

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

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Annabelle Cleeland—Deputy Chair

Chris Couzens

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Gary Maas

Cindy McLeish

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WITNESSES *(via videoconference)*

Dr Brooke Huuskes, Senior Lecturer, Centre for Cardiovascular Biology and Disease Research; and

Dr Stacey Hokke, Research Fellow, Judith Lumley Centre, School of Nursing and Midwifery, La Trobe University.

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

I would like to just quickly introduce my colleagues that are appearing with me today so you can see everybody. We have got Chris Crewther; Deputy Chair Annabelle Cleeland; my name is Ella George, and I am the Chair of this Committee; Christine Couzens; and Gary Maas. And joining you on the screen we have also got Cindy McLeish.

Thank you very much. Welcome, Dr Brooke Huuskens and Dr Stacey Hokke from La Trobe University. Thank you very much for taking the time to appear before our inquiry today.

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

Brooke HUUSKES: Great. Thank you for giving us the opportunity to share some of the work we have done today. To give you some background, young people under the age of 25 are one of the most under-represented groups in Australia on the organ donor register. We know that most young people agree with the idea of organ and tissue donation; however, only 10% have actually signed on to the organ donor register. In 2022 we received funding from the Organ and Tissue Authority to explore young people's knowledge and awareness of organ donation and the registration process, to help us understand why so few young Australians have registered. Through speaking with young people, we aimed to gain insight on their knowledge, attitudes and perceptions on organ donation and the registration process and factors, informational needs and messaging preferences that may influence their motivation to register as well.

We conducted a qualitative study involving online focus groups with 44 young people. They were recruited from around La Trobe, including both metropolitan and our regional campuses located around Victoria. Three-quarters of our participants were women and most were studying a health- or science-related degree. Half had already registered as an organ donor prior to the focus groups, and 25% had a personal connection—so they knew someone who was waiting, who had had a transplant or were involved in the donor family side of things. Through these focus groups we identified a number of themes, and they indicated that there was a significant lack of awareness and understanding of organ and tissue donation among young people. Many young people were also not aware of the importance of having conversations about this or that they needed to join the register. Young people did express a strong desire to make informed decisions but felt there was a significant lack of information available to them. This was the main barrier in them signing up to be an organ donor.

Broadly we encountered two groups of young people: we encountered those who thought that the decision was relatively quick and easy and just needed the opportunity to register and those who really wanted to make informed decisions about the topic. As I mentioned, this latter group really found that information difficult to find. An additional barrier to registering was that thinking about organ and tissue donation incited fear in the young people because it was associated with death. The role of family influences and navigating government systems were also some of the barriers. However, motivating factors included altruism, contributing to society, knowing how simple the registration process is, possible incentives and also media representations of successful stories of young people who had gone through the organ and tissue process.

Stacey HOKKE: We also identified a number of ways to better communicate with young people about organ donation and registration. Firstly, young people identified a need for information to be provided at an earlier age, and they suggested embedding content in school curricula, often in high school but sometimes as early as primary school. This would help reduce the perception of organ donation as a taboo topic. Having multiple opportunities and reminders to sign up to the register from early adolescence, for example, was viewed by young people to be beneficial. They felt that they needed a push to take the step to register as a donor and said that being contacted at multiple time points before reaching adulthood would help facilitate that. Regarding where to disseminate information, unsurprisingly social media was the most common space for promoting

registration to young audiences. Young people suggested social media because it is where they live, and overall they thought that a social media presence was really critical for improving awareness among young people. Beyond social media, participants suggested advertising in public spaces that they visit, such as university campuses, their workplace and public transport.

In regard to how messages should be delivered to young people, they recognise that information needs to be delivered quickly given their short attention spans, and they suggested two main types of ad formats. That included brief messages—for example, static images on social media or posters in some of those public spaces—as well as short videos, so 60-second grabs delivered via social media. For those brief messages, they just highlighted how they should be simple, attention-grabbing headlines and snappy facts about the social benefits of organ donation or some bite-sized infographics that really emphasise how quick and easy it is to register. For the videos, participants recommended two types of content. That was educational content to fill some of the knowledge gaps that were identified in our research as well as emotive videos, so sharing personal stories from transplant recipients. And young people really wanted to hear firsthand experiences of organ and tissue donation from people who are a similar age to them.

Lastly, we should just mention that young people stressed the importance that the purpose of promoting donation and registration should be to inform but not convince others to join the register. The young people we spoke to were really cognisant of the diversity with their communities and emphasised that information needs to be delivered in an inclusive and culturally appropriate way. They also acknowledged that donation is a sensitive topic and needs to be treated with respect.

Informed by our findings, we have identified six evidence-based recommendations to improve registration rates among young Australians. We found that young people just do not know enough about organ and tissue donation, and this ultimately has resulted in inaction. Our first recommendation is to create educational resources and increase knowledge dissemination to young people to really enable that informed decision-making.

Secondly, we found that parents do play a pivotal role in young people's donor registration status, and young people did not appreciate the need for family discussions about their donation preferences and were unaware that their family are ultimately responsible for making the final decision. So our second recommendation is to build awareness of the importance of family conversations and to support effective family discussions. Those campaigns can target young people but also their parents, given the key influencing role that they have in young people's lives still.

Thirdly, a key finding is that organ and tissue donation quite simply is just not on young people's minds, and that is likely because it has not been adequately promoted to them up until now. Young people felt that they needed the extra push to register and to seek more information. They wanted to know about organ donation, but they did not know where to find that reputable information. Few study participants recognised DonateLife or knew what they did. So our third recommendation is to invest in community awareness campaigns targeted to young people to increase the visibility of organ donation but also to increase the visibility of DonateLife as a central place for information and registration. I will just hand back to Brooke quickly, and she will wrap up for us.

Brooke HUUSKES: Thanks, Stace. Our research gathered information also about specific messaging content that resonates with young people and the locations where that messaging should be placed to reach the maximum amount of young people. Our fourth recommendation is to create messages that specifically target young people and mobilise motivating factors and to disseminate this where young people live—mainly, as Stacey said, on social media and in physical spaces that young people visit frequently. All advertising and educational content must be delivered by or contain people that are of the same age or younger than the target demographic, and messaging should remain positive and not talk about death.

Learning about organ and tissue donation over time will likely increase the chances of young people signing up to be an organ donor, so our fifth recommendation is to embed organ and tissue donation into school curricula and facilitate information-gathering opportunities from adolescents across young adulthood. Engaging with young people at multiple times will support them to be adequately informed and lessen the cognitive load of decision-making. And lastly, young people thought that blood donation was promoted really well in Australia and suggested that organ and tissue donation should draw upon Lifeblood marketing strategies, so our sixth

recommendation is to learn from and partner with Lifeblood to use similar strategies and incentives to increase organ donation rates among young people.

The next phase of this research, based on the fact we were lucky enough to receive a small amount of funding from the Organ and Tissue Authority, is to implement or to start addressing recommendations 1 to 4. So we are in the process of developing and disseminating digital education resources targeted at young people, and we are doing this in collaboration with La Trobe University and harnessing their social media presence. That is all we have. Thank you.

The CHAIR: Great. Thank you, Brooke and Stacey. It is a very remarkable and unique piece of research. Thank you so much for your submission and for providing us your research as well. We will now start with a few questions for you.

I would be particularly interested to hear in a bit more detail about what some of those next stages are and how you would be partnering with La Trobe University to get some of those messages out. Would you be able to go into that in more detail for us, please?

Brooke HUUSKES: Of course. We have partnered with a production company to help us make these educational videos, and I think we have maybe six videos that are each addressing the topics that young people found the biggest knowledge gaps in. Some young people in our group did not even know what organ donation was, so the first video we are making is: what is organ donation. The next one is kind of like: who benefits from organ donation? Why is it important to register? Did you know that there was a register? All of those things are going to be our educational content, and we are also going to have some other videos that are not going to be as detailed but that are really going to address that group that felt it was an easy decision but just needed the opportunity to register. They are going to be, like Stacey said, quick snappy facts because that seemed to be motivating for young people to join.

We are in the development phase of those videos, and we are collaborating with the La Trobe University media team, who are going to disseminate this information via their socials and—Stacey, help me out, what are they called?—paid spots.

Stacey HOKKE: La Trobe will use their organic reach. They already engage with—I do not know—let us say, 500,000 young people across the country, but they will also run some paid advertising which we got funding to do. We will also have a dedicated media plan that La Trobe will kind of spruik on our behalf to various youth media agencies to try and get the message across that these educational videos are now available and they can find out more information.

The CHAIR: Great. Well, I cannot wait to have a look at them myself. One of your recommendations was partnering with Lifeblood to increase the number of young people who register as organ and tissue donors. Do you see the videos as being a part of that, are you looking at other strategies or do you have other ideas around that?

Stacey HOKKE: Good question. I think in every focus group that we had the young people said just how common it is to see Lifeblood promoted and that it is done really well. So there is opportunity perhaps, not through the videos but when they are in a Lifeblood centre, for example, to have a pamphlet about organ donation or when they are getting their hematocrit checked and those sorts of things it would be like, 'Hey, have you heard about organ and tissue donation?'

Young people also said how there are incentives—that Lifeblood use incentives like team building and 'collect the most points' and have a sticker, and there are drives for blood donations as well. That might look a little different for organ and tissue donation, where it is a kind of one-off registration process, but that does not mean that similar strategies could not be applied through DonateLife, for example, jumping on what has been working really well to engage young people in blood donation as well as organ and tissue donor registration. Is there anything you wanted to add, Brooke?

Brooke HUUSKES: Just saying that part of that, I think, is that organ donation is a one-off registration thing, but young people also suggested that maybe congratulating people for being on the register for a year or a certain amount of time or for reaching milestones for how long they have been on the register could be a way to kind of engage more with them.

Stacey HOKKE: I think with the videos that we have got planned now—we have not had any discussions with Lifeblood at this stage, but that does not stop that from happening in the future. The content we develop will be shared with DontateLife, and of course we are open to many conversations and further opportunities to increase young people's engagement with this type of content.

The CHAIR: Great. Thanks for that. We actually just had Lifeblood in before you to discuss some of their strategies, so it is fantastic timing to be having this conversation with you both as well this afternoon.

Stacey HOKKE: Great.

The CHAIR: Great. I will now hand over to some of my colleagues to ask some questions. I will hand over to Gary.

Gary MAAS: Terrific. Thanks very much, Ella. I think Cindy wants to say something.

Chris CREWETHER: She has got to go, she said.

Gary MAAS: Oh, you have got to go. See you, Cindy.

Chris CREWETHER: I will ask her questions for her.

Gary MAAS: Thanks, Stacey, and thanks, Brooke, for your time. Just from personal experience, my historical experience—I guess we would call this being IRL, in real life—many, many years ago when you got your drivers licence you put a sticker on the back of it and that meant you were a donor. You had a little card to read about what being an organ donor meant. You knew that putting that sticker on did not necessarily hold you to it, but it was an indicator that should the worst happen that was what you had registered as. The most powerful part of doing that was the conversation that you would have as an 18- to 24-year-old with your parents or your family in your household.

In many respects what I have garnered from your report and what you have spoken about in terms of your recommendations today is that the world has moved on and kids—sorry, I used the word 'kids'; I should not do that—live on their technology and live in an online world, so the conversation has to take place in another way. I guess I am speaking as a parent as well here. How do we kind of traverse that to make that conversation happen? Because ultimately when it does get to the other end, there has to be a conversation with medical personnel and so on to allow that to happen. But how do we get to that point, I guess, of traversing the online and the IRL world? It is just a simple one to start with.

Brooke HUUSKES: Yes. I think it comes down to education, personally. People in our focus groups did not know the importance of those conversations to start with, and so you are right—giving them the opportunity to have those conversations is really important, whether or not they see something on social media and that stimulates the conversation with the parents. We came across some young people that knew that they had different opinions to their parents and thought that that conversation was going to be really hard for them. I guess one of the videos that we are thinking of creating is about how to actually initiate and have those conversations with your parents, because some people do find it challenging. Is there anything else, Stacey, that you want to say?

Stacey HOKKE: I was just going to add that with some of the young people we spoke to, they have had a conversation with their parents, and their parents have said, 'I don't need to register. You know my wishes. You know my preferences.' And that was kind of what they thought about joining the donor register too, 'Oh, I don't need to. My parents know my wishes,' for example. So I think, as Brooke said, it is education for young people, but it is also education for parents of those young people to say, you know, 'Yes, perhaps a brief conversation is great, but it needs to go that step further in actually joining the register.'

In regard to how we can actually harness social media more effectively, I remember speaking to some young people and they told us that they had joined the register, saw how quick it was and so they shared a screenshot with their WhatsApp family group, for example, or they saw an advertisement or saw something about organ donation on their social media and then shared that through their own networks, so that kind of kept the ball rolling and kept the conversation going through their social media channels. So if there is a way for us or others to kind of get on that and say, 'Share the message; have a conversation face-to-face or on social media'—there

are many ways to have conversations now online or IRL. So, yes, there are some other ways that those family conversations can be had in today's age.

Gary MAAS: Thanks. That is really helpful. I have just one more question, more of a supplementary, and it continues down the drivers licence and registering path because we have, I think, had some slightly different evidence from what your research report presents. So the research that you had states that for young people whose first exposure was at the time of receiving their drivers licence, this was perceived as confronting as they associated driving a car with fear of imminent death, and the approach did not result in the intended action of signing up to the registry or having a conversation with family. So if the research is indicating that encouraging registration through drivers licences may not be the best approach, I am just wondering what your view is on, I do not know, the potential to reintroduce donor registration through the driver licensing system.

Stacey HOKKE: I think we had not pieced together—that is how I signed up to be an organ donor myself. I got my little thing in the mail, then I got my drivers licence and off I went. But, yes, to hear quite a few young people say that to them that was confronting because they thought that they would end up in an accident and therefore die—that is not something that had crossed my mind. So, yes, that was just really interesting. Perhaps that is the different evidence that you have heard across the day today.

I think it just goes back to the idea of multiple touchpoints. If, when you turn 18 and you get your drivers licence, that is the first time you have heard about organ donation, of course that is confronting. But if there have been earlier time points, whether that is through embedded school curricula—it could even be sporting groups or other things, those core activities, that children do—having multiple touchpoints I think and that earlier education means that when they do perhaps receive that information in the mail, it is perhaps not as confronting. Anything to add, Brooke?

Brooke HUUSKES: Yes. I just think that having it on the licence again might be great for those people that just need the extra push—'Oh, yeah, I've been thinking about that. I'll sign up.' From the current way that things are—forgetting—we want to embed it in school curricula and have these multiple touchpoints earlier. But, like I said, a lot of young people want to make really informed decisions about it, and I am not sure that that exchange when they get their licence is going to be enough for them to make those informed decisions. So I do not know whether it would be beneficial to the people that want to make those informed decisions. They probably want to go out and do their own research and then come back and make their decision later.

Gary MAAS: Thanks very much.

The CHAIR: Thanks, Gary. Over to you, Chris.

Chris CREWTHER: Thank you, Chair. Thank you very much, Stacey and Brooke, for your evidence today. And I love the background, by the way, Brooke. It is like a combination of *The Matrix*, a disco and *Tron* or something. It is very good.

Brooke HUUSKES: Thank you.

Chris CREWTHER: I had to mention *Tron* in a hearing. I just have a couple of questions. The first one is from me and the second one is from Cindy McLeish, who unfortunately had to leave. We heard from earlier witnesses, particularly DonateLife, around the need to reutilise the VicRoads system to link straight to the Australian Organ Donor Register. And they noted figures like in South Australia, which is the only state that has that direct link through the licence registration process, where the registration rate is 72% versus a 23% organ registration rate in Victoria. In particular, DonateLife in their submission said:

... the Victorian driver licence system and the AODR – along with a public awareness campaign – is the single thing that will make the most significant impact to registration, over time.

Noting that and your submission as well and some of the questions and comments before, what do you think about that as an effective means to actually sign up young people in combination with other means? And by other means, do you think that we should also have contact points with the government, say, with vaccinations or school registration or visits to doctors for young people, sports clubs, dance clubs and so on—the multiple different contact points that young people have—to try and get them involved?

Brooke HUUSKES: Yes, is my answer. Multiple contact points is something that for young people now is starting to be definitely needed, I think, and wanted. Some of them even said, ‘When I go to the GP, it would be great if they could sign me up for it and I could have a discussion with my GP about the pros and cons and everything about organ donation.’ I think if we had it coming from as many different angles as possible, that would be the best thing. In regard to the education, I think as long as the education is particularly targeted at young people—so answering the questions they have, their knowledge gaps, giving them the opportunity to register and placing all of that where young people live, would be the most effective. Someone suggested an advertisement on TV, and I said, ‘Do you watch TV?’, and they said, ‘Actually no, we don’t, but if you make a Netflix documentary, that would be great. It’d get a lot of attention.’ I said, ‘Great. No worries. I will take that back. Let’s just make a Netflix doco and you can all watch it.’ What do you think, Stacey?

Stacey HOKKE: I think it just comes back to multiple touchpoints, multiple education. It sounds like DonateLife are keen to engage VicRoads again. We know that from our interviews during the peak of the COVID pandemic period when people were checking in on their phones with the COVID app, that is how they came across that they could update their donor registration status—so, yes, just multiple touchpoints. I think perhaps for young people as well one of the barriers was that they did not have their own Medicare card and therefore could not sign up themselves. So if a drivers licence is something that is their own that they have got themselves and that is in their wallet, then that makes sense too.

Chris CREWITHER: Thank you. The other question I have is also from Cindy. She said: have you seen good awareness/quality messaging in other states that you would recommend—whether that is another state in Australia or perhaps you have also got some international experience you can refer to as well?

Stacey HOKKE: Messaging about organ donations specifically?

Chris CREWITHER: Yes, I think organ donations but also particularly targeting young people as well—messaging that might actually work. With the messaging that you are developing at the moment, have you seen similar messaging elsewhere that has worked—that has an evidence base that it has worked elsewhere—whether it is in South Australia or in other states?

Brooke HUUSKES: I have not come across anything. No, nothing is coming to mind, other than our messaging preferences are all driven by what our group of young people said. We did not explicitly ask them if they had heard—actually, we did. We did ask them if they had heard of organ and tissue donation or seen advertising, and the answer was no—overwhelmingly, for the majority—but we never got into the details of, ‘if you did see advertising, what was it like?’ and things.

Chris CREWITHER: Now, noting your *Matrix* background, I have a question about: do you think young people could be engaged through different TV and other apps, whether YouTube Kids or Netflix? Even on a main screen, when you have flicked it onto the TV to watch it, whether it is Binge or other platforms, do you think there could be a link to ‘Donate’ that could be embedded there or advertising that could be on there and so on as a way to get to young people?

Stacey HOKKE: I think it is certainly something to consider. There obviously needs to be more research to see if that is actually something that young people would engage with. We know from the people that we spoke to that there are so many different social media platforms that they engage with and they have all got different ways to get messaging across. Often they will just be watching a video on YouTube or TikTok, for example, and not even be aware that it is about a public health message of some kind. So I guess that inconspicuous or inadvertent kind of messaging that pops up to them is just another way to ingrain it and get the message across.

Chris CREWITHER: Or maybe even a way to register using a system, so you actually have a button you can click on on YouTube Kids that you actually click on to register, something like that—obviously with parental involvement of course.

Brooke HUUSKES: YouTube was a platform that young people said they use and visit a lot, so it is definitely a place worth investigating for those kinds of things.

Stacey HOKKE: I guess—sorry, just one more thing to add—reflecting on our research, there was that group of participants for whom it was not just a simple ‘Here’s a click button to go and register.’ They needed more information and different educational resources, so it is accommodating ‘Yes, there’s different ways that

you can register and it can be done easily,' but also ensuring that there is adequate education so they are making an informed decision, especially for the young people of Australia.

Chris CREWETHER: Thanks.

The CHAIR: Thanks, Chris. Christine.

Chris COUZENS: Thank you. Thank you both for your contribution today. We really appreciate it. You are doing some amazing stuff with your research. You talked about the young people's focus groups that you were using. Did you have First Nations and CALD communities, for example, involved in those focus groups, or did you have separate focus groups for that group of young people? I am just interested to find out who was in the focus groups.

Stacey HOKKE: That is a really good question. We did ask people about their Indigenous status. None of the participants in our study were. We did ask them about their cultural background, including what language they spoke at home and which country they were born in, and I think about two-thirds spoke English and were born in Australia—so kind of reflective of La Trobe's population of students at least. So we did have some cultural diversity within our sample that represents what we had expected to find, but we did not hold specific CALD focus groups for those people. It was just spread across. But we do recognise that there is more research needed to be done to understand the specific needs of different population groups within the young adult population.

Chris COUZENS: And we have heard a bit about utilising schools, for example, for young people to get that message out there and for better education around what being a donor means. Some are saying that it is really difficult to access the education system because they are already under demand, so have you got any ideas or thoughts around how that might be achieved and the significance of getting into the schools?

Brooke HUUSKES: I think a few young people said that they have nurses come into schools and talk about blood donation, and they suggested that maybe the discussion of organ donation could be a part of that. I have not been in the school system for a really long time, so I do not know how things are anymore.

Chris COUZENS: Me either.

Brooke HUUSKES: I do not know how things are anymore, but that is the closest thing from our focus groups that someone suggested about how to get into the schools.

Stacey HOKKE: Just to add, recognising that there may be challenges to embedding something within the school curriculum when they are already maxed out, universities or TAFEs provide great opportunity to embed stuff within the higher education curricula, and that is what some of our focus group participants suggested as well. So there are other opportunities across the education sector to embed some education.

Chris COUZENS: And what do you see as the challenges or barriers to getting that information out there? Is it lack of resources, or is it lack of ability to get to a broad cross-section of young people?

Brooke HUUSKES: I maybe think it is a bit of both. To develop something to embed into a university, even if it is just—sorry, first aid courses were another thing that participants suggested maybe organ and tissue donation can be spoken about. I do not know whether that is good or not, just thinking about it, but there were other opportunities that they were suggesting that this could be spoken about. Embedding something in a university takes a lot of time and energy and, yes, resources obviously are a key part in that. I had a dream that I wanted to embed something like this in all health science-related degrees at La Trobe University, but then if that managed to happen, how would that then roll out to the rest of Australia and things like that? That is a lot of time and effort and connection. So, resources—and what was the other thing you mentioned, sorry?

Chris COUZENS: Just the challenges and barriers that will be there.

Brooke HUUSKES: Yes. I had something, sorry. Stacey, if you want to add something, it might come back to me.

Stacey HOKKE: I just want to note that the overwhelming majority of young people we spoke to had never seen an ad or anything about organ donation. So, yes, there is an element of education, and there is the

resourcing that is required to enable that education to happen. There is also a stream around just general awareness—so those short social media posts or grabs or something, or it is a billboard at your tram stop and those sorts of things. There are other avenues that seem relatively straightforward that are an easier approach to get the ball rolling and get young people thinking about organ donation.

Brooke HUUSKES: And I think that probably would hit more of the target demographic, doing that. If you advertise at universities, only university students are going to see the messaging, but if you advertise in public spaces where young people are, like, as Stacey was saying, some major tram or bus stops, then you are going to get more people seeing the message.

Chris COUZENS: Great. Thank you.

The CHAIR: Thanks. Annabelle, thank you.

Annabelle CLEELAND: I had nearly the exact same questions, Chris. I will skip a few, but I was quite interested in the demographics of the 44 participants and the cultural diversity and if there were any themes, even if there was a small number represented. Is there another level of research that you hope to conduct that you identified initially that really needs further examination?

Brooke HUUSKES: I will start, Stacey—I am sure you can finish a lot stronger than me. We do recognise also that our group of young people are at university, so I guess you might call them highly educated compared to another young person that you just encounter on the street. So that is something that we have considered. But also I guess I go back to the fact that even they still did not know what organ donation was; there is still this massive knowledge gap, even among those educated people. We did have a few people from overseas—they were international students—and they sometimes spoke about the differences between what happens in their countries around this and Australia. We had questions like, ‘If I’m an international, how do I get onto the register?’ and things like that. There is the Medicare issue and things for those young people.

But for me I guess the difficult thing with CALD is it is always a limitation in studies like this, right, because we are not CALD ourselves. If we wanted to engage in that research, we would probably need people who were from those backgrounds to make sure that discussions were not biased in any way and people felt comfortable about speaking up about these topics. I think that more research would need to be done, like you suggested, with different types of young people, not at universities settings or with more of those CALD community groups. I think they are a bit hard to recruit to studies like this because of the nature of how our focus groups are set up.

Annabelle CLEELAND: Okay. Without repeating, if you were able to extend your research or go to that next level, what do you feel has to be further examined? Not necessarily just focusing on the diversity of cultural backgrounds or demographics, did you spot something that you think we should be looking at?

Stacey HOKKE: I think one avenue could be parents—parents of young people in particular—to really get into the family dynamics and household situations that enable meaningful conversations to be had. That would benefit young people joining the register but also many generations and segments of the population. And just building on what Brooke was saying, our research was a very small pocket of money to hear from 44 young people, so, yes, it is only just the beginning. I know there is other research across Australia that has focused on CALD backgrounds and other age groups as well. Yes, I think there is a definite need for more of this type of research across the country.

Annabelle CLEELAND: Just a couple more, sorry. Did you lean on any research for your own information that would be important for the Committee to know? Have you seen any current research that we could also look at in this space that might not be necessarily focusing on young people?

Stacey HOKKE: We, as good academics, performed a literature search. We have built up an EndNote library—if that means anything to you—and found nothing really recent or in Australia. We did come across—you may be familiar with it—the BETA report. I cannot remember what that stands for—my apologies—but that was a report released maybe last year by the government looking specifically at young people. Is that familiar to you?

Annabelle CLEELAND: Yes, we know about it. But we will also refresh ourselves.

Stacey HOKKE: For our research, I guess, that was more survey based. It really looked at—Brooke, correct me if I am wrong—different kinds of slogans and what was most engaging to young people. Ours was a qualitative study and just had a slightly different focus, but that would be one thing to look at. A lot of other research, from memory, is international and is more about opt-in, opt-out, and there is just a different context to the Victorian or Australian situation.

Annabelle CLEELAND: I will just say finally I guess that we learned about DLV and Lifeblood and the difference in their marketing budget and opportunities there. Have you observed any sorts of awareness and education programs that are affordable? Are there any collaborative opportunities that you see that might mean that DLV can leverage freely off that sort of awareness?

Stacey HOKKE: Regarding Lifeblood, sorry, or—

Annabelle CLEELAND: I think the difference in marketing between them financially is very significant, so is there any opportunity that you see through DonateLife Victoria to leverage off that education and awareness through other opportunities to reach young people?

Brooke HUUSKES: Well –

Stacey HOKKE: Sorry; you go, Brooke.

Brooke HUUSKES: You might have been about to say the same thing: the grant that we got. Is that what you were going to say, Stacey? There are organisations out there—I am trying to think of some besides La Trobe University—that have access to young people that DonateLife could collaborate with, I guess is what you are asking, to disseminate that information besides collaborating with Lifeblood. Yes, there might be opportunities, but I think it was just amazing how many times young people mention Lifeblood. I think the amount of times they are exposed to them on their social media and the actual campaigns that they run are just really engaging for young people. Before we develop our dissemination strategy for our project, we have a youth advisory group that we are going to be talking to to ensure that the messaging that we put out there is relevant to them and includes stuff that they basically want to see.

Stacey HOKKE: I was just going to add to what Brooke said that our conversations with the media team at La Trobe—they are so interested in this kind of work and they cannot wait to disseminate it across their social media platforms. I imagine many other universities would be in a similar boat. It is just a fantastic social opportunity, and the social good that can come out of collaborating with DonateLife I think many universities would be happy to jump on.

Annabelle CLEELAND: With the four recommendations that you are working on now what do you hope to achieve? Do you have sort of targets that you hope to see donor registration increase by, and what would that look like?

Brooke HUUSKES: First, La Trobe social media team are going to have metrics for us. We are going to have a dedicated website where we host all of the educational and opportunity videos, so we will be able to see how many times they are watched and how many times people visit the page. The ultimate goal is the call to action, which is to register. But if there is a knowledge gap, just our knowing how many people go to the actual page where they can view the videos is an interesting end point for me to have a look at. But ultimately obviously the goal is to increase the number of young people on the organ donor register. How many? I might have to look back through the grant to figure out the reach that La Trobe media said that we might be able to get. I think it is somewhere in the order of 600,000 to 700,000 young people they think that they can reach through the strategy that we are going to implement. And so, oh, my God, can you imagine if even 10% of that joined the register. It is going to be phenomenal. But like I said, because we identified those information gaps, I am really interested to see how many people actually go to the videos and watch the videos to learn more and then hopefully register.

Stacey HOKKE: And just to note that in our report that we send back to DonateLife at the end of the year—we will be doing some campaign tests to see what performed well, so we will be able to feed that back to DonateLife, and that can inform the future campaigns that they might run as well. So it is, I guess, an unknown; we are hopeful, but we will know more in six months time.

Annabelle CLEELAND: I should have opened with this, but I just wanted to say also: a really big congratulations to both of you. It is a unique space, and you have delved in. I genuinely believe it is going to improve things and help people and help save lives as well. So congratulations for all you have done, and I look forward to watching your career, actually.

Brooke HUUSKES: Thank you.

Stacey HOKKE: Thank you so much. That is lovely of you to say.

The CHAIR: Thank you, Brooke and Stacey. Thank you so much for appearing before the Committee today and for your contribution to this inquiry. It is a very unique piece of research and it has given us a lot to think about. On behalf of the Committee, if you could keep us informed as to any future research that you are looking at. We cannot wait to see your videos, so please send through those links when they are live, but any updates that you would like to share with the Committee about the promotional activity that you are doing would be fantastic. We are looking at reporting at the end of March 2024, so we have got a long period of time in which we are doing this work. It would be great to touch base with you perhaps later on in the year to see how things are going.

I do not think we have any questions on notice for you—if there was anything that we asked you to come back to. We will provide you with the transcripts as well, so have a read through of those, and we ask you to verify those transcripts.

I would like to take this opportunity on behalf of the Committee to thank all the witnesses who have given evidence to the Committee today, as well as the Hansard team, the Committee Secretariat and the security team here.

The Committee will continue its public hearings on this inquiry on Friday 23 June. I declare this hearing adjourned. Thank you.

Committee adjourned.