Introduction of a statutory opt-out system for organ donation for Northern Ireland

Consultation Response

ON BEHALF OF THE CHURCH OF IRELAND CHURCH AND SOCIETY COMMISSION

11/02/2021

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Organ Donation Consultation
Department of Health
Room 1 Annexe 1
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To whom it may concern,

The Church and Society Commission (CASC) of the Church of Ireland has prepared the following response to the public organ donation consultation.

CASC is an advisory group, serving the Standing Committee of the General Synod, and engages with legislatures and governments on a variety of issues, including legislation. The mission of CASC is to provide oversight and direction for the Church of Ireland's work, in respect to social theology in action. CASC's views only become representative of the Church of Ireland after being approved by its General Synod.

Yours Sincerely,

Stuart Wilson
Graduate Intern,
Representative Church Body
On behalf of the Church and Society Commission,
Church of Ireland

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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]?

N/A

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

N/A

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

N/A

Q4. Would a move to a statutory opt-out system change your decision regarding organ donation?

N/A

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.

CASC feels that the answer to this is dependent on the age of the individual, as those over 16 deemed capable of making informed decisions can themselves consent to medical procedures.

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?

- **Adults who lack capacity**
- **Visitors, including cross-border workers from ROI & tourists to Northern Ireland**
- **People who are only 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**

CASC would agree that all the above should be exempt from deemed consent for organ donation.

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?

CASC would strongly agree.

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?

CASC would strongly agree.

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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?

N/A

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?

CASC would agree.

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?

CASC would neither agree or disagree, provided people were fully aware of the implication of changes.

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?

CASC strongly agrees that faith should continue to be taken into consideration.

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)

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.

See overleaf for CASC comment.

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Organ Donation and Consent

Introduction

The Church and Society Commission of the Church of Ireland is fully supportive of the ethos that giving is an essential part of being a Christian, whether that be of financial aid, of time or of the person. Donation of organs of one's body to others is a supreme example of this both after death, and even more so as a living donor. It is part of this giving, that it should be voluntary. There does not appear to be a theological argument against the change in practice from an opt-in to an opt-out one. However, we are sensitive to those whose religions hold different views, such as the body being as complete as possible for burial, the discomfort that there is over the transplantation of cadaver organs, and the reaction of many, including, Christians to the removal of body parts.

In its 2008 report to the General Synod, the Commission's predecessor – the Church in Society Committee – stated: "Organ donation is to be seen as an entirely consistent Christian act; both of caring for those less well off, and responding to Our Lord's example of, and instruction to, heal and show compassion."

The 2014 General Synod endorsed the **flesh**and**blood** campaign (FAB) which aims to raise the profile of blood and organ donation within the Church, in the UK and Ireland, and encourage such donation as a personal gift as well as equipping individuals and churches as advocates for donation. The Church of Ireland became an associate of the campaign.

For many years there has been public and political debate, not only on the issue of organ donation itself but especially the issue of consent, to which the Assembly has previously issued a Consultation Document (2013). These debates have been very much predicated on the shortage of donor organs, that has partly arisen from the reduction in potential organs from victims of road traffic accidents, which is much to be welcomed, and the demographic changes of the population with an increase in aging.

There also remains a significant mismatch between (a) the number of people who say that they would wish to be donors but who are not on the register, and (b) the number of people who are on the register and would be suitable as donors but whose wish is ultimately declined by family.

In part to address these issues we note that the Assembly is again proposing a Soft Opt-out Consent for organ transplantation. The possibility of this change has been discussed by CASC over the years and the results of these deliberations have been presented and adopted by the Church at its General synod. During these years and continuing until today our decision has been not to recommend a change, even though that may appear to be counter intuitive.

What is the Evidence to support an Opt-Out Consent?

We would suggest considering the evidence from Spain, which is held up as an exemplar of a good response, and within the UK the early results from Wales.

Spain introduced a presumed consent for organ transplantation in 1979, but due to various issues over those wishing not to become donors, a royal decree stated that opposition to organ donation could be expressed in any way, and this became interpreted in Spanish law as "ask the family", as

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most likely to know. In practice therefore the Spanish system is essentially an "opt in" with family's wishes final. Spain does not have an opt-in register or a means of recording opt-out.

During the following 10 years there was no significant change in the rate of consent to organ transplantation. In 1989 Spain introduced a comprehensive organ donation system, the main feature of which was the training and placement of transplant coordinators in the major procurement hospitals, but with an oversight of the situation in smaller hospitals. These coordinators were drawn from intensive care physicians, who had nothing to do with the transplant team. They are required to make a daily assessment of potential donors, both within and outside intensive care. National training is an essential component and is regularly updated.

In a review in 2010 Spain had a donation rate of 34-35 per million population, the UK was approximately 15 per million, whereas in 1989 both had similar rates of about 14 per million, and similar refusal rates of about 30-40%, but in Spain this latter figure had fallen to 15% in 2010, but the UK was unchanged (Fabre et al,2010)

The other important item was to recognise the importance of the family, who ultimately make the decision. There will be many factors affecting that decision, from trust in the medical profession, the process of donation itself and the professionalism of the approach, apart from knowledge of the desires of the potential donor. Trust is probably the major item. Will consideration of a person as a potential donor affect their management? The family see a person who is not dead in a conventional sense but is breathing, on a ventilator, and is a good colour and warm. Will there be under treatment?

The Spanish experience does not support a change in the mode of consent but really stresses the need for family discussions as to the feelings of individual members long before the situation ever arises, and the nature of the whole approach and discussion with the family at the time that donation is being considered and asked for.

The experience in Wales is very short and COVID-19 has affected transplantation in 2020. However the figures available into 2019 have shown minimal improvement in the numbers of transplants, little change in refusal rates by family and on the whole match any minor changes with those that have occurred in England and Scotland, where there has been no change in consent laws (Noyes J et al 2019)..

When the figures are examined for Northern Ireland, they show that the consent rate when families are approached is just over 60%, and then for the DCD group only about 60% of those become actual donors. From evidence elsewhere it seems unlikely that a change in consent will alter these figures. We are not given the reasons for not using consented organs, if this is due to a medical or other practical one then again, the changing of consent will not improve the number of organs donated.

Conclusion.

The Church and Society Commission fully supports the desire of the Department of Health to tackle the problem of the shortfall of donor organs for transplantation.

However, CASC does not feel that the evidence is adequate to support a change of consent from that of an opt-in to an opt-out policy. The evidence is that where there has been improvement in availability this has been the result of better public education and especially the training and placement of specialist transplantation coordinators (SNOD in Northern Ireland). The Commission

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did note the use of training of intensive care physicians to identify potential donors, not only in Intensive Care but in other departments, and the ongoing training involving all those involved.

Even if the evidence of any benefit was tending more towards a change in the type of consent CASC would believe that the significant change in ethos that this requires outweighs any minimal bonus. To remove the aspect of altruistic giving that underlies the present situation is very precious and should not be lightly changed. As Margaret McCartney writing in the British Medical Journal said; "what is the effect of presuming donation? A forced, presumed, or expected gift is not a gift. A striking feature of families who have allowed donation has been the desire to help others and the feeling that some shred of good has come out of their profound loss. If the sum of free will to donate is decreased, how can this benefit be realised to the same extent?" and Fabre et al in their conclusion "Spain has shown… that the highest levels of organ donation can be obtained .....without presumed consent".

Church in Society Committee: A Response to New Organ Donation Proposals Put Forward by Prime Minister Gordon Brown. 2008; https://www.ireland.anglican.org/resources/220/a-response-to-new-organ

Church and Society Commission: Discussion Paper, Organ Donation and Consent. 2016; https://www.ireland.anglican.org/resources/300/organ-donation-discussion-paper

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Fabre J, Murphy P, Matesanz R. Presumed consent: a distraction in the quest for increasing rates of organ donation. BMJ2010;356:c4973. doi:10.1136/bmj.c4973 pmid:20959281.

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