

Delivering a revolution in public behaviour in relation to organ donation: year one delivery plan

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This document has been prepared for NHS Blood and Transplant, 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.

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

- A strategy for delivering a revolution in public behaviour in relation to organ donation
- Delivering a revolution in public behaviour in relation to organ donation: a summary of the evidence.

Specifically, this document outlines the delivery plan needed in year one to achieve the three behaviour change objectives defined in "A strategy for delivering a revolution in public behaviour in relation to organ donation", namely:

- 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.

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1. Introduction

The strategy for delivering a revolution in public behaviour in relation to organ donation (strategic framework) identifies 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.

The table below summarises the specific recommendations needed to deliver each objective.

Objective		
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
Recommendations		
<ul style="list-style-type: none"> • Use the goodwill of charities, corporates, major employers (including the NHS) and the media in recruiting potential donors • Further exploit the potential of government transaction sites to deliver new registrants • Develop and test a 'member-get-member' style programme • Develop a targeted direct marketing campaign to under-represented groups • Increase the investment in face-to-face and community engagement activities, including with those in black and minority ethnic (BAME) groups • Develop partnerships with commercial and third sector organisations that have relationships with people who are living with health conditions or who are planning what they would do in the event of their death 	<ul style="list-style-type: none"> • Expand the use organ donor card beyond new registrants, and consider alternative physical and virtual symbol(s) of intent to donate • Develop an ongoing relationship management programme for registrants, to ensure they remember their commitment and share their intent to donate with friends and family • Focus on children and young people as change-makers within the family, rather than exclusively as registrants in their own right • Develop tools (including face-to-face, digital, social, viral and physical prompts) to enable people to have contained but constructive conversations about end-of-life • Expand the existing activity to address concerns around the impact of donation on burial and cremation practices 	<ul style="list-style-type: none"> • 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 • Develop and test broadcast and social content (long time lengths, deliberative) that frame donation as a positive step within the grieving process • 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

Overarching recommendations

National/local model, ODR as a marketing tool, Audience segmentation, Governance, Evaluation

This paper outlines how the overarching recommendations should be delivered. It goes on to outline how each of the objective-specific recommendations should be delivered in year one and makes suggestions as to how the recommendations can be developed in years two and beyond.

A four nation approach

Scotland, Wales and Northern Ireland are already delivering evidence-based public engagement campaigns. Indeed, many of the recommendations in this paper have been developed using learnings and insights from their work.

While each nation has differing audience profiles and priorities, there may be opportunities to integrate activity and the four nations may wish to come together to deliver particular recommendations collectively. Therefore, it is advised that NHSBT consults with all four health departments at the outset of year one to agree how they might work best together and identify where there are opportunities to collaborate.

2. Delivering overarching recommendations

2.a A national/local model

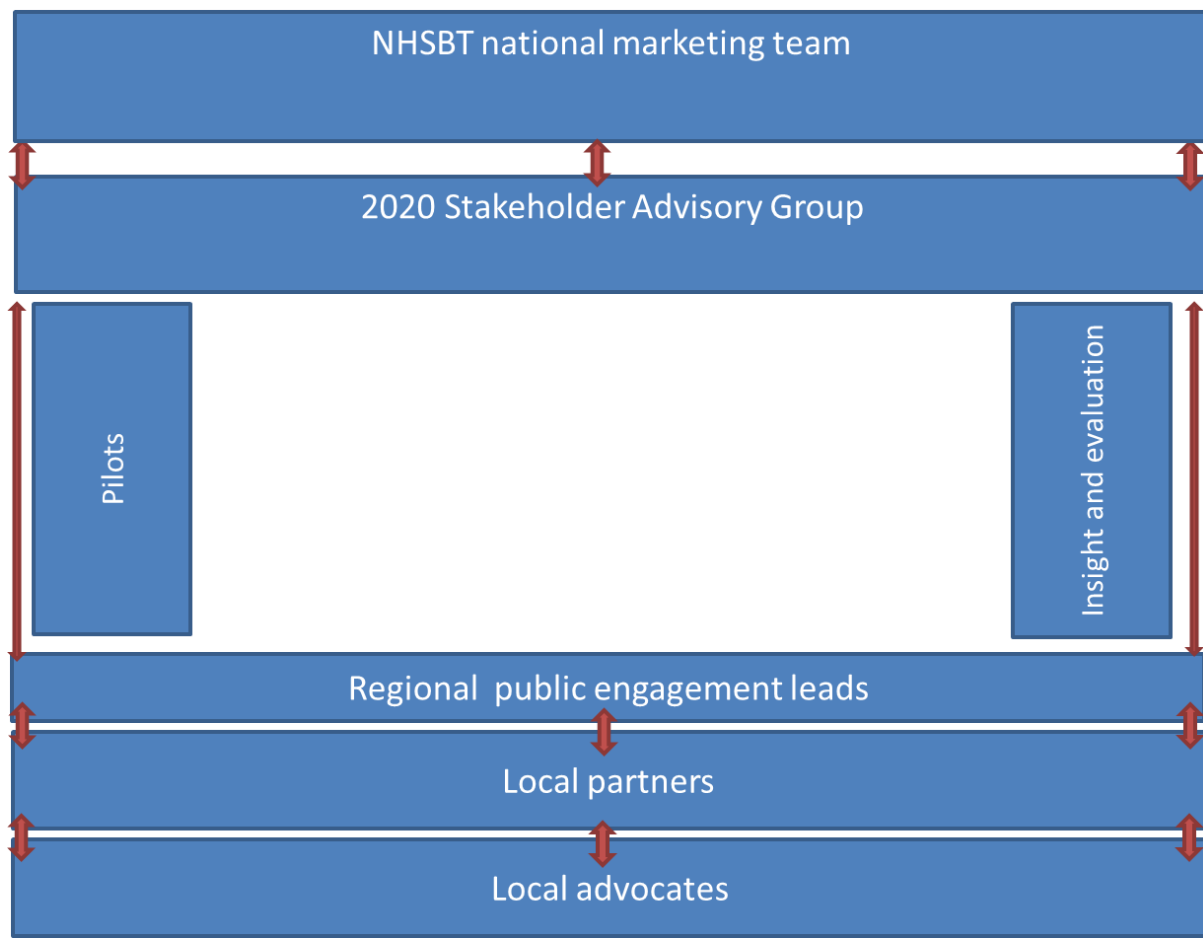
Partnerships are critical to creating social movements as they can create the right environment to effect behaviour change. The national/local model places both national and local partners at the heart of delivery, however the emphasis must be on empowering local partners to deliver as much as possible. Local partnerships are increasingly important as public health issues are devolved to local authorities, and local voices and channels have been identified as the one of the most effective routes of engagement.

A good model to follow would be that employed by the marketing department of Public Health England (formerly housed 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.

This flexible model allows broad national marketing messages to be adapted for very specific local audiences and needs, while ensuring consistency and support from the NHSBT national team. Local voices and connections will be crucial to engaging people and changing their behaviour. Activity must be flexible because of the highly nuanced needs of each audience. For example, even within the London region, Hindus in North West London have different attitudes to donation to Hindus in East London, and will therefore require a different approach¹ and this model allows for such a detailed level of variation.

It is intended to be a two-way approach, with learnings and recommendations for activity coming from a grassroots level, rather than being directed entirely from the national team. Therefore, clear feedback loops need to be established.

¹ Quoted by NHSBT (Paula Aubrey, London Regional SNO-OD manager)



NHSBT national marketing team

NHSBT's national marketing team is responsible for co-ordinating implementation of the strategic direction, delivery of agreed UK-wide activity and specific programmes within England and evaluating effectiveness to keep the strategy updated. At a national level the NHSBT team requires integrated campaign leads that analyse the evidence; develop and manage national campaign activity; and monitor and direct regional activity. This team will need to bring together their expertise across a variety of channels, as well as around research and insight and stakeholder engagement.

2020 Stakeholder Group

There is an existing 2020 Stakeholder Group, chaired by Professor Gurch Randhawa, responsible for informing and initiating work on the implementation of *Taking Organ Transplantation to 2020*, particularly in relation to changing public attitudes and actions regarding donation.²

² Terms of reference for this group are included in the appendices

This group should be used to offer views and insight on behaviour change, support for delivery, new ideas for engaging audiences and guidance on mediating risks.

Regional public engagement leads

It is important that there is a dedicated regional public engagement lead to ensure consistency, provide support and feed back insight.

There are currently 12 Regional Collaboratives which meet twice a year and bring together the CLODs, SN-ODs and ODCs in their area. It may be that the Collaboratives' role is expanded to take on a broader public engagement role, or alternatively, each Collaborative could be partnered with a member of the national marketing team who would then work with the Collaborative on public engagement.

Local partners, including Organ Donation Committees

This group will be responsible for delivering activity at a local level. Local partners are a combination of stakeholders (such as SN-ODS, NHS communications teams), partners (such as Local Authorities, schools and faith leaders) and grassroots advocates (such as transplant patients and donor families). In many cases, it is expected that the existing Organ Donation Committees will take the lead in managing the partners (if they are not already doing so).

Supporting local partners

Working with local partners has the advantage of adding capacity to the national team, as well as ensuring that the activities delivered resonate and engage with the audiences. In some areas there will already be informal partnerships that can be quickly harnessed to deliver the new strategy. However, in other areas, the national and regional team will need to instigate partnerships and establish a network.

As has been said, devolving the delivery brings great benefits but also increased exposure to risk. Therefore, NHSBT needs to provide guidance and support for local partners to ensure consistency and to mitigate any potential issues.

The national team will need to provide as much detailed local knowledge and insight as possible. Many local partners may be able to fund their own activity, but NHSBT may also want to consider providing seed funding for innovations that are being developed locally or provide technology to support partners (for example, tablets to take to an event to allow for on-the-spot sign ups).

We recommend NHSBT hold a series of launch events to present the strategy and showcase best practice in delivery.

These events should be supplemented with:

- Online forum for local partners to share learnings and resources

- Toolkits and templates, available to download. This allows for frequent updating and the inclusion of new user-generated content
- Press release/photo call templates so that local partners reflect national PR activity
- Regular e-bulletins – updating on new developments, celebrating success and sharing best practice.

This should also discourage local partners from creating their own materials, diluting the messages and preventing them from benefiting from the amplification provided by the national level activities.

National partnerships should be leveraged to create opportunities for local partners. Wherever possible, groups of local partners should be invited to co-create activities and new materials.

By the end of year one, NHSBT should be considering the planning cycles for local and national partners, as they both need around six months to develop activity. In year two, NHSBT needs to move to a position where there is a published annual plan giving details of activity to allow partners to prepare and resource activity appropriately.

Local advocates

Local advocates are those who have given consent or received organs and they will be needed to help local partners deliver activity.

Personal stories are recognised as one of the most impactful means of communicating organ donation, particularly if the stories are told face-to-face. For example, giving talks to community groups, schools, employers and acting as spokespeople in the media.

It is important that local case studies are highlighted to the national media team, to publicise the story at a national level.

It is hoped that through the marketing activity, more local advocates will become involved. As they are volunteers, we recommend that NHSBT fund one of its network of third-sector partners, for example the Donor Family Network or Live Life Then Give Life, to manage volunteers and provide them with training to ensure that they are prepared for public discussion and understand the specific messages promoted by other campaign activities. This should provide the necessary risk assessment and mentoring that is often needed.

The local advocates would be expected to be involved in co-creation and idea generation as part of their local partnership and should have access to the stakeholder forum, toolkits and updates (as detailed above).

2.b Develop and validate a registrant journey to leverage the ODR as a marketing tool

The ODR is one of the largest databases in the country. The primary function of the ODR is not to act as a marketing database, nor should it be. However, opportunities are being missed.

Improving the functionality of both the ODR and the public facing website will allow NHSBT to:

- Develop an ongoing relationship with registrants so that they start to feel like members of a community, and are encouraged to share their decision and contribute content and promote organ donation more widely among their peers
- Capture richer data which can be used for evaluation and future campaign development. It also means that there is the ability to provide local partners with feedback on the effectiveness of their activity and for the national team to use this to identify best practice
- Take better advantage of low-cost digital channels to engage the public and prompt conversations about organ donation.

There are three key actions needed to enhance the ODR and website.

First, the registration process needs to encourage people to give an email address when they sign up. NHSBT needs to provide a rationale for this. We suggest something along the lines of “please help us save postage by giving us your email address”. Additionally, if possible, within the registration process people should be asked to supply postcode and ethnicity data. Data Protection means that this will not be a mandatory field, but if it is positioned correctly then registrants may be prepared to provide their data.

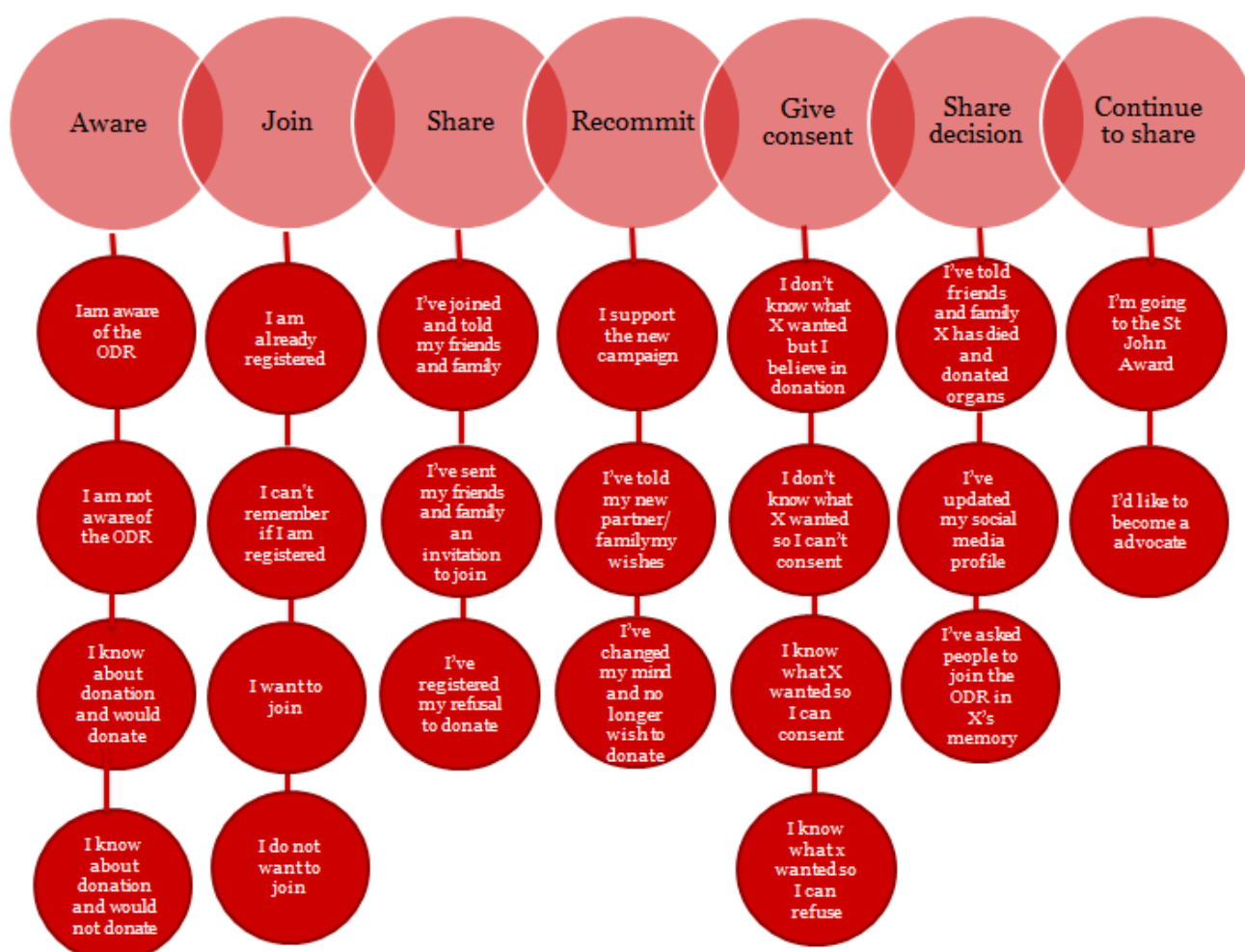
Secondly, the content of the public-facing website should be improved, so that it becomes a hub for registrants and donor families with resources offering advice and support on how to discuss their wishes with their family and how to ask them what their wishes are, plus myth busting and FAQs. Importantly, it should also be a place for people to share their stories and experiences of organ donation with one another.

Many registrants may never have any reason to come to the site since most people sign up through a partner. However, if the website has content that people want to see and they feel that they need to visit to be part of the community, then there will be the opportunity to capture data on these registrants, where previously no information has been shared by the partner.

Finally, once the first two steps are complete, NHSBT can start to use digital channels more extensively. For instance, managing the relationship with registrants through low-cost, automated tactics, i.e. when a person joins they can request that their Facebook page be automatically updated, immediately starting the conversation about their wishes. Another example would be the use of QR codes embedded in posters and other marketing materials which make it easy for people to immediately signal a digital intention to join the ODR. With this new technique, a potential registrant can be instantly taken to the website to register, so the website needs to be attractive to the potential registrants.

We recommend that registrants and potential members are involved in the design of the public-facing website. Furthermore, all digital activity, including activity developed with partners, should be optimised using A/B testing. A/B testing is a simple way to test changes to a webpage against the current design and determine which ones produce positive results. It is a method to validate that any new design or change to an element on your webpage is improving your conversion rate before you make that change to your site code.

To support the development of the ODR, we have developed a registrant journey that demonstrates how the ODR can be leveraged at each stage.



The strategic framework identified the target audiences and the need for audience insight in order to re-balance the ODR towards people who are more likely to donate. It is recommended that NHSBT undertakes a thorough audience segmentation in year one, examining:

- demographics (including geography, religion and ethnicity)
- psychographics
- communication behaviours (who they trust as information sources and how they share information)
- media use

2.c Governance

2.c.i 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

There are a large number of organisations and individuals who have a vested interest in organ donation, and who have already expressed opinions on what they believe a potential strategy should be, or who will need to be actively engaged in delivery. For example:

- SN-ODs and CLODs
- The four UK health departments
- Clinicians specialising in transplantation
- Intensive care teams
- Other clinicians
- Leading academics specialising in the area
- NHS communications teams
- National charities such as Diabetes UK, British Heart Foundation, National Kidney Federation
- Patient groups
- Smaller third sector organisations such as the Donor Family Network and Transplant Sport
- MPs who have demonstrated interest in the issue (positive or negative)
- Faith organisations such as the Muslim Council of Britain, Hindu Council UK and the British Union Conference of Seventh-day Adventists.

NHSBT needs to develop a stakeholder management programme, to maximise opportunities for engagement and cooperation. Stakeholders should be mapped against:

- Level of influence
- Support for/opposition to organ donation and the strategy
- Ability to provide expertise and contribute to behaviour change.

For key stakeholders it may be necessary to develop specific activities, such as face-to-face briefings. Other stakeholders could be managed as part of the partnership programme, and for some email updates or stakeholder PR coverage may suffice as an engagement activity.

NHSBT staff are also stakeholders and internal communications will be important to ensure that colleagues are fully supportive of the new strategy.

NHSBT is already developing a web space for stakeholders, so it is suggested that this be expanded over time according to feedback from stakeholders.

It is recommended that responsibility for overseeing the management of stakeholders is allocated to one team/person and that the map is kept updated and new insights shared across the national, regional and local teams.

Proactively managing stakeholders will help to manage potential risks and keep all interested members engaged with the long-term strategy.

2.c.ii Develop and maintain a risk register and crisis management plan

The strategic framework identifies that there is increased risk with the new recommendations and that before activity is launched NHSBT will need to develop a risk register and crisis management plan for each initiative.

2.d Evaluation

At the outset of the year, before any activity goes live, it is necessary to establish the starting point for the audience's attitudes and behaviours and establish a baseline for future evaluation. This baseline can then be used to set fair and realistic KPIs.

It may be possible to use existing research to establish the baseline, however it is likely that new tracking research will need to be commissioned to supplement this. The evaluation framework offers recommendations on what should be measured and how to capture this information (see page 57 of the strategic framework).

At the end of the year (March 2015), the first evaluation should be carried out.

Additionally, the outputs of each recommendation should be captured and any third parties who are involved in the delivery should be asked to provide an evaluation as part of their brief.

3. Delivering objective one: 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

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

Year one

NHSBT already responds positively to approaches from partners for blood and organ donation, and it is recommended that this activity is continued and extended. Organ donation relies on altruism and partners should be approached to support donation by offering customers, employees and members etc. the chance to join the ODR.

This is a straightforward, easy to implement request to partners as in many cases it will require little more than using their digital channels to facilitate opportunities for people to sign up to the ODR.

An employee engagement partnership should be developed for NHS staff to ensure that the NHS leads by example and provides advocates for organ donation.

The NHS is the largest employer in Europe. However, it is unknown how many NHS employees are members of the ODR and, even of those who are registered, how many have shared their decision with their family.

A national partnership should be formed with NHS Employers and local partners should approach their local NHS.

Senior management should be seen to personally endorse organ donation and consent and encourage staff to join the ODR and share their decision.

For new employees in the future, an opportunity to register should be included in recruitment packs (positioned alongside Gift Aid, employee support/counselling and life insurance forms).

Once this has been established it can be used as an example to encourage other public sector employers to embed ODR membership with their employees, as well as other sectors, particularly in sectors which employ large numbers from “hard pressed” or BAME groups:

- Manufacturing
- Leisure
- Retail
- Transport
- Call centres
- Construction

Year 2 onwards

Once the ODR has been revised and the website improved, NHSBT could trial a media partnership using QR codes to increase membership, using posters positioned around the workplace.

Diminishing returns will mean that by year 4 recruitment to the ODR will be at a peak, therefore recruitment activity can be moved into maintenance mode.

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

Year one

It is recommended that NHSBT partners with the Government Digital Service to establish further pilots with other government websites, for example GOV.UK and NHS Choices. Using the network of local partners, NHSBT should also develop pilots with local authority websites.

This is an opportunity to continue to test the messages that were developed by the Cabinet Office's Behavioural Insights Team to establish if there are varied responses from different segments and trial new images. For example, a national message of 'three people die every day' versus a local message of 'two people in Bristol die every day'.

Data capture should be built into any pilots so that NHSBT can both learn from the activity, and also develop relationships with the new registrants. Partners should be approached to discuss how there may be opportunities to collaborate to capture and share audience data (particularly around gender, socio-economic group and ethnicity). New registrants should also be prompted to provide their details upon sign-up.

As this activity builds on an established foundation, it should be relatively easy to develop and deliver within year one.

Year two onwards

NHSBT should continue to test new messages and images in years two and three.

Diminishing returns will mean that by year four recruitment to the ODR will be at a peak, therefore recruitment activity can be moved into maintenance mode.

3.c Develop and test a ‘member-get-member’ programme

Year one

Currently, only new registrants to the ODR receive a welcome letter and donor card from NHSBT. After this, there is no further contact and no more demands are made of the registrant. (It is their family who are required to make the decision at the point of consent or authorisation.)

Around one third of registrations are duplications, implying that many people are unsure or have forgotten if they are signed up to the ODR and there is no evidence to suggest that joining the ODR automatically leads to discussing this decision with their family.

Inherent to this activity is the requirement to share the decision to join so it becomes a “teachable moment”.

In year one, it is suggested two pilots are undertaken to test ‘member-get-member’ activity.

- a) Direct marketing with duplicate registrants. Duplicate registrants should be sent a letter/email/MMS:
 - reminding them that they are already registered
 - thanking them for their ongoing commitment
 - prompting them to share their decision with their family
 - providing them with a donor card
 - prompting them to update their details (especially email contacts) to receive new updates
 - asking them to invite their friends to join.
- b) Digital marketing and Customer Relationship Management (CRM) trial, where automated emails /MMS are sent to registrants who have already provided their contact details. It is suggested that variations of automated emails and MMS are tested with sample groups of different audience segments, to understand which creative approaches and messages are most effective for which audiences. The communication should:
 - Prompt registrants to share their decision with their family and ask family members what their wishes are
 - Add their decision to their social media profiles (using provided emblems, badges)
 - “Like” the NHSBT Facebook page for updates
 - Extend the invitation to their friends by forwarding an invitation to join the ODR to their network of contacts.

Scotland has already trialled these activities successfully, and NHSBT and the other health departments can benefit from its learnings to deliver similar activity. NHSBT has the technical capability³ to manage the pilots within year one, however, for wider roll-out it will require investment in the ODR and the software currently used by NHSBT.

Year two onwards

The most successful messages should be rolled out nationally to all registrants.

NHSBT should continue to test new messages and creative with sample groups on an annual basis.

As much as possible there should be a shift away from postal channels to lower cost digital channels.

Diminishing returns will mean that by year 4 recruitment to the ODR will be at a peak, therefore recruitment activity can be moved into maintenance mode.

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

Year one

The strategic framework identified the target audiences and the need for audience insight in order to re-balance the ODR towards people who are more likely to donate. It is recommended that NHSBT undertakes a thorough audience segmentation in year one, examining:

- demographics (including geography, religion and ethnicity)
- psychographics
- communication behaviours (who they trust as information sources and how they share information)
- media use.

The audience segmentation will inform the proposition and creative development as well as the test matrices for a targeted direct marketing campaign.

It is suggested that a minimum number of variations of messaging and creative are tested concurrently with different audience segments. Contact details can be purchased from the electoral register if needed (and existing ODR registrants removed).

³ Managing the pilots was discussed by the NHSBT communications teams at a stakeholder workshop and was determined to be manageable with existing software and resources.

To explore the potential of lower cost channels, in addition to trialling traditional postal direct mail channel, propositions should be tested using digital channels (i.e. email and MMS).

For ease of management, it is suggested that this activity is managed as part of the same project as the ‘member-get-member’ pilot.

Additionally, toward the latter half of the year, it is suggested that NHSBT trial paid-for digital media, using a combination of pay-per-click biddable media, sponsored posts etc. The results from this trial can be used to develop a more extensive paid-for campaign in year two (if it is deemed to be a worthwhile investment).

Year two onwards

NHSBT should continue to test new messages and creative with sample groups on an annual basis.

As much as possible there should be a shift away from postal channels to lower cost digital channels.

Diminishing returns will mean that by year 4 recruitment to the ODR will be at a peak, therefore recruitment activity can be moved into maintenance mode.

In year two, depending on the results of the pilot, there may be a rationale to increase the spend on paid-for media, including biddable digital media and pay-per-click, as well as outdoor advertising using QR codes.

3.e Increase the investment in face-to-face and deliberative activities, engaging some of the most “hard to reach” groups and those from black, Asian and minority ethnic (BAME) communities

Year one

This recommendation relies on a combination of bespoke activity at a local level, guidance for which will be included in the local toolkits, as well as “piggy-backing” on national partnerships. In addition to BAME audiences, there is a need to develop specific activity for niche audiences, such as men aged 40 plus or the elderly, who may not be responsive to, or targeted by, more mainstream activity.

BAME groups

NHSBT should continue to focus on implementing the recommendations outlined in the Faith Engagement and Organ Donation Action Plan, produced by Professor Gurch Randhawa of the University of Bedford, which concluded that there would need to be:

- more engagement, particularly at a local level, using major festivals such as Diwali, Eid, Vasant Navrati and Vaisakhi as an opportunity to promote organ donation to vast gatherings of followers
- engagement 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
- ensuring all faith-based media are actively engaged with organ donation via interviews with faith leaders, news stories, paid-for TV features etc.

Guidance will need to be produced for local partners on how to approach and co-produce activity with local faith leaders.

“Hard to reach”

In year one, NHSBT should apply learnings from Brazil’s “Immortal Fans” and look to target men aged 40 plus by trialling activity with key sports clubs (for example Football, Rugby League, Rugby Union and Cricket). Ideally, partners would provide:

- co-branded marketing materials
- space and time at matches/games for recipients and donor families to talk about their experience
- free advertising space at stadiums, editorial in programmes, fan magazines etc.
- access to players for PR activity.

In year one, the approach is expected to be made by local partners to local clubs. National partnerships should be sought with sporting bodies such as the Rugby Football Union, English Cricket Board and Football Association, but as these relationships may take several months to establish, no “live” activity should be expected until year two.

National and local, charity and public sector partnerships

For both BAME and “hard pressed” groups, NHSBT should approach charities who have a large reach to these audiences. The approach can be made at a local level, but we recommend that there is a national approach first so that there is the chance to create consistent activity across the country. For example, Age UK has a national membership of over 55s plus over 170 local branches across England, Scotland and Wales providing services to the over 55s, and regularly holds events which local partners could attend.

Public and third sector community teams for local authorities, JobCentre Plus and Housing Associations should also be approached in year one to deliver activity. This will need to be co-designed and produced and may take several months to establish, and the results may not be apparent until year 2.

Year two onwards

Toolkits should be refreshed annually and new guidance produced as necessary. New partnerships should continually be sought.

3.f 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

Year one

Certain organisations already have “permission” to discuss death and promote conversations about end of life as part of their purpose. This activity is about harnessing those relationships so that they include prompts to talk about organ donation.

NHSBT already works with the National Council for Palliative Care and the Dying Matters Coalition, and this partnership should be continued. Additionally, health charities such as Diabetes UK, British Heart Foundation and Cancer Research⁴ should be approached as potential partners.

Ideally, partners would provide:

- Co-branded direct mail to their members
- Instruction to local groups to work with local partners and advocates
- Space in newsletters, websites and other channels.

By capitalising on the altruism integral to organ donation, NHSBT should develop national partnerships with solicitors to prompt clients to express their intention to donate in their will. The Law Society should also be approached to ensure that organ donation is included within the downloadable Will templates available on the internet. Funeral Directors should also be approached to prompt customers to consider joining the ODR.

Year two onwards

In year two, NHSBT should build on its understanding of the existing communications channels and strategies of these partner organisations and be working in collaboration, so that organ donation becomes an integral part of the organisation’s messaging.

⁴ It is understood that people with cancer may not be suitable donors, however, Cancer Research has an extensive database, which includes the families members of those affected by cancer who may be receptive to message about end of life.

It is expected that by the end of year three partnerships can transition to 'business as usual' as the involvement from appropriate partners will have been secured.

4. Delivering objective two: To stimulate conversations and debate about donation, particularly through leveraging the ODR as a marketing tool

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

Year one

There is an appetite for having emblems of commitment to organ donation. NHSBT currently sends a donor card to new registrants, but there is also scope to test other physical and digital emblems.

Other “real life” emblems could be a pin badge or bracelet, which could be piloted through different regions.

Digitally, there is a range of options to pilot, including Facebook badges, Twibbons, as well as exploring options for mobile phones.

Year two onwards

Electronic wallets⁵ are an emerging trend and in year two or three it is suggested that NHSBT look to partner with a provider to trial the inclusion of donor decisions within the wallets.

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

Year one

In year one, this will partly be tested through the ‘member-get-member trial’. The results from this should provide appropriate messages for each segment which can then be developed to roll out nationally.

However, local partners should also look to hold events and media debates that stimulate recommitment from existing registrants. Instructions for this should be incorporated into the local partner toolkit.

Registrants who wish to recommit should demonstrate support by visiting the ODR website to sign up for the digital emblems (as outlined above) and share their status on their social networking profiles.

⁵ Electronic wallets are devices that allow an individual to make electronic transactions. This can include purchasing items online with a computer or using a smartphone to purchase something in a shop. Increasingly, these wallets are being made not just for basic financial transactions but to also authenticate the holder's credentials. For example, a wallet could potentially verify the age of the buyer to the store while purchasing alcohol.

Year two onwards

Once the ODR is established as a marketing tool, NHSBT should look to shift communication with registrants away from expensive postal channels to low-cost digital channels and send ‘member’ bi-annual communications using a campaign hook, such as National Transplant Week and a personal hook such as the anniversary of their registration.

4.c Develop tools to enable people to have constructive conversations about end of life

Year one

NHSBT needs to facilitate people to have conversations about their wishes and learn about the wishes of their family.

In year one, NHSBT should follow the examples from Nottingham and Glasgow and Clyde and other local initiatives, and support local partners to deliver media campaigns that are reinforced by digital and face-to-face events. Media templates and guidance should be provided by the national team.

There is the opportunity to further test the “I have” materials. However, new propositions maybe needed. NHSBT should test messages based on the proposition “make sure your wishes are honoured” in one or two regions and compare the responses.

National PR should be used to amplify local activity. To date, national PR has been successful in promoting the “I have” materials, and this should be continued.

New content and messages could be trialled at a national level using YouTube (and potentially other more niche video sharing websites), giving the opportunity to trial different messages with different audiences before developing them for other channels in year two.

Year two onwards

It is not expected that these pilots will be completed until late into year two. Once they have been evaluated, the toolkits should be updated and the campaigns should be run again, possibly using National Transplant Week as a hook.

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

Year one

There are many options to engage children and young people, including expanding the schools programme, using targeted social media and partnering with youth organisations.

To expand the schools programme will involve two strands of activity. At a national level this will involve stakeholder engagement with the Department of Education to encourage the formal inclusion of donation within the curriculum and pastoral teaching programmes. It will also require informal partnership activity with organisations such as the Association of Colleges and PHSE Association, as well as health charities that have established schools programmes such as the British Heart Foundation to encourage schools and FE Colleges to educate students on organ donation.

Local partners and advocates will be crucial for this activity. It is suggested that specific guidance is developed for local partners around working with schools, including key messages on how to work with local advocates and role-playing ideas to help young people discuss donation with their family. Many Organ Donation Committees already have a schools programme, so in year one it is about changing the emphasis of these sessions and building on the existing relationships with local schools and colleges.

To support this activity there should be marketing materials to stimulate the conversation. These may include the donor cards, plus myth-busting leaflets that young people can take home and use to discuss donation with their families.

Scotland has already started work to expand their schools programme and the NHSBT national team and the 2020 Stakeholder Group should look to use any learnings that emerge from the Scottish initiative.

National and local partnerships should also be sought with youth organisations such as National Unions of Students, Clubs for Young People, Make Space, The Scout Association and Girl Guiding.

As part of the social media activity that NHSBT is developing, they should look to develop content for sites such as Habbo Hotel that are popular with children who are too young to register for social networking sites such as Facebook.

Year two onwards

It is likely that the work with schools will take at least two years to be developed, so results should not be expected before year three.

Local activity should be run on an annual basis and the toolkits updated regularly to reflect best practice and changes to the curriculum.

In year two, NHSBT should build on its understanding of the existing communications channels and strategies of partner organisations and be working in collaboration, so that organ donation becomes an integral part of the organisation's messaging.

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

Year one

'Remember a Charity' (an organisation that encourages more people to consider leaving a charitable gift in their will) claims that:

"By using humour to communicate a sensitive subject we've been able to take huge steps forward, making our unique work stand out...Results from audience surveys have shown that the campaign has started to overcome taboos and change public perception around the subject of wills."

This approach could be tested by NHSBT.

PR will be the key channel for this activity, using editorial coverage in the national, local and online media⁶ to educate and inform the public about the donation process and bust myths about its impact on burial and cremation practices.

In year one NHSBT should develop short digital clips that bust myths in an entertaining and accessible way (for instance using animation or celebrity) which encourage sharing and forwarding.

Face-to-face also plays a crucial role in educating people, and local partners should work with third parties to hold events where local advocates and clinicians can address questions and concerns and provide reassurance about the process.

There is a lack of detailed information about the process of donation and this should be included within the ODR website, and supporting materials should be produced to be distributed at the events for people to take away to digest and discuss at home.

⁶ National and local media includes both print and broadcast media and online media includes blogs and twitter

As part of its new public awareness campaign, Northern Ireland is addressing myths and misunderstandings and it is suggested that early in year one, NHSBT reviews the successes and learnings from the Northern Ireland campaign and uses these to develop this activity in more detail.

Year two onwards

Some of the myths and misunderstandings are deeply embedded, so it is expected that this activity may need to run for at least two or three years to achieve an impact.

In year two, NHSBT should consider if there is a role for advertising to help address myth busting. This could be purely focused on lower cost digital advertising, but there may also be a role for broadcast advertising on television and in cinemas.

5. Delivering objective three: Changing the behaviour of donor families, irrespective of the ODR status of their loved one

5.a 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

Year one

While there have been great moves forward in terms of understanding audience motivations and barriers to consent over the past few years, there is still a lack of insight into the “real” reasons why families refuse.

To date, no detailed research has been done with families who refuse at the point of consent.⁷

More specialist research is needed in this area to understand the most likely triggers and messages needed to motivate and create behaviour change at the point of consent.

Ethnographic research is suggested. Ethnographic research usually involves observing people in their natural, real-world setting, and can be combined with in-depth interviews post event.

This type of research would most likely need to involve a university cognisant of how to devise and carry out such a project and obtain the necessary consent from participants and approval from relevant ethics boards.

An example methodological approach would be initially to follow a number of families in each of the nine regions of England, plus Scotland, Wales and Northern Ireland, who have a loved one in a potential donor situation for whom they may or may not give consent. The whole process and decision could be followed through observation and note-taking which would need to be completely unobtrusive, anonymous and in line with all ethical guidelines. Advice would be taken from ethics boards on how much participants could be asked about their thoughts and feelings and by whom, if this is not forthcoming and openly expressed. This could lead to the initial part of the study being relatively long term (possibly a year) and needing more than one on-the-ground researcher who would be on call for the duration of the research fieldwork.

The study should identify at least eight families in each key region/country who refused consent and then invite them to take part in a post event interview, approximately six months from their donation decision. The interview would reflect on their experiences and whether a change in any factors would have changed their

⁷ Professor Magie Sque has started looking at this area and has completed some limited research. The learnings from her work can be used to inform and shape more detailed work.

decision. We would advise aiming to secure at least three family interviews per region/country. The research may also want to ensure that key audience segments and ethnicities were represented in the participants. All interviewers would be skilled in emotive interviewing and would ensure that those being interviewed had the necessary support in place should they need it before, during or after the interview.

All interviews would be recorded and transcribed anonymously, although they would be linked to the relevant anonymous notes of each family's donation experience.

All data would then be analysed to see if any common themes emerge, potentially looking at:

- The Past – family's prior knowledge and attitudes of donation which may have affected their decision
- The Present – the moment in time that the family were asked about donation and factors in and around that moment that may have affected their decision
- The Future – perceived expectations and outcomes from the donation decision.⁸

This piece of work also needs to be reviewed in the context of the improvements to the clinical and hospital-based interventions. It has the potential to be combined with the evaluation of these other interventions.

Year two onwards

It is expected that this research will take around two years to complete, so in year three NHSBT should review the results to understand what new propositions and activities will need to be developed.

5.b Develop and test broadcast and social content (long time lengths, deliberative) that frames donation as a positive step within the grieving process

Year one

Peer-to-peer communication can be a powerful vehicle for delivering messages and normalising behaviour. Digital channels (social networking sites, YouTube etc.) are low cost and can be highly targeted. It is recommended that NHSBT pilot peer-to-peer communications via these channels with a sample of audience segments. For example, using content generated by donor families or transplant recipients.

Additionally, in year one NHSBT should look to develop broadcast editorial content partnerships, either by approaching a production company or existing charity-led programming such as Children in Need or Comic Relief. This would be with a view to

⁸ Based on methodology suggested by Professor Magi Sque

embedding key messages in their programming; utilising the charitable aspect of donation and positioning organ donation within the “need” segments of these programmes. There could also be a verbal prompt to join the ODR and link the ODR from the programme’s website.

There are significant lead times for these types of activity and it is expected that the first year would be spent making the approach and developing content with results not appearing until year two/three.

Year two onwards

If this activity is considered to be successful then it should be continued for the remaining years of the strategy.

In year two, NHSBT should also begin to develop advertiser-funded programming, which allows a campaign/organisation to embed their messages within the editorial content of a programme.⁹

Please note that this is not exclusively intended to be television programming; there is also a role for partnerships with radio and digital channels.

NHSBT will need to seek content partnerships to deliver this strand. This means approaching corporate partners, along with a broadcast/media partner so that the costs of developing the content are shared.

5.c 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

Year one

The Order of St. John Award is a relatively new development that has already started highlighting the benefits of donation. In 2013, the PR around the Award generated 144 pieces of positive print coverage,¹⁰ and there is a belief that there is the potential to expand this event.¹¹

We recommend that NHSBT discuss with the Order of St. John developing the award ceremony into a high profile event involving celebrities, as well as donor families. As a larger event, it could be broadcast on television or included as a category in the

⁹ Examples of Advertiser Funded Programming from Channel 4 can be found here: http://www.channel4sales.com/advertising/sponsorship/ad_funded_programmes.

¹⁰ NHSBT St. John evaluation. The cutting service does not pick up broadcast or regional online media so the true total of coverage generated is higher.

¹¹ Increasing the profile of the Donor Award was suggested by numerous stakeholders at NHSBT events and during the depth interviews.

Pride of Britain Awards.¹² This is an opportunity to both promote the role of donation as a positive part of the grieving process and celebrate those who have donated organs, as well as generate new registrations, spark conversations, bust myths and engage new audiences with the subject of organ donation.

However, it is understood that some donor families may shy away or not be ready for attention and therefore, it is suggested that regional events are held simultaneously and that these should be solely focused on bringing donor families together.

This will require a significant financial investment, so it is advised to seek sponsorship from a corporate partner. A broadcast media partner should also be found, to ensure full coverage of the event.

Year two onwards

If the activity is considered to be successful then it should be continued on an annual basis. From year two, NHSBT may want to consider integrating this event with National Transplant Week (NTW).

NTW is a well-established event. The preparation for the year one (2014/15) campaign is at an advanced stage of planning. Discussions are already under way on possibly holding NTW at a different point in the calendar, so that it has broader appeal in Scotland and Northern Ireland. This provides the opportunity for NTW and the Order of St. John Award event to be combined.

Bringing the two activities together will allow for more efficient use of resources, and gives the opportunity to refresh the aims of NTW – bringing the focus as much to the donor families as to the recipients.

¹² The awards attract an audience of around seven million viewers every year in a primetime slot on the ITV1 network in England, Scotland, Wales and Northern Ireland – making it the highest rated awards show of its kind on British television.

6. Challenges and considerations

- New ways of working. We are confident that the skills to deliver these recommendations exist within NHSBT's network, indeed many of the activities we are recommending have already been trialled either locally or by one country. However, the strategic framework and delivery plan may require NHSBT to adopt new integrated ways of working.
- A long-term approach and investment. This is time-intensive and activity will not deliver an immediate upturn in consent rates. NHSBT needs to invest in year one and two in a programme of testing and learning to establish the optimal communications mix to deliver increased consent rates over time.
- Longer planning cycles. Local and national partners need at least six months' notice, so NHSBT needs to move to a position where it publishes an annual plan and provides details of forthcoming campaigns to allow national and local partners to plan their involvement.
- Co-creation and collaboration. Working in partnership requires NHSBT to co-create activity and be more flexible with its brand guidelines, empowering partners to take the lead and deliver activity on its behalf.
- Integrated evaluation. As there will be improvements to clinical processes and other new interventions, it will be difficult to attribute an increase in consent rates directly to marketing. Therefore, understanding the barometers of change will be important in determining if activity has been successful.

7. Budget

The strategic framework recommended a review of 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. The budget allowance for year one for each activity is based on the assumptions outlined. These are budget allowances only and an indication of what is likely to be needed to deliver the recommendations. NHSBT will need to develop full briefs, scopes of work and cost estimates for each activity.

Activity	Assumptions	Allowance
Support for local partners	<ul style="list-style-type: none"> Development and production of toolkits and guidance Development and production of online stakeholder forum (including e-bulletins) 9 regional roadshows (including venue hire/travel etc.) 	£100,000
Local partner campaigns	<ul style="list-style-type: none"> Seed funding for local innovations and supporting materials (there are over 150 ODCs already but it is not expected that every area will receive additional funding) 	£200,000
Management of local advocates	<ul style="list-style-type: none"> Funding for a third party to train local advocates, provide health and safety/risk assessments and mentoring and guidance 	£50,000
Develop the ODR as a marketing tool	<ul style="list-style-type: none"> Improvements made to ODR, including data capture and A/B testing Development of public-facing website, including relationship management tools 	£250,000
Development of materials, including the organ donor card	<ul style="list-style-type: none"> Print and production of Organ Donor Cards Development of two to three alternative physical and digital emblems of support to trial 	£300,000
Direct marketing	<ul style="list-style-type: none"> Paid-for digital media pilot Direct marketing and 'member-get-member' pilots Relationship management programme 	£250,000
National partnerships	<ul style="list-style-type: none"> Recruitment, activation and management of 10 to 15 key partners, including seed funding 	£250,000

PR	<ul style="list-style-type: none"> • In 2012/13, £70,000 was spent on NTW. For year one we anticipate more extensive PR activity, including: <ul style="list-style-type: none"> ○ Myth-busting campaign ○ Development of media partners ○ Amplification of partnership activity ○ Development of tools to support conversations about end of life 	£150,000
Development of the St. John Organ Donation Award	<ul style="list-style-type: none"> • This assumes costs of event and resources are shared with partners therefore this would be a contribution towards the costs for venue hire, event management, travel expenses for donor families and promotion and PR of the events 	£150,000
Ethnographic research	<ul style="list-style-type: none"> • The ethnographic research is expected to take around two years to complete so in year one the budget allows for the payment of a first instalment, with the remainder being paid in year two. This also allows NHSBT to amend or cancel the project if it is no longer deemed necessary 	£50,000
Evaluation	<ul style="list-style-type: none"> • Based on industry best practice of spending 10% of budget on evaluation 	£200,000
TOTAL		£2,000,000

8. Appendix

8.1 Evidence and rationale

The table below outlines the evidence and rational for each recommendation.

Recommendation	Rationale
Expand the current partnership programme, harnessing the goodwill of charities, corporates, major employers (including the NHS), and the media in recruiting potential donors	<p>Low-cost channel whereby NHSBT capitalises on the trusted relationship the organisation has with the target audiences.</p> <p>Employer organ donation campaigns have been successful in the USA.</p> <p>In a study of 30,000 employees at 45 companies, promoting organ donation messages through internal forms of media (newsletters, posters on bulletin boards, paycheck stuffers etc.) increased donor rates by 13.6%. When there were personal interventions in the workplace, through colleagues talking about their experiences of organ donation or work sites being visited by speakers with direct experience donation, rates went up more. (http://www.intechopen.com/download/get/type/pdfs/id/27730).</p> <p>The NHS Employers organisation works in partnership with the Department of Health, supported by the Social Partnership Forum, to deliver the national seasonal flu campaign for NHS staff. Vaccination uptake in healthcare workers with direct patient care continues to increase, from 35 per cent in 2010/11 to 45 per cent in 2011/12 and 46 per cent in 2012/13. (http://www.nhsemployers.org/HealthyWorkplaces/StaffFluVaccination/Pages/seasonal-flu-campaign.aspx)</p>
Further exploit the potential of government transaction sites to deliver new registrants	<p>The DVLA gave the ODR 1.7m new registrants between 2011 and 2013.</p> <p>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 and using particular messages around reciprocity.</p>

	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/267100/Applying_Behavioral_Insights_to_Organ_Donation.pdf
Focus on children and young people as change-makers within the family, rather than exclusively as registrants in their own right	<p>Since 2005, a national organ donation schools pack, possibly the first of its kind anywhere, has been made available to all secondary schools across Scotland. This pack, which also addresses tissue donation, was updated and re-launched in 2010 and a recent independent evaluation showed that 98% of teachers who have used the pack say it is relevant and engaging for students, while 88% of pupils recognised the importance of organ donation and would recommend its continued use in schools.</p> <p>http://www.scotland.gov.uk/Resource/0042/00427357.pdf</p>
Develop and test a ‘member-get-member’ programme	<p>In 2011/2012, a Scottish direct mail campaign was sent out to a million people aged over 35 and not on the register. This earned an impressive 13% response rate and was followed up by an equally successful ‘member-get-member’ programme.</p> <p><i>(Organ Donation Scotland, Marketing recap 2010 – present, 20th September 2013)</i></p>
Develop a targeted direct marketing campaign to under-represented groups	<p>In 2011/2012, a Scottish direct mail campaign was sent out to a million people aged over 35 and not on the register. This earned an impressive 13% response rate and was followed up by an equally successful ‘member-get-member’ programme.</p> <p><i>(Organ Donation Scotland, Marketing recap 2010 – present, 20th September 2013)</i></p>
Increase the investment in face-to-face and deliberative activities, including those with black and minority ethnic (BAME) groups	<p>In an evaluation of NHSBT’s Faith roadshows it was found that, following 28 events, there had been 1,198 new registrations. <i>(BAME Organ Donation Educational Activity, Aug 2013)</i></p> <p>Kidney Research has been piloting a peer educator project. So far, the peer educators have met over 20,000 people in mosques, temples, melas, and at cultural events across the UK. This work has resulted in 1,500 new people signing up to the organ donor register so far.</p> <p>https://www.kidneyresearchuk.org/research/showcase---health-equality</p> <p>Nottingham – ran a series of successful roadshows which increased the number of registrations achieved in the area by nearly 50% (compared to when only media</p>

	<p>activity was used).</p> <p>http://www.odt.nhs.uk/pdf/toto2020_changing_public_behaviour.pdf</p> <p>In the Brazilian Sport Recife “Immortal Fans” campaign, families of donors and transplant recipients were at matches to talk about their experience. Fans signed up for a Sport Club Recife organ donor card at the stadium, through a Facebook app or online, plus an advert was shown at the club stadium on match days:</p> <ul style="list-style-type: none"> • 51,000 people registered for a card • Organ donations went up 54% in the country during the year the campaign ran. The campaign is thought to have played a significant part in the increase. <p>http://www.brandchannel.com/home/post/Recife-Ogilvy-Cannes-Lions-061813.aspx</p>
<p>Develop partnerships with commercial and third sector organisations that have relationships with people who are living with health conditions (e.g. Diabetes UK, British Heart Foundation, Stroke Association) or who are planning what they would do in the event of their death (e.g. solicitors, funeral directors)</p>	<p>Remember A Charity was formed in 2000 and now has over 140 of the UK’s charities, who work together to encourage more people to consider leaving a charitable gift in their Will, once they’ve looked after their family and friends. It aims to make legacy giving a social norm. 74% of the UK population support charities, only 7% currently leave a legacy to them when writing a will. The percentage of solicitors and Will-writers who ‘never’ prompt about charity has halved in the past two years. SPA Future Thinking research shows that the proportion of solicitors and Will-writers who ‘never’ prompt has fallen from 22% in 2011 to 10% in 2013, while those who ‘sometimes’ prompt has increased from 19% to 26%. 35% of advisors ‘always’ prompt, which is 10% higher than two years ago. Research shows that those advisors who always prompt about charitable legacies have a higher proportion of their clients leaving charitable bequests in Wills.</p> <p>Remember A Charity led a six-month trial with the Cabinet Office Behavioural Insights Team and Co-operative Legal Services, which showed that when solicitors or Will-writers simply mentioned to people that leaving a gift to charity was an option, the percentage of people who did so rose from just 5% to 10%. Legacy giving rose again, to 15%, when people were asked if there were any charities that</p>

	<p>they were passionate about; average donations also increased by 50%.</p> <p>http://www.rememberacharity.org.uk/</p>
Expand the use of organ donor card beyond new registrants, and consider alternative physical and virtual symbol(s) of intent to donate	<p>71% feel that being able to pick up donor cards would encourage donation. (<i>Optimisa Research: NHSBT Organ Donation 2013 research: Understanding current attitudes and behaviours towards organ donation within England</i>)</p>
Develop a relationship management programme, to ensure registrants remember their commitment and share their intent to donate with friends and family	<p>One third of the people who complete the ODR joining form online each year are already registered, implying that they have either forgotten that they are registered or are demonstrating a recommitment. (<i>Source: NHSBT</i>)</p>
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	<p>44% of people have never discussed organ donation and 22% do not want to talk about death. (<i>Optimisa, as above</i>)</p> <p>71% said “it annoyed me to think that my wishes might not be respected”. (<i>Optimisa, as above</i>)</p> <p>A campaign in Glasgow and Clyde, called Respect my Dying Wish, urged people to tell their loved ones about their decision to donate and to ask them to respect their dying wish. The three-month campaign used media platforms to launch a lively debate on the issue, including Facebook, YouTube and twitter and has a dedicated interactive website, plus a YouTube channel where viewers can comment on, or share, what they see. People could create their own digital donor message card that can be sent to friends and family via email, twitter or Facebook.</p> <p>Outputs were high (for a local campaign):</p> <ul style="list-style-type: none"> • 868 likes on Facebook • 143 Twibbon supports • 5,545 views on YouTube • 290 followers. <p>https://www.facebook.com/RespectMyDyingWish</p> <p>Details of Nottingham activity can be found above.</p>

	There is limited evidence about a proposition to “make sure your wishes are honoured”, therefore this needs to be trialled.
Expand the existing activity to address concerns around the impact of donation on burial and cremation practices	<p>The Optimisa research identified many areas of myth and misunderstanding:</p> <ul style="list-style-type: none"> • I worry hospital staff might not do their best to save my life (18%) • I don’t want to think about my 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 do not want my organs to go to someone who does not deserve them (11%) • I don’t know enough about it (11%) • I’m too old – my organs would not be of any use (10%). <p><i>(Optimisa, as above)</i></p>
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	<p>There is limited understanding of the reasons for refusal and even the information that exists is not trusted. Therefore there is a need to explore this sensitive area in more detail to find the levers for behaviour change.</p>
Develop and test broadcast and social content (long time lengths, deliberative) that frames donation as a positive step within the grieving process	<p>The ‘From the Heart’ campaign resulted in the highest number of new sign ups to the ODR in one day – 17,779. http://www.organdonation.nhs.uk/campaigns/other_campaigns/detail.asp?id=8</p>
Further develop the Order of St. John Award for Organ Donation as a high	<p>The Award only started in 2013, so there is yet to be evidence of its impact. Therefore year one is about trialling the opportunity to expand on this activity and</p>

profile annual celebration of the generosity of donors and their families	<p>measure the results.</p> <p>Two of the posts by NHSBT on the St John Award got 229 likes between them. A Daily Mail online story about one of the award recipients had 54 shares. Year one will be an opportunity to test if there is greater potential in this event.</p>
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8.2 Terms of Reference of 2020 Stakeholder Group

- To bring together representatives of all those with a key role in implementing those actions relating to changing public attitudes and behaviour within *Taking Organ Transplantation to 2020*.
- With regard to the diverse nature of the UK population and in consultation with stakeholders, develop plans for encouraging and enabling the voluntary sector to change public attitudes and actions regarding organ donation.
- Encourage a UK-wide approach to implementation, whilst recognising the differing systems and approaches across the four UK Health Administrations.
- To ensure that the delivery plans are aligned and reduce the risk of duplication of effort.
- To identify and take action to address any risks to successful implementation of the strategy.
- To agree and monitor: milestones for implementation; measures of progress; measures of success.
- To contribute to the work of the 2020 Oversight Group (Chaired by Elisabeth Buggins and responsible for the oversight and co-ordination of the implementation of *Taking Organ Transplantation to 2020*), particularly:
 - mid-term review of *Taking Organ Transplantation to 2020*, to ensure that the strategy remains fit for purpose;
 - collation and publication of regular progress reports.

Reporting systems

The Stakeholder Group will report to the 2020 Oversight Group. There should be at least two members of the Stakeholder Group on the 2020 Oversight Group.

Secretariat

To be provided by NHS Blood and Transplant.

Frequency of meetings

Three times per year in the first two years, reducing to twice a year thereafter. The meetings should be held after meetings of the Implementation Oversight Group.

Remuneration

The Chair and members will be reimbursed for their travel and subsistence costs. They will not be paid for attending the meeting.