



Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Organ and Tissue Donation
(Deemed Consent) Bill:
Belfast Health and Social Care Trust;
Public Health Agency

11 November 2021

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:

Mr Colm Gildernew (Chairperson)
Mrs Pam Cameron (Deputy Chairperson)
Ms Paula Bradshaw
Mr Alan Chambers
Mrs Deborah Erskine
Ms Órlaithí Flynn
Mr Colin McGrath
Ms Carál Ní Chuilín

Witnesses:

Ms Janet Johnson	Belfast Health and Social Care Trust
Dr Dominic Trainor	Belfast Health and Social Care Trust
Ms Catherine McKeown	Public Health Agency
Dr Catherine Millman	Public Health Agency
Mr Stephen Wilson	Public Health Agency

The Chairperson (Mr Gildernew): I welcome by StarLeaf Ms Janet Johnson, who is interim director for anaesthetics, critical care, theatres and sterile services and surgery. That is quite a title. Can you hear us OK, Janet?

Ms Janet Johnson (Belfast Health and Social Care Trust): I can hear you. Are you able to hear me?

The Chairperson (Mr Gildernew): Yes, we are hearing you loud and clear, Janet. Welcome this morning.

We are also joined by Dr Dominic Trainor. Dr Trainor is clinical lead for organ donation. Can you hear us OK, Dr Trainor?

Dr Dominic Trainor (Belfast Health and Social Care Trust): Yes, I can indeed, Chair. Can you hear me OK?

The Chairperson (Mr Gildernew): Yes, we are hearing you loud and clear, Dominic. Thank you.

From the Public Health Agency (PHA), we are joined by Mr Stephen Wilson, who is director of operations. Can you hear me OK, Stephen?

Mr Stephen Wilson (Public Health Agency): I can indeed, Chair. Can you hear me?

The Chairperson (Mr Gildernew): Loud and clear, thank you.

We have two others in this session. We have Dr Catherine Millman, who is health intelligence manager. Catherine, are you hearing us?

Dr Catherine Millman (Public Health Agency): Yes, I can hear you, thank you. Can you hear me?

The Chairperson (Mr Gildernew): We are hearing you loud and clear, Dr Millman. Thank you.

Finally, we have Catherine McKeown, who is organ donation promotion manager. Can you hear us, Catherine?

Ms Catherine McKeown (Public Health Agency): I can. Thank you, Chair. Can you hear me?

The Chairperson (Mr Gildernew): Yes. We are hearing you all. Thank you. Obviously, that is a very experienced and knowledgeable panel. However, in the interests of time, can one of you lead principally on an answer when we come to questions and answers, unless there is something additional, so that we can keep answers to members as succinct as possible? I would appreciate that. Janet, are you opening with remarks, or how do you want to deal with the presentation? After that, we will go to questions and answers.

Ms Johnson: Dr Trainor will lead from a clinical perspective on behalf of Belfast Trust.

The Chairperson (Mr Gildernew): Thank you. Dominic, please go ahead with your presentation.

Dr Trainor: Good morning, everybody. I am a consultant intensive care physician and anaesthetist in the Royal Victoria Hospital in Belfast. I am also clinical lead for organ donation in the Belfast Trust, and, since 2018, I have been the regional lead for organ donation in Northern Ireland. Back in 2008, the UK Government task force issued 14 key recommendations that have transformed organ donation and transplantation over the past decade. Through the implementation of those recommendations throughout the NHS, we have increased the number of deceased organ donors from roughly 800 in 2008 to approximately 1,600 in the year prior to the onset of COVID. That year-on-year increase in deceased donation has resulted in roughly 4,000 organ transplants a year prior to our being struck with COVID. Over the past decade, we have witnessed a year-on-year decrease in the organ transplant waiting list, and, although we are not good at saying it, it is probably one of the biggest and most remarkable achievements of the modern-day NHS when you think of the number of stakeholders involved in an organ donation and transplant.

We have been able to bring about that change in donation and transplantation through our clinical staff on the floor having the confidence to refer potential organ donors to our specialist nurse service and to approach the family of potential donors. Over the past decade, we have really made organ donation a normal and routine part of end-of-life care in our intensive care units, but the challenge now is to make organ donation an expected part of end-of-life care. We really need to move the conversation around organ donation out of the hospitals and into homes and into wider society, which, I think, we are starting to do. In my eyes, there has never been greater support for organ donation, both from the public and in the political sphere. We need to embrace the opportunity. In addition to that, when we look forward to where we want to be in the next 10 years, we need to plan for a resilient and sustainable workforce with employees and healthcare staff who are highly trained and equipped with the resources to allow us to do the job. Also, we want to create a world-class system that the patients and the public are proud to be part of and have trust and confidence in.

The Chairperson (Mr Gildernew): Thank you. I believe that the PHA is also doing a short presentation.

Mr Wilson: Yes, Chair. Thank you. I echo everything that Dominic has said. The agency is an arm's-length body of the Department and has two main roles in relation to organ donation and transplantation. First, we provide expert public health input to the commissioning of donation and transplantation services. Secondly, we are responsible for promoting knowledge and informed discussion about organ donation across all sections of the population. That includes the agency working to develop public awareness in consultation with stakeholders over the past 10 years.

In relation to input into commissioning, unfortunately today we are not joined by our lead consultant, Dr Catherine Coyle, who has a long-standing commitment, but we are happy to take specific questions on commissioning etc and public health input into that away and come back with written answers. I suppose we are really here in relation to the second role, namely developing public awareness and engagement. I am joined by two other Catherines: Catherine McKeown, organ donation promotion and engagement manager, and Catherine Millman, who, in her role as a health intelligence manager, has led our research and evidence reviews relating to raising awareness and support for organ donation. I should add that, in my role as director of operations, I have responsibility for a range of functions, including communications and health intelligence. I have had primary responsibility for and oversight of the agency's public information campaign programme relating to organ donation.

Following the Assembly's introduction of a statutory duty for the Department of Health to promote organ transplantation, the Department introduced a policy that included for the first time a comprehensive rolling communications programme and recurrent funding. It is important to emphasise that those commitments — a rolling communications programme and recurrent funding — would not be impacted by the proposed move to a statutory opt-out system. The existing duty to promote would remain in place during and after the implementation of any new system. We welcome the further statutory provisions of the Bill that would enhance the existing programme of education and communication.

In relation to deemed consent, we have been working closely with colleagues in the Department and in NHS Blood and Transplant throughout the public consultation. We are now in a period of intensive planning for a comprehensive communications programme that will roll out if the Assembly decides to pass the Bill. Public education and communication have been and will continue to be an essential part of any change in the law; the two must go hand in hand.

I will pass over quickly to Catherine, who will say a few words about the promotion and education work.

Ms McKeown: Should the Assembly pass the Bill, the Department's plan will include a 12-month implementation period to enable us to roll out the programme before going live and a further 12 months of engagement thereafter. The programme will deliver ongoing outreach and engagement activities supported by mass awareness campaigns at key intervals. The objective will be to ensure that the legislative changes are fully understood across all sections of the population and that as many people as possible are aware of the law change and of how to register decisions. We looked at how that was achieved successfully in Wales, England and Scotland, and are planning an effective communication strategy with two main phases. The first will run for a period of 12 months across 2022, preparing people for the fact that the law is changing. The second phase will commence in 2023, when the legislation comes into effect, and will make it clear that the law has changed. The strategy will continue to employ a collaborative approach, which is currently delivering great benefits for the promotion of organ donation.

Programme development will be evidence-based, using our own research as well as research and experience from the other UK regions. We will tailor our activity to specific audiences, as well as the general population, to ensure that those audiences are engaged in the most appropriate manner for them. Engaging with children and young people is important, so the completion and launch of our schools resources will be a key vehicle. Other engagement work will reach out to older audiences and faith and BAME audiences, as well as working with the community and voluntary sector to reach the grassroots of society.

The majority of that work will continue, as Stephen said, as part of the rolling programme for the promotion of organ donation. Much of it is achieved at little or no cost due to the current coordinated and collaborative working approach. Our campaign planning will examine the use of a range of media channels to ensure maximum exposure. Most importantly, the gift of organ donation and the acknowledgement of the selfless act of donors and their families will continue to be central to all of our activity.

The Chairperson (Mr Gildernew): Thank you, Catherine. I have a couple of questions, and then I will go to members' questions. Thank you all for those presentations. This is an area in which there is huge interest and potential. My colleague Pat Sheehan proposed a similar private Member's Bill and was pleased when the Department indicated that it was bringing forward this Bill.

Dominic, one of the things that struck me in your presentation was that we are seeing year-on-year decreases at present. I think you said that; you can clarify that if I picked it up incorrectly. Will you

outline your thinking as to why that is happening and how the Bill will address that and improve the situation around organ donation?

Dr Trainor: We have seen a progressive increase in deceased donation over the past decade primarily because of the implementation of the government task force's recommendations, which it issued back in 2008. Each trust has appointed a clinical lead for donation, as well as an organ donation committee that is chaired, usually, by a non-executive director. Other members, such as specialist nurses, sit on that committee. They are responsible for the governance and processes around organ donation in each trust. The success over the past 10 years has come about because of clinicians working alongside our specialist nurses, referring potential organ donors, utilising a collaborative approach to the family and making organ donation a normal part of end-of-life care. Our specialist nurses are now in those conversations, whereas, prior to 2010, they rarely got in. That has helped to improve the numbers around deceased donation. Unfortunately, COVID has set back those statistics. We estimate that we are currently sitting around levels that we saw in 2014, which means that around 7,000 people are waiting for a transplant. Deceased donation has also taken a hit during the COVID pandemic, but we are starting to recover from that.

The Bill will help to place more of an expectation on the public that organ donation will be asked about in the rare situation in which somebody dies in the circumstances that permit donation to potentially proceed. Only one in 100 people who die do so in circumstances that potentially permit donation to proceed. That is why it is so important for us to identify those people and refer them to our specialist nurse service. The law change will help to create the expectation on a societal level that organ donation will be asked about and approached in the circumstances where it is clinically indicated.

The Chairperson (Mr Gildernew): My second question is for whomever is best to lead off on it. How would you address the concerns of family members about not being fully included in the conversation and about things being done that they would not agree with or would find difficult? How would you address those concerns, and what would the process be, in a practical sense, for families if the situation arises where organ donation would be a potential path?

Dr Trainor: That concern has been raised by some individuals with regard to the legislative change. In those circumstances, a multidisciplinary team will discuss with the family what is in the best interests of a patient who is dying or has died in an intensive care unit. As part of that conversation, we look at the values, wishes and beliefs of that patient. Everything that we do in those circumstances is based on what we, alongside the family, feel is in the patient's best interests. That includes their wishes with regard to organ donation. The families are an intricate part of that and are absolutely vital in that setting, because they can tell us what the patients' wishes would have been. They need to tell us about the medical history. Ultimately, it is the families who will say yes or no to organ donation. The final decision will always rest with the family. We have seen and been reassured by the evidence from Wales. The fears that existed around the role of the family were the same when soft opt-out was discussed in Great Britain. We have seen evidence from Wales that, in roughly 25% of family approaches where deemed consent comes into play, families still say no, and they can say no. At the end of the day, we are dealing with a grieving family; everybody involved in the process recognises and understands that. Their role will not be diminished.

The Chairperson (Mr Gildernew): Thank you. I will go to members. I will go, first of all, to the Deputy Chair, Pam Cameron. I then have Carál, Paula, Colin, Deborah and Órlaithí indicating at this stage. Pam, go ahead, please.

Mrs Cameron: Good morning, Chair. Thank you. Thanks, panel, for your attendance this morning on what is a sensitive and emotive subject. We welcome you to the Committee.

I have a couple of questions about deemed consent and the outworkings of that. Many people are always concerned that organ donation could happen against an individual's wishes. That is a primary concern for many people. From my point of view, as somebody who has always carried a donor card and has been on the register since becoming an adult, my concern is about a potential donor's wishes not being honoured and that, even though an individual has made it clear that they wish to donate, should that opportunity arise, their family members may block or object to that and it does not happen. What can be done to protect the wishes of somebody who is clear about their wish to donate?

Dr Trainor: Is that question for me? I am conscious that I do not want to hog the whole thing.

Mrs Cameron: That question is for whomever would like to answer it.

Dr Trainor: You have raised an important point about the family's role. We know from statistics on a UK level that, since 2010, over 500 families have overruled the known wish of a patient who has, like you, signed up to the organ donor register (ODR). We refer to that as an "ODR override". It happens. It comes back to my point, and, in a way, it helps to address the fears. You can look at it in two ways. It can help to address the fears surrounding the role of the family, because, at the end of the day, we are dealing, as I said, with a grieving family and, depending on the circumstances of their loved one's death and the age of the patient, that grief can obviously be enormous. Therefore, we understand why, in those extremely stressful circumstances, some families will not be able to cope with the questions surrounding organ donation. The best way to avoid that scenario is through public health education and campaigning around the need for people to sign up to the organ donor register, tell their loved ones their wishes and be adamant so that somebody else does not speak for you when you are unable to at the end of life and take that decision away from you.

Mrs Cameron: Thank you, Dr Trainor. Can you provide numbers for organ donations in Northern Ireland? Obviously, transplantation is done on a UK-wide basis. Can you give us a brief overview of how many transplants we do and what type in Northern Ireland and where the rest are done? Setting Northern Ireland's population aside, can you tell us a bit more about where access to organs comes from in general?

Mr Wilson: I suggest that Dominic or Janet might be best to answer that one.

Dr Trainor: Our deceased donor pool in Northern Ireland — that is, the number of patients who die in circumstances that will permit potential organ donation — is in and around 80 every year. Around 2008, we had about 20 deceased donors. Over the last decade, we have increased that to between 40 and 50, and, in the last two years, we have had 51 deceased donors. It is important to mention the role of living donation, especially for kidney transplant, and the successes that our trust has had with the living donor kidney programme, which is world-class. Over the last five years, they have transplanted 70 to 80 living donors' kidneys into recipients, which has exceeded the numbers in the deceased donor programme in Northern Ireland. Since 2017, there have been 541 organ transplants to citizens in Northern Ireland. That gives you an idea of the number of people out there with transplants. On a UK level, around 55,000 or 56,000 people live with organ transplants today as a result of the organ donation transplant programme.

Mrs Cameron: That is super. Chair, if you do not mind, can I ask one last quick question? I know that we are short on time, but I just want to ask about deemed consent and the controversy around it.

Do you agree that the biggest tool to increase organ donation is the controversy around this type of legislation, as that forces the conversation to go from hospital to home?

Dr Trainor: Yes, I agree. The very fact that we are talking about organ donation this morning: we probably would not have envisaged that 10 years ago. The greater the number of conversations around the issue, the better; and the greater the number of people talking about it, the better, even if they disagree with the proposed legislation. If this is brought in, we will basically have a hybrid system that includes the opt-in register, and the greatest driver in families saying yes to organ donation is if their loved one is on the register. We know that consent rates are 90% in that circumstance. In addition to the opt-in register, we already have the opt-out register, and, in those difficult conversations, that will bring clarity to the situation. In addition, people are able to nominate surrogate decision-makers, so the choice available to citizens with regard to their decision around organ donation has never been greater. The right or the will to exercise autonomy around the issue is also there for everybody.

Mrs Cameron: Thank you.

The Chairperson (Mr Gildernew): Bearing it in mind that Committee members may not know whom to direct their question at, some of you should identify who should pick up an answer. If any member of the panel wants to contribute a supplementary point, just put your hand up physically or raise your hand on-screen, and I will try to pick you up. It is difficult to see everyone in such a large meeting, so I may miss out.

Ms Ní Chuilín: I thank the panel for coming to the Committee this morning to discuss such an important issue. Colm mentioned that our colleague Pat Sheehan was delighted when the Department

adopted the Bill, because it is so important. I do not know who is the best person to answer my questions, but I will give them to you. You can decide who is fit to answer the questions.

First of all, the promotion has largely been down to the families and organisations. They have done a marvellous public job of raising awareness in conjunction with others. Mainly the families and, indeed, some of the lobbyists have done a fantastic job. I want to put that on record. What additional work — this question might be for the PHA — can you do to ensure that the issue of organ donation receives the attention it deserves? Secondly, the clinical leads in each trust, which come from the British Government's task force in 2008, are to be welcomed. In itself, that has made a difference to communication. However, the big issue in all matters of health and social care is workforce planning, and you have raised that today. In Wales, there is a legislative duty on the Minister to provide resources and specialist skills. What is your feeling about that? What conversations are you having about workforce planning to ensure that the intensivists, specialist skills and everything else that is needed for successful transplants are in place?

Chair, given that we are pressed for time, I will leave it there. *[Pause.]*

The Chairperson (Mr Gildernew): Stephen, you are on mute. I cannot hear you. I am not sure if other members can hear you.

Mr Wilson: Yes. Apologies, I was on mute. Catherine McKeown will pick up the first question, and either Janet or Dominic will say a few words on the workforce planning issue.

Ms McKeown: Thanks, Stephen. I very much want to put it on record that our partners, particularly our charity partners, have been campaigning and working hard on organ donation for years. Since I came into post, the collaborative nature of that work has been incredible, and it has made a huge difference to what we have been able to achieve in the last year.

As I mentioned, there is now a rolling communications plan to promote organ donation as part of the Department's duty to promote. If this legislation is passed, that will only be enhanced. As mentioned, it will consist heavily of outreach and engagement activity so that we can target as many audiences throughout Northern Ireland as possible. It will happen anyway, but, should the legislation pass, we will uplift our public awareness campaign activity at regular intervals to support that to make sure that there is enough breakthrough and weight behind the messaging and activities to reach out to as many areas of society as possible.

We will be hands-on and will liaise directly with faith networks, the Northern Ireland Council for Voluntary Action, the Community Faiths' Forum, the Age NI Consultative Forum, the PHA's regional minority ethnic migrant steering group and the Northern Ireland Civil Service-led race and ethnicity champions. All of those networks are in place, and we are tapping into that as much as we can. We have set up focus groups to engage with representatives from a range of communities to find out what people need to know about the legislation, how they want to be communicated with and the materials they need, such as translations, videos and animations, to make things as accessible and easy to understand as possible. Legislation and legislative change can be complex topics, so we want to make that as clear and easy to access as possible. That is our hands-on day-to-day engagement work, which is facilitated and mobilised by our partners amplifying and cascading the information. As mentioned, we will employ public awareness campaigns for additional breakthrough and support. We will plan that out carefully to make sure that we do it in the most cost-effective way through a range of channels that will, again, target people on multiple touchpoints throughout their daily lives.

The Chairperson (Mr Gildernew): Thank you, Catherine. Who is answering the second question on the workforce?

Dr Trainor: Janet, do you want to say anything about the workforce and what we have been through over the last 18 months or so?

Ms Johnson: I am happy to do that, Dominic. Thank you. Obviously, over the last 18 months in particular, as Dominic said, there have been pressures on the intensive care units because of COVID. Consequently, our concerns relate to that and the need to enhance and develop our intensive care workforce from a nursing perspective and a clinician perspective.

Specifically on the Bill, it is important for us to have access 24/7 to senior nurses for organ donation, and it is important that they are fully trained and educated. We have senior nurses in all of the

intensive care units across Northern Ireland. Equally, we need the clinical leadership that the intensivists bring to that. Therefore, we need to have access 24/7 to a consultant intensivist as well. That is key to our workforce and to supporting families and the nurses who assist families in making those difficult decisions. From our perspective, there is a need to further build that workforce, both nursing and medical, in all our units to make sure that that is sustainable going forward.

Dominic, is there anything further that you want to say specifically on intensivists? Obviously, they are the key individuals who, alongside our nursing colleagues, support families to make those difficult decisions at what are difficult times for them.

The Chairperson (Mr Gildernew): Briefly, if you can, Dominic. It might be an idea to forward to us some written detail on the planning that is going into the workforce. Go ahead, Dominic.

Dr Trainor: In addition to what Janet said, from a transplant point of view, we liaised with our renal transplant team on the document that we submitted in response to the call for evidence, and they were in broad agreement with the trust's approach to the legislative proposal. It is perhaps pertinent to mention at this point that they said that it is all very well saying that we want more organ donors and organs, but, as part of the planning, we need to have the necessary resources, such as access to and staff for theatres, so that, when an organ comes up and is gifted, we can utilise it. That is of the utmost importance. That is not unique to the Belfast Trust or Northern Ireland; the strains and pressures on the system are NHS-wide. I was in a meeting yesterday with the National Organ Donation Committee (NODC), and it said that the retrieval teams that fly over to retrieve organs are under staffing and resource pressures as well, so it is NHS-wide. We definitely need to consider that in the overall context of the Bill.

The Chairperson (Mr Gildernew): OK. Can you send us some detail on what the resource requirement would be on the basis of an improving situation?

Ms Bradshaw: Thank you, panel, for the answers so far. I have two issues that I do not think have been covered yet. The first is about the fact that one of the charities stated that children over 16 should be able to give deemed consent. Do you have any thoughts on the age in the Bill being lowered from 18 to 16? For me, the other issue, particularly in South Belfast, is how the communication strategy will address not just different cultural and ethnic backgrounds but potential language barriers in order to get the information across.

Dr Trainor: If it is OK, Chair, the second question may be another one for Catherine.

The Chairperson (Mr Gildernew): Yes, certainly. Go ahead, Catherine.

Ms McKeown: I outlined a number of the networks that we work with. They will be very much to the fore in liaising with communities on exactly what they need. The PHA, of course, already translates its public health materials into a number of languages. For the publications on our website, we use technology that can automatically translate materials or read aloud for those who are visually impaired. We will certainly apply all the usual accessibility criteria to our materials, but we need to find out from the people on the ground what is needed and create those materials for people. We will also pull together information packs for people and resource toolkits for communities, community leaders, groups and organisations to push out on their channels on our behalf. Those will be created for people as needed; we do not want to presume what people want but to find out what they need.

Ms Bradshaw: Before you come on to the second question, having worked with ethnic minority community groups over the past number of years, I suppose that it is not necessarily about people being able to read the materials but about educating the community leaders and making them the community educators. A lot of people have positions of trust, and they are in a good position to talk through the issues. You are covering that with us, but I wanted to make that point.

Ms McKeown: Yes.

Mr McGrath: I thank the panel members for their presentation today. It is an important issue, which many people are ready and willing to support, so it is good that we have the opportunity to have the briefing today.

By way of background, will you give us an update on roughly how many organs might be received from a donor and how many lives that would help, on average, to illustrate how many lives can be positively affected by somebody being part of the system?

When an individual donates, are their organs offered UK-wide or Ireland-wide, or are they kept in Northern Ireland? What is the reach of the use of those donations?

Dr Trainor: Thanks for that question. In Northern Ireland, there are currently 134 patients waiting for an organ transplant, but it is an NHS-wide organ donation and transplantation programme. Organs are allocated on the basis of clinical need. For example, those waiting for a liver transplant who are at the top of the super-urgent transplant list will receive a liver, if it matches, as a priority. The answer to whether the organs stay in Northern Ireland is, "No, not necessarily". Our transplant recipients receive hearts, livers or kidneys from across the UK. Similarly, when we have a deceased donor in Northern Ireland, their organs are allocated on a UK-wide basis. We are part of that programme.

Given that other parts of the UK have moved to the soft opt-out legislation, you could argue that it is time that we also do so, on the basis of consistency across the mechanism in which we work. Certainly, from our figures, we can see that our transplant recipients benefit from the soft opt-out legislation that has come into play in the rest of the UK. Of the 541 transplant recipients in the last five years, 30 organ transplants have come to our citizens through the deemed consent soft opt-out pathway. Patients already potentially benefit from the legislation in other parts of the UK. The average number of organs that a deceased donor has donated in Northern Ireland, going back over the years, is roughly three or four organs. Organs are offered and matched, as I say, according to their condition and the clinical need.

Part of looking to the future of organ donation is the concept of organ optimisation, which is about making sure that every deceased donor is capable of donating the maximum number of organs. There is lots of interesting research and innovation to promote that in the clinical framework. On the transplant side, there is a need to increase accountability and decision-making around the receipt of organs, and work needs to be done on the transplantation side, just as we have done on the donation side over the last decade, in terms of governance of the transplantation process. That will help improve donation rates and, ultimately, transplant rates, which is the outcome measure that we are interested in.

Mr McGrath: That is good. Thank you for that, Dominic.

The Chairperson (Mr Gildernew): I am aware that Paula's question about 16-year-olds and 18-year-olds was not addressed. We could, maybe, follow that up in writing, if we do not get back to it before the end of the session. I will ask the Clerk to follow that up in writing, Paula, if that is OK.

Mrs Erskine: I thank the panel. This is such an important issue, and I strongly support the principle of organ donation.

My question is for Catherine and the PHA. Is it the PHA's view that public information awareness initiatives have effectively maxed out the rates of organ donation under the current legislative framework? I know that she talked about the promotional activities that the PHA will be involved in should this come into legislation, but I wonder how that promotional activity will differ under a deemed consent regime.

The Chairperson (Mr Gildernew): Are you happy to take that, Catherine?

Ms McKeown: Yes, that is fine. Thank you. The key thing to say is that, consistently, over recent years, support for organ donation has been gradually increasing through the number of people here signing on to the organ donor register and the number of people discussing their wishes and realising the importance of discussing their wishes. However, there is always more work to do, particularly around opt-out legislation, should that be introduced. We constantly have new people coming to Northern Ireland, and we have young people progressing through society, so we need to constantly inform and educate people about organ donation and promote it, and we need to consider whether that should also switch to a message around legislative change.

The key thing is that organ donation saves lives. Organ donation is your decision. It always has been your decision, and it will remain your decision. Our key message will still be to register as an organ donor, whatever that decision is, and share that decision with family and close friends. As Dominic

said, it reinforces your personal position on organ donation and gives you that autonomy and that feeling of empowerment that you are making that decision for yourself. If you want your decision to be honoured in death, the best way to do that is to make that clear to those close to you so that they will be certain of what you want when that time arises. Those two key actions are still really relevant as we go forward with the legislation. The only difference will be that we need to educate people on what the legislation is, when it is coming into effect, what it means for them and how they record their decisions. We need to make it really easy for people to record a decision to opt in or opt out. It is really about providing reassurance and helping people to reaffirm or make an informed decision on organ donation, whatever that decision is.

The Chairperson (Mr Gildernew): Paula has her hand back up. That may be about the additional part of her question. Paula, do you have your hand raised again?

Ms Bradshaw: Yes, I wanted to ask about the 16-year-olds.

The Chairperson (Mr Gildernew): Yes, refresh the question in our minds, please.

Ms Bradshaw: One of the charities suggested that children over 16 should be able to give deemed consent, not just those over 18. What are the panel's views on lowering the age?

Dr Trainor: Does anyone from the Public Health Agency have an opinion on that?

Mr Wilson: We have not discussed that, Dominic. I am not sure whether you, from the professional side, have.

Dr Trainor: No. There is an evidence session with the charities after this, so it might be worthwhile having a chat with them. I mentioned consistency across the NHS in what we do, and in the other jurisdictions the age is 18, so it may be prudent, at least initially, to keep the age at 18 purely on the basis of consistency. There may be others who give evidence after us — those from NHS Blood and Transport and from the charities themselves — who may be able to add further weight in answer to that question.

Ms Flynn: I thank the panel for all their feedback and answers. Dominic, you raised the need for a sustainable workforce and all the essential resources that go with that. What local pressures on staff and resources is the service facing? How quickly will that system need to respond or adapt if and when legislation is introduced?

Dr Trainor: The pressures that the system faces are unprecedented. In the intensive care unit and other units where we work, because of the increased number of patients who are coming through, we have had to redeploy staff from other areas. That has been well documented. In the context of organ donation, the issue with redeploying staff from other areas of the health service is that they might find the end-of-life scenario in intensive care particularly stressful. We are asking people to manage or be part of a situation that they may not be overly familiar with. That places stress on the staff. There is a large number of redeployed staff, and it is well documented that that has affected the theatre throughput and elective surgery. That has been well documented and discussed.

In terms of resources and organ donation, the patients who die in intensive care in circumstances in which they can be an organ donor are already in intensive care. Those are patients with things like a devastating and terminal brain injury, and we will already be looking after them in the intensive care units. The legislation will not increase the number of patients, but it may increase the number of families who agree to organ donation, and that may increase the number of organ retrievals that the system needs to cope with. Certainly, NHS-wide, that most likely will be the case, and it is important that we think of ways to help deal with it. The way to deal with that is to collaborate with colleagues across the NHS, find solutions and help each other's regions in the short term. I do not know whether I have answered your question.

Ms Flynn: You did, Dominic. Thanks very much. I am conscious that I asked about the local pressures, although there is no surprise there because, obviously, we are in different circumstances with COVID and people have been moved around and theatre capacity has been impacted. The real question — I suppose that you answered it — was whether our local system could cope if we were to get the hoped-for increase in organ retrieval and collection. That is obviously a wider conversation that

you are having with colleagues in Britain and those in the wider system. Thank you. I appreciate that answer.

My second question is for Catherine from the PHA. It is about the mass awareness campaigns that you plan. I know that there is a big demand for public awareness campaigns on a wide range of issues and that there are calls for the PHA to promote those as widely as possible. I think of the bigger TV advertisement campaigns and those on mainstream radio channels. My question is this: if the legislation passes, are you looking at options to promote that messaging on those mainstream media outlets?

Finally, is any preparation taking place in the PHA for the training for staff in the NHS? I think of doctors, nurses and clinicians and our GPs and community pharmacists. If the legislation is brought in, is there a programme of work to get the message out to all those outlets so that everyone is trained up when they are dealing with the public and with patients?

Ms McKeown: Thank you. The answer to your first question is, "Very much so". We will look at a range of above-the-line and below-the-line media. The above-the-line media is the high-profile, mass media, such as TV and radio. We will also look at options such as direct mailings so that we can, potentially, hit every household.

Through-the-line media, as it is sometimes described, would be all of our digital and social channels. That is where you get really targeted and specific to audiences. We have a lot of research about the breakdown between males and females and how readily they talk about organ donation. Therefore, it is really about tweaking individual media, say, for example, a digital ad, to a male or female audience so that we can get really specific. We will very much use TV etc for mass awareness campaigns.

There are additional things, such as the likes of Sky AdSmart, that allow you to get really specific to audiences so that you pay only for the ads that the people whom you want to see them see them, if you know what I mean. There is less wastage is what I am saying.

On your second question, NHS Blood and Transplant will, together with the Health and Social Care (HSC) system here, take forward training for staff. Its representatives will be able to pick that up and give you a bit more detail on that in their evidence session.

Ms Flynn: That is great, Catherine. Thanks very much.

Mr Chambers: This may be a question for Dr Trainor. I suppose that the bottom line is whether the Bill has the potential to make a significant contribution to increasing organ transplants, which will mean that many more lives in Northern Ireland could be transformed. Does the physical transfer of donated organs between GB and Northern Ireland carry additional logistical challenges?

I finish by taking the opportunity to place on record my appreciation to a party colleague, Jo-Anne Dobson. She first brought the issue into the political arena a number of years ago, when she tried to bring a similar Bill forward.

The Chairperson (Mr Gildernew): Going back to you first, Dominic.

Dr Trainor: I think that the first question was whether there is the potential for the legislation to create an increased number of transplants. The answer is that the potential is there. The public and political support that is evident is something that we should embrace and work with constructively. The other regions — Scotland, Wales and England — have all moved to this model. Certainly, whilst the numbers that result from that legislative change in Northern Ireland might be relatively small, you have to think of organ donation and transplantation on a UK-wide, NHS-wide level. When you think about the data on that level, there is certainly the clear potential for that to increase the number of donations and the number of transplants, which is, ultimately, what we are interested in.

It is worth saying that, because it is a hugely complex process, legislative change in itself probably will not be enough. We need to work with Catherine, Stephen and people in the Public Health Agency to really bolster the change. Ultimately, it will be the public who change the transplantation rate. It will not be the legislation; it will be the people. We have already talked about the work that is going on in the community. I hope that that answers the first question.

The second question was about the additional logistical challenges of transferring organs across the UK. A number of cardiothoracic and retrieval teams are on 24/7, 365 days a year. Those are the teams that would be contacted by our specialist nurses in the event that we had an organ donor who had consented and the process had started, say, today. Those retrieval teams fly over to Northern Ireland and set up in the theatre in whichever hospital the donor is in. The retrieval operation takes place. Any retrieved organs will then be transferred to the transplant centre, wherever that may be, in the NHS jurisdiction. There are logistical challenges. Rarely, we have trouble with, say, inclement weather; sometimes, we get that, but very rarely. Usually, that part of the process — the transferring of organs — is, in my experience, quite smooth. Although it could be a potential issue, the pathways that exist to transfer organs to transplant centres are well established at this stage.

Mr Chambers: Thank you.

The Chairperson (Mr Gildernew): Thank you, Alan and Dominic. I have some final questions, partly as a result of Alan's question. We have heard that there is cooperation, I believe, across the island of Ireland and between Ireland and Britain with regard to organ donation. Does that still exist? Will it be impacted by the draft legislation? Is there any impact on that cooperation as a result of Brexit?

Mr Wilson: Again, Dominic might be best placed to answer those questions.

Dr Trainor: In the past, we have had the consent of a deceased organ donor whose organs, perhaps, have not been suitable, for whatever reason, for a UK recipient. In that situation, our specialist nurses can go outside the NHS and offer that organ to, potentially, someone in the Republic of Ireland or Europe. Certainly, we in the Belfast Trust had a team fly from Germany to retrieve an organ that was not suitable for any UK recipient. Therefore, there is cooperation on that issue within and between countries when the need arises.

There have been potential implications from Brexit. I think that you have a session with NHS Blood and Transplant after us. There will be people there who are better placed than me to answer that question.

The Chairperson (Mr Gildernew): OK. Thank you. I really appreciate your attendance this morning. The session has been shorter than we would have liked, but we got through a lot of key business. If members have other questions that they did not get a chance to ask, please forward them to the Clerk and he will process them for a response.

For now, Janet, Dominic, Stephen, Catherine and Catherine, thank you all for attending, for your presentations and for answering members' questions. I wish you all the best for the future.