

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Tuesday 25 July 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESSES *(via videoconference)*

Mr John Richardson, Assistant Director, Organ Donation,

Professor Derek Manas, Medical Director, Organ and Tissue Donation and Transplantation,

Dr Dale Gardiner, Associate Medical Director, Deceased Organ Donation,

Ms Lisa Mumford, Head of Organ Donation and Transplantation Studies, Statistics and Clinical Research,

Mr Phil Walton, Project Lead, Deemed Consent Legislation, Blood and Transplant, and

Dr Cathy Miller, Head of Education and Professional Development, Organ and Tissue Donation and Transplantation.

The CHAIR: Good afternoon, and good morning to our witnesses joining us from the UK. We will now recommence the public hearings into the Legislative Assembly's Legal and Social Issues Committee's Inquiry into increasing the number of registered organ and tissue donors. My name is Ella George, and I am the Chair of the Committee. I am joined today by Deputy Chair Annabelle Cleeland and Members Gary Maas and Meng Heang Tak.

I welcome joining us from the United Kingdom—we are very lucky to have these witnesses appearing today from the National Health Service, Blood and Transplant—John Richardson, Dale Gardiner, Lisa Mumford and Phil Walton. Thank you very much for joining us today.

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

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

John RICHARDSON: Thanks very much. I am John Richardson, the Assistant Director for Organ Donation. I will provide a bit of background to the system we have here before questions. The UK first established an opt-in organ donation register almost 30 years ago in 1994. Currently we have 28.6 million citizens on the register with an opt-in decision, and that represents around 43% of the UK population. The majority of our opt-in registrations come via the driver and vehicle licensing agency, and last year 73% of our opt-in registrations came via that route. 53% of the 1,430 deceased organ donors that we had last year were on the opt-in organ donor register, so that is just over 700 people where we knew their decision from the register and they went on to donate. Potential organ donors who have an opt-in registration still represent our highest rate of consent, at around 90%, and whilst families of potential donors do not have a legal right to veto or overrule a decision, last year there were 137 cases where the next of kin did not support the donation decision and in those cases donation did not proceed.

In 2015 opt-out or deemed legislation was first implemented in Wales, and this was followed by England in 2020 during the pandemic, Scotland in 2021 and then Northern Ireland earlier this year on 1 June. As part of the implementation in Wales we were required to offer an opt-out option on the organ donor register, and across the four countries of the UK we now have around 2.5 million people who have registered a decision to opt out of organ donation. Opt-out legislation in Wales was launched with a comprehensive media campaign and household mail drop, and in the years post implementation we did see a statistical increase in the organ donation consent rate. In England, where we have the highest population of the four countries, the launch of opt-out was much more challenging due to the pandemic, with limited opportunities to publicise the change. Like many countries we have seen the overall consent rates post pandemic drop, from 69% in 2021 to 61% in 2022–23. Given the timing of the new legislation, particularly in England, it may never be possible to distinguish between the COVID and the opt-out legislation effects.

Operationally we continue to implement best practice to maximise consent rates, ensuring that the donation conversation is planned and that one of our specialist nurses in organ donation is present for the discussion. Our nurses are highly trained in consent, and the training is refreshed annually. We are very happy to share our experience with you and to answer any questions that you have.

The CHAIR: Wonderful. Thank you, John. Before we move into questions from Members, would anybody else like to make any opening comments or are you happy for us to start with questions? Great. I will take that as we are happy to go with questions then. Wonderful.

The first question I have for you: just by way of background, as I am not too sure how familiar you are with the Australian registries in place, there are separate registers for organ and tissue donors, blood donors and stem cell donors, and I understand in the UK you are bringing all of this together with your organisation, is that correct?

John RICHARDSON: Organisationally we work together, yes, but the registry that I am discussing here is specifically for organ and tissue donation.

The CHAIR: Okay. So what we are really looking at is increasing the number of registered donors. One thing that strikes me about that is, when you have three different places to register to be a blood donor, to be a stem cell donor and to be an organ and tissue donor, that essentially you have to register your interest three times. Is that still the case in the UK? Do you have to register separately for those?

John RICHARDSON: Yes, you do.

The CHAIR: Yes, okay. I was hoping you would say, ‘We’ve got one register and it’s much easier and simpler’, but I am not sure that I can ask that question, because you do have the same registry system as we do.

John RICHARDSON: Yes, exactly the same

The CHAIR: Great. In that case then, I still will ask a question about organ and tissue donation registration processes. We have heard evidence that the best or most effective way is a simple process, and I am wondering if you can speak to anything that you have observed through your experiences in the UK around successfully increasing the number of registrations through a simple, straightforward and easily accessible process?

John RICHARDSON: Yes, I think from my experience, the easiest way to get people on the register is for them to do it whilst they are doing something else. As I mentioned during my opening comments, the bulk of our opt-in registrations come from people who are renewing their driving licence. Currently we are looking at other types of partnerships that would work in a similar way, so when someone is interacting with the government to undertake another task, they would be offered the option of putting their name on the organ donor register. As I said, 73% of our opt-in registrations came via that route.

During COVID we developed a relationship with our NHS app, and again we saw a spike in the number of people that were registering because they were going on to the app for their COVID passport and other things. It meant that while they were undertaking that, they could opt in and put their name on the register.

The CHAIR: Funny you mention that, because that is the exact same experience we have had in Australia where the Services Australia app had a link to registering to become an organ donor, and people were going on there for their COVID vaccination certificates as well, at the same time. Dale, you have got your hand up there.

Dale GARDINER: Yes, I am Dale Gardiner, I am the Associate Medical Director for Deceased Organ Donation—actually originally from Brisbane, so I am an Australian who now lives in the UK, so I am well aware of the Australian circumstance. Just to add to what John is saying, you are correct that with multiple ways into the register, it can become confusing, so we are in a process of simplifying some of those ways in. We used to have GP registrations, but they are becoming quite difficult because they are often paper-based and an electronic system is often the easiest. But if you rely on people going to a website or using an app and they have no other reason to go there, there is quite a hurdle or barrier to get over for them to take that action, as opposed to what we have found is, when they are, as John said, doing other activities like renewing their driving licence, it becomes a much more simple system for them and less of a barrier.

I would also add that I think our observation is that people join as part of, not as a health decision. It is less a health decision for them, but very much more as a representation of who they are as a person that they want to be a donor, they want to give that altruism, their end-of-life considerations, and we often tackle it in that, as opposed to big promotions in hospitals that we have to get out to the public and make it easy for them to register.

The CHAIR: Great. I will just pause the questions here just to note a couple of people have joined the meeting. So from the National Health Service Blood and Transplants, Derek Manas has joined. Welcome, thank you for joining us today.

Derek MANAS: Hi. Sorry, I was trying to get on. Thanks.

The CHAIR: No problem at all. Welcome. And we have also had another Committee Member join us, Chris Crewther. All right, so just one more question from me with regard to registrations: since you have moved into the opt-out system, are people still registering to join the organ register in the UK?

John RICHARDSON: Yes, we do now have both the options to opt in and opt out on our own website, and I believe on the NHS app. Via the driver and vehicle licensing, people can still only opt in. The opt-out option is not part of the driver and vehicle licensing route.

The CHAIR: Okay, great. Thank you.

Dale GARDINER: Just to explain, that is to ensure that we have a live outcome. When someone goes on the app or on the website, it is immediately registered. There is a delay with the licence, which is why we want to ensure that when people register their opt-out, it is immediately registered, and that is why we maintain that. To add, we had 900,000 people on the opt-in register last year and a million the year before, so we are still seeing very, very high numbers of opt-ins every year, even with the introduction of the opt-out as an option.

The CHAIR: Okay. We have also had Cindy McLeish, who is one of the Committee Members, join us on Zoom as well. Welcome, Cindy. I will hand over to Committee Members now for some questions. Annabelle.

Annabelle CLEELAND: Thank you. Fascinating, thank you. Dale, I hope that our Aussie accents are giving you a taste of home.

Dale GARDINER: Thank you. Yes.

Annabelle CLEELAND: I am keen to know some background about the decision to go down the path of an opt-out system. What happened? Why was there a decision to adopt the opt-out system in 2020?

John RICHARDSON: It was 2015 for Wales. Dale, I do not know whether you or Phil want to take this one.

Dale GARDINER: Yes. Phil, do you want to go first?

Phil WALTON: Yes, absolutely. Good morning from the UK. Good evening to you guys. I am Phil Walton. I led on the operational delivery of the opt-out legislation across the four countries over the last decade. The catalyst for the delivery of the opt-out legislation across those four UK nations was driven by the governments themselves, and that was after broad consultation with the general public to ascertain their feelings on whether moving to an opt-out system would be a good idea. In all four of those nations it was very well supported, so the government were onto a winner. If they were going to introduce this as a policy, it would be supported by the general public and hopefully a success. So that was the catalyst behind it. NHS Blood and Transplant are the only organ procurement organisation in the United Kingdom, so we were tasked with the responsibility of operational delivery for that.

Annabelle CLEELAND: Okay. And then what sort of impact has that opt-out system had on family consent?

Dale GARDINER: It is complicated, as John highlighted right at the beginning. We will go back to Phil in a second. Wales has the best evidence, because Wales introduced it in 2015 and did not have the issue of COVID. What we observed in Wales was that it took a number of years to cause an increase in the consent rate, but after 33 months there was a statistical increase in the consent rate, compared to England, which is our comparator nation in the research that we did. Actually it was twice as high, when it was risk-adjusted, to get consent in Wales at that point. So that was very positive. Others will share, but it has been much more complicated because COVID did reduce the consent rate nationally for many reasons, and I know it is similar in Australia, where the consent rate has dropped as well. That makes it very hard to unpick the difference. Certainly we do not hear anecdotally that there are problems with families saying it is because of the opt-out that they are now not giving consent. That does not seem to be the reason. It seems to be much more to do with the general dissatisfaction there can be in society and the potential loss of trust at times. But we are seeing improvements in that now, and we feel like we are coming out of those COVID challenges. Phil, do you want to add to that?

Phil WALTON: No. I think you have captured everything that I was going to say, Dale. I think, just as John said in his opening remarks, it is still too early for us to say. I think Wales was a very, very good test case, but we have to understand that that population is quite small. It is broadly a white population as well, so some of the challenges that come with a diverse population were not seen in the same way in Wales as they are seen in

other parts of the United Kingdom. So we were still learning as we went through with England about some things that we had never touched on before when it came to implementing in Wales. And then, as Dale has just said, kind of the post-COVID effects and the political challenges that we see with our NHS currently—we are not going to be able to untangle that for some time, I do not think, if at all.

Annabelle CLEELAND: Dale, finally, with your understanding of Australia's community and clinical barriers in increasing donor registration, what would be your advice for us on where to go from here?

Dale GARDINER: What we have learned, particularly with the law implementation, is that a law cannot work in isolation. It can lay a foundation—it can lay a culture-change foundation—but it is just the beginning step, and what you need is promotion and education. Wales worked best because it actually had both simultaneously. It was a law change and it was also operational. It was an investment in the clinical staff who support and approach families, and it was also a promotion campaign and an education campaign. We did two of those things in England when we introduced opt-out, but our promotion campaign was very limited because it was happening in 2020 during the COVID time. We have also learned that you need to sustain activities. Promotion is not just a wham-bam couple of months. This is culture change. It takes years, but we do believe that we are reflecting what the general population feels about organ donation, and the huge widespread support we have in both countries for organ donation in our public and a legislation change, or making it easier to register, are all reflective of delivering that for the public.

Annabelle CLEELAND: Thank you, Chair.

The CHAIR: Great. Thank you. Gary.

Gary MAAS: Thanks, Ella. Thank you all very much for your appearance today. I am just interested in demography and I guess the comparison of demographics as the opt-out systems have taken place in the four nations. With opt-out, is there a similarity in who has dropped out between the four nations? I suspect getting information from Northern Ireland might be a bit tricky, but are there are similarities in groups that have been opting out?

John RICHARDSON: Lisa, would you know the answer to that question?

Lisa MUMFORD: We did have a spike in the number of ethnically diverse people opting out. I guess there were campaigns in the UK that were not to do with NHS Blood and Transplant that spiked people opting out, so things through Twitter and other avenues in social media where there was some fake information that was publicised around the UK, and they were specifically targeted at our ethnic minority population of the UK. So that spiked opt-outs. We seemed to see a big spike in that demographic just prior to the release of the opt-out legislation as well in all of the four nations as it went through. In terms of age—so that is another thing that we monitor—we found that we had a slightly higher spike in our younger population, but that did not seem to carry through to our 50-plus. Those are the two demographics that we mainly focus on. I do not know, Phil, if you had any more detail.

Phil WALTON: No, I think that covers what I would have said as well. Thanks.

Dale GARDINER: Just to answer the question about nations within the UK and the differences, Wales has a 6.4% opt-out. They went first, so there was a lot more uncertainty in that. In many ways the peak, as Lisa highlighted, happens as the legislation is introduced and then implementation, but after that it is very steady; there are not really big jumps in opt-out. England has 3.7, Scotland has 3.2 and Northern Ireland, which has only just introduced, may be the one bucking the trend with only 0.4% opt-out, reflecting, we think, a very strong support for the legislation based around the campaign of Dáithí Mac Gabhann, a little boy waiting for a heart transplant. That human personification of the issue at hand and the life-saving opportunity we think potentially has given very strong support. It is also useful to note that when the legislation was introduced in the UK, in all four nations there was bipartisan support for that legislation, which certainly has helped us to have smooth implementation, and it reflects wide public support.

Gary MAAS: Thank you. Dale, I think you mentioned before that there are still significant numbers of people who are opting in. Is there any comparison data available on the groups that are opting in across the four nations?

Dale GARDINER: Not to hand specifically across the four nations, but generally, as Lisa said, it is the 16-year-olds and upwards, mainly as they get their licences, and then there is a drop-off from that age group. That is the peak. We have an over-representation of people from higher socio-economic groups compared to lower socio-economic groups, when compared to the UK population, on the organ donor register. Then, as we said before, there is a higher percentage of opt-outs from our more diverse populations.

Gary MAAS: Given that, have there been any targeted education campaigns for those culturally diverse communities?

Dale GARDINER: I think Phil worked extremely hard, and I will let him add to this because he was very involved. What we found was that by changing to opt-out it opened up conversations with community leaders from our diverse populations in the UK in ways we had not been able to do before. Organ donation was just not on their radar as something they wanted to discuss or were interested in discussing. But because of the legislation change we actually had an opportunity to engage a lot with many community leaders, and I would say that our relationship with different diverse communities in the UK is the best it has ever been. We have very close relationships with many of the leaders of different faith groups in the UK, and this has been very helpful in just being able to provide the true message of education. So even if people do opt out, they are doing so in an educated way and it is an informed decision, rather than it being out of fear that something is just not true or in ways that were not practised. Phil, you did a lot of that engagement. Do you just want to add to that on the opportunity it brought?

Phil WALTON: Yes. I think there are a couple of things to cover. I think, as you started our outreach with, many of the faith groups were really important, and actually it was a legacy item that continued for us to be able to provide support during COVID times when we started seeing things like COVID-vaccine hesitancy. With those sorts of things, we were able to put the NHS in contact with people that we had worked with to build on the trust that we developed at that time. As Dale said, particularly with perhaps the Jewish community and the Muslim community, who had previously been reticent over many years to get involved in organ donation, they actually opened their arms and kind of said, 'How is this new law going to affect us?' I think the bottom line with any of this is that if anybody wants to have a conversation, you jump all over it and you get involved as best as you can and listen to what their challenges are when it comes to how a law might affect their religion and their rituals and those sorts of things. We were very proactive in supporting and working with those groups to help them understand how organ donation and their faith could be aligned.

Outside of the faith discussion, I think it is important just to recognise that there are a number of other things that we need to consider within our general population. Firstly, there are the digitally disadvantaged. Our lower socio-economic groups might not have easy access to the internet, mobile phones and those sorts of things. Particularly in Wales, Scotland and Northern Ireland, we were able to do a household mail drop. So every household in those countries received a leaflet that said, 'The law's changing. This is how it's going to affect you. Go here for more information.' In those countries that was a very positive thing. It seemed to work very well. We got lots of inquiries about it, but also it was a mechanism to drive people to the website to make a decision. Also on top of that we need to think about the easy-read versions for people; the average reading age in the UK is something about 9 or 11 years of age. When you put something out in the public, it needs to be understood by the masses, so making something easily readable and easily understood is very important to us. And then finally, making that material and those assets available in the most predominantly spoken languages in your country—so obviously in Wales we have an English and Welsh version, but we also have versions for Urdu, Punjab, Polish, Chinese and those sorts of things. So there are many different avenues to think about in those areas.

Gary MAAS: That is all excellent evidence. Thank you very much. Thanks, Ella.

The CHAIR: Thanks, Gary. I will also just acknowledge that Cathy Miller from NHS Blood and Transplant has joined the Zoom. Thanks for coming along today, Cathy. Chris, would you like to have a few questions? Thanks.

Chris CREWETHER: Thank you. Well, thank you for your evidence all the way from the UK. It is much appreciated. I am interested in just understanding a bit more about what are the various contact points in the UK, and particularly in Wales as well, where people can opt out. Does that include, for example, when people register to get a licence or renew a licence and so on? What are the contact points generally?

John RICHARDSON: Yes. Phil, do you want to take that question?

Phil WALTON: Yes, no problem. As Dale mentioned earlier on, we have limited the number of opportunities where people can access the opt-out register. That is a safety precaution, really. It came out in our public consultation that if the worst-case scenario were to happen—that a donation went ahead and an opt-out registration was found—that was going to be a bit of a catastrophe from our point of view, and I think it is something that we would want to actively avoid. For people to be able to register and opt out, it needs to be seen immediately. So we have got a national contact centre, which is basically a call centre. People can ring up and they can make an inquiry and they can make a decision—they can opt in, they can opt out and they can even nominate somebody to make the decision for them, and that registration will show up immediately. The NHS app, which John mentioned earlier on, was evolved and developed from an organ donation point of view during the COVID period, so 2019–20. Again that is an instantaneous registration, so you can opt out and it can be seen immediately on our registration. And then there is the website as well; same deal, you log on, you put your details in and your registration will be seen immediately.

So they are the three ways that you can register your opt out. You can obviously also opt in in those same areas, as well as via other forms with other partners across the UK. The driving licence can be done on a paper form. That will take a couple of weeks for that registration to be seen, so that is why we do not offer the opt out there. We obviously have other partners—you know, supermarkets and those sorts of things—that exist in the UK where you can make a registration but those registrations are not seen immediately.

Chris CREWITHER: Noting you have got the opt-out model but you have still got the NHS ODR available and people can choose to register to donate—the ability to actively register to donate, has that been kept in place to increase family assent rates, or is there another reason to maintain that?

John RICHARDSON: Yes. I mean, as I said in my opening comments, we still see our highest consent rate from those people that have actively registered an opt-in decision. Around 90% of families will support the decision to donate where they know that there is an opt-in registration, so that is really our primary reason for maintaining the register as we do.

Chris CREWITHER: Was there some discussion in the UK to go to a more hard opt-out model, where it is much harder for families to oppose or to not give assent to a decision that has been made by an individual to donate, at all?

John RICHARDSON: I think legally we are on a strong standing there that families do not have the right to veto that decision, but we know the negative publicity that could come from a case like that could potentially be more damaging to donation, and often these are very complex family situations. Although our nurses are highly trained to challenge that decision, and Cathy can speak a bit more about that, and we absolutely do challenge in those situations, I do not think it would be in our best interests to proceed with donation in those cases.

Chris CREWITHER: Thank you. Thank you, Chair.

The CHAIR: Great. Thank you. Annabelle, you have another question.

Annabelle CLEELAND: Is Cindy asking questions?

The CHAIR: No, Cindy is just listening.

Annabelle CLEELAND: Oh, great. I just wanted to see whether between the four countries you have done an economic assessment of the benefit of increasing organ donations, by any chance?

Lisa MUMFORD: That is a difficult question to answer. We have looked at the economic benefit of transplantation overall across the UK, not by the four nations. We have done an economic analysis to say what is the benefit of kidney transplantation, heart, lung, liver et cetera, based on how many years surviving and the cost of, in kidney, for example, a patient remaining on dialysis, and in all but the lung we found that there was an economic benefit to transplantation. So that is the analysis that we undertook for that.

Annabelle CLEELAND: Thanks, Lisa. Just one thing we have not touched on is the profile. Dale, is the profile of organ donors similar to Australia in terms of the health of the organs?

Dale GARDINER: Yes, it is. Clinically it has been 20 years since I worked in Australia, but I do not think things have changed remarkably. We are culturally very similar. Our populations—with some differences; particularly obviously the Aboriginal and Torres Strait Islander, First Nations, in Australia are different and have different needs—are very similar. What we are seeing is that our donors are older—60% of our donors in the UK are over the age of 50. So whereas some people have this almost mythical belief of a young man on a motorcycle without a helmet, that is not a donor. That just does not happen. It is people over the age of 50, my age, who have an intracranial haemorrhage—a bleed in their brain, sudden and catastrophic—which are by far the vast majority of our donors. Australia also has that ageing demographic of donors, which is why it is interesting when you talk about promotion and education campaigns in schools. We think they are very important, but it is less because that child will get their licence and register to donate and then become a donor, because that seems very unlikely. What it is we often think of children in school education as change makers within their families. They go home and talk to their parents, and even more than their parents they might talk to their grandparents, who actually are the age where people may become organ donors. We also are aware that actually decision-makers in an organ donation situation are not necessarily the peers of a young person, they are the older people in the room—their parents and others—so it is important to have, we think, that mindset of what we are trying to achieve with our education. But our legislation change did open up doors to allow us in England to introduce school education, because it did reflect a whole society and a whole across all the departments of government change from beyond just a health matter to something that actually resonates across into other areas, and that has been very, very helpful for us.

Annabelle CLEELAND: Thank you. Thanks, Chair.

The CHAIR: Great. Thank you. I have a few more questions to wrap us up with. You have pre-empted my next question, which was around community awareness and education campaigns for young people. I would really like it if you could expand a little bit more on the schools education programs that you provide.

Dale GARDINER: Phil, do you want to tackle that, or Cathy? Who is the best person to tackle that?

Phil WALTON: Yes, I am happy to make a start on that. I think there are a couple of things to say. Actually getting organ donation on the curriculum is a real challenge. I think when you go to any department in government and say, 'We need to prioritise this,' they are obviously juggling that amongst all the other priorities that they have to deal with, but it was a real coup for us to get that on the curriculum in England. It has been on the curriculum in Scotland for many, many years, and I think we are moving to that in Wales and Northern Ireland, so it is not universal across the United Kingdom.

The other thing that we have worked on started in Wales, which is a scheme called the Rising 18s—so those people who are 17 years of age. Obviously there is sight of that at a central level, and we target those groups. The government target those groups and say, 'You're coming up to your 18th birthday. Deemed consent will apply to you from your 18th birthday. This is how this is going to affect you.' Similar schemes happen across the rest of the United Kingdom. The legislation in Scotland is a little bit different—deemed consent is applicable from 16—but the same scheme kind of applies at that level as well. Making people aware as they are turning 18, or 16 in Scotland, that the law is going to actually affect them and giving them information or signposting of how to get more information about that has been really important for us. Again, for young people our marketing colleagues have done a great job in terms of engagement through social media. Obviously young people spend a lot of their time on multiple social media platforms, but one of the biggest ones we have seen more recently and seen real engagement on is through a platform called Twitch, which is where gamers spend a lot of their time. I am now tiptoeing into areas that are not my speciality because I do not game and I am not that great on social media, but apparently there has been huge engagement on that platform, with people having conversations, being signposted to relevant areas and those sorts of things. So engaging in places where young people meet, and often now that is more virtual, has been a real benefit for our campaigns.

The CHAIR: Great. With regard to getting organ and tissue donation onto the school curriculum, at what age are students learning about it?

Dale GARDINER: Cathy, do you know? The problem is it varies across the four nations. We run a more secondary school—high school—program in England but it does vary. Just to say, it is probably no surprise that Scotland has the highest opt-in. It is 53% of their population that has opted in, and they have been running the schools campaign the longest. They also within their legislation have a commitment from government to

promote organ donation as part of their legislation, and they have been doing that for a long time. And I think there is no surprise why they have the highest opt-in in the country. Phil, do you want to jump in?

Phil WALTON: I had to go looking on our website just to double-check it. The schools curriculum is key stage 3, key stage 4, so that is 11- to 16-year-olds, so that is our secondary education where it is targeted.

The CHAIR: Yes, great. School education is something that has been raised from multiple witnesses throughout our inquiry, and there are different views as to what age group that should start at and where the focus should be—whether it should be in the younger years or whether it should be at the time you turn 16 and you can register to become an organ donor. If you have got any further information as to any research that you have done around that, I am sure the Committee would appreciate seeing that if it is possible for that to be shared as well.

Derek MANAS: I can add that actually one of our networks is doing that research at the moment, because uptake in schools—it is really a toolkit that the schools have, and the curriculum is for the teachers' discretion. The problem is that some of the schools take to that really well and others do not. We are doing a study at the moment looking at the take-up and actually what the outcome is, and that whole aim was that the children have the conversation then with their families. That is really what it is about, but we are not sure that is actually happening. That work is being done currently, so I am very happy to share whatever comes out of that audit with you.

The CHAIR: That would be great. I think that would be of significant interest to us to have a look at that work. The next thing I just wanted to touch on was, just with regard to stem cell donations and registered stem cell donors, we have heard from witnesses this week that of three in four stem cell donations in Australia, the stem cells are actually sourced from overseas, and so there is not a large pool of donors in Australia. I am just wondering if you could touch on the UK experience, whether you are able to source stem cell donations from within the UK, or maybe some of those challenges that you face, or any advice that you would have to the Victorian jurisdiction in increasing the number of registered stem cell donors here.

John RICHARDSON: It is not an area that anybody on this call would deal with. Now, some may have expertise, so I will leave it to my colleagues to jump in, if anyone can answer that question.

Derek MANAS: I can tell you most of the stem cell donors come from within the UK. There is a very big charity which promotes stem cell donation, and they have done an amazing job of it. It does support the NHS in donations, massively. We have a director of stem cell transplantation, and, I mean, he is the person who you should speak to, really. But most of our donors come from within the UK, yes.

The CHAIR: Okay, thank you. Are there any further questions from the Committee Members? Great. All right, well, in that case, thank you all very much for appearing before the Committee today and for your contribution to this inquiry. We greatly appreciate your contribution, and also appreciate the time difference, so thank you for starting your day a little earlier than usual.

You will be provided with a proof version of today's transcript to check, and verified transcripts will be published on the Committee's website.

This concludes today's public hearings. I thank all the witnesses who have given evidence today, as well as Hansard, the Committee Secretariat and the security team here. I declare this hearing adjourned. Thank you.

Committee adjourned.