

Promoting Organ Donation in Northern Ireland

NHSBT Board Update, July 2018

Latest:

- Consultation report and final policy statement currently under consideration by DoH senior management - final changes to be made before publication (soon) and implementation by Steering Group and Regional Coordinator.
- Small numbers attended a series of public meetings however these were constructive and included patient groups, political representatives, donor families and transplant recipients. 145 written questionnaire responses were received from the public, healthcare professionals, education providers, voluntary organisations and political parties. We particularly thank NHSBT for constructive input to this process.
- Vast majority of written/verbal responses strongly supported the draft policy proposals, many providing useful suggestions about where efforts should be focussed.
- No major objections were raised, however a small number of respondents expressed concerns including the role of government, and availability of sustained funding to support the communications programme.
- Some responses were provided both in support of, and against, the future introduction of soft opt-out, although this was not specifically asked as part of the consultation.
- Discussion ongoing with PHA on regional coordinator role.

Background:

1. Part 4 of the Health (Miscellaneous Provisions) Act (NI) 2016 provides a duty for DOH(NI) to promote organ transplantation by providing information and increasing awareness about donation. It includes a duty to promote a campaign informing the public at least once a year, and a duty to lay an annual report at the Assembly, which every 5 years should include the opinion of the Department about whether the Act has been effective and any further amendments to the law it considers appropriate at that time.
2. The Organ Donation Clinical Advisory Group (ODCAG) developed a policy statement to guide the Department and HSC in the implementation of the new statutory duty. A public consultation on the draft policy statement ran 11 December 2017 to 5 March 2018.
3. The draft policy sets out two main objectives: **to encourage positive actions and behaviours in relation to organ donation**, such as discussing our organ

donation wishes with family and close friends, or joining the Organ Donor Register (ODR); and **to develop and provide appropriate awareness training for healthcare professionals** involved along the consent journey.

4. Within these objectives the policy contains 6 commitments aimed at making more organs available for transplantation through a sustained increase in the rate of consent for donation to proceed to the UK strategy target of 80% by 2020. The commitments are summarised below:

- 1) **Developing a rolling 3-year integrated HSC Communications Programme**, combining regional and local promotional activities with NHSBT's UK-wide media campaign activity, tailored to meet priorities identified for Northern Ireland. The ODCAG recommends this approach having considered international best practice in communications aimed at long term behavioural and cultural change in organ donation. Whilst NI has signed up to UK strategic commitments, there has not previously been a coordinated approach to communications activity.
- 2) **Providing ring-fenced annual funding to deliver the Communications Programme** activity through a new Regional Coordinator, with priorities determined and overseen by a new HSC Steering Group chaired by the Department, and maintaining links with NHSBT to facilitate the delivery of evidence-informed UK-wide media campaigns within the available budget.
- 3) **Utilising the potential of civic society to develop effective partnerships with other sectors** including: the business community (e.g. through bespoke Corporate Social Responsibility programmes); the statutory sector (e.g. schools, colleges, libraries); and the community and voluntary sector (e.g. sport clubs).
- 4) **Working with Local Government** to build on Councils' commitment to improving health and wellbeing, and their existing strong links with communities. Following a Council and HSC Trust workshop earlier this year, the ODCAG has developed a Local Government Code of Practice setting out broad principles and activities which we envisage that Councils will adopt following consultation.
- 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.** 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 also recognise the key target group of over 50s from which the majority of deceased donors come, but amongst whom there is a need for greater awareness and understanding to counter misconception.

- 6) **Providing high quality organ donation awareness training for medical professionals**, focusing on those involved at various stages along the consent journey. Opportunities have been identified for this training to be included in training for medical students, medical trainees, GP trainees, nurses, and in the revalidation process for consultants and specialists. Subject to available resources the Department aims to work HSC, training bodies, universities, and NHSBT to implement this.

Regional Organ Donation Coordinator Role

5. The ODCAG has recommended the creation of this role in order to ensure the comprehensive delivery of the policy commitments across the region. Further to discussion with NHSBT, it is envisaged that the post should be employed within HSC in NI (probably Public Health Agency) with appropriate linkages and support from NHSBT to link with campaign developments/insights from GB. To be developed with PHA.
6. The job outline reflects the Department's draft policy commitments and therefore will focus on the development and implementation of the Communications Programme, including coordinating the delivery of media campaigns (with PHA), and local partnership development, working in conjunction with Trust committees and local government. It is envisaged that some degree of administrative support would also be required.

Steering Group

7. A Northern Ireland Organ Donation Steering Group will be responsible for overseeing the development and delivery of the Communications Programme. The Department will chair this group, with representation from NHSBT provided by the regional coordinator and SNODs.