



Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Organ and Tissue Donation
(Deemed Consent) Bill

9 September 2021

The Committee Clerk: He has joined by phone.

The Chairperson (Mr Gildernew): OK. We are hearing you clearly enough, Ryan. Do you want to go ahead with your briefing? We will then move on to members' questions.

Mr Wilson: Yes, thank you, Chair. Good morning. Thank you to the Committee for the opportunity to brief it on the Organ and Tissue Donation (Deemed Consent) Bill. I am Ryan Wilson, director of secondary care in the Department of Health. My team has policy responsibility for organ donation and transplantation. I am joined by my colleague Ian Plunkett, the Bill team manager for this legislation.

We met many of the members of the Health Committee at an event hosted by the British Heart Foundation in January as part of our public consultation. After a very positive consultation process, we are very grateful to be here with a draft Bill ahead of the Second Stage debate on 20 September. At the meeting in January, we discussed that there were very tight timescales ahead in order to enact the Bill within the current mandate. For that reason, we welcomed the decision by the Health Committee to open its call for evidence over the summer recess. That will make things much more achievable in the months ahead, and it permitted us to do some detailed planning and engagement over that period.

A briefing paper has been shared with members. We apologise if it has been received late. I will go through some of the paper's main points and we are happy to take any questions about it.

The donation of organs and tissues after death already helps to save and improve many lives in Northern Ireland every year. One donor can transform the lives of up to nine people. The main objective of the Bill is to increase the current rate of consent in the small number of cases in which it is clinically possible for organ donation to proceed after a person's death. Doing so will increase the overall number of donors and, ultimately, the overall number of life-saving organs that are available for transplantation. To set that in context, I have a few key figures to run through. Only 1% of us will die in circumstances where organ donation is clinically possible. That is, in hospitals that have intensive care or life support available. That is generally someone for whom intensive care has no prospect of bringing about recovery.

In general numbers terms, the UK population is about 67 million people. There are just over 600,000 deaths, on average, per year, and only about 7,000 of those deaths are potential organ donors. It is a small number, and an even smaller number go on to become a donor. With the Bill, as with deemed consent systems in neighbouring countries, a change in the law will not increase the donor pool; rather, we are talking about trying to maximise the donation opportunities by increasing the consent rate from within that very small pool.

Last year in Northern Ireland, there were 51 deceased donors, which resulted in 113 transplants throughout the UK. In total, 87 Northern Ireland residents received transplants. About 115 people in Northern Ireland are on the transplant waiting list, and every year about 10 to 15 people in Northern Ireland die whilst waiting for an organ transplant. While we do well in our consent rates generally and have positive attitudes and behaviours in this country around organ donation, the demand for transplanted organs continues to outstrip the supply.

Forty-nine per cent of our population has joined the NHS organ donor register. That is a steady increase from 30% in 2013. Many more than that — consistently about 90% of our population — say that they support organ donation, but, despite that, about a quarter or a third of families decide to not proceed with a donation when faced with the decision at a difficult time. In Northern Ireland, and other UK regions until recently, the consent rate has remained at about two thirds of potential donors. The overall strategic aim is to achieve a sustained and world-class consent rate of 80% or higher, year on year.

Turning to the consent system that we have in place in Northern Ireland, we have an opt-in framework for consent for organ donation to proceed after a person's death. That means that donation will only ever proceed if the person had given their expressed consent for organ donation during their lifetime, usually by signing up to the organ donor register, and/or the person's family supports the donation proceeding after death. In the absence of a decision being recorded on the organ donor register, or the family being unaware of their loved one's donation intentions, the family is asked to make a decision on the person's behalf. The effect of the proposed change in the Bill will be to shift the focus of the donation conversation, which is conducted with families at the end of life by expert NHS specialist nurses to establish the known decisions of their loved ones. Every other part of the end-of-life care pathway will remain unchanged and will be conducted in line with current clinical and professional standards.

The current statutory framework for consent will require new primary legislation in the form of the Bill to change the system in Northern Ireland from one where people can choose to opt in or out of the organ donation register to a new statutory opt-out system in which consent is deemed or presumed, except in certain exempt circumstances or where a person has made a decision to opt out during their lifetime. That is often referred to as deemed consent.

Turning to the Bill, the legislation that underpins organ donation and transplantation in England, Wales and Northern Ireland is the Human Tissue Act 2004, which covers all aspects of consent around organ donation by the living and the deceased. We consulted the public on policy proposals on how deemed consent could be introduced, and we based that on the systems in place in Wales, England and Scotland. The explanatory and financial memorandum, which members will have received, describes how clause 1 would give effect to the following policy proposals: it will be considered that everyone living in Northern Ireland agrees to donate their organs when they die unless they have confirmed otherwise by opting out of the organ donation register, they have otherwise made their decision known, or they are from one of the excluded groups. Individuals will still have the choice whether they want to become a donor. Families will continue to play an important role in the consent process in all cases. However, whilst the nature of the end-of-life discussion with families will change, they will always be asked about the last known organ donation decision of their loved one to ensure that it is still accurate.

Decisions based on faith and belief will continue to be respected. Deemed consent should not be applied in cases where organs are being donated for research purposes. There is already a separate process for that covered by the Human Tissue Act 2004. Deemed consent should not be applied in the case of novel and rare types of transplants such as faces, limbs and genitals. Deemed consent will only apply to human organs normally considered for transplantation: hearts, lungs, livers, kidneys, pancreas and small bowel, as well as tissue including heart valves, corneas and bone.

The groups that are proposed to be exempt from the deemed consent provisions include children and young people under the age of 18 — they can still become organ donors, but their consent is not deemed under this system — adults who lack the capacity to understand the new system, people whose identity is unknown, and people who are not ordinarily resident in Northern Ireland, and that includes tourists, cross-border workers, people who are temporarily resident in Northern Ireland, including students, armed forces personnel, and people who work on placements.

In technical terms, the Bill achieves those changes by proposing amendments to the relevant sections of the Human Tissue Act 2004. Clause 1 also seeks to amend sections 15 and 16 of the Health (Miscellaneous Provisions) Act (Northern Ireland) 2016. Members may recall that the Act was introduced by the Assembly in 2016 after the Health Committee had considered a Private Member's Bill to introduce deemed consent at that time. The Health (Miscellaneous Provisions) Act introduced a statutory duty on the Department to promote and report on organ donation. That work has developed to a point where we have a comprehensive communications programme that runs year-round. I hope that we will have the opportunity to speak about that with Public Health Agency colleagues later in the Bill process. That work will continue regardless of whatever the Assembly decides on the deemed consent Bill.

However, the Bill effectively proposes an extension to the existing duty to promote: specifically, to promote and inform the public about deemed consent and the individual's right to opt in or out of deemed consent. That is a very important provision that we have included on clinical advice. The provision ensures that, in future, information will always be given to the public and future generations about the law. That process will be embedded in our existing rolling communications programme.

Since the Committee last considered this issue in 2015-16, there have been developments. It is worth mentioning what has happened in the intervening five years. At that time, Wales was becoming the first region of the UK to implement a system of deemed consent that came into effect from December 2015. At that time, it was felt that Northern Ireland should observe developments in Wales for several years. The Welsh consent rate has increased in that period from 58% in 2015 to 70.7% in 2020. The impact was not immediate, and it took several years to take effect following extensive media promotion and an information campaign by the Welsh government.

In England, a new opt-out system came into effect on 20 May 2020. The new system is now firmly embedded and is working well. However, it is probably too soon to analyse any long-term impact on consent rates. Scotland's opt-out system came into effect on 26 March 2021. Moreover, there is an increasing level of acceptance, understanding and support among the clinical community and the public for deemed consent. Whilst it would not be appropriate for us, as officials, to speak on the

behalf of clinicians, we trust that the Committee will want to hear from clinicians and professional bodies in due course. However, we can say that, since our consultation, we have had extensive engagement with the clinical community. Our view is that the overall context has shifted in that time. That is likely because the Welsh system has now reached a level of maturity, which provides assurance, and because of the successful implementation of deemed consent systems in England and Scotland. There has also been a notable increase in public support and understanding, and that is reflected in the positive responses that we have received to our public consultation. The credit for that needs to go to local campaigns by people such as Dáithí Mac Gabhann, Lucia Quinney Mee and Jo-Anne Dobson, their families and many others. They have raised public awareness and understanding about organ donation to a level at which, we feel, there is a very strong base of support for and public confidence in the concept of deemed consent.

I will look briefly at some of the recent consent rates across the UK nations. The rates relate to potential donors, where a consent conversation has taken place with families. In 2019-2020, Northern Ireland's consent rate was at 64%. It has been fairly consistent across recent years. England's was at 68.3%, Scotland's at 64.8% and Wales's at 70.7%, as I mentioned. We have included in our briefing paper the consent rates for the most recent published year — 2020-21 — but it should be noted that those figures are not directly comparable with previous years. That is mainly because of the impact of COVID-19. Although we have seen a positive consent rate in Northern Ireland, at 79%, we have to put that in context. It is important to note that, across the UK, there was a 25% fall in the total number of deceased organ donors in that year and a 28% decrease in the total number of organs donated. To put that in context, we have to remember that Northern Ireland has a relatively small population and donor pool, so the consent rate is prone to relatively high peaks and low troughs from year to year. We welcome that high consent rate, but the proposed change in legislation is a way in which to grow and sustain it in the long term.

I will speak briefly on implementation. We are working towards achieving Royal Assent for the Bill, subject to the Assembly's and the Committee's approval, by the end of this mandate. We are therefore aiming for Royal Assent by around April of next year. We envisage that approximately one year of implementation planning will be required thereafter, because several pieces of work will need to be undertaken following approval by the Assembly. Legislation will be required to be laid at Westminster under the negative resolution procedure to amend the relevant sections of the Human Tissue Act 2004. In addition, the Human Tissue Act created the Human Tissue Authority as the UK regulator for overseeing the legal consent requirements. It provides advice and guidance to professionals, via codes of practice. It is therefore likely that a new code of practice will need to be developed by the Human Tissue Authority for changes in Northern Ireland, as was the case in Wales and England, and there will be a need for a period of training on those changes and codes of practice for the relevant clinicians and healthcare professionals. Finally, following enactment, there will be a need for a period of major public engagement. As I said, a lot of detailed planning is under way on how we will add that to, and embed it within, the existing communications. We welcome the opportunity to provide more detail on that through question and answer, or later in the process. In the interests of time, we can pause there and take questions from members.

The Chairperson (Mr Gildernew): Thank you. That was very useful. At this time, in the interests of brevity, because we are under time pressure, my only question is on the public consultation. I was pleased to hear you say that there is increased public support, and I acknowledge and agree with your comments about all those who have been campaigning. The Deputy Chair and I met Dáithí Mac Gabhann and his family. It was one of the first meetings that we had. It was a very early meeting. I acknowledge and praise their campaign. As you mentioned, others have been campaigning for many years. I am delighted to be considering the issue in the Health Committee now. That is great progress.

The consultation was finalised in February. When will its findings be published?

Mr Wilson: Very soon, Chair. Apologies on our behalf: that work needs to be cleared for publication through the Department. We have given a summary in the briefing paper about the high-level outcome from the consultation. It was a well-supported public consultation. We had almost 2,000 responses from a really wide range of members of the public. Over 100 healthcare professionals responded, and there were 15 responses from health professional groups or organisations.

The Chairperson (Mr Gildernew): I have been through the highlights, and that is a welcome indication, but, especially given the high public interest and public interaction, it is hugely important that it be published. When you say "very soon", are we talking about before the end of this month?

Mr Wilson: I hope so, yes.

Mrs Cameron: Thank you, Ryan and team, for your presence at the Committee to brief us on the Bill. It is a very sensitive and often contested issue. I welcome the fact that we are talking about it this morning, and, as the Chair said, in 2020, meeting Dáithí Mac Gabhann was one of the first things that we did together as Chair and Deputy Chair. It is good to see us getting to a stage at which we are looking at this issue. I also welcome the fact that the First Minister gave approval for the Bill to proceed by way of urgent procedure to the Assembly after the Donate4Dáithí campaign gained traction.

I also put on record the work on the issue that Jo-Anne Dobson, a former MLA, did on the Health Committee in the past. At that stage, we probably were not there when it came to awareness. A lot of good work has been done since then, and that is also very welcome. Awareness of the subject is probably the most important part, in that we must make sure that people are fully aware of the consequences, of what the issues are and of what the opportunities arising from organ donation are.

Can you outline briefly how the soft opt-out system has impacted on rates of consent for organ donation in other jurisdictions? Can you tell us about the proposed exemptions and how they compare with provision in other regions? One concern is the definition of "friend of long standing". How will that be agreed? If you can tell us a wee bit more about that, that would be great.

Mr Wilson: I will take those points in order. First, the awareness around the provisions of the Bill and the proposed changes is a big part of our planning, and that is under way. The aim will be to make sure that the message goes out across multiple channels to multiple audiences and that we try to reach every member of the population here to make them aware of what the changes are and what their options are. As I said, that will be a continuous responsibility and will be put into the annual programme every year. There are already good levels of awareness and support for organ donation, but it will be really important to get across the message about individual choices.

We have been working with NHS Blood and Transplant, which is the organisation that coordinates and oversees donation and transplantation across the UK. That body has overseen this in the other regions, and it brings a lot of experience, including a lot of insight into public knowledge and public behaviour and into where those communications can really be effective. We are factoring that into our plans. You asked about rates of consent. There are many countries around the world with deemed consent, but they have different health systems and histories. In drawing comparisons, we therefore try to look at nations that are culturally similar. Wales gives us the best example, because of the maturity of deemed consent, as it came into effect there in 2015. Wales is now almost six years in. It has seen a steady increase, to the point at which the consent rate is now at over 70%. That has gone hand in hand with ongoing public information campaigns. It has been acknowledged that it takes time to build that cultural change slowly and steadily.

As I said, we have included some of the figures from the most recent full year, but I would take those with a pinch of salt, given the impact of COVID across the whole system. There has been good consent in Northern Ireland, but we need to look at the history of donation and consent rates in order to see that they have been fairly static at around two thirds — 64% — for a number of years.

The Chairperson (Mr Gildernew): Sorry, Ryan, for interrupting. Given the time constraints on the meeting, may I suggest that, if there is more detailed information, it may be easier for you to forward that to us in writing?

I ask members and the panel to be as brief as possible today. Thank you.

Sorry, Ryan. Go ahead.

Mr Wilson: I will try to be brief. On the proposed exemptions, the provisions of the Bill are more or less identical to the systems that are in place in Wales, England and Scotland. We have borrowed quite a lot from the English legislation, which is short and sweet. You will see from the text of the Bill that it really just makes changes to the underlying human tissue legislation.

The exemptions for people under the age of 18, people who are not ordinarily resident and people who lack mental capacity are the same and would operate in the same way. The changes to the human tissue codes of practice will be written into the Northern Ireland codes in a similar way, so there will be consistency in how those are applied.

On your question about "friend of long standing", the Human Tissue Act contains a long-standing hierarchy of qualifying relationships, and that allows clinicians and specialist nurses to look at whom the deceased person knows, is close to or is likely to have confided in on these decisions. It is acknowledged that that is not always the nuclear family, and that is why there is a hierarchy. Quite often, "friend of long standing" can be fairly loosely applied. It is a question within that specialist conversation with families, where the specialist nurses are qualified to establish whether those relationships and decisions are well known and can be relied on in order for the decision to go ahead. If there is any doubt around that, there will not be any donation of organs.

Hopefully, that covers those points. Yes, I am happy to send more detail in writing if that would be helpful.

The Chairperson (Mr Gildernew): Thank you. We have a maximum of 10 minutes. Members can, I am sure, forward to the Committee Clerk any questions that might arise for a written response, should that be the case.

Ms Hunter: Thank you, Ian and Ryan, for being here this morning. In the interest of time, I have just one question, and it is around educating the under-18s. Is there more that we could do, or is the Department of Health liaising with the Department of Education on promoting the idea of donation in schools? I would hate to think that there is a missed opportunity to talk about consent and donation there. An update on that would be helpful.

Mr Wilson: That is perhaps one that we could write to you about, because there is a lot going on in that space. I refer to the programme of communications, which is now well developed and runs effectively all year. A big part of that is looking at different age groups in which cultural change can be effectively embedded.

We have had a regional coordinator/manager of organ donation campaigns in place for over a year. That role is based in the Public Health Agency and has made a huge difference. Good work has always been done around Northern Ireland, but it has never been done in a regionally coordinated way. That is now happening.

There has been good engagement with the Department of Education, and some leaders from various schools across the region have stepped up, taken the reins and developed really good materials for different age groups that teachers can freely download. It will take an effort to spread that across the region, but that work is well under way. If we get a chance to come back to the Committee during the Bill's formal Committee Stage, we can perhaps spend a bit more time going into the detail of the work that is already under way. As I said, the information on the provisions of the Bill will be embedded in those programmes.

Ms Hunter: Thank you.

Mr Carroll: Chair, I echo your comments about wee Dáithí and the campaigners. I want to put that on record.

I have two questions. You mentioned that people whose identity is unknown will be exempt from the opt-in. Will you expand on that? Are they undocumented people, refugees or asylum seekers? Who are they?

The increase in organ donation is very welcome and important. Is the main opposition to it from people with strong religious views? Can that increase be increased further? Is there any modelling being done on dispelling myths and encouraging more and more people to come forward? That 20% jump was and is significant. If we could increase that further, it would be even better.

Mr Wilson: Thank you. Sorry, Gerry, but can you remind me what your specific point was about the exemptions from opt-in?

Mr Carroll: Yes. Your phrase was "people whose identity is unknown". I want to know what that means.

Mr Wilson: OK. Donation of organs will not proceed in such cases. There are rare occasions on which people can present as such, generally in intensive care. Hospitals will make every effort to identify a

person. We covered that question in an engagement session yesterday. If necessary, hospitals will phone the police and try their best to get a relative or someone who knows the deceased person. That is just a standard part of the pathway in an organ donation conversation. If there is nobody there to verify the identity of a person, donation simply cannot proceed. There will be no change to that under this legislation. That is why it is specified as an exemption.

You asked whether the main opposition is on religious grounds. We have not received anything that you would call opposition to the Bill. There is interest in it, and religious and faith groups are interested to know what it means, but they will probably want to respond to the Committee's evidence call and have the chance to discuss the matter in more detail with you. We have not received anything by way of opposition to the provisions, however. Generally, faith or community groups are supportive of anything that might improve consent rates.

Dispelling the myths about organ donation is already a key part of all the messaging. It is threaded through every channel of communication. There is generally a good level of support among the public for organ donation, and that has been helped by the campaigns. Beneath the surface, however, there are varying levels of understanding about the actual process. As I said at the start, there is a very small pool of people for whom organ donation may be a possibility. There can be myths, and we already try to provide clarity in our communications. Education is a big part of it. As I said, that will continue regardless as part of those communications. We will continue to address those questions as they arise.

Mr Carroll: Thanks.

Ms Bradshaw: I want to get total clarity on the deemed consent model for under-18s. I am thinking more about pre-teens, who would not really understand the information in front of them. What is the situation with children?

Mr Wilson: What we are getting at is whether the current system will change. Any under-18 can become a donor currently. If somebody were to pass away at that age, the family would take the decision in those unfortunate circumstances. That having been said, there are very good levels of understanding. We know through the children and young persons' behaviour and attitudes surveys that organ donation is understood at a decent level. The reason that they would be exempt from the provisions of deemed consent is that — this is similar to the systems that are in place across the UK — people in that age group can still become organ donors, but the fact is that it will remain a decision for their family. I hope that that clarifies it for you.

Ms Bradshaw: OK. This may have been touched on, but my second question is about the LGBT community. For example, we know that, for patients in palliative care, some families — hopefully, this is rapidly changing — are not aware that they are in a same-sex couple. The partner, as the person closest to them, would probably be able to provide an insight into their final wishes. What you are doing to make provision for circumstances in which those conversations need to happen but the relationship is not known about?

Mr Wilson: To clarify, are you asking about the hierarchy of those relationships and who would have a say?

Ms Bradshaw: Yes, certainly, but I am also asking how things could be better facilitated and how the communication could be improved so that clinicians, for example, who will be having possibly sensitive conversations going forward, are provided with guidance and support to navigate such situations in what is a highly sensitive grieving period?

Mr Wilson: I can probably answer that in general terms, but the better opportunity might come when the Committee moves to the formal scrutiny stage. You will want to hear from the specialist nurses who have those conversations and from the clinicians in intensive care. They are the ones with the experience of the range of difficult and sensitive conversations with families, other relatives and other loved ones. They can give you a more detailed answer based on their experience. The codes of practice are the underlying guidance that helps professionals in those scenarios. We take your point about the need for communication with specific groups and about factoring them into the plans for public awareness.

Ms Bradshaw: Thank you.

The Chairperson (Mr Gildernew): Thank you, Ryan and Ian, for your presentation this morning and for the commitment given to send on further information about some of the questions asked and about the publication of the consultation. Thank you for that. We wish you both all the best in the time ahead.