

Response ID ANON-MRF5-XGN8-Y

Submitted to **Public Consultation on the introduction of a statutory opt-out system for organ donation for Northern Ireland**
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About You

I am responding...

On behalf of an organisation

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Your Organ Donation Decision

Q1 Would you be willing to donate your organs and / or tissue after your death [under the current legal system of consent in Northern Ireland]?

Not Answered

Q2 Have you already recorded your donation decision, e.g. by joining the NHS Organ Donor Register or otherwise?

Not Answered

Q3 If you answered 'yes' to the above, have you shared your decision with your loved ones? Please tick all that apply

Other- :

4 Would a move to a statutory opt-out system change your decision regarding organ donation?

Not Answered

Exemptions to Opt-out legislation

Q5 To what extent do you agree that opt-out legislation should NOT apply to children (those under 18 years) and that the donation decision should be made by those with parental responsibility? Rate your agreement with this statement.

Strongly disagree

Q6 Do you think that any of the following people should be exempt from deemed consent for organ donation and the family should provide that consent? (please tick all those that apply)

Adults who lack capacity, Visitors, including cross-border workers from ROI & tourists to Northern Ireland, People who are temporarily resident in Northern Ireland (e.g. students from overseas or ROI, overseas Armed Forces personnel), people on work placements from overseas or ROI, Prisoners, People whose identity is unknown

Other-:

The Role of the Family and Loved Ones

Q7 To what extent do you agree that, in situations where there is a known decision to donate recorded on the NHS Organ Donor Register, the family should always be asked about the last known organ donation decision of their loved one, to ensure it's still accurate?

Strongly disagree

Q8 To what extent do you agree that, in situations where there is no known organ donation decision, the family should always be asked about whether their loved one would have objected to organ donation?

Strongly Agree

Q9 Which of the following statements best summarises how the introduction of opt-out legislation would influence your support for donation of a loved one's organs and/ or tissues?

Not Answered

Novel and Rare Transplants

Q10 To what extent do you agree that organs and tissues that could be used for rare or novel types of transplantation (e.g. limb or face) should be excluded from opt-out legislation?

Strongly Agree

Research

Q11 To what extent do you agree that the donation of organs and tissues for research purposes should be excluded from statutory opt-out and the family approached for express consent?

Strongly Agree

Faith and Beliefs

Q12 To what extent do you agree that people's faith or beliefs should continue to be taken into consideration as part of the donation discussion after any move to an opt-out system?

Strongly Agree

Raising Awareness of the Change in Legislation

Q13 What do you think is the most important and effective activity for raising awareness of the law change? (please select no more than 3)

TV, radio, Social media adverts, Local councils

Other:-

Q14 If you have any other comments or views you would like to express in relation to the proposed opt-out legislation, please comment below.

Please comment below :

The Royal College of Surgeons (England) in Northern Ireland welcomes the opportunity to respond to the Department of Health's consultation on introducing 'opt-out' consent for organ and tissue donation in NI.

RCS (Eng) has a policy position on organ donation

(<https://www.rcseng.ac.uk/about-the-rs/government-relations-and-consultation/position-statements-and-reports/public-policy/>). We support the "soft opt-out" provisions that specify families are approached for consent and given the right to refuse organ donation if they strongly object. This will preserve the role family members and healthcare professionals play in consent for organ donation.

As a top-line summary we support the proposed opt-out system provided it is accompanied by investment in the infrastructure supporting organ donation and transplantation services, as well as delivery of a public awareness campaign and hope it will lead to an increase in donation and transplantation rates.

However, as demonstrated by the evidence in Spain, we also believe it is vital for the Government to increase investment in the resources and infrastructure supporting organ donation and transplantation services. This should include better training for healthcare professionals to approach potential donor families and an increase in the numbers of specialist nurses and transplant coordinators.

In addition, we urge the Government to instigate a properly funded public awareness campaign on organ donation during the year of "transition" to the new law to help people understand the changes and discuss with friends and family.

We note and support exceptions for children under 18 years old, people who lack the mental capacity, visitors to NI and temporary residents.

Organ transplantation remains one of the most important advances in modern medicine, enabling the treatment of patients who have failed, damaged or missing organs. We are aware that in Northern Ireland in 2019/20, the consent rate for donation to proceed after death in Northern Ireland was 64%. The current UK-wide strategy (2013-2020) sets a target consent rate of 80%.

Organ and Tissue donation saves and improves many lives each year and one donor has the potential to save nine lives. Last year in Northern Ireland, there were 51 deceased donors, resulting in 113 transplants throughout the UK. In total, 87 Northern Ireland residents received transplants.

We note that this consultation, and the proposed changes in the law, do not relate to living organ donation (kidneys, part of the liver, and tissue) and relate only to the system of consent for organ donation to proceed after a person has died. Northern Ireland has a world-class living donor kidney transplantation programme, which will not be impacted by the proposals outlined in this consultation.

We are aware of DOH statistics, referenced in the consultation notes that show 11 people died last year in Northern Ireland waiting on an organ transplant, and the 115 people who are currently on a transplant waiting list. The Health Minister in this same document also states that:

“Almost a million people (48%) in Northern Ireland have joined the NHS Organ Donor Register. Many more (over 80%) have said that they would consider donating an organ. However, when faced with the decision, we know that around a third of families will decide not to proceed with donation.”

We recognise that if implemented these changes will take some time to implement. We support the Minister's view that it is more important than ever that we plan for the future healthcare needs of all our citizens.

RCS (Eng) has a policy position on organ donation (see link above). In that document we highlight the case in Wales, where since the introduction of the opt-out system in 2015, there has been an increase in both consent rate and donation rate. The consent rate increased from 58% in 2015 to 70.7% in 2020. The impact was not immediate and took several years to take effect, and was accompanied by an extensive media promotion and information campaign (<https://associationofanaesthetists-publications.onlinelibrary.wiley.com/doi/full/10.1111/anae.15055>).

In England, a new opt-out system came into effect from 20 May 2020, however it is too soon to analyse any impact on consent rates. Scotland's opt-out system will come into effect from 26 March 2021.

A number of other countries in Europe have adopted opt-out systems for organ donation including Croatia, Netherlands and Portugal. Spain introduced its system in 1979 and has the highest donor rates in Europe, with 40 donors per million people compared to just under 20 in the UK. However, donor rates only began to increase 10 years after the law was introduced. Much of Spain's success is credited to the establishment of a new national transplant organisation to coordinate the donation and transplantation process, including the appointment of transplant coordinators who instigate conversations with the family of potential donors.

We do feel that people should have more ways to record a decision about organ and tissue donation than just the Organ Donor Register (ODR).

We strongly support the proposal for there to be as many ways as possible to record a decision about organ and tissue donation, including through routes such as registering with a GP, dental surgery or optician. It would be useful for these changes to be made whether or not the opt-out system of consent is introduced. Increasing public awareness of the ODR should help to increase the numbers of donors and knowledge of a person's decision. This in turn would build confidence in the system and support healthcare professionals when they approach families for consent to proceed with a donation.

We support the opportunity for people to include certain information about their decision to donate on ODR. For example, some people may prefer to specify which organs they would like to donate.

We support the British Transplant Society's 2017 analysis (https://bts.org.uk/wp-content/uploads/2017/03/170308_BTS_-Response.pdf) that “assessments of the effects of opt-out laws on donation rates are hampered by differences in cultural attitudes, economic conditions, availability of intensive care units, numbers of transplant co-ordinators, degree of governmental support and other factors, whose influence may be important but uncharted”.

As stated above, we would not wish the introduction of an opt-out system to have a negative effect on the relationship and feeling of trust between healthcare professionals and potential donor families, particularly if they object to donation. It is clear from best practice cases where organ donation has been achieved that this relationship is key to facilitating the process. Therefore we believe it is vital for the NI Government to increase investment in the resources and infrastructure supporting organ donation and transplantation services. This should include better training for healthcare professionals to approach potential donor families and an increase in the numbers of specialist nurses and transplant coordinators.

We also recommend the NI Government undertakes a public awareness campaign to highlight the need for more organ donors, whether or not the opt-out system of consent is introduced. In particular, we hope that increasing public awareness on organ donation will lead to an increase in donors who often refuse consent due to faith and cultural concerns.

Equality Screening, Disability Duties, Human Rights Assessment and Rural Screening

Q15 If you have comments or views you would like to express in relation to the Equality Screening, Disability Duties and Human Rights Assessment Template or Rural Screening Document that accompany this consultation document and can be found at <https://www.health-ni.gov.uk/consultations/organ-donation>, please comment below.

Comments :