

Response to the Department of Health's consultation on promoting organ donation and transplantation in Northern Ireland
March 2018

- 1 The Nuffield Council on Bioethics is an independent organisation that examines and reports on ethical issues arising from developments in biological and medical research that concern the public interest.
- 2 This consultation response draws on the conclusions and recommendations of our *Human bodies: donation for medicine and research* report, published in 2011.¹

Question 1: Do you agree that a long term communications programme should be developed to promote organ donation through local, regional and national initiatives through various platforms?

- 3 Yes. Improving public awareness of organ donation through effective communication should be a key part of the Department's aim to "drive increased rates of organ donation in Northern Ireland." Individuals must be well-informed about organ donation, and this should be done through the provision of easily-accessible information.

Question 2: What activities do you think should be included in the communications programme?

- 4 The activities that are developed should emphasise the importance of discussing wishes around organ donation with family members. Evidence suggests that discussion of organ donation with family members is associated with higher rates of consent / authorisation. The most recent potential donor audit found that when a patient had not expressed a wish to donate or their ODR status was unknown at the time of potential donation, the consent / authorisation rate was 46.7%; but where their wishes were known at the time of potential donation via the ODR, the rate was 90.5%.²
- 5 In our report we also suggest that public information about organ donation should include reference to the potential *research* uses of organs and tissues, and that potential donors should have the option of authorising such uses in advance.³

¹ Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research*, available at: <http://nuffieldbioethics.org/project/donation>.

² See Table 13.1 in NHS Blood and Transplant (2017) *Organ donation and transplantation: activity report*, available at <https://www.organdonation.nhs.uk/supporting-my-decision/statistics-about-organ-donation/transplant-activity-report/>.

³ Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research*, paragraph 7.40.

We believe that research should not be seen as a ‘second-class’ use of organs, but instead should be promoted as a mainstream use of donations that cannot be used directly in transplant.

Question 3: Do you agree that ring-fenced funding should be provided to coordinate and deliver communications activity by a regional coordinator?

- 6 We agree that it is essential that a communications programme is well-resourced on a long term basis. The recent evaluation of the change to an opt-out system in Wales, for example, showed a dip in public awareness after the initial publicity about the change wore off.⁴ Ring-fencing funding would be one helpful way of ensuring that priority was given to organ donation publicity, without funds having to compete against other pressing needs in the health budget.
- 7 Spain, often seen as the gold standard for organ donation, emphasises the importance of constructing a “positive social climate for donation and generating trust in the organ donation system”.⁵ Spain’s national transplant organ and transplant body, the Organización Nacional de Trasplantes, achieves this by working closely with the media; providing communications training courses for their coordinators; and making personnel and information easily accessible to the public, press or professionals, primarily through their 24-hour telephone number.

Question 5: Do you agree with the proposed approach to developing tailored partnerships with employers, the statutory sector, and the community and voluntary sector?

- 8 Yes. Increasing awareness of organ donation is known to increase donation rates, and we would agree that integrating discussions into people’s everyday lives through partnerships and a multi-faceted approach as described, is to be encouraged.
- 9 In our 2011 report, we argue that the ‘stewardship’ role of the state includes taking action actively to promote donation, in order to ensure that the NHS is able to offer fair access to donation services of all UK residents. Lower donation rates in some Black, Asian and minority ethnic (BAME) communities is linked with less access to suitable organs, and this is a matter of considerable concern. In this context, good relationships between NHS trusts and local community and faith leaders to foster understanding and trust are particularly important.⁶

⁴ Welsh Government (2017) *Evaluation of the Human Transplantation (Wales) Act: impact evaluation report*, available at: <http://gov.wales/docs/caecd/research/2017/171130-evaluation-human-transplantation-wales-act-impact-en.pdf>, at page 3.

⁵ Fabre J, Murphy P and Matesanz R (2010) Presumed consent: a distraction in the quest for increasing rates of organ donation *BMJ*, available online: <http://www.bmj.com/content/341/bmj.c4973.full>.

⁶ Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research*, paragraph 7.38.

Question 7: Do you agree that collaboration between Local Councils and Health and Social Care is an effective means of promoting organ donation in local communities?

10 See above, Q5.

Question 9: Do you agree that promotional activities should be targeted at key audiences including older citizens and children and young people?

11 Yes. As we emphasise above, we would also add BAME donors to the list of key audiences.

Question 11: Do you agree delivering appropriate training for healthcare professionals can be an effective way of increasing the level of consent for donation to proceed?

12 Yes – the findings and recommendations of the Organ Donation Taskforce (ODT) were very much based on the evidence that significant increases in the number of organs donated after death could be achieved by improving every aspect of the organ donation infrastructure, including the training and skills of the specialist nurses working with the newly-bereaved families. Our own report endorsed these findings.

13 In addition to training, there is a clear need to invest to expand and strengthen the network of specialist nurse (SN-OD) for bereaved families. The regular audits of donation in the UK show that the support of an SN-OD has a significant impact on organ donation.

14 Again, citing the Spanish model, training is recognised as an essential part of its organ donation system. All professionals that deal directly or indirectly with organ donation are offered regular training in general and specific aspects of the organ donation process, such as donor screening, dealing with the family, and legal aspects.⁷

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⁷ Organización Nacional de Trasplantes (2018) *What exactly is the Spanish Model?*, available at <http://www.ont.es/home/Paginas/Enqueconsiste.aspx>.