

HTA's Response to the Consultation on Promoting Organ Donation and Transplantation in Northern Ireland

Introduction

1. The Human Tissue Authority (HTA) welcomes the opportunity to respond to the Department of Health's consultation on promoting organ donation and transplantation in Northern Ireland.
2. The HTA is the statutory regulator responsible for overseeing the consent provisions within the Human Tissue Act 2004 (HT Act); the HTA is charged with ensuring that appropriate and valid consent is in place when organs and tissue are donated from deceased and living people for the purpose of transplantation.
3. The HT Act, in terms of consent for deceased organ donation, covers England and Northern Ireland and requires consent for a number of activities - including organ donation - to be an active and positive act. In Wales, a deemed consent system for organ and tissue donation after death is operational as a result of the implementation of the Human Transplantation (Wales) Act 2013.
4. When the word "organ" is used in this document, it should be read to include whole organs, part organs, and tissue.

5. As a statutory regulator, it is not the role of the HTA to either support or object to the proposals of the Northern Ireland Assembly.
6. This consultation response document seeks to give HTA's views based on our experience of regulating in this field, where appropriate in relation to the consultation questions.

The consultation

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?

7. The HTA welcomes the intention for a long term, and therefore sustainable, communications programme that would seek to raise public and professional awareness of organ donation and transplantation. In our role as the regulator, we would emphasise the importance of maintaining public and professional confidence in the organ donation system, and therefore any communications programme should take account of the legal and statutory framework which underpins practice in this area.
8. Our experience tells us that attitudes to organ donation are very personal for each individual, and can vary widely for a multitude of reasons; this will shape how conversations around donation are approached and proceed, and further emphasises the importance of individuals making their wishes known to their family. Although it will not be possible to tailor a programme for individuals, it is therefore important that any communications programme reflects regional and local aspects, as well as national ones.
9. When considering platforms, any plans for a communications programme should also include details on how to reach communities that may not be in regular contact with care services and the information they provide. This will include individuals and groups who may face barriers to receiving or understanding messages

disseminated by the communications campaign, for example: where English is not their first language, people with no fixed abode and people with learning difficulties.

10. The HTA would recommend that any success measure is set before the programme of communications begins, and independently evaluated so a true picture of the impact can be determined.

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

11. The HTA does not have specific suggestions for activities in the programme, but we would advise that you consult with other organisations who have run, or plan to run, similar awareness campaigns, such as NHS Blood and Transplant, Welsh Government, and Scottish Government.

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

12. The HTA does not take a view on the funding arrangements of the communications programme, but we would advise that you have a plan in place that ensures the greatest coverage nationally and regionally, to have the best impact on increasing public awareness in a meaningful way.

Question 4: What do you think should be the funding priorities?

13. The HTA does not take a view on what the funding priorities should be, beyond that they are targeted at ensuring the public understand and can make an informed choice about organ donation and transplantation.

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

14. Working with key stakeholders in the system can be an effective way to better target different audiences and take into account the needs of different populations and demographics. We would also welcome the inclusion of information about regulation in the area of organ donation and transplantation when engaging with the public, as one of the key ways in which public confidence is maintained. The HTA has produced public guides to our Codes of Practice,

which explain what people should expect when they come into contact with HTA-licensed establishments. These are available on our website here -

<https://www.hta.gov.uk/guidance-public/public-guides-hta-codes-practice>.

Question 6: Which partnerships do you think would be most effective in encouraging positive behaviours in relation to organ donation?

15. The HTA does not have any specific partnerships to recommend.

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?

16. The HTA considers local authorities key stakeholders in ensuring a collaborative approach is effective and works for local populations, as well as with national partners such as the Public Health Agency, and voluntary and charitable organisations that support organ donation.

Question 8: What promotional activities would you wish to see delivered in this way?

17. The HTA does not have any preferences to share with regard to promotional activities.

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

18. The HTA does not take a view on whether a targeted or generic approach should be adopted, but you may wish to consider the follow points:

- i. feedback and evaluation from other organisations who have carried out similar work;
- ii. any specific needs amongst certain demographics and areas in Northern Ireland; and,
- iii. the resources made available for this activity.

Question 10: In what ways do you think this could be approached?

19. See above.

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

20. Research into this area has shown that increased training and education amongst professionals can be an effective way of increasing the level of consent for donation to proceed.

21. Appropriate training should include relevant aspects of the legal and regulatory framework, which is essential to ensure professional confidence is maintained in the organ donation system. The HTA publishes a [Code of Practice for professionals working in organ donation](#) and transplantation - which we would encourage you to share with professionals working in this area.

Question 12: In what ways do you think this could be approached?

22. The HTA does not take a view on the approach, but considers that appropriate consideration should be given to including wider groups of healthcare professionals, in particular those involved in end of life care, as well as those directly involved in organ donation and transplantation.