20s or something?

Tony HOLLAND: We certainly do not tell them who the organ goes to. There cannot be any identifying information, so it will not necessarily say the state or the hospital or anything like that. I think it says as much as it has gone—actually, I am not 100% sure. I had better not answer that, because I do not know. We certainly give the families information—the fact that the kidneys have been used, the liver has been used, the lungs have been used. We tell them what organs have been utilised, or if they were not able to be utilised, because it does not always work as predicted. They might go in expecting to get two kidneys and a liver and a set of lungs, but the lungs may not be viable or whatever. We tell them that as well, because we are transparent, but we just do

not give any identifying information. So a bit like, you know, ‘Your blood has gone to St Vincent’s,’ we do the same sorts of things—not as quickly as what Lifeblood does, but we do send them information.

Chris CREWETHER: Are you legally blocked from giving information or is it more of a choice that –

Tony HOLLAND: Oh, absolutely, yes. We cannot provide any identifying information; it is against the law for us to do that.

Chris CREWETHER: Do you think that is something that should be changed in the law, to give some flexibility for that?

Tony HOLLAND: Our position is: we do not comment on that. There are all sorts of benefits and there are all sorts of problems.

Chris CREWETHER: Now, after your earlier testimony—we heard from Alfred Health, and they had raised about sometimes the need for more complexity in the registration process in terms of finding out more information. For example, sending information to next of kin and family members, but also some more information about what a person might want to do in their later phase of life when they might be nearing the point of giving over their organs. I had raised a point that it might be a simple registration process to start with, followed by more of a follow-up afterwards to get some more of that data. Do you have any views on Alfred Health’s position on that?

Tony HOLLAND: Our position is fairly clear on this: we believe that the simpler the registration process, the more automatic the process, the better it is. I think to add a second step would potentially be extremely problematic.

Chris CREWETHER: At the stage, though, that the person is registered, they are in the system, and after that some more questions have been sent to people.

Tony HOLLAND: I do not know that that has been tested. I think that would have to be tested and verified from other jurisdictions across the world to see what they have done. But I think the biggest issue is to get the simplification of the registration process in place first, because that is the key driver—that and the conversation. They are the two key drivers, and I think other things—it may well be of benefit, but it might not be. We would have to do more research around it.

Chris CREWETHER: Yes. And this is perhaps a question for you, Stuart. I did ask this question earlier—I know that an opt-out mechanism would not work in giving blood; I do not think anyone would want to be forced to have to give blood—but what is your view in terms of an opt-out mechanism for organ donations?

Stuart CHESNEAU: We have actually discussed that at Lifeblood, and we think that is a good idea. I think that would be a good idea. It is an opt-out in certain countries and it works well, as I understand it. Again, I am not speaking from a position of deep knowledge—I am not an organ donation expert—but I think that would work. You are right; I do not think you would want to do that for blood. I think they do that in China, and I do not think that is a great idea. But, yes, I think it would make sense for this—to put people on the registry and get them to opt out.

Chris CREWETHER: Thank you. That is all.

The CHAIR: Thanks, Chris. Gary.

Gary MAAS: Thanks, Ella. Yes, and thank you both for coming in today. I would just like to loop back to the app. You may not have these stats on hand—please feel free to provide them at another time if you can, if the data is collected around this. You have said that there are 550,000 donors around the country—is that right?

Stuart CHESNEAU: Yes. Well, I have rounded up. There is about 537,000, yes.

Gary MAAS: So I am just wondering: what proportion of those are donors who would have registered through the app? And my supplementary question is: how many people have downloaded the app, as well?

Stuart CHESNEAU: I would have to take that on notice. I would say—I will take that on notice, but it is in general a high proportion of those because you can book it. We are appointment-based, so you can walk into a donor centre and say, ‘I want to donate today.’ That is only a very small—that is 5% that do that. We do have a call centre in South Australia through which we call people and make appointments. Some people make a repeat appointment after they donate. The rest of the majority, and we have got, as I said, 2.23 million appointments made in a 12-month period, I would say six –

Gary MAAS: So 2.3 million appointments are made through the app over a 12-month –

Stuart CHESNEAU: No, are made to donate –

Gary MAAS: Oh, generally. Yes, right.

Stuart CHESNEAU: I would say—and I am guessing; I can get you the numbers—60 to 70% of those are through digital channels, if not more. So, yes, most people. Downloads of the app, I do not know. I will find out. But it is either that or through donateblood.com.au, so the majority come through there. And we can see it, because it is much easier to cancel and reschedule through the app—which is a problem for us, but it is a service that the donors wanted. And when we have really rolled out the app, we see a lot more. So it is the majority.

Gary MAAS: You also talked about the spread of donors within that in terms of age groups. If there are any statistics available around the age groups that are using the app for those sorts of purposes, that would be good.

Stuart CHESNEAU: I can get those. We have got a whole body of work that describes the success of the app, so I can send that to you.

Gary MAAS: Terrific. Thank you. Also, are you familiar with the Service Victoria app at all?

Stuart CHESNEAU: No.

Gary MAAS: And you, Tony?

Tony HOLLAND: Minimally. Once it gets more services on it, it will be better, but yes, I am familiar with what they have done in New South Wales, for example.

Gary MAAS: Yes, so look, the Service Victoria app is a government-based app which, you know, you can register for your licence on it, you can make payments in all sorts of areas, registration, you can get the \$250 power saving bonus, all sorts of things. Would you be able to see if something like an organ-donor-type app might fit within that kind of offering?

Tony HOLLAND: I do not think an app is the answer, because you would use it once, and what are you going to use it for again? So I do not think we need an app, but I think we need a link. It needs to link into –

Gary MAAS: Yes. In terms of a link, yes—so it is like the \$250 power saving bonus. You are not going to do that more than once –

Tony HOLLAND: No, but I think, as I said this morning, every single item on that app needs to have a button: ‘Would you like to be an organ donor?’ And as soon as you click it, bang, you are straight into the Medicare AODR. I reckon that is the answer. So, with every possible chance there is of an interaction with a government agency, there is that chance to click, ‘Yes, I want to be an organ donor.’

Gary MAAS: Yes. We talked about security this morning and cybersecurity as well. I understand that through the Lifeblood app you are collecting basic data on people. How is all of that kept? I cannot really ask that. Just in terms of security, are you confident that the security measures on that are –

Stuart CHESNEAU: Yes. I am not sure I can go into the details of how we ensure a cybersecure environment, but we have a large cybersecurity team. It is all cloud-based. There is two-factor authentication. There are lots of firewalls. There are lots of phishing exercises. We are very concerned, because other blood services around the world have been breached, and we had our own issue with data security as well –

Gary MAAS: Maybe a better question would be: are there any challenges that are associated with that data collection?

Stuart CHESNEAU: No. It carries risk, because you are carrying personal information, but it is not just the general information when they register, about age and address, et cetera. We carry all of their test results as well and all of their answers to their questionnaires, and there are some very private answers, so it is absolutely paramount. So, if we were to add more data in for the right reason, it would not be a concern.

Gary MAAS: This is my last question. I will just switch to the grant funding. Funding comes from different sources—Commonwealth funding, state government funding, et cetera. You have talked about the different components that you have used that budget to spend money on. What is the education component within the budget?

Stuart CHESNEAU: Do you mean within the marketing budget? Education?

Gary MAAS: Is it within the marketing budget, or is it separate?

Stuart CHESNEAU: No, it is within the marketing budget. Education and awareness are all part of what the marketing budget is there for. There are some specific activities around certain times of the year that are more outcome-focused for the number of donations we need—we call it an ‘always on’ approach to education and awareness—but a large proportion of that \$10 million to \$14 million that we spend nationally is around awareness.

Gary MAAS: Thanks very much.

Stuart CHESNEAU: A pleasure.

The CHAIR: Just to wrap up, I just have one more question that I would like to ask. We have not really touched on in great detail stem cell donation and the bone marrow donor registry. I am just wondering if you have any thoughts on how in Victoria we can show some national leadership in these areas and any reflections that you might have on these two areas.

Stuart CHESNEAU: We are in active conversation around this with governments at the moment and we have a submission in with the Commonwealth around what our role could be for this one, so I am not sure how much to discuss that one at this point. I think there is a need to increase those people on the ABMDR—the Australian Bone Marrow Donor Registry. Lifeblood is funded to recruit a set amount through our fixed donor centre network nationally and then to do the follow-up testing to make sure that we understand all of the demographics. It is quite tied to a certain age and gender but also what their kind of HLA outlook is, which is some of the matching process down the track. But there is more that we can do. We have the network, we are good at the recruitment of donors and also the testing down the back. It needs to be at the right price, and we also need to figure out how to target people outside of just our donor panel. That is what we are in conversation with the Commonwealth about at the moment.

The CHAIR: If those conversations progress, is that something you could potentially share with the Committee at a later point in time if you feel it is relevant to our inquiry?

Stuart CHESNEAU: I think we would very much like to come back and talk to you more about this one. I might just need to come back to you on that. It is very, very topical. If you provide the opportunity to come and discuss it, yes, I would love to. I think there is a lot more we could talk about. And I think if Victoria wants to take the leadership in this space, there is a lot that we could do to increase. At the moment I think the number—I happen to know the number—I think we have got a target of 1297 recruitments into the ABMDR in Victoria. As a target, that is not very many. I think we could do a lot more, again through awareness and again through the brand that we have got as long as we can do it at the right price and as long as that is something that the Commonwealth and the ABMDR would want, and that is a different conversation.

Annabelle CLEELAND: Can we receive a copy of your submission?

Stuart CHESNEAU: I do not know. I would not like to say whether you can or cannot. But I will ask that question. I will ask another question. You have asked for a couple of things on notice. What is the process for that?

The CHAIR: That is pretty much how I am going to wrap things up. So just regarding questions on notice, we do ask that you come back to us within two weeks, and we will provide you the questions on notice along with the transcript so that you can review everything that we have discussed today.

Thank you, Stuart, and thank you again, Tony, for appearing before the Committee today and for your contribution to this inquiry. It has certainly given us more to think about, and we very much appreciate your expertise in this area. We also thank you for your time in preparing your presentation to us and the evidence that you have presented today.

As I mentioned, if we could have those questions on notice within two weeks—and we will be in touch with the transcripts. We will just take a short break now before we receive our next witnesses. Thank you.

Witnesses withdrew.