

NHS Blood and Transplant

Strategy to deliver a revolution in public behaviour in relation to organ donation

– a direction of travel

Introduction

The strategy to increase UK donation and transplantation rates, *Taking Organ Transplantation to 2020*, requires a change in public behaviour so that people donate when and if they can, and it becomes a normal and expected part of end of life care.

With an average of three people a day dying in need of an organ transplant this behaviour change is vital to improving public health. The number of people who die each year in circumstances where they might be able to donate is very small, less than 5000, so we need to increase the number of organs retrieved from a finite pool of donors. Despite the significant rise in deceased donations over the past six years, consent/authorisation¹ rates (from families of the deceased) to organ donation have remained around 55-60% which means that about 4,470 organs are 'lost' every year.

The aim of *Taking Organ Transplantation to 2020* is to increase the consent/authorisation rate to over 80%, from 57% in 2012/13. An 80% consent/authorisation rate would approach or match those in the highest performing countries such as Spain.

At a superficial level, there is no problem with public attitudes to organ donation. Most opinion polls show the vast majority of the population is in favour of organ donation and would consider donating some or all of their organs. However, evidence shows that there are low levels of awareness of organ donation and the need for transplants, also that it is not something most people personally experience.

As a first step to addressing the challenge to deliver a revolution in public behaviour in relation to organ donation NHS Blood and Transplant appointed 23red to help carry out an independent audit of past and current public health behaviour change activity. Over a three month period 23red worked with NHSBT and our partners and stakeholders across the health and voluntary communities and with the four UK Governments to review activity at a local, national and international level to develop a consensus on the most appropriate interventions to change behaviour to help achieve the 80% target over the six years to 2020.

The result is *A strategy for delivering a revolution in public behaviour in relation to organ donation* and the supporting *Delivering a revolution in public behaviour in relation to organ donation: year one delivery plan*. These set out in detail the initiatives and rationale for a number of activities which, together, are expected to deliver the change in behaviour necessary to help increase consent/authorisation rates. In addition, all the research reviewed as part of developing the strategy is listed and briefly summarised in *Delivering a revolution in public behaviour in relation to organ donation: a summary of the evidence*.²

1. Authorisation is used in Scotland.

2. The papers are at:

The strategy provides an overarching framework for activity across the UK at a local and national level. It confirms that there is no one 'magic bullet' that will solve the problem. Instead it sets out a range of activity which, if adopted consistently over time, will shift attitudes. It endorses work which is already underway and should continue:

- Partnerships programme
- Wider use of Government transaction sites
- Face-to-face community engagement
- Tools to support the end-of-life conversation
- Address myths and misunderstandings
- Test and develop broadcast and social media content.

It also identifies new areas which should be tested and piloted informed by behaviour change experience elsewhere:

- Make more use of the existing NHS Organ Donor Register encouraging the 20 million plus registrants to become more vocal in their support for organ donation and target under-represented groups
- Reach out to children and young people as change makers who can stimulate conversations and debate in their families, with friends and in their communities
- Carry out a piece of research to understand why people say no at the point when they are faced with making a decision to support deceased donation
- Build on the sense of pride in donation to share the benefits and comfort it can give to donor families at a very sad and difficult time as well as to recipients whose lives are saved or significantly improved.

Strategic framework

The strategic shift in NHS Blood and Transplant's approach to changing public attitudes to organ donation can be summarised as:

1. Conversation and debate

Past activity has focused on getting people to sign up for the NHS Organ Donor Register as it is known to lead to higher consent rates (86% consenting versus 48%). However, to reach 80% consent overall focusing on the Organ Donor Register alone would require an additional 35m people to join the register, which would be unprecedented (comparable to the electoral roll). The focus going forward will be to make the commitment to the register work harder, using it as a tool to stimulate conversation supporting the drive to socialise and normalise donation.

2. Educating families

Research shows that people do not know that they will be asked to consent to donation on behalf of loved ones, or that their own wishes may be overturned. Future activity will be specifically targeted to encourage conversation and debate in families.

3. Local and targeted

There is a need to reach out to those groups underrepresented on the Organ Donor Register through more targeted and localised activity, which would be delivered face-to-face. Specifically this activity will be focused on Black, Asian and Minority Ethnic communities; over-50s and those from more disadvantaged socio-economic groups.

4. 'Normalising' donation

There will be a continuation of the focus on partnerships and prompted choice to support 'normalisation' of organ donation with the aim of making it an expected part of end-of-life care.

5. Understanding the impact of other interventions

Wales has legislated to introduce a system of deemed consent from 2015 supported by an awareness campaign. In addition, there is more to be understood from the conversation Specialist Nurses Organ Donation and clinicians have with potential donors and their families and what influences the final decision.

Objectives

The behaviour change strategy contributes to the aim to increase consent/authorisation rates to 80% by 2020. The strategy's three objectives are designed to provide a focus for activity to be carried out by a wide range of partners and stakeholders at a national and local level to help achieve this aim:

1. Increase the number of people on the ODR by at least 50% by 2020 (from a baseline of 20m in 2014), rebalancing it towards people who are older (50+) and from DE socio-economic groups
2. Stimulate open conversations and debate about donation, particularly through leveraging the Organ Donor Register as a marketing tool
3. Present donation as a benefit to families in end-of-life and grieving process.

These three objectives are supported by 20 recommendations (annex A) detailing specific interventions and activity. Some of this work is already underway, near term, and will continue where there is evidence of impact. Alongside this are initiatives which have promise, longer term, which will need to be developed in more detail and tested to demonstrate their potential contribution to increasing consent/authorisation rates.

Controlled trials will take place in selected local areas over the next one to two years to test the effectiveness of the proposed activities and to establish clear performance measures. Full roll

out will follow, subject to investment, if the interventions are successful. Therefore we are unlikely to see an increase in consent/authorisation rates from this activity before year three.

NHSBT will now work with partners and stakeholders to bring the strategy to life and develop the recommendations into specific, detailed delivery plans.

Strategy to Deliver a Revolution in Public Behaviour in relation to Organ Donation

– recommended actions

Full details for each of the recommendations including supporting evidence and suggested delivery plans are contained in *A strategy for delivering a revolution in public behaviour in relation to organ donation* and the supporting *Delivering a revolution in public behaviour in relation to organ donation: year one delivery plan* (www.nhsbt.nhs.uk/who-we-are/introducing-the-board/board-papers/papers_mar14).

Overarching

These are recommendations of principle.

Review investment on awareness raising and behaviour change, first scoping activity via lower cost owned and earned channels ensuring best use of the circa £2 million per annum budget. Based on the shape of other similar programmes, eg Public Health England's Change4Life, smoking cessation and healthy older people, NHS Blood and Transplant may need to budget in future for spend of around £10 million per annum to cover a media mix including television, press, outdoor, digital, direct, PR and extensive local marketing if they prove necessary to achieve the desired outcomes.

Adopt a national/local model to share and scale up successful local activity and to allow broad national messages to be adapted to meet specific local audiences and needs.

Develop and validate a registrant journey that leverages the Organ Donor Register as a marketing tool.

Develop an evaluation framework, in line with Cabinet Office best practice.

Initiate a stakeholder mapping exercise, so that those stakeholders who are most able to contribute to behaviour change are empowered and encouraged to do so.

Develop and maintain a risk register and crisis management plan.

Near term

Many of these recommendations cover activity that is already underway in one or more the four UK countries and for which is there is evidence of success. We will continue with these programmes sharing best practice.

Expand the current partnership programme, harnessing the goodwill of charities, corporates, major employers (including the NHS) and the media in recruiting potential donors.

Further exploit the potential of government transaction sites to deliver new registrants.

Increase the investment in face-to-face and community engagement activities, particularly those in "hard to reach" groups including black, Asian and minority ethnic (BAME) groups.

Develop partnerships with commercial and third sector organisations that have relationships with people who are living with health conditions that could lead to them needing a transplant, or who are planning what they would do in the event of their death.

Develop tools (including face-to-face, digital, social, viral and physical prompts) to enable people to have contained but constructive conversations about end-of-life.

Expand the existing activity to address concerns around the impact of donation on burial and cremation practices.

Develop and test broadcast and social content (long time lengths, deliberative) that frame donation as a positive step within the grieving process such as advertiser funded programming, advertorials and partnerships with media owners.

Longer term

There are a number of recommendations that will need to be developed and trialled to test their potential to change behaviour. If successful, business cases will be drawn up to secure support to establish the programmes on a more permanent basis.

Develop and test a 'member-get-member' style programme.

Develop an audience segmentation model and targeted direct marketing campaign to under-represented groups.

Expand the use of the organ donor card beyond new registrants, and consider alternative physical and virtual symbol(s) of intent to donate.

Develop an ongoing relationship management programme for registrants, to ensure they remember their commitment and share their intent to donate with friends and family.

Focus on children and young people as change-makers within the family, rather than exclusively as registrants in their own right.

Engage with stakeholder groups and clinicians in the development of a research programme to observe and gain insight into the experiences, emotions and deliberations of families going through the donation decision.

Further develop the Order of St. John Award for Organ Donation as a high profile annual celebration of the generosity of donors and their families.