

PROMOTING HUMAN ORGAN DONATION AND TRANSPLANTATION IN NORTHERN IRELAND



Yes I donate
ORGAN DONATION

Consultation Proposals & Response Questionnaire

11 December 2017 – 12 March 2018

Consultation Proposals

Policy Objectives and Key Commitments

Reflecting international best practice, activities to promote organ donation by Health and Social Care (HSC) organisations in Northern Ireland will focus on **two primary objectives** to be implemented through **six key commitments** to drive increased rates of organ donation in Northern Ireland.

Objective 1: Encouraging positive actions and behaviours in relation to organ donation

Positive actions and behaviours means making our organ donation wishes known. This primarily involves encouraging potential donors to join the Organ Donor Register (ODR), and helping people to discuss their organ donation wishes with family and friends. The Department working with the HSC will deliver this objective by developing and implementing the following measures, focussing on activities that encourage the consent discussion, drive registration, develop the ODR as an effective marketing tool, and support promotion at a local level.

Commitments 1-5

The Department commits to increasing awareness of organ donation and the rate of consent by families by:

1. Developing a long term integrated HSC Communications Programme;
2. Providing ring-fenced funding to coordinate and deliver communications activity;
3. Utilising the potential of civic society to engage with all sectors of the community;
4. Working with Local Government to engage with local community based initiatives;
5. Engaging with key target audiences including older citizens and children and young people, to ensure greater levels of awareness and responsibility by the current and future adult population.

Objective 2: Developing appropriate training for healthcare professionals to increase levels of consent in order to achieve the 2020 strategy target of 80%

Commitment 6

The Department commits to increasing awareness of organ donation and the rate of consent by families by:

6. Providing high quality organ donation awareness training for healthcare professionals.

Further detail on these commitments and consultation questions is provided below.

Commitment 1: Develop a long term integrated HSC Communications Programme

Mass media advertising has been successful to a point in promoting positive attitudes towards organ donation, encouraging positive behaviours and influencing conversations, however the effect of this approach in isolation can be short-lived. When combined with a sustained and co-ordinated programme of activities embracing contemporary marketing techniques the impact can potentially be more beneficial. This approach aims to embed a shift in public attitudes and a change in behaviours over the longer term, resulting in an anticipated higher rate of consent to donation.

Public Information campaigns have, in the past, been delivered in Northern Ireland on an ad hoc basis by various stakeholders including charities, the Public Health Agency and NHS Blood and Transplant (NHSBT)¹, working either individually or collectively, and in the absence of a coordinated, strategic and ongoing approach to communications.

The Department therefore proposes the development of a rolling 3-year integrated HSC communications programme, with annual priority plans. The programme will combine regional and local promotional initiatives with NHSBT's expertise and UK-wide evidence-informed campaign activity in a way that is suitably tailored to meet priorities identified for Northern Ireland organ donation activities.

The communications programme and annual plans will take account of existing public information sources² by engaging with the public on organ donation issues through various platforms including the mass media, social media and local promotional events.

Annual plans will place particular attention on coordinating promotional activities in collaboration with relevant stakeholders (including charities, patients, donor families, HSC Trusts, local councils), around key dates for organ donation each year.

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?

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

¹ [NHS Blood and Transplant \(NHSBT\)](#) is a Special Health Authority in the NHS which is responsible for the allocation of organs for transplantation is across Northern Ireland, England, Scotland and Wales; management of the Organ Donor Register (ODR); and running public information campaigns in relation to organ donation.

² The website <https://www.organdonationni.info> is the primary source of public health information about organ donation in Northern Ireland, providing statistics, promotional resources, responses to Frequently Asked Questions, and links to facilitate registration on the NHS Organ Donor Register (ODR).

Commitment 2: Providing ring-fenced funding to coordinate and deliver communications activity

The Department commits to providing a ring-fenced annual budget to fund the Communications Programme, to include delivery of promotional activities by a regional coordinator.

The role of the coordinator will include the development and delivery of the communications programme, overseen by a steering group to include Health and Social Care (HSC) commissioners, HSC Trusts, clinicians and specialist nurses who are involved in organ donation and transplantation, as well as patient representatives. It will determine annual plans identifying priority areas for promotional campaign activity and funding in Northern Ireland, monitor the effectiveness of the programme and ensure consistency in its delivery across the region.

The coordinator will also be responsible for maintaining appropriate links with NHSBT's ongoing campaign activity at a UK level, in order to advise the steering group and coordinate as appropriate the delivery of any campaigns that will further Northern Ireland priorities within the available budget.

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

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

Commitment 3: Utilising the potential of civic society to engage with all sectors of the community

The communications programme will place particular focus on developing partnerships with employers and related business organisations, statutory organisations such as public libraries and universities, and community and voluntary organisations to maximise their contribution to promoting organ donation. Each of these bodies engage with their particular audiences, such as employees, clients and volunteers, through a variety of interfaces which have the potential to help drive ODR registration. Partnership working presents an opportunity to promote organ donation via these networks by tailoring communications in order to maximise their effectiveness.

Technology and contemporary communications will be used as far as possible, e.g. developing compelling, emotive and regular content for delivery through partners' websites and social networks, and using providing staff and customers with web links to both the ODR and to organ donation information.

Employers: Working initially with HR leaders in large employers, campaigns will support the provision of advice and resources to facilitate the development of bespoke Corporate Social Responsibility (CSR) programmes. Through these programmes, employers provide information and encourage staff to learn about organ donation, discuss their views and wishes with friends and family, and join the ODR. CSR programmes can also identify organ donation champions to take the lead in promoting organ donation within their respective organisations and communities, with appropriate support from the Department and HSC bodies. Some local companies have shown leadership in developing such initiatives, which can be used to educate and encourage others to do likewise.

Statutory Sector: Activities will seek to develop partnerships with statutory sector service providers will deliver tailored messages for various user groups, for example:

- Potential opportunities to collaborate with the Northern Ireland Blood Transfusion Service in jointly promoting blood and organ donation;
- Working with the network of Northern Ireland libraries as important community hubs to display information, provide literature, and host educational events;
- Working with schools and colleges – see also paragraph (v) below – to develop appropriate curricular and extra-curricular programmes to educate students about organ donation.

Community and Voluntary Sector: these organisations, particularly those involved in organising and playing sports, promoting health and wellbeing, or representing the interests of health service patients, collectively involve significant numbers of the

Northern Ireland population who are generally receptive to positive health messages. Activities will therefore seek to build partnerships with these organisations, to help stage promotional/learning events, and to provide information and resources which are suitable to the needs of their members.

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

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

Commitment 4: Working with Local Government to engage with local community based initiatives

Local Government's strong links with communities present a significant opportunity for positive engagement about organ donation at the local level. The Department therefore commits to working with HSC bodies and Northern Ireland's 11 local councils to collaborate on the development and implementation of local promotional campaigns using a variety of established communications channels. The aim will be to build on local community plan objectives aimed at improving the health and wellbeing of their citizens. The promotion of organ donation is seen by councils as an important element of that responsibility.

Local campaigns will be underpinned by a code of practice to support local councils: in the development of appropriate links with NHSBT to help deliver national promotional activities at a community level; closer partnership working between councils and HSC Trusts to jointly plan and coordinate promotional activities, messages and events; the development of volunteer networks to facilitate these activities; and the sharing of best practice across local government.

The Department will also publish local organ donation statistics available for every council area to support these local activities. Through this collaborative approach the Department aims to increase the number of ODR registrations and rates of donation in each council area.

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?

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

Commitment 5: Engaging with key target audiences including older citizens and children and young people, to ensure greater levels of awareness and responsibility by the current and future adult population

People of any age can register to be an organ donor³. It is therefore particularly important that children and young people are provided with appropriate information about what this means at an early age, in order to help them make an informed choice and discuss this with their friends and family.

The *Young Persons' Behaviour & Attitudes Survey 2016*⁴ shows that children and young people in Northern Ireland have mostly favourable views in relation to organ donation, generally seeing it as something positive that can come out of someone's death. However, there is scope to improve their understanding around some aspects of organ donation, and less than half of those surveyed had discussed their views with their close family members.

Recognising the value of encouraging positive attitudes amongst young people towards health and wellbeing matters in general, the Department commits to ensuring that the communications programme will include a co-ordinated approach to working with schools and youth organisations in order to increase knowledge and understanding about organ donation, and encourage young people to discuss the subject amongst friends and family.

It will support and build upon established good practice that has been developed by local champions within Northern Ireland (including teachers, youth leaders, and pupils), to make educational resources and support available to expand and deliver curricular and extra-curricular programmes tailored for various age groups. The Department of Health will work with the Department of Education to facilitate the delivery of this part of the plan.

Furthermore, contrary to the myth that someone's age might prevent them from becoming an organ donor, it is important to remember that patients who die in circumstances where donation may be possible are considered individually, irrespective of how old they are. For example, in 2016/17, the average age of a deceased donor in the UK was 51, with 60% of donations coming from the over 50 age group⁵. The

³ Everyone irrespective of age or health and who is considered legally competent can join the NHS Organ Donor Register. Doing so provides legal consent for the donation of organs. Children can register but their parents, guardians or those with parental responsibility will be asked to provide their consent should the child's death lead to donation being considered.

⁴ <https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/YPBAS2016ToplineResults.pdf>

⁵ Whether or not someone's organs after death can be safely used to help others is determined at the time through a number of assessments. Information from the patient's clinical and social history is also considered from medical records and the person's next of kin.

average age of a living donor was 47%, with 44% of donations coming from the over 50 age group⁶.

The communications programme will therefore also seek to deliver appropriate clear 'myth busting' messages to encourage those in older age groups to consider and discuss their organ donation wishes.

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

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

⁶ Potential living kidney donors undergo a series of tests to ensure that they are suitable and that it is safe for them to donate.

Commitment 6: Providing high quality organ donation awareness training for healthcare professionals

Only a small proportion of people die in circumstances where it may be possible for their organs to be donated. It is vitally important that in these circumstances families are given the option of consenting to organ donation. Usually this will be in a hospital intensive care setting, and the approach to families must be sensitively managed. They should be referred as early as possible to a *Specialist Nurse - Organ Donation (SNOD)* working within the intensive care unit and equipped with the specialist knowledge and skills to discuss donation and, if known, their loved one's wishes.

In order for referral opportunities to be realised, it is also important that all health professionals involved in the journey with that patient and their family are equipped with appropriate knowledge about organ donation and about the SNOD referral process.

Through this approach, discussing organ donation should become a normal part of end-of-life care for the families of patients in these circumstances. All families, where organ donation is a possibility, will be approached in line with best practice principles.

The Department has endorsed NICE CG135⁷, and NHSBT Best Practice Guidance on approaching the families of potential organ donors⁸, which reinforce that every approach to those close to the patient should be planned with the multidisciplinary team (MDT), should involve the SNOD, and should be clearly planned taking into account the known wishes of the patient. The ODR should be checked in all cases of potential donation, and this information must be discussed with the family as it represents the eligible donor's legal consent to donation.

In the UK as a whole in 2016/17, consent rates when a SNOD was involved in the discussion with the potential donor's family were 68.6%, compared to 27.5% when a SNOD was not involved.

These figures clearly demonstrate the positive difference that effective referral by appropriately trained professional makes to securing the consent of families. Maximising potential donation opportunities when they arise is the key to improving the consent rate and achieving the 2020 target of 80%. Non-referral of potential donors and the resultant low consent rates represent missed opportunities to save lives, and should therefore be minimised.

Reflecting the above, the Department will work with the HSC, training bodies, universities, and NHSBT to develop and deliver appropriate training for various

⁷ <https://www.nice.org.uk/guidance/CG135>

⁸ http://odt.nhs.uk/pdf/family_approach_best_practice_guide.pdf

healthcare professionals involved at all stages of the consent journey. This will include GPs, medical students, medical trainees, consultants and specialist doctors, and trainee and post-registration nurses working in secondary care settings, in order to increase their awareness of organ donation issues and their understanding of the SNOD referral process.

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?

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

How to Respond in Writing

Please send your completed responses by 5.00pm on Monday 12 March 2018 to:

Email: OrganDonationConsultation@health-ni.gov.uk

Hard Copy: Organ Donation Consultation
Department of Health
Room 1, Annex 1
Stormont Estate
Belfast
BT4 3SQ

Further Information and Related Documents

Large print, Braille and alternative language versions of this document are available on request to the above email address or postal address.

If you have any questions please contact OrganDonationConsultation@health-ni.gov.uk

Promoting Human Organ Donation and Transplantation in Northern Ireland:

A consultation on a policy to increase organ donor numbers

CONSULTATION RESPONSE FORM

I am responding:

As an individual _____

As a health and social care professional _____

On behalf of an organisation _____

(please tick one option)

About you or your organisation:

Name:	Dr Deepak Dwarakanath
Job Title:	Vice President
Organisation:	Royal College of Physicians of Edinburgh
Address:	9 Queen Street
	Edinburgh EH2 1JQ
Tel:	0131 247 3673
E-mail:	I.paterson@rcpe.ac.uk

Commitment 1: Develop a long term integrated HSC Communications Programme

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?

Yes

No

Please feel free to comment below, providing evidence to support any alternative proposal:

Yes: this is vital. Considerable investment in terms of time and resource needs to be spent on continuing public education and improved infrastructure to support families and clinical teams, both in the current “opt in” authorisation system and in the possible circumstances in the future of a move to “opt out”.

The available international evidence supports the fact that ‘opt out’ legislation is associated with increased rates of deceased organ donation. However, **the legislation itself may not be the major determining factor** for organ donation as some countries with “opt in” systems still have higher organ donation rates than countries which have adopted “opt out” legislation.

A higher rate of organ donation will reflect increased public awareness, societal attitudinal change to donation, and improved clinical infrastructure.

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

There is considerable international evidence available which highlights examples of good practice in this regard. The College recommends seeking expert opinion from those who have done this successfully, such as the team led by Rafael Matesanz in Spain.

Conversations about donation are part of society in Spain and it is ensured that the public have awareness of organ donation through many different channels. A successful communications programme will embed the positive aspects of organ donation in the public’s consciousness.

Commitment 2: Providing ring-fenced funding to coordinate and deliver communications activity

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

Yes x

No

Please feel free to comment below, providing evidence to support any alternative proposal:

The College agrees that considerable investment in terms of time and resource needs to be spent on continuing public education.

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

Please see answer to question 2: the College recommends seeking expert opinion from those who have done this successfully, such as the team led by Rafael Matesanz in Spain.

Commitment 3: Utilising the potential of civic society to engage with all sectors of the community

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

Yes x

No

Please feel free to comment below, providing evidence to support any alternative proposal:

The College supports an inclusive approach being taken in order to reach different audiences.

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

Partnerships with schools and further and higher education will be important to embed the discussions around organ donation at an early stage, however all partnerships are worth exploring as raised awareness across all ages and sections of society will be helpful.

Commitment 4: Working with Local Government to engage with local community based initiatives

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?

Yes x

No

Please feel free to comment below, providing evidence to support any alternative proposal:

Local Government offers channels of communication which may help to raise awareness with harder to reach members of the public.

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

Local Government regularly has contact with members of the public on various issues from waste collections to housing benefits. There is potential to include messaging about organ donation in these communications as well as through the wide networks of local government facilities and activities, for example, posters in libraries, leaflets in sports centres or a drop in speaker at evening classes.

Commitment 5: Engaging with key target audiences including older citizens and children and young people, to ensure greater levels of awareness and responsibility by the current and future adult population

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

Yes

No

Please feel free to comment below, providing evidence to support any alternative proposal:

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

As mentioned in question 6, partnerships with schools and further and higher education will be important to embed the discussions around organ donation at an early stage, however all partnerships are worth exploring as raised awareness across all ages and sections of society will be helpful. In financially restricted times it is however sensible to target resources where they are likely to have the most impact.

Commitment 6: Providing high quality organ donation awareness training for healthcare professionals

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

Yes x

No

Please feel free to comment below, providing evidence to support any alternative proposal:

This is extremely important.

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

In parallel with public education, improved infrastructure and resource to support families and clinical teams at the time of organ donation is essential. Specially trained healthcare staff are essential to the process of successful organ donation and increasing donation rates.

The role of the Specialist Nurse for Organ Donation (SNOD) is key in circumstances such as this to provide sensitive assistance and support to the potential donor's family and ensure that communication remains open and transparent.

Please use the text box below to provide any additional comments you wish to provide regarding the promotion of organ donation in Northern Ireland:

The College wishes to reiterate the view of our Fellows that a higher rate of organ donation will reflect increased public awareness, societal attitudinal change to donation, and improved clinical infrastructure.

In terms of infrastructure, for example, Fellows have described situations where there is a loss of potential donated organs due to surgical considerations. There are occasions where transplantation is unable to proceed because there is a lack of retrieval or a transplant surgical team, because they are already operating on other patients. Some emphasis should therefore be placed on identifying areas of improvement on the transplant side.

