



NHSBT Organ Donation: 2013 research

Understanding current attitudes and behaviours towards organ donation within England

RESEARCH REPORT

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Executive Summary

A key challenge for NHSBT is in prompting people to consider the importance of organ donation and change the perception that it is the exception rather than the norm

It is clear that organ donation is a topic which many have never been exposed to in any way, whether that be in discussions with family or friends or from external communications and campaigns. People tend to feel uncomfortable talking about death and associated topics. Moreover there is very little prompting people to consider the issue nor care sufficiently to motivate them to support organ donation, whether that be by registering on the ODR or by making their wishes known to those closest to them. As organ donation is often not within people's sphere of knowledge or experience it is easy for people to distance themselves from the topic and believe that is it not something that will ever relate to them. They may struggle to empathise/ understand how many people are waiting for donations and how their lives are affected in the abstract.

There is an opportunity to target 1 in 3 of population who would consider donating all or some of their organs (but whom are not yet fully convinced)

Theoretical support for organ donation is relatively high (85%) however this does not translate into similar levels of personal support. 51% say that they are definitely willing to donate some or all of their organs, whereas in reality only 31% are signed up on the ODR. Additionally while 31% would consider donating their own organs, they would not describe their decision as definite, or necessarily consider donating all of their organs. This creates an opportunity for NHSBT to not only address some of the barriers but also make the benefits of organ donation more tangible to encourage support.

There are a number of strong motivations for NHSBT to communicate, however the benefit to 'self' rather than 'society' should be emphasised

At a total level, there appear to be a number of strong motivational factors to supporting organ donation:

- It would be improving and saving the lives of others (65%);
- Someone I love could one day need a transplant (58%);
- My organs will only go to waste when I die (58%).

However it is interesting to see the differences between what motivates those definitely willing to donate vs those unsure. Those willing to donate their organs are more likely to view organ donation as a social responsibility they are more likely to see more benefits in it, appreciating both the benefit to the recipient as well as the benefit to self. Compared with

those who are unsure how they feel about donating their organs who are affected by a more limited number of considerations – key amongst these is the consideration that someone they love could someday need a transplant, providing a more tangible and familiar benefit of donation. Any communications or marketing campaign is likely to be most effective if it strikes an emotional chord and personal connection with the individual. Importantly, children tend to evoke an emotive response, even if the child is not known to the individual. Prompting people to think or understand how organ donation might affect their own lives one day will be a particularly powerful motivator.

There are a number of concerns and barriers around organ donation, some of which could be easily dispelled or remedied by a frank conversation with friends or family

Among the key barriers to donating organs personally are a mistrust of medical professionals, discomfort in thinking about and talking about death:

- 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%);

A lack of trust in the medical profession emerges as the single most common reservation towards organ donation. There is a fear that doctors might prioritise others, for example, saving younger/healthier people and opting to save multiple lives in place of one individual. It is unsurprising, given that individual wishes are rarely discussed with loved ones, that there are concerns (and assumptions made) that relatives may be upset about the decision to donate. The anticipated reaction of the wider family and wider community can therefore act as a barrier to individual donation.

Additionally there are a number of misconceptions around organ donation that do present concerns for individuals. However, once discussed and explored they can be alleviated, allowing people to rationalise and discount as real barriers to supporting organ donation. Common misconceptions included; 'I am too old or too sick for my organs to be of use' or 'I can't give blood so can't give organs'.

Overall support for organ donation amongst BME groups is lower and some barriers are more pronounced in certain Muslim groups

People from BME communities demonstrate significantly less support for organ donation than the rest of the UK population. In principle, a majority (77%) are in favour of organ donation and 29% are strongly in support of it, but these figures are significantly lower than the overall UK population (where theoretical support stands at 86% overall, with 51% supporting it strongly)

While 35% of the population as a whole are definitely willing to donate all of their organs, this figure reduces to 19% when we look at our BME sample as a group. There is little

difference between the population as a whole and the Indian proportion of our BME sample, but much less willingness in our Bangladeshi and Pakistani sample, where religious considerations appear to be more of an influencing factor.

Whilst all BME groups are significantly more likely to raise religious objection than a general UK sample, religion or faith barriers are raised by a far higher proportion of Pakistani (36%) and Bangladeshi (26%) respondents, than Indians (8%) or Black respondents (8%).

Lower willingness to donate amongst those from black BME groups are in part linked to lower levels of trust in the NHS than in the population as a whole. Other concerns more pronounced from BME groups include fear of upsetting family members and a lack of knowledge about organ donation, indicating the need for more discussion and education around the process.

Religion has the potential to both raise awareness and encourage support / consent

Few people of faith, whether practicing or lapsed, are aware or certain of the official position of their religion on organ donation. Equally, few can recall the topic ever being discussed in their place of worship, either by their own faith leaders or within their faith community. Many assume this to mean that organ donation is not looked upon favourably. From discussions with both the general public and stakeholders there is a strong sense that the most effective way to encourage donation will be from within these communities so that any fears and concerns can be addressed by the appropriate authorities.

There is an opportunity to further promote the ODR and in doing so address misconceptions around the process of showing support

In-keeping with research findings that organ donation is rarely in the public eye and often unconsidered prior to our discussions, we found when speaking to people that understanding of the ODR was low. There are confusions about the actual process of becoming a donor, how support is demonstrated, who is eligible to donate and receive organs and what organs can be donated. Letting people know that they can opt into donating some rather than all of their organs could be an important message. Of the 82% who would consider donating their organs 30% would only consider doing so if they had some control over what is and isn't signed up to on the register.

Encouragingly the majority said they are aware of the register (84%), however 30% of the population described it incorrectly. 14% saying it captures consent for bodies to be used for medical testing; 10% that it contains the names of those who are willing to be live donors; 5% that the ODR records support in principal.

Many of those who have not registered on the ODR but support organ donation give practical reasons for not having done so, 15% don't know enough about organ donation and 14% didn't know that there was a register – a clear sign that further publicity of the ODR is needed.

There is appetite for publicly available donor cards, and a role for cards to prompt conversation

The tangibility of supplying a donor card has value for some, and the majority of people (71%) feel that being able to pick up donor cards would encourage donation. Qualitatively we found a certain amount of fondness for the old organ donor cards and 15% of our sample believes that they currently carry a card or recall having one in the past. Making donor cards more generally available is seen as a positive way of encouraging donation. Perhaps more importantly, it is felt that a card would act as a tangible prompt to discussing organ donation.

Raising awareness that families will be asked for consent may prompt some conversations between family members

Awareness that family or close friends will be approached about organ donation in the event of a loved one's death is relatively low. It is clear that such situations are rarely, if ever, considered and spontaneous awareness that people may be asked to agree to donation after a loved one's death is very low unless they have prior personal experience. This is concerning given just half of people have spoken to someone about organ donation, and only slightly more of those on the ODR have told someone that they have registered (61%). Moreover, organ donation is significantly less spoken about in BME communities than in White British households. Only 36% of our BME sample had spoken to someone about organ donation and only 21% had spoken to their family or close friends. There is potential therefore for NHSBT to prompt conversations by promoting the message of individuals making a decision so that families do not.

Prior discussion is the factor most likely to encourage familial consent, even more than registration to the ODR

Being on the ODR and having discussed wishes is the most powerful scenario in facilitating consent, with 90% claiming they would agree to their loved one's organs being donated in this scenario. Most are driven by a strong desire to respect the deceased's wishes, which have been made clear to them through a dual communication.

Interesting, agreement levels continue to be relatively high (79%) when wishes have been discussed but the person has not signed up to the ODR, implying that ODR sign up makes minimal difference if wishes have been communicated. This is reinforced by a perception that when someone is on the ODR and has discussed their wishes, ODR sign up is seen to validate discussion rather than vice versa. 54% of those who would agree say that it wouldn't matter if the person had signed the ODR as long as they'd personally said what they wanted. Main barriers to agreeing are an expectation that if their loved one felt

strongly about organ donation they would have signed the ODR (36%). There is potential to challenge this in communicating findings from this research of higher levels of support even if someone has not communicated their wishes.

When wishes are unknown, opinion is divided on whether agreement would be given

When a loved one's wishes are unknown, not agreeing to donation is often seen as the easiest or 'safest' option: for some it is the automatic default response to say 'No' and for some of those who are unsure initially, there is a tendency to think that when actually in that situation they would be more likely to refuse than to agree.

There is a clear link between personal views about organ donation and willingness to donate on behalf of loved ones when their views on donation are unknown. In the absence of any other information, it is likely that family members will use their own personal views about donation if trying to reach a considered decision.

There is also significant concern about going against a person's wishes in case they did not want to be a donor (36% of those unsure and 42% of those who would refuse). It is frequently acknowledged that there is little discussion or action taken about organ donation. However if a person has not communicated in some way that they wish to be an organ donor it is often assumed that this means that they do not want to donate rather than that they have just not done anything about it. Similarly, there are some expectations that if a person wanted to be a donor then they would have either signed up to the ODR or spoken about their wishes. Again this presents an opportunity to highlight that the majority of people do support organ donation but have not necessarily ever discussed the topic.

1 THE BACKGROUND: AN OVERVIEW/ PROJECT CONTEXT

NHSBT manage the national voluntary donation system for blood, tissues, organ and stem cells, and also the supply of life-saving products that are needed by NHS patients. As part of this remit NHSBT are also responsible for the NHS Organ Donor Register (ODR) which records the wishes of those who want to become a donor on their death.

Donor rates in the UK are markedly lower than in many other Western European countries. Whilst it is recognised that there are a range of factors behind this, including differences in culture, public healthcare systems and approaches to attracting donors, a key goal set out in the draft *Taking Organ Transplantation to 2020: A UK Strategy document*, is for the UK to ‘match world class performance in organ donation and transplantation’.

A key route to delivering continued improvement in the levels of organ donation in the UK is effective communication with the public to inform and influence attitudes and behaviours towards organ donation (especially among BME communities¹). In order to support the future strategy, NHSBT identified a need for research to:

- Measure progress in terms of public awareness and action, and set a baseline against which future progress can be monitored
- Gain insight to help shape and focus future activity on each of the key areas (as part of the 2013-2020 strategy), but with particular focus on **consent rates**, in order to inform the development of future communication and messaging

In 2008, NHSBT established a Taskforce which introduced a series of initiatives to increase the organ donation rate to 50% by 2013 and it was widely reported on 11th April 2013 that NHSBT had successfully hit this target. In order to maintain this progress, in moving the UK towards global parity, the Taskforce has identified three key areas to address as part of its 2013 – 2020 strategy:

1. Donation Rates – At present, registration rates for the ODR are below one in three, in spite of a majority not being against organ donation in principle. Whilst overall donation rates have increased over the last 5 years, this is largely because more people have been asked². Increasing overall ‘supply’ remains a major policy goal, particularly amongst BME audiences who are under-represented (4% of the ODR vs. 8% of the UK population) but over represented in terms of their need of organ donations.

¹ By BME we refer to all those self-classifying as Asian/ Asian British, Black/ Black British, Chinese or other minority ethnicities or multiple ethnicities.

² Taking Organ Transplantation to 2020: A UK Strategy Draft v5.0

2. Consent Rates – Family refusal rates are a significant barrier to increasing donations and there have been limited improvements in these since 2008. The UK continues to have one of the highest family refusal rates (higher amongst UK BME communities), meaning that there is a marked loss of potential donation as a result of non-consent. Critically, next of kin may still refuse donation even if told their relative was on the ODR. Whilst families remain significantly less likely to refuse when told their next of kin was on the register there remains a need to encourage potential donors to discuss their intentions with friends and family. Given that only 5,000 people a year die in circumstances where they can be a donor, NHSBT have identified this as a crucial area for increasing overall donation rates.

3. Misconceptions – NHSBT feel that organ donation should be seen as a social responsibility and a mark of good citizenship, but there remain a number of misconceptions and barriers to joining the ODR and families subsequently agreeing to donation. For example, there is a drop off in sign-up amongst older people (45+) who are more likely to feel that their organs are no longer useful; a growing concern going forward given the UK’s ageing population. A number of factors also underpin the challenge of increasing donation rates amongst BME audiences, and NHSBT have worked closely with faith leaders to produce literature, which seeks to repudiate the often cited view that ‘donation is against my religion’.

1.1 Research Objectives

The objectives of this research fall into four broad areas

To collect a deeper understanding of the attitudes and behaviours around organ donation

1. Explore and understand the range of attitudes towards organ donation and identify where differences exist across a range of audiences, including ethnic and socio-economic groups
2. Identify current thinking and emerging trends and, where possible, to compare these against previous research findings
3. Explore how organ donation can be further normalised in the UK and identify key words which evoke a positive response

To appreciate support for and barriers against organ donation

4. Gauge overall levels of organ donation support across the different audience groups
5. Identify the underlying real levels of support (identifying societal versus personal levels)
6. Explore the motivations behind the support for donation and explore what factors/messages/beliefs create positive behaviour

7. Identify the barriers which influence the lack of support including beliefs and misconceptions and identify how these obstacles could be overcome

To understand attitudes towards consent and how consent levels could be improved

8. Explore attitudes towards consent across different audience groups, including the reasons why next of kin may withhold consent and the role and relevance of family providing consent
9. Identify how prior knowledge of wishes may impact on willingness to agree to donation
10. For those on the ODR, explore whether they have discussed their wishes and explore the barriers to discussing them

To measure perceptions of the Donor Card and ODR

11. Explore current levels of awareness and understanding of the ODR
12. Explore reactions to reintroduction of the donor card and how this would impact on perceptions of the ODR
13. Explore whether the card makes people feel more positive towards organ donation and potential impact on family refusal rates

2 METHODOLOGY AND SAMPLE

The programme of research used to address the objectives fell into three key sections (each with its own fieldwork), which have been brought together into one set of findings.

2.1 The 'Define' stage

To ensure an initial common understanding of the current knowledge, situation, and the priorities for NHSBT, this initial stage comprised of two parts:

2.1.1 Hypothesis lab

This initial extended briefing session included a detailed knowledge-share around the current challenges and opportunities facing NHSBT. This ensured that appropriate hypotheses were defined for testing in all subsequent phases of the research. The goal of this stage was to gain sufficient insight into organ donation to be able to present it in detail to members of the public, providing explanations where appropriate. Additionally, it ensured that research would not duplicate previous insight generated within NHSBT.

2.1.2 Stakeholder depths

We conducted ten x one-hour interviews with clinicians, specialist nurses and charities, either face to face or over the telephone. These were split as follows:

- **6 x interviews with Clinicians (CLOD's and SNOD's)** who have expertise approaching bereaved families about organ donation. Their expertise is vital in truly understanding the circumstances faced by bereaved families and the barriers to consent which the clinician have to deal with. In addition, their first-hand experience helped to ground the research in reality, as we explored how they think families may react to the various ways forward identified at the *hypothesis lab*
- **4 interviews with Charities** who are actively engaged in promoting organ donation and offering support to organ donor's families or to transplant patients. These interviews offered an organisational perspective of the issues of enacting current policy.

2.2 The 'Explore' stage

The exploratory stage in the research was designed to get close to potential donors, and understand the detail of why current donation rates, particularly consent rates, are lower than in other countries. Also to understand responses to the current organ donation process and to develop a view on the individual biases that might influence different groups not to donate/consent.

2.2.1 'Mr and Mrs' in-home sessions

These interviews were conducted with couples in their home and included a paired element and some one-to-one interviewing. By separating couples for interview in their own home

we were able to isolate individual views before bringing couples back together to observe how these views interacted with one another.

In total 24 'Mr and Mrs' sessions were conducted between 15th May and 12th June 2013, each approximately 1½ hours in length. The sample for these interviews included a mix of different levels of support for organ donation, ethnicities, socio-economic and religious backgrounds.

2.2.2 'Mr and Mrs' general public sample breakdown

	Profile	Total 'Mr & Mrs'
ABC1	18-30 Pre-family	2
	25-40 Young family	2
	55+ Empty nesters	2
C2DE	18-30 Pre-family	2
	25-40 Young family	2
	55+ Empty nesters	2
TOTAL Samples		12

2.2.3 'Mr and Mrs' BME sample breakdown

	Profile	Total 'Mr & Mrs'
ABC1	18-30 Pre-family Black Caribbean	1
	18-30 Pre-family Indian Hindu	1
	25-40 Young family Pakistani Muslim	1
	25-40 Young family Black African	1
	55+ Empty nesters Indian Sikh	1
	55+ Empty nesters Bangladeshi Muslim	1
C2DE	18-30 Pre-family Pakistani Muslim	1
	18-30 Pre-family Black Caribbean	1
	25-40 Young family Indian Sikh	1
	25-40 Young family Bangladeshi Muslim	1
	55+ Empty nesters Indian Hindu	1
	55+ Empty nesters Black Caribbean	1
TOTAL Samples		12

2.2.4 Family Triads

In addition to the Mr and Mrs sessions, 14 Family Triads were conducted to increase understanding of the impact of organ donation decisions on the wider family, be it families with older children who have left home, or younger children who are old enough to need to make decisions, but not necessarily financially independent. These sessions were dual moderated incorporating solo and group interviewing. In total 14 'Family Triad' sessions were conducted between 15th May and 12th June 2013, each approximately 2 hours in length. We conducted family triads with both the general public and BME groups.

2.2.5 Family Triads general public sample breakdown

	Profile	Family Triads
ABC1	35-55 Older family	2
	55+ Empty nesters	2
C2DE	35-55 Older family	2
	55+ Empty nesters	2
TOTAL Samples		8

2.2.6 Family Triads BME sample breakdown

	Profile	Family Triads
ABC1	35-55 Older family Black African	1
	35-55 Older family Bangladeshi Muslim	1
	35-55 Older family Indian Hindu	1
	35-55 Older family Black Caribbean	1
C2DE	35-55 Older family Pakistani Muslim	1
	35-55 Older family Indian Sikh	1
TOTAL Samples		6

2.3 The 'Measure' stage

The measurement part of the study comprised a 20-minute online survey recruited through a research panel to ensure that appropriate quotas could be managed. The survey excluded strong rejecters of organ donation, but was otherwise representative of the adult population of England, with a boost of those key ethnic minorities where there is a particularly low donation rate.

2.3.1 Quantitative survey sample structure

	Profile	Sample size
Core sample	All respondents 18+	1,007
	Quotas on age, gender and regions of England	
	Data weighted on gender, age, ethnicity and SEG to be representative	
Boost BME sample	Black / black British / Caribbean / African	151
	Indian / Pakistani / Bangladeshi	308
	Other ethnicities (including those with multiple ethnicities)	83
	TOTAL Sample	1,549

Data reported at total level were weighted to be representative of national breakdowns on gender, age, ethnicity based on 2011 census data.

3 SOCIETAL ATTITUDES TOWARDS ORGAN DONATION

It is important that this research visits overall societal attitudes towards organ donation to measure, explore and understand any shifts in attitudes since the 2009 research. The previous NHSBT 2009 research highlighted the need for heightened awareness and understanding of organ donation. It was clear at that point that whilst most who were not on the register already did not object to donation in principle, organ donation was not a topic people felt comfortable thinking about or discussing with friends or family.

3.1 Awareness and discussion of organ donation in general

It is clear that the communication challenge for NHSBT still exists. Organ donation is not a top of mind subject, nor is it considered on a regular basis, so it is easy for the general population to distance themselves from it. For many this interview was the first time they had considered the issue of organ donation in depth or confronted their own personal views on becoming a donor. In total only 50% of people have discussed organ donation previously and of these 74% (only 37% of the total population) have spoken to their close friends or family about their own wishes.

Those in AB social grades are the most likely to have discussed organ donation. Women more so than men (54% vs. 45% respectively) and those who are married or living with their partner (55% compared to 41% of singles).

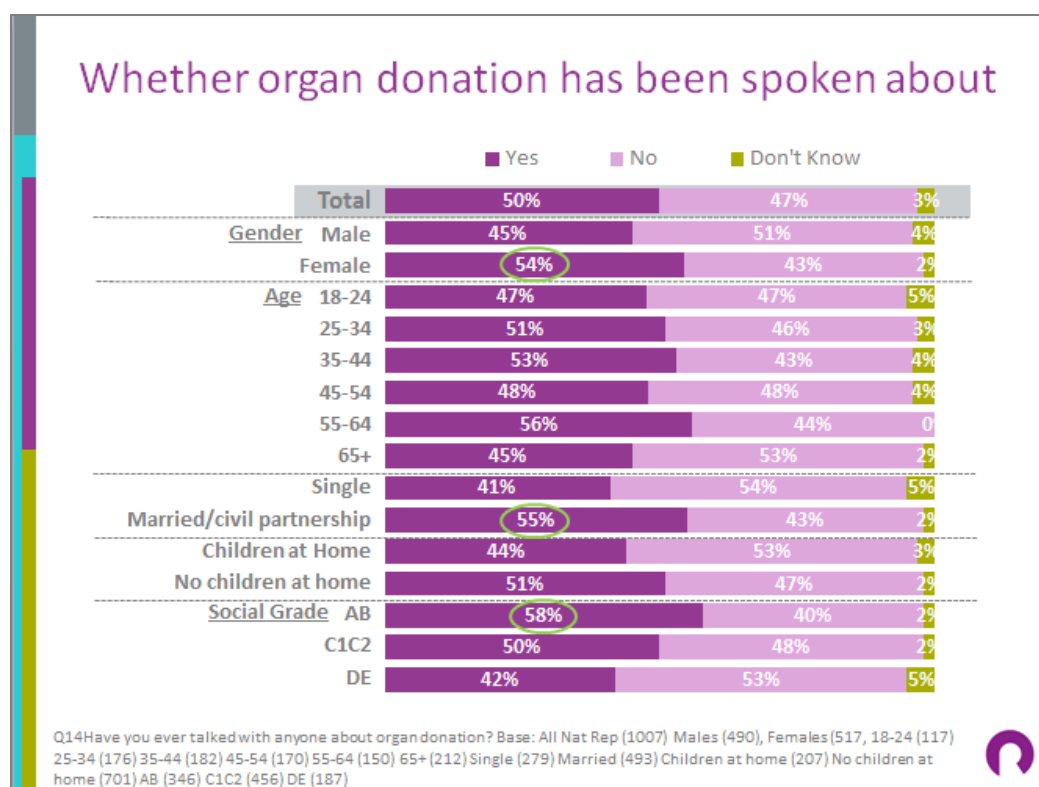


Figure 1 Table illustrating whether or not organ donation spoken about

The low discussion rates with regard to organ donation is inevitably related to its intrinsic link with death; a subject which remains a sensitive, complex and uncomfortable one for people to consider. Moreover, it is something which some avoid discussing through fear of causing upset within the family. There is an expectation that others will find the topic uncomfortable if it is raised, particularly in the case of parents talking to their children.

“There is just no way I could talk about it with my daughter, I just know she is too emotional and would stop the conversation”

Female, Empty Nester, White British, Manchester

Initial discussions around organ donation can focus on ‘living’ donations rather than donation after death, as awareness of this appears to be higher. People are generally keen to avoid discussions about death and the benefits of living donation also appear more immediate and tangible; you are likely to be helping someone you know personally, such as a close friend or family member.

“If someone in my family needed a live donation I would not sit around questioning it”

Female, Young Family, Manchester

While people are uncomfortable thinking about and contemplating their own or others’ mortality, for most organ donation has not been discussed as it has not come up in conversation; it is a topic that has not been given thought to rather than that the conversation itself is taboo. As shown in Figure 2 below, 44% of those who have not discussed organ donation said this was due to the conversation simply never coming up. Collectively, 60% describe it as a conversation they have either not thought about or not got around to having. This is compared to 22% attributing their lack of discussion to not wanting to think about their own death and 13% saying they would worry that the discussion might upset the person they were speaking to. The tendency to attribute lack of thought is apparent across all age groups, social grades, religions and ethnicities.

This unwillingness to consider death is evidenced in that a third of the population has not discussed or prepared *anything* in preparation for death; they have made no arrangements for their funeral nor have they taken out life insurance or made child care provisions. This percentage is lowest for those aged 65 plus, where 91% have made some arrangements and 63% have spoken to someone about them, and highest for adults under the age of the 35, where only 47% have made some provisions and 34% have discussed these.

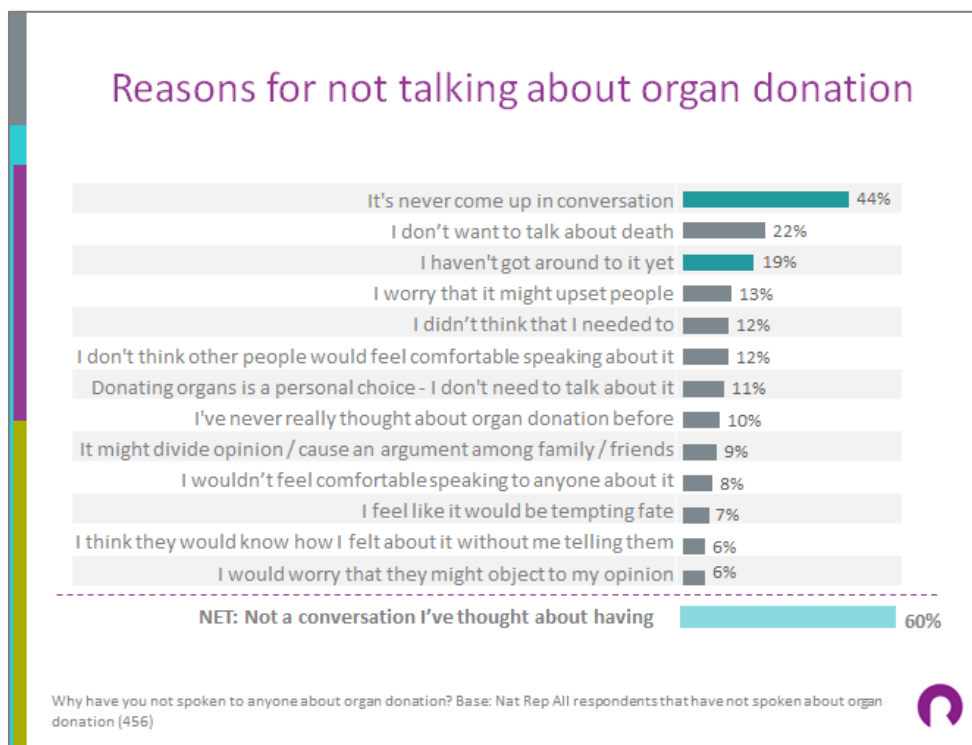


Figure 2 Table of reasons for not speaking about organ donation

While in the immediate aftermath of this project’s fieldwork there was much publicity about organ donation and whether England should embrace an opt-out system³, at the time of the fieldwork there was much to suggest that the subject needed to be brought more front of mind. Just over half (54%) of people said they had not heard any recent publicity about organ donation with an additional 10% not sure whether they had, or not. When someone had seen publicity about the issue, they most commonly claimed to have seen it in a doctor’s surgery, clinic or hospital so in an environment likely to be outside of their day to day life. In discussion it becomes apparent that other health campaigns such as cancer research, blood donation and heart disease get more exposure and coverage in the media and that there is a need to prompt people to think about organ donation, and to care sufficiently about it.

“I would assume it’s not as well supported as it doesn’t get as much coverage as other charities such as Cancer Research. You never hear anything about it”

Daughter, Older family, Sikh, London

³ The British Medical Association (BMA), many transplant surgeons, and some patients' groups and politicians are keen to see Britain adopt a system of "presumed consent", where it is assumed that an individual wishes to be a donor unless he or she has "opted out" by registering their objection to donation after their death. In July 2013 it was confirmed that such a system would come into force in Wales by 2015. The Welsh Assembly’s majority vote in favour of an “opt out” system hit the headline in July 2013 after this project had come out of field

Across the qualitative research very few people had been affected individually or were able to refer to any 'personal' stories of organ donation after death. Some were able to cite recent media coverage of organ donation from programmes such as ITV's 'From the Heart' or from discussions on Radio 4 or storylines on TV, but these did not affect them as far as to compel them to register their support or to think of organ donation as commonplace or something that could affect them.

"There have been lots of things on TV in the last few months about organ donation and it did set me thinking"

Female, Empty Nester, White British, Manchester, Not on the ODR

3.2 Attitudes to organ donation

In principle, organ donation is well supported. In total, 86% support organ donation after death and 51% are strongly in support of it. Collectively only 1% of the population are either strongly or somewhat opposed to organ donation.⁴ Levels of support in principle among those not already registered on the Organ Donor Register in 2009⁵ was 83% (43% strongly in favour). Our research shows that support for organ donation among those unregistered in 2013 is currently 76%, with the biggest reduction among those strongly in favour (29%). This is perhaps not surprising given the increase in registered donors since 2009. We would expect that those signing up since 2009 to be those most strongly in favour of organ donation. As the number of people registering increases, we predict that those remaining unregistered will be less in favour of donation. This suggests that while there are still a number of strong supporters that remain unregistered, fundamental attitudinal shifts will be more important in increasing registration over the coming years.

⁴ Anyone who strongly opposed organ donation was not interviewed as part of this survey but their level of opposition was captured before they exited the survey. The 1% opposition stated includes those who strongly opposed organ donation in principle (0.004% of the population).

⁵ In 2009 a further study was commissioned and conducted by Synovate. Those who were already registered on the ODR or who were strongly opposed to organ donation in principle were excluded from this research as the focus of the study was to understanding how best to persuade those who had not register their support for organ donation so that registration levels could be lifted

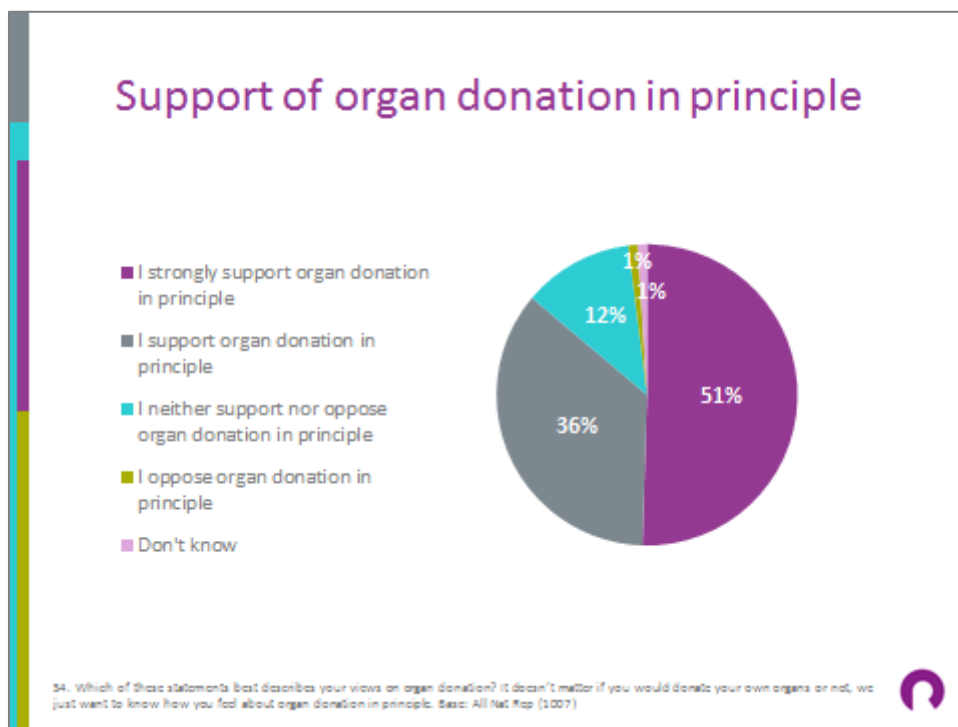


Figure 3 Support for organ donation when considering it in principle

Associations with organ donation are also overwhelming positive. When asked what they thought of organ donation after death only 6% spontaneously say something negative compared with 78% who give a positive response. The most popular spontaneous reactions are to describe it as a good idea (27%) or beneficial (33%). Positive associations were reinforced during discussions, as when prompted with a range of words to describe how they feel about organ donation, people generally opt for more positive language. Words such ‘Hope’, ‘Happy’ and ‘Rewarding’ are picked where people recognise the benefits to recipients and their family rather than from the donor perspective. Spontaneously, the word ‘Comfort’ is used to describe how the donor family may feel in giving consent, relating to the belief that something good is coming out of a sad situation.

When considering words such as ‘Proud’ and ‘Heroic’ the majority demonstrate modesty and humility and would not want to associate these words with their own organ donation.

“It would be a bit like blowing my own trumpet, look at me, I am a hero for donating my organs. I am not at all!”

Woman, Empty Nester, White British, Leeds

However, people are more open to using the word ‘proud’ to describe how they would feel about consenting to donate a loved ones’ organs, linked to feelings of contentment and comfort in ‘doing good’. This is an important distinction to keep in mind from a communications perspective.

In some cases more negative words are initially chosen. ‘Sad’ is mentioned when considering the circumstances in which a donation would be made and when contemplating

their own or loved ones passing away. 'Scary' is sometimes used to describe organ donation particularly where people have questions or concerns about the process.

Generally, as organ donation is not a subject that people are readily able to relate to and because there is minimal exposure to the subject, this creates a perception that it happens infrequently. Some chose the word 'alien' to describe associations with organ donation, which reinforces the belief that organ donation is the exception rather than the norm and something they are unlikely to be affected by.

The impact of this is seen when considering what could potentially motivate the general population to consider supporting organ donation, as from qualitative discussions it is apparent that it is not seen as a social responsibility. In fact this research indicates some negativity towards the idea of organ donation being a social duty and even the concept of 'society' can be dismissed, with concern about helping 'strangers' and those who don't deserve it. This is reflected to a lesser extent quantitatively with one in ten (11%) of the population mention that they don't want to donate to someone that 'does not deserve it'.

3.3 Ethnicity and attitudes towards organ donation

Organ donation is significantly less spoken about in BME communities than in the population overall. Only 36% of our BME sample had spoken to someone about organ donation and only 21% had spoken to their family or close friends.

People from BME communities also demonstrate significantly less support for organ donation than the rest of the population. In principle, a majority (77%) are in favour of organ donation and 29% are strongly in support of it, but these figures are significantly lower than the overall population where theoretical support stands at 86% overall, with 51% supporting it strongly.

4 INDIVIDUAL ATTITUDES TOWARDS ORGAN DONATION

The research conducted in 2009 made it clear that most people in the general population and from BME communities would support organ donation when it related to them personally – if they needed a transplant or if someone they knew needed one. Most said they would also be willing to help someone they cared about by being a living organ donor.

It was also clear that this willingness to donate organs to loved ones did not always extend to the public in general and what a person would accept for themselves was not necessarily what they would be willing to give to others. 17% of the population were admitted that they would accept an organ transplant if they needed one, but would not be prepared to donate their own organs. Overall, 37% did not disagree with this statement.

4.1 Willingness to donate own organs

Whilst 86% of the population support organ donation in principle, this is not to say that everyone is comfortable with the idea of donating their own organs or willing to do so. As shown in Figure 4 below, in reality only half (51%) of those interviewed said they would definitely be willing to donate some of or all of their own organs; theoretical support does not always translate to a firm commitment. While 31% would consider donating their own organs, they would not describe their decision as definite, or necessarily consider donating all of their organs.

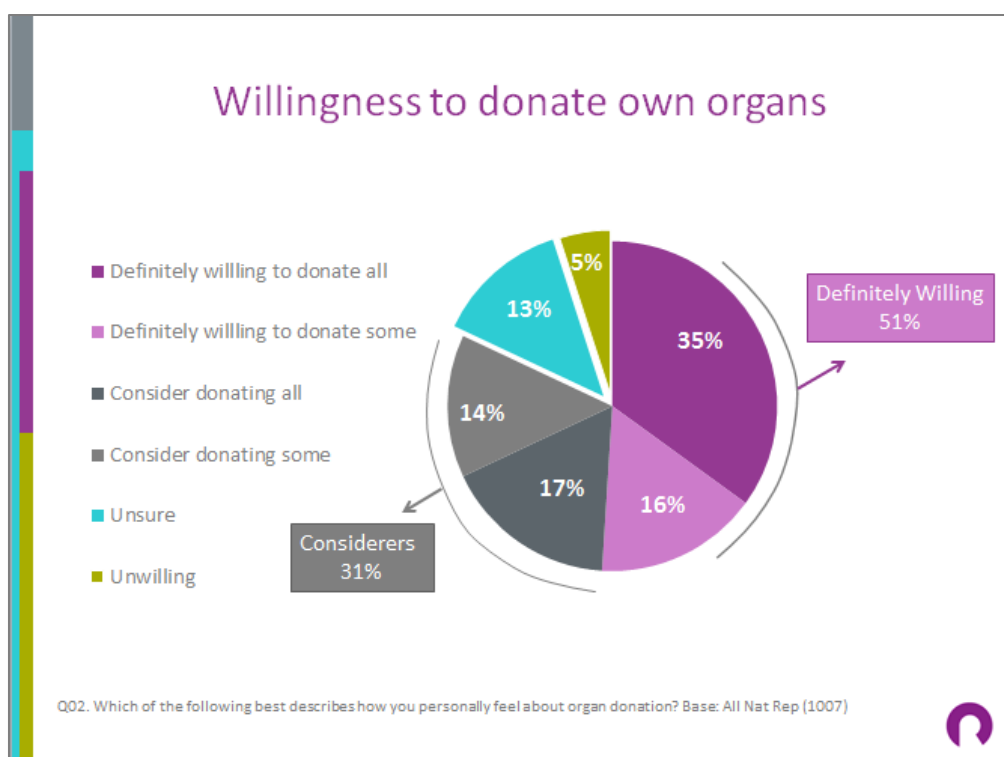


Figure 4 Statements of views on organ donation

In discussion, a fairly flippant, rational view was upheld when organ donation was considered at a general level, but it became apparent that some people were uncomfortable discussing it once asked to think about their own mortality and whether they would be willing to donate their organs. While some are comfortable with the idea of donating their organs, 18% are not.

“You don’t like to think about when you’re dead; it’s a scary thought – thinking about giving away part of you”

Female, Older Family, White British, London

There is consensus that the decision to support organ donation is a deeply personal and individual choice which should be respected. Organ donation is viewed as a serious decision which should be made with a clear and rational mind.

There is some discomfort with agreeing to donate *all* organs and willingness to consent to absolute donation increases with age, until a person reaches their mid-sixties, (see Figure 5 below). Whilst the majority of people feel confident that consenting to organ donation does not automatically mean that they are compelled to donate all of their organs, there remains a small amount of uncertainty about this.

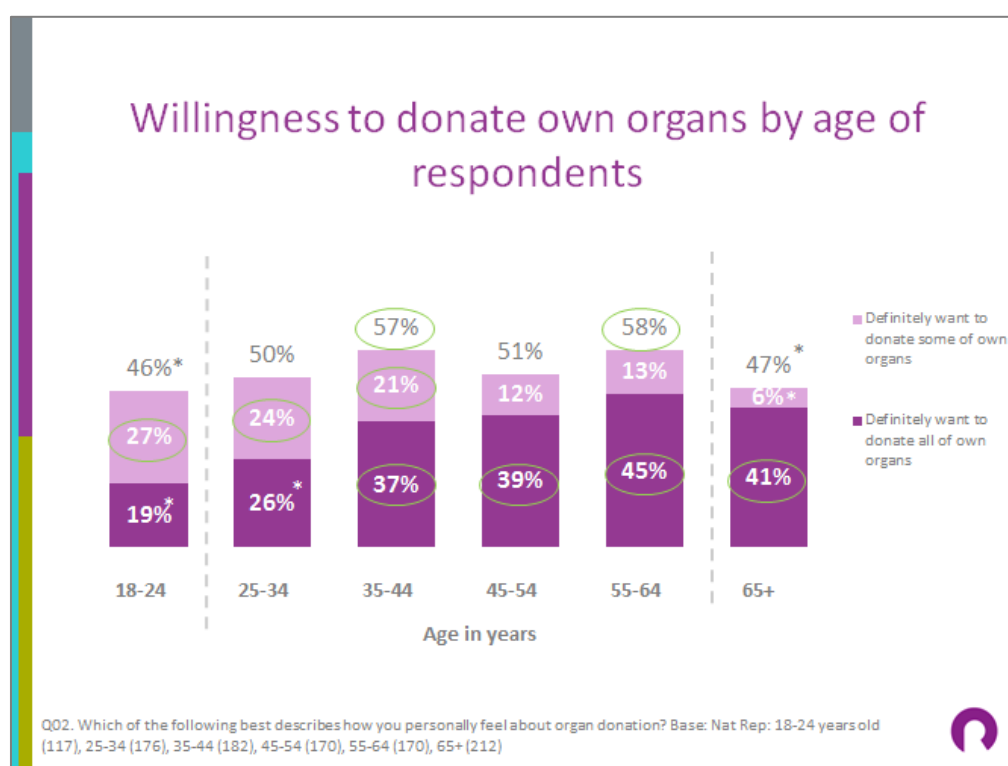


Figure 5 Attitudes to organ donation broken down by age

Letting people know that they can opt into donating *some* rather than *all* of their organs could be an important message. Of the 82% who would consider donating their organs 30% would only consider doing so if they had some control over the organs they donate.

Women aged 35-54 years are significantly more committed to donating their organs than any other demographic. Two-thirds say they are definitely willing to donate all of or some of their organs.

There is a greater propensity to consider organ donation amongst those 35 years and above (84%) than those 18-34 (79%). Consideration drops significantly once a person reaches 65 years and this correlates with an increased belief that they would be too old to donate their organs. A quarter (26%) of those above the age of 65 said that this was a concern when considering organ donation compared with 5% of people under the age of 65.

Those in AB social grades and those with a higher final level of education (degree or above) are also significantly more willing to definitely donate. That those with high levels of education are most willing to donate their organs supports the need for an educational message and greater public knowledge of organ donation, both in terms of the benefits and 'myth-busting'.

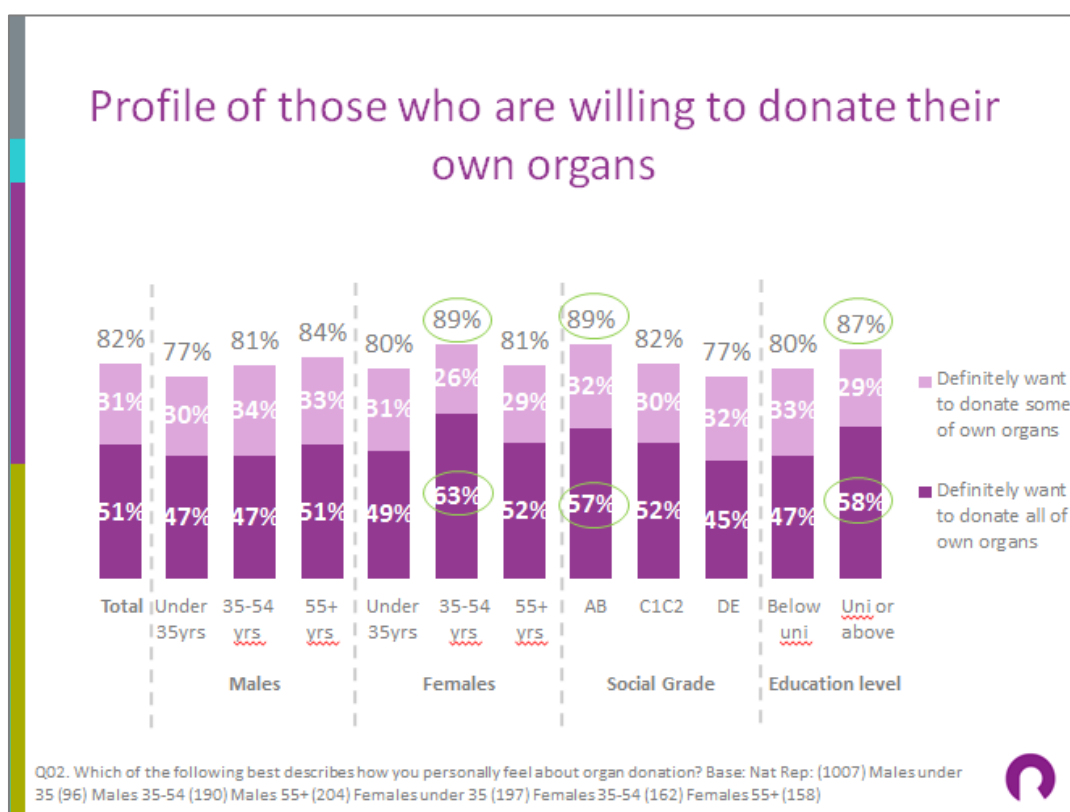


Figure 6 Gender, Social grade & Educational profile of those willing to donate own organs

4.2 Motivations to support organ donation

People are aware of the benefits of organ donation and many are already persuaded that it is a good thing to do. 65% agree that they would be improving and saving the lives of others if they did donate their organs after death, and a sizable proportion of the population takes a practical approach to organ donation: 58% believe their organs would otherwise go to waste.

“You’re giving something that’s going to [have a] use and it’s not just going to waste I think – because once you’re buried or cremated, or whatever, it’s wasted when it could have been used”

Male, Older Family, Indian Sikh, Leeds

A key reason to support organ donation is altruism; helping others and ensuring something good comes from a sad situation. This is even more compelling if organ donation involves helping close relatives or friends to live either after their own death or helping a close relative with a living donation. This makes the benefit of donation much more tangible and familiar and the thought that a loved one could someday need a transplant can be motivating enough for some to support organ donation.

Generally, motivations tend to be more at the individual rather than societal level, and this is a key differentiator between those who are willing to donate and those who are not. Only those who are willing to donate or to consider donating their organs are likely to view organ donation as a social responsibility. As shown in Figure 6 below, those who support organ donation see more benefits in it, appreciating both the benefit to the recipient as well as the benefit to self but those who are unsure how they feel about donating their organs are effected by a more limited number of considerations – key amongst these is the consideration that someone they love could someday need a transplant. Agreement with the statement *‘It feels good to know I could help someone when I die’* is high and at 69% amongst those who are definitely willing to donate, reducing significantly to 47% among those who would consider donating their organs. Agreement reduces further still, to only 19%, among those who have yet to decide how they feel towards organ donation and to 5% amongst those who are unwilling to donate their organs.

There are relatively high levels of agreement amongst those who are undecided and unwilling to donate their organs, that organ donation is an unselfish act. That they are willing to view donors in a positive light indicates some warmth towards organ donation in principal, however their interpretation of it being unselfish suggests it may be a weightier decision for them and one that incurs some personal (emotional) cost. Alternatively, those in favour may simply not wish to blow their own trumpet by describing themselves in this way. Painting donation in an affirmative and rewarding light may prove persuasive and encourage higher levels of consideration amongst those who currently feel unable to commit.

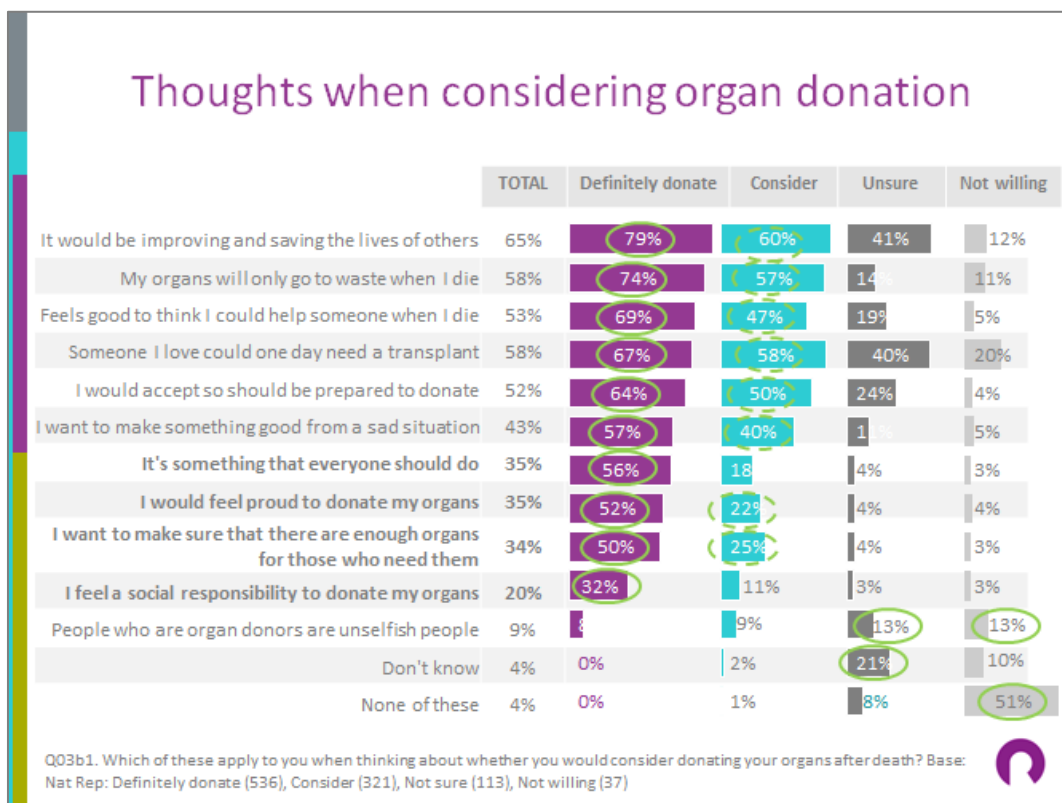


Figure 7 Thoughts on organ donation broken down by willingness to donate

Any communications or marketing campaign is likely to be most effective if it strikes an emotional chord and personal connection with the individual. Prompting people to understand how organ donation might affect their own lives one day is a particularly powerful motivator. People are unaware and find it difficult to empathise or understand how many people are waiting for donations and how their lives are affected. When considering their own willingness to donate only 52% took into account the fact that they might one day need a transplant. A slightly higher 58% considered whether a friend or relative of theirs might need one.

Highlighting the length of transplant waiting lists, and the need for higher levels of donation should help people understand the real human value of organ donation. Thinking about children needing organs tends to evoke a particularly emotive response, and is likely to be an entry point for engagement for many. However, this must be balanced against making people feel they are being manipulated.

4.3 Barriers to supporting organ donation

There are a number of concerns and barriers around organ donation, some of which could be easily dispelled or remedied by a frank conversation with friends or family. In this section

we have discussed the three main barriers that exist and explained a number of misconceptions which also effect understanding of organ donation.

As shown in figure 8 below, a lack of trust in the medical profession emerges as the single most common reservation towards organ donation. There is a fear that doctors might prioritise others, for example, saving younger/healthier people and opting to save multiple lives in place of one individual.

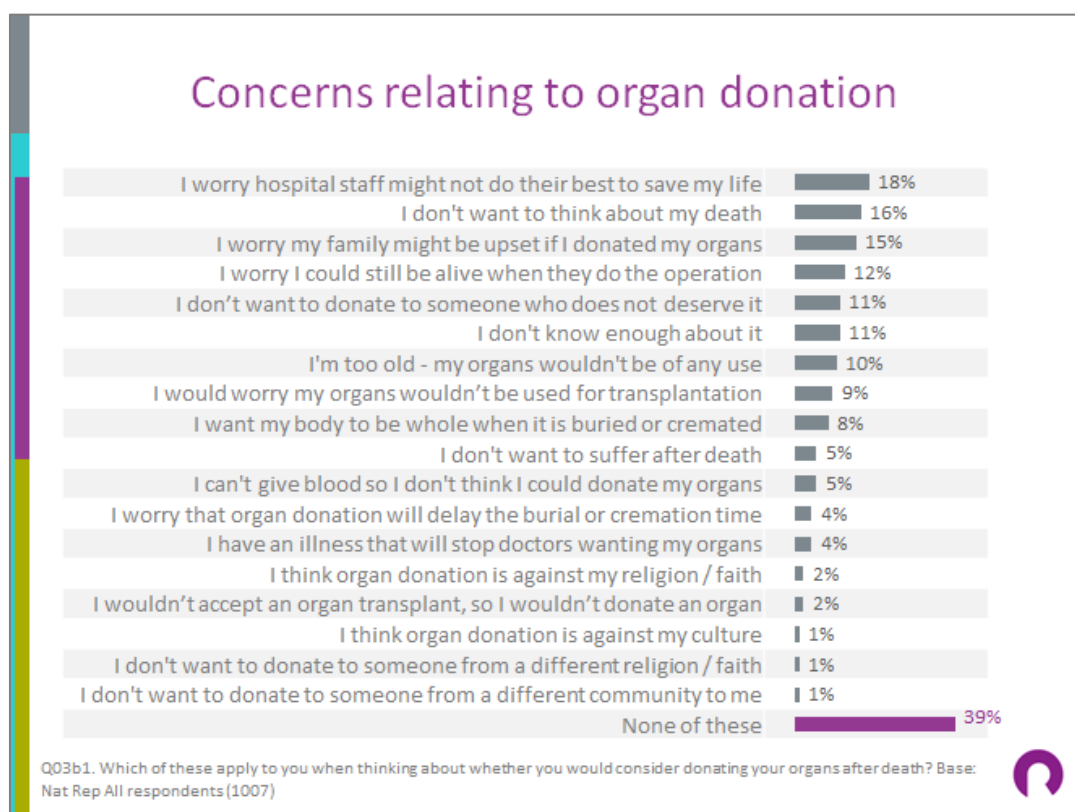


Figure 8 Statements of concerns about organ donation

There is a fear that doctors will not respect the body and wishes of the deceased and a concern that if you sign up to the ODR 'they' will 'take' everything they can. This is perpetuated by a misunderstanding of which 'organs' can be used and the perception that body parts such as the brain, arms and legs can be taken.

Additionally, there are fears and misconceptions over how the body is treated during donation, with concerns that the bodies will be 'ripped apart'. Lack of trust in the medical profession also results in some concern that doctors will not fully check that they are unable to resuscitate the deceased and so there is a genuine fear that you may still be living/conscious when the organ retrieval takes place.

“It might sound silly because you’d be dead, but still the fear of being alive when you are operated on puts people off”

Male, Older Family, White British, London

This mistrust heightens a feeling that others are trying to gain from their loss, for example ‘they’ (the system/the doctors/ faceless recipients) are trying to take something away.

Concern about upsetting the family / wider community is also a barrier to supporting organ donation. Given that individual wishes are rarely discussed with loved ones, there are concerns (and assumptions made) that relatives may be upset about the decision to donate.

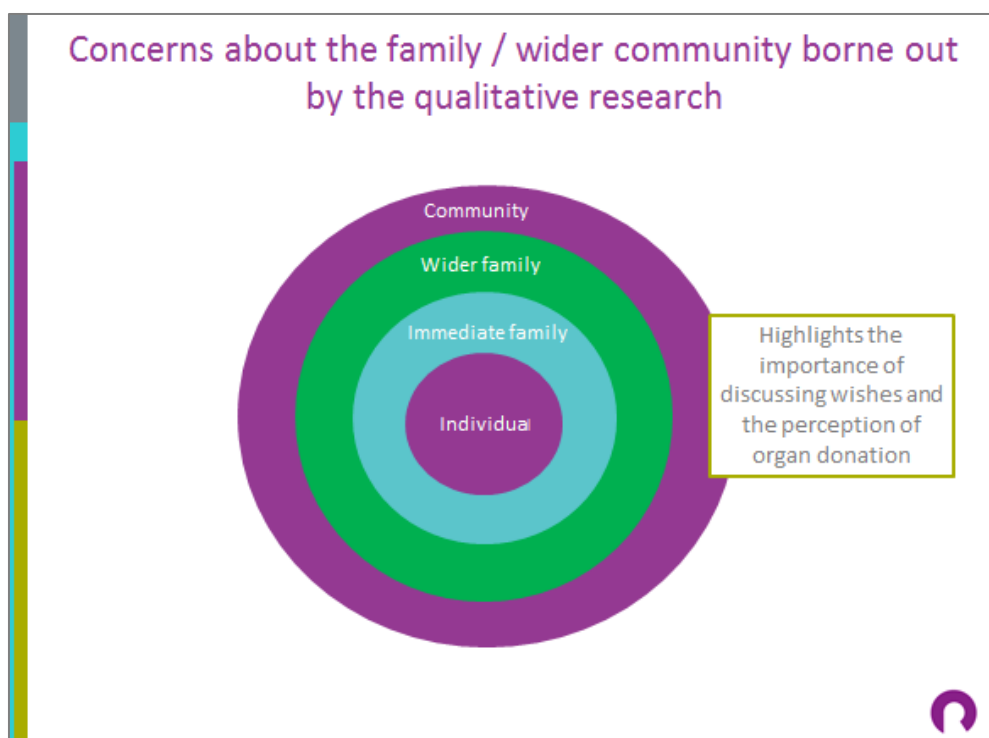


Figure 9 Diagram of various layers of concern and influence on attitude to organ donation

As discussed earlier there is a general avoidance of talking about death and, amongst some, a superstition that by thinking and talking about death, it could become a reality. This clearly acts as a barrier for even considering signing up to the ODR.

“I know it sounds ridiculous but it feels a bit like tempting fate”

Female, Older Family, White British, Manchester

Another barrier, particularly for those unsure or unwilling to consider donating their own organs, is a strong attachment to the physical form after death particularly with regard to keeping the body whole. In particular, the belief of keeping the body whole can evoke a strong emotional response, which people sometimes struggle to articulate. Some are able to provide more rational reasons for the desire to keep the body whole relating to concerns about organ donation altering the appearance of the body and whether this affects the ability to view the body in an open casket. For some there is a belief that they want to leave this life as they entered the world and/or that the body is still needed after death and as such they do not want it to be missing some organs. Incorporated in this is the wish for the deceased to rest in peace and concern that organ donation somehow disturbs the soul at the time of passing.

Often when a person holds one or a few of these beliefs but agrees with organ donation in principle these barriers can outweigh any potential benefits, making it seem too daunting a step to sign up to the ODR.

Additionally, there are a number of misconceptions around organ donation that present concerns for individuals. However, once discussed and explored they can be alleviated, allowing people to rationalise and discount them as real barriers to supporting organ donation. For example:

- A belief that they are too old or too sick for organs to be of use. Some expectation that there will be an age limit on donation, e.g. those over 60 being unable to donate. This highlights the need to educate on the need for organs and potential use of organs from a range of donors of all ages
- There are also some cases where potential donors have been told they are unable to give blood due to medication/illness and have therefore assumed they would not be able to donate organs. Again this highlights a role for education in alleviating these misconceptions
- A belief that organs will not be used for transplantation but used 'wrongly'. For some there is a concern that organs will not be used for the purpose of saving lives but will be used for other 'less worthy' causes e.g. medical research, or in the worst case sold or unused

Overall, 61% have some reservations towards organ donation. Women and those aged 35-54 (that is those who are also most willing to donate their organs) are significantly more likely to have concerns than men or those who are pre family or post retirement. This is in part explained by a greater concern for the family and whether the discussion might upset someone (20% of women mentioned this, compared to 11% of men). Women are also less likely to want to think about death (20% women, 13% men) and more likely to be suspicious about the medical profession and likely worry that hospital staff might not do their best to save their life (22% of women, 14% men) or operate whilst they were still alive (15% women, 10% men). Here again, the importance of 'myth-busting' must be reiterated.

4.4 Ethnicity and consideration of organ donation

People from BME groups tend to be less open to organ donation than the population as a whole, both in terms of donating their own organs and agreeing to donation on behalf of a loved one. While this is often underpinned by religious and cultural considerations, which we go on to discuss in section 4.5, there is also very low awareness at a societal level of the particular needs of BME groups around organ donation.

While 35% of the population as a whole are definitely willing to donate all of their organs, this figure reduces to 19% when we look at our BME sample as a group. As shown in figure 9 below, there is little difference between the population as a whole and the Indian proportion of our BME sample, but much less willingness in our Bangladeshi and Pakistani sample, where religious considerations appear to be more of an influencing factor. Lower willingness to donate amongst those from Black BME groups (Black British/ Caribbean/ African) are in part linked to lower levels of trust in the NHS than in the population as a whole.

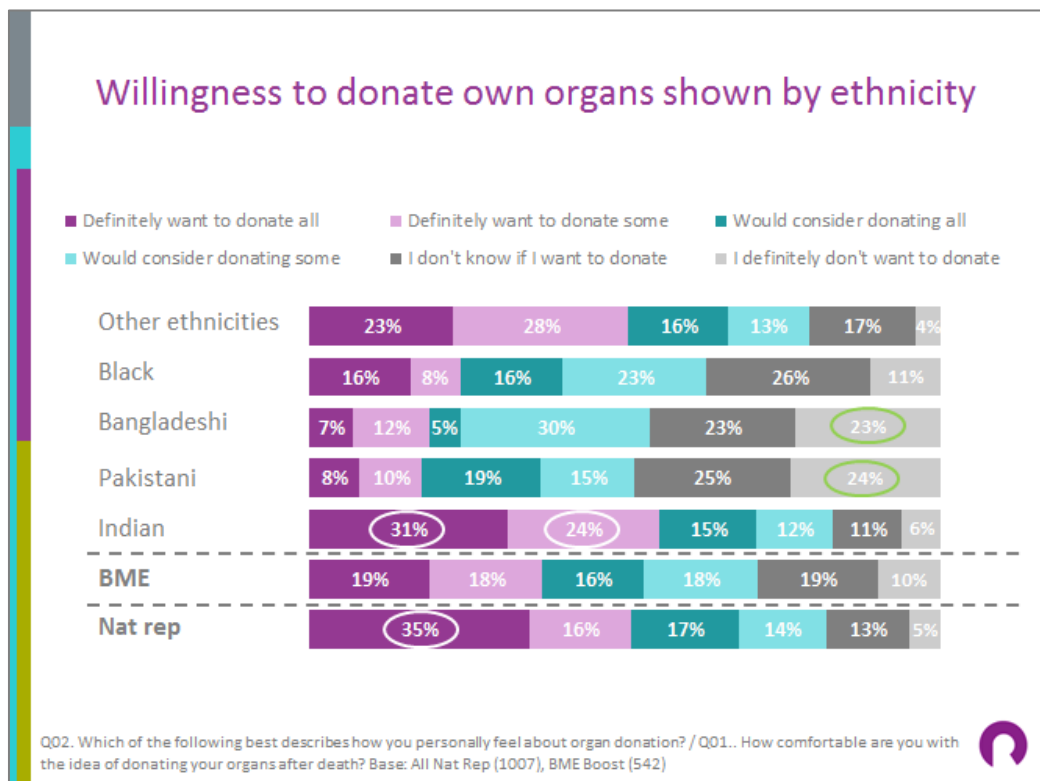


Figure 10 Willingness to donate broken down by ethnicity

While BMEs are significantly less willing than the sample as a whole to donate *all* of their organs, overall willingness to donate *some* organs differs very little. For this reason publicising the fact that people can chose the organs they donate may be effective for these groups.

During discussions we found that death and dying is not often discussed nor is it on people's radars. It was clear from the depth interviews that people rarely think about or discuss their wishes regarding any aspect of death or after death unless their lives have been touched directly by terminal illness or accidental death. People from BME groups are no different in this respect, although we did in some BME groups observe more of a generational gap, with young adults particularly wary of raising any topics (not just death or dying) perceived to be likely to cause distress to parents and older relatives.

We also found that BMEs are significantly more likely (17% vs. 11% of the total population) to say that they do not know enough about organ donation, which indicates a need for more education around the process.

While trust in the medical profession appears to be less of an issue – figure 10 below shows that worry about not being saved, or of still being alive when organs are removed is significantly less common among the BME sample – there are some differences within BME groups. Those classifying themselves as Black Caribbean or African tend to know less about organ donation and to have lower levels of trust in the medical profession, than those of Asian origin. Many in our Asian sample made reference to 'stories from home' about organs being removed without consent, or being sold illegally so they tended to have more trust in the UK medical profession.

Asian respondents and particularly those of Pakistani and Bangladeshi descent are more likely to reference an objection to delayed burial/ cremation or to mention a desire for their body to remain whole. These heightened concerns among Asian respondents account for the significantly higher proportion of BMEs referencing these barriers - 12% mention the desire to be buried/ cremated whole and 7% that it could delay burial/ cremation - than the population overall. Religious barriers are also not consistent across ethnicities. Whilst all BME groups are significantly more likely to raise religious objection than the general population, religion or faith barriers are raised by a far higher proportion of Pakistani (36%) and Bangladeshi (26%) respondents, than Indians (8%) or Black respondents (8%). Overall and again, shown in Figure 11, 13% of BMEs raise religion as a barrier to donation compared to 2% of the general population.

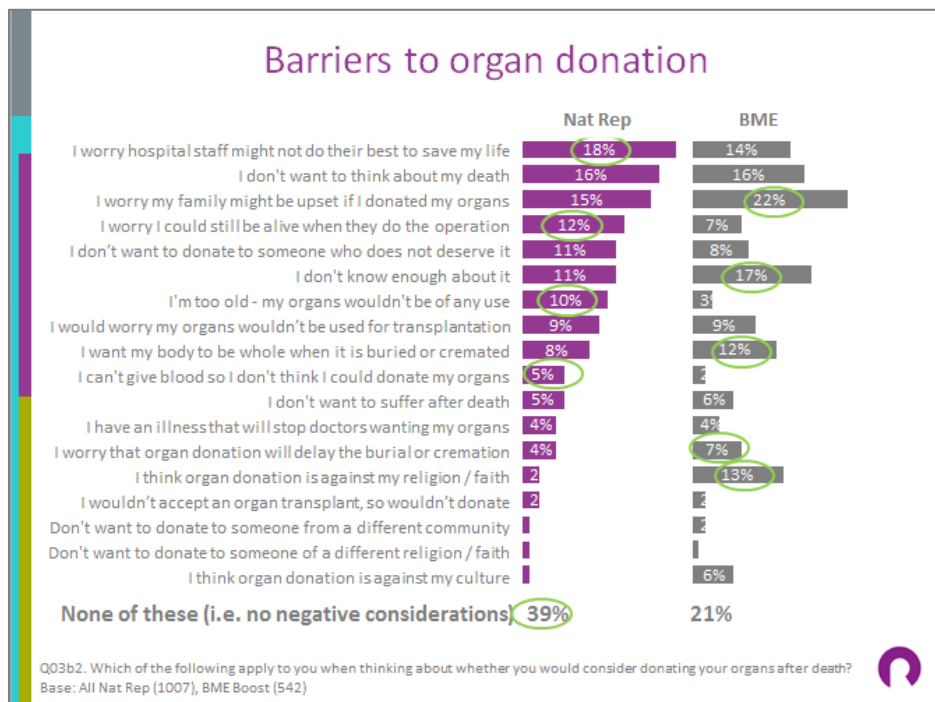


Figure 11 Statements of barriers towards organ donation

We see that concerns about upsetting family members are significantly greater in BME groups than in the population as a whole. This is apparent across BME communities and not specific to any one ethnicity. The community view can also be influential, particularly where there is a concern that they might be the first in the community to donate and that they may be going against tradition. This can stem from wanting to show respect for their culture, when older relatives place importance on keeping with traditions. In some cases younger generations were more accepting of Western traditions and beliefs but did believe that older relatives would not be as open. For this reason they are concerned that organ donation would be upsetting and frowned upon by family and relatives. In some cases there is concern about how older relatives may react to loved ones being “cut up”.

In some cultures, community often extends to religious leaders, elders and influential people within the area. Other concerns relate to putting an additional burden on the family, particularly when other priorities such as, arranging funeral traditions are acknowledged.

“I would fear being the first person to partake in organ donation and wouldn't want to be considered abnormal for doing it. If I was to bring up the concept of organ donation with my parents I know I would be laughed at... It is just something random to bring up and just unheard of”

Female, Younger Family, Bangladeshi Muslim, Manchester

As already discussed, an ability to see the benefits of organ donation is much more prevalent in those willing to donate. Amongst our BME sample as a whole, three benefits stand out as having more resonance, and these are all important among the general population also:

- Helping to save or enhance the lives of others
- Knowing that someone may be helped as a result of one's own death
- Recognising that a loved one might one day need a transplant

Feeling proud to donate one's own organs has less traction, although this sentiment resonates more with Indian BMEs (32%) than with other ethnicities (25% overall).

Across the BME sample, Pakistani and Bangladeshi people are less likely than other ethnicities to see the benefits.

From discussions, it was clear that awareness of the particular needs of BME communities in respect of organ donation is low, and tends to be limited to people who have gained knowledge as a result of being personally affected. A minority of our BME sample have lost relatives to heart, liver or kidney disease. While these families tend to be more aware of the predisposition of some ethnic groups to certain illnesses, the link to organ donation is rarely made unless the possibility of a transplant was discussed in the context of the loved one's medical treatment. Even where there is awareness of the link between illness and ethnicity, only a couple of individuals in our sample appear to be aware of any issues with tissue matching or blood groups and therefore of the importance of having more potential donors from within ethnic groups. Discussions with stakeholders suggested that more needs to be done to highlight these particular needs, and that such messages will need to be fairly hard-hitting to be effective. Organ recipients are felt to be especially useful in communicating the importance of having greater numbers of potential donors within BME communities.

4.5 Impact of culture, religion and tradition on own organ donation

Not surprisingly, culture, religion and tradition all have a considerable impact on how people view organ donation. These factors cut across individual and familial considerations.

4.5.1 Religion

Religion is commonly stated as a top of mind reason why society might not discuss or support organ donation. This is regardless of whether that individual is religious themselves or whether they know someone who is religious and particularly vocal in their views. Most are aware that Jehovah's Witnesses refuse the giving or receiving of blood and therefore incorrectly assume the same applies for organs. While many assume that other religions will prohibit donation as well, there is little clarity about which religions they think might object. There is often an assumption rather than knowledge that more 'traditional' religions, e.g. Islam, Judaism, may be opposed to donation due to beliefs about the afterlife and sanctity of the body.

“I know that for some religions individuals need to be buried with all their parts intact”

Woman, Empty Nester, White British, Leeds

However, in reality, just 2% of our total sample thinks that it is against the teaching of their own religion or faith. While this figure rises when we look at the BME population, the figure is still only 13% and heavily skewed towards Muslims, followed by Christians. In this research, 70% of those who thought that organ donation is against their faith are Muslim, as shown in Figure 12.

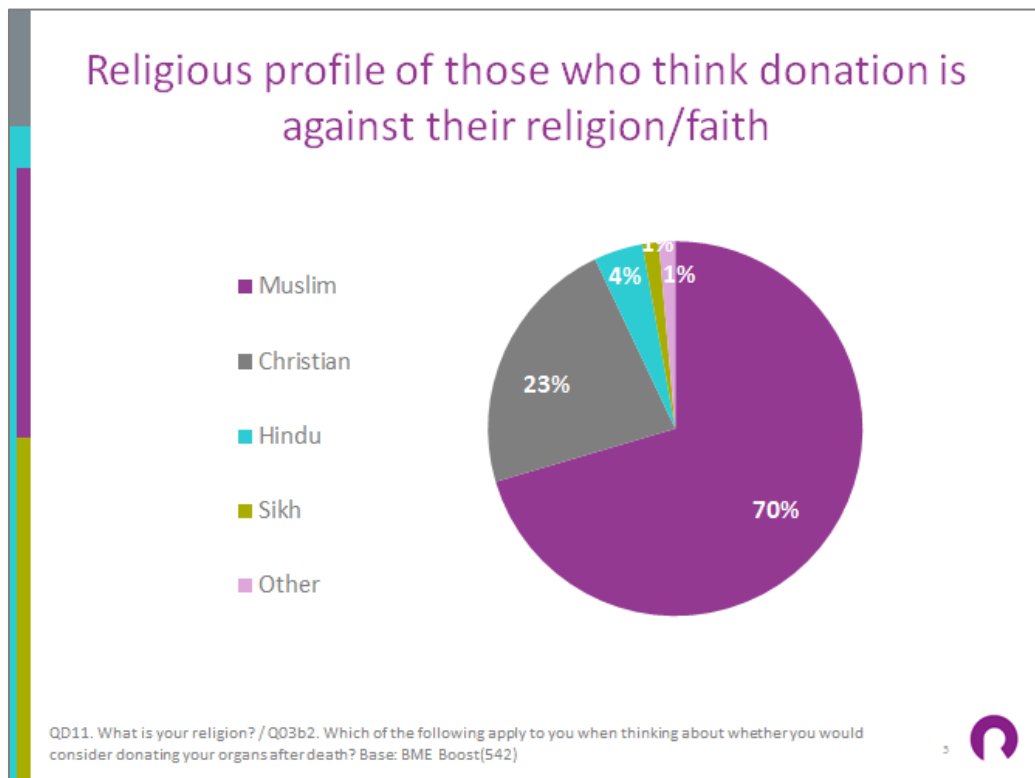


Figure 12 Religious profile to attitudes towards organ donation

In the qualitative research we found that few people of faith, whether practicing or lapsed, are aware or certain of the official position of their religion on organ donation. This is reflected quantitatively, with 33% of those who claim that organ donation is against their religion stating that they don't know this for sure and 31% saying that they would need to look into it more. Equally, few can recall the topic ever being discussed in their place of worship, either by their own faith leaders or within their faith community (just 18% have discussed it with someone in their religion). Many assume this to mean that organ donation is not looked upon favourably: almost one-quarter (23%) claim that they 'just know' it is against their religion. Crucially, we know both from the individuals we spoke to and from our discussions with stakeholders, that the views of individual leaders tend to be highly regarded, and in many cases will have more influence on followers than any 'official'

position. In some cases, people are following faith leaders who are themselves based overseas rather than in the UK. Across all of our interviews with people of different faiths, there is a strong belief that the most effective way to encourage donation is through faith leaders within individual communities, so that any fears and concerns can be addressed by those having the most influence and authority.

Within the BME faith groups we spoke to, Sikhs and Hindus are the most likely to view organ donation positively, and the least likely to say that organ donation is against their religion. Some see it as an act of charity, and as such tend to have an altruistic view, especially seeing the benefits of helping save or enhance the lives of others. While we observe a high degree of openness to organ donation within these two religions, few in our qualitative sample are aware of the 'official' position, or confident about what the views of their personal leaders or community elders might be. Equally, few know who to talk to for reassurance/endorsement of their own views. As a result, many feel that more work is needed with temple leaders and elders to help them encourage followers to think about the topic.

It is also important to note that we observed some inter-generation issues, with younger Sikhs and Hindus conflicted between their own positive views of donation and their concern not to upset their parents and older relatives. In one family discussion we observed a good deal of tension in a Hindu family when a mother learned that her 21 year-old son had signed up to the ODR via his driving license; despite being willing to donate her own organs and being clear on her reasons for this, she found it difficult to contemplate consenting on behalf of her son. Similarly, a young Sikh mother we spoke to was very supportive of donation in terms of her own, her husband's and her mother's organs, but worried about how she would be viewed by the wider Sikh community if she consented to her children's organs being donated.

While Christianity appears to have less influence on attitudes towards organ donation than some faiths, personal beliefs around what happens after death can have an impact. People who believe in resurrection envisage a need to be 'whole' in the afterlife, while others believe in the continuation of the soul but see no need for the body after death. As with other religions, individual church leaders can be highly influential and are likely to be very effective in encouraging congregations to think about organ donation.

The Muslim people we spoke to are the most divided in terms of their views about organ donation, however the majority were in favour (two-thirds do not think their religion prohibits organ donation). Many perceive it to be an issue on which the religion itself is divided, and tend to take their cue from the imams and muftis they know from their own or other mosques they visit. That said, it is not seen as widely discussed or a priority for discussion, and as such a definitive position is felt to be some way off.

"If we can't agree on something as simple as when Christmas is, I can't see us reaching agreement on something as complex as this"

Bangladeshi Muslim, Young family, Manchester

Most of the individuals we spoke to base their own views on their personal interpretation of the Qur'an, either taking the view that saving just one life can be likened to saving the whole of mankind, or that one's body is not one's own but belongs to Allah. Some actively seek additional guidance to that received in their closest circles; this includes using Islamic websites to search for answers to questions about different issues, and 'fatwa shopping'. Younger people (and more specifically younger females) appear to be more open to organ donation, but this is often in conflict with the views of their parents and the religious leaders at their father's or husband's mosque.

Amongst those, predominantly younger, Muslims we spoke to who are more open to organ donation, few feel able to commit to supporting it without the approval or permission of either family or their own religious leaders. Discussions with some of the clinical practitioners at the Stakeholder stage support this, suggesting that offering potential donor families the opportunity to speak to an imam provided by NHSBT is rarely helpful, as there is a perception that inevitably the person provided will be 'pro donation' rather than someone who sees both sides of the debate.

While the main reasons for seeking approval are fear of the consequences i.e. on the Day of Judgment and a desire not to act against the wishes of family elders / authority figures, there also seems a deep reluctance not to be the first to do something widely perceived as controversial.

Islamic requirements for swift burial, treating the body as sacred, and not modifying the body in any way after death all add to concerns about whether or not organ donation is acceptable for Muslims.

There is also an issue around where the organs go to. One young father we spoke to expressed strong views about his organs going to someone outside his own community. Specifically, he has real concerns about his organs going to British non-Muslim soldiers who might be engaged in military activity against Muslims. His view is that he would much more willing to donate his organs if he was in an Islamic country at the time of his death as opposed to in the UK. While we cannot be sure that this is a commonly held view, we sense that it is not an exceptional one. It is likely that greater awareness of the need for organs within specific communities might help encourage people with similar views to review their stance on organ donation.

In practice, from our discussions with stakeholders, people of all faiths can struggle with organ donation when it comes to organ retrieval. This is complicated in part by some religions not recognising brain stem death (for some this is a belief that the soul and the brain are separate). Keeping organs vital until they can be retrieved can be confusing for potential donor families – is the person alive or dead? – and can feel like 'playing God'. Essentially, some potential donor families can feel that in consenting, they are in some way involved in or responsible for their loved one's death. From the clinical practitioners'

perspective, there is a role for more education across the population, religious and secular, in terms of how death is defined.

4.5.2 Culture and tradition

Irrespective of an individual's religious beliefs, culture and tradition are hugely important in shaping willingness to donate or give consent to donation on behalf of others. As already discussed, organ donation is not perceived as 'the norm' in England and there is no culture of donating, supporting donation or openly discussing the topic.

While some people talk to relatives about their wishes for after their death, this is by no means commonplace and tends to happen only when triggered, for example being touched by an accident, serious illness or bereavement. Some people don't feel able to discuss their after death wishes in any circumstance, for fear of upsetting their loved ones, and others simply don't think about it. This is evidenced by the fact previously discussed that few have prepared for death in any significant way. From the qualitative discussions, after death wishes, where expressed, focus on the funeral, favourite hymns, burial vs. cremation, or the individual's estate; organ donation doesn't feature. Part of any attempt to normalise donation will need to address this.

Funeral traditions inevitably influence attitudes and decisions around organ donation, in two principle ways. Firstly, when we speak to families about their experience of bereavement it is clear that there is a common tendency to go into 'organisational mode' with the days following the death being fully occupied with making funeral arrangements. This is partly a function of keeping busy in shock and grief, but it is also an obviously frenetic time in families where there is a tradition of large scale funerals, with extended family and members of the wider community attending, or where the deceased had expressed a wish to 'go home' or where family tradition dictates that the body is flown overseas for burial or cremation. One family we spoke to, whose parents moved to the UK from Bangladesh described having a loft full of bedding, pots and pans ready to accommodate extended family in the event of having to organise a funeral. Others talked about belonging to funeral committees specifically set up to assist with funeral planning. In all of these cases it is easy to imagine how 'closed' families can be to discussions about organ donation, as there is so much to think about and arrange.

Secondly, funeral traditions themselves are perceived to present barriers. Specifically, these include:

- Speed – of particular importance for Islam, Judaism, repatriation
- Viewing the body (at the hospital, at the funeral home, open casket at or immediately prior to the funeral)
- Preparing the body for the funeral – washing, dressing, sitting with, praying over, decorating

Unsurprisingly, given the lack of awareness of organ donation and the retrieval process, few are prepared for the time organ retrieval can take. While in reality this very rarely delays funeral arrangements, the perception that it might can cause concern.

Both the in-home interviews and the stakeholder discussions confirmed that fears exist about the condition and appearance of the body post organ retrieval. While clinical practitioners and SNODs in particular work hard to allay these fears, it can be difficult to reassure families that the body can be viewed 'as normal'. The same goes for washing the body. Again there is a need for more education, in particular around the care taken and the respect shown during and after organ retrieval.

Aside from religious requirements surrounding funeral arrangements, most secular families will have their own tradition of burial or cremation. Burial for example is prevalent in Black Caribbean communities and for Catholics, while non-Muslim Asians tend to follow a tradition of cremation. In the qualitative discussions we found that individuals and families who choose burial are more likely to wish to be buried 'whole', and to have a greater emotional attachment to the physical body. People who choose or have a family tradition of being cremated, in contrast, are more likely to see their body as something they have no further use for once dead. As such, they are more likely to be open to organ donation.

5 ODR AND DONOR CARDS

Organ donor cards are historically and symbolically linked to support for organ donation. For many they are still a means in themselves of recognising someone is officially registered as an organ donor. The research highlighted a need to what the ODR actually is and its relationship to organ donor cards. Overall it is felt that widespread reintroduction of donor cards would be more likely than the ODR to act as a catalyst for discussion about organ donation. Support for dual signatory cards is more varied and similar clarification of its position would be crucial.

5.1 Organ donor register

5.1.1 Awareness and understanding of the ODR

We found when speaking to people that awareness and understanding of the ODR could be improved. There are confusions about the actual process of becoming a donor, how support is demonstrated, who is eligible to donate and receive organs and what organs can be donated. Figure 13 shows that whilst an encouraging 84% said they are aware of the register, 30% select an incorrect definition. 14% say that it captures consent for bodies to be used for medical testing; 11% that it contains the names of those who are willing to be live donors; 5% that the ODR records support in principle.

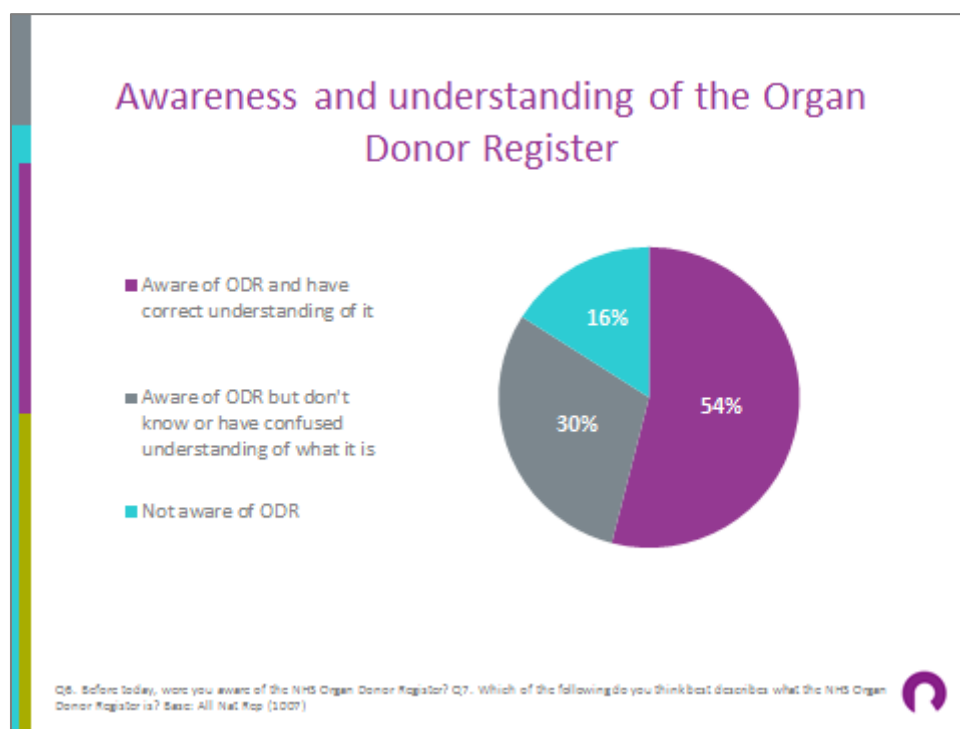


Figure 13 Awareness and understanding of the ODR

5.1.2 ODR registration

According to registration figures, sign up to the ODR is primarily through the NHS organ donation website www.organdonation.nhs.uk⁶. There are, however, a number of ways that people can sign up to the ODR and the variety of methods affords some misapprehension as to whether a person has registered their consent or not - and by which method they have chosen to do this. 11% only realise (or think) they have signed the official register once they are informed that registration is legitimate when recorded through non direct methods such as through a Boots Advantage Card or when registering for a new passport.⁷

Half (49%) believe they have signed up to the ODR, whilst registration figures show that only 31% have in fact done so⁸. Speaking to those who believed they have registered with the ODR it is apparent that some are unable to clearly recall whether they had joined the register, particularly if it had been a number of years since they registered. Some explained that they had tried to check if they are still on the register but found the process of checking difficult and the outcome remaining uncertain. In many instances people signed up again to be sure, but this was not always the case.

This suggests that potentially a fifth (c.18%) of the population erroneously believe they are already on the ODR. A targeted message to encourage people to check whether they really are registered could prove effective; however this must be combined with an infrastructure that allows people to do so easily.

A further quarter (23%) are definitely willing (8%) or would consider donating (15%) and are not currently registered with the ODR so there is a need to promote registration channels more clearly and to emphasise the importance of leaving written and/ or spoken consent.

In line with overall willingness to donate, claimed awareness and registration to the ODR are significantly lower among people from BME communities; 39% overall say they have signed up to the ODR. Registration levels differ by ethnicity and by faith. Pakistani (26%) and Bangladeshi (23%) respondents are least likely to have registered with the ODR, whilst levels of sign up are highest amongst Indians (44%). 52% of Hindu's had registered their consent – which is broadly in line with the general population average – while only 28% Muslims claim to have registered.

5.1.3 Reasons for not registering with the ODR when a person is supportive of organ donation

Many of those who have not registered on the ODR but support organ donation give practical reasons for not having done so, which are shown in Figure 13 below. 15% don't

⁶ Information provided by NHSBT

⁷ There are a number of ways to sign up to the ODR, namely telephoning the Organ Donor Line, or by giving permission when completing a driving license application, registering with a new doctor or GP, applying for a Boots Advantage Card, new passport or when registering for a European Health Insurance Card as well as when applying directly online or for an organ donor card

⁸ Nhsbt.co.uk

know enough about organ donation and 14% didn't know that there was a register – a clear sign that further publicity of the ODR is needed. The most common reason for not registering is again routed in the issue of organ donation not being top of mind. Of those who are supportive of organ donation, but not on the organ register, 32% attribute this having not 'got around to it yet'. As stated earlier an avoidance and unwillingness to consider death is also apparent, with 14% accounting their lack of registration to them not wanting to think about death.

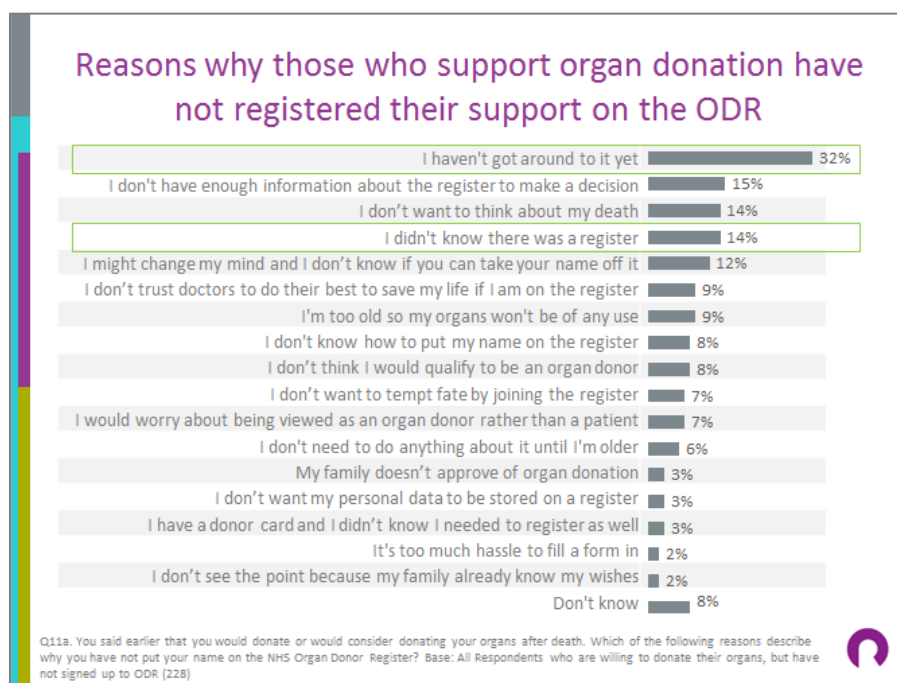


Figure 14 Reasons why supporters of organ donation have not signed the ODR

5.2 Donor cards

Before the ODR was introduced in 1994, donor cards were available for people to obtain and carry as a sign that they would like to be a donor. 38% of the sample believes that they currently carry a card or recall having one in the past.

There appears to be an attachment to the old organ donation cards with many talking fondly about carrying them around, as a way to show their support.

"I used to carry one, I remember them well. My dad used to have one too. It's a good way to act as a reminder and show your wishes. Everyone should really have one"

Male, Empty Nester, White British, Leeds

With the establishment of the register, donor cards should now be issued to those who have signed up to it. Our research highlights that in fact some perceive they are on the register but cannot recall receiving a card.

“I am pretty certain I signed up, they asked when I took out my driving license and I wouldn’t have said no, but I never heard from them and definitely don’t have a card”

Female, Young Family, White British, Leeds

50% of the general population and 66% of BMEs currently believe that if someone has an organ donor card this is a sign that they are definitely on the NHS Organ Donor Register. This is one of the most common misconceptions surrounding organ donation. It’s no surprise, therefore, that only 39% of those on the ODR (19% of the total population) have both signed up to the ODR *and* obtained an organ donor card.

The tangibility of supplying a card also has value for some, and the majority of people (71%) feel that being able to pick up donor cards would encourage donation. Making donor cards more generally available is seen as a positive way of encouraging donation. Perhaps more importantly, it is felt that a card would act as a tangible prompt to discussing organ donation. There is also acknowledgement of the value of the register. It is seen key in formalising the decision to be a donor and in fact two-fifths (42%) feel that card holders should also have to join the ODR. Conversely for 28% this can be too formal and daunting a step, preferring instead to just carry a card.

Additionally there is some uncertainty as to the role of the card alongside the ODR. Key questions include whether the card would act as a formal statement of intent and whether you would need to sign up to the ODR if you already had a card. Some suggest providing donors with the choice to link the card to the ODR in a simple and easy way. Ideas include having cards with a QR code or cards that could be activated in cash machines.

5.2.1 Counter signatory on donor card

The idea of counter-signing the card does seem to have traction for some in ensuring that family wishes are discussed and it is felt that this would help to bring the decision out into the open. Just over half (57%) feel that dual signatures are a good idea for encouraging a conversation with loved ones about organ donation. However there are questions about whether this would be legally binding and whether consent would still be sought. Since it is presumed that family members would still be asked to give consent, some issues are raised about the implications if the person asked to give consent is not the same one who originally countersigned the card.

6 FAMILIAL ATTITUDES TOWARDS ORGAN DONATION

At present, if a person is on the NHS Organ Donor Register and dies in circumstances where their organs could be donated, their closest family or friends will be asked to confirm the person's wishes before organs are donated. Family or friends may also be asked when the person is not on the ODR, and they have the ability to refuse donation in either situation.

NHSBT has identified that family refusal rates are a significant barrier to increasing overall organ donation rates, and in order to increase the conversion of potential to actual donors, family agreement rates must increase. The UK has one of the highest family refusal rates in Europe: 45% of families did not agree to donation in 2011/12 compared with 19% in Spain and 4.7% in the Czech Republic, and refusal rates are even higher in UK BME communities at 76%.

Previous advertising campaigns have focused on encouraging people to join the ODR to show their wishes to donate after death rather than familial consent. Internal NHSBT findings suggest that families are most likely to agree if a person is on the ODR **and** has personally discussed their wishes, but currently many opportunities for a person to be a donor are lost because they have not communicated their donation wishes to those closest to them.⁹

6.1 Awareness and understanding of families being asked to agree to organ donation

Awareness that family or close friends will¹⁰ be approached about organ donation in the event of a loved one's death is relatively low. It is clear that such situations are rarely, if ever, considered and spontaneous awareness that people may be asked to agree to donation after a loved one's death is very low unless they have prior personal experience. Whilst prompted awareness is higher, there are still misconceptions by some that permission from family will not be needed:

- 12% believe that if a person is on the ODR, organ donation will take place without any family consultation;
- 38% believe family will be informed but not asked for permission;
- Only 40% are aware that they will be asked to agree to donation regardless of whether their loved one is on the ODR or not.

This means there is limited motivation or impetus to discuss and make others aware of wishes. Whilst 91% think it is important to discuss their donation wishes, in reality only half have spoken about organ donation in any context. As shown in Figure 15 below, only 37%

⁹ Information provided by NHSBT.

¹⁰ Family and friends will always be asked for permission if a relative / acquaintance dies in circumstances where their organs can be used for transplant.

have actually communicated their wishes to those closest to them (those who would be asked about organ donation in the event of their death).

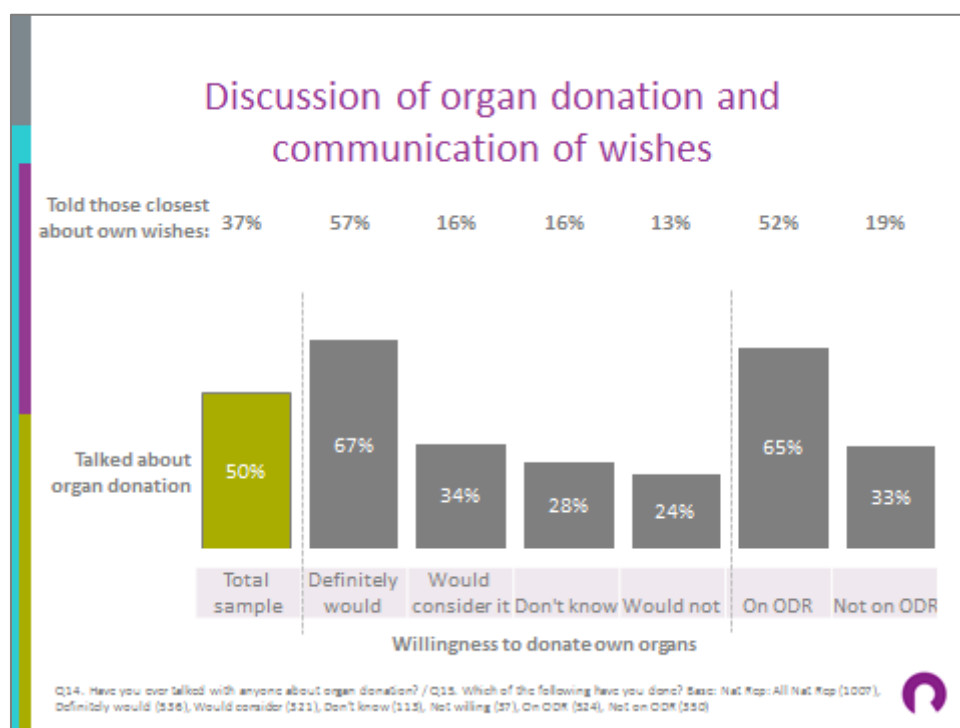


Figure 15 Discussion of wishes broken down by willingness to donate and whether on the ODR

Although those who definitely want to donate their own organs and those who have signed up to the ODR are the groups most likely to have communicated their wishes, a significant proportion still have not done so (only 57% and 52% respectively have, as shown in the figure above). Hence around half of those who most strongly support organ donation have family who do not definitively know their wishes.

6.2 Reactions to families being asked to agree to organ donation

As shown in Figure 16 below, almost half (48%) believe that asking families to agree to organ donation places too much burden on them when their loved one is on the ODR. A similar proportion (44%) feels it is too much burden when their loved one is not on the ODR.

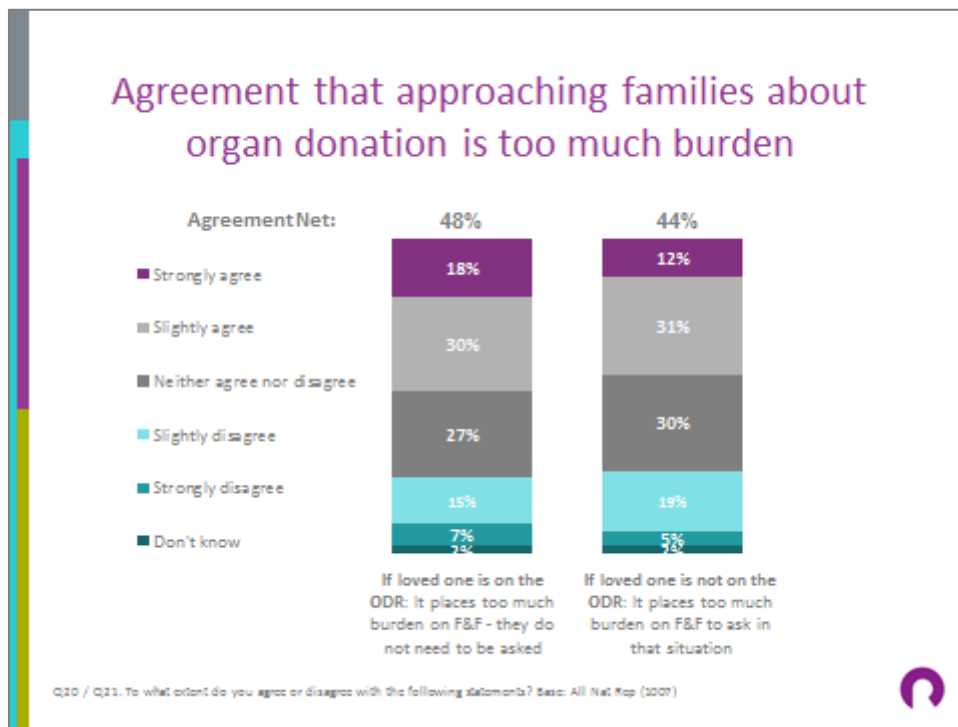


Figure 16 Agreement with statement about family agreement being a burden when loved on is on ODR and not

It is expected that family will already be in a stressful position and are being asked about organ donation when this may be the least of their priorities. Questions about organ donation may be viewed as intrusive at a time of grief and shock if it is the first time donation has been discussed and particularly if the death is under sudden or unexpected circumstances. Organ donation is thought to be a decision which should be made with a clear and rational mind, but it is expected that family members will be unable to think rationally and so the weight and responsibility of having to make such a decision can feel too much for some. For this reason, some may feel more comfortable being informed of their loved one’s wishes rather than being asked to confirm them, especially if family have limited or no prior awareness of wishes.

“It’s a hard question to answer when you think about it really isn’t it? Grief is a funny thing and I’ve had a lot of it in my life”

Male, Empty Nester, White British, Sutton Coldfield

There is also some concern that opinions about donating may be divided between family members and most want to reduce the need for any additional upset or cause for disagreement in such an emotional situation. The need for the reassurance of a family consensus is a necessity for most, and few think they could make a decision about donating on someone else’s behalf alone.

6.2.1 When a loved one is on the ODR

As there is little spontaneous consideration of the possibility of families being asked to agree to donation, it is often difficult for people to express their views about this during discussions since they are only just beginning to form opinions about it.

When a loved one is on the ODR, there are mixed views about how best to approach families about donation. People are generally unclear about the best role for families. There are relatively high levels acceptance for a range of different approaches (e.g. informing vs. asking) shown in Figure 17 below. Overall people feel that families should be involved and respected however there is an opportunity for NHSBT to take the lead in shaping the precise level of involvement when the person is on the ODR.

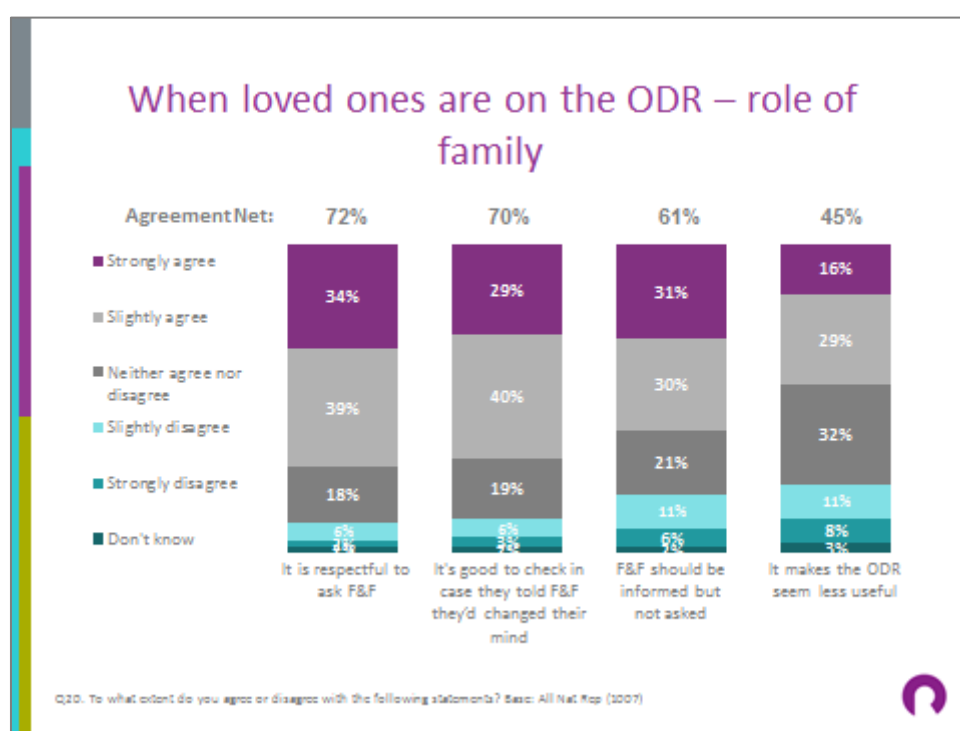


Figure 17 Agreement with statements about family being asked to agree when a loved on is on the ODR

Above all else there appears to be strong agreement that it is important for individuals' wishes to be respected. When asked what opinions they have towards organ donation, the statement with highest agreement overall (77%) is that organ donation is an individual's choice and not for others to decide. At a total level, 71% claim that it annoys them to think that their own or others' wishes might not be respected, but this is significantly higher for those who definitely want to donate their own organs (78% agreement compared to 64%).

Some are affronted by the thought that their family may be asked to agree on *their* behalf especially if they know that their next of kin is less comfortable about organ donation than themselves or if they perceive asking families to be a burden. Some can initially feel motivated

to join the ODR so that their family do not have to make a decision about organ donation on their behalf, but the fact that families will still be asked can often negate this.

Discussions show that a small number of people who are already on the ODR become quite angry at the thought of consent being sought, believing it is their right to donate and theirs alone. This is only exacerbated if they believe there is a possibility that their personal wishes may be overridden by their own family.

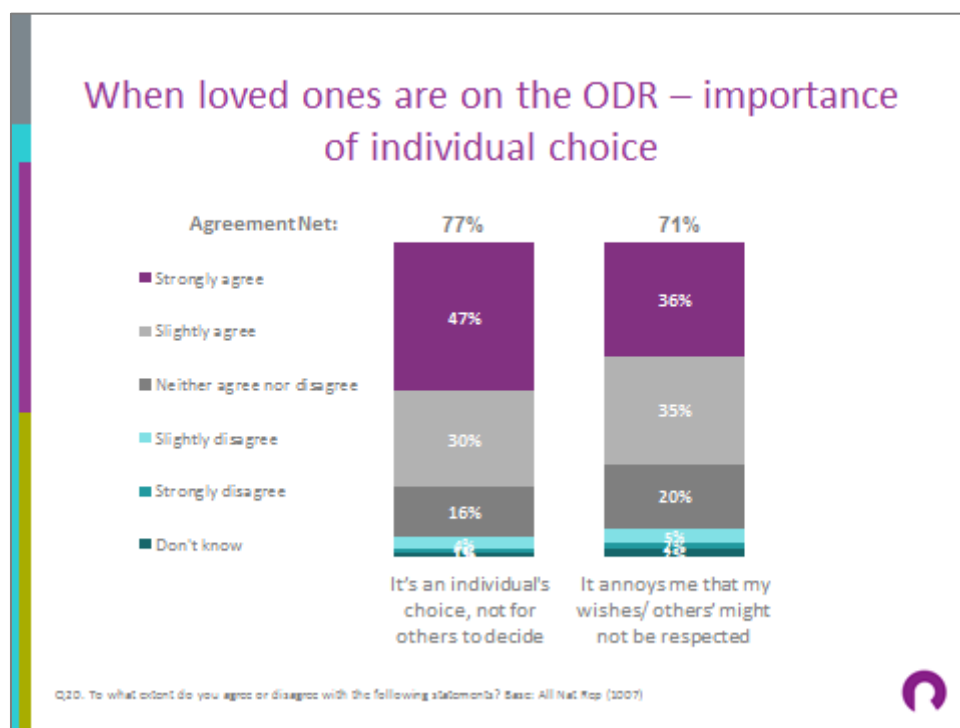


Figure 18 Agreement with statements about family being asked to agree when a loved one is on the ODR continues

6.2.2 When a loved one is not on the ODR

When a loved one is not on the ODR, checking whether families are aware of donation wishes is considered more agreeable. As shown in Figure 17 below, 71% feel that families should be given the chance to donate organs on their loved one’s behalf. Although there is sometimes an expectation that a person would have signed up to the ODR if they supported donation, less than one third (30%) see a lack of ODR sign up as sufficient indication that a person does not want to be a donor. The majority accept that families should be asked even when the person is not registered, suggesting that CLODs and SNODs need not feel overly hesitant in approaching families of unregistered people (although we acknowledge that in reality emotions may mean families are less receptive in this circumstance).

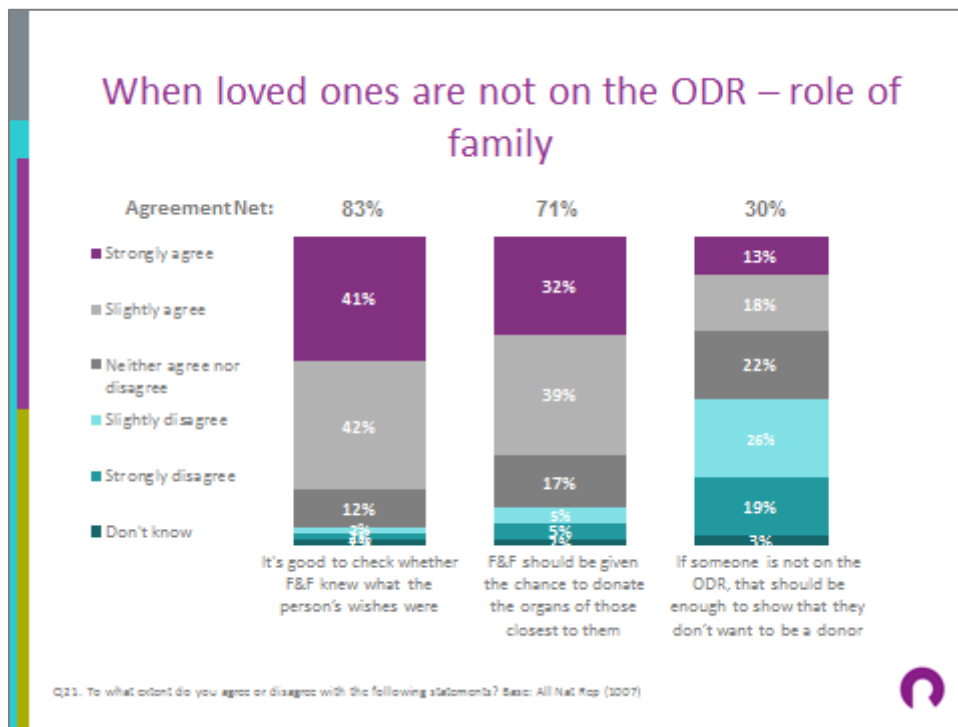


Figure 19 Agreement with statements about family being asked to agree when a loved one is not on the ODR

Although two-thirds accept being informed rather than asked when a loved one **is on** the ODR, figure 20 indicates that significantly fewer (34%) agree that donation should happen automatically when a person is **not** on the ODR. A high proportion (79%) believes it is respectful to ask friends or family. Presuming that a person's organs can be donated can be perceived to be taking away personal choice, when organ donation is currently often seen to be a deeply personal decision rather than a social responsibility.

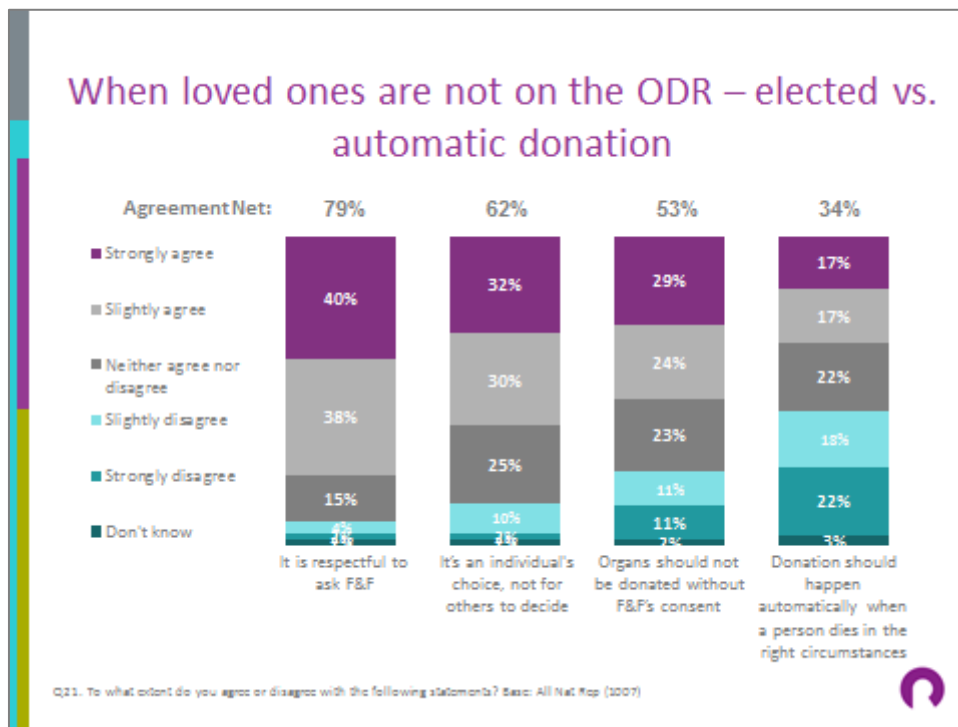


Figure 20 Agreement with statements about family being asked to agree when a loved on is not on the ODR, Cont

6.3 Expected response to being asked to agree to organ donation

During both the qualitative and quantitative stages of research, four different scenarios were used to understand expected response when being asked to agree to donation on behalf of a loved one, as detailed in Figure 21 below. These cover the varying levels of prior individual consent (ODR sign up and prior verbal consent) which a person may have given regarding their own organs.

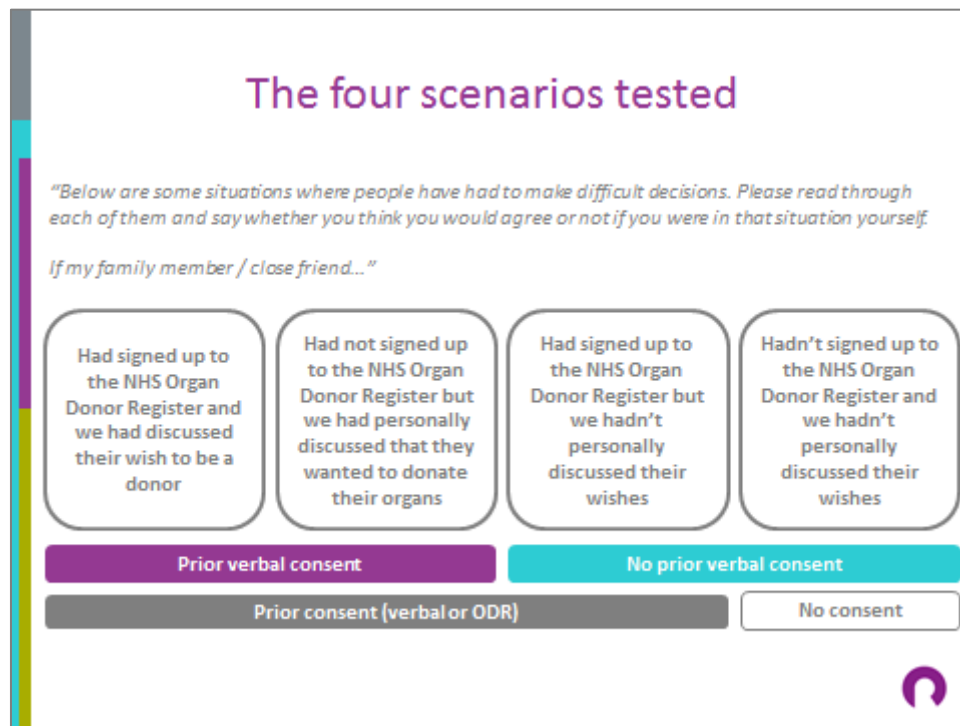


Figure 21 The four scenarios tested covering varying levels of consent

The extent of prior awareness of a loved one's wishes has a clear influence on expected response when being asked about donating on their behalf, as illustrated by Figure 22.

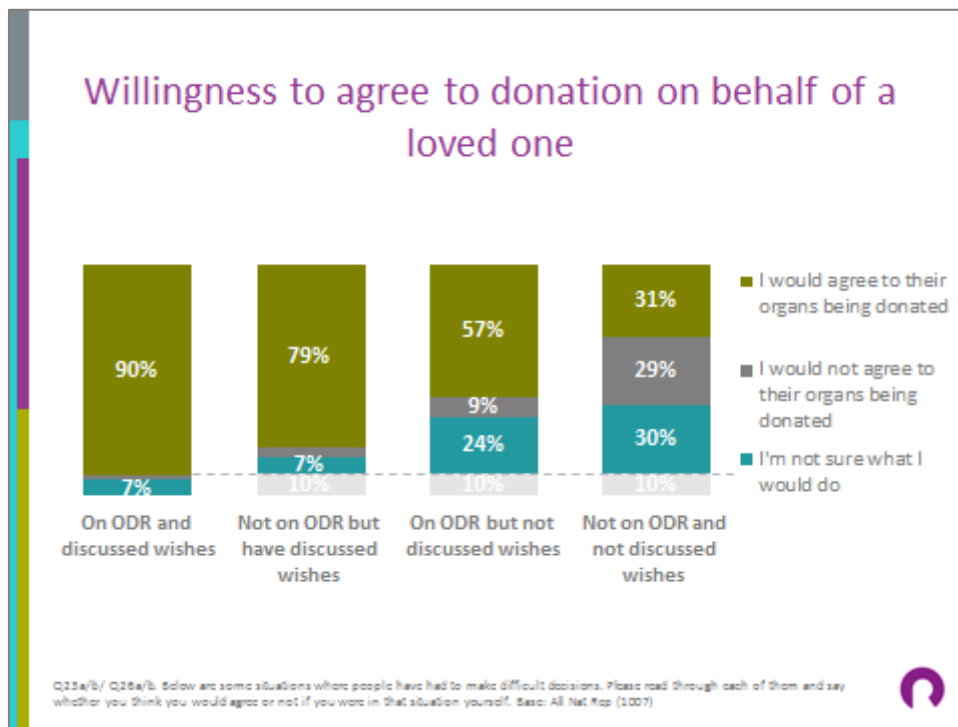


Figure 22 Willingness to agree to donation in each of the four scenarios

Scenario 1: On the ODR and discussed wishes

Being on the ODR and having discussed wishes is the most powerful scenario in facilitating consent, with 90% claiming they would agree to their loved one’s organs being donated in this scenario. Most are driven by a strong desire to respect the deceased’s wishes, which have been made clear to them through a dual communication. Key barriers for those who are unable to agree are expected feelings of guilt (24%) and not wanting to think about their loved one being ‘cut up’ (22%).

“I think if that’s their wish and that’s what they’ve decided and they’ve made that decision while they were alive then I would want to uphold it”

Female, Young Family, Sikh, London

Scenario 2: Not on the ODR but have discussed wishes

Agreement levels continue to be relatively high (79%) when wishes have been discussed but the person has not signed up to the ODR, implying that ODR sign up makes minimal difference if wishes have been communicated. This is reinforced by a perception that when someone is on the ODR and has discussed their wishes, ODR sign up is seen to validate discussion rather than vice versa. 54% of those who would agree say that *it wouldn’t matter if the person had signed the ODR as long as they’d personally said what they wanted*. Whilst those who would refuse in this situation are in a minority, main barriers to agreeing are an

expectation that if their loved one felt strongly about organ donation they would have signed the ODR (36%) and a worry that they might have changed their mind after speaking about it (33%).

Scenario 3: On the ODR but have not discussed wishes

As illustrated in Figure 18 above, the absence of prior verbal consent results in the most marked decrease in agreement and an increase in uncertainty, even when the person is on the ODR. It is clear that discussion of wishes is a more powerful motivator for families to agree than ODR sign up alone. The shock of being presented with this information in an already difficult situation is expected to raise a number of questions. Both outright refusers and those who are unsure would want proof that the person had signed up to the ODR (35%, 33%), with refusers also wishing to know when the person joined. Qualitative discussions reveal distrust amongst a small handful of people, who question what safeguards are in place on the ODR and whether it would be possible to sign other people up without their knowledge.

“Can you register somebody else for organ donation not to their knowledge? What procedures, what safeguards are in place to make sure that doesn’t happen?”

Male, Older Family, Black British, Nottingham

Awareness of the different ways of signing up to the ODR can also raise issues: since some ‘tick-box’ sign up methods (such as through the driving license application form) can cause some concern that the person might have signed up unintentionally or without proper consideration. Hence it is perhaps unsurprising that almost three in ten feel that having never spoken about with the person they don’t know what their wishes are and a similar proportion have concerns that the person might have changed their mind after signing up. Although few discuss their organ donation wishes, some question why the person wouldn’t have told them if they had signed up.

Scenario 4: Not on the ODR and have not discussed wishes

In line with NHSBT’s internal findings, the absence of any prior consent (neither on the ODR nor discussed wishes) is the scenario resulting in lowest levels of agreement. When a loved one’s wishes are unknown, not agreeing to donation is often seen as the easiest or ‘safest’ option: for some it is the automatic default response to say ‘No’ and for some of those who are unsure initially, there is a tendency to think that when actually in that situation they would be more likely to refuse than to agree.

The main barrier both for those who would refuse and those who are unsure is not being aware of what their loved one's wishes might be, as illustrated in Figure 23 below.

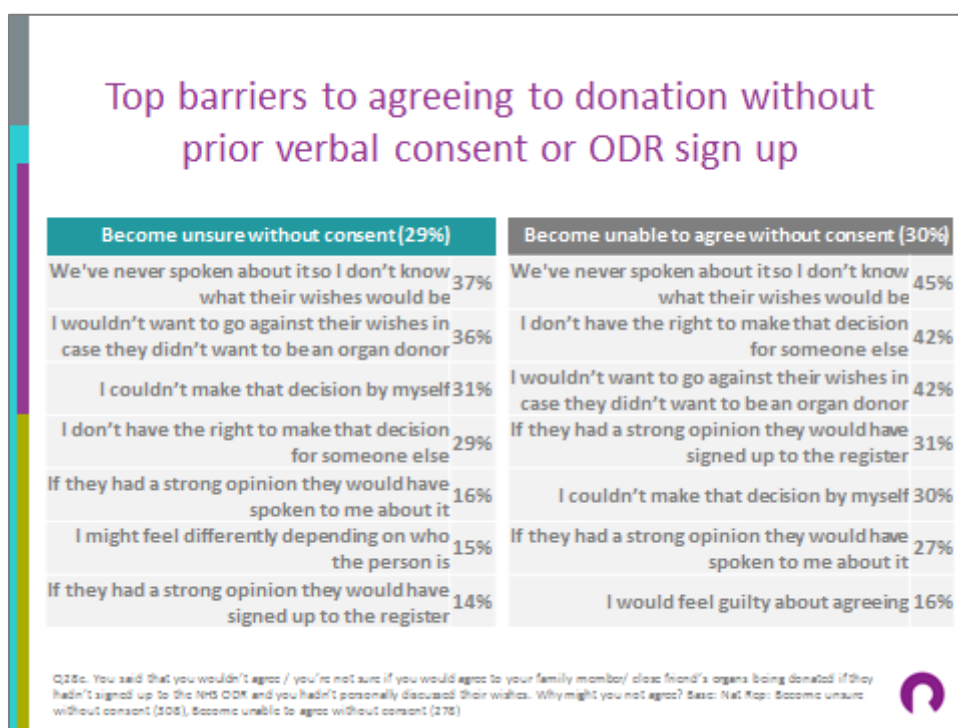


Figure 23 Top barriers to agreeing to donation without prior consent

There is also significant concern about going against a person's wishes in case they did not want to be a donor (36% of those unsure and 42% of those who would refuse). It is frequently acknowledged that there is little discussion or action taken about organ donation. However if a person has not communicated in some way that they wish to be an organ donor it is often assumed that this means that they do not want to donate rather than that they have just not done anything about it. Similarly, there are some expectations that if a person wanted to be a donor then they would have either signed up to the ODR or spoken about their wishes.

"Because I haven't got a clue, maybe I know that she would help others but I feel as if that's not my right to make that decision"

Female, Young family, White British, Birmingham

6.4 Ethnicity and how this affects family agreement to organ donation

As already discussed in section 4.4, ethnicity has an impact on willingness to donate, whether this is for one's own organs or agreeing to donation on behalf of a loved one.

Taking the 4 scenarios we tested, BMEs are significantly less likely than the population as a whole to agree to donation in any of the scenarios, as illustrated in Figure 24 below.

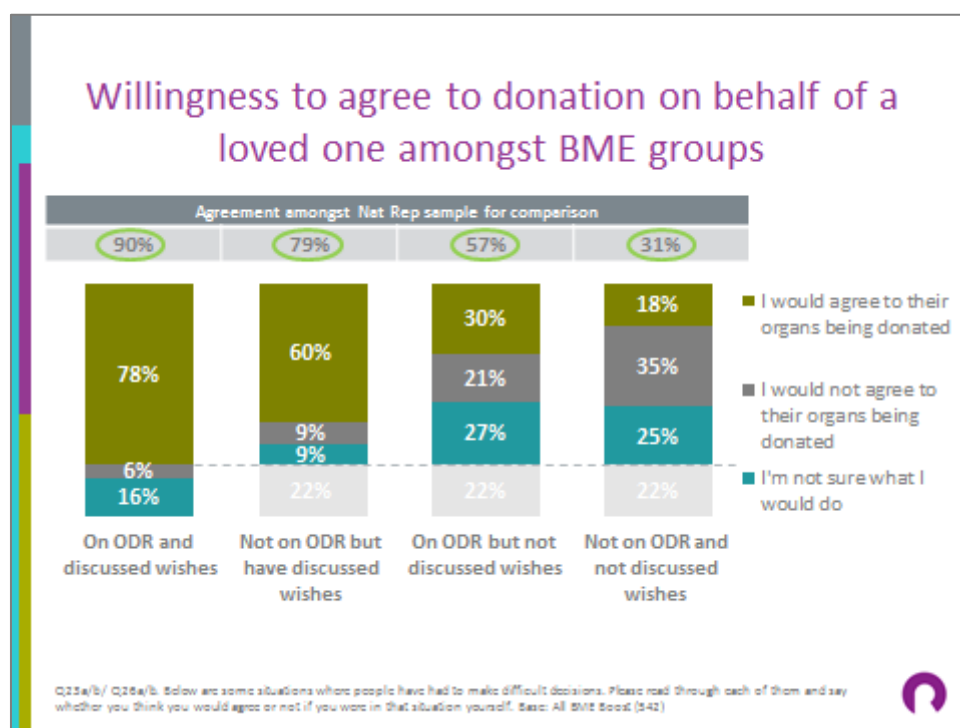


Figure 24 BME willingness to agree to donation in each of the four scenarios

As shown in the figure above, willingness to agree to donation on behalf of loved ones amongst those from BME communities follows a similar pattern to the population as a whole. However, agreement levels are significantly lower overall.

Being on the ODR and having discussed wishes has the most positive impact and gives the best chance of the individual’s wishes being respected: 78% would agree compared to 90% for the population as a whole. If the individual is not on the ODR but wishes have been discussed, 60% would agree to donation. Willingness to agree halves (to 30%) if the person is on the ODR but wishes have not been discussed, underlining the need for families to talk about organ donation whatever the cultural or religious challenges might be. In the absence of any prior consent, likely agreement falls to 18% (BME) compared to 31% (population). This implies a clear need to continue to work within BME communities to encourage debate and support for organ donation per se.

6.5 Factors encouraging family agreement to organ donation

Whilst the potential to save someone’s life has widespread resonance as illustrated by Figure 25 below, those who would agree and those who are unsure about agreeing in the absence of ANY prior consent tend to have slightly different priorities in terms of their motivations.

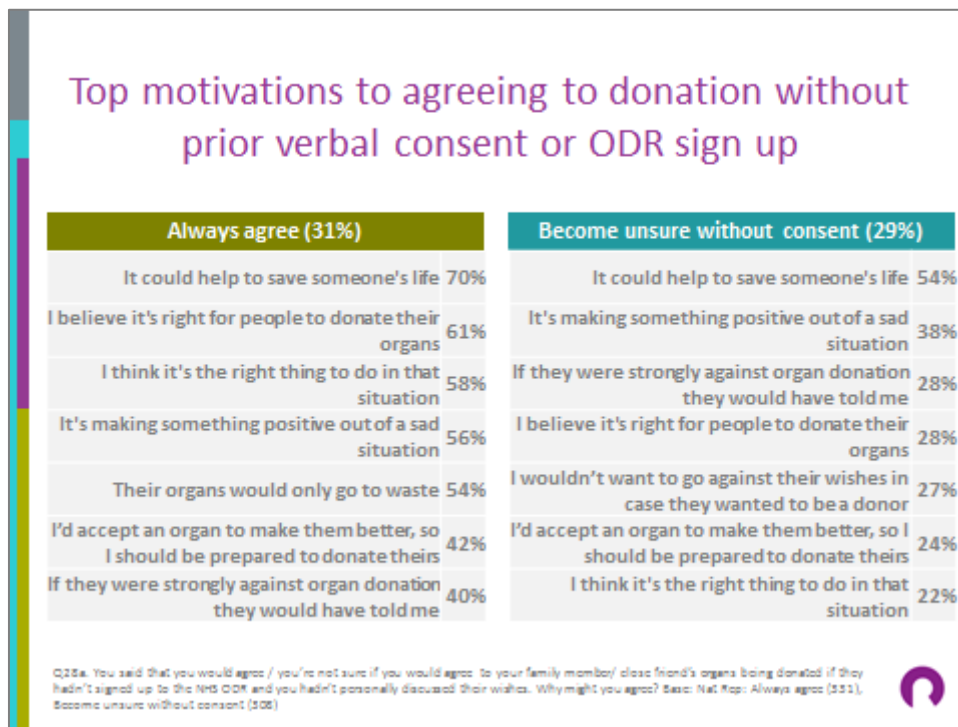


Figure 25 Top motivations to agreeing to donation without prior consent

Those unsure tend to consider more the wishes of the deceased, with one of their main motivations being the belief that they would be aware if their loved one strongly opposed donation (28%). There is also some concern about not wanting to go against the deceased's wishes in case they *did* want to be a donor, but this is a significantly smaller consideration than not wanting to go against their wishes in case they *didn't* want to be a donor (27% vs. 36% as shown in Figure 23 previously). Further discussions reveal that there appears to be much more fear about potential consequences and feelings of guilt about agreeing in the latter situation, including some suggestions of the person's 'spirit' knowing if they agreed to donation against their wishes. In reality we know that since 82% definitely want to or would consider donating all or some of their organs, agreeing to donation is more likely to be in line with the person's wishes than refusing. But without this knowledge, most would prefer to 'err on the side of caution' by refusing.

Those willing to agree without any prior consent are more likely to focus on their personal beliefs as motivation. Figure 25 above shows that feelings that it's **right** for people to donate their organs (61%) and agreeing to donation being the **right** thing to do in that situation (58%) are most likely to resonate with this group.

"If there was nobody else around then I would say yes OK, because after my death I don't want my organs wasted, so why should this person's organs be wasted?"

Female, Empty Nester, Hindu, Nottingham

6.5.1 The effect of personal views on family agreement

As shown in Figure 26 below, there is a clear link between personal views about organ donation and willingness to donate on behalf of loved ones when their views on donation are unknown. In the absence of any other information, it is likely that family members will use their own personal views about donation if trying to reach a considered decision, although their strength of feeling may not be as definitive as when thinking about personally donating.

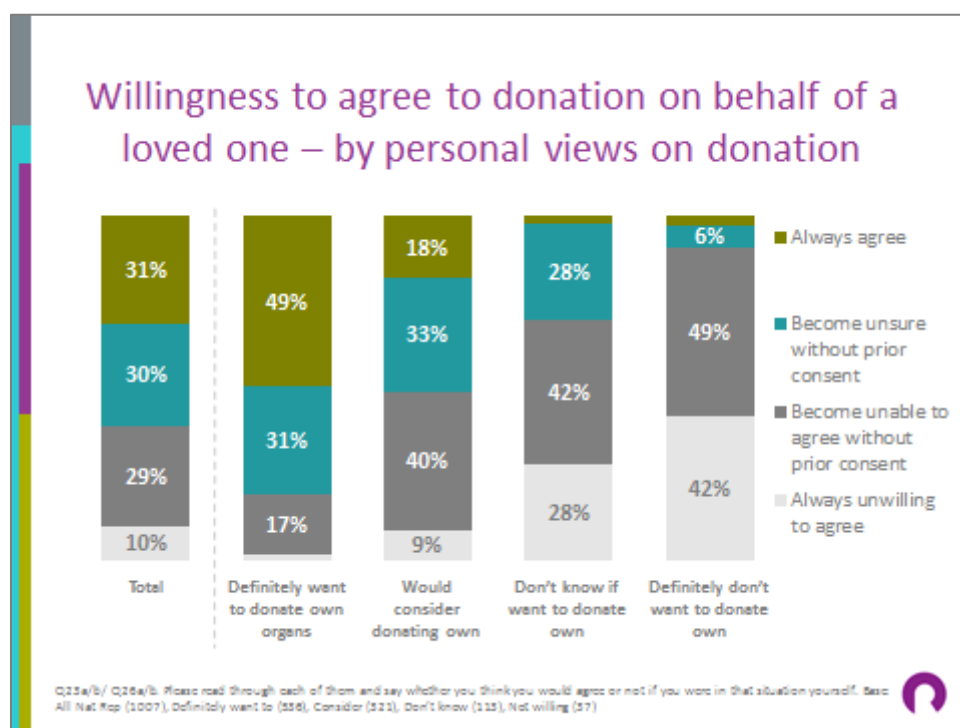


Figure 26 Willingness to agree to donation broken down by own views on donation

When a loved one's wishes are unknown, agreement amongst those who definitely don't want to or don't know if they want to donate their *own* organs is minimal (3% and 2% respectively as in the figure above). Often those who do not themselves support organ donation may find it difficult to understand the position of someone who does. So when wishes are unknown it is more common to assume that the deceased's views are in line with the person being asked to agree, therefore making it easier to refuse.

Agreement is significantly higher amongst those who definitely want to donate their own organs than all other groups (49% as shown in Figure 24 above). But still half of this group remain unable to agree without prior consent. Whilst personal views are a clear influence on expected response, agreeing on behalf of others is perceived to be a much more emotive action than agreeing for oneself. Hence even the strongest supporters can feel conflicted when asked to make such a decision for someone else, with the thought of a loved one's organs being 'taken' causing much more conflicting feelings than 'giving' their own.

6.5.2 Other factors which may encourage family agreement

Other factors may also help those who are unsure come to a decision and, as mentioned previously, being able to discuss and come to a consensus with other family and friends is the most influential of these, as shown in Figure 27 below.

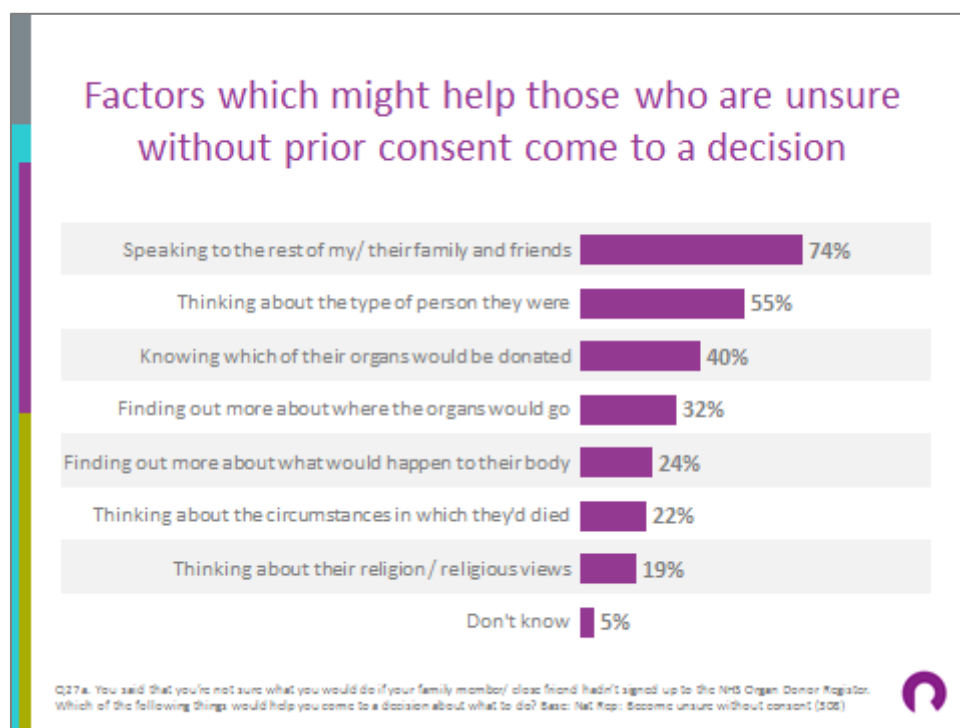


Figure 27 Factors which may help those who are unsure about donation without prior consent come to a decision

“I’d probably have to sit down with the part of the family and discuss it and see what the family’s views are”

Son, Older Family, Sikh, Leeds

Also shown in the figure above, over half (55%) would think about the type of person they were, including their personality and actions in life such as how charitable a person they were. Whilst the actual donation process is often a lesser consideration, a third (32%) would be aided in coming to a decision by finding out more about where their organs would go, highlighting the need to make the benefits of organ donation more tangible.

7 SHIFTING PERCEPTIONS

7.1 Misconceptions

As referenced earlier, there is clearly confusion and scope for education about organ donation, particularly around the Organ Donor Register and the requirement for family agreement to donation. But when asked directly, public perceptions of organ donation are broadly in line with reality. Figure 28 shows the proportion able to correctly identify the validity of a number of facts about organ donation.

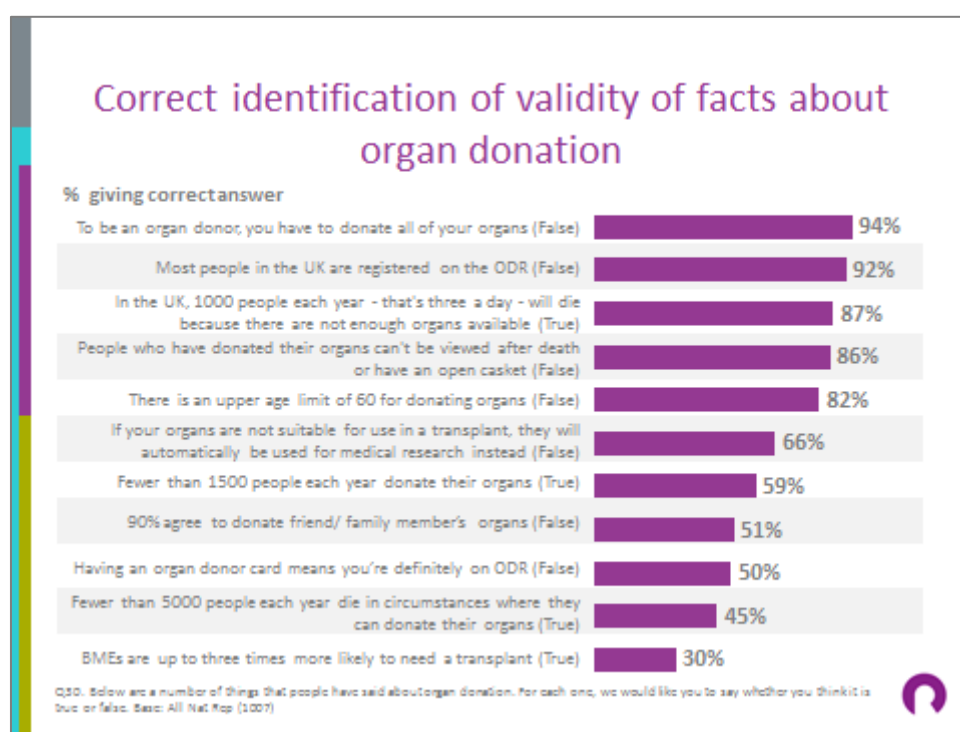


Figure 28 Correct identification of validity of organ donation facts

However, there are some common misconceptions, with fewer than two thirds able to correctly identify whether some facts about organ donation are true or false, especially around **consent rates, the ODR and organ availability**. Critically, most of these key misconceptions, if correctly understood, have potential to highlight the personal impact individuals can have by either donating their own organs or agreeing to donate on behalf of loved ones. However, the most significant detachment from reality is around needs amongst BME groups, with only 30% aware of the increased requirement for transplants within these communities compared with the general public. Also as shown in the Figure 28, less than half (45%) are aware of the number of people who die each year in the in circumstances where organ donation can take place.

7.2 Shifts in attitude

After being made aware of some of the facts about organ donation, there is a subtle shift in views: as referenced in Figure 29 below, at a total level 20% say that they feel differently about organ donation having completed the survey.

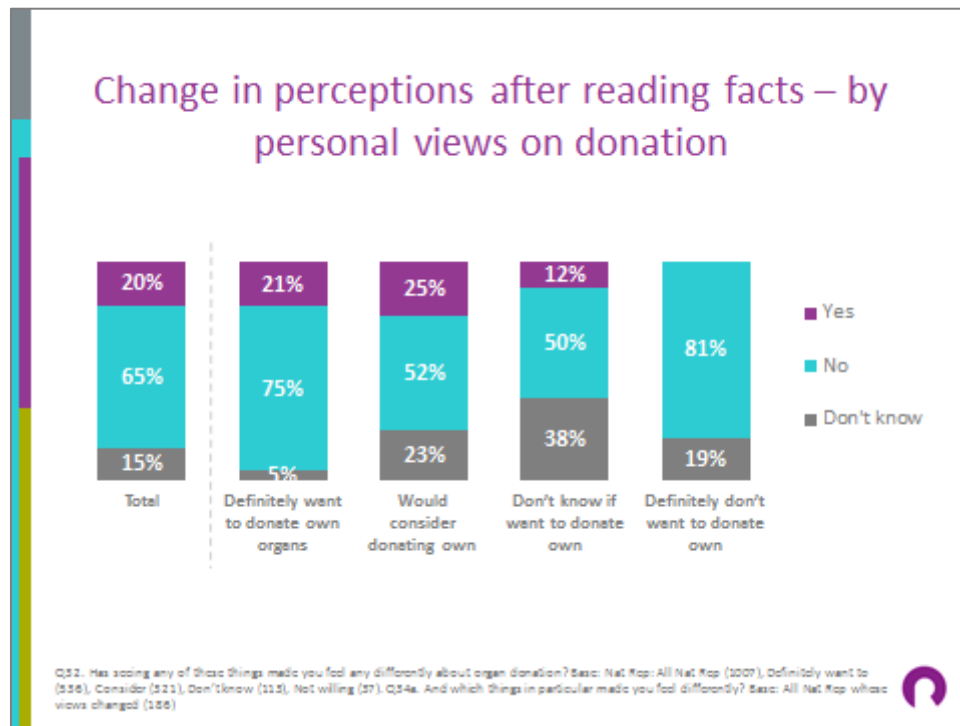


Figure 29 Influence of organ donation facts on perception broken down by personal views on organ donation

Whilst not significantly higher than other groups, those who originally say they would *consider* donating their own organs are most receptive to being made aware of some of the facts about organ donation (25% change their views). This suggests that this is a key group to target in terms of education. As the figure above illustrates, receptiveness to information declines as uncertainty about personally donating increases, although there remains some value in raising awareness among those who currently don't know if they want to donate. Those who definitely don't want to donate are unlikely to be swayed in their views regardless of education (0% have their views changed).

All of those whose views change are influenced positively, and personal views of donation are more likely to have been affected than views about agreeing to donation for others. However, there is still a reluctance to completely commit. Figure 30 below shows that the majority who would previously consider or were unsure are *more likely* to consider donating or agreeing for those closest rather than now *definitely* wanting to.

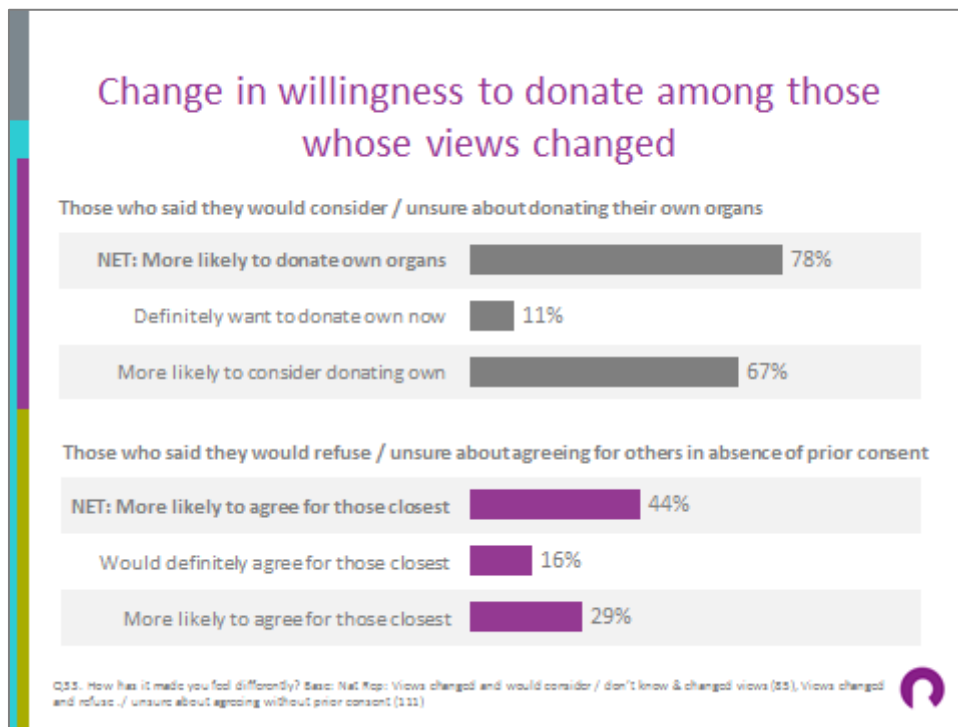


Figure 30 Influence on those whose views were changed by organ donation facts

The influence of facts is not necessarily related to whether people are able to correctly identify them. For example, 94% are aware (or assume) that they do not have to donate all of their organs to be a donor, but this fact is the most influential on views (for 56% of those whose views changed) suggesting that NHSBT must keep reinforcing even the most well-known but effective messages.

Conversely, the small number of people who die each year in circumstances where they could donate their organs is one of the facts with the highest resonance (33%) but fewer than half are aware of this. The benefits of communicating this to encourage donation has potential to be twofold: making a person's individual decision to donate seem much more valuable and acting as a reassurance to those who aren't completely convinced that the likelihood of them actually donating is low.

Following discussions, there were suggestions that people felt motivated to speak to others in their family about organ donation and ensure that their donation wishes (whether positive or negative) are known, in addition 16% of those whose views change claim they would be more likely to speak to family about donation wishes. Amongst all those interviewed, there were additionally a number of spontaneous mentions of being given the motivation to talk with others about organ donation, whether this be to discuss the subject generally or to communicate wishes, as shown in Figure 31 below. This highlights an understanding of the need to discuss wishes, and receptiveness to doing so once the issues surrounding donation rates are communicated.

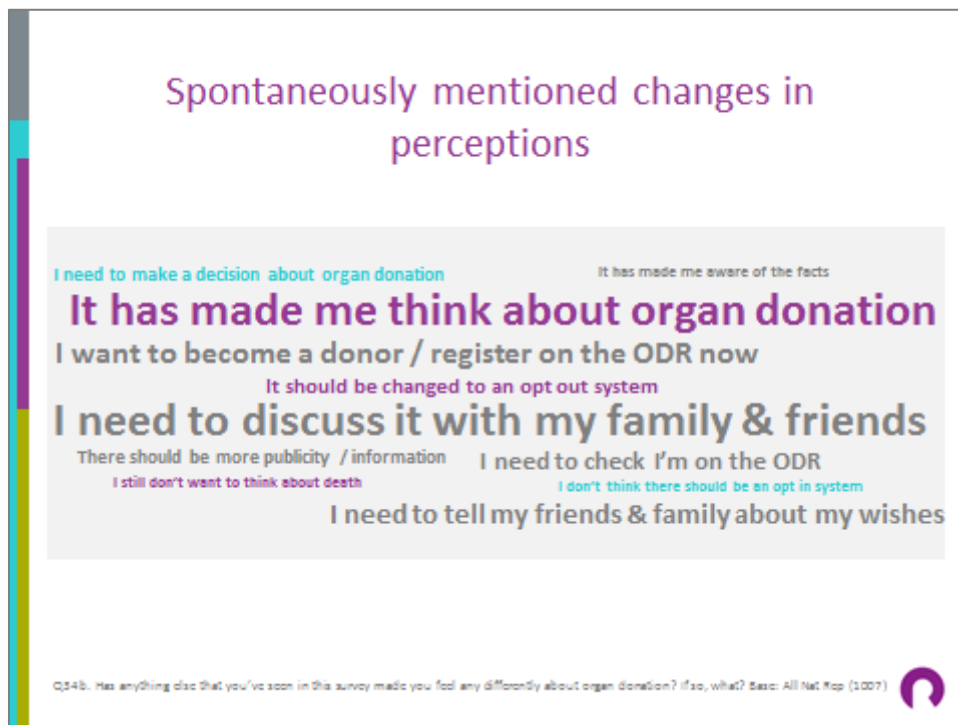


Figure 31 Wordle of spontaneously mentioned changes in perception

7.3 Ethnicity

Although awareness of the increased need for transplants in BME communities is higher amongst those whom this affects, there still remain significant misconceptions: just 47% are aware of this fact. At an overall level, significantly fewer people from BME communities are able to identify the validity of most of the facts about organ donation. However, a higher proportion could identify that fewer than 5000 people die each year in circumstances where their organs could be donated and that fewer than 1500 actually go on to donate.

A significantly higher proportion of people from BME communities claim to feel differently about organ donation after reading some of the facts (35% compared to 20% in general population). Black African and Indian people and those from 'Other' ethnicities are most likely to have been affected by the information. Of those whose views change, 68% claim they would be more likely to donate their own organs and 45% more likely to consider agreeing on someone else's behalf. Whilst minimal (2% and 1% respectively) some are negatively affected by increased awareness and are less likely to donate their own organs or consider agreeing for someone else. The increased need for organ donation in BME communities is significantly more motivating for this group than the general population.

8 STAKEHOLDER PERSPECTIVE

A number of clear themes emerge from the stakeholder interviews with a good deal of consistency between the views of external stakeholders and those working within NHSBT, namely the Clinical Leads Organ Donation (CLODS) and Specialist Nurses Organ Donation (SNODS). Many of the issues discussed are supported by what we observed in the interviews with members of the public. These themes can be grouped into six categories;

1. Awareness
2. Education
3. Positioning
4. Timing
5. Normalising Organ Donation
6. Infrastructure

The first five of these relate to how NHSBT can work with the general public to increase donor / consent rates, while the sixth highlights some observations around organ donation from an infrastructural perspective. While not strictly within the scope of this study, we have included a brief summary of all six of these for the sake of completeness.

It should be noted that while the six themes are discussed here individually, in practical terms they are interdependent, with a great deal of overlap between them. In the view of most of the stakeholders we spoke to, it will be necessary to address all of these in order to increase consent rates.

8.1 Awareness

Almost all of the stakeholders referenced the need to raise public awareness of organ donation and related issues. By awareness we mean simple knowledge about what organ donation is, why people need transplants, the type of illnesses that lead to a need for organs, how organ donation after death works, how many people can benefit and why there are long waiting lists. The stakeholder view is that a primary reason for not consenting is the potential donor family never having thought about the topic at all, and the difficulty in having to contemplate it while grieving and in shock. While this overlaps with the need for individuals and families to talk about their wishes in advance of the situation, there is nevertheless a perception that organ donation is simply not on the radar for most of the public most of the time, and it is this, combined with being approached about donation shortly before or after bereavement, that makes it so difficult to give consent. The relatives of the potential donor are trying to process multiple information sources at once, and it is the view of some stakeholders that inevitably this will lead to a situation where it is easier to say 'no' and end the discussion.

For some of the stakeholders, raising awareness is inextricably linked with normalising organ donation. While a couple of the SNODs we spoke to felt that awareness is improving, targeting young people now who might one day be faced with having to make a decision about their parents is considered paramount.

Several of the stakeholders we spoke to feel that a long-term drive to raise awareness of organ donation starting with education in primary school and continuing through university and beyond is the only real way to secure a meaningful uplift in knowledge. School education in particular is seen as an area where more can be done by the government and local authorities, relieving some of the burden on NHSBT. In the interviews we conducted, only a few of the children we met in the family discussions recall learning about organ donation at school.

While most of the stakeholders feel that raising awareness in young people is especially important, there is also a strong feeling that it is crucial to emphasise to the public at large that people of all ages, ethnicities and circumstances can equally need a donor or be a donor.

8.2 Education

While our discussions with both stakeholders and the public confirm that for most people death and dying are rarely discussed until or unless such conversations become unavoidable, it is clear that increasing public knowledge about the procedures and protocols for organ donation is essential. Currently, lack of knowledge is leading to all kinds of incorrect assumptions being made, and it is these assumptions that create the most fear and concern about becoming a donor or consenting on behalf of someone else.

As with raising awareness, there is a belief among some stakeholders that some education is needed as early as possible, for example at primary school. In particular, there is a strong sense that learning about death, the difference between brain stem death and circulatory death, how death is diagnosed, and what happens to the body after death, (especially in terms of not feeling pain), needs to happen in childhood. More specific information about organ donation, the necessary timescales and the protocols of organ retrieval can then be provided at a later stage - as part of schools' PSHE programmes or in universities - to encourage young people to think about and discuss organ donation with their peers and their families. This should lead to people being able to make informed decisions about becoming a donor earlier in life, so that ticking a box on a driving license or other application form is less abstract and more considered. Inevitably there will be challenges with this approach, not least the need for sensitivity towards different religions and ethnicities. The discussions with stakeholders suggest that work needs to be done to overcome these challenges and ways found to facilitate education.

While formal education is a priority for many, and something that they feel should be lobbied for by NHSBT, for one or two stakeholders there is also a role for NHSBT in publicly

addressing, responding to and correcting inaccuracies around organ donation that are driven by the media.

8.3 Positioning

There appear to be mixed views among stakeholders about how families should be approached when being asked to consider donating the organs of their loved ones. While CLODs and SNODs find it much easier to start a conversation if the patient is on the ODR, the majority of the time (around 7 in 10 are unregistered)¹¹ this is not the case and the conversation has to be started 'cold'.

Where the patient is on the ODR, informing the family of that fact and explaining what is going to happen is felt to be more effective than asking for consent. It is also felt to be less of a burden on the family. In our discussions we found that many CLODs and SNODs take this approach. This does not mean that consent is not sought; by explaining what will happen first and giving families time for this information to be taken on board, it is felt to be easier for them to subsequently confirm the patient's wishes.

Where the patient is not on the ODR, the most effective approach is felt to be to encourage the family to think about what the patient would have wanted, rather than what the family wants. What kind of person were they? What would they want to do if they were able to make the decision? A lot of emphasis is placed on the possibility of making something positive happen out of a sad situation, something which had resonance for many of the families we spoke to.

While SNODs are highly respected and valued, there is nevertheless some acknowledgement that SNODs are predominantly white, female, and either Christian or of no particular faith. There is some sense, particularly among clinical practitioners, that more needs to be done to encourage uplift in numbers of nurses from BME and different faith groups, as well as more male nurses. This could be particularly useful in taking discussions further when religious beliefs or assumptions are seen to be influencing the views of those being asked for consent, and also when working with families where the views of male relatives are likely to be more influential than those of female relatives.

Religion is raised as a common barrier to consent, particularly when talking to practitioners. This is not only one of the biggest challenges faced by CLODs and SNODs; it can also cause tensions between the medical team providing care and the OD specialists. Once an objection is made on religious grounds, some practitioners feel that there can be no further discussion, while others believe it is important to continue to have a dialogue, particularly if they sense that the objection is masking other fears and uncertainties. All of the practitioners we spoke to feel that more needs to be done to enlist the help of religious

¹¹ Nhsbt.co.uk

leaders in positioning and promoting organ donation as a positive act. In particular this means working with religious communities at a very local level, as it is understood that it is individual leaders that will have the most influence.

8.4 Timing

All of the stakeholders we spoke to raised timing as an issue. Firstly, there is great time pressure during the period when consent is sought. While it is inevitable that in-hospital discussions about organ donation happen when a patient has just died or is very close to death, it is also acknowledged (and borne out in our interviews with the public where bereavement has been experienced) that having to think about organ donation while in shock and grieving is the worst possible time for families. Practitioners acknowledge the importance of getting the timing right and there is consensus that this can only be learned through experience. This underlines the importance of having experienced SNODs, which means trying to find ways to avoid 'burn out', so that SNODs remain in role for longer. It also underlines the importance of raising awareness of organ donation so that families can have discussions about their wishes long before any decision around consent is needed.

The other aspect of timing relates to organ retrieval. Some families withdraw consent once they realise that retrieval can take 6-12 hours. While this can sometimes be resolved by reaching agreement about when is the appropriate time to say goodbye – i.e. before or after retrieval or at both stages, some stakeholders feel that it would be useful to work towards the possibility of reducing the time needed for retrieval.

8.5 Normalising organ donation

While this is very much linked to education and awareness, most of our stakeholders feel that there are additional ways of normalising donation in the UK.

Comparisons are drawn between the UK and other countries where organ donation has a higher profile and is considered something to be celebrated. In the US there are many different websites about donation and special events/days are held to acknowledge donors and donor families. There is a strong sense that more could be done in the UK to celebrate organ donors, so that it gains acknowledgement similar to the celebration of blood donation. This would not only reinforce the benefits of donation and raise awareness, it would also begin to change the public perception that organ donation is the exception rather than the norm.

Many of our stakeholders believe there is great value in working with recipients to 'humanise' the benefits of organ donation. The inability of many to see beyond their own grief and take a wider view suggests that this could be very helpful.

Being part of the storyline in popular TV programmes – in particular soaps – is known to raise the profile of social issues. When organ donation has been included on British TV in the

past, on programmes such as Coronation Street and Casualty, increase in donation/registration on the ODR was noticeable. Most importantly, storylines can be used to portray organ donation as a normal part of life/death considerations.

Organ donor cards are also believed to have a role to play in normalising donation. Although while not felt likely to be of much practical use unless or until they are linked to the ODR, the key benefit of reintroducing publicly available cards is perceived to be their visibility and therefore potential for encouraging discussion between friends and family members.

8.6 Infrastructure

Some of the issues raised in the stakeholder interviews do not relate directly to encouraging individuals and families to support donation and give consent, but are focused instead on facilitating more opportunities for donation.

Concerns include the exclusion of A&E departments from the transplant infrastructure. In Spain, where donation rates are high, it was 10 years after the introduction of presumed consent before rates really increased. This is believed to be in part because there as in the same time period there had been an increase in the number of ITU beds, meaning that more patients can be moved from A&E to ITU.

Some CLOD's and SNOD's expressed a feeling of working in isolation with other medical professionals working to other targets and aims, where organ retrieval is not a top priority. This can result in a perception that there are missed opportunities and a less efficient process.

The fact that not all hospitals support organ transplants, or only support transplants of particular organs, means that many families who could be approached for donation are never approached, whether the patient is on the ODR or not. This is of particular concern to some of the stakeholders we spoke to, as these are seen as wasted opportunities.

There is also concern that more needs to be done to encourage Government ministers to support organ donation; there is a perception that it is a topic that many politicians shy away from. However, this may have to change as a result of the recent Bill passed by the Welsh National Assembly (July 2013), and subsequent public debate around the issue (note this Bill was passed after our period of fieldwork was conducted in England).

9 RECOMMENDATIONS

Our findings suggest that there are a number of opportunities for NHSBT organ donation communications to build on some of the motivations and challenge barriers to supporting organ donation.

Emphasise the real impact of individual/familial decisions on organ availability

Any communications or marketing campaign is likely to be most effective if it strikes an emotional chord and personal connection with the individual. That is not to say that the more rational idea of wasting organs does not resonate, 58% believe their organs would otherwise go to waste, however the message still needs to connect to the real impact of donation. Prompting people to think or understand how organ donation might affect their own lives one day will be a particularly powerful motivator. People are unaware and find it difficult to empathise or understand how many people are waiting for donations and how their lives are affected.

Therefore there is a need to raise public awareness of organ donation and related issues: why people need transplants, the type of illnesses that lead to a need for organs, how many people can benefit and why there are long waiting lists.

By addressing some key misconceptions, there is potential to highlight the personal impact individuals can have by either donating their own organs or agreeing to donate on behalf of loved ones. Lesser known facts to communicate which may shift perceptions include:

- Around 1000 people each year die waiting for an organ
- Fewer than 5000 people die each year in circumstances where they would be able to donate

Both of which could reinforce that your choice to donate is more valuable, but with the latter also having potential to reassure those less committed that it might not happen anyway!

Linked to this there is a need to make benefits of organ donation more tangible

The concept of saving 'others' can be abstract to consider, particularly amongst those less committed to supporting organ donation. A key challenge therefore is in making the benefits more tangible to the individual.

The most significant detachment from reality is around needs amongst BME groups, with only 30% of the general public aware of the increased requirement for transplants within these communities (and only 47% awareness even amongst BME groups). It is likely that

greater awareness of the need for organs within specific communities might help encourage people with similar views to review their stance on organ donation.

There are several ways that the benefits of organ donation can be humanised, whether that be by storylines in soaps/on TV, promotion of the impact of organ donation on both the recipient and the donor family or public celebration of organ donors, so that it gains acknowledgement similar to the celebration of blood donation. This would not only reinforce the benefits of donation and raise awareness, it would also begin to change the public perception that organ donation is the exception rather than the norm.

Continue to promote from within BME communities

There is potential to continue efforts in enlisting the help of religious and community leaders in supporting organ donation. Crucially, the views of individual leaders tend to be highly regarded, and in many cases will have more influence on followers than any 'official' position. Therefore fears and concerns can be addressed by those having the most influence and authority.

Religious leaders are key in positioning and promoting organ donation as a positive act. Few people of faith, whether practicing or lapsed, are aware or certain of the official position of their religion on organ donation. Equally, few can recall the topic ever being discussed in their place of worship, either by their own faith leaders or within their faith community. Many assume this to mean that organ donation is not looked upon favourably

Additionally efforts should be focused on the Islam population. Currently, while 35% of the population as a whole are definitely willing to donate all of their organs, this figure reduces to 19% when we look at our BME sample as a group. Moreover there is much less willingness in our Bangladeshi and Pakistani sample, where religious considerations appear to be more of an influencing factor.

Religious leaders also have a role in building awareness of the need for increased support amongst BMEs and educating about organ donation. BMEs are significantly more likely (17% vs. 11% of the total population) to say that they do not know enough about organ donation, which indicates a need for more education around the process.

Some stakeholders suggested the need to increase numbers of SNODs from BME and different faith groups to further engage these groups.

Encourage people to share their wishes whatever they are

Stakeholders hypothesise that the reason for withholding consent is that the potential donor family having never having thought about the topic at all, and the difficulty in having to contemplate it while grieving and in shock. In total only 50% of people said they had discussed organ donation previously and of these 74% (only 37% of the total population) had spoken to their close friends or family about their own wishes. 60% of those who have not discussed it describe it as a conversation they have either not thought about or not got around to having. Therefore NHSBT must focus on how best to engage people with the topic and our research highlights several ways to bring the conversation into living rooms:

There initially at least needs to be something to raise awareness and inform people about organ donation so that it becomes a more top of mind issue, whether this be through advertising, inclusion in storylines on television programmes or by increased education in schools. Even making people aware that their families will be asked to consent, promoting the unknown wishes scenario as a talking point, can make people feel that they need to talk about their wishes with their closest family.

The reintroduction of publicly available donor cards could promote conversations as organ donor cards are believed to have a role to play in normalising donation. Although while not felt likely to be of much practical use unless or until they are linked to the ODR, the key benefit of reintroducing cards is perceived to be their visibility and therefore potential for encouraging discussion between friends and family members. Our research suggests that having an optional link from publicly available cards to the ODR, thus putting the decision in the donor's hands, would be most effective. This process should be straightforward and convenient for the donor (eg. Activation of card via cash machine or QR code on card linking to ODR)

Raise awareness that the majority support organ donation, even though they don't talk about it

Whilst the potential to save someone's life has widespread resonance, only 31% of population are willing to agree to donation when their loved one's wishes are unknown. There is general consensus that objecting to donation in this instance is the easiest decision and least likely to offend.

A key message to communicate therefore is that in reality, 82% of the population definitely want to or would consider donating all or some of their organs. Consequently the decision to agree to the donation of loved ones organs is more likely to be in line with the person's wishes than the decision to refuse the donation.

Additionally the assumption that a loved one would have shared their wishes if they had felt strongly about organ donation can be challenged; 31% of those who are definitely willing to donate and 63% who would consider donating their organs have never spoken about it.

This once again asserts the importance of discussing organ donation with friends and family but it also provides an important message of reassurance to families who are troubled by the lack of consent left by their loved one.

Implement a shift from 'ask' to 'inform' (familial consent)

Family refusal rates are a significant barrier to increasing overall organ donation rates, and in order to increase the conversion of potential to actual donors, family agreement rates must increase.

Whilst support for a system of presumed consent does exist is it not fully supported; there are mixed views among stakeholders and the public about how families should be approached and evidence to support an argument for why England should or should not follow Wales's decision to embrace an opt-out system.

As far as the public is concerned the question of whether relatives or friends should be asked or informed differs depending on the circumstances:

- When someone has registered with the ODR the tendency is to support the approach to inform - 61% feel that if a person has signed up to the ODR, families should be advised of their wishes but not asked to agree to it going ahead
- When a loved one is not on the ODR most are in favour of asking for consent and only 34% agree that donation should happen automatically without any consultation with loved ones
- Only 34% agree that donation should happen automatically, however a softer-style opt out system was not asked about. It is possible that the current inability to opt-out (i.e. to be able to safeguard against donating one's own organs if one is not in favour of doing so) actually contributes toward the feeling of uncertainty, and defaulting to 'no' among families when wishes are unknown.'

While following a system of presumed consent may be considered too big or contentious a change, a move towards families being 'informed' rather than 'asked' when a person is registered on the ODR would appear to be well-supported.

Address myths and confusion around age, illness, protocol (treatment of the body)

Increasing public knowledge about the procedures and protocols for organ donation is essential so that people can make informed decisions about whether they would be willing to donate their own or loved one's organs. A lack of trust in the medical profession emerges as the single most common reservation towards organ donation and reassurance that donation can only happen once a person is clinically dead and that registering with the ODR is not tantamount to registering for medical research is an important communication message.

Most people also lack knowledge about what happens to the body after death, and from the discussions with clinical practitioners, it is clear that this is an area where more knowledge would help potential donor families to feel more open to organ donation. Asian respondents and particularly those of Pakistani and Bangladeshi descent are more likely to reference an objection to delayed burial/ cremation or to mention a desire for their body to remain whole. There is a need for more education around the care taken and respect shown during and after organ retrieval and a need to highlight the timescale needed to observe these. That organ retrieval rarely delays funeral arrangements may prove an important message when families throw themselves into funeral 'organisational mode'.

Age, illness and an inability to donate blood are all attributed as reasons for not registering with the ODR or considering organ donation. There is general agreement that school initiatives to myth bust and normalise the discussion of organ donation should be addressed so that these concerns are minimised.

Address myths and confusion around donor card/ODR

A third (34%) of those who are definitely willing to donate their organs have currently not registered with the ODR or aren't sure if they are. This indicates the need to promote registration channels more clearly and to emphasise the importance of leaving written and/or spoken consent.

The lack of clarity that surrounds how to show support and when/if you are on the register must also be addressed with education about what the ODR actually is and the role of the ODR/card. Our research highlights that potentially a fifth (c.18%) of the population erroneously believe they are on the ODR. A targeted message to encourage people to check whether they really are registered could prove effective; however this must be combined with an infrastructure that allows people to do so easily.

10 APPENDICES

10.1 Attitudes to organ donation

For the purposes of tracking attitudes to organ donation, people were asked their strength of agreement with a series of attitude statements. Most of these were included in the 2009 study, however at the time of this report the 2009 data was unavailable for comparison purposes (however given the different sample definitions, comparability would be somewhat limited). The statements are included here as a benchmark among the general population (excluding those strongly opposed) for comparison against future surveys to gauge shifts in attitude. The themes emerging from these statements correlate with the findings from the remainder of the survey.

Figure 32 shows that in principle, most agree that they feel they will not need their organs after they die, and there is a strong desire for affairs to be in order, particularly amongst older respondents. It seems that organ donation has the *potential* to part of the process of considering death. However, as we know, consideration of any aspect of death is actively avoided by many, two-fifths agree that death is too upsetting to think about.

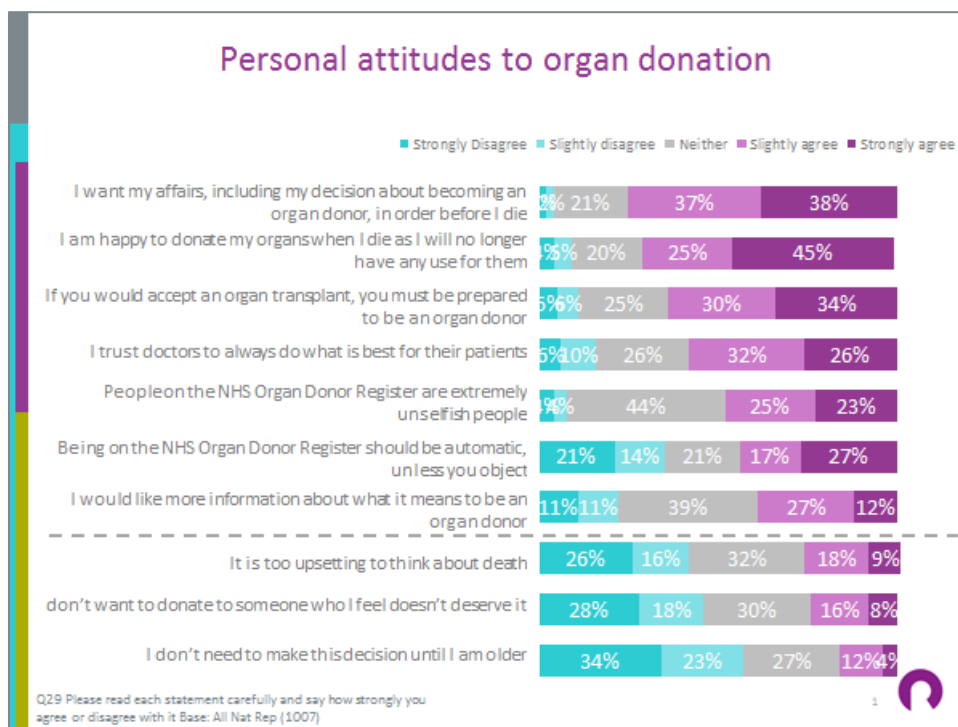


Figure 32: Agreement with personal attitudes towards organ donation

Nearly two thirds believe that if you will accept a donated organ, you must be prepared to donate your own, suggesting the positioning of the 2009 campaign still resonates. However a quarter say they do not want to donate to someone they feel doesn't deserve it, this is

more likely among those who are unsure about donating themselves suggesting messages must also focus on the recipients (children were universally seen as ‘deserving’ among those we spoke to in discussions).

Support for automatic registration (opt-out) is split, with a fifth neither able to agree nor disagree. Although strong agreement (27%) outweighs strong opposition (21%), this is still a significant minority that are opposed. It appears that such a scheme would still come up against some resistance at the current time.

Two-fifths of respondents would like more information on organ donation, again highlighting the need for further education.

A quarter (Figure 33, below) worry about still being alive if their organs are taken for donation, and three in 10 that doctors may not do their best to save donors. This is most prevalent among women aged over 55. Not liking to think of being cut up or used for medical research are also concerns for a similar proportion.

Far fewer are concerned with wishing to remain whole, delaying funerals or burials, or tempting fate. This ties in with findings from elsewhere in the study suggesting that these concerns are more important for a minority (for religious reasons in some cases), but for those holding them, they are deep rooted.

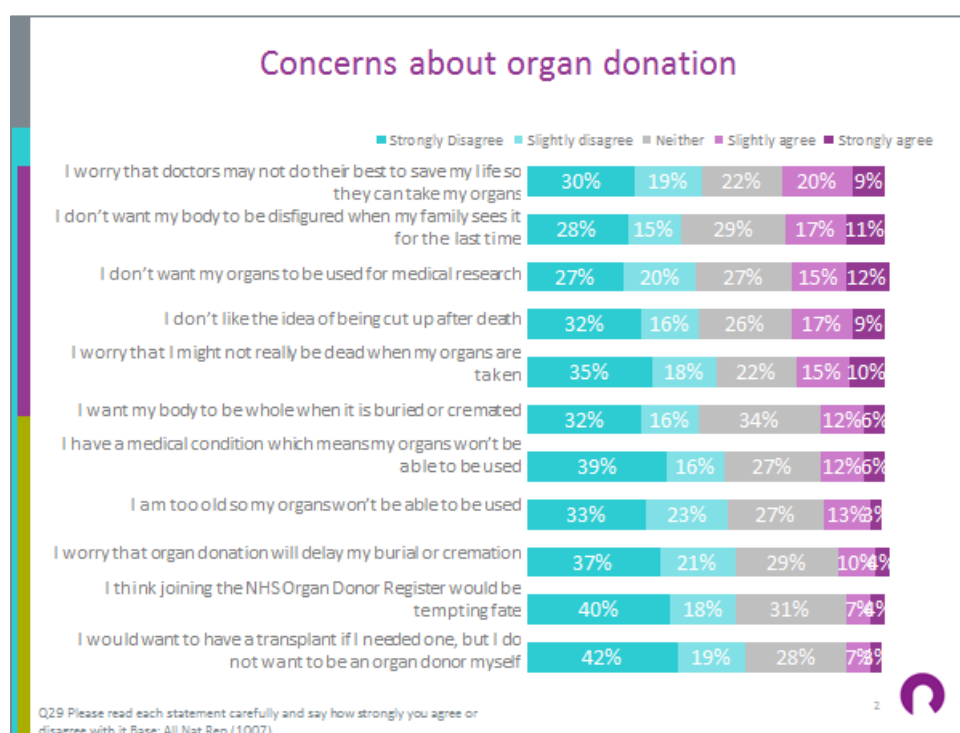


Figure 33: Agreement with concerns around organ donation

Religion and culture are not barriers for the majority (Figure 34, below), and few identify them as a definite barrier (5% and 4% respectively). However around a fifth are unable to say either way. Agreement with religious and cultural barriers increases among BME respondents, with a fifth (19%) agreeing with these statements. Donating within communities resonates for a fifth (21%) who agrees they would be more prepared to donate under these circumstances.

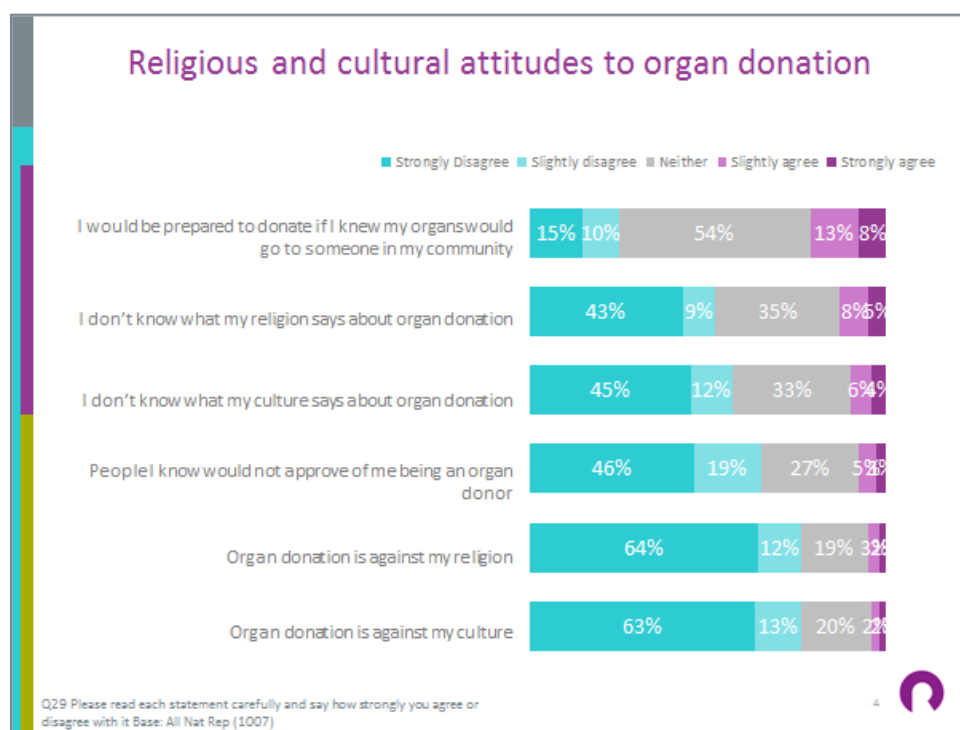


Figure 34: Agreement with religious and cultural attitudes to organ donation

The majority are in favour of family involvement (Figure 35, below), with seven in ten agreeing that they want their family to know how they feel about being a donor and that they need to make a decision about becoming a donor so their family doesn't have to when they die. Further evidence that a message about the importance of talking about organ donation (whether people are willing to donate or not) has the potential to resonate. However a similar proportion also feels that they trust their family to do the right thing on their behalf, which may contribute to complacency in discussing the issue. Highlighting that, in reality, families often don't know what the 'right' decision is may convince people that they need to discuss the issues more.

Encouragingly, only a minority (22%) agree that they don't like the idea of talking to their family about donation, although this is still a significant proportion. Fewer than one in six agrees that their family would actually object.

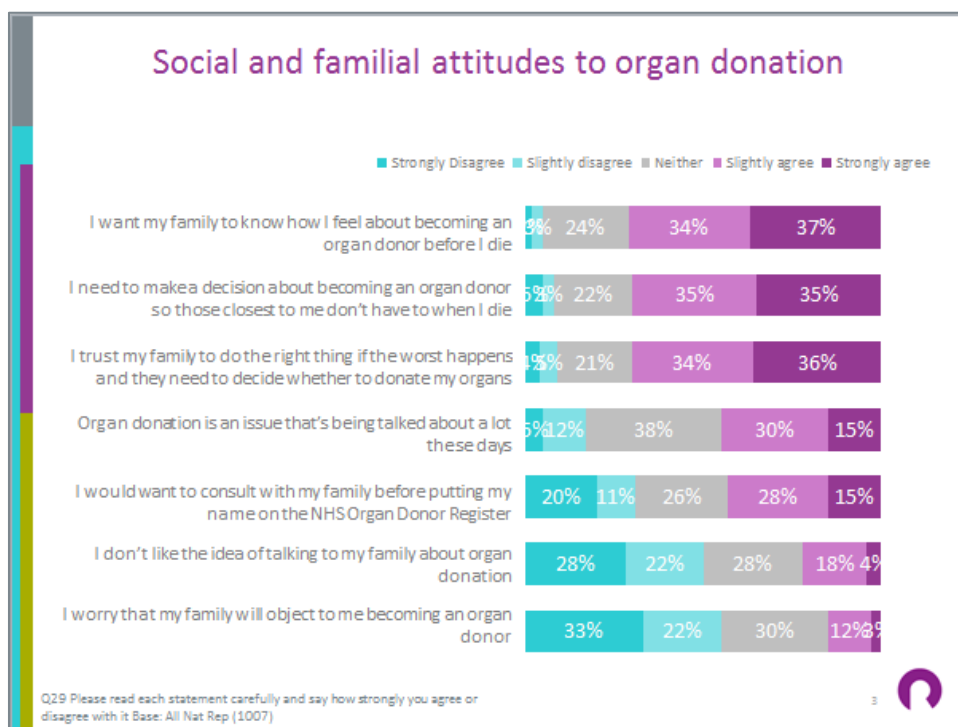


Figure 35: Agreement with social and familial attitudes to organ donation

10.2 Qualitative stakeholder discussion guide

Intro/ warm up	Purpose of section: Put respondents at ease, introduce the research, find out some background details, get the respondent talking	10 minutes
	<p><i>Introduction</i></p> <ul style="list-style-type: none"> • Thank for taking part • Introduce self and Optimisa Research • Broad outline/structure of the session • No right or wrong answers, informal, • Privacy/anonymity – audio, why, use for research only • Ask for any questions and concerns before starting • Explain that we are interested in their views – we understand that they are integral to the process of identifying potential donors and gaining consent and may have a view of NHSBT from a donor perspective so are interested in their professional perspective <p><i>Warm Up</i></p> <p><i>MODERATOR TO ASK RESPONDENT TO INTRODUCE THEMSELVES:</i></p> <ul style="list-style-type: none"> • Name, Job Title, How long you have worked at organisation? • Brief description of organisation’s role and aims • Description of job role, aims and day to day duties • Experience as a SNOD/CLOD 	
Attitudes and barriers to organ donation	Purpose of section: Explore perceptions of support and barriers towards organ donation	20 minutes
	<ul style="list-style-type: none"> • How do you currently feel about levels of support for organ donation in the UK at the moment? • How do you think organ donation might be normalised in the UK? • What are the main issues to address? • What do you think are the barriers to Organ Donation? • Which are the main barriers? Why these? • Are there any sections of the population who these apply to more/less? IF NOT MENTIONED SPECIFICALLY EXPLORE BME COMMUNITIES • How has this changed? If at all? • What barriers are easier to address? • How could these barriers be tackled? • Do you think donors/ donor families feel proud? 	
Attitudes towards consent	Purpose of section: Understand experiences and attitudes around the consent process	15 minutes
	<ul style="list-style-type: none"> • What are your experiences of the consent process and 	

	<p>dealing with families? MODERATOR EXPLORE COMMON THEMES/ISSUES TO FEED INTO SCENARIOS FOR THE NEXT STAGE</p> <ul style="list-style-type: none"> • What are your experiences with BME groups? PROBE IN DETAIL • Why do you think people consent to donation for their next of kin? • What do you think are the main reasons people do not consent? Explore differences when the person is on/not on the ODR) • What do you think are common concerns and questions that people have? • How can these concerns be addressed? • How has this changed? If at all? • What factors make people more/less likely to consent? <p>MODERATOR TO EXPLORE IN DETAIL FACTORS/MESSAGES AND BELIEFS AND PROBE AROUND THEIR EXPERIENCES</p> <ul style="list-style-type: none"> • How do you think donor families feel about giving/not giving consent? Explore the concept of pride and what this means • How much of an impact do you think the relationship of the person to the deceased has on consent? • How much of an impact do you think prior knowledge has on willingness to consent? • EXPLORE OTHER FACTORS MENTIONED AND THEIR PERCEIVED IMPACT • How much of an impact do you think prior family conversations have on willingness to donate? • What do you think prompts these conversations? • What do you think would encourage conversations between family members? • What do you think prompts a refusal? • What are your thoughts on if next of kin were informed rather than asked? • Should families be involved <u>at all</u> in the consent process? 	
Donor card/ODR	Purpose of section: Explore and review the impact and relevance of the donor card and its relationship with the ODR	10 minutes
	<ul style="list-style-type: none"> • What role do you think the organ donor register currently plays? • What are the strengths/weaknesses? • How could more people be encouraged to sign up? • What role do you think the donor card currently plays? • How do you feel about the re-introduction of donor cards? • Would this make a difference to consent rates/What might be the potential impact? • How could they be used to make a difference to consent rates? SPONTANEOUS AND THEN PROBE INTO NEXT OF KIN COUNTER SIGNATORY ON CARD 	

	<ul style="list-style-type: none"> • What might the potential impact to the ODR be? • What if the two were to run alongside each other? • Is it necessary to have a register? 	
Summary	Purpose of section: Bring close to discussion	5 minutes
	<ul style="list-style-type: none"> • What are the key messages that NHSBT should be communicating to encourage and normalize organ donation? • What could be done to improve consent rates? • Any other thoughts? • Thank and close 	

10.3 Qualitative Mr & Mrs discussion guide

Intro/ warm up	Purpose of section: Put respondents at ease, introduce the research, find out some background details of respondents, relax them, get the respondent talking	10 minutes
Joint section with couple together	<p><i>JOINT SECTION: CONDUCT THIS PART OF THE INTERVIEW WITH COUPLE TOGETHER</i></p> <p><i>INTRODUCE THE RESEARCH AS SPEAKING TO A BROAD CROSS SECTION OF THE POPULATION TO OBTAIN THEIR HONEST VIEWS. EVERYONE IS LIKELY TO HAVE DIFFERENT VIEWS AND THERE IS NO RIGHT OR WRONG ANSWERS.</i></p> <ul style="list-style-type: none"> • Thank respondents for taking part • Introduce self and Optimisa Research • Independent agency – honest opinion • Broad outline/structure of the session • No selling/privacy/anonymity • Voice recorder • Ask for any questions and concerns before starting <ul style="list-style-type: none"> • A little bit about themselves <ul style="list-style-type: none"> ○ Family ○ Children ○ Job ○ Hobbies/interests • Ask each partner to describe the other to the moderator; personality, attributes etc • Their relationship <ul style="list-style-type: none"> ○ How long have you been together? Lived together? <p><i>MODERATOR EXPLAIN THAT FOR THE REMAINING PART OF THE DISCUSSION, WE WOULD LIKE TO SPEAK TO THE PARTNERS INDIVIDUALLY AND BRING THEM BACK TOGETHER TOWARDS THE END OF THE SESSION.</i></p> <p><i>REASSURE IF NEEDED WHY WE ARE SPEAKING TO THEM INDIVIDUALLY: TO UNDERSTAND THE PERSPECTIVES OF BOTH PARTNERS IN DEPTH.</i></p>	
Attitudes and awareness to organ donation	Purpose of section: Explore and understand current attitudes towards organ donation. Unearth current awareness and thinking around organ donation	15 minutes
Individual section	<ul style="list-style-type: none"> • What do you think is society’s view of organ donation? • What proportion of the population do you think would be prepared to give organs? Explore reasons for more/less support • Where do these attitudes come from? 	

	<ul style="list-style-type: none"> • More specifically, what attitudes do you think people hold? <p>MODERATOR TO ASK RESPONDENTS TO EXPLORE THE RANGE OF ATTITUDES FROM THE MORE POSITIVE TO THE NEGATIVE, EVEN IF THEY DON'T HOLD THOSE VIEWS THEMSELVES</p> <ul style="list-style-type: none"> • • What types of people do you think are more/less likely to hold these attitudes? • Is organ donation something that is discussed in society? • Why/why not? • What do you know about organ donation? • What have you heard? • How do you feel about organ donation? <p>MODERATOR TO HAVE A RANGE OF IMAGES ON A MOOD BOARD AND WORDS ON SORTCARDS. ASK EACH RESPONDENT TO PICK IMAGES/WORDS WHICH REPRESENT HOW THEY FEEL. SEE APPENDIX 1.</p> <ul style="list-style-type: none"> • For each ask them to explain why they have chosen what they have? • How do they make them feel? • Ask individuals to describe thoughts, feelings and beliefs 	
Support for/barriers against organ donation	Purpose of section: Explore the reasons behind support for organ donation and what creates positive behaviour. Explore the barriers which prevent support and how these best could be overcome	15 minutes
	<ul style="list-style-type: none"> • What do you think are the main reasons why people support/oppose organ donation? • What other reasons are there? • Why do you think they hold these views? <p>MODERATOR TO SHOW SORTCARDS WITH BARRIERS/SUPPORTING FACTORS. POSITION THAT THESE ARE THINGS <u>WHICH OTHER PEOPLE HAVE SAID</u> TAKING EACH IN TURN EXPLORE REACTIONS TO EACH. SEE APPENDIX 2. ASK EACH INDIVIDUAL TO RANK PROMPTED BARRIERS/SUPPORTING FACTORS</p> <ul style="list-style-type: none"> • Why do you think people hold these beliefs? • What drives them? • How influential are they? 	
ODR	Purpose of section: Explore awareness and understanding of the ODR	5 minutes
	<p>IF NOT ON THE DONOR REGISTER:</p> <ul style="list-style-type: none"> • What do you know if anything about the organ donor register? <p>MODERATOR INTRODUCE A DESCRIPTION OF THE ODR (SEE</p>	

	<p>APPENDIX 3)</p> <p>IF ON THE ORGAN DONOR REGISTER:</p> <ul style="list-style-type: none"> • What do you know about how you can show your support for organ donation? 	
Consent to organ donation	Purpose of section: Explore attitudes towards consent	25 minutes
	<ul style="list-style-type: none"> • Would you be aware of the wishes of any family member? • If yes, what has made you aware? • If conversations have been had between family members what has prompted these conversations? • What proportion of the population do you think would be prepared to consent for their next of kin? • Why do you think this? What do you see as the main barriers/supporting factors? <p>MODERATOR TO GO THROUGH EACH SCENARIO AND ASK RESPONDENTS TO CONSIDER HOW THEY MIGHT FEEL/REACT:</p> <p><u>SCENARIO ONE:</u> IF A CLOSE RELATIVE HAS DIED AND YOU KNEW THEY WERE ON THE ORGAN DONOR REGISTER AND THE MEDICAL PROFESSIONALS ASKED YOU TO CONFIRM THEIR WISHES, WOULD YOU AGREE TO THEIR ORGANS BEING USED?</p> <p><u>SCENARIO TWO:</u> IF A CLOSE RELATIVE OF YOURS DIED AND YOU DID NOT KNOW HOW THEY FELT ABOUT ORGAN DONATION, WOULD YOU AGREE TO THEIR ORGANS BEING USED?</p> <p><i>MODERATOR CHOOSE SCENARIO THREE OR FOUR BASED ON WHETHER THE INDIVIDUAL IS ON THE ODR</i></p> <p><u>SCENARIO THREE:</u> IF YOU WERE ON THE ORGAN DONOR REGISTER AND YOUR FAMILY GAVE CONSENT, HOW WOULD YOU FEEL? SIMILARLY IF THEY WITHHELD CONSENT, HOW WOULD YOU FEEL? (With and without having had a conversation about your wishes)</p> <p>Why do you think a family member might not give consent even if you were on the register – and had told them about your wishes?</p> <p><u>SCENARIO FOUR:</u> IF YOU WERE NOT ON THE ORGAN DONOR REGISTER AND YOUR FAMILY GAVE CONSENT, HOW WOULD YOU FEEL? SIMILARLY IF THEY WITHHELD CONSENT, HOW WOULD YOU FEEL?</p> <p>FOR EACH ASK:</p> <ul style="list-style-type: none"> • To explain their answer/thinking 	

	<ul style="list-style-type: none"> • How would it make you feel? • What questions/concerns would you have? • What factors influence your decision? Explore impact of who the relative was • Why might people say the opposite? Can you see why people would have issues with any of the scenarios? • Why might people go against the wishes of the loved one? • How do you think your partner would answer? • If you were told the following the facts / about the process how might you react? Would this change your views? How? <p>Facts</p> <ul style="list-style-type: none"> • <i>Organs that can be donated by people who have died include the heart, lungs, kidneys, liver, pancreas and small bowel. Tissues such as skin, bone, heart valves and corneas can also be used to help others</i> • <i>The organ or tissue recipient will be someone (or several people) from the transplant list who is in greatest need. You may receive information on recipients if you wish</i> • <i>It can be difficult to accept that death has occurred when your loved one still has a heart-beat, but if the ventilator were to be switched off breathing would not be possible</i> • <i>Once brain stem tests have been performed and death has been confirmed the ventilator would be turned off. However if you would like to consider organ donation, it will be necessary to leave the ventilator on so that donation can take place</i> <p>The process</p> <ul style="list-style-type: none"> • <i>The staff caring for your loved one will contact a specialist nurse in organ donation who carers for potential organ/tissue donors and their family/friends. He/she will provide information about organ and tissue donation and, should you decide to proceed, will organise the process</i> • <i>The specialist nurse will discuss in detail with you which organs and tissues can be donated</i> • <i>In order for the organs to remain suitable for transplantation, the operation to remove the organs will need to take place very soon after death has been certified by the doctor.</i> • <i>Specialist doctors and their teams may be called in from other hospitals to carry out the operation</i> • <i>The retrieval operation takes approximately four to six hours</i> • <i>This operation is carried out with the same care and respect as any other operation and the specialist nurse in organ donation is present throughout</i> • <i>The operation site will be carefully stitched and dressings applied</i> • <i>Organ and tissue donation will not affect the normal process of arranging a funeral</i> • <i>The family can see the body afterwards</i> <p>FOR EACH MODERATOR TO ASCERTAIN WHEN/IF VIEWS CHANGE AND</p>	
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	WHAT PROMPTS THIS CHANGE	
Summary/ close	Purpose of this section: To cross examine couples attitudes towards consent. To obtain key points of takeout from both individuals	20 minutes
Joint section with couple	<p><i>JOINT SECTION: CONDUCT THIS PART OF THE INTERVIEW WITH COUPLE TOGETHER</i></p> <p>EXPLAIN THAT WE'D NOW LIKE TO TALK ABOUT SOME OF THE THINGS WE'VE ALREADY TALKED ABOUT WITH THEM INDIVIDUALLY, BUT NOW TOGETHER</p> <ul style="list-style-type: none"> • Go through each scenario and encourage couple to discuss and debate their views • Where are the similarities/differences? Why? • How would they feel? Explore feelings of pride • Have opinions changed? Why? What prompted changes? • Explore respecting each other's wishes • How do they now feel about organ donation? • What is your single biggest barrier/ supporting factor for organ donation? <p>Donor Card:</p> <ul style="list-style-type: none"> • Have you ever heard of organ donor cards? How? Where? • Have you ever had a card/known anyone with a card? <p>MODERATOR TO INTRODUCE EXPLANATION OF DONOR CARDS (SEE APPENDIX 4)</p> <ul style="list-style-type: none"> • How do you feel about people being able to pick up organ donor cards anywhere as opposed to registering and receiving one? • How might that make you feel about organ donation? • How would you feel if your partner had a card – would you take this as evidence they supported organ donation and wanted to donate their organs? <p>MODERATOR TO INTRODUCE SCENARIO: AN ORGAN DONATION CARD IS AVAILABLE TO PICK UP. IT REQUIRES YOUR NEXT OF KIN TO SIGN THE CARD.</p> <ul style="list-style-type: none"> • Why might NHSBT do this? • Who would be likely to pick this up? • Could you imagine people getting next of kin to sign cards? Why/Why not? • Why might people say the opposite? • If you picked up the card, would this encourage you to have a conversation with your partner / next of kin? • If your partner asked you to counter-sign the card would this encourage you to ask in more detail about their wishes? <p>IF TIME REVISIT AND COMPARE COUPLES ANSWERS TO THE PROPORTIONS OF THE POPULATION THAT THEY FEEL WOULD</p>	

	<p>SUPPORT ORGAN DONATION AND THAT WOULD CONSENT</p> <ul style="list-style-type: none">• How are their answers similar/different? MODERATOR TO ENCOURAGE DEBATE• What are the key takeouts from today? <p>Thank and close</p>	
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10.4 Qualitative Family Triad discussion guide

Introduction/ warm up	Purpose of section: Put respondents at ease, introduce the research, find out some background details of respondents, relax them, get the respondent talking	10 minutes
Joint section with couple together	<p><i>JOINT SECTION: CONDUCT THIS PART OF THE INTERVIEW WITH COUPLE TOGETHER</i></p> <p><i>INTRODUCE THE RESEARCH AS SPEAKING TO A BROAD CROSS SECTION OF THE POPULATION TO OBTAIN THEIR HONEST VIEWS. EVERYONE IS LIKELY TO HAVE DIFFERENT VIEWS AND THERE IS NO RIGHT OR WRONG ANSWERS.</i></p> <ul style="list-style-type: none"> • Thank respondents for taking part • Introduce self and Optimisa Research • Independent agency – honest opinion • Broad outline/structure of the session • No selling/privacy/anonymity • Voice recorder • Ask for any questions and concerns before starting • A little bit about themselves <ul style="list-style-type: none"> ○ Family ○ Job ○ Hobbies/interests ○ Typical family life ○ Typical weekend/weekday • Ask each to describe the other to the moderator; personality, attributes etc <p>MODERATOR EXPLAIN THAT FOR THE REMAINING PART OF THE DISCUSSION, WE WOULD LIKE TO SPEAK TO EACH FAMILY MEMBER INDIVIDUALLY AND BRING THEM BACK TOGETHER TOWARDS THE END OF THE SESSION.</p> <p>REASSURE IF NEEDED WHY WE ARE SPEAKING TO THEM INDIVIDUALLY: TO UNDERSTAND THE PERSPECTIVES OF THE WHOLE FAMILY IN DEPTH.</p>	
Attitudes and awareness to organ donation	Purpose of section: Explore and understand current attitudes towards organ donation. Unearth current awareness and thinking around organ donation	10 minutes
Individual section	<ul style="list-style-type: none"> • What do you think is society’s view of organ donation? • What proportion of the population do you think would be prepared to give organs? Explore reasons for more/less support • Where do these attitudes come from? • More specifically, what attitudes do you think people hold? 	

	<p>MODERATOR TO ASK RESPONDENTS TO EXPLORE THE RANGE OF ATTITUDES FROM THE MORE POSITIVE TO THE NEGATIVE, EVEN IF THEY DON'T HOLD THOSE VIEWS THEMSELVES</p> <ul style="list-style-type: none"> • • What types of people do you think are more/less likely to hold these attitudes? • Is organ donation something that is discussed in society? • Why/why not? • What do you know about organ donation? • What have you heard? • How do you feel about organ donation? <p>MODERATOR TO HAVE A RANGE OF IMAGES ON A MOOD BOARD AND WORDS ON SORTCARDS. ASK EACH RESPONDENT TO PICK IMAGES/WORDS WHICH REPRESENT HOW THEY FEEL. SEE APPENDIX 1.</p> <ul style="list-style-type: none"> • For each ask them to explain why they have chosen what they have? • How do they make them feel? • Ask individuals to describe thoughts, feelings and beliefs 	
Support for/barriers against organ donation	Purpose of section: Explore the reasons behind support for organ donation and what creates positive behaviour. Explore the barriers which prevent support and how these best could be overcome	10 minutes
	<ul style="list-style-type: none"> • What do you think are the main reasons why people support/oppose organ donation? • What other reasons are there? • Why do you think they hold these views? <p>MODERATOR TO SHOW SORTCARDS WITH BARRIERS/SUPPORTING FACTORS. POSITION THAT THESE ARE THINGS <u>WHICH OTHER PEOPLE HAVE SAID</u> TAKING EACH IN TURN EXPLORE REACTIONS TO EACH. SEE APPENDIX 2. ASK EACH INDIVIDUAL TO RANK PROMPTED BARRIERS/SUPPORTING FACTORS</p> <ul style="list-style-type: none"> • Why do you think people hold these beliefs? • What drives them? • How influential are they? 	
ODR	Purpose of section: Explore awareness and understanding of the ODR	5 minutes
	<p>IF NOT ON THE DONOR REGISTER:</p> <ul style="list-style-type: none"> • What do you know if anything about the organ donor register? <p>MODERATOR INTRODUCE A DESCRIPTION OF THE ODR (SEE APPENDIX 3)</p>	

	<p>IF ON THE ORGAN DONOR REGISTER:</p> <ul style="list-style-type: none"> • What do you know about how you can show your support for organ donation? 	
Consent to organ donation	Purpose of section: Explore attitudes towards consent	20 minutes
	<ul style="list-style-type: none"> • Would you be aware of the wishes of any family member? • If yes, what has made you aware? • If conversations have been had between family members what has prompted these conversations? • What proportion of the population do you think would be prepared to consent for their next of kin? • Why do you think this? What do you see as the main barriers/supporting factors? <p>MODERATOR TO GO THROUGH EACH SCENARIO AND ASK RESPONDENTS TO CONSIDER HOW THEY MIGHT FEEL/REACT:</p> <p><u>SCENARIO ONE:</u> IF A CLOSE RELATIVE HAS DIED AND YOU KNEW THEY WERE ON THE ORGAN DONOR REGISTER AND THE MEDICAL PROFESSIONALS ASKED YOU TO CONFIRM THEIR WISHES, WOULD YOU AGREE TO THEIR ORGANS BEING USED?</p> <p><u>SCENARIO TWO:</u> IF A CLOSE RELATIVE OF YOURS DIED AND YOU DID NOT KNOW HOW THEY FELT ABOUT ORGAN DONATION, WOULD YOU AGREE TO THEIR ORGANS BEING USED?</p> <p><i>MODERATOR CHOOSE SCENARIO THREE OR FOUR BASED ON WHETHER THE INDIVIDUAL IS ON THE ODR</i></p> <p><u>SCENARIO THREE:</u> IF YOU WERE ON THE ORGAN DONOR REGISTER AND YOUR FAMILY GAVE CONSENT, HOW WOULD YOU FEEL? SIMILARLY IF THEY WITHHELD CONSENT, HOW WOULD YOU FEEL? (With and without having had a conversation about your wishes)</p> <p>Why do you think a family member might not give consent even if you were on the register – and had told them about your wishes?</p> <p><u>SCENARIO FOUR:</u> IF YOU WERE NOT ON THE ORGAN DONOR REGISTER AND YOUR FAMILY GAVE CONSENT, HOW WOULD YOU FEEL? SIMILARLY IF THEY WITHHELD CONSENT, HOW WOULD YOU FEEL?</p> <p>FOR EACH ASK:</p> <ul style="list-style-type: none"> • To explain their answer/thinking 	

	<ul style="list-style-type: none"> • How would it make you feel? • What questions/concerns would you have? • What factors influence your decision? Explore impact of who the relative was • Why might people say the opposite? Can you see why people would have issues with any of the scenarios? • Why might people go against the wishes of the loved one? • How do you think your family members would answer? • If you were told the following facts / about the process how might you react? Would this change your views? How? <p>Facts</p> <ul style="list-style-type: none"> • <i>Organs that can be donated by people who have died include the heart, lungs, kidneys, liver, pancreas and small bowel. Tissues such as skin, bone, heart valves and corneas can also be used to help others</i> • <i>The organ or tissue recipient will be someone (or several people) from the transplant list who is in greatest need. You may receive information on recipients if you wish</i> • <i>It can be difficult to accept that death has occurred when your loved one still has a heart-beat, but if the ventilator were to be switched off breathing would not be possible</i> • <i>Once brain stem tests have been performed and death has been confirmed the ventilator would be turned off. However if you would like to consider organ donation, it will be necessary to leave the ventilator on so that donation can take place</i> <p>The process</p> <ul style="list-style-type: none"> • <i>The staff caring for your loved one will contact a specialist nurse in organ donation who carers for potential organ/tissue donors and their family/friends. He/she will provide information about organ and tissue donation and, should you decide to proceed, will organise the process</i> • <i>The specialist nurse will discuss in detail with you which organs and tissues can be donated</i> • <i>In order for the organs to remain suitable for transplantation, the operation to remove the organs will need to take place very soon after death has been certified by the doctor.</i> • <i>Specialist doctors and their teams may be called in from other hospitals to carry out the operation</i> • <i>The retrieval operation takes approximately four to six hours</i> • <i>This operation is carried out with the same care and respect as any other operation and the specialist nurse in organ donation is present throughout</i> • <i>The operation site will be carefully stitched and dressings applied</i> • <i>Organ and tissue donation will not affect the normal process of arranging a funeral</i> • <i>The family can see the body afterwards</i> <p>FOR EACH MODERATOR TO ASCERTAIN WHEN/IF VIEWS CHANGE AND</p>	
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	WHAT PROMPTS THIS CHANGE	
Speak to other family members	Purpose of this section: To understand the individual views of other family members	45 minutes
	MODERATOR TO REPEAT ALL PREVIOUS SECTIONS INDIVIDUALLY WITH ANOTHER FAMILY MEMBER	
Summary/ close	Purpose of this section: To cross examine family's attitudes towards consent. To obtain key points of takeout from both individuals	20 minutes
Joint section with family	<p><i>JOINT SECTION: CONDUCT THIS PART OF THE INTERVIEW WITH FAMILY TOGETHER</i></p> <p>EXPLAIN THAT WE'D NOW LIKE TO TALK ABOUT SOME OF THE THINGS WE'VE ALREADY TALKED ABOUT WITH THEM INDIVIDUALLY, BUT NOW TOGETHER</p> <ul style="list-style-type: none"> • Go through each scenario and encourage family to discuss and debate their views • Where are the similarities/differences? Why? • How would they feel? Explore feelings of pride • Have opinions changed? Why? What prompted changes? • Explore respecting each other's wishes • How do they now feel about organ donation? • What is your single biggest barrier/ supporting factor for organ donation? <p>Donor Card:</p> <ul style="list-style-type: none"> • Have you ever heard of organ donor cards? How? Where? • Have you ever had a card/know anyone with a card? <p>MODERATOR TO INTRODUCE EXPLANATION OF DONOR CARDS (SEE APPENDIX 4)</p> <ul style="list-style-type: none"> • How do you feel about people being able to pick up organ donor cards anywhere as opposed to registering and receiving one? • How might that make you feel about organ donation? • How would you feel if your partner had a card – would you take this as evidence they supported organ donation and wanted to donate their organs? <p>MODERATOR TO INTRODUCE SCENARIO: AN ORGAN DONATION CARD IS AVAILABLE TO PICK UP. IT REQUIRES YOUR NEXT OF KIN TO SIGN THE CARD.</p> <ul style="list-style-type: none"> • Why might NHSBT do this? • Who would be likely to pick this up? • Could you imagine people getting next of kin to sign cards? 	

	<p>Why/Why not?</p> <ul style="list-style-type: none"> • Why might people say the opposite? • If you picked up the card, would this encourage you to have a conversation with your partner / next of kin? • If your partner asked you to counter-sign the card would this encourage you to ask in more detail about their wishes? <p>IF TIME REVISIT AND COMPARE FAMILY'S ANSWERS TO THE PROPORTIONS OF THE POPULATION THAT THEY FEEL WOULD SUPPORT ORGAN DONATION AND THAT WOULD CONSENT</p> <ul style="list-style-type: none"> • How are their answers similar/different? MODERATOR TO ENCOURAGE DEBATE • What are the key takeouts from today? <p>Thank and close</p>	
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10.5 Qualitative Mr & Mrs and Family Triad discussion guide appendices

Appendix 1

Words to describe an organ donation:-

- Heroic
- Sad
- Dangerous
- Scary
- Alien
- Normal
- Rewarding
- Frowned upon
- Unnecessary
- Happy
- A duty
- Hope
- Pride
- Honourable

Appendix 2

Barriers to organ donation sort cards:-

- 'I don't want my organs to be used for medical research'
- 'I'm too old my organs won't be of any use'
- 'I don't need to make this decision until I' am older'
- 'I worry my family will object to me being on the organ donor'
- 'I don't like the idea of talking to my family about organ donation'
- 'I worry doctors might not do their best to save my life'
- 'I want my body to be whole when it is buried/cremated'
- 'I worry donation will delay the burial/cremation time'
- 'Organ donation is against my culture'
- 'Organ donation is against my religion'
- 'I don't want to donate to someone who does not deserve it'
- 'I don't want to suffer after death'
- I have an illness that will stop doctors wanting my organs
- I wouldn't want an organ so I wouldn't give one

Motivating factors towards organ donation sort cards:-

- 'I need to make the decision about being an organ donor so my family don't have to when I die'
- 'It would be improving and saving the lives of others'
- 'I want to make something good out of a sad situation'
- 'Someone I love could one day need a transplant'
- 'My organs will only go to waste when I die'
- 'If I would accept an organ I must be prepared to give one'
- 'I would be prepared to donate if I knew my organs would go to someone in my community'
- 'People who are donors are viewed as extremely unselfish people'
- 'I feel a social responsibility to donate my organs'
- I would feel proud to donate my organs / consent to donating a loved one's organs

Appendix 3

A description of the Organ Donation Register

The NHS Organ Donor Register is a national, confidential list of people who are willing to become donors after their death. It can be quickly accessed to see whether an individual has registered a willingness to be an organ donor. It can literally be a life-saver. So that in the event of your death there's a chance that your organs could help someone else to live.

Putting your name on the NHS Organ Donor Register makes everyone aware of your wishes and makes it easier for them to agree to your donation.

Millions of people carry donor cards or are on the register.

When you register it is important that you tell those closest to you about your decision. Even if your name is on the register, the person closest to you in life will be asked to confirm that you had not changed your mind. Putting your name on the register demonstrates your consent to the use of your organs for transplantation.

Appendix 4

A description of Organ Donor cards

Before the Organ Donor Register was introduced, donor cards were widely available for people to obtain and carry as a sign that they wanted to be a donor.

Donor cards are now only issued when someone has registered to be on the Organ Donor Register.

10.6 Quantitative questionnaire

Organ donation online questionnaire

Intro	<p>Welcome to the survey and thank you for agreeing to take part.</p> <p>The survey is about health and will take around 20 minutes to complete, depending on the answers you give.</p> <p>We are interested in your views on some issues that some people can find sensitive. However, any and all information you can give will be extremely helpful so please do tell us all that you can. There are no right or wrong answers - it is what you think and feel personally that is most important and all the information you give in this study will be kept confidential, with your views mixed in with others.</p> <p>We would like to begin by asking you a few questions about yourself as there is a particular target audience in mind for this survey. Please note that we appreciate everyone's intention to participate in the survey and your time and interest to take part has been noted.</p> <p>Please click 'next' to start the survey</p>
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Screener / quota questions

S1	Gender
Base	All respondents
Routing Definition	All respondents
Question type	Qgender
Programming instruction	
Question text	Are you...?
Respondent instruction	Please select one answer only
CODE	
1	Male
2	Female

S2	Age
Base	All respondents
Routing Definition	All respondents
Question type	Qopen
Programming instruction	Screen out if under 18
Question text	How old are you?
Respondent instruction	Please type your age in years into the box below
	Please group ages for quota and analysis purposes:
1 - CLOSE	Under 18
2	18-24

3	25-34
4	35-44
5	45-54
6	55-64
7	65+

S3	Region
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	Screen out if code 10, 11, 12 or 13
Question text	Where do you live?
Respondent instruction	Please select one answer only
CODE	
1	East Anglia
2	East Midlands
3	London
4	North East England
5	North West England
6	South East England (excluding London)
7	South West England
8	West Midlands
9	Yorkshire and the Humber
10 - CLOSE	Scotland
11 - CLOSE	Wales
12 - CLOSE	Northern Ireland
13 - CLOSE	Outside the UK

Intro

This survey is about organ donation and what people think about issues related to this. Organ donation is the giving of organs to someone else who needs a healthy organ. In this survey, we will be thinking about donating organs after death, rather than living donations (e.g. where someone donates one of their kidneys to someone who needs one).

S4	Whether agree with organ donation in principle
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	Screen out if code 5 is selected
Question text	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.
Respondent instruction	Please select one answer only
CODE	

1	I strongly support organ donation in principle
2	I support organ donation in principle
3	I neither support nor oppose organ donation in principle
4	I oppose organ donation in principle
5 - CLOSE	I strongly oppose organ donation in principle
85	Don't know

Personal attitudes to organ donation and the ODR

Q1a	Views on organ donation
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	What are your thoughts on organ donation after death?
Respondent instruction CODE	Please select one answer only OPEN

Q1	Comfort with idea of organ donation
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	How comfortable are you with the idea of donating your organs after death?
Respondent instruction CODE	Please select one answer only
1	Very comfortable
2	Quite comfortable
3	Neither comfortable nor uncomfortable
4	Quite uncomfortable
5	Very uncomfortable
85	Don't know

Q2	Willingness to donate own organs
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Which of the following best describes how you personally feel about organ donation?
Respondent instruction CODE	Please select one answer only

1	I <u>definitely</u> want to donate all of my organs after death if possible
2	I <u>definitely</u> want to donate some of my organs after death if possible
3	I would consider donating all of my organs after death
4	I would consider donating some of my organs after death
5	I don't know if I want to donate my organs after death
6	I definitely don't want to donate my organs after death

Q3a	Spontaneous reasons for wanting/ not wanting to donate organs
Base	All respondents
Routing Definition	All respondents
Question type	Qopen
Programming instruction	
Question text	<p>What makes you [TEXT SUB if code 1 or 2 at Q2: want / TEXT SUB if code 5 at Q2: not sure if you want to / TEXT SUB if code 6 at Q2: not want] to donate [TEXT SUB if code 1 at Q2: all of] your organs after death?</p> <p>[TEXT SUB if code 3 at Q2: Why would you consider donating all of your organs after death?]</p> <p>[TEXT SUB if code 4 at Q2: Why would you consider donating some of your organs after death?]</p>
Respondent instruction CODE	<p>Please type your answer into the box below</p> <p>OPEN</p>

Q3b_1	Considerations about organ donation
Base	All respondents
Routing Definition	All respondents
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	Below are some things that people have said for why they want to donate their organs. Which of these apply to you when thinking about whether you would consider donating your organs after death?
Respondent instruction CODE	Please select all that apply
1	Someone I love could one day need a transplant
2	My organs will only go to waste when I die
3	I would accept an organ transplant so I should be prepared to donate one
4	People who are organ donors are viewed as extremely unselfish people
5	I feel a social responsibility to donate my organs
6	I would feel proud to donate my organs
7	It would be improving and saving the lives of others
8	I want to make something good out of a sad situation
9	It's something that everyone should do
10	I want to make sure that there are enough organs for those who need them

11	It makes me feel good to know that I could be helping someone when I die
84	Other, please write in:
85	Don't know
87	None of these

Q3b_2	Considerations about organ donation
Base	All respondents
Routing Definition	All respondents
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	Below are some things that people have said for why they don't want to donate their organs. Which of these apply to you when thinking about whether you would consider donating your organs after death?
Respondent instruction	Please select all that apply
CODE	
1	I would worry my organs wouldn't be used for transplantation
2	I'm too old - my organs wouldn't be of any use
3	I worry my family might be upset if I donated my organs
4	I worry hospital staff might not do their best to save my life if they knew my organs were available for donation
5	I want my body to be whole when it is buried or cremated
6	I worry that organ donation will delay the burial or cremation time
7	I think organ donation is against my culture
8	I think organ donation is against my religion / faith
9	I don't want to donate to someone who does not deserve it
10	I don't want to suffer after death
11	I have an illness that will stop doctors wanting my organs
12	I wouldn't accept an organ transplant, so I wouldn't donate an organ
13	I can't give blood so I don't think I could donate my organs
14	I worry I could still be alive when they do the operation
15	I don't want to donate to someone from a different religion / faith to me
16	I don't want to donate to someone from a different community to me
17	I don't want to think about my death
18	I don't know enough about it
84	Other, please write in:
85	Don't know
87	None of these

Q3c	Religious reasons
Base	All respondents who think organ donation is against their religion / faith
Routing Definition	All respondents who code 8 at Q3b
Question type	Qopen
Programming instruction	
Question text	You said that you think organ donation is against your religion/ faith. What

	makes you believe this?
Respondent instruction CODE	Please type your answer into the box below OPEN

Q4	Whether spoken to anyone in religion / faith about organ donation
Base	All respondents who think organ donation is against their religion / faith
Routing Definition	All respondents who code 8 at Q3b
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	You said that you think organ donation is against your religion / faith. Which of the following describe how you're aware of this?
Respondent instruction CODE	Please select all that apply
1	I discussed it with a religious leader / clergy
2	I discussed it with friends and family of the same religion / faith
3	I did my own research
4	From my own interpretation of my religion / faith's scripture
5	I've heard a religious leader / scholar speaking about it
6	I just know it's against my religion / faith
7	I think it's against my religion / faith but I would need to look into it more
8	I don't know for sure it's against my religion / faith
84	Other, please write in:
85	Don't know

Q5	Reasons religion / faith doesn't allow organ donation
Base	All respondents who think organ donation is against their religion / faith
Routing Definition	All respondents who code 8 at Q3b
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	Below are some reasons that other people have given for why they think organ donation is against their religion / faith. Do you know which, if any, of the following applies to your religion / faith?
Respondent instruction CODE	Please select all that apply
1	The body shouldn't be altered before burial / cremation
2	The body needs to be buried / cremated as soon as possible after death
3	There must be an open casket / people need to be able to view the body
4	The body is sacred even after death
5	A person's spirit / soul is still present as long as their body is being kept artificially alive
6	The body is still needed by the person after death
7	Physical changes to their body in this life may affect someone in the next life / afterlife
8	The spirit / soul may still be present in the body in the hours after death

9	It's wrong to have someone else's organs inside you
10	There are varied opinions on organ donation in my religion / faith. I wouldn't want to be an organ donor unless there is a clear answer
84	Other, please write in:
85	Don't know
87	None of these

Q5a	Cultural reasons
Base	All respondents who think organ donation is against their culture
Routing Definition	All respondents who code 7 at Q3b
Question type	Qopen
Programming instruction	
Question text	You said that you think organ donation is against your culture. What makes you believe this?
Respondent instruction	Please type your answer into the box below
CODE	OPEN

Q6	Awareness of the ODR
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Before today, were you aware of the NHS Organ Donor Register?
Respondent instruction	Please select one answer only
CODE	
1	Yes
2	No
85	Don't know

Q7	Understanding of the ODR
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	Randomise order of statements
Question text	Which of the following do you think best describes what the NHS Organ Donor Register is?
Respondent instruction	Please select one answer only
CODE	
1	A confidential database which holds the wishes of people who have decided that they would like to be an organ donor after death. Putting their name on the register is consent to the use of their organs for transplantation
2	A confidential database of people who have decided that they want to donate their organs (e.g. kidney) while they are still alive
3	A list of people who want to show their support for organ donation in principle

4	A database of people who have agreed that their organs can be used for medical research after death
85	Don't know

INTRO

The NHS Organ Donor Register is a confidential, computerised database which holds the wishes of people who have decided that they would like to be an organ donor after their death. It can be quickly accessed to see whether an individual has registered a willingness to be an organ donor. Putting your name on the register demonstrates your consent to the use of your organs for transplantation.

Q8	Whether on the ODR
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Have you put your name on the NHS Organ Donor Register?
Respondent instruction	Please select one answer only
CODE	
1	Yes, definitely
2	Yes, I think so
3	No, I don't think so
4	No, definitely not
83	I can't remember
85	Don't know

Q9a	How they signed up to the ODR
Base	All respondents who have signed up to the ODR
Routing Definition	All respondents who code 1 or 2 at Q8
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	There are many different ways to put your name on the NHS Organ Donor Register. How did you do this?
Respondent instruction	Please select all that apply
CODE	
1	By adding your details to the online NHS Organ Donor Register website
2	By telephoning the Organ Donor Line
3	When completing a driving license application form
4	When registering with a new doctor or GP's surgery
5	When applying for a Boots Advantage Card
6	When applying for a new passport, using the leaflet enclosed with the application form
7	When registering for a European Health Insurance Card (EHIC), using the leaflet enclosed with the application form
8	When applying / signing up for your organ donor card
9	By sending a text message to the Organ Donor Line

84	Other way, please write in:
85	Don't know / can't remember
87	I'm not sure I have put my name on the NHS Organ Donor Register

Q9b	Check whether they may have signed the ODR
Base	All respondents who have not or don't know if they have signed the ODR
Routing Definition	All respondents who code 3, 4, 83 or 85 at Q8
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	There are a number of ways of putting your name on the NHS Organ Donor Register. Please can we just check whether you might have put your name on the register in one of the following situations?
Respondent instruction	Please select all that apply
CODE	
1	By adding your details to the online NHS Organ Donor Register website
2	By telephoning the Organ Donor Line
3	When completing a driving license application form
4	When registering with a new doctor or GP's surgery
5	When applying for a Boots Advantage Card
6	When applying for a new passport, using the leaflet enclosed with the application form
7	When registering for a European Health Insurance Card (EHIC), using the leaflet enclosed with the application form
8	When applying / signing up for your organ donor card
9	By sending a text message to the Organ Donor Line
84	Other way, please write in:
85	Don't know / can't remember
87	I haven't put my name on the NHS Organ Donor Register

Q10	Whether spoken to anyone about signing up
Base	All respondents who have signed up to the ODR
Routing Definition	All respondents who any of codes 1 to 85 at Q9a or 1 - 84 @ Q9b
Question type	Qsingle
Programming instruction	
Question text	Have you told anyone that you have put your name on the NHS Organ Donor Register?
Respondent instruction	Please select one answer only
CODE	
1	Yes
2	No
85	Don't know / can't remember

Q11a	Reasons not on the ODR even though willing to donate own organs
Base	All respondents who are willing to donate their organs but have not signed up to the ODR

Routing Definition	All respondents who code 1, 2, 3 or 4 at Q2 AND code 87 at Q9b
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	You said earlier that you would donate or would consider donating your organs after death. Which of the following reasons describe why you have not put your name on the NHS Organ Donor Register?
Respondent instruction	Please select all that apply
CODE	
1	I don't think my religion / faith would allow me to be an organ donor
2	I don't think my culture approves of organ donation
3	My family doesn't approve of organ donation
4	I don't want to think about my death
5	I don't know how to put my name on the register
6	I don't have enough information about the register to make a decision
7	I don't think I would qualify to be an organ donor
8	I don't trust doctors to do their best to save my life if I am on the register
9	I don't want my personal data to be stored on a register
10	I have a donor card and I didn't know I needed to register as well
11	I don't want to tempt fate by joining the register
12	I didn't know there was a register
13	I'm too old so my organs won't be of any use
14	I don't need to do anything about it until I'm older
15	It's too much hassle to fill a form in
16	I haven't got around to it yet
17	I might change my mind and I don't know if you can take your name off it
18	I don't see the point because my family already know my wishes
19	I would worry about being viewed as an organ donor rather than a patient
84	Other, please write in:
85	Don't know
87	I have put my name on the NHS Organ Donor Register

Q11b	Top 3 reasons not on the ODR even though willing to donate own organs
Base	All respondents who are willing to donate their organs but have not signed up to the ODR
Routing Definition	All respondents who code 1, 2, 3 or 4 at Q2 AND code 87 at Q9b
Question type	Qmulti
Programming instruction	Randomise order of codes. Show if respondent selects more than 3 codes at Q11a. Filter codes - show those selected at Q11a. Force selection of exactly 3 codes
Question text	And which are the main 3 reasons you have not put your name on the NHS Organ Donor Register?
Respondent instruction	Please select all that apply
CODE	
1	I don't think my religion / faith would allow me to be an organ donor
2	I don't think my culture approves of organ donation
3	My family doesn't approve of organ donation

4	I don't want to think about my death
5	I don't know how to put my name on the register
6	I don't have enough information about the register to make a decision
7	I don't think I would qualify to be an organ donor
8	I don't trust doctors to do their best to save my life if I am on the register
9	I don't want my personal data to be stored on a register
10	I have a donor card and I didn't know I needed to register as well
11	I don't want to tempt fate by joining the register
12	I didn't know there was a register
13	I'm too old so my organs won't be of any use
14	I don't need to do anything about it until I'm older
15	It's too much hassle to fill a form in
16	I haven't got around to it yet
17	I might change my mind and I don't know if you can take your name off it
18	I don't see the point because my family already know my wishes
19	I would worry about being viewed as an organ donor rather than a patient
84	Other: [Text inserted at Q11a]
85	Don't know
87	I have put my name on the NHS Organ Donor Register

Q12	Importance of telling people your wishes about donating your organs
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	How important do you think it is to tell those closest to you of your wishes about donating your organs after death?
Respondent instruction	Please select one answer only
CODE	
1	Very important
2	Quite important
3	Neither important nor unimportant
4	Quite unimportant
5	Very unimportant
85	Don't know

Q14	Whether ever spoken to anyone about organ donation
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Have you ever talked with anyone about organ donation?
Respondent instruction	Please select one answer only
CODE	

1	Yes
2	No
85	Don't know

Q15	Topic of conversation about organ donation
Base	All respondents who have talked to someone about organ donation
Routing Definition	All respondents who code 1 at Q14
Question type	Qmulti
Programming instruction	
Question text	Which of the following have you done?
Respondent instruction	Please select all that apply
CODE	
1	Talked to those closest to you to tell them how you feel about being an organ donor
2	Talked to those closest to you to find out how they feel about being an organ donor
3	Talked to other family or friends about how you / they feel about organ donation
4	Talked to family or friends about whether the government should make organ donation automatic
5	Talked to someone in the medical profession (e.g. GP, nurse) about organ donation
6	Discussed organ donation generally
7	Talked to a religious leader / clergy about organ donation
84	Other, please write in:
87	Don't know / can't remember

Q15a	Friend/ family member spoken to
Base	All respondents who have talked to next of kin/someone about organ donation
Routing Definition	All respondents who code 1- 4 or 6 at Q15
Question type	Qmulti
Programming instruction	
Question text	Who was it that you spoke to about organ donation?
Respondent instruction	Please select all that apply
CODE	
1	Mother
2	Father
3	Spouse/ Partner
4	Son/ Daughter
5	Sibling
6	Close friend
84	Other, please write in:
87	Don't know / can't remember

Q16	Why spoken to someone about organ donation
Base	All respondents who have spoken to someone about organ donation

Routing Definition	All respondents who code 1 at Q14
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	What prompted you to speak to someone about organ donation?
Respondent instruction	Please select all that apply
CODE	
1	I wanted to tell them my wishes so it doesn't come as a shock
2	I wanted to get their opinion / advice
3	I wanted to find out their wishes about organ donation
4	I had been affected by a recent bereavement
5	I / someone I know needed an organ transplant
6	I had recently signed up to the NHS Organ Donor Register
7	They asked me my opinions about organ donation
8	They had recently signed up to the NHS Organ Donor Register
9	I saw a TV programme / heard a radio programme about it
10	I read an article about it
11	I saw an advert about it
12	They wanted me to know their wishes about it
13	Someone I know had recently joined the NHS Organ Donor Register
14	I wanted to ensure my donation wishes are carried out
84	Other, please write in:
85	Don't know

Q17	Why not spoken to someone about organ donation
Base	All respondents who have not spoken to someone about organ donation
Routing Definition	All respondents who code 2 at Q14
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	Why have you not spoken to anyone about organ donation?
Respondent instruction	Please select all that apply
CODE	
1	I didn't think that I needed to
2	I haven't got around to it yet
3	I wouldn't feel comfortable speaking to anyone about it
4	I worry that it might upset people
5	Donating organs is a personal choice so I don't need to talk to people about it
6	I feel like it would be tempting fate
7	I don't want to talk about death
8	I don't think other people would feel comfortable speaking about it
9	I think they would know how I felt about it without me telling them
10	I would worry that they might object to my opinion
11	It might divide opinion / cause an argument among my family / friends
12	It's never come up in conversation
13	I've never really thought about organ donation before

84	Other, please write in:
85	Don't know

Attitudes towards consent and reactions to consent scenarios

Q19	Awareness that consent is needed for organ donation
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle for A, Qsingle for B
Programming instruction	Randomise order of codes within each statement
Question text	Which of the following do you think is true if a person dies in circumstances where their organs could be donated?
Respondent instruction	Please select one answer for each statement
CODE	
A	If a person is on the NHS Organ Donor Register...
1	The person's organs are donated without close family and/ or friends being consulted
2	Close family and/or friends are told that the person's organs will be donated, but are not asked for permission
3	Close family and/or friends are asked to confirm the person's wishes and they can refuse if they want to
B	If a person is <u>not</u> on the NHS Organ Donor Register...
1	Their organs cannot be donated under any circumstances
2	Their close family and/or friends may be asked and they can decide to donate the person's organs if they wish

Q20	Reaction to consent if on ODR
Base	All respondents
Routing Definition	All respondents
Question type	Qmulti
Programming instruction	Randomise order of statements
Question text	If a person <u>is on the NHS Organ Donor Register</u> and dies in circumstances where their organs could be donated, their closest family and/or friends will be asked to confirm the person's wishes about wanting to be an organ donor. In this case, their close family and/ or friends can make the final decision about whether or not the person's organs are donated. Close friends will only be asked their consent in the absence of close family Thinking about this, to what extent do you agree or disagree with the following statements?
Respondent instruction	Please select one answer for each statement
CODE	
A	Organ donation should be an individual's choice, it's not for other people to decide
B	It annoys me to think that my wishes/ someone else's wishes might not be respected
C	It's good to check in case the person told someone that they had changed their

	mind
D	It is respectful to ask the person's family/ close friends
E	It places too much burden on the family/ close friends - they do not need to be asked
F	The family should be informed of their wishes, but not asked for consent
G	It makes the NHS Organ Donor Register seem less useful
1	Strongly agree
2	Slightly agree
3	Neither agree nor disagree
4	Slightly disagree
5	Strongly disagree
85	Don't know

Q21	Reaction to consent if not on ODR
Base	All respondents
Routing Definition	All respondents
Question type	Qgrid
Programming instruction	Randomise order of codes
Question text	<p>If a person is <u>not</u> on the NHS Organ Donor Register and they die in circumstances where their organs could be donated, their closest family and/or friends will be asked about organ donation. In this case, those closest to them can make a decision about whether or not the person's organs are donated.</p> <p>How do you feel about this?</p>
Respondent instruction	Please select all that apply
CODE	
1	Organ donation should be an individual's choice, it's not for other people to decide
2	It's good to check whether the family knew what the person's wishes were
3	It is respectful to ask the person's family
4	It places too much burden on the family to ask in that situation
5	If someone is not on the register, that should be enough to show that they don't want to be an organ donor
6	Organs should not be donated without family consent
7	Organ donation is important and relatives or friends should be given the chance to donate the organs of those closest to them
8	Organ donation is important and should happen automatically when a person dies in circumstances where their organs could be donated
1	Strongly agree
2	Slightly agree
3	Neither agree nor disagree
4	Slightly disagree
5	Strongly disagree
85	Don't know

Q22	Importance of telling people your wishes about organ donation after knowing about consent
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	How important do you now think it is to tell your closest friends and family your wishes about donating your organs after death?
Respondent instruction	Please select one answer only
CODE	
1	Very important
2	Quite important
3	Neither important nor unimportant
4	Quite unimportant
5	Very unimportant
85	Don't know

Q23	Scenario 1: Willingness to consent if family member is on ODR and discussed wishes Scenario 2: Willingness to consent if family member is on ODR but not discussed wishes
Base	All respondents
Routing Definition	All respondents
Question type	Qgrid
Programming instruction	
Question text	Below are some situations where people have had to make difficult decisions. Please read through each of them and say whether you think you would agree or not if you were in that situation yourself.
Respondent instruction	Please select one answer for each situation
CODE	
A	If my family member close friend <u>had signed up to the NHS Organ Donor Register...</u> ...and we <u>had</u> discussed their wish to be a donor
B	...but we <u>hadn't</u> personally discussed their wishes
1	I would agree to their organs being donated
2	I would not agree to their organs being donated
85	I'm not sure what I would do

Q24a	Spontaneous reasons wouldn't consent in Scenario 1
Base	All respondents who would not agree or not sure if on ODR and discussed
Routing Definition	All respondents who code 2 or 85 for statement A at Q23
Question type	Qopen
Programming instruction	

Question text	<p>[TEXT SUB if code 2 for statement A at Q23: You said that you wouldn't agree to your family member/ close friend's organs being donated if they <u>had signed up</u> to the NHS Organ Donor Register <u>and you'd personally discussed</u> their wishes.]</p> <p>[TEXT SUB if code 85 for statement A at Q23: You said that you're not sure what you would do if your family member/ close friend <u>had signed up</u> to the NHS Organ Donor Register <u>and you'd personally discussed</u> their wishes.]</p> <p>Why is that?</p>
Respondent instruction CODE	<p>Please type your answer into the box below</p> <p>OPEN</p>

Q24b	Prompted reasons wouldn't consent in Scenario 1
Base	All respondents who would not agree or not sure if on ODR and discussed
Routing Definition	All respondents who code 2 or 85 for statement A at Q23
Question type	Qmulti
Programming instruction	Code list to be split across two pages. Randomise order of codes on each page and across pages
Question text	And looking at the reasons below, which of these apply to you when thinking about refusing to consent to your family member/ close friend's organs being donated <u>if they were on</u> the NHS Organ Donor Register <u>and you had discussed</u> their wishes?
Respondent instruction CODE	Please select all that apply
1	I wouldn't like to think about them being cut up
2	I don't want them to suffer after death
3	I worry what they would look like after donating their organs
4	They might have changed their mind after signing up to the register
5	I think organ donation is against my/ their culture
6	I think organ donation is against my/ their religion / faith
7	I worry what people in my community would say
8	I worry what people in my family would say
9	I worry that organ donation will delay the burial or cremation time
10	I don't have the right to make that decision for someone else
11	I wouldn't want their organs to be donated to someone who doesn't deserve it
12	I don't like the idea of their organs being in someone else's body
13	I would feel as if I was giving up hope on them getting better
14	I might feel differently depending on who the person is
15	I couldn't make that decision by myself
16	I would feel guilty about agreeing
17	I worry that their organs wouldn't be used, even if I did agree
18	I worry that doctors wouldn't do their best to save the person's life
19	It's too much of a burden to ask in that situation
20	I don't like the idea of someone benefitting from my loss
84	Other, please write in:

85	Don't know
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Q25a	Spontaneous reasons wouldn't consent in Scenario 2
Base	All respondents who would not agree or not sure if on ODR but not discussed
Routing Definition	All respondents who code 2 or 85 for statement B at Q23
Question type	Qopen
Programming instruction	
Question text	<p>[TEXT SUB if code 2 for statement B at Q23: You said that you wouldn't agree to your family member/ close friend's organs being donated if they <u>had signed up</u> to the NHS Organ Donor Register <u>but you hadn't personally discussed</u> their wishes.]</p> <p>[TEXT SUB if code 85 for statement B at Q23: You said that you're not sure what you would do if your family member/ close friend <u>had signed up</u> to the NHS Organ Donor Register <u>but you hadn't personally discussed</u> their wishes.]</p> <p>Why is that?</p>
Respondent instruction CODE	<p>Please type your answer into the box below</p> <p>OPEN</p>

Q25b	Prompted reasons wouldn't consent in Scenario 2
Base	All respondents who would not agree or not sure if on ODR but not discussed
Routing Definition	All respondents who code 2 or 85 for statement B at Q23
Question type	Qmulti
Programming instruction	Code list to be split across two pages. Randomise order of codes on each page and across pages
Question text	And looking at the reasons below, which of these apply to you when thinking about refusing to consent to your family member/ close friend's organs being donated if they were on the NHS Organ Donor Register <u>but you hadn't discussed</u> their wishes?
Respondent instruction CODE	<p>Please select all that apply</p> <p>1 I wouldn't like to think about them being cut up</p> <p>2 I don't want them to suffer after death</p> <p>3 I worry what they would look like after donating their organs</p> <p>4 They might have changed their mind after signing up to the register</p> <p>5 I think organ donation is against my/ their culture</p> <p>6 I think organ donation is against my/ their religion / faith</p> <p>7 I worry what people in my community would say</p> <p>8 I worry what people in my family would say</p> <p>9 We've never spoken about it so I don't know what their wishes would be</p> <p>10 I wouldn't believe that they were on the register</p> <p>11 I would want proof that they were on the register</p> <p>12 I would want to know when they joined the register</p> <p>13 I worry that organ donation will delay the burial or cremation time</p> <p>14 I don't have the right to make that decision for someone else</p>

15	I wouldn't want their organs to be donated to someone who doesn't deserve it
16	I don't like the idea of their organs being in someone else's body
17	I would feel as if I was giving up hope on them getting better
18	If they had a strong opinion about organ donation they would have spoken to me about it
19	I might feel differently depending on who the person is
20	I couldn't make that decision by myself
21	I would worry that they didn't really want to donate their organs
22	I would feel guilty about agreeing
23	I worry that their organs wouldn't be used, even if I did agree
24	Their spirit might know if I'd agreed to it against their personal wishes
25	I worry that doctors wouldn't do their best to save the person's life
26	It's too much of a burden to ask in that situation
27	I don't like the idea of someone benefitting from my loss
84	Other, please write in:
85	Don't know

Q26	Scenario 3: Willingness to consent if family member is not on ODR but discussed wishes Scenario 4: Willingness to consent if family member is not on ODR and not discussed wishes
Base	All respondents
Routing Definition	All respondents
Question type	Qgrid
Programming instruction	
Question text	Below are some further situations where people have had to make difficult decisions. Please read through each of them and say whether you think you would agree or not if you were in that situation yourself.
Respondent instruction	Please select one answer for each situation
CODE	
A	...but we <u>had</u> personally discussed that they wanted to donate their organs
B	..and we <u>hadn't</u> personally discussed their wishes
1	I would agree to their organs being donated
2	I would not agree to their organs being donated
85	I'm not sure what I would do

Q27a	What might affect decision for people unsure
Base	All respondents who are unsure for Scenario 3 or 4
Routing Definition	All respondents who code 85 for statement A and / or B at Q26
Question type	Qmulti
Programming instruction	Randomise order of codes

Question text	<p>You said that you're not sure what you would do if your family member/ close friend hadn't signed up to the NHS Organ Donor Register.</p> <p>Which of the following things would help you to come to a decision about what to do?</p>
Respondent instruction	Please select all that apply
CODE	
1	Thinking about the type of person they were
2	Thinking about their religion / religious views
3	Thinking about the circumstances in which they'd died
4	Finding out more about what would happen to their body
5	Finding out more about where the organs would go
6	Knowing which of their organs would be donated
7	Speaking to the rest of my/ their family and friends
8	Other please specify
85	Don't know
87	None of these

Q27c	Spontaneous reasons wouldn't consent in Scenario 3
Base	All respondents who would not agree or not sure if not on ODR but discussed
Routing Definition	All respondents who code 2 or 85 for statement A at Q26
Question type	Qopen
Programming instruction	
Question text	<p>[TEXT SUB if code 2 for statement A at Q26: You said that you wouldn't agree to your family member/ close friend's organs being donated if they <u>hadn't signed up</u> to the NHS Organ Donor Register <u>but you had personally discussed</u> that they wanted to donate their organs.]</p> <p>[TEXT SUB if code 85 for statement A at Q26: You said that you're not sure what you would do if your family member/ close friend <u>hadn't signed up</u> to the NHS Organ Donor Register <u>but you had personally discussed</u> that they wanted to donate their organs.]</p> <p>Why is that?</p>
Respondent instruction	Please type your answer into the box below
CODE	OPEN

Q27b	Reasons would consent in Scenario 3
Base	All respondents who would agree or not sure if not on ODR but discussed
Routing Definition	All respondents who code 1 or 85 for statement A at Q26
Question type	Qmulti
Programming instruction	Randomise order of codes

Question text	<p>[TEXT SUB if code 1 for statement A at Q26: You said that you would agree to your family member/ close friend's organs being donated if they <u>hadn't signed up</u> to the NHS Organ Donor Register <u>but you had personally discussed</u> that they wanted to donate their organs.]</p> <p>[TEXT SUB if code 85 for statement A at Q26: You said that you're not sure what you would do if your family member/ close friend's <u>hadn't signed up</u> to the NHS Organ Donor Register <u>but you had personally discussed</u> that they wanted to donate their organs.]</p> <p>Why might you agree?</p>
Respondent instruction	Please select all that apply
CODE	
1	I believe it's right for people to donate their organs
2	I think it's the right thing to do in that situation
3	It's making something positive out of a sad situation
4	It could help to save someone's life
5	I have known someone who needed a transplant
6	It would bring me some comfort
7	I would accept an organ to make them better, so I should be prepared to donate theirs
8	I know my family believe in organ donation
9	I would feel proud to donate their organs
10	If they were strongly against organ donation they would have told me
11	Their organs would only go to waste
12	I would feel selfish if I didn't agree
13	I worry that I would regret it afterwards if I didn't agree
14	I would want to respect their wishes
15	It wouldn't matter if they hadn't signed the NHS Organ Donor Register as long as they'd told me what they wanted
84	Other, please write in:
85	Don't know

Q27d	Reasons wouldn't consent in Scenario 3
Base	All respondents who would not agree or not sure if not on ODR but discussed
Routing Definition	All respondents who code 2 or 85 for statement A at Q26
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	<p>[TEXT SUB if code 2 for statement A at Q26: You said that you wouldn't agree to your family member/ close friend's organs being donated if they <u>hadn't signed up</u> to the NHS Organ Donor Register <u>but you had personally discussed</u> that they wanted to donate their organs.]</p> <p>[TEXT SUB if code 85 for statement A at Q26: You said that you're not sure what you would do if your family member/ close friend <u>hadn't signed up</u> to the NHS Organ Donor Register <u>but you had personally discussed</u> that they wanted to donate their organs.]</p> <p>Why might you not agree?</p>

Respondent instruction	Please select all that apply
CODE	
1	I wouldn't like to think about them being cut up
2	I don't want them to suffer after death
3	I worry what they would look like after donating their organs
4	They might have changed their mind after having spoken to me
5	I think organ donation is against my/ their culture
6	I think organ donation is against my/ their religion / faith
7	I worry what people in my community would say
8	I worry what people in my family would say
9	I worry that organ donation will delay the burial or cremation time
10	I don't have the right to make that decision for someone else
11	I wouldn't want their organs to be donated to someone who doesn't deserve it
12	I don't like the idea of their organs being in someone else's body
13	I would feel as if I was giving up hope on them getting better
14	If they had a strong opinion about organ donation they would have signed up to the register
15	I might feel differently depending on who the person is
16	I couldn't make that decision by myself
17	I would worry that they didn't want to donate their organs
18	I would feel guilty about agreeing
19	I worry that their organs wouldn't be used, even if I did agree
20	I worry that doctors wouldn't do their best to save the person's life
21	It's too much of a burden to ask in that situation
22	I don't like the idea of someone benefitting from my loss
84	Other, please write in:
85	Don't know

Q28b	Spontaneous reasons wouldn't consent in Scenario 4
Base	All respondents who would not agree or not sure if not on ODR and not discussed
Routing Definition	All respondents who code 2 or 85 for statement B at Q26
Question type	Qopen
Programming instruction	
Question text	<p>[TEXT SUB if code 2 for statement B at Q26: You said that you wouldn't agree to your family member/ close friend's organs being donated if they <u>hadn't signed up</u> to the NHS Organ Donor Register <u>and you hadn't personally discussed</u> their wishes.]</p> <p>[TEXT SUB if code 85 for statement A at Q26: You said that you're not sure what you would do if your family member/ close friend <u>hadn't signed up</u> to the NHS Organ Donor Register <u>and you hadn't personally discussed</u> their wishes.]</p> <p>Why is that?</p>
Respondent instruction	Please type your answer into the box below
CODE	

	OPEN
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Q28a	Reasons would consent in Scenario 4
Base	All respondents who would agree or not sure if not on ODR and not discussed
Routing Definition	All respondents who code 1 or 85 for statement B at Q26
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	<p>[TEXT SUB if code 1 for statement B at Q26: You said that you would agree to your family member/ close friend's organs being donated if they <u>hadn't signed up</u> to the NHS Organ Donor Register <u>and you hadn't personally discussed</u> their wishes.]</p> <p>[TEXT SUB if code 85 for statement B at Q26: You said that you're not sure what you would do if your family member/ close friend <u>hadn't signed up</u> to the NHS Organ Donor Register <u>and you hadn't personally discussed</u> their wishes.]</p> <p>Why might you agree?</p>
Respondent instruction	Please select all that apply
CODE	
1	I believe it's right for people to donate their organs
2	I think it's the right thing to do in that situation
3	It's making something positive out of a sad situation
4	It could help to save someone's life
5	I have known someone who needed a transplant
6	It would bring me some comfort
7	I would accept an organ to make them better, so I should be prepared to donate theirs
8	I know my family believe in organ donation
9	I would feel proud to donate their organs
10	If they were strongly against organ donation they would have told me
11	Their organs would only go to waste
12	I would feel selfish if I didn't agree
13	I worry that I would regret it afterwards if I didn't agree
14	I wouldn't want to go against their wishes in case they wanted to be a donor
84	Other, please write in:
85	Don't know

Q28c	Reasons wouldn't consent in Scenario 4
Base	All respondents who would not agree or not sure if not on ODR and not discussed
Routing Definition	All respondents who code 2 or 85 for statement B at Q26
Question type	Qmulti
Programming instruction	Randomise order of codes

Question text	<p>[TEXT SUB if code 2 for statement B at Q26: You said that you wouldn't agree to your family member/ close friend's organs being donated if they <u>hadn't signed up</u> to the NHS Organ Donor Register <u>and you hadn't personally discussed</u> their wishes.]</p> <p>[TEXT SUB if code 85 for statement A at Q26: You said that you're not sure what you would do if your family member/ close friend <u>hadn't signed up</u> to the NHS Organ Donor Register <u>and you hadn't personally discussed</u> their wishes.]</p> <p>Why might you not agree?</p>
<p>Respondent instruction</p> <p>CODE</p> <p>1</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p> <p>6</p> <p>7</p> <p>8</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p> <p>16</p> <p>17</p> <p>18</p> <p>19</p> <p>20</p> <p>21</p> <p>22</p> <p>23</p> <p>24</p> <p>84</p> <p>85</p>	<p>Please select all that apply</p> <p>I wouldn't like to think about them being cut up</p> <p>I don't want them to suffer after death</p> <p>I worry what they would look like after donating their organs</p> <p>I think organ donation is against my/ their culture</p> <p>I think organ donation is against my/ their religion / faith</p> <p>I worry what people in my family would say</p> <p>We've never spoken about it so I don't know what their wishes would be</p> <p>I worry that organ donation will delay the burial or cremation time</p> <p>I don't have the right to make that decision for someone else</p> <p>I wouldn't want their organs to be donated to someone who doesn't deserve it</p> <p>I don't like the idea of their organs being in someone else's body</p> <p>I would feel as if I was giving up hope on them getting better</p> <p>If they had a strong opinion about organ donation they would have spoken to me about it</p> <p>If they had a strong opinion about organ donation they would have signed up to the register</p> <p>I might feel differently depending on who the person is</p> <p>I couldn't make that decision by myself</p> <p>I wouldn't want to go against their wishes in case they didn't want to be an organ donor</p> <p>I would feel guilty about agreeing</p> <p>I worry that their organs wouldn't be used, even if I did agree</p> <p>Their spirit might know if I'd agreed to it against their personal wishes</p> <p>I worry that doctors wouldn't do their best to save the person's life</p> <p>It's too much of a burden to ask in that situation</p> <p>I don't like the idea of someone benefitting from my loss</p> <p>I worry what people in my community would say</p> <p>Other, please write in:</p> <p>Don't know</p>

Agreement with organ donation statements

INTRO

On the next few screens, you will see a number of statements that other people have made about organ donation. Please read through each one carefully and say how strongly you agree or disagree with it. There is no right or wrong answer

- we just want your honest opinion

Q29	Agreement with statements about organ donation from 2009 survey
Base	All respondents
Routing Definition	All respondents
Question type	Qgrid
Programming instruction	Please split onto a number of screens, e.g.. 7 per screen. Randomise order or statements within screens and across screens
Question text	Please read through each statement carefully and say how strongly you agree or disagree with it
Respondent instruction	Please select one answer for each statement
CODE	
A	I don't want my organs to be used for medical research
B	I am too old so my organs won't be able to be used
C	I have a medical condition which means my organs won't be able to be used
D	I would like more information about what it means to be an organ donor
E	I don't need to make this decision until I am older
F	I am happy to donate my organs when I die as I will no longer have any use for them
G	I don't want to donate my organs to someone who I feel doesn't deserve it
H	I worry that my family will object to me becoming an organ donor
I	I don't like the idea of talking to my family about organ donation
J	I worry that I might not really be dead when my organs are taken
K	I worry that doctors may not do their best to save my life so they can take my organs
L	I don't like the idea of being cut up after death
M	I want my body to be whole when it is buried or cremated
N	I worry that organ donation will delay my burial or cremation
O	I don't want my body to be disfigured when my family sees it for the last time
P	Organ donation is against my religion
Q	Organ donation is against my culture
R	I don't know what my religion says about organ donation
S	I don't know what my culture says about organ donation
T	I want my family to know how I feel about becoming an organ donor before I die
U	I want my affairs, including my decision about becoming an organ donor, in order before I die
V	I would want to consult with my family before putting my name on the NHS Organ Donor Register
W	I need to make a decision about becoming an organ donor so those closest to me don't have to when I die
X	I trust doctors to always do what is best for their patients
Y	People on the NHS Organ Donor Register are extremely unselfish people
Z	If you would accept an organ transplant you must be prepared to be an organ donor
AA	Being on the NHS Organ Donor Register should be automatic, unless you say you object
BB	I trust my family to do the right thing if the worst happens and they need to decide whether to donate my organs

CC	Organ donation is an issue that's being talked about a lot these days
DD	I would be prepared to donate if I knew my organs would go to someone in my community
EE	I would want to have a transplant if I needed one, but I do not want to be an organ donor myself
FF	It is too upsetting to think about death
GG	People I know would not approve of me being an organ donor
HH	I think joining the NHS Organ Donor Register would be tempting fate
1	Agree strongly
2	Agree slightly
3	Neither agree nor disagree
4	Disagree slightly
5	Disagree strongly

Knowledge about organ donation

Q30	True / false exercise
Base	All respondents
Routing Definition	All respondents
Question type	Qgrid
Programming instruction	
Question text	Below are a number of things that people have said about organ donation. For each one, we would like you to say whether you think it is true or false.
Respondent instruction	Please select one answer only
CODE	
A	To be an organ donor, you have to donate all of your organs
B	Fewer than 5000 people each year die in circumstances where they can donate their organs
C	Fewer than 1500 people each year donate their organs
D	People who have donated their organs can't be viewed after death or have an open casket
E	If you have an organ donor card then you are definitely on the NHS Organ Donor Register
F	There is an upper age limit of 60 for donating organs
G	People from Black or Minority Ethnic Groups are up to three times more likely to need an organ transplant
H	90% of people agree to their family member's/ close friend's organs being donated when they're asked to give consent
I	Most people in the UK are registered on the NHS Organ Donor Register
J	In the UK, 1000 people each year - that's three a day - will die because there are not enough organs available
K	If you're on the NHS Organ Donor Register and your organs are not suitable for use in a transplant, they will automatically be used for medical research instead
1	True
2	False

Programming instruction	<p>Please insert a screen here showing the respondent's score for the number of answers they got right. Correct answers are:</p> <p>Code A = False Code B = True Code C = True Code D = False Code E = False Code F = False Code G = True Code H = False Code I = False Code J = True Code K = False</p>
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Q31	True / false exercise - show answers
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	Time lag of 20 seconds before the next button appears
Question text	Below are the correct answers to each of the statements we just showed you. Please read through these and then click Next to go onto the next question
Respondent instruction	Please select one answer only
CODE	
1	FALSE - You can specify which organs you wish to donate and can choose whether you would prefer to donate all of them or a select number
2	TRUE
3	TRUE
4	FALSE - Organs are removed with the greatest care and respect and afterwards the surgical incision is closed and dressed in the normal way. Arrangements for viewing the body after donation are the same as after any death
5	FALSE - Before the NHS Organ Donor Register was introduced, organ donor cards were widely available for people to obtain as a sign that they wanted to be an organ donor, but was not part of a formal database. Donor cards are now only issued when a person has joined the register. Not everyone on the register will have a new card and not everyone carrying an old card will be on the register
6	FALSE - It is the person's physical condition, not age, which is the deciding factor about organ donation. Organs from people in their 70s and 80s have been transplanted successfully
7	TRUE
8	FALSE - 55% of people who are asked actually agree to their family member/ close friend's organs being donated (although this increases to 90% if their close friend/ relative is on the NHS Organ Donor Register and they've discussed their wishes)
9	FALSE - Only around 30% are on the NHS Organ Donor Register
10	TRUE
11	FALSE - Organs that cannot be used for transplant will only be used for medical or scientific research purposes if specific permission has been obtained from their close family and/ or friends.

Q32	Whether any of the facts change their views about anything
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Has seeing any of these things made you feel any differently about organ donation?
Respondent instruction	Please select one answer only
CODE	
1	Yes
2	No
85	Don't know

Q33	How the facts change their views
Base	All respondents whose views changed after seeing facts about donation
Routing Definition	All respondents who code 1 at Q32
Question type	Qmulti with validation so that contradictory answers cannot be coded
Programming instruction	
Question text	How has it made you feel differently?
Respondent instruction	Please select all that apply
CODE	
1	I definitely want to donate my own organs now
2	I would definitely agree to donating the organs of those closest to me now
3	I'd be more likely to consider donating my own organs now
4	I'd be more likely to consider agreeing to donating the organs of those closest to me now
5	I'm less likely to donate my own organs now
6	I'm less likely to agree to donating the organs of those closest to me now
7	I'm more likely to speak to my family about my / their wishes about organ donation now
8	I'm less likely to speak to my family about my / their wishes about organ donation now
84	Other, please write in:
85	Don't know

Q34a	Which facts change their views
Base	All respondents whose views changed after seeing facts about donation
Routing Definition	All respondents who code 1 at Q32
Question type	Qmulti
Programming instruction	
Question text	And which things in particular made you feel differently?
Respondent instruction	Please select all that apply
CODE	

1	You can specify which organs you wish to donate and can choose whether you would prefer to donate all of them or a select number
2	Even though over half a million people die every year in the UK, fewer than 5000 die in circumstances where they would be able to donate their organs
3	Due to factors such as family members/ close friends not agreeing to organ donation, fewer than 1500 people each year actually donate their organs
4	Arrangements for viewing the body after donation are the same as after any death
5	Not everyone on the register will have a new card and not everyone carrying an old card will be on the register
6	It is the person's physical condition, not age, which is the deciding factor about organ donation. Organs from people in their 70s and 80s have been transplanted successfully
7	People from Black or Minority Ethnic Groups are up to three times more likely to need an organ transplant
8	55% of families who are asked actually agree to the organs of those closest to them being donated (although this increases to 90% if their family member/ close friend is on the NHS Organ Donor Register and they've discussed their wishes)
9	Only around 30% are on the NHS Organ Donor Register
10	There are currently more than 10,000 people in the UK who need a transplant, and around 1000 people each year die waiting for an organ
11	Organs that cannot be used for transplant will only be used for medical or scientific research purposes if specific permission has been obtained from those closest to them.
85	Don't know

Q34b	Anything else that has changed their views
Base	All respondents
Routing Definition	All respondents
Question type	Qopen
Programming instruction	
Question text	Has anything else that you've seen in this survey made you feel any differently about organ donation? If so, what?
Respondent instruction	Please type your answer into the box below
CODE	OPEN

Q35	Publicity about organ donation
Base	All respondents
Routing Definition	All respondents
Question type	Qmulti
Programming instruction	Randomise order of codes, but show codes 12, 13 and 14 together
Question text	Have you seen or heard any advertising or any other information or publicity about organ donation in any of the following places recently?
Respondent instruction	Please select all that apply
CODE	
1	TV advertising

2	Radio advertising
3	Newspaper or magazine advertising
4	Poster advertising
5	Article in national newspaper
6	Article in local newspaper
7	Article in magazine
8	Leaflet
9	Item on news on television or radio
10	TV programme
11	Radio programme
12	Something on Facebook
13	Something on another social networking website
14	Something on another site on the internet
15	Email
16	Heard people talking about it
17	At a hospital, GP surgery or clinic
18	At a National Blood Service donation session
84	Somewhere else (please write in)
85	Don't know
87	None of these

Q36	Organ donor card
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	Include images of organ donor cards
Question text	Do you personally carry an organ donor card?
Respondent instruction	Please select one answer only
CODE	
1	Yes definitely
2	I think I do but I'm not sure
3	No but I used to have one
4	No I've never had one
85	Don't know

Q36a	Donor card to show had registered on ODR
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Before the organ donor register was created, organ donor cards used to be available to pick up in public places such as libraries, doctors' surgeries etc. People could carry these cards to show that they were willing to donate their organs in the event of their death. What do you think about the idea of re-

	introducing these cards?
Respondent instruction	Please select one answer only
CODE	
1	It would encourage donation if people could just carry a card rather than joining the register
2	It would encourage more donation but they should also have to join the register
3	I don't think it will make much difference to organ donation rates
4	It could reduce donation rates if people lose the cards without joining the register
85	Don't know

Q36b	Dual signatures
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Do you think it's a good idea to have donor cards which need to have two signatures - one by the donor and one by a close family member and/ or friend to encourage a conversation about organ donation?
Respondent instruction	Please select one answer only
CODE	
1	Yes
2	No
85	Don't know

Q37	Whether discussed anything else about after they pass away
Base	All respondents
Routing Definition	All respondents
Question type	Qmulti
Programming instruction	Randomise order of codes
Question text	Thinking about your own personal wishes, have you done any of the following?
Respondent instruction	Please select all that apply
CODE	
1	Discussed whether I want to be buried or cremated
2	Discussed / made my funeral arrangements
3	Written a will
4	Made plans for who would look after my children / dependents in the event of my death
5	Purchased life insurance / assurance
6	Purchased a grave plot
7	Talked about who I would like to have certain possessions in the event of my death
87	None of these

Q38	Anything else they would like to add
Base	All respondents
Routing Definition	All respondents
Question type	Qopen
Programming instruction	
Question text	Is there anything else that you would like to tell us on the topic of organ donation?
Respondent instruction CODE	Please type your answer into the box below OPEN

Demographics

INTRO	Thank you for your answers so far. We would just like to ask some more questions about you.
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QD1	Marital status
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Which of these best describes your current marital status?
Respondent instruction CODE	Please select one answer only
1	Single
2	Not married but living with partner
3	Married / civil partnership
4	Divorced / separated
5	Widowed
86	Would rather not say

QD2	Number of children
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	How many children do you have?
Respondent instruction CODE	Please select one answer only
1	None
2	1
3	2
4	3

5	4
6	5
7	More than 5
86	Would rather not say

QD3	Ages of children
Base	All respondents with children
Routing Definition	All respondents who do NOT code 1 or 86 at QD2
Question type	Qmulti
Programming instruction	
Question text	What are the ages of your children?
Respondent instruction	Please select all that apply
CODE	
1	0 to 4
2	5 to 9
3	10 to 14
4	15 to 17
5	18 or over
86	Would rather not say

QD4	Children living at home
Base	All respondents with children
Routing Definition	All respondents who do NOT code 1 or 86 at QD2
Question type	Qsingle
Programming instruction	
Question text	Do you have any children under 18 who live with you some or all of the time?
Respondent instruction	Please select one answer only
CODE	
1	Yes
2	No
86	Would rather not say

QD5	Working status
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	What is your current working status?
Respondent instruction	Please select one answer only
CODE	
1	Full-time employed
2	Part-time employed
3	Working full or part-time in the voluntary sector

4	Self-employed
5	Unemployed and seeking work
6	Unemployed and not seeking work
7	Working in household
8	On a government sponsored training scheme
9	Retired
10	Semi-retired
11	In full time education
85	Other
86	Would rather not say

QD6	SEG
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	<p>Which of the following professions best describes the main/highest income earner in your household?</p> <p>If the chief income earner is retired and has an occupational pension, please answer for their most recent occupation.</p> <p>If the main/highest income earner is not currently in paid employment but has been out of work for less than 6 months, please answer for their most recent profession.</p>
Respondent instruction	Please select one answer only
CODE	
1	Higher Managerial/ Professional (e.g. established doctor, solicitor, board director in large organisation)
2	Intermediate Managerial/ Professional (e.g. newly qualified doctor, board director of small organisation, middle management in large organisation, principal officer in civil service)
3	Supervisory or clerical/ junior managerial/ professional (e.g. office worker, salesperson, student doctor, foreman)
4	Student
5	Skilled manual worker (e.g. skilled bricklayer, carpenter, plumber, driver)
6	Semi or unskilled worker (e.g. apprentices of trade, caretaker, park keeper, shop keeper)
7	Casual worker - not in permanent employment
8	Housewife/ Homemaker
9	Retired or living on state pension
10	Unemployed or not working due to long-term sickness
11	Full time carer of other household member
86	Would rather not say
	<i>Please recode occupation for UK in the script as follows:</i>
	Code 1 = GRADE A

	Code 2 = GRADE B Code 3 or 4 = GRADE C1 Code 5 = GRADE C2 Code 6 = GRADE D Code 7,8,9,10,11 = GRADE E
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QD7	Education
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	Do you have any educational qualifications that are recognised in the UK?
Respondent instruction	Please select one answer only
CODE	
1	Yes
2	No
86	Would rather not say

QD8	Education level
Base	All respondents who have an educational qualification
Routing Definition	All respondents who code 1 at QD7
Question type	Qsingle
Programming instruction	
Question text	What is the highest qualification you have completed?
Respondent instruction	Please select one answer only
CODE	
1	NVQ or equivalent
2	GCE / GCSE / O-level or equivalent
3	A-level or equivalent
4	Pre-degree foundation course/ diploma / HND or equivalent
5	Undergraduate degree
6	Masters
7	Doctorate/ PhD
8	Professional qualification
85	Other
86	Would rather not say

QD9	Disability
Base	All respondents
Routing Definition	All respondents
Question type	Qmulti
Programming instruction	

Question text	Do you have any long-term physical or mental impairment which limits your daily activities or the work you can do, including problems due to old age?
Respondent instruction	Please select all that apply
CODE	
1	Mobility impairment
2	Age related mobility difficulty
3	Visual impairment
4	Hearing impairment
5	Learning difficulty
6	Mental health condition
7	Serious long term illness
8	Asthma
9	Arthritis
85	Other, please write in:
86	Would rather not say
87	None of these

QD10	Ethnicity
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	How would you describe your ethnic origin?
Respondent instruction	Please select one answer only
CODE	
1	White British
2	White Irish
3	Any other White background
4	Mixed - White and Black Caribbean
5	Mixed - White and Black African
6	Mixed - White and Asian
7	Mixed - any other mixed background
8	Asian or Asian British - Indian
9	Asian or Asian British - Pakistani
10	Asian or Asian British - Bangladeshi
11	Asian or Asian British - any other Asian background
12	Black or Black British - Caribbean
13	Black or Black British - African
14	Black or Black British - any other Black background
15	Chinese
85	Other, please write in:
86	Would rather not say

QD11	Religion
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Base	All respondents
Routing Definition	All respondents
Question type	Qsingle
Programming instruction	
Question text	What is your religion?
Respondent instruction	Please select one answer only
CODE	
1	None
2	Christianity - Anglican or Church of England
3	Christianity - Roman Catholic
4	Other Christianity
5	Islam
6	Hinduism
7	Sikhism
8	Buddhism
9	Judaism
85	Other, please write in:
86	Would rather not say

QD12	Strength of religion
Base	All respondents who have a religion
Routing Definition	All respondents who do NOT code 1 or 86 at QD11
Question type	Qsingle
Programming instruction	
Question text	Which of the following statements most applies to you?
Respondent instruction	Please select one answer only
CODE	
1	I lead my life following the teachings and customs of my religion / faith
2	I try to lead my life following the teaching and customs of my religion / faith but I don't always manage to do so
3	I would like to follow the teachings and customs of my religion / faith more closely, but not all are applicable nowadays
4	I follow the spirit of the teachings and customs of my religion / faith, but I don't follow them exactly
5	I am religious, but do not follow the teachings and customs of my religion / faith
6	I am not very religious but I follow some of the traditions and customs of my religion / faith
85	Don't know
86	Would rather not say
87	None of these

QD13	Internet access
Base	All respondents
Routing Definition	All respondents
Question type	Qsingle

Programming instruction	
Question text	How frequently do you access the internet?
Respondent instruction	Please select one answer only
CODE	
1	Everyday or almost everyday
2	Around 4 or 5 days per week
3	Around 2 or 3 days a week
4	Around once a week
5	Around once a month
6	Less often than once a month
7	Never

QD14	Social networking sites
Base	All respondents who access the internet
Routing Definition	All respondents who do NOT code 7 at QD13
Question type	Qmulti
Programming instruction	
Question text	Are you registered on any of the following social networking websites?
Respondent instruction	Please select all that apply
CODE	
1	Facebook
2	Bebo
3	MySpace
4	Faceparty
5	Friendster
6	Twitter
7	Hi Five
8	Net Log
9	WAYN
84	Other, please write in
87	None of these

QD15	Frequency of social networking site usage
Base	All respondents who are registered on any social networking site
Routing Definition	All respondents who do NOT code 87 at QD14
Question type	Qsingle
Programming instruction	
Question text	How often do you typically use social networking sites such as [TEXT SUB: insert answers from QD14]?
Respondent instruction	Please select one answer only
CODE	
1	Everyday or almost everyday
2	Around 4 or 5 days per week
3	Around 2 or 3 days a week

4	Around once a week
5	Around once a month
6	Less often than once a month

QD16	Activity on Facebook
Base	All respondents who are registered on Facebook
Routing Definition	All respondents who code 1 at QD14
Question type	Qmulti
Programming instruction	
Question text	Which, if any, of the following have you done on Facebook?
Respondent instruction	Please select all that apply
CODE	
1	Liked the NHS Organ Donation Facebook page
2	Posted your organ donation wishes on your Timeline
87	None of these
85	Don't know

INTRO	Thank you for taking part in this survey. Your opinions are much appreciated.
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