Northern Ireland Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Organ and Tissue Donation (Deemed Consent) Bill: Department of Health

25 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 Gerry Carroll
Mr Alan Chambers
Mrs Deborah Erskine
Ms Órlaithí Flynn
Mr Colin McGrath
Ms Carál Ní Chuilín

Witnesses:

Mr Ian Plunkett	Department of Health
Mr Ryan Wilson	Department of Health

The Chairperson (Mr Gildernew): From the Department of Health, I welcome, via StarLeaf, Mr Ian Plunkett, the head of the Organ and Tissue Donation (Deemed Consent) Bill team, and Ryan Wilson, director of secondary care. Who will make the opening remarks, or is it both of you? Ian, who is making the presentation?

Mr Ian Plunkett (Department of Health): It is Ryan.

The Chairperson (Mr Gildernew): OK. Ryan, please go ahead.

Mr Ryan Wilson (Department of Health): Thank you, Chair. I have a few brief opening remarks. I thank the Committee for the opportunity to come back to discuss the Bill. Ian and I were grateful to provide our introduction to the Bill on 9 September. We followed the Committee's evidence sessions with some of our partners and stakeholders that took place on 11 November. Following that, the Minister provided the Committee with a detailed response to the range of issues that have been raised to date. We hope that that has been helpful, and Ian and I are happy to elaborate on any of those points or other questions that the Committee may have at this stage.

We are aware that the Bill is widely supported, and we assure the Committee that we are planning, along with our delivery partners, to be in a state of readiness from next March to go into 12 months of intense preparation and planning for communication and training in order for the deemed consent provisions to go live from March 2023, if that is what the Assembly decides. I will pass it back, Chair. Our detailed response is in the Minister's letter, and we are happy to pick up on any of those points.

The Chairperson (Mr Gildernew): Thank you. The response states that four additional specialist nurses for organ donation would be required. What would the additional funding requirement be for that element of the future service?

Mr Wilson: I will pass to Ian for that. He is the Bill manager and is in the process of putting together our business case for the overall investment that, we think, would be necessary. Ian can give you some detail on the anticipated cost.

Mr Plunkett: We anticipate that the cost of the four additional staff required to run the new system would be about £212,000 per annum. That would help the resilience of the current team, and two additional staff would make the system work once the new opt-out system comes in.

The Chairperson (Mr Gildernew): At times, offers of organs have been made either way across the border, and European organ donation is possible in certain circumstances. That situation arises. Are there implications flowing from Brexit that could create difficulties in that respect? Is there anything in the Bill that has been explored as a way of streamlining the process across the island?

Mr Wilson: I will take the questions in turn. In the evidence that you heard from NHS Blood and Transport (NHSBT) witnesses a couple of weeks ago, they provided detail on the planning that they did in the lead-up to EU exit. In their experience since the UK left, the main message is that there has not really been any impact on donation and transplantation. The Committee will understand it by looking at how the organ allocation system works. If there are occasions when an organ is not able to be used in the UK pool, it is offered to neighbouring countries, beginning with the EU. On occasion, such organs are accepted.

Those networks and pathways are well established, and, to date, we have not seen any impact of Brexit on them. Planning is going on in the Department on developing what is known as a "common framework for organs, tissues and cells". That is to set a framework for the quality and safety standards for the movement of those materials. Nothing in the Bill would have any impact on that. What will change as a result of what is proposed is the focus and emphasis of the donation conversation with the families of potential donors. In short, we do not anticipate any impact as a direct result of Brexit.

You also asked about the extent of collaboration with colleagues in the South. At official level, we have had good links over the years with colleagues in the Department of Health in Dublin on organ donation and opportunities for collaboration at clinical level. That has led to the arrangements that occasionally enable some residents of the Republic of Ireland to avail themselves of the kidney transplant service in Belfast. The Committee may be aware that the Republic of Ireland is on a journey towards legislating on organ donation. Its starting point is different from ours, because it is covering a range of issues around organs and tissues that, in our case, are covered by the Human Tissue Act 2004. Part of that is the introduction of deemed consent provisions in the South for the first time. It is similar in the objective of moving to a place of deemed consent, where possible, but it takes a different starting point.

We agreed to stay in contact with colleagues as they develop that. They are looking to bring a Bill to the Dáil in the early part of next year, but it will be much more wide-ranging legislation than ours.

The Chairperson (Mr Gildernew): OK. Thank you. Ryan, my final question was prompted by your mentioning of cell donation. Are stem cell donation and transplantation included within the scope of the Bill? Do they fall under it?

Mr Wilson: No. It is a related issue as it involves donation for the benefit of people with blood cancer and certain blood conditions. There are occasions when family members or non-related people can donate stem cells to help people through a transplant. It is a separate service and, in Northern Ireland, takes place through the haematology service in Belfast City Hospital.

In September, the Department ran some promotional and awareness campaigns about blood cancers, which included information on stem cells. To put it in simple terms, it is a different message. There is a level of public awareness about that issue that is probably in a different place from public knowledge of organ donation. There are reasons that we do not promote the two together. A different set of behaviours and learning needs to be addressed with stem cells.

Stem cells are not covered in the Bill. The Bill specifically refers to the donation of organs after somebody has died, which, you will be aware, would be in very rare circumstances to begin with. Hopefully, that answers your question.

The Chairperson (Mr Gildernew): Yes. Thank you for that clarification. That answers my question.

Mrs Cameron: Ryan and Ian, thank you for your attendance at the Committee. I have a couple of questions for you.

I want to ask about the scope of the Bill for those who are usually resident in Great Britain but die in Northern Ireland. Would that present practical and legal difficulties? How would someone's eligibility be proven, and what arrangements would need to be put in place to consult family members who live in other jurisdictions? Would those factors cause delays and, ultimately, make donation in a timely fashion unfeasible? That is my first question.

Mr Wilson: Sorry. May I just clarify? Was your question about somebody who is not resident here but who may die in those circumstances and their family lives elsewhere?

Mrs Cameron: It is the inclusion of those who are usually resident in Great Britain who die in Northern Ireland.

Mr Wilson: OK. In those circumstances, if those persons were not usually resident here, they would not fall within the Bill's provisions on deemed consent. That was one of the questions that we consulted the public on. Deemed consent should apply to people who are usually resident, and certain tests would have to be met for those criteria to be applied.

That does not mean that those people cannot become organ donors. It goes back to the point about conversations with families or people in a qualifying relationship. We want to assure the Committee that that already happens and will continue to happen under the deemed consent provisions. That is a really essential part of the pathway. For deemed consent to apply, a conversation to ascertain a person's last-known decisions or otherwise needs to take place. Consent cannot be deemed in those cases. If the family happens to live in GB or in another jurisdiction altogether, every effort will be made to contact the family and loved ones. On the rare occasion when contact cannot be made and no relative can be traced, organ donation will not proceed. It does not proceed under those circumstances at the moment, and it will not proceed under these provisions.

Mrs Cameron: That is great. Thank you. When scoping the Bill, what research was undertaken on the capacity of 16-year-olds to provide informed consent for organ donation? Was one of the factors in the decision to exclude this cohort the likelihood that it would create a precedent for other forms of public participation? What stance have other UK regions taken on this?

Mr Wilson: In our public consultation, we included a question about which groups should come under deemed consent and which should be exempt. Essentially, we have followed the path that has been taken by other regions of the UK, specifically England and Wales, which are covered by the same legislation as us, the Human Tissue Act 2004. That is the Act where the age of consent applies. You may have picked up from the consultation response that, in total, 37% of the respondents thought that the age group should be lower, and some comments were aimed specifically at the 16-to 18-year-old group. We know that some in that age group support that.

We want to be really clear that virtually anybody from any age group can join the organ donor register, and anybody can become an organ donor after their death. We absolutely agree that 16-to 18-year-olds are capable of understanding this legislation and what organ donation is about. We are talking, however, about whether deemed consent should apply to people in that age group: should their consent be presumed in the absence of an affirmative decision during their lifetime? That is a slightly separate question, and, in that sense, we are in keeping with the other nations. If, in the future, there is an overall question about 16-year-olds' wider rights — voting and things like that — that could be revisited. For practical and technical reasons, it would be difficult to be at variance with other nations governed by the Human Tissue Act.

Mrs Cameron: That is great. Thank you. Finally from me, is there currently a mechanism in the Bill to ensure that regulations can be introduced to add donation *[Interruption]* by deemed consent, should the technology or techniques advance in coming years?

Mr Wilson: I will ask Ian to address that. *[Interruption.]*

The Chairperson (Mr Gildernew): Ian, before you come in, may I ask everyone to place themselves on mute? Some background noise is coming through.

Mr Plunkett: Sorry, my dog is going mad here. Hopefully, he will settle down.

The Chairperson (Mr Gildernew): That explains the background noise.

Mr Plunkett: Apologies. Will you repeat the question? I was completely distracted.

Mrs Cameron: Sure, no problem. I am just glad that it is not my dog that is barking for a change.

Is there currently a mechanism in the Bill to ensure that regulations can be introduced to add organs to the scope of deemed consent, should the technology and techniques advance in the coming years?

Mr Plunkett: Should the legislation go through, we anticipate introducing secondary legislation immediately afterwards. That will specify which organs and tissues are included in the deemed consent. That leaves us with the option that, if it becomes normal to donate any other organs or tissue, we can go through the process of adding to that list.

Mrs Cameron: That is perfect. Thank you very much.

Mrs Erskine: Thanks for coming to the Committee, Ryan and Ian. Sorry, I am getting a bit of feedback. Can you hear me?

The Chairperson (Mr Gildernew): We hear you. The sound is a bit poor from people who are in rooms in the Building. We are following you, but please be as clear and as slow as possible, Deborah.

Mrs Erskine: OK, no problem. The Chair asked a question about staffing and things like that. Will the resource requirements of the Bill have a disproportionate impact on certain trusts, given the specialised staff and functions that will be needed? Was a resource needs assessment conducted prior to drafting? How will the lead-in time account for any necessary preparations?

Mr Wilson: Thank you, Deborah. I will start, and Ian can fill in some of the details of how the resources are accounted for in our planning.

I will describe the infrastructure/resource currently in place. Organ donation can come from any of the intensive care units across the system. We anticipate that we might see an increase of 10 to 15 donors a year across those units as a result of these measures. We are talking about people who have already been admitted to ICU because of various injuries or conditions, so, when it comes to how that resource will be spread out across those units, there is no additional impact on numbers. The main impact is on the specialist nurse team, which is an existing network of specialist nurses whose role comes in at the end of life and during that conversation with families. That is where we initiate the donation conversation and, following that, the retrieval process. The main impact is the need to increase resilience within that team: that network of specialist nurses. At the moment, our planning assumption is that it would be appropriate to add four nurses to that team. How they are spread across the units will be up to the team's management. The units are different sizes, a donor could come up in any of those units, and, as far as I know, the team works across the region and across units.

You asked about the resource needs assessment. That work is ongoing, alongside the Bill, as part of our business case process. Certain elements will need additional investment, and specialist nursing is one of those areas. Some upfront investment in intensive public engagement and education will be needed for 12 months before and after going live. Public engagement and raising awareness will be ongoing. We are factoring those elements into our business case planning. With the increase that we expect, there will be further demand on the UK-wide retrieval teams who come in when consent is given. We envisage an incremental increase in line with the increase in the consent rate. All of that is factored into the planning and into the business case that is under way.

Ian might want to add more detail or check whether that has answered your questions or is along the right lines.

Mr Plunkett: You asked about the impact being disproportionate across the region. There are 10 ICUs across Northern Ireland, and we cannot really tell where the service will be needed. The specialist nurses organ donation (SNODs) will go where they are required, and that will involve a cost. Sitting here, we cannot determine where those costs will be spent. Where the additional funding is required will be decided on a case-by-case basis to deal with the situation and where across the region it arises.

Mrs Erskine: If we expect loads more people to come into the organ donation system, four additional staff does not seem that many. I wonder whether, in future years, we will need more staff. We will have to wait and see, after the roll-out of the legislation, whether we will need additional staff. Has there been any forward thinking about its outworkings and whether we will need additional staff in, say, five years' time?

Mr Plunkett: As you know, NHS Blood and Transplant is responsible for running the whole organ donation network. That has been factored into all the costs. We are looking at costs, on the basis of NHS Blood and Transplant's figures, over the next five years as a minimum. NHS Blood and Transplant constantly looks at what is required, and that requirement has the potential to increase over time. We are looking at the impact over the next five years.

Staff will be lost through natural wastage and so on, so NHSBT constantly looks down the line to see what we need to do and whether we need to start recruiting additional staff. They might be replacement rather than additional staff. We are looking at between 10 and 15 additional donors per annum, and we have assessed that increase as needing four nurses. As you say, we cannot determine what might be needed beyond that, but we have looked ahead, and our figures are based on what is, we think, realistic over the next five years.

Mrs Erskine: OK. Thank you.

Mr Wilson: We recognise the huge pressure that has been on intensive care for almost the past two years. I will put that into context. We know that the overall critical care system for Northern Ireland is in need of additional resilience. What we are talking about is a small number specifically relating to the potential pool of organ donors. In previous evidence sessions, I think, the Committee heard that about 1% of deaths in Northern Ireland or across the UK happen in circumstances where donation may be possible. That number becomes even smaller when you factor in things such as clinical contraindications. We are talking about people who have already been admitted to ICU, which is around 80 people a year. Currently, about 40 or 50 of them will become deceased donors. We are talking about bringing the consent rate up in that small pool from around 60% or 65% to 80% or better, if we can. The number is small, but, if you think of the lives that can be improved and saved by their donations, it is significant. That is the target.

I go back to Deborah's question. There will not be an additional pressure or impact on what we already see in intensive care units; it is about converting those potential opportunities into consented donors. That is where the additional resource will be needed: in the specialist nurse team. The additional four nurses will build a lot of resilience into the existing team. You have heard about the expertise and experience that we are lucky to have in the SNOD team in Northern Ireland. We would add to that and build it for the long term. Of course, we would keep it under constant review with our colleagues in NHSBT in case there is additional need, but, for the moment, we think that four would be sufficient.

Ms Ní Chuilín: Thank you, Ian and Ryan. Ryan, you said that everyone is trying to achieve the world-class standard of 80%. There has been a huge workforce planning issue, however. This is a bespoke speciality. I want to tease out the duty on the Minister in Wales to provide specific and/or bespoke resources. Are there plans to include such a duty for our Minister in the legislation? Given that we are still in a pandemic, will there be a role for intensivists in the team that is needed for organ donation and transplants?

Mr Wilson: Thank you, Carál. As regards the duty that was placed on the Welsh Minister, as you know, Wales was the first of these nations to introduce deemed consent. The Welsh Bill went through in 2013 and was the first of its kind. The reason why there was that provision in the legislation was to ensure that it was backed up with the necessary resources. Our position is that the existence of a new statutory duty around deemed consent brings with it a responsibility to provide the resources.

Combined with that, we have just entered into a new 10-year strategy with NHS Blood and Transplant, which is to take things to the next level. You will have heard about the foundations and infrastructure

that were put in place from 2008, after the task force made its recommendations. That is still the level now, and the new strategy brings that to the next level. Deemed consent is one measure in that strategy, which will, we think, bring us to 80%. There is a lot more in the strategy around organ optimisation and utilisation and continuing to build on public education and clinical education. We have a strategic commitment to a range of measures as well as to what will become a statutory requirement. For that reason, the Department would not support putting something into legislation. I do not think that it is necessary. I am not aware of any other area in our public health system where we make statutory regulations around ring-fencing resources. The duty will come anyway. *[Inaudible owing to poor sound quality.]*

Ms Ní Chuilín: Having been in two Departments, I find it interesting when "inescapable" and "escapable" budget headings are put forward. You say that no duty to ring-fence resources is in the legislation. The resource needs to be ring-fenced on a proportional percentage. If it is not there, it does not happen. It is like the safe staffing legislation. There were all these commitments. Had we had safe staffing legislation, we might not have had a mass resignation from the ICU in the Royal. I do not know what the reasons for those resignations were. The point that I am making is that, sometimes, if something is not in legislation, it does not happen. That is where my concern is, to be honest.

Mr Wilson: I appreciate the concern. We deal with terms like "inescapable" and "escapable" often as well. I relate this to the Department's existing statutory duty, which goes back to the Health (Miscellaneous Provisions) Act (Northern Ireland) 2016. That is when the Committee considered the issue previously. What came out of that was the duty on the Department to promote organ transplantation. As a result of that, we have a protected budget, which is what has enabled us to set up the infrastructure around the promotion and education side of organ donation. A couple of weeks ago, you heard from Catherine in the Public Health Agency about the communications programme that she coordinates. That was brought about by the fact that we have a dedicated budget for that. That is protected, if you like, in the Public Health Agency's wide range of responsibilities. After almost two years now, it is beginning to gather real momentum and make serious headway by bringing together all the existing good work into a combined programme. For that reason, we can be confident that this area is relatively safe in terms of how it will be prioritised.

The Chairperson (Mr Gildernew): Thank you. Carál, do you have anything else?

Ms Ní Chuilín: No.

The Chairperson (Mr Gildernew): I thank Ian and Ryan for answering the Committee's queries. That has been very useful. We can let you go now, gentlemen. Thank you for attending this morning. The Committee will continue its considerations.

Mr Plunkett: Thank you.

Mr Wilson: Thank you.