

Organ & Tissue (Deemed Consent) Bill

***Summary Report Following
Consultation and Engagement
with the Public***

September 2021

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1. Introduction

PCC invited members of the public to give their views on the Organ and Tissue (Deemed Consent) Bill which will change the current system in Northern Ireland, in which people can choose to 'opt in' or 'opt out' on the NHS Organ Donor Register (ODR), to a new statutory opt-out system.

We did so in two ways – via an online survey and with a focus group hosted by the Department of Health and attended by members of the public, , and representatives of groups with an interest in the subject. Members of the NI Assembly Committee for Health also attended, including Health Committee Chair Colm Gildernew, Pam Cameron, Jonathan Buckley, Gerry Carroll, Cara Hunter and Alan Chambers.

The findings from both cohorts are reported on separately, with a conclusion, which serves as our response to the consultation, unifying both sets of findings.

2. Survey Cohort

Twenty- four members of the public responded to a survey set up by the PCC.

The survey questions were adapted from the changes and amendments to the Human Tissue Act 2004 and the Health (Miscellaneous Provisions) Act (Northern Ireland) 2016, with the Organ and Tissue (Deemed Consent) Bill. It was set up by PCC staff and accessible through Survey Monkey. The survey was open to all members of the public. The survey was open from 12th August 2021 to 16th September 2021.

The project was promoted through the PCC's social media and through the PCC's Involvement team and Membership Scheme through emails and postal newsletters.

A full survey can be found in [Appendix 1](#).

2.1 Analysis and reporting

The data was analysed by a member of the Patient and Client Council's (PCC) research team. Quantitative analysis of the categorical response data was conducted, with qualitative analysis of the free text responses. The free-text responses were categorised into appropriate themes. These themes were developed into a coding frame for each free text question in MS Excel, which allowed each response to be assigned one or more codes or themes during the full analysis. Codes were then counted and analysed to identify common themes, views and experiences within responses. Where responses did not fit the identified themes, the Research team agreed to add themes (or modify) where necessary.

2.2 Findings

In total there were 24 respondents to the survey. Respondents were asked if they agreed with the change to the 2004 that consent to organ and tissue donation in NI will be deemed to have been given by a potential adult organ donor before their death unless they had expressly stated that they did not wish to be an organ donor or an exception applies. The majority, 79.2% (n=19/24) agreed with this, whilst 20.8% (n=5/24) said they disagreed.

4 out of 5 people agree with the changes to the Organ and Tissue (Deemed Consent) Bill.

When asked to explain their answer most respondents (n=12/20) felt this would increase donations and be more effective than having to opt in to donate, they felt that although many would like to donate, they do not sign up to do so. Some (n=3/24) mentioned that this would be a hard decision for those grieving to make a choice about donating on behalf their loved ones and they might be too distraught to make a decision at the time. A few (n=2/20) people said that there should be sufficient information given to people on how to opt out, and the same number said that consent should still be sought before a donation.

- *"I would like to donate but haven't completed the paper work."*
- *"So many people are dying while waiting for organs and it is a very difficult decision for grieving families to make. Some families also find it difficult to discuss things around death. I feel that most people would be happy to save lives but just don't get round to making the decision."*
- *"We know that many agree with organ donation and "intend to sign up" but don't get to it. This may help include some of those. The process, and accompanying education campaign, will raise the profile of organ donation and allow the topic to be discussed more widely."*
- *"Often when relatives are distressed in this situation they are too emotional to make a rational decision at very short notice and this take[s] the decision making out of their hands."*
- *"I do not believe that the state or any part of it should have automatic access to organs without explicit prior consent."*
- *"I think it should remain an opt-in system, which is much clearer in regard to consent. This gives health care professionals too much power, and it will be statutory and legal power over individuals and families in distress/trauma/grief"*

2 out of 3 people felt that where a close relative or friend evidenced the deceased would not have consented to be an organ donor, that this should prevent organ donation in this instance.

Respondents were also asked if they agreed that deemed consent should not apply where a person in a qualifying relationship to the deceased (partners,

certain family members or a friend of long standing) provides information to conclude that the deceased potential organ donor would not have consented to be an organ donor. 66.7% (n=16/24) of respondents agreed and 33.3% (n=16/24) of respondents disagreed with this point.

The respondents were asked to explain their answer, some (n=4/21) said that should be donor choice whilst they are alive and not up to those in a qualifying relationship to decide after they die. Others (n=3/21) expressed concern that this was a difficult decision for those in a qualifying relationship to make whilst they are grieving. A few (n=2/21) said that asking people to make this decision could cause divisions in families with opposing views.

- *“The State, or any other agency, must never be allowed to remove and use an organ from a person, alive or dead, without due consent.”*
- *“I don't think families are always in the right frame of mind after a death especially if it is sudden.”*
- *“I agree it gives those with strong beliefs who may not have registered their wishes a voice. However, it may cause dispute within families- especially of some have views that are divergent and are held personally by them and not the deceased. Needs to be carefully implemented”*

In the survey respondents were asked if they agreed that there should be exceptions to some groups of adults. These include people who are short-term visitors or are temporarily resident in Northern Ireland for less than 12 months immediately before dying e.g. overseas workers, students, overseas Armed Forces personnel; and people who lacked the capability to fully understand the consequences of deemed consent for a significant period before dying. In total, 83.3% (n=20/24) of respondents agreed and 16.7% (n=4/24) of respondents disagreed.

4 out of 5 people noted that the exceptions to deemed consent, as outlined in the bill, should be observed.

When asked to explain their answer many (n=7/24) respondents said that this would help to protect vulnerable people and those who cannot consent. A few (n=2/24) said that some people may not want to donate due to cultural reasons.

- *“What about people who lose capacity due to conditions such as brain injury, early onset dementia ... but who have the opportunity to opt out before losing capacity and don't make use of it? Would it not be reasonable to assume that they have no particular objection to organ donation?”*
- *“It would be inappropriate and insensitive to attempt to apply deemed consent to people who are lacking in capability to understand the consequences or who would not have had opportunity to fully understand and agree to the*

provisions, especially if they are from places of origin where similar consent is not deemed.”

When asked if they agreed that the Department’s existing statutory duty to report to the Assembly at least once every five years, the opinion of the Department of Health as to whether both the 2016 Act and the new Organ and Tissue Donation (Deemed Consent) Act, have been effective in promoting transplantation should be extended, 76.5% (n=13/17) said that they agreed, with 23.5% (n=4/17) saying that they disagreed.

8 out of 10 people said the Act should be reviewed every five years.

Respondents were asked to explain their answer. Most (n=8/17) said that it was good to review the Acts to see how effective they have been and keep the issue on the Assembly’s agenda whilst also raising awareness.

- *“Reporting, as well as good accountability keeps the issue present in Assembly business and provides opportunity to reconsider more effective means of education and implementation where necessary and opportune.”*
- *“The Department should continue to report on the effectiveness of both the 2016 Act and the new Act, so that there is evidence available to assess the impact of the change in law.”*

Finally, respondents were asked if they agreed with the change that there was a responsibility for the Department of Health to inform the public at least once a year specifically about deemed consent and how a person can during their lifetime record their own decisions about transplantation after their death of parts of their body, or appoint someone to make decisions after their death about transplantation of parts of their body. Of those who responded, 84.2% (n=16/19) said that they agreed and 15.8% (n=3/19) said that they disagreed.

4 out of 5 people noted that the exceptions to deemed consent, as outlined in the bill, should be observed.

When asked to elaborate on their answer, respondents said that it would act as a reminder to opt out (n=5/12) of those who disagreed. Some said (n=3/12) there needed to be education about process namely what the changes to the laws are and how to opt out if a person desired.

- *“Useful to remind people to make the decision and tell their families about it.”*
- *“It seems reasonable to provide public information about deemed consent, so that people wishing to opt out have every opportunity to do so.”*
- *“It really needs to be very clear how to opt out. So far how to go about opting out is unclear”*

3. Focus Group

PCC staff facilitated discussion and took notes at an Organ & Tissue Donor Bill Consultation event hosted by the Department of Health on 15th September 2021. The event was attended by members of the NI Assembly Committee for Health, members of the public and representatives of groups with an interest in the subject.

Four questions were asked. These were:

- What are your thoughts on the opt-out (deemed consent) system – do you think it will result in an increase in organ donations? If not, what other considerations should be implemented?
- What are your views on who should be exempt from the deemed consent system?
- How should health professionals approach the issue of consent with families?
- How can the Department for Health promote organ donation in Northern Ireland?

In response to the first question many participants said that they had received a transplant. This may account for a positive bias towards the Bill in many of the responses. They shared their experiences of waiting for an organ and the mental and physical impact of waiting for a donor as well as the often long wait for a donor.

Participants hoped the changes would mean that there were more organs for transplant accessible and consequently a better quality of organs and more matches available. One participant stated that they would likely need another transplant in their life but if the Bill passed *“hopefully this means we won't have to wait 5 years”* for an donor to be available.

One participant noted that there also needed to be the infrastructure to aid the potential increased organ and tissue donations. They said that this funding for this needed to go into the Bill too. Another participant noted that financially dialysis was more expensive and that in long term a transplant is more cost effective, therefore this could save money within Health and Social Care.

A participant said that they welcomed the Bill as it meant there would now be one system in the whole of the UK. Participants noted that if the Bill passed there must still be education and awareness around donations and stated that *“supply does not [necessarily] meet demand”*. There was also discussion around the need for more information and education on becoming a living donor. They emphasised the need to change people's mind-sets to make donation the norm not the exception.

Some spoke about concerns around misinformation and fear about deemed consent, namely that ultimately up to the family to decide. Therefore discussions and education must occur to tackle misinformation and alleviate people's fears. There was also discussion about people's fears about having a conversation about death

being a donor and that some people were superstitious about carrying an organ donor card as they felt that it “*may tempt fate*”.

In response to the second question participants felt that the list of those exempt was comprehensive. A few participants had questions about who should be exempt from the deemed consent system. One participant asked if those under the age of 18 could give consent. It was explained that the Bill currently excludes under 18s from having consent deemed, but that those aged 12 years old and above could give their consent to donate or refuse to donate.

It was also asked if prisoners were exempt. It was explained that they are exempt from deemed consent if they die in prison as they are not free, however their families can consent to donation.

On the third question, around how health professionals should approach the issue of consent with families, participants agreed that staff needed to be trained to have these discussions with loved ones. They also emphasised the importance of having family involved in the discussion. They also noted that families needed to be educated and aware of their loved ones wishes when it came deemed consent knowing it was their deceased ones choice. One participant said that medical staff will need trained but also there needs to be time given to make sure families aware that they could be asked this question and that they should ask each other what their wishes are in regards to deemed consent.

Participants asked how the process worked in the rest of the UK. They were told that medical staff will check the organ donor register. If the person is on it they will inform their loved ones that, that was this was their wish. If they are not on the register, they will tell their loved ones that they had not raised an objection or opted out, therefore that constitutes a willing donor, unless their loved ones say this was not the persons wish.

Finally, participants were asked how the Department of Health could promote organ donation in NI. Many said that there needed to be a sustained advertising campaign, both in the first year of the Act and beyond to keep awareness amongst the public. Participants said that this should be an ongoing campaign there will always be a need for new donors. It was also mentioned that this campaign must be well funded.

Participants said that the Department of Health needed to use a variety of media to reach the biggest audience possible, both print and digital media. Some participants spoke about a campaign the Western Trust ran a campaign over Valentine’s Day to promote registering for an organ donor card. They also said that awareness could be raised in public spaces like schools, church groups, Men’s Sheds and other community groups to promote a conversation around letting your loved ones know your wishes about deemed consent. It was also stated that the information must be accessible and easy to understand and that the public needed to understand why the

laws are changing. Again it was emphasised that medical staff needed to be educated and trained to have these discussions with families.

Again, the participants mentioned that the promotion and campaigns must emphasise the importance of letting your views be known to loved ones. They also said that there was the opportunity to change the messaging from “*why should I be a donor?*” to “*why should I not be a donor?*” The majority of the participants agreed that personal stories were most effective way to promote and encourage people to be on a register or give consent.

It was mentioned that in the rest of the UK surveys were used to evaluate how well people were informed about deemed consent.

4. Conclusion

It is the view of PCC, being informed by public discourse, that the changes to the Organ and Tissue (Deemed Consent) Bill should proceed. This will increase donations, reduce wait times for organ donations, standardise the organ donation system across the whole of the UK, and be more effective than having to opt in to donate, but, sufficient information must be given to people on how to opt out. Information must be accessible and easy to understand and that the public needed to understand why the laws are changing. Consent should still be sought before a donation, and there should be exceptions to some groups of adults in order to help to protect vulnerable people and those who cannot consent or will not consent for cultural reasons.

This new Bill will need funding for a sustained advertising campaign and to train medical staff in broaching this subject with loved ones of a deceased family member.

“Whether the opt in or opt out system is implemented, the essential part of the system is the understanding and consent of all involved, and especially the understanding and ability of family members to confirm their loved ones wishes in the few circumstances where transplant becomes an option ... continued education will be vital.”

Appendix 1 – Survey

Organ and Tissue Donation (Deemed Consent) Bill Survey

The Organ and Tissue (Deemed Consent) Bill was introduced by the Minister of Health on 5 July 2021. The purpose of the Bill is to increase the current rate of consent for organ donation to proceed after a person's death, by changing the current system in Northern Ireland, in which people can choose to 'opt in' or 'opt out' on the NHS Organ Donor Register (ODR), to a new statutory opt-out system.

Under this system consent is deemed or presumed except in certain exempt circumstances, or if a person has made a decision to opt out during their lifetime. This is often referred to as "deemed consent".

Under the current rules in Northern Ireland, a person is considered a possible organ donor following their death if they actively took steps to consent in their lifetime or in the absence of a decision made in life, the family can consent on the patient's behalf.

Whilst a change in the law will not increase the number of cases in which it is clinically possible for organ donation to proceed after a person's death, it has the potential to increase the consent rate in situations where a potential organ donor has been identified. This is generally a person for whom further intensive care has no prospect of bringing about recovery.

Click here to read the [Bill](#) in full.

Click here to read the [Explanatory and Financial Memorandum](#).

The Bill amends the 2004 Act to provide that consent to organ and tissue donation in NI will be deemed to have been given by a potential adult organ donor **before** their death unless they had expressly stated that they did not wish to be an organ donor or an exception applies.

This is often referred to as an “opt-out” system of consent as a person will be deemed to have given consent to becoming an organ donor unless they have otherwise stated.

Do you agree with this change?

- Yes
- No

Please explain your answer:

The Bill states that deemed consent will not apply where a person in a qualifying relationship to the deceased (partners, certain family members or a friend of long standing) provides information to conclude that the deceased potential organ donor would not have consented to be an organ donor.

This has been referred to as a “soft opt-out” system.

Do you agree with this point?

- Yes
- No

Please explain your answer

The Bill provides exceptions to some groups of adults. Deemed consent provisions will not apply to:

- people who were short-term visitors or temporarily resident in Northern Ireland for less than 12 months immediately before dying. E.g. overseas workers, students, overseas Armed Forces personnel; and
- people who lacked the capability to fully understand the consequences of deemed consent for a significant period before dying.

Do you agree with these exemptions?

- Yes

- No

Please explain your answer

The Department's existing statutory duty to report to the Assembly to include, at least once every five years, the opinion of the Department of Health as to whether both the 2016 Act and the new Organ and Tissue Donation (Deemed Consent) Act, have been effective in promoting transplantation will be extended.

Do you agree with this extension?

- Yes
- No

Please explain your answer

The Bill includes a responsibility for the Department of Health to inform the public at least once a year specifically about deemed consent and how a person can during their lifetime record their own decisions about transplantation after their death of parts of their body, or appoint someone to make decisions after their death about transplantation of parts of their body.

Do you agree with this change?

- Yes
- No

Please explain your answer