

# TRANSCRIPT

## LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

### **Inquiry into increasing the number of registered organ and tissue donors**

Melbourne—Friday 23 June 2023

#### **MEMBERS**

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

#### **WITNESSES** *(via videoconference)*

Ms Maryaan Essa, Bilingual and Bicultural Health Educator, Arabic,

Ms Dai Nguyen, Bilingual and Bicultural Health Educator, Vietnamese, and

Ms Hanh Thi Pham, Bilingual and Bicultural Health Educator, Vietnamese, Multicultural  
Centre for Women's Health.

**The CHAIR:** Good afternoon. We will now recommence public hearings of the Legislative Assembly's Legal and Social Issues Committee's Inquiry into increasing the number of registered organ and tissue donors. My name is Ella George and I am Chair of the Committee, and I am joined by my colleagues Gary Maas; Annabelle Cleeland, Deputy Chair; Cindy McLeish, who is just rejoining the table; and Chris Crewther. Welcome to witnesses from the Multicultural Centre for Women's Health. I welcome Maryaan Essa, Bilingual and Bicultural Health Educator; Dai Nguyen, Bilingual and Bicultural Health Educator; and Hanh Thi Pham, Bilingual and Bicultural Health Educator. Thank you very much for your time today and for joining us.

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

**Maryaan ESSA:** Thank you, everyone. My name is Maryaan Essa and I am one of the health educators at MCWH. This opening statement has been developed by the Multicultural Centre for Women's Health, MCWH, the national voice for migrant and refugee women's health and wellbeing. MCWH is a Victorian women's health service established in 1978 that works both nationally and across Victoria to promote health and wellbeing of migrant and refugee women and gender-diverse people across Australia. We do this through research and publication, participation in advisory groups and Committees, written submissions and training and capacity building. MCWH also works directly with women and gender-diverse people in the community, providing multilingual health education on women's health and wellbeing across a range of issues and topics through the use of nationally accredited, trained community-based health educators.

The summary: what was the project about and for? In 2018 MCWH successfully received funding through the community awareness grant program and conducted a project titled 'Your contribution saves other lives'. The main purpose of the project was to help people from culturally and linguistically diverse—CALD—backgrounds and their families to make informed decisions on organ and tissue donation and transplantation. The project was comprised of two main components. The first one was reviewing the existing resources developed by DonateLife and redeveloping likely shortened resources in format—for example, a foldable booklet and short 2- to 3-minute videos. And the second part was raising the community's awareness and building community members' understanding of the benefits of donations and transplantation through tailored education sessions, which were conducted by a bilingual peer educator team.

The outcomes of the project—the project produced a set of in-language Arabic, Chinese and Vietnamese one-page information fact sheets, and we also have a set of short, in-language videos, featuring our Arabic, Chinese and Vietnamese speaking bilingual health educators about 'Why it is important to become an organ and tissue donor?', 'Why it is important to discuss your desire and will of becoming a donor with family?' and also 'How or what are the ways of registering?', reviewed, edited, shortened and existing animated videos provided with a voice-over in three community languages: Arabic, Chinese and Vietnamese. The in-language resources—information sheet, videos and animated videos—are publicly accessible via a dedicated project webpage, aiming to help many people, in particular those from migrant backgrounds, talk to their family about the issue and encourage many people to register as a donor.

With the limited funding that we received, we were able to deliver and facilitate nine in-language education sessions to the targeted communities: Arabic, Chinese and Vietnamese. We reached 171 women from these backgrounds. The evaluation of the impact of the sessions were observed by extensive discussions held in the sessions and the number of women willing to consider becoming organ donors. Overall, there was a lot of expressed interest in the topic, with participants having little previous knowledge about organ and tissue donation. They were reassured that the body could still be used in an open-casket funeral and that so many people could potentially benefit from one donation. There were concerns about whether money changed hands in the process, and many did not realise that the family was consulted, after death, about their wishes. People

would consider organ donation after the sessions and that they had the facts and the information about the process. Many women also said they would now go back to their families and discuss the issue.

Not knowing how to register as a donor was another barrier identified from the education sessions. Hearing lived, real-life stories, on the other hand, was deemed one of the enablers. It was great to see at least 13 people committed to register as organ donors. I would like also to share some quotes from the sessions we did. One quote said:

After attending this session, I will consider organ donation as it could save many lives.

Another person said:

I will register to be a donor as long as my organs are still useful for other people as I understand it's important after today's session.

Another said:

In this session, I have received valuable information about tissue and organ donation, its effect on other people live, the urgent need of it, and way to register online as an organ donor.

Another quote:

This session has changed my attitude regarding organ donation. Giving lives to people who need organ transplant is a very humanitarian action and a noble thing to do.

Thank you.

**The CHAIR:** Thank you. That was an excellent opening statement. It sounds like you have learnt a lot from the project that you undertook, and there are some great learnings that we can also take on. I will hand over to Gary for the first question. Thank you.

**Gary MAAS:** Thank you all very much for your time today. Just one question from me: I just wanted to know—and I understand we have diverse communities represented here today so maybe there will be a couple of answers—what information or processes would better facilitate family consent to organ and tissue donation for members of multicultural communities? I know this is a bit hard on Zoom, so shall I call out a name? Dai, did you want to go first maybe?

**Dai NGUYEN:** Sorry, could you please repeat? I could not hear properly.

**Gary MAAS:** Sure, I will come closer to the mike. So what information or processes would better facilitate family consent to organ donation for members of multicultural communities?

**Dai NGUYEN:** Yes. In my experience and opinion, for the Asian cultures deeply rooted cultural belief has somehow stopped people from organ donation. For my children, it was easy for me to ask them to consent for me because they were born in Australia, but it was not easy for me to ask my parents from overseas, because they still affect from Asian cultures. They do not want—they believe when you pass away, they want the full body, and if you donate something, a part of your body, in the next life your body will be missing some part. It was not easy for most Asian people.

Even some of the health educators—I mean some people who work with us—tried to convince me I should not. They believed that—if I even tried to explain to them all the processes, it was not easy at all. So when I tried to convince them, for me, why I donate, I talked about myself first. I went to register for the organ donation because I feel that I owe Australia. Australia is a great country that I should do something for, because I was a single mum and I used to rely on the Centrelink benefit. Even though it was a long time ago, I appreciated that, so I wanted to repay to Australia. And I taught that to people, and I donate blood and organs and everything I could possible. So many people, they follow me and they say, 'Oh, it is good to do something for people,' because I convinced them that when you pass away, you cannot hold your body or anything.

**Gary MAAS:** Sorry to interrupt. I think it is really interesting what you said about the conversation that you had with your parents, that it was very different to the conversation that you had with the next generation.

**Dai NGUYEN:** Yes, totally different. My children were so easy. They said it is a good thing to do, so they encouraged me to do it. But for my parents I had to spend more time to convince them that they should change their mind about organ donation, and so I just convinced them that when you do a good thing, do not worry too

much what happens next. So just do the good things. That is all. You believe in Buddha, but you worry about the next life. If you really do the good thing, why are you concerned so much about what you get? Just be concerned about what you give, do not worry too much about what you get. So that is what I convinced them of, and they said okay.

**Gary MAAS:** Thank you. It is really interesting. We have heard a little bit of evidence today from multicultural and multifaith communities and the layers that are within that. It is very helpful. Thank you.

**Dai NGUYEN:** Thanks.

**The CHAIR:** Great. Thank you. I will ask the next question. Maryaan, in your opening statement you spoke to some of the barriers that the communities felt—for example, being able to have an open casket funeral, families' wishes and money potentially changing hands. Are there any other barriers to registering to become an organ donor that you have identified?

**Maryaan ESSA:** Yes, sure. Speaking about my community, organ donation is not that common a thing back home. So when people are here and other people talk about organ donation, they do not understand the topic at all. Another thing is the language barrier. People with limited English, when they need to apply, they think it is going to be hard for them to apply, because everything is in English. They do not understand the process of applying as well and registration. In addition to that, other things like 'How will they treat my body?', 'What about my family?' and those kinds of things are the most common barriers that I have found through talking to people in different sessions. Thank you.

**The CHAIR:** Thank you very much. Would anybody else like to add a response to that question about other barriers faced by different communities?

**Dai NGUYEN:** Yes. For me, my friend—she is Chinese—believes that they sell all the organ tissue. Even if sometimes I try to give more information, she still believes that sometimes you are not dead and they still take it from you. She said, 'Maybe they grab your organs when you still had a chance to live but they do not want to save you, just so they can get your organ.'

**The CHAIR:** Sorry to interrupt. We are just struggling to hear you. I think something might have happened to your microphone.

**Dai NGUYEN:** Okay, so I will try this one. They believe that even when their body is not dead, because people really want to get organs, they might put them in a situation that they take their organs even if their brains have not really died yet. Do you get what I mean? They do not believe in the system. They said, 'Don't be naive. It doesn't work for free. They will take your organ tissue even if you have not passed away yet.' Like, your brain still works but they still take it from you if you register for that one. They still have a lack of information about organ donation from their culture, because in Australia we donate, but in some other countries they sell your organs, and that is what they worry about.

**The CHAIR:** Okay. Thanks, Dai.

**Dai NGUYEN:** On the other hand, my sister lives in the Netherlands, in Holland, and it is compulsory. If you do not want to donate, you have to register for 'do not take it'; otherwise it is compulsory for them to take your organs.

**The CHAIR:** Opt-out. Thanks, Dai. Hanh, did you want to add anything about some of the barriers?

**Hanh THI PHAM:** Yes. Thank you for having me. I agree with all my colleagues about that, and because that is new information to my community. I speak Vietnamese and I deliver the session to people with advanced age, so the barrier here is their children. During the session, the elderly people were enthusiastic—with the talk, with the information—but when they shared it with their children, there is a barrier, because their children did not have that information. So, their children talked about religion, like my colleagues talked about, according to the Buddhist religion, the organs need to stay there overnight, they cannot be removed, otherwise the soul will be damaged. Or if people have not died yet, and since they have already registered, the doctors also want them to die soon in order to take away their organs. There are old concepts like that, because they have old information in their country—because, like Dai said, in our country they often sell the organs. Not

often, but someone stole the organs, and something like that happened. So, one of the leaders told us, ‘This is new information. We need to spend time to talk again and again; then they can embed it in their minds.’ We have to talk to the children as well, I mean the young people—we cannot only focus on the advanced-age people.

**The CHAIR:** Thank you. Annabelle.

**Annabelle CLEELAND:** Thank you. Two quick questions: do you believe that if we have got a lot of websites, one in particular with DonateLife, if there were more opportunities for language on these websites and the information that already exists, would that improve the education and awareness in your different communities?

**Dai NGUYEN:** Probably, yes. I think Vietnamese—they do not have much information. My friend works at SBS radio, and they interviewed me about this once, and after this some of my friends asked me to register for them. So, I mean, because I just went there for only one time, it still impacted many people. And if we have more advertisements in Vietnamese, I mean in our language, probably many people should follow. Similar to the blood donation, they have a group of people follow that group. I think at the moment many people do not have enough information. If you do a website and more advertisements or release news on SBS in their own language, probably it will work well, I think.

**Annabelle CLEELAND:** Just a little question: with the OTA grant funding, was there a key performance indicator of how many people you should engage to receive that grant?

**Dai NGUYEN:** For the grant? Sorry, I do not know.

**Annabelle CLEELAND:** No? That is okay. No, that is fine.

**The CHAIR:** Cindy.

**Cindy McLEISH:** Thank you. I have got a very quick question. Earlier Dai mentioned about having different conversations with her parents and her children. Given that all of the training and the education that you have been doing was with women, how are the men in your communities approaching this? Do they have different views?

**Dai NGUYEN:** I think actually we often work with women. Men do not have much chance to talk with us, so I am not quite sure.

**Cindy McLEISH:** But I mean at home, within your families, not within this project. If you have these discussions, do the men have different views?

**Dai NGUYEN:** I think for my family, men take things easier than women. It is not too hard to convince men but harder to convince women, I think.

**Cindy McLEISH:** And what about the others? Do they agree?

**Maryaan ESSA:** Same for me. It is something that women and men are interested in. Through my community engagement sessions, when we talk about donations, I find that men are interested as well to know what the system is here, how they can donate and all those things that we discussed today.

**Cindy McLEISH:** Fabulous. Thank you. That is all from me.

**The CHAIR:** Thank you. Chris.

**Chris CREWITHER:** Thank you, Chair. Firstly, thank you for giving evidence today and for your evidence so far. I just have some quick questions about the grant funding that you received, and thanks for the submission of the grant information here. How much was the grant funding for that project, if you know?

**Maryaan ESSA:** We do not know, sorry.

**Chris CREWITHER:** I just note that the grants website listed, which ends with ‘organ-tissue-donation’, is a blank link. It does not go anywhere anymore. I did manage, though, to find an alternative website, which is

‘The most generous gift of all’, which is on the Multicultural Centre for Women’s Health website, but it was extremely hard to find that resource. I had to actually Google to try and find that resource. It was not easy to find through the website. Is that something that maybe could be made more prominent on your website so people can actually find that page about organ donations, given the original link is down?

**Maryaan ESSA:** Sorry about that experience—that you found it hard to see—but I can pass to Joyce. She can discuss that with you.

**Chris CREWITHER:** The other one was about the videos. I thought the videos were actually very good—in Mandarin, Arabic and Vietnamese. I noted, though, that the video views had only gone up over the last four years for the Chinese video from eight to 39 views now; for the Arabic it went from 22 to 72 views; and for the Vietnamese it went from 200 views to 302 views. So over the last four years there has not been much uptake in views of those videos, and I think part of the reason perhaps might be that the videos themselves were not contained on the website and were actually very hard to find even by me on YouTube. Is there a way that you could put those videos up on your website and perhaps even communicate with DonateLife and others to share those videos, to make the most of the fact that you have got these excellent videos that are just not being viewed at the moment?

**Maryaan ESSA:** I will pass the feedback to MCWH, and I think some people due to limited technical knowledge, they don’t know how to open the video. I find that when we go out to the community and talk to them, they are most interested in community sessions and education information sessions because most of them would have limited technology skills. It could be that reason as well, but I will definitely take that feedback as well to the MCWH.

**Chris CREWITHER:** Is there a way that we can just get these videos out? That would be my general comment, because I think they are excellent videos; they are just not being seen. If there is any way that you three can help promote those videos better or that we as a Committee or others could help promote those videos, then I think that would be helpful.

**Dai NGUYEN:** Yes. I promise that after this meeting I will promote them as well. It is more like because the voice over was my voice, I felt like I did not want to show off, but after this I actually will promote the video of that –

**Chris CREWITHER:** The Vietnamese video was the most viewed, so you have done a reasonably good promotion of getting that out, but, yes, it would be good to get it out even more.

**The CHAIR:** Thanks, and thank you, Maryaan. That is also great feedback for the Committee—that you find community information forums a better way to communicate with different multicultural communities. That brings us to the end of our time today. Thank you all very much for appearing on behalf of the Multicultural Centre for Women’s Health. Your evidence today has been really interesting for Committee Members to hear, so thank you for your contribution. The Committee will now take a short break before we prepare for our next witness.

**Witnesses withdrew.**