A strategy for delivering a revolution in public behaviour in relation to organ donation

Prepared by 23red for NHS Blood & Transplant

March, 2014
This document has been prepared for NHS Blood and Transplant (NHSBT), the Special Health Authority with responsibilities across the United Kingdom in relation to organ donation and transplantation.

It will also be of use to NHSBT’s partners and stakeholders, (within the NHS, across Government and within local communities) and any agencies that will be involved in its delivery.

It addresses Outcome One of the recently published strategy, *Taking Organ Transplantation to 2020*, which is:

“Attitudes to organ donation will change and people will be proud to donate, when and if they can”.

Outcome One should be understood in concert with the three other outcomes detailed in the 2020 strategy, which separately address the changes that need to happen in NHS hospitals and staff working in donation, NHS hospitals and staff working in transplantation and NHS commissioners:

- Outcome Two: excellent care in support of organ donation will be routinely available and every effort made to ensure that each donor can give as many organs as possible
- Outcome Three: more organs will be usable and surgeons will be better supported to transplant organs safely into the most appropriate recipient
- Outcome Four: better support systems and processes will be in place to enable more donations and transplant operations to happen.

This document is intended to be viewed in the context of two companion documents:

- Delivering a revolution in public behaviour in relation to organ donation: year one delivery plan
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1. **Introduction**

Organ transplantation is one of the miracles of modern medicine. In the UK, 4,212 transplants took place between 1st April 2012 to 31st March 2013 saving 1,160 lives, and dramatically improving the lives of 3,052 others. In addition, 3,697 people had their sight restored through a cornea transplant. These donations were made possible through the generosity of 1,101 living and 1,212 deceased donors.

Organ transplantation is not only a life-saving but a money-saving procedure, since it saves the cost of treatments such as dialysis. Work in 2010 found the transplant programme delivered a cost saving to the NHS of £316 million per annum (or about £40,000 per transplant); these savings had the potential to increase further as the number of transplant procedures rose.

In the UK, organ transplantation has always relied on altruism, trust and anonymity.

While organ transplantation can transform lives, it is not a risk-free procedure. This is a highly emotive area and those who work in transplantation bear witness to donor and recipient families’ grief, guilt, disappointment, hope and joy.

The number of deceased organ donors has increased by 50% in the past five years. This progress was driven by improvements in infrastructure, such as the introduction of a 250-strong centrally employed workforce of trained Specialist Nurses in Organ Donation (SN-ODs), a UK-wide network of Clinical Leads in Organ Donation (CLODs), and a National Organ Retrieval Service.

While more people have donated organs, this is largely because more people have been asked. The consent or authorisation rate (the percentage of families who, when asked, agree to donation), has remained broadly static.

In 2013, the four UK health departments and NHS Blood and Transplant published a new strategy for organ donation, *Taking Organ Transplantation to 2020*, which set out the following aims for the next seven years:

- Increase the consent/authorisation rate to 80% (currently 57%), approaching or matching rates in better performing European nations, such as Spain
- Increase the number of deceased donors per million population to 26 (currently 19.1)
- Transplant 5% more of the organs offered from consented, actual donors
- Aim for a deceased donor transplant rate of 74 per million population (currently 49).

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2 West Midlands Specialised Commissioning Team: *Organs for Transplants: An analysis of the current costs of the NHS transplant programme; the cost of alternative medical treatments, and the impact of increasing organ donation*, October 2010.
3 From 809 deceased donors in 2007/8 to 1,212 in 2012/13.
4 As of July 2013, when the 2020 strategy was published.
The strategy recognised that achieving these aims required action on the part of NHSBT, NHS hospitals, staff and commissioners, but also on the part of society and individuals, so that “attitudes to organ donation will change and people will be proud to donate, when and if they can”.

A range of actions are therefore required to deliver a revolution in public behaviour in relation to organ donation.

1a. The brief to 23red

23red is an integrated creative communications agency with hands-on experience of planning and delivering effective behaviour change strategies for charity, public sector and commercial clients.

In December 2013, NHSBT commissioned 23red to develop a seven-year strategic framework to deliver “a revolution in public behaviour” to increase consent rates and help deliver Outcome One of the 2020 strategy.

The detailed brief from NHSBT is reproduced in the appendices.

This framework needs to work across the UK. This presents some challenges, in part because there are some cultural differences that need to be considered, but principally because there are policy differences which impact upon what can and should be said in the different countries. In particular, Wales will introduce a “soft opt-out” system of consent to deceased donation from 1 December 2015. Under this system, unless a person has made an express decision to be or not to be a donor, then their consent to donation may be deemed to have been given – i.e. doing nothing will be the same as choosing to be a donor.

The other UK countries will watch these changes with interest. The Welsh Government will be carrying out an independent impact evaluation of the new legislation, taking into account contextual and underlying factors. The first results are due in 2016/17.

Whatever the outcome from the change in legislation in Wales, a range of actions is still required to create behaviour change across the UK.

1b. Methods used

23red’s methodology included the distribution of an invitation to contribute to interested parties, a thorough document review, desk research to fill identified gaps in knowledge, a suite of depth interviews with stakeholders, and other tools such as TGI audience analysis and Lexis Nexis press coverage. Full details are set out in the appendices.
The process included holding a series of strategic workshops with key stakeholders to share the emerging insights and seek input into the strategic framework and delivery plan.

In addition, a peer review panel was convened to review the methodology and to critique the strategy itself and we would like to thank the following for their time and expertise in helping us develop this strategy: Sheila Mitchell, Marketing Director, Public Health England (PHE); Richard Bowyer, Director of Marketing and Public Fundraising, Great Ormond Street Hospital Children’s Charity; Professor Greg Maio, School of Psychology, Cardiff University; and Elizabeth Fagan, Marketing Director of International and Brands, Boots.

The authors would like to thank the individuals and organisations who contributed to this document, particularly clinicians, recipients, donor families and patients, who freely gave their time during the busy holiday season and to those who took part in the stakeholder workshops.
2. Executive summary

Despite a 50% increase in deceased donors over the past five years, there are still not enough organs available for transplantation. As a result, there are over 7,000 people currently waiting for an organ. Three people die on average each day in the UK because an organ could not be found for them. Since the number of people who die each year in circumstances where they might be able to donate is very small (<5,000), it is vital that NHSBT increases the number of organs it retrieves from the finite pool of potential donors.

The four UK health departments and NHSBT have just published a new strategy, Taking Organ Transplantation to 2020, which sets out the ambitions, and the actions required to achieve those ambitions, over the next seven years. The strategy looks at a wide range of immediate and potential actions including changes in clinical practice, further development of the infrastructure around donation, and legislation. On this last point, the Welsh Assembly has voted to introduce a soft version of presumed consent in 2015. The other UK countries will watch these changes with interest to see the impact on the consent and donation rates.

One of the new strategy’s actions is to change public attitudes so people donate when and if they can and it becomes a normal and expected part of end of life care. 23red’s brief was to identify the steps that need to be taken across the UK to deliver this shift in public behaviour in relation to organ donation and, consequently, an increase in consent/authorisation.

Our analysis of the data provided by NHSBT and others indicates that (with the exception of some ethnic minority and faith groups), there is no problem, at least at a superficial level, with attitudes towards organ donation. The vast majority of the population are in favour of donation in principle and prepared to at least consider donating some or all of their organs. The problem is with family consent (or, in Scotland, “authorisation”) rates, which have remained unchanged at about 57% for many years. This means that every year, about 4,099 organs are “lost” because, when a person dies, their families refuse to allow their organs to be removed. The target in the 2020 strategy is to increase family consent rates to 80% by 2020.

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5 The Human Tissue Act 2004 provides the legal framework for organ donation in England, Wales and Northern Ireland and uses the term “consent”. The Human Tissue (Scotland) Act 2006 covers practice in Scotland and uses the term “authorisation”. Throughout this document the term “consent” is intended to include “authorisation”.

7 This is based on Potential Donor Audit (PDA) 2012-2013 data which suggests 1,242 families refused organ donation in that financial year. Please note that the PDA data for 2012-2013 does not include patients in cardiothoracic ICUs and patients aged over 75 years. The Organ Donation and Transplantation Activity Report 2012/2013 indicates that where a family does consent to donation, an average of 3.3 organs are transplanted.
Since consent rates are higher when a potential donor is known to be on the organ donor register (ODR), much of NHSBT’s past activity has focused on encouraging people to register as organ donors. While this document recognises the value of the ODR and calls for a radical increase in registration, driving more people to the ODR alone will be insufficient to achieve the 80% target for consent rates.

“If we put a million people onto the register tonight... we’d get five extra donors next year, which is not where we need to be. We need 500 extra donors next year.” (Depth Interview)

In order to achieve the 80% target it is necessary to also leverage the ODR, so that new joiners go on to have conversations with their family about their wishes in the event of their death.

The Potential Donor Audit (PDA) data from 1st Apr 2010 to 31st Mar 2013 reveals that having a conversation about wishes is the key to securing consent.

**Apr 2010 to Mar 2013**

<table>
<thead>
<tr>
<th>Wish type</th>
<th>Family approached</th>
<th>Family consent</th>
<th>Consent Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal discussion</td>
<td>415</td>
<td>398</td>
<td>96</td>
</tr>
<tr>
<td>ODR, donor card and verbal discussion</td>
<td>335</td>
<td>322</td>
<td>96</td>
</tr>
<tr>
<td>Donor card and verbal discussion</td>
<td>132</td>
<td>126</td>
<td>95</td>
</tr>
<tr>
<td>ODR and verbal discussion</td>
<td>650</td>
<td>606</td>
<td>93</td>
</tr>
<tr>
<td>ODR and donor card</td>
<td>72</td>
<td>60</td>
<td>83</td>
</tr>
<tr>
<td>Donor card only</td>
<td>35</td>
<td>27</td>
<td>77</td>
</tr>
<tr>
<td>ODR only</td>
<td>820</td>
<td>586</td>
<td>71</td>
</tr>
<tr>
<td>Other only (Via will or other nominated representative)</td>
<td>3</td>
<td>3</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: PDA data 1st Apr 2010 – 31st Mar 2013

For the first time, NHSBT will thus attempt to achieve behaviour change among donor families as well donors themselves. This will require a major cultural shift throughout the UK. NHSBT will need to tackle common myths and misunderstandings around organ donation (particularly as it relates to burial or cremation). Moreover, it necessitates that families appreciate that this is a decision that they will be asked to take, discuss it in advance and come to view donation as a natural and positive step in the grieving process.
Since this is a highly emotive area, it is recommended that NHSBT tread carefully, testing, piloting and evaluating new initiatives before rolling them out more widely. There is already competency and skills within NHSBT’s network to pilot at a local level, and we would urge a greater shift towards supporting and empowering local areas, as opposed to purely national activity.

Further, we would encourage NHSBT to continue an already-visible trend towards cooperation, collaboration and co-creation with the charitable sector, other partners, faith and BAME groups and donor and recipient families. This will involve a move away from traditional broadcast media (although this may play a supporting role) towards more co-created content (editorial and programming), social media, face-to-face engagement and direct and relationship marketing (although there is potentially a role for low cost paid for digital and print advertising).

This is not a silver bullet strategy. Just as the 50% increase in deceased organ donors over the past five years was achieved by many system changes, some of them incremental, some of them transformative, this strategy calls for many actions, some of them building and improving upon what has been done to date, some of them breaking new ground.

We propose three objectives for the next seven years:

- To 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
- To stimulate conversations and debate about donation particularly through leveraging the ODR as a marketing tool
- To present donation as a benefit to families in end-of-life and grieving process.

This framework recommends twenty specific actions needed to deliver these objectives. (Detail on delivery can be found in the companion document “Delivering a revolution in public behaviour in relation to organ donation: year one delivery plan”).

**Overall**

1. 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, NHSBT may need to budget in future for spend of around £10 million 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.
2. 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.

3. Develop and validate a registrant journey that leverages the ODR as a marketing tool.

**Increasing the rate of registration to the ODR**

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

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

6. Develop and test a ‘member-get-member’ style programme.

**Rebalancing the ODR towards people most likely to donate**

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

8. 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.

9. 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.

**Leveraging the ODR to create more family conversations about end-of-life**

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

11. Develop an ongoing relationship management programme for registrants, to ensure they do not forget their commitment and share their intent to donate with friends and family.

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

13. 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.

14. Expand the existing activity to address concerns around the impact of donation on burial and cremation practices.
Changing the behaviour of donor families, irrespective of the ODR status of their loved one

15. 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.

16. 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.

17. 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.

Measurement and evaluation

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

Governance

19. 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.

20. Develop and maintain a risk register and crisis management plan.

If the recommendations are applied in full we would expect the following indicative outcomes over the seven year period covered by the strategy:

- The increase in registrations will be steady and start immediately, plateauing in years three/four, as registrations are expected to peak at around 30 million.

- The changes in the consent/authorisation rates will not increase dramatically for a number of years, but will gather pace and rise exponentially as donation is normalised such that consent rates reach 80% by year seven.

This framework should be reviewed and updated frequently as new evidence emerges.
3. Changing public behaviour in health

3a. Experiences from across public health

There is a strong history of engaging with the public to change behaviours in health, for example there are, and have recently been, programmes that:

- Ensure compliance with legislation that is designed to improve health outcomes, such as the introduction of rear seat belts in cars.\(^8\)
- Support individuals who decide to change their behaviour in advance of, or in response to, legislation (for example by supporting smokers who wished to make a quit attempt around the introduction of the Smokefree legislation).\(^9\)
- Manage demand for services, for example by increasing the number of people with lung cancer who go to see their GP in the early stages of disease, thus making it possible for them to receive potential life-saving treatment.\(^10\)
- Increase access to programmes that facilitate positive behaviours, for example over 60,000 children have taken part in the Change4Life Schools Sports Clubs.\(^11\)
- Support people through difficult and complex behaviour change journeys, for example by providing SMS messaging to people who are trying to give up smoking.\(^12\)
- Bring together coalitions of the previously disparate willing to work together under a common banner (as in the Change4Life social movement).\(^13\)
- Popularise previously taboo health issues, as Movember has done for male cancers.\(^14\)

A good behaviour change programme is rooted in insights into the target audience, and bespoke to the task as defined. It can involve any and all of the following: community engagement; education and training; media engagement; the production and distribution of products and tools (leaflets, apps, risk profilers); digital, social and viral content; partnership marketing programmes; direct marketing (electronic or paper); ongoing relationship management; and broadcast media (such as television advertising or PR).

3b. Previous learning from organ donation

As part of this project, we have reviewed recent initiatives by the UK Health Departments and NHSBT to change behaviour, whether nationally or locally-led. Past initiatives have mostly had the behavioural goal of encouraging people to join

\(^8\) Rear Seat Belts, Sudden Impact: How can we measure the cost of a life? Jackson V et al., IPA Effectiveness Awards 2000.
\(^11\) Evaluation of the Change 4 Life School Sports Clubs Programme, SPEAR, Canterbury Christ Church University, August 2011.
\(^12\) Department of Health: NHS Smokefree SMS service, DMA Awards, 2012.
\(^13\) Change4Life One Year On, Department of Health, 2010.
\(^14\) See uk.movember.com
the Organ Donor Register. While we go on in this document to highlight other behaviours that need to change, there is learning from the past initiatives that should be captured and has potentially broader application, for example:

- Organ donation is responsive: activity typically generates immediate and measureable public action; with regard to the Organ Donor Register, short-term uplifts in registration of five times the norm vs. previous year have been reported.\(^{15}\)
- Sustained investment delivers incremental benefit, for example, in Scotland where the Human Tissue (Scotland) Act of 2006 places a statutory obligation on the Scottish Government to raise awareness of organ donation, membership of the ODR is over ten percentage points ahead of the rest of the UK, starting from an initially lower base.
- Public investment in organ donation leverages additional commitment. NHSBT has managed to deliver significant no-cost and low-cost amplification against modest expenditure through public relations and CSR.
- Programmes that are customised to meet local needs (and fully integrated with local services) deliver proven benefits in terms of actual behaviour change. For example in Nottingham, a fully-integrated programme of activity including community engagement, staff outreach and education, local and regional media and face-to-face events generated an additional 14 consents (21 vs. 7 for the same 5 month period in the previous year). This resulted in 19 extra transplant recipients (35 vs 16).\(^{16}\)
- While organ donation is an emotive and occasionally contentious area, most communication with the public, even in crisis situations, has had a positive outcome. For example, NHSBT’s 2010 admission of data recording errors, which resulted in the wrong organs being removed from 25 donors, generated adverse media coverage but resulted in increased ODR registration.
- NHSBT already has considerable skill and expertise both at the centre and throughout its network; there is a culture of innovation, measurement and sharing; among those stakeholders we interviewed, perceptions of the organisation are positive and improving.
- Organ donation is cost-effective and delivers rapid return on investment (see page 51).

There is thus a strong base from which to construct the future strategic framework.

\(^{15}\) Organ Donor Register: when it is better to receive than give. IPA 2011.
\(^{16}\) Nottingham University Hospitals Deceased Donation Data 2012-2014. The five month periods being compared are Apr 1 – Aug 23 2012 and Apr 1 – Aug 23 2013.
4. **The strategic framework**

The outputs from the desk research, our depth interviews and other analyses have informed, and are referenced throughout, this section. In addition, a summary of all the insight work is included in the appendices.

4a. **The business problem**

Despite the 50% increase in deceased donors in the past five years, there are still not enough organs available for transplantation in the UK. As a result, over 7,000 people are currently waiting to receive an organ. Many wait years, with significantly reduced quality of life, for an organ to become available and, on average, three people die every day because an organ could not be found for them or because they became too sick for transplantation.

“It’s put my life on hold really… I’d like children but... I don’t know what the future holds. So it’s kind of put a stop on anything like that because I’m just thinking well, what if it all goes wrong and I’m not about anymore?”

(Depth interview)

The sad reality is that, in the majority of cases, for a transplant to take place, someone must die. NHSBT would never wish for the number of people who die in circumstances where donation is possible to increase. Indeed the Department of Health, the NHS, Public Health England, the Department for Transport, local authorities and many others across society work hard to decrease the number of such deaths. It is therefore vital that NHSBT retrieve the largest possible proportion of the finite number of available organs.

This can be achieved either by increasing the number of people willing to donate their organs or by increasing the number of families of eligible donors who consent to (or, in Scotland, “authorise”) donation (or by some combination of both).

This issue will not be addressed exclusively by engaging with the public. Other actions (addressing Outcomes Two, Three and Four in the 2020 Strategy), which will impact upon the behaviour of NHS trusts and staff and NHS Commissioners, are also being considered in parallel to this strategy which focuses on the actions needed to change public behaviour.

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17 While the number of living donors (1,101) is almost equivalent to the number of deceased donors (1,212), living donors can only give one organ (a kidney or, less frequently, a liver), whereas deceased donors give an average of 3.3, and sometimes as many as nine, organs for transplantation. The majority of organs thus come from deceased donors.

18 Anecdotal evidence from clinicians who took part in the depth interviews sand workshops says that donation rates are lower for donation following circulatory death (DCD) than for donation following brain death (DBD) but this difference is due to the delay before the process of organ retrieval can begin, rather than to any difference in attitude or willingness to donate.
4b. Understanding how behaviour needs to change

The main issue is not with public attitudes, indeed the UK population is mostly in favour of (and very seldom opposed to) organ donation.

![SUPPORT OF ORGAN DONATION IN PRINCIPLE](image)

**Q54. Which of these statements best describes your views on organ donation? It doesn’t matter if you would donate your own organs or not, we just want to know how you feel about organ donation in principle.**

*Base: All Nat Rep (1007)*


Similarly, attitudes towards organ donation in Northern Ireland were generally positive, with 84% of respondents agreeing with the statement ‘I support the general idea of organ donation for transplantation purposes’.

Not only are people in favour in principle, but the majority are prepared to donate, or at least consider donating, all or some of their own organs.

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19 Organ Donation: Public attitudes and stakeholder engagement in Northern Ireland 2013.

20 Although much may depend on how the question is asked. Research by Ipsos MORI in 2010, revealed that, when the question is broken down further, only 21% of the population (fewer than are registered donors) are certain that they would donate after they have died.
Only 5% of people stated that they were definitely unwilling to donate.

As of March 2014, over 20 million people have already registered their desire to donate their organs after their death. The Organ Donor Register continues to grow by close to a million people (net) every year, without substantial public engagement. Indeed, most of those who join do so via channels that are not owned by NHSBT, such as the DVLA website or when they register with a GP. The ODR is thus one of the largest voluntary databases in the UK.
The behavioural problem that needs to be addressed is with consent rates.

Between April 2012 and March 2013, 2,918 families were asked for their consent to recover organs from their loved ones. Of these, about 43%, or 1,242 families, refused. This figure is high, particularly when compared to other European countries, for example in Spain, fewer than 20% of families withheld their consent.\(^{21}\)

\(^{21}\) Note: there are many reasons for higher consent rates in other countries, not all of whom are driven by public attitudes. These include differences in clinical practice (e.g. the existence of a network of doctors trained to identify potential donors and speak to bereaved families; having more intensive care beds available). This is why the strategy to change public behaviour is only one element of the broader strategy, *Taking Organ Transplantation to 2020.*
Families from black, Asian and minority ethnic (BAME) groups were more likely to withhold consent (68% did so). Unfortunately, we cannot calculate consent rates by social class, as socio-economic groups or postcode data are not recorded until after consent is given.

Adjusting for those families where consent was given but retrieval did not take place, a refusal rate of 43% equates to 832 lost donors per annum, a missed opportunity to save or transform 2,746 lives. Reaching the target of 80% of families consenting would result in an additional 439 deceased donors, potentially saving or transforming 1,449 lives each year.

Since NHSBT cannot “grow the market” of people who die in circumstances where donation might be possible, it needs to increase consent rates. The principle objective against which activities should be measured in the next seven years is thus improvements in consent rates.

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23 Last year organs were retrieved from 67% of consented patients. Reasons for not retrieving organs include: organs being deemed medically unsuitable upon medical inspection or by recipient centres, prolonged time to asystole, and Coroner/Procurator fiscal refusal (Potential Donor Audit, April 2012 – March 2013).
4c. Role of the Organ Donor Register (ODR)

History of the ODR

The ODR was established in 1994, following a five-year campaign by a donor family. It is a confidential, computerised database, which records the wishes of people who have decided that, after their death, they want to leave a legacy of life for others.

The ODR has also been used as a tracking mechanism for the effectiveness of marketing campaigns (for which it has tended to be the call-to-action) and as a “barometer of public opinion”, further evidencing public support for organ donation.

Influence of the ODR

Consent rates demonstrate the positive impact of the potential donor being registered on the ODR. When this is the case, 86% of families give their consent; when the potential donor is not on the ODR, consent rates fall to 48% (i.e. about half refuse).

Note that while 30% of the population is on the ODR, only 24% of potential donors are on the ODR. This reflects the differing age profiles of ODR registrants and people who die in circumstances where donation is possible, the latter being older on average (see discussion on page 26).

Knowing that a potential donor is on the ODR is extremely valuable for Specialist Nurses in Organ Donation (SN-ODs) and Clinical Leads in Organ Donation (CLODs), who can use that information to frame the conversation with the potential donor’s family.
“It [the register] does massively help because we’ve just got that extra tool, haven’t we? Now you can check the register, you can print a copy out and take it with you to show the family as well, ‘look at what your loved one’s decided and look when he did it. He did that five years ago, put himself on the register’. So that’s really, really helpful to us... it changes the way that you approach the family as well, we’ve always historically said ‘what would he have thought about donation, what do you all think?’, which we still do, but we say it in a different way now. It’s all ‘oh, he’s on the register, let’s make this happen’.” (Depth interviews)

However, even when the potential donor is known to be on the ODR, 14% of families still oppose donation. In 2012-2013, that equated to 97 families not consenting when their loved one was on the ODR. The figure for overruling a wish to donate increases to 105 families when looking at not only those who were on the ODR but also those who expressed in another way a wish to donate organs.

**Potential for the ODR to contribute to the target**

As previously mentioned, NHSBT’s published target is to achieve consent rates in excess of 80% by 2020. We have duly given consideration to whether it is possible to achieve this target solely by increasing the size of the ODR.

It is a relatively simple calculation that, if consent rates stay at 86% for people who are on the ODR and 48% for those who are not, meeting the target would require over 84% of the population to be on the ODR.

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24 PDA data Apr 2012 – Mar 2013

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To reach 84% by 2020 would require an additional 35 million people to join the ODR. This near universal registration level would be unprecedented, almost equivalent in size to the electoral register.

We can think of no previous examples of a government campaign (or even a non-Government campaign) attracting a total of 55 million people without any financial incentive or opt-out mechanism. For comparison, the Tesco clubcard database is currently 17 million people, and this rewards people every time they shop.25

Even if it were possible to get to such high joining levels voluntarily, it is unlikely that consent rates would not be impacted. In particular, we would expect that consent rates among the remaining 16% of families would fall below 48%, as this audience contracts around the small minority of people who are known to be opposed to donation.

Moreover, reaching and motivating an extra 35 million people is likely to be cost-prohibitive. In the current economic climate, it seems profligate to spend large amounts of public money generating 35 million responses, when what we really need to change is the decisions of less than a thousand families. Indeed, since there is no guarantee that the people who happen to die in the right circumstances will be among the 35 million, there is a risk of “using a sledgehammer to miss a nut”.

We are thus forced to conclude that driving people to the ODR, while a positive action, will be insufficient to meet the 2020 target of 80% of families consenting. To meet that target, more families will need to consent to donation, irrespective of whether the potential donor is on the ODR.

Achieving the target will indeed require a revolution in public behaviour and changes in the cultural norm. Not only will people need to take action, they will need to tell others of their wishes and these people will need to behave differently in the event of their loved one’s death.

**Note on the impact of the ODR as an intervention**

While knowing that someone is on the ODR is valuable when the decision to donate is being made, some stakeholders we interviewed suggested that the ODR’s role is principally to flag up potential donors whose families would most likely have said yes in any case. It is certainly true that the steady growth in the ODR over the past two decades has not, in fact, resulted in an increase in consent rates.

As the chart below illustrates, consent rates fluctuate a good deal year on year, reflecting the small size of the universe of potential donors. There is no discernible upward trend (which is what might have been expected from more people joining the ODR). A likely interpretation is that, as a greater proportion of potential donors join

25 Source: dunnhumby
the ODR, consent rates drop for non-ODR families, i.e. the “likely to donate” have been moved from one classification to another.

Source: PDA data 1 October 2009 to 31 December 2013.

We would therefore counsel NHSBT that joining the ODR should not be viewed as a one-off act. People on the ODR need to be moved from “registrants” to “members”, so that their decision remains salient, and they are mobilised to encourage others to support organ donation.

*Leveraging the ODR as a marketing tool:*

By leveraging, we mean:

- For each individual, joining the ODR should be a “teachable moment” or prompt for discussion among the registrant’s immediate and wider social network; this discussion should encompass both donation and the registrant’s wishes in the event of his or her death
- Membership of the ODR should be activated, so that registrants are reminded they are on the ODR, tell others and invite them to join, essentially becoming ambassadors for organ donation
- The ODR should be an access point for tools and support materials to facilitate conversations about organ donation and end of life.
To illustrate our point, we have generated two “archetypal” scenarios; the first is the worst case scenario which could currently occur\(^26\).

**Scenario 1: “Michael”**

In 1994, Michael, aged 30, joined the ODR while renewing his driving licence in the post office; he received a paper donor card, which he carried around in the plastic wallet containing his licence, until it fell out five years later.

Michael told his mother, Marjorie, and his girlfriend, Laura, about becoming an organ donor.

In 2014, Michael suffers a stroke and, despite all attempts to save him, dies in hospital. Since he split up with Laura shortly after joining the register and Marjorie died last year, it is his estranged wife, Sandra, and his two children, aged 9 and 12, who are at the hospital when he dies.

A SN-OD informs Sandra that Michael was on the ODR. Sandra had never heard Michael mention this and she never saw a donor card; Sandra is unsure whether a decision Michael made twenty years ago is what he would have wanted today; in any case, Michael’s wishes are not her main concern; her priority is to get the funeral sorted and spare her children any more pain.

Sandra opposes donation; she feels guilty when she thinks that strangers may die as a result of her decision, but she tries not to think about it.

Our second scenario reflects the desired situation going forwards, in which membership of the ODR is leveraged to improve consent rates.

**Scenario 2: “Joshua”**

In 2014, Joshua, aged 50, has a transient ischaemic attack (or mini-stroke), which he survives with no significant impairment. However, the TIA acts as a wake-up call. Joshua had not made a will, nor had he ever discussed his wishes in the event of his death with his partner, Tom. He talks to Tom about this and they decide to make their wills together. Their solicitor suggests that they should also discuss organ donation, which they do, and both decide to join the Organ Donor Register. They receive plastic cards which they put in their wallets. NHSBT’s website allows them both to automatically update their Facebook statuses, to show their friends that they have registered to become organ donors. Each of them also invites ten friends to sign up to become donors.

\(^{26}\) Note: these scenarios are composites of what currently happens and are not based on any individual families; any resemblance to real families is coincidental.
Every year, Joshua receives two emails from NHSBT. One, on the anniversary of his joining the register, reminds him he is registered to be a donor and that he should make sure his loved ones know his wishes; the second, during National Transplant Week, asks him to invite more friends to join the ODR. It contains a link to stories about some of the people who have received transplants, and also about those who have sadly died while waiting for transplants in the past year; he is invited to like and share this link with his friends.

In 2020, Joshua suffers a major stroke and, despite all attempts to save him, dies in hospital. While waiting for news, Tom keeps all their friends and family updated via social media.

When Joshua dies, a SN-OD comes to see Tom. She has Joshua’s organ donor card in her hand, which she has taken from his wallet. Tom’s first words are “Good, so you already know he wanted to donate his organs.”

At Joshua’s funeral, Tom explains that, while he will never stop grieving Joshua’s death, he takes some small comfort from knowing that other people will live as a result of Joshua’s generosity.

The difference between these two scenarios could be summarised as:

- The existence of artefacts to enable discussion
- Partnership links to the ODR
- Viral transmission of positive attitudes to donation
- The inclusion of donation within end-of-life and grieving process.

Ongoing contact will be crucial and will start to transition registrants towards feeling like ‘members’. In 2011 a public engagement study conducted by KPMG found that 63% of the public would be in favour of future contact from NHSBT after registering on the ODR. Of the options given, most people favoured infrequent (once every two years or less) contact; however, this question was asked in the context of “checking details are still correct” 27. Therefore, we would advise NHSBT to test responses to ongoing contact with a proportion of the database, probably starting with opted-in new joiners, before rolling out more widely.

4d. Target Audience Insight

There are two (overlapping) types of people whose behaviour we would want to change:

- Potential donors
- The families of potential donors.

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27 Organ Donor Register Public Engagement Study, KPMG, 2011.
What we know about potential donors

Everyone irrespective of age or health and who is considered legally competent can join the NHS Organ Donor Register. Children may join (although parental consent is required before donation can take place). In Scotland, requirements for gaining authorisation for the removal and use of organs from a deceased person for transplantation are laid down by the Human Tissue (Scotland) Act 2006 and are regulated by Scottish Ministers. While many of us may be willing to donate our organs, very few of us will be called upon to do so. Of the over 500,000 deaths in the UK every year only about 5,000 people die in circumstances in which donation might be possible, the most common causes of death being strokes and brain haemorrhages.

While anyone could die of a stroke or a brain haemorrhage, there is a demographic bias driven by age and influenced by lifestyle (such as smoking, obesity and alcohol consumption).

The profile of donors is therefore older than both the population in general and the profile of the ODR, in particular there are many more people in the 50-59 and 60-69 age groups and far fewer people in the 25-34 and 45-49 age groups.

Source: UK Transplant Registry/Organ Donor Register.

28 Guidance on requirements under the Act is available at: http://www.hta.gov.uk/_db/_documents/Information_about_HT_%28Scotland%29_Act.pdf
Both the ODR population and the population of those who subsequently donate are biased towards white British people relative to the UK population. Programmes are in place to engage more effectively with black, Asian and minority ethnic (BAME) groups and faith communities, however, the ability to assess the impact is hampered by the lack of relevant data. Going forward it is advised that NHSBT explore ways to collect more robust ethnicity and faith data to help track the effectiveness of activity with these audiences.

Source: UK Transplant Registry/Organ Donor Register.

There is also a conspicuous difference in the socio-economic position of donors relative to the ODR.

**ACORN** (acronym for *A Classification Of Residential Neighbourhoods*) is a geo-demographic information system categorising UK postcodes into various types based upon census data and other information such as lifestyle surveys.
The ODR population contains more “wealthy achievers” and “urban prosperity” than the population of potential donors, which is biased towards “hard pressed” and “moderate means”.

This bias is apparent when donors are compared to the UK population: 39% of people who donate are “hard pressed” or “moderate means” vs. 29% of the total population.

CACI, who owns the Acorn intellectual property, has provided helpful descriptors of Wealthy Achievers and Hard Pressed (see appendices).

Data were not available on the Acorn profiles of people responding to past campaigns. Based on the audience profile of the ODR, we would hypothesise that campaigns may well drive response from younger, higher socio-economic groups.

Going forwards, it is vital that NHSBT understand people from the “Hard-Pressed” and “Moderate Means” groups, particularly those aged over 50, so that they can rebalance the ODR towards people who will be more likely to donate.

**Insights into people in DE socio-economic groups**

There is a wealth of insight and information available from the research compiled by other Government departments, particularly the Department of Health and Public Health England, targeting the hard-pressed group and DE socio-economic groups in general. Since health problems typically manifest in mid and later life, much of the insights also centre on people aged over 50.
To summarise, it is known that:

- People in the DE socio-economic groups are less engaged with their health generally: they are more likely to smoke, to be overweight or obese and to have inactive or sedentary lifestyles; in later life, if they notice signs or symptoms of disease they may put off going to see the doctor for longer than is the case in wealthier, more highly educated groups.  

- This group can have a fatalistic attitude to health outcomes, being more likely to believe that “if you’re going to get ill, there is nothing you can do to change that.”

- They often have a tendency to place greater value on short term immediate benefits over long-term planning; some lead quite chaotic lives; they are less likely to engage in activities that require long-term planning, such as taking out a personal pension or making a will.

- While they are 45% more likely than the general public to have visited a GP in the past 12 months, they tend to be more critical of the NHS, to report that they did not feel involved in decisions concerning their care and to be unaware of the choices available to them.

- With regard to their media consumption, they tend to watch more television, and listen to more hours of radio than ABC1s; they are more likely to read tabloid newspapers than broadsheets; when they watch television news, it is more likely to be ITV than the BBC and they are less likely to watch documentaries.

- While mobile phone penetration is now high among all groups, people in the DE group are less likely to have a smart phone, a tablet computer or an e reader; they are less likely to use a second screen while viewing television. This is likely to change as the penetration of smart phones increases over the next couple of years.

- 79.1% of “Hard Pressed” use the internet and 76.1% use the internet once a day or more. DEs have higher numbers of friends on social networking sites (DE’s have 276 friends, vs. an average of 237).

- Within this group, family ties can be very close. For example it is more common for two or three generations to live in geographic proximity and to see one another frequently. Children can be important change-makers within households.
and adults may make changes to please their children that they would not make in their own interests.

- There is often greater emphasis on solidarity with one’s peers and one’s network over individual achievement or advancement, so decisions may be made at a household, family, community, faith or workplace, rather than individual level.

- People in this group often live their lives at a hyper-local level, being closely connected to their immediate community.

Whilst there is a wealth of insight available on the audience groups, it would be helpful for NHSBT to undertake a more detailed audience segmentation in order to inform and support campaign development.

What we know about Families of Potential Donors

In the UK, relatives are asked to give their consent to organ donation. Although this consent is not a legal requirement when the potential donor is on the ODR, in practice, clinicians respect the wishes of the family. If the individual is not on the ODR, the family’s decision is absolute. As part of the 2020 strategy, SN-ODs and CLODs are in active discussions about how to frame this question in order to maximise consent levels, for example moving from “do you know if he wanted to be an organ donor?” to “do you know if he had any objection to organ donation?” and we anticipate that such changes, if adopted, will impact consent rates positively.

Since they are from the same family, the socio-economic group of decision-makers will often (although not always) be similar to the socio-economic group of donors.

Given the broad age spread of potential donors, family decision-makers may be parents, spouses or partners, siblings, children or other family. Often, more than one person will be involved and time is taken to allow the family to come to a decision.

Interviews with SN-ODs and CLODs highlighted the complexity of this decision when many family members are involved, who may have different views. In some circumstances, families are reduced to voting:

“I’ve had one family had a vote, and I lost it four to three.”

(Depth interview)

One of the challenges is that about half of all people have not spoken about donation.

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38 For example, see: Change4Life Three Year Marketing Strategy, Department of Health October 2011.
39 Ibid.
40 See: Tobacco Control Marketing and Communications Strategy 2008-10, Department of Health.
41 Not only do the family need to give legal consent, but their cooperation is needed to establish the medical and social history of the potential donor; donation is thus not possible without the family’s active involvement whether or not the individual’s donation wishes are known.
The numbers who have talked about organ donation are even lower in Wales and Northern Ireland: 38%\(^42\).

The top reason for this in the Optimisa research is that “it’s never come up in conversation” (44%), followed by “I don’t want to talk about death” (22%)\(^43\).

Only 40% of people are aware that they will be asked to agree to donation regardless of whether or not their loved one is on the ODR\(^44\). Families are thus in a truly unenviable situation: they may not know their loved one’s wishes and they are asked for a decision they did not realise was theirs to take. The pain families experienced was described in one of our depth interviews:

“So the worst thing we can do... is ask a family and then they genuinely don’t know what their loved one wanted and then, regardless of what they say, yes or no, that does literally live with them every day of their life. And for the ones who say yes, they kind of take solace from the fact someone’s lives were

\(^{42}\) Public Attitudes to Organ Donation, Baseline Survey 2013 & Organ Donation: Public attitudes and stakeholder engagement in Northern Ireland 2013.

\(^{43}\) Optimisa Research, 2013.

\(^{44}\) Ibid.
saved even though they didn’t know what their loved one wanted. But the ones who say no, the guilt and the not knowing is terrible. I’ve interviewed these people and you’re visibly moved by... because you think ‘God, these people live with this every day’.”

We do not know a great deal about the processes families go through in making their decisions. This is understandable, as, while there is support available for families from SN-ODs and CLODs, much of the discussion will happen in private.

When surveyed, people express support for organ donation. However, there may be a world of difference between theoretical support for donation, and the reality of making a donation decision at a time of profound shock and grief.

To date, no detailed research has been conducted into the reasons families refuse at the point of consent. Observational research (such as ethnography) has proved difficult, due to the sensitive nature of the situation. It is, however, something we would urge NHSBT to pursue further.

Currently 43% of all families refuse consent (52% when the donor is not on the ODR). When questioned, the main reasons families give for refusing consent are that the patient had either stated in the past that he or she did not want to be a donor or that the family suspected that he or she did not want to be a donor.

### REASONS FOR NOT TALKING ABOUT ORGAN DONATION

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s never come up in conversation</td>
<td>44%</td>
</tr>
<tr>
<td>I don’t want to talk about death</td>
<td>22%</td>
</tr>
<tr>
<td>I haven’t got around to it yet</td>
<td>13%</td>
</tr>
<tr>
<td>I worry that it might upset people</td>
<td>12%</td>
</tr>
<tr>
<td>I didn’t think that I needed to</td>
<td>11%</td>
</tr>
<tr>
<td>I don’t think other people would be comfortable speaking about it</td>
<td>9%</td>
</tr>
<tr>
<td>Donating organs is a personal choice - I don’t need to talk about it</td>
<td>8%</td>
</tr>
<tr>
<td>I’ve never really thought about organ donation before</td>
<td>7%</td>
</tr>
<tr>
<td>It might divide opinion/cause an argument among family/ friends</td>
<td>6%</td>
</tr>
<tr>
<td>I wouldn’t feel comfortable speaking to anyone about it</td>
<td>5%</td>
</tr>
<tr>
<td>I feel like it would be tempting fate</td>
<td>5%</td>
</tr>
<tr>
<td>I think they would know how I felt about it without me telling them</td>
<td>5%</td>
</tr>
<tr>
<td>I would worry that they might object to my opinion</td>
<td>5%</td>
</tr>
<tr>
<td>NET: Not a conversation I’ve thought about having</td>
<td>66%</td>
</tr>
</tbody>
</table>

Why have you not spoken to anyone about organ donation? Base: Net respondents that have not spoken about organ donation (491)
We should emphasise that these questions are asked at a highly emotional time. SN-ODs and CLODs we spoke to suspected that there might be deeper or more complex reasons driving families’ decisions, but that they recognise that it is inappropriate to probe too deeply at such a sensitive time (and indeed that families might find it hard to verbalise what they are feeling).

In 2007, a team of researchers interviewed families who had refused organ donation. Their research found that:

“Donation decisions depended on a number of converging factors in each situation and not necessarily on the views of relatives about donation, or the reported wishes of the deceased in life, except if the person had stated that they did not wish to be an organ donor. Therefore, reported pro-donation views held by the family, or the deceased in life, did not guarantee donation. Protecting the dead body, which related to keeping the body whole and intact was the most frequently-recurring theme.

“‘Families’ wishes to protect the dead body may stimulate tension between the notions of ‘gift of life’ as supported by transplant policy and ‘sacrifice’ of the body, which must be made if organ donation is to proceed. This could account for the decision of participants to decline donation even if their deceased relative previously held positive views about organ donation.”

This was backed up by anecdotal evidence from the workshops we held with stakeholders and suggests that many families, when faced with the decision of whether to allow donation “default to no”; reasoning perhaps that it would be worse to give away an organ against the deceased’s wishes than to retain an organ against the deceased wishes. Organ donation requires something to be done; refusal does not. Behavioural economists call this phenomenon inertia (the tendency to maintain the status quo). Inertia can be overcome either by making the desired action easier or by providing a powerful motivator, so that families see a benefit to themselves in donation.

In a recent television programme, Steve Ince, father of donor Tom Ince, described his feelings when faced with this decision:

“It would have been easier, if I am honest, to say no. It would have been much easier to say, ‘No, leave him alone, he’s been through enough. I don’t want you to touch him.’ But that wasn’t Tom’s wish. That was just me as a father trying to protect him, but if we had wavered, there would be people who wouldn’t be alive today.”

46 The Greatest Gift, ITV1, December 19, 2013.
Here, Mr Ince powerfully describes his need to “default to no” but also explains two powerful motivators: the satisfaction of having respected his son’s wishes and the consolation of knowing that lives were saved.

**What we know about black, Asian and minority ethnic (BAME) families and faith groups**

BAME families are less likely to give their consent to donation. This compounds an already hazardous situation for potential BAME recipients: people from BAME communities are up to three times more likely to need an organ, but less likely to donate one. Ethnicity matters because a good match is more likely if the donor and recipient are from the same ethnic group.

Some of the reluctance to donate may be due to differing attitudes towards the NHS and its role in British society. Research has shown that black and Asian people are more likely to be critical of NHS care; Asian people are more likely to be critical of NHS waiting times and to be less likely to believe that the NHS is “crucial to British society”\(^{47}\).

Other reasons may relate to religious or cultural practices. While no major UK religion is opposed to organ donation, different ethnic and faith groups have different concerns, often relating to burial or cremation practices or beliefs about the afterlife for example:

- Some Muslim scholars object to organ donation on the grounds that, after death, the body belongs to Allah and so the organs are not anyone’s to give away, resulting in what could be seen as a desecration of the body\(^{48}\).
- While no religious law prohibits Hindus from donating their organs and tissues, a minority argument says that, if someone donates an organ as intrinsic to the body as a heart, the recipient will have to return the favour in the donor’s next life\(^{49}\).
- There are no objections to donation within Sikh faith communities, Jewish communities or Buddhism. However, individuals may have concerns about practical issues:

\begin{quote}
All my research with all communities shows that the biggest issue is people didn’t know anything about organ donation and then, when they think about it, people will say “I want to know what’s going to happen to my body, whether a burial or cremation will be delayed”.
\end{quote}

(Depth Interviews)

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\(^{47}\) Understanding Public and Patient Attitudes to the NHS, IPSOS MORI 2006.


\(^{49}\) ibid
Among predominantly Christian communities, there are different cultural practices:

“We bury our dead quite quickly, it’s unusual for someone not to be buried within three days of dying in Northern Ireland, so people think ‘if I do that it’s going to hold it up’.”

(Depth Interviews)

### 4e. Behaviour change objectives

Given what we have said so far, we would propose the following seven-year objectives:

<table>
<thead>
<tr>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>To 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</td>
</tr>
<tr>
<td>To stimulate conversations and debate about donation particularly through leveraging the ODR as a marketing tool</td>
</tr>
<tr>
<td>To present donation as a benefit to families in end-of-life and grieving process</td>
</tr>
</tbody>
</table>
5. Delivering the objectives

There are three objectives for behaviour change:

- To 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
- To stimulate conversations and debate about donation particularly through leveraging the ODR as a marketing tool
- To present donation as a benefit to families in end-of-life and grieving process

5a. To increase the number of people on the ODR by at least 50%, rebalancing it towards people who are older (50+) and from DE socio-economic groups

On the surface, there are few barriers to joining the ODR. In a recent survey, 45% of people who are not currently on the ODR claimed, when asked, that they “would join now if it was possible to do so” (although willingness is lower among BAME groups).

![Likelihood of registering on ODR 'right now'](image)

<table>
<thead>
<tr>
<th>'General population' not registered</th>
<th>45</th>
<th>34</th>
<th>22</th>
</tr>
</thead>
<tbody>
<tr>
<td>BME not registered</td>
<td>16</td>
<td>66</td>
<td>18</td>
</tr>
</tbody>
</table>

*Source: Q5- If it were possible to do so, would you put your name on the NHS Donor Register right now? Base: all 'general population' sample (n=1,560) / all BAME sample (n=1,463)*


Making joining as simple and easy as possible could thus be expected to boost registration, indeed a recent pilot into prompted choice, created in conjunction with the Behavioural Insights Team at the Cabinet Office, showed that it was possible to increase the numbers of those joining through the DVLA website by up to 96,000 people per annum from this source alone at no additional cost.\(^{50}\)

Beyond increasing the rate at which people join, NHSBT also needs to change the profile of the ODR, by over-delivering on groups who are more likely to donate.

There is good learning available here from Scotland, which in 2010 piloted a direct mail campaign to a million people, aged over 35 and not on the register. This earned

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\(^{50}\) Applying Behavioural Insights to Organ Donation: preliminary results from a randomised controlled trial, Cabinet Office, December 2013.
an impressive 13% response rate and was followed up by an equally successful ‘member-get-member’ programme.

We would advise NHSBT to learn from the Scottish experience and develop a pan-UK (with appropriate customisation for Wales) direct marketing campaign (electronic and postal), to those groups known to be under-represented on the ODR, such as those who would be classified as hard-pressed by Acorn.

In addition, we recommend a programme of pilots including:

- Further use of Government transaction sites (e.g. passport applications, HMRC)
- Face-to-face outreach through government and third sector agencies already active with the core target audience (e.g. Job Centre Plus and Heart Start training)
- Activity with and via human resources departments in major workforces, such as the Royal Mail, Asda, Amazon, Tesco, etc. In particular, we recommend a lead-by-example campaign within NHS workforces, where all senior management publically endorse donation and encourage all NHS workers to join the ODR and be ambassadors for donation\textsuperscript{51}
- Additional direct marketing, co-branded with the relevant charities, to those members of their databases who are at elevated risk of needing an organ in future (for example because they have type two diabetes), stressing the reciprocal altruism message
- Partnerships with organisations that speak to people who are planning for their death, such as solicitors and funeral directors
- Train the trainer programmes, involving volunteers attached to local transplant units
- Local engagement (e.g. pairing of local dialysis units with major employers).

The proposition for this activity should be “reciprocal altruism” (expressed in the example below as “If you needed an organ transplant would you have one? If so please help others.”) since recent work by the Behavioural Insights Team at the Cabinet Office confirmed that this was the most motivating message to encourage sign-ups to the ODR.

\textsuperscript{51} Anecdotal evidence suggests that NHS staff are currently no more or less likely to support donation than the general public.
It could be argued that one of the reasons “reciprocal altruism” is so powerful is that it utilises Terror Management Theory\textsuperscript{52}, which argues that most human action is taken to ignore or avoid the inevitability of death. By joining the ODR, the registrant is symbolically insuring him or herself against the possibility of dying from organ failure.

\textit{Note on duplication in the ODR}

NHSBT informed us that one third of the people who complete the ODR joining form online each year are already registered. NHSBT is rigorous in cleaning and “de-duping” the ODR (so that these people are not double counted in the annual reports of registrations). However, the statistic suggests the following:

- A third of response duplicates previous actions; while this may have some value (e.g. reconfirming the individual’s positive attitude towards donation), it is inefficient
- Either people lack confidence that NHSBT still knows they are on the ODR (which is possible, since the ODR is twenty years old, and people may underestimate NHSBT’s ability to keep track of them through house moves, name changes, and email address changes) and/or
- People have forgotten that they are on the ODR (likely, since they may have joined up to two decades ago and as a side step in an unrelated transaction).

\textsuperscript{52} See: the Denial of Death, Becker, E, 1973.
This indicates that NHSBT needs to continue communicating with people to remind them that they are on the ODR. Re-registrants should be included in all new joiner communications.

5b. To stimulate conversations and debate about donation particularly through leveraging the ODR as a marketing tool

About half the population have never discussed organ donation, with people in the DE socio-economic group less likely than ABs to have discussed it. 39% of those who believe they are on the ODR have never told anyone about their decision to donate, or do not remember doing so\textsuperscript{53}.

This suggests that:

- People need acceptable prompts or conversation starters. These could be interesting pieces of content (for example the recent ITV ‘Greatest Gift’ programme, with which NHSBT took part)
- People need support to manage and help to “contain” the conversation: ideally we’d like to be able to help people convey that they are registered to be an organ donor, suggest that others also register to become a donor, without straying into a Big Conversation about DEATH. The “I have” work that NHSBT has recently developed starts to move into this area but could go further.

A more deliberative approach has already been piloted locally in Nottingham, where a highly cost-effective (£25-30,000 in total) integrated campaign was developed comprising face-to-face events, local PR, outreach from the local dialysis unit, use of local celebrities, such as footballers, radio phone-ins (acknowledging both sides of the debate, e.g. “tell me why you don’t want to be a donor”). It succeeded not only in boosting registration but in boosting consents. This activity generated an additional 14 consents (21 vs. 7 for the same 5 month period in the previous year).

This resulted in 19 extra transplant recipients (35 vs. 16)\textsuperscript{54}.

\textsuperscript{53} Understanding current attitudes and behaviours towards organ donation within England, Optimisa Research, 2013.
\textsuperscript{54} Nottingham University Hospitals Deceased Donation Data 2012-2014. The five month periods being compared are Apr 1 – Aug 23 2012 and Apr 1 – Aug 23 2013.
We would recommend that the Nottingham example, along with the experience of other areas of good practices such as Torbay, Worcester, Glasgow and Clyde, be mainaulised into a toolkit that other local areas can use to replicate the experience.

Additional channels for increasing conversations about donation (and making the future donor’s wishes known) include:

- Expanding the use of the organ donor card beyond new registrants, and considering alternative physical and virtual symbol(s) of intent to donate
- A relationship management programme, piloted initially with opted-in new ODR joiners, to encourage them to talk to their families; this should include genuinely new registrants and those who are already on the register and have joined again (since if they have forgotten they are on the register, they are unlikely to have told family members)
- Editorial content, particularly case studies
- Social media, particularly creation of viral content
- Programmes that focus not only on recruiting children but in using children and young people as agents of change within the family, prompting discussions about donation and encouraging their parents and grandparents to join the ODR
- Face-to-face events, where people can have their concerns considered and addressed
- Community and faith engagement programmes that allow faith leaders to lead discussion on donation
- Further utilisation of National Transplant Week, e.g. integrating it with other events such as the Order of St. John Award.

There is scope to develop and test new propositions in this area. For example, the recent Optimisa research found that 77% of respondents believed that organ donation is the individual’s choice and not for others to decide, moreover 71% (rising to 78% among those who definitely wanted to donate their organs) said that “it annoyed me to think that my wishes might not be respected”.

This sentiment is reflected in Wales. Almost three quarters (73 per cent) of Welsh respondents in a public survey agreed that the deceased person’s wishes about donating their organs should be respected, no matter what the family thinks55.

Meanwhile, in Northern Ireland two thirds of respondents (64%) agreed that ‘it is not acceptable for your family/close friend to overturn your wishes to become an organ donor in the event of anything happening to you’56.

Based on this, we would recommend developing and testing communications based on a “make sure your wishes are honoured” proposition.

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55 Public Attitudes to Organ Donation, Baseline Survey 2013.
56 Organ Donation: Public attitudes and stakeholder engagement in Northern Ireland 2013.
5c. Presenting donation as a benefit to families in the grieving process

This is the most challenging task but it will be crucial if NHSBT is truly to deliver a revolution in public behaviour. While there is a role for clinical/hospital based interventions, public engagement on this subject will be fundamental to success.

Currently, transplantation is viewed as a benefit to the recipient first and the donor second (who, in life, has the comfort of thinking that someone may live as a result of their generosity). However, the decision to donate is taken by, or in conjunction with, the donor’s family. For families, this decision can bring distress and guilt, however it is made. Donation is currently a separate process, not yet a fully integral part of end-of-life care and has no perceived function, indeed it potentially holds up the process of burial and grieving.

As a culture, we tend to be reticent about death. However, one of our interviewees pointed out that the current debates around right to die and end of life care provide an opportunity to open up a wider debate around what constitutes a good death:

“People are starting to talk a bit more about death and end of life care. I think medicine’s advanced to such an extent that we’ve been very successful in prolonging life, but much less successful in prolonging good quality life. There’s been a discussion about euthanasia in the Supreme Court this week; there are discussions about right to die and assisted suicide; we’re having Dignitas in various countries or equivalent. I think people are starting to talk more openly about it.”

Research examining bereaved families’ experiences of donation highlighted that, for some families, donation was associated with a belief that their relative would “live on” (transcendence) through the recipient:

“We underplay issues like the benefits to the family... we say it does good to the recipient but it also does good to the family”

(Depth interview)

“You’ve got to find some tools that give you the mechanism of carrying on or surviving, whichever way you want to describe it, and one of the tools that gives you that mechanism and purpose is certainly organ donation, without a shadow of a doubt.”

(Depth interview with donor family)
good nature going into them, because she was very good natured, she didn’t get angry and that and do anything to anyone. I thought, so in a way part of her lived then. Perhaps part of her will actually come to life.”

Charities who gain significant income from legacies refer to a similar phenomenon of “symbolic immortality”, the belief that, when a person has died, something of his or her spirit lives on through a gift. This thought can be a considerable consolation to families and friends in the grieving process.

Donation remains a rare occurrence. Most people who have to make a donation decision will not have the benefit of knowing someone who has received or is waiting for an organ, nor a family who have donated. We need to find ways to make the stories of those who have done so more salient so that more people feel they “know of” someone who has donated and it is perceived as being “normal” and is less of an exceptional or rare act.

We doubt that it will be possible to engage people with conventional communications, such as advertising, on this issue. However, communications vehicles that work over longer time lengths, deliberate an issue and tell a story (such as editorial, case studies, advertiser-funded programming) have the potential to take people through this thought process, so that, if they ever find themselves having to make a donation decision, they have a predisposition towards donation and can recall a positive role model.

We would observe that these communications need to provide a degree of “edutainment”: outside of school, people seldom engage with content that is preachy; there needs to be some reward for reading or viewing.

Indeed this sort of messaging has been used already in the editorial content developed as part of the programme of activity in Nottingham (see page 39 for more details):

There is also a need to address some common misperceptions about organ donation (for example that, following donation, an open coffin is not possible). This is

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S7 Bereaved families experiences of organ and tissue donation, Sque et al., University of Wolverhampton, June 2013
currently being done as part of a new, broader public awareness campaign developed in Northern Ireland which may well have wider applicability.

**CONCERNS RELATING TO ORGAN DONATION**

- I worry hospital staff might not do their best to save my life: 18%
- I don’t want to think about death: 16%
- I worry my family might be upset if I donated my organs: 15%
- I worry I could still be alive when they do the operation: 12%
- I don’t want to donate to someone who does not deserve it: 11%
- I don’t know enough about it: 11%
- I’m too old - my organs wouldn’t be of any use: 10%
- I would worry my organs wouldn’t be used for transplantation: 9%
- I want my body to be whole when it is buried or cremated: 8%
- I don’t want suffer after death: 5%
- I can’t give blood so I don’t think I could donate my organs: 5%
- I worry that organ donation will delay the burial or cremation time: 4%
- I have an illness that will stop doctors wanting my organs: 4%
- I think organ donation is against my religion/faith: 2%
- I wouldn’t accept an organ transplant, so I wouldn’t donate an organ: 2%
- I think organ donation is against my culture: 1%
- I don’t want to donate to someone from a different religion/faith: 1%
- I don’t want to donate to someone from a different community to me: 1%
- None of these: 39%

_Q03b. Which of these apply to you when thinking about whether you would consider donating your organs after death? Base: Nat Rep All respondents (100?)_

There is scope to develop and test the messages that have been created by both Nottingham and Northern Ireland along with new propositions in this area.

6  Additional communications requirements

6a. Dedicated communication for black, Asian and minority ethnic communities

Clearly there is a need for further engagement with BAME communities.

The depth interviews conducted for this project, combined with the desk research, revealed that some religious groups and faith leaders have felt that NHSBT “glossed over” their concerns in the past, or failed to appreciate the nuances and complexity of their position, because it was keen to establish a pro-donation faith consensus.

In recent years, NHSBT is felt to have been listening more and to be more open to debate, diversity and dissent. This is reflected in the faith engagement strategy, which calls for more engagement, particularly at a local level and with those working in health services; a review of languages used, to reflect an increasingly diverse population; involving staff in sharing best practice relating to effective faith engagement; liaising with the Faith Communities Engagement Team at the Department for Communities and Local Government; and ensuring all faith-based media are actively engaged with organ donation via interviews with faith leaders, news stories, paid-for TV features, etc.

This new approach is in line with the evidence base on engagement with BAME communities. For example, a recent international review of 18 mass media and educational interventions which aimed to increase rates of organ donation among BAME populations, noted that:

“Mass media interventions alone reported no significant change in the intention or willingness to register. Educational interventions either alone or combined with mass media approaches were more effective in increasing registration rates, with a strong interpersonal component and an immediate opportunity to register identified as important characteristics in successful change.”

Significant engagement work with BAME and faith communities is also underway in Wales as part of the communications programme for the introduction of a soft opt-out system (see below), and there may be opportunities to learn from those experiences.

6b. Bespoke communication for Wales

The National Assembly for Wales voted in July 2013 to introduce a soft opt-out system for consent to deceased donation. This will apply to adults (over 18s) who are ordinarily resident in Wales for 12 months or more. Under the new system, which will apply from 1 December 2015, people will have the choice of either opting in,

opting out or doing nothing and having their consent deemed – which will be the same as choosing to be a donor.

At launch, the Welsh Minister for Health and Social Services predicted that the move would increase transplant rates by 25%\(^60\). There are grounds for confidence in this assertion. Analysis published in 2006\(^61\) concluded that:

“On the whole... when other determinants of donation rates are accounted for, presumed consent countries have roughly 25–30% higher donation rates than informed consent countries on average”.

The Welsh Government reviewed the international evidence in December 2012\(^62\) and concluded that an association exists between presumed consent legislation and increased donation rates. Welsh Ministers have always acknowledged that legislative change must be seen as one of a number of measures to be taken to improve the donation rates. They expect the new legislation to provide the conditions and context for altering societal attitudes and behaviour towards consent to organ donation.

In introducing a legislative change, the communications task is thus very different in Wales to the rest of the UK. The Welsh Government is now undertaking a two year programme of communications in order to inform the Welsh public about the legislation change. The requirement is less for a behaviour change campaign than for a communications campaign that enables the smooth introduction of legislation which is itself designed to change behaviour.

The objectives of this campaign are:

- To explain the rationale for the legislation to Welsh people
- To ensure that citizens understand their choices (and what will happen if they do not make an express decision to either opt in or opt out)
- To signpost people to the opt-in and opt-out facility
- To ensure that discrete audiences (such as border populations and students) understand the implications for them.

The team in Wales has put together a thorough and professional communications programme, which was launched two full years before the legislation comes into force. The communications campaign is themed around “time”, and has three distinct phases:

- Time to think about organ donation
- Time to talk about organ donation
- Time to choose.

\(^60\) http://www.bbc.co.uk/news/uk-wales-25168045.
£2 million has been set aside for this campaign and a thorough programme of monitoring and evaluation has been put in place.

As well as conducting a traditional paid-for campaign, there are or will be a number of specific pieces of work, including:

- Ensuring that people who live on the border are clear on which system applies to them
- Engaging with the student population, who may be considered as ordinarily resident in Wales during their course of study at a Welsh university
- Reaching parts of the community which may not consume traditional media, including those from BAME and faith groups, ensuring that people with sensory impairment or those who lack capacity have the information they need in accessible formats
- Aiming communications at children and young people through a mixed media approach
- Working with stakeholders, charities and their supporters to maximise the opportunities to provide information via their various events and media outlets.

6c. Role for traditional paid-for media, such as advertising

Much of NHSBT’s previous investment has been in paid-for channels, particularly advertising. While these channels have been successful in driving rapid response, they are costly:

- The Scottish campaign, developed in 2007, delivered an extra 108,000 registrants to the ODR at a cost of £340,000, i.e. £3.14 per additional registrant.
- The English campaign, developed in 2010, delivered an extra 96,000 registrants to the ODR at a cost of £1.2 million, i.e. about £12.50 per additional registrant.

It should be stressed that both campaigns generated significant additional free media coverage in the short term and had the potential to pay back over the long term (since organ donation is a cost-effective procedure). However, relying on paid-for channels to deliver an additional seven million registrants above the run rate (i.e. to double annual registrations) would require an investment in paid-for media that may be cost-prohibitive in the current economic climate (given the many other tasks for marketing):

- Assuming a cost per registrant of £3.14, the required budget would be £22 million over seven years

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63 Life After Death: the difficult business of signing people up to the Organ Donor Register, Moffat G et al., IPA Advertising Effectiveness Awards 2007.
64 Organ Donation: when it is better to receive than to give. Angear, B, APG Creative Planning Awards, 2011.
- Assuming a cost per registrant of £12.50, the required budget would be £87.5 million over seven years.

While we can foresee a role for paid-for broadcast communication going forwards, we do not recommend it as the lead medium. Its role should be less to drive registration and more to spark debate and create a positive climate in which other activities can boost registration.
7. **How this strategy works with other levers to change behaviour**

The National Institute for Health and Care Excellence (NICE) issued guidance on using theoretical models of behaviour change to design health interventions in 2007. Having reviewed the available literature on behaviour change models, NICE did not recommend a specific model for health behaviours, commenting that:

“The psychological literature is extensive and provides a number of general models of health behaviour and behaviour change. However, the research literature evaluating the relevance and use of these models is inconsistent. For example, it includes multiple adaptations of particular models, poor study designs and studies that fail to take account of all the confounding factors. Having considered some of the more commonly used models of health behaviour, the Programme Development Group concluded that the evidence did not support any particular model.”

Further, NICE is currently updating its guidance. The draft of the new guidance has been sent out for consultation. The text of the draft guidance indicates a further hardening of NICE’s stance against the use of behaviour change models, particularly linear models, such as Prochaska and Diclemente’s “Stages of Change”:

“The Programme Development Group was concerned that training programmes still describe the stages of change model (also known as the transtheoretical model) as a theoretical basis for behaviour-change interventions. The PDG wanted to highlight that, although it may help practitioners to understand their client’s experience of behaviour change, it is not a theory that explains and predicts such change. It noted that the evidence indicates that interventions based on this model alone are not effective.”

We have not, therefore, recommended a specific behaviour change model for organ donation. What follows below is a registrant journey, showing the various touch points at which activity might trigger change. It should not, however, be viewed as a linear or sequential model. We do not expect each (or indeed any) individual to move through each stage; rather, each will make his or her own journey; the purpose of the diagram is to flag the various points at which interventions might be possible.

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8. **Budget**

In recommending a budget, we have been mindful of three questions:

- What level of investment would deliver a positive return on investment?
- What level of investment is proportionate to the task?
- What level of investment is required to meet immediate and future needs?

**Delivering a return on investment**

Organ transplantation is cost saving. Work in 2010 showed that the organ transplantation programme delivered a return on investment to the NHS of £316 million per annum\(^\text{67}\), or £40,000 per organ transplanted. Increasing the number of organs transplanted would deliver further savings. Since a deceased donor gives on average three organs for transplant, one family’s decision to consent to donation delivers approximately £132,000 to the NHS\(^\text{68}\).

Unlike other health programmes, where savings to the NHS may take many years to realise, the financial return from organ transplantation starts immediately. It is thus an excellent candidate for investment.

Meeting the 80% target would require an additional 658 families a year to be persuaded to consent to donation. Since each of those additional decisions would individually deliver a return of £132,000, meeting the 80% target would deliver a cost saving to the NHS of £86 million. Thus, NHSBT could invest £50 million per annum in meeting the target, and still deliver a substantial positive return.

Clearly, however, such a budget is inappropriate in the current economic climate (and indeed unnecessary).

**What level of investment is proportionate to the task?**

Most publicly funded consumer engagement to change health behaviours is managed by Public Health England (PHE), which details its budgets, following scrutiny and approval by the Cabinet Office, in its annually-published plans.

The last published budgets for PHE’s three major campaigns were:

- **Smoking cessation\(^\text{69}\):** £13.3 million
- **Healthy older people\(^\text{70}\):** £12.2 million
- **Change4Life\(^\text{71}\):** £10.9 million.

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\(^\text{67}\) West Midlands Specialised Commissioning Team: *Organs for Transplants: An analysis of the current costs of the NHS transplant programme; the cost of alternative medical treatments, and the impact of increasing organ donation*, October 2010.

\(^\text{68}\) This is based on the average donor donating 3.3 organs.


\(^\text{70}\) Ibid.

\(^\text{71}\) Ibid.
Note that these three campaigns included television as well as press, outdoor advertising, digital products and tools, direct marketing, PR and extensive local marketing. Importantly, the campaigns also leverage significant spend from outside of the public sector, through partnership and earned media, so in reality the total investment is higher.

It is therefore not unrealistic for NHSBT to argue for an annual budget in the region of £10 million by year seven. Based on our calculations above, if the programme meets its objectives, such a budget would deliver a return on investment of over £13 for every £1 invested.²²

What level of investment is required to meet immediate and future needs?

While many of the recommendations in this strategy concern the rolling out of initiatives that have already been tested (and evaluated) on a smaller scale, there are also some newer (and riskier) proposals.

We therefore recommend that NHSBT test and pilot each new initiative, so that the impact on public behaviour and on transplant rates can be modelled. The budget for year one will thus be considerably lower than year seven. Any increase on the year one budget would thus be justified on the basis of proven results.

We have proposed an estimated budget for all the recommendations for year one (see page 34 of the Delivery Plan). If all of these are adopted it would require a minimum budget of £2 million for 2014-15.

Budget increases post 2015 will depend upon the rate at which data can be collected and analysed (and the capacity within the system to roll out multiple initiatives). Where possible, we would urge NHSBT to calculate the cost per additional consent, to aid in the planning of roll-out budgets.

Based on our experience of delivering other campaigns within the public and private sector, we recommend planning for an “S Curve” in expenditure, as follows:

²² Reaching 80% = 658 additional donors = £131.6 million (658 x £200,000) = ROI of 13/1.
9. The trajectory of registrations and consent rates

The below illustration shows the potential trajectory of both registrations and consent rates and is intended to be indicative of the outcomes to be expected over the seven year period covered by the strategy. As can be seen, the increase in registrations will be steady and start immediately, plateauing in years three/four, as registrations are expected to peak. On the other hand, the changes in the consent/authorisation rates will not increase dramatically for a number of years, but will gather pace and rise exponentially as donation is normalised.

This assumes:

- That there is a budget available to invest in public engagement and activity and this is sustained for the full seven years
- That there will be a “peak” in registrations for the ODR at around 30 million.
10. Risks and mitigations

Organ transplantation carries risk; organ donation is a highly emotional subject; human behaviour and responses to stimuli are unpredictable; and different people may respond in different ways. We would therefore recommend that NHSBT follow a programme of testing, learning and refinement for all new initiatives. A good model to follow would be that employed by Public Health England (formerly in the Department of Health) in its Be Clear on Cancer campaign, which tested each new message locally, regionally and then nationally, so that the impacts on public understanding and attitudes, behaviours within the NHS and demand for services could be modelled.73

The people who might be called upon to tell their stories include donor and recipient families and people waiting for organs. These can be vulnerable, grieving or despairing people. The ethics of exposing them to publicity need to be properly considered and their emotional and practical needs considered and met.

There are other risks that need to be thought through. Allowing people to tell their stories more openly threatens the anonymity of donation (since organ donation is still a relatively infrequent occurrence and people can work out who their donor/recipient was). Moreover, the archetype of a donor in popular culture tends to be a young, healthy individual, tragically killed in a car accident. Showing a more typical spread of donors could further open up the current media debate on the use of high risk organs.

In rolling out programmes, it is important that success factors be clearly identified (to avoid, for example, roll out of a national campaign without the local on-the-ground support that may be crucial to its success) and risks (and their mitigation) flagged. Where possible, we would recommend that a toolkit or manual be produced so that others can follow the success model.

Further, the new strategy will necessitate the development of a risk register and crisis management plan for each new initiative.

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11. Evaluation Framework

We would recommend that NHSBT measure its progress against this strategy and framework over the next seven years by putting in place a rigorous evaluation programme. In this, it should follow best practice across Government by conforming to the Cabinet Office evaluation framework (reproduced below):

Applying this framework to NHSBT’s marketing would require that it measure:

<table>
<thead>
<tr>
<th>Out-takes:</th>
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<tbody>
<tr>
<td><strong>Aim</strong></td>
<td>Demonstrate understanding of organ donation, and improved knowledge around common myths.</td>
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</tbody>
</table>

Use key questions to establish knowledge level. Questions should include:

Knowledge of ODR:
- If you sign up to the ODR you have to give all your organs
- Signing up to the ODR ensures that your organs will be donated after your death.

Knowledge of organ donation and consent:
- There are not enough organs available for transplant
- My organs might not be used for transplantation
- There is an age limit on who can donate
- Hospital staff might not do their best to save my life if they knew my organs were available for donation
- Organ donation will delay the burial or cremation time
- I think organ donation is against my culture
- I think organ donation is against my religion/faith
- I could still be alive when they do the operation
- It is not possible to have an open coffin if organ donation has taken place.

Demonstrate a continued improvement in positive attitudes towards donation.

Use key question to establish attitudes:
- I support organ donation.

Demonstrate a continued improvement in emotional measures. Use key questions to establish feelings:
- If someone I loved were to die I would take some comfort from knowing that their organs had been used to save the life of another person.

<table>
<thead>
<tr>
<th>Methodology</th>
<th>Online panel survey tracker, which could be combined with some face-to-face quantitative surveying. This would help ensure that hard-to-reach audiences are included.</th>
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<tbody>
<tr>
<td></td>
<td>The sample needs to be representative of the UK population with a BAME boost if needed. A sample size of at least 1,000 people is recommended with a boost of around 500 BAME’s.</td>
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<td></td>
<td>Although everyone would be asked about the influence of religion, family and community on organ donation, specific attention would need to be paid to BAME responses.</td>
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<td></td>
<td>There is always a risk of false self-reporting where channels are concerned, so agencies should be asked to ensure that answers are weighted appropriately.</td>
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<td></td>
<td>The survey should also cover channels. NHSBT needs to ascertain which channels are proving most effective in improving knowledge. We would ask people to recall where they have seen messages and what they remember from the messages.</td>
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<table>
<thead>
<tr>
<th>Frequency</th>
<th>The survey needs to be run pre-the launch of any new activities to establish a baseline.</th>
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<tr>
<td></td>
<td>The first evaluation should be run at the end of March 2015 at the end of the pilot period. This should be followed by an annual panel survey along the lines of year 1, unless volume of campaigns and communications necessitates</td>
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</table>
**Intermediate outcomes**

| **Aim** | Increase in conversations about donation, signing up to the ODR, transplantation and end of life.  
Set a baseline of the levels of conversations/discussion had through various channels using the tracking survey outlined for measuring the out-takes.  
More people registering on the ODR particularly those from lower socio-economic and BAME groups. |
| **Methodology** | Panel and face-to-face tracking methodology as outlined above.  
Monitor levels of conversations on NHSBT’s Facebook and Twitter page. This monitoring would include volume and tone of conversations as well as, where possible, the types of people who are having the discussions.  
Monitor levels of conversations on non-NHSBT social media.  
Use software such as sm2, Topsy or Radian 6 and human tracking to monitor non-NHSBT owned social media. This monitoring would include volume and tone of conversations as well as, where possible, the types of people who are having the discussions. N.B. there is a limit to how much these pieces of software can capture due to privacy settings.  
Track ODR registration by channels.  
Tracking of new sign ups to the ODR to include all demographics.  
Specific analysis will be needed to ensure sign ups from lower socio-economic groups and BAME are captured. |
| **Frequency** | Use current levels of registration for each audience segment as a baseline at the beginning of year one.  
Then annual tracking survey and data analysis. |
| **Outcomes** | Increase in consent rates. |
| **Aim** | In addition to the information currently captured, the Potential Donor Audit (PDA) needs to include the following for all stages in the donor journey:  
- Acorn profile  
- Region of residence of donor  
- Whether the next of kin can recall discussing organ donation with the eligible donor; relationship of next of kin to donor. |
(Some of the above are on the PDA but not at every stage and are not always reported on.)

Econometric modelling may also be utilised to ascertain the effect of NHSBT communications and partnerships versus other factors. It does this by computing all factors that may affect consent rates and calculating the size of the effect that they may have on consent rates. These factors would include:

- NHSBT communications and partnerships
- Media coverage around organ donation
- Coverage of the opt out system in Wales.

<table>
<thead>
<tr>
<th><strong>Frequency</strong></th>
<th>The existing PDA can be used to establish a baseline at the outset of year one.</th>
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<tr>
<td></td>
<td>Then monthly, quarterly and yearly publishing/circulation of PDA, which must include:</td>
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<tr>
<td></td>
<td>- Age</td>
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<td></td>
<td>- Ethnicity</td>
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<tr>
<td></td>
<td>- Acorn profile</td>
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<tr>
<td></td>
<td>- Relationship of next of kin to donor</td>
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<tr>
<td></td>
<td>- Cause of death</td>
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<td></td>
<td>- Region of death (ODS team)</td>
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<tr>
<td></td>
<td>- Region of residence of donor</td>
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<tr>
<td></td>
<td>- Whether the next of kin can recall discussing donation with potential donor organ donation</td>
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<td></td>
<td>- Whether potential donor is on the ODR</td>
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<td></td>
<td>- Whether the next of kin had a conversation about donation with the potential donor</td>
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<tr>
<td></td>
<td>- Refusal reason given</td>
</tr>
<tr>
<td></td>
<td>- Annual econometric modelling.</td>
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</table>

Best practice suggests that the appropriate proportional spend on evaluation is approximately 10% of the total budget.

**Stakeholder evaluation**

As much of the activity relies on the support from partners and stakeholders it is recommended to conduct a stakeholder survey. Questions on the marketing activity could be introduced into NHSBT’s existing stakeholder audit and an additional online quantitative survey run with local partners.
12. Appendices

12a. Brief to 23red

23red were appointed to this task following a competitive tendering process.

The brief from NHSBT asked for:

*Research and analysis – understanding the challenge*

- A review and analysis of current thinking, campaign approach and activity to date and an assessment of its impact;
- Analysis of existing research, data and assumptions to identify what has been preventing public behaviour change to date including identifying if additional specific research and data are necessary;
- Engagement with key stakeholders from each of the four UK health departments, members of the transplant community, NHSBT staff, members of the National BAME Transplant Alliance and representatives from the BAME and faith communities, charities and partners active in this field.

*Development of a strategic framework*

- Clear articulation of the strategic context and challenge/s;
- Assessment of the key insights that are acting as barriers to donation;
- A framework setting out the choices to address the key insights;
- A breakdown of the audiences and required actions.

*Detailed work plan*

- Development of a detailed work plan to describe the different work streams required to address the challenge/s and insights;
- The specific tasks within each work stream, highlighting dependencies with other agencies/stakeholders;
- The questions to be answered/knowledge gaps that need to be filled;
- The key challenges/issues to be taken into account;
- Responsibilities for delivery.

The aim is this plan will be developed into briefs for the different stakeholders, partners and agencies to deliver, as required.
Final report

- Final report to include recommendations for the seven year strategy with a more detailed one-year action plan. For each recommendation we want a clear evidence base for the proposed approach:
  - The insight and rationale driving each recommendation
  - How the anticipated change will enhance efficiency and effectiveness and the potential scale of the impact
  - The likely ease and cost of implementation
  - Dependencies with other stakeholders/agencies
  - An implementation plan detailing how the campaign will develop over time
  - An action plan for year one including briefs for research and testing and KPIs
  - Performance KPIs/targets, evaluation and feedback loop to inform ongoing development of the strategy.

- Definition of the constraints/challenges that may impact the project’s success, associated risks and mitigating actions.

12b. 23red proposal

23red has used a mix of methods to answer this brief, including:

- Distribution of an invitation to contribute to parties who were likely to hold research and data which might help to inform the strategy, resulting in the submission of 5 documents.

- Convening a peer review panel, to review the proposal for the development of the strategy and the strategy itself.

- A document review, which included responses to the invitation to contribute, other publicly available information, and existing data held by NHSBT. This covered over 43 reports and documents.

- A desk research programme to fill identified gaps in knowledge. Tools and processes included:
  - Social media monitoring, conducted via our in-house tool SM2, as well as a manual audit of NHSBT’s social media presence
  - Identifying the latest thinking and best practice in the field and considering a range of alternative behaviour change models
  - TGI audience analysis
  - Lexis Nexis press coverage
  - Creative monitoring.

- A suite of depth interviews with a representative sample of key stakeholders.
• Benchmarking against external standards, including:
  o Performance against KPIs – benchmarking against the existing baseline measurements and subsequent targets set;
  o International case studies;
  o Behaviour change – evaluating NHSBT organ donation strategy against an agreed behaviour change model.

• A series of strategic workshops were held with key stakeholders to share the key insight and seek input into the strategic framework.

12c. ACORN descriptors:

Category 1
Wealthy Achievers

These are some of the most successful and affluent people in the UK. They live in wealthy, high-status rural, semi-rural and suburban areas of the country. Middle-aged or older people predominate, with many empty nesters and wealthy retired. Some neighbourhoods contain large numbers of well-off families with school-age children, particularly in the more suburban locations.

These people live in large houses, which are usually detached with four or more bedrooms. Almost 90% are owner-occupiers, with half of those owning their home outright. They are very well educated and most are employed in managerial and professional occupations. Many own their own business.

Car ownership is high, with many households running two or more cars. Incomes are high, as are levels of savings and investments.

These people are established at the top of the social ladder; they are healthy, wealthy and confident consumers.

Category 5
Hard-Pressed

This category contains the poorest areas of the UK. Unemployment is well above the national average. Levels of qualifications are low and those in work are likely to be employed in unskilled occupations. Household incomes are low and there are high levels of long-term illness in some areas.

Housing is a mix of low-rise estates, with terraced and semi-detached houses, and purpose-built flats, including high-rise blocks. Properties tend to be small and there is much overcrowding. More than 50% of the housing is rented from the council or a housing association.

There are a large number of single-adult households, including many single pensioners and lone parents. In some neighbourhoods, there are high numbers of black and Asian residents.

These are the people who are finding life the hardest and experiencing the most difficult social conditions.
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