

Organ donation

Public attitudes and stakeholder engagement
in Northern Ireland 2013



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Executive summary

In June 2013, a representative sample of the public (n=1,012) responded to a survey about their attitudes towards organ donation. At the same time, a process of stakeholder engagement began, which involved 16 discussion groups with key stakeholders as requested by the Health Minister (including organ donation charities, those on the transplant waiting list, transplant recipients, donor families, and Health and Social Care staff). Discussion groups took place between June and August 2013 and proformas were also completed. The central purpose of this public and stakeholder engagement process was to inform the direction of a public information campaign that will be developed by the Public Health Agency (PHA).

Organ donation and registration on the Organ Donor Register

Eighty four percent of respondents supported the idea of organ donation. However, support was lower for the idea that we should all register for organ donation (55%) or that it is unacceptable not to donate your organs (26%).

More than a third (36%) of respondents were not aware of the Organ Donor Register (ODR). Awareness was lowest among the youngest (16–29 years) and oldest (over 65 years) age groups.

Those who had no awareness of, or had not yet registered on, the ODR were asked about future intentions to sign the ODR. Findings show that there is strong potential to mobilise 29% of respondents who said they would be likely to sign the ODR in the future, and potential to persuade a further 30% who did not know whether they would register. Indeed, only 16% of respondents said they were unlikely to, or definitely not likely to, register on the ODR.

Reasons for respondents not signing the ODR included: not wanting to donate (35%), having not thought about it (31%), believing organ donation is against religious beliefs (9%), and being unclear about how to register (5%). Of those who said they did not want to donate (n=60), the majority said they did not want their body experimented on (84%).

Knowledge about organ donation was generally low among respondents, who answered on average three questions out of seven correctly. Approximately one in five respondents incorrectly thought 'it is possible for a brain dead person to recover from their injuries', 'the same doctors who look after you when you are seriously ill perform transplants' and 'only the organs of younger people are good for transplantation'.

Four factors were found to drive respondents' attitudes towards organ donation, of which 'spiritual (traditional) beliefs' (eg 'the body should be kept whole for burial') was the main one. This was followed by 'medical distrust' (eg 'if I sign an organ donor card, doctors may take away my organs before I'm actually dead'), the 'ick' factor (eg 'I don't like the idea of my body being cut into when I've died') and 'perceived benefits' (eg 'organ donation is a gift of life for whoever receives it').

Spiritual (traditional) beliefs, medical distrust and the 'ick' factor were negative attitudes that were more prevalent in: those aged 65 years and over, those in socioeconomic groups C2DE, Catholics, nationalists, those with a long-term limiting

illness or disability, those who described their health as fair/poor, and those who were not registered on the ODR.

Seventy eight percent of respondents said they would be willing to accept an organ if they needed one.

Younger people (aged 30–64 years), those in socioeconomic groups ABC1, those with no long-term limiting illness or disability, those who rated their health as excellent/good, and those who were exposed to organ donation or transplantation, either personally or through family or friends, were more likely to be:

- supportive of organ donation;
- aware of the ODR;
- registered on the ODR;
- willing to accept an organ.

Discussing organ donation with your family/friends

Seventy eight percent of respondents agreed that it is important to discuss your donation wishes with your family and/or friends. However, only 38% had done so and only 43% thought their family/close friend would know their wishes.

Just over half (52%) of respondents said they knew the donation wishes of their wife/husband/partner, and fewer knew the wishes of their parents (32%), siblings (27%), children (29%) or close friend (26%).

Those who had discussed their donation wishes with their family/close friend were more likely to: be aged 30–64 years, belong to socioeconomic group ABC1, be unionist, have no long-term limiting illness or disability, rate their health as excellent/good, be on the ODR and/or have been exposed to organ donation/transplantation.

Eighty eight percent of those who said their family/close friend would know their donation wishes thought their family/close friend would agree with their wishes, but this fell to 29% when they did not think their family/close friend would know their wishes. This suggests that people may be less likely to discuss their donation wishes with their family/close friend if they are concerned their family/close friend would not agree with their decision.

Sixty four percent did not think their family/close friend should be able to overturn their donation wishes if they were approached for consent.

What can be done to improve organ donation in Northern Ireland?

Stakeholders felt it is important to normalise organ donation. Informing the public by providing correct information and dispelling myths were considered essential. Educating the younger generations was also considered crucial. These, in conjunction with improving infrastructure within Health and Social Care, would be important steps to increase organ donation within Northern Ireland.

There was unanimous support across all stakeholder groups for a well-resourced and sustained public information campaign to raise awareness of organ donation and

make organ donation a cultural norm. Stakeholders felt that a public information campaign should focus on discussing donation wishes with your family/friends. A testimonial approach was considered effective in conveying memorable messages about donation, not just from the perspective of recipients, but also of donor families.

Stakeholders felt it is important that any facts, figures or messages given in a public information campaign should be positively framed – focus on the number of lives that can be saved from donation rather than the number of people who die while waiting on a transplant.

The soft opt-out/presumed consent debate

The current 'opt-in' system of organ donation, where individuals are asked to register their willingness to be a donor after death, has been the subject of debate for many years across the UK. Recently in Northern Ireland, there has been increased discussion on a change from 'opt-in' to a system of 'soft opt-out'/presumed consent, where it is assumed that an individual wishes to be a donor unless they have opted out by registering their objection.

A minority of respondents (29%) were aware of a current debate about the system for organ donation in Northern Ireland. Fifty six percent of respondents said they would be in favour of changing to a soft opt-out/presumed consent system, 18% said they were against this change, 8% said they needed more information and 18% did not know. However, when asked if they agreed with the statement 'everyone should be presumed to be an organ donor unless they register a wish otherwise', fewer (49%) agreed, indicating some confusion about the idea.

The majority (59%) of those who said they were in favour of changing to a soft opt-out/presumed consent system (n=570) said the soft opt-out/presumed consent system will save lives, while 25% said it will increase the number of organs available.

Fifty one percent of those who were against changing to a soft opt-out/presumed consent system (n=178) said the change removes choice or takes control away from the individual, while 16% said people might not be aware of the new system (and therefore no choice is made).

In relation to stakeholders, support for soft opt-out/presumed consent was higher among organ donation charities, transplant recipients, those on the transplant waiting list, and the British Medical Association (BMA). Those who were less supportive of the proposed legislative change emphasised that they were not strictly opposed to the legislation, but believed now is not the right time and raised concern about the public's readiness.

Sixty two percent of respondents said they would not object to organ donation if the soft opt-out/presumed consent system was introduced. Twenty two percent did not know what they would do and 16% said they would register their objections to donation (of which 2% were currently on the ODR).

Fifty four percent of respondents supported the idea of introducing a mandatory system where people are required by law to make a decision about organ donation. Twenty five percent were against this and 20% needed more information to help them decide. The preferred mandatory registration system was through your GP (59%).

Fifty seven percent of GPs in Northern Ireland said they would be willing to record organ donation wishes on patient records.

The advantages of introducing soft opt-out/presumed consent legislation identified by stakeholders included: marking a cultural change, encouraging altruistic behaviour among the public, a potential increase in donors and available organs, and the ability to capture those who are ambivalent about donation. At the least, the proposed legislative change was considered by some to be better than doing nothing to raise the profile of organ donation.

Concerns among stakeholders about the introduction of soft opt-out/presumed consent included: the possibility of feeding into medical distrust (public perception of a conflict of interest for medical staff considering end of life care), a general feeling that people will not actively seek out an 'opt-out' register, and a fear that use of the ODR (which will still be in operation) may decline. This means more families could be in a situation of not knowing their loved one's wishes, so decision-making (consent) among donor families becomes more difficult. The pool of potential donors could reduce from the current situation, where all families are asked to consider donation if medically appropriate (whether their loved one is on the ODR or not), to one where only the families of those not on the 'opt-out' register are asked.

Other concerns included: losing the notion that donation is a gift, creating public confusion that stops people opting-in, and the issue becoming a 'political football'. There are general concerns that the gains made in Northern Ireland over the last five years could be lost if the public is not fully in favour of a change.

Some stakeholders said they had changed their opinion from being supportive of the proposed legislative change to becoming more cautious about implementing it at this time.

Finally, 43% of respondents felt that more can be done with the current opt-in system before changing to soft opt-out/presumed consent. Stakeholders noted that a change in legislation would require a significant programme of raising awareness about the opt-out registration system, while also continuing to promote organ donation among the general public.

1 Introduction

1.1 Background

Through organ donation, one person can save or benefit the lives of up to nine people. Organ donation is cost-effective for the NHS in comparison to treating those in need of an organ.¹

The number of people currently on the transplant waiting list exceeds the number of available organs, with a 40% increase on the waiting list since 2001. The number of people on the transplant waiting list often underestimates those in need of a transplant.

In response to the demand for available organs, the Organ Donation Taskforce² made 14 recommendations and set a target to increase organ donation across the UK by 50% by 2013. Recently, NHS blood and transplant (NHSBT) provided a detailed strategy *Taking organ transplantation to 2020*³, which aims to increase donation consent to above 80%.

The General Medical Council (GMC) guidance *Treatment and care towards the end of life: good practice in decision making* requires consultant staff who have clinical responsibility for patients who are potential donors to exercise a duty to consider organ donation as part of end-of life care⁴.

1.2 Organ donation in Northern Ireland

In Northern Ireland, a total of 123 transplants took place in 2012/13 and 190 people were on the transplant waiting list as of March 2013⁵. Approximately 15 people die each year while waiting for a transplant.

In total, 31% of the Northern Ireland population are on the organ donor register, a figure that has been steadily increasing. However, more than a third of families refuse to give consent to the donation of their loved one's organs when faced with this choice. A common reason for refusing to give consent is that the potential donor's family were not aware of their loved one's wishes.

In Northern Ireland, the Assembly passed a motion in 2012 with a commitment that the Health Minister would look at how organ donation could be increased. In February 2013⁶, a press release illustrated the need to engage with the public and encourage debate around changing the current system of organ donation in Northern

¹http://www.organdonation.nhs.uk/newsroom/fact_sheets/cost_effectiveness_of_transplantation.asp

² Organ Donation Taskforce. (2008). *The potential impact of an opt-out system for organ donation in the UK: an independent report from the Organ Donation Taskforce*. Retrieved from

<http://www.bts.org.uk/Documents/Publications/The%20potential%20impact%20of%20an%20opt%20out%20system%20for%20organ%20donation%20in%20the%20UK.pdf>

³ http://www.nhsbt.nhs.uk/to2020/resources/nhsbt_organ_donor_strategy_long.pdf

⁴ NICE. (2011). *Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation*. NICE Guideline 135.

⁵ http://www.organdonation.nhs.uk/statistics/downloads/northern_ireland_june13.pdf

⁶ <http://www.northernireland.gov.uk/index/media-centre/news-departments/news-dhssps/news-dhssps-february-2013/news-dhssps-05022013-minister-organ-donation.htm>

Ireland to a soft opt-out system. In April 2013⁷, a ministerial press release outlined work to be undertaken by the Public Health Agency (PHA), which would help inform a major public information campaign to enhance awareness and understanding of organ donation in a bid to increase donation rates. This involved a public engagement programme and aimed to:

- survey public opinion across Northern Ireland on how increased consent for organ donation can be achieved;
- have discussions with representatives from transplant-related charities, donor families, those on the transplant waiting list and the HSC community, to bring together the views of these important stakeholders.

1.3 Donation systems

Currently in the UK, organs and tissue from a potential donor will only be used if that is their wish. According to the Human Tissue Act (2004), which came into effect in September 2006 in England, Wales and Northern Ireland, organs and/or tissue from a potential donor will only be used if they consent to donation prior to death. The act stipulates a hierarchy of close relationships from which consent can be obtained in the absence of the deceased's consent. The hierarchy is as follows:

- a nominated representative;
- spouse/partner;
- parent/child;
- brother/sister;
- grandparent/grandchild;
- niece/nephew;
- step-parent;
- half-brother/half-sister;
- friend of long standing.

People can indicate their wishes in a number of ways, such as telling a relative or close friend, carrying an organ donor card, or recording their wishes on the NHS Organ Donor Register (ODR). Registering their wishes on the NHS ODR makes it easier for HSC staff to establish a person's wishes, but those closest to the person are still asked for their consent to donate, to minimise any distress to the family. Ultimately, this means the family makes the final decision regarding organ donation.

Approximately 90% of people in the UK⁸ support organ donation. UK figures for 2012/13 show that 55% of potential donor families consent to donation if their loved one's wishes are not known⁹, with this figure rising to 96% when a loved one has made their wishes known. In Northern Ireland, for donation following brain death, the consent rate is 62% when the loved one's wishes are not known, with this figure rising to 88% when the loved one is on the ODR. Of those families who did not consent to donation, 23% said the main reason was that they were not sure their loved one would have agreed to donation. This highlights the importance of family discussions about organ donation.

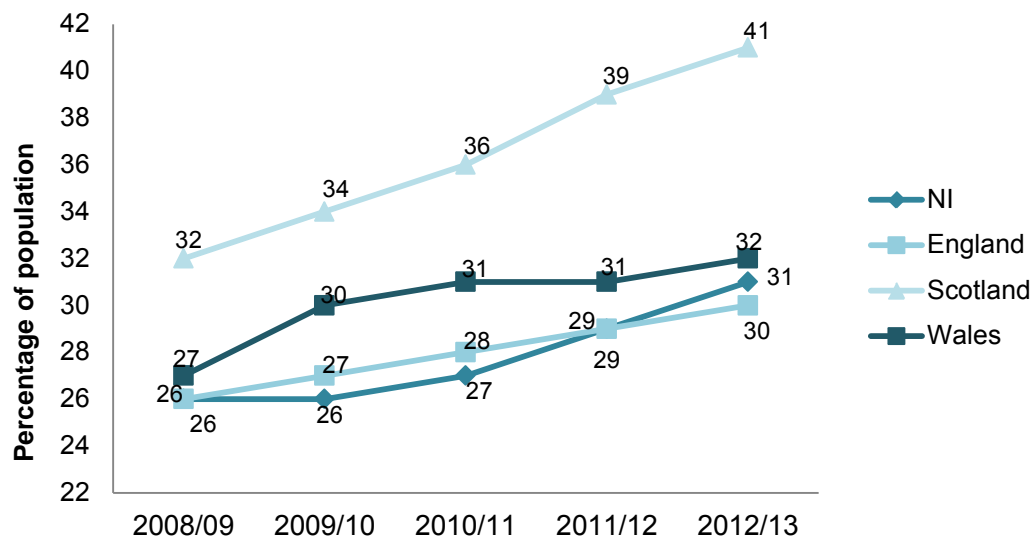
⁷ <http://www.northernireland.gov.uk/index/media-centre/news-departments/news-dhssps/news-dhssps-april-2013/news-dhssps-290413-minister-announces-next.htm>

⁸ http://www.organdonation.nhs.uk/newsroom/fact_sheets/did_you_know.asp

⁹ http://www.organdonation.nhs.uk/statistics/potential_donor_audit/pdf/pda_report_1213.pdf

Over the last five years, the number of people on the ODR in Northern Ireland has increased, with more than half a million people (567,200¹⁰) now registered. This represents 31% of the Northern Ireland population, which is a rise from 26% in 2008/09 (NHSBT data). Figure 1 shows that Northern Ireland, England and Wales have very similar population levels registered on the ODR, while Scotland has the highest ODR level in the UK, at 41% of the population.

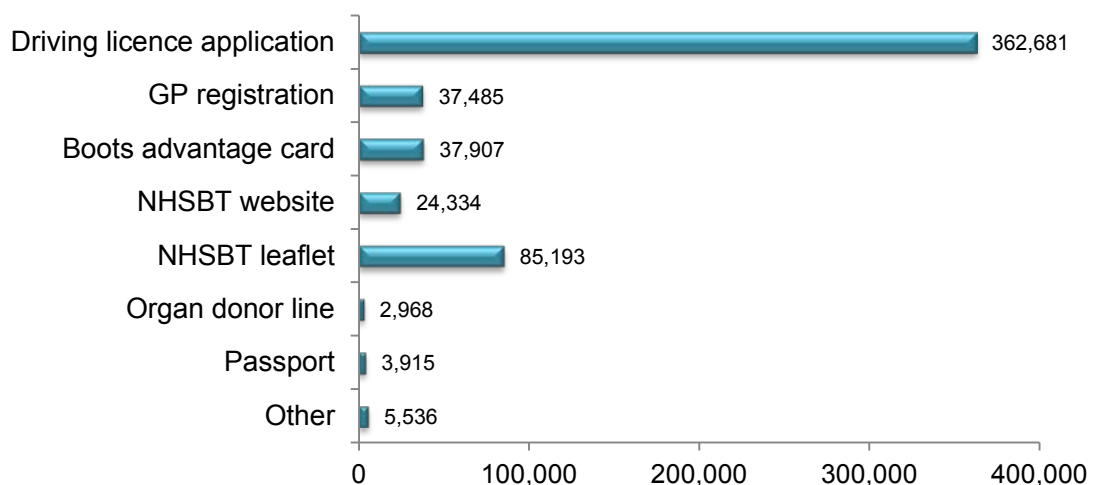
Figure 1: Percentage of population on the ODR, by UK region



Organ donation and transplantation activity data: NHS blood transplant annual data published April 2013.

In Northern Ireland, the most popular way of registering on the ODR has been a driving licence application, followed by an NHSBT leaflet (see Figure 2). Where gender is known, 45% on the ODR are male and 54% are female.

Figure 2: Source of ODR registration for Northern Ireland



¹⁰ Data provided by NHSBT, correct as of 11 October 2013

1.3.1 Presumed consent: the debate

There are three main systems that can be used in countries to determine citizens' donation status. The systems are as follows:

1. **Opt-in (informed consent):** Individuals opt-in or register their wishes to say they are willing for their organs to be used after death. However, the family of the deceased are asked for consent to proceed with donation.
2. **Soft opt-out (presumed consent):** Individuals are presumed to consent to organ donation after their death unless they have registered their wishes to opt-out. However, the family of the deceased are asked for consent to proceed with donation.
3. **Hard opt-out (mandated consent):** Individuals are presumed to consent to organ donation after their death unless they have registered their wishes to opt-out. Consent from the family of the deceased is not sought before donation.

Due to the discrepancy between the number of donors and the number of organs needed, the systems of organ donation within countries have been scrutinised, which has led to considerable debate surrounding the issue.

Many European countries have adopted opt-out systems, of which Spain is considered the 'gold standard' as donation rates there are the highest in the EU. However, caution is advised in attributing rates of donation in Spain to a presumed consent system. It is worth noting that donation rates in Spain did not rise until 10 years after presumed consent legislation was introduced¹¹. Furthermore, higher donation rates coincided with improved infrastructure and organ donation being accepted as a cultural norm.

Despite this cautionary note, countries with the highest organ donation rates have presumed consent systems of donation. The Tuscany region of Italy partially introduced a presumed consent system and doubled its organ donation rates within one year. In Belgium, less than 2% of the population have opted out of the presumed consent system. However, the introduction of a presumed consent or soft opt-out system carries some risk. In Brazil, the introduction caused fear and distrust in the government among some of the population, leading to the presumed consent law being abolished.

In recognition of the complex issues and widely differing viewpoints surrounding systems of consent, the Organ Donation Taskforce was asked to look at the range of issues involved in an opt-out system of consent, taking into account the views of the public and stakeholders on the clinical, ethical, legal and societal issues. This resulted in a report by the Organ Donation Taskforce entitled *The potential impact of an opt-out system for organ donation in the UK: an independent report from the Organ Donation Taskforce*.¹² The report concluded that it was not appropriate to introduce a presumed consent system in the UK at that time due to the risks involved (including reducing levels of donation, increasing public distrust etc).

However, in September 2013 a new Human Transplantation Act received royal assent in Wales. The act introduces a soft opt-out system for consent to deceased

¹¹ Rieu, R. (2010). The potential impact of an opt-out system for organ donation in the UK. *Law, Ethics, and Medicine*, 36, 534-538.

¹²<http://www.bts.org.uk/Documents/Publications/The%20potential%20impact%20of%20an%20opt%20out%20system%20for%20organ%20donation%20in%20the%20UK.pdf>

organ and tissue donation from 2015. This law will come into effect fully on 1 December 2015. Until then, the current opt-in system will remain in place.

1.4 Notes on the report and statistical references

This report outlines key findings and secondary analyses from a survey of public attitudes, knowledge and behaviour in relation to organ donation. Fieldwork for the public attitudes survey was conducted in June 2013 and a series of discussion groups with key stakeholders were convened between June and August 2013.

The questionnaire for the public attitudes survey was derived from several sources, with the majority of questions having been previously validated. Questions relating to current donation behaviours and proposed legislative changes, which were previously used in research conducted by the Welsh and Scottish governments, were included to maintain comparability as much as possible. Attitudinal questions were previously validated in academic research (see section 4.1 for detailed discussion).

Please note that throughout the report, the Organ Donor Register is referred to as the ODR.

The survey findings also refer to those who 'were exposed to organ donation'. This refers to any individual with a close family member, relation or friend who was the recipient of an organ transplant, was currently on the waiting list at the time fieldwork was being completed, or had ever donated an organ.

Throughout the report, results are presented giving mean (average) scores and are often presented as M. Base numbers are included in all tables and figures to indicate the number (n) of respondents on which percentages are based. In all instances, percentages may not add up to 100 due to rounding.

This report refers to a statistical technique (factor analysis) that is used as a means of data reduction. This technique is used to group items in a survey in a way that allows for meaningful interpretation. For example, personality questionnaires are usually described as having sub-scales (such as extraversion, neuroticism, agreeableness etc) that have been identified using factor analytical techniques.

Statistically significant findings are shown where appropriate, and three levels of significance are present: $p \leq 0.05$; $p \leq 0.01$; $p \leq 0.001$. For instance, if a finding is significant at the $p \leq 0.05$ level, it would be expected in a similar population 95 times out of 100. Significance is an indication of how likely it is that your results are due to chance and a significance level of $p \leq 0.05$ indicates there is a 95% chance that the results are true.

2 The public engagement approach

The public engagement approach requested by the Health Minister has been two-fold, including a survey of the general public and a series of discussions with relevant stakeholders.

2.1 Public attitudes survey

Social Marketing Research (SMR) was procured to undertake the public attitudes survey on behalf of the PHA in June 2013. SMR provided a statistical report, which is available on request. The aim of the survey was to assess public knowledge and attitudes to organ donation and assess support for changing the current opt-in system.

A total of 1,012 members of the Northern Ireland general population (aged 16 years and over) were surveyed between 14 and 30 June 2013 about their views on organ donation. The sample was representative of the population based on Census 2011 data for gender, age, class and area (LCG and LGD) (for more detail on sampling and a copy of the questionnaire see SMR report¹³).

The surveys were conducted face-to-face with respondents in their own homes and all data were recorded using Computer Assisted Personal Interviewing (CAPI) devices. All interviewers were fully briefed about the topic of organ donation, including consent systems. This face-to-face approach ensured that respondents were clear about the issues covered in the survey and were able to ask questions throughout.

The survey was divided into four sections as follows:

Section A: Attitudes and knowledge about organ donation

Section B: Awareness of ODR and current behaviour

Section C: Proposed changes to organ donation registration systems

Section D: Demographic information

2.2 Stakeholder engagement

The ministerial briefing identified key stakeholders to be included in the engagement programme: HSC staff, transplant charities, those on the transplant waiting list and donor families. Engagement was mainly through a series of discussion groups that were moderated by PHA staff using a discussion topic guide (see Appendix A) and supplemented by some online feedback from healthcare staff unable to attend.

Discussion groups took place at a time and location convenient to stakeholders to maximise the number of individuals available to participate. The number of individuals participating in groups ranged between 2 and 13, with discussions lasting between 30 minutes and one and a half hours.

The HSC staff included in the stakeholder engagement were mainly those directly involved in organ donation and included staff at all five Health and Social Care Trusts

¹³ SMR. (2013). *Survey of public attitudes to organ donation in Northern Ireland*. September 2013

(Table 1). HSC staff including clinicians (consultant physicians, surgeons, anaesthetists and clinical leads for organ donation) and a small number of nurses attended the groups.

The NHSBT invited the PHA to attend an organ donation event for nurses in June 2013. During the event, a stakeholder engagement proforma was distributed to all nurses in attendance. Approximately 50 nurses (working in intensive care, emergency departments and theatres) attended the event and 48 completed the proforma. Of those who completed the proforma, 46 were female, 24 worked in Intensive Care Units (ICUs), 18 worked in theatres and six worked in emergency departments covering all Trust areas. The proforma asked nurses about their role and views on organ donation, a public information campaign and consent systems for donation.

An online version of the proforma was produced by the PHA and distributed via the Critical Care Network (CCaNNI) email distribution list, with 20 responses received.¹⁴ Of these, 12 were female, 15 were clinicians and five were nurses. Thirteen worked in ICU and a further six said they worked in critical care. The remaining four were anaesthetists. All of the respondents said they worked in a role related to organ donation.

Table 1: Method of engagement with HSC staff

HSCT	HSC area	HSC staff	Approach	Number attending
Western	ICU Altnagelvin		Group discussion	3 clinicians 1 sister
Southern	ICU Craigavon		Group discussion	5 clinicians 2 sisters
Belfast	Regional ICU RVH		Group discussion	11 clinicians
	ICU City		Group discussion	2 clinicians 1 SNOD
	ICU Mater		Group discussion	1 clinician 1 sister
Northern	ICU Antrim Area		Group discussion	3 clinicians
	ICU/anaesthetists Causeway		Group discussion	4 clinicians 1 sister
South Eastern	ICU Ulster		Group discussion	2 clinicians 1 SNOD 4 nurses
Regional	CCaNNI		Online proforma	20 responses
Regional	Specialist nurses for organ donation (SNODs)		Group discussion	6 SNODs
Regional	ICU/ED/Theatre nurses		Proforma	48 responses
Regional	Nurses Renal Unit City Hospital		Group discussion	7 nurses

¹⁴ It is not possible to calculate a response rate for the proforma distributed to CCaNNI as there is no way to tell whether all those on the mailing list received the invitation to complete the proforma as some email addresses may not have been valid and some individuals may not have read the email received.

Other discussion groups were held with charities, those on the waiting list, transplant recipients and donor families (see Table 2). Charities in the engagement programme included the Northern Ireland Transplant Forum (including representatives from all Northern Ireland charities), the Liver Support Group and Transplant Games NI. The charity discussion groups also included those on the waiting list and transplant recipients.

Table 2: Public engagement programme: charities, waiting list, recipients and donor families

Group	Representatives	Approach	Number of attendees
Northern Ireland Transplant Forum	Charities Recipients Waiting list	Group discussion	13
Donor families	Donor families	Group discussion	3
Liver support group	Recipients Charities	Group discussion	3
Recipients	Recipients	Group discussion	4
Transplant Sport NI	Charities Recipients Waiting list	Group discussion	6
British Medical Association	BMA	Group discussion	5

3 Public attitudes survey: attitudes and behaviours towards donation

This section presents key findings from the public attitudes survey along with some additional analyses that were conducted to gain a more in-depth understanding (top level findings can be found in the SMR report, available on request).

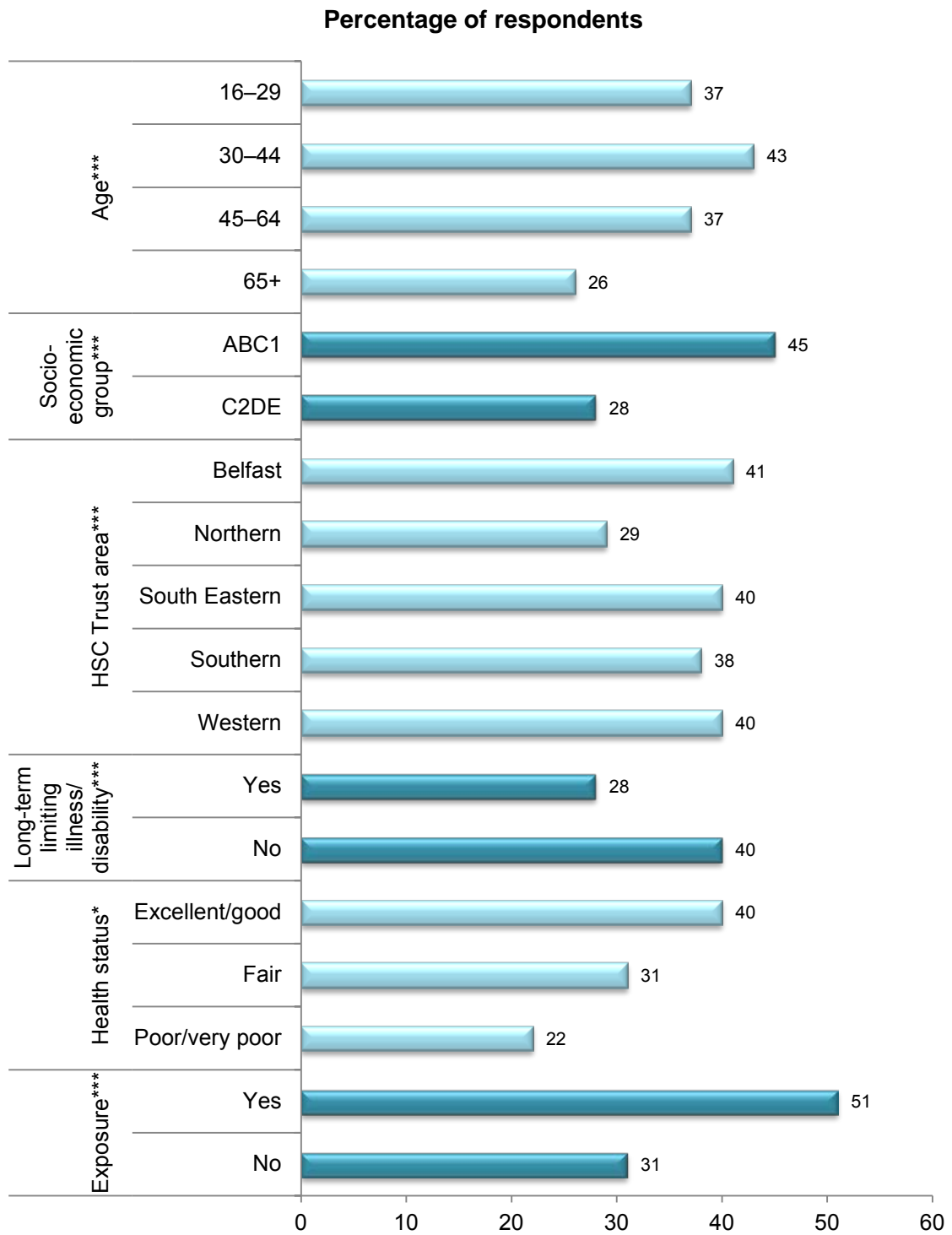
3.1 Awareness of the Organ Donor Register and registration on it

When asked, two thirds of the sample (64%) said they were aware of the NHS Organ Donor Register (ODR). Awareness of the ODR was significantly higher among:

- those aged 30–44 years (16–29 years, 59%; 30–44 years, 71%; 45–64 years, 67%; 65+ years, 58%, $p \leq 0.001$);
- socioeconomic groups ABC1 (ABC1, 71%; C2DE, 59%, $p \leq 0.01$);
- residents in the Southern Health and Social Care Trust area (Belfast, 60%; Northern, 64%; South Eastern, 63%; Southern, 76%; Western, 59%, $p \leq 0.01$);
- Protestants (Catholics, 59%; Protestants, 70%; none, 61%, $p \leq 0.01$);
- unionists (nationalists, 61%; unionists, 72%; other, 56%; refused to answer, 59%, $p \leq 0.001$);
- those with exposure to organ donation (79% v 60%, $p \leq 0.01$).

Of those who were aware of the ODR ($n=650$), 37% said they had put their name on it, 52% had not and 11% could not remember. Putting one's name on the ODR was significantly associated with being aged 16–64 years, in socioeconomic groups ABC1, having no limiting long-term illness or disability, being in excellent/good health, and being exposed to organ donation. Individuals living in the Northern Health and Social Care Trust area were least likely to have signed the ODR (Figure 3).

Figure 3: Relationships between key variables and registering on the ODR (n=650)

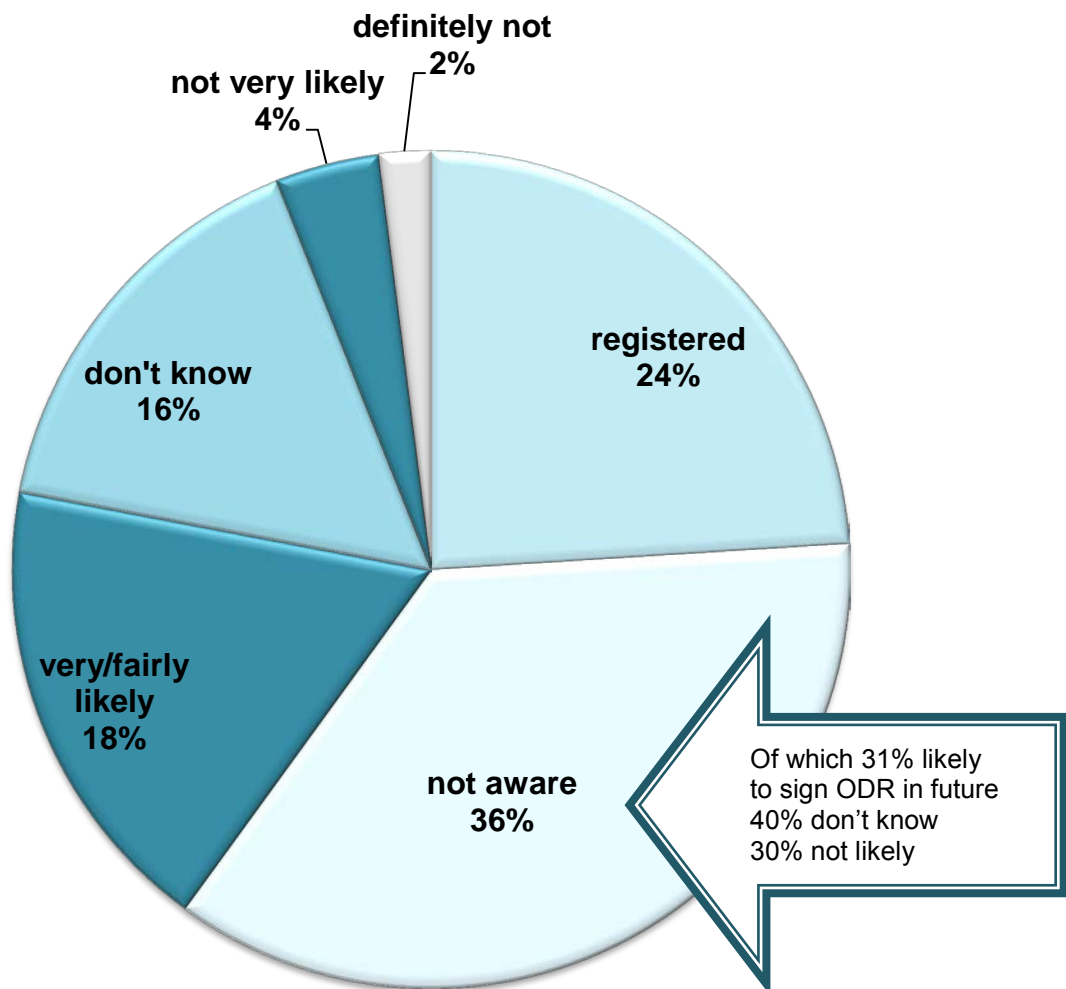


***p≤0.001; **p≤0.01; *p≤0.05

Of the full sample (n=1,102), the number of people who said they were on the ODR equated to approximately one quarter of respondents (Figure 4). Those who were aware of the ODR but had not put their name on it (40% of the full sample) were asked how likely they were to register in the future, with 18% of the full sample saying they were very or fairly likely to register and 16% saying they did not know. Only 6% of the full sample who were aware of the ODR said they were not very likely, or definitely not likely, to register.

Among the 36% of the full sample who were not aware of the ODR, 31% said they were likely to sign it, 40% did not know and 30% said they were not likely to sign it. This suggests there is strong potential to encourage a significant proportion of the population who said they are likely to sign the ODR in the future. Furthermore, there may be some potential to encourage those who said they did not know whether or not they would register in the future.

Figure 4: Chart showing respondents' ODR status, and potential status (full sample n=1,012)

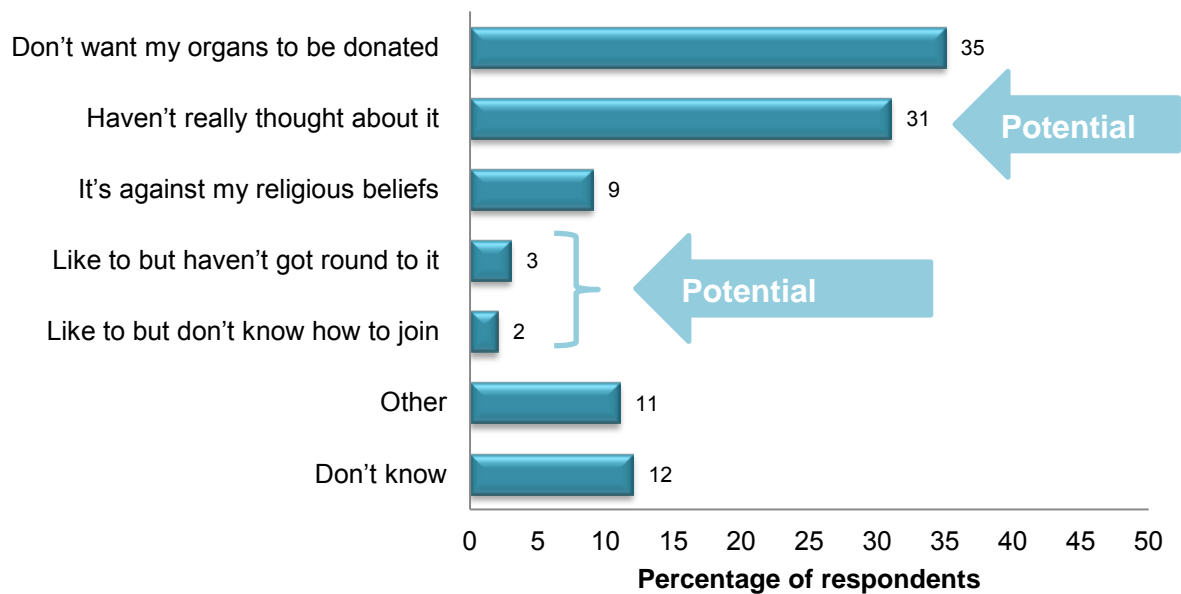


Further analyses were conducted to find out more about those respondents who said they were not very likely or definitely not likely to sign the ODR in the near future. These respondents were more likely to:

- be aged 65 years and over;
- be in socioeconomic groups C2DE;
- have a limiting long-term illness or disability;
- be in fair or poor health;
- live in the Western and Northern Health and Social Care Trust areas.

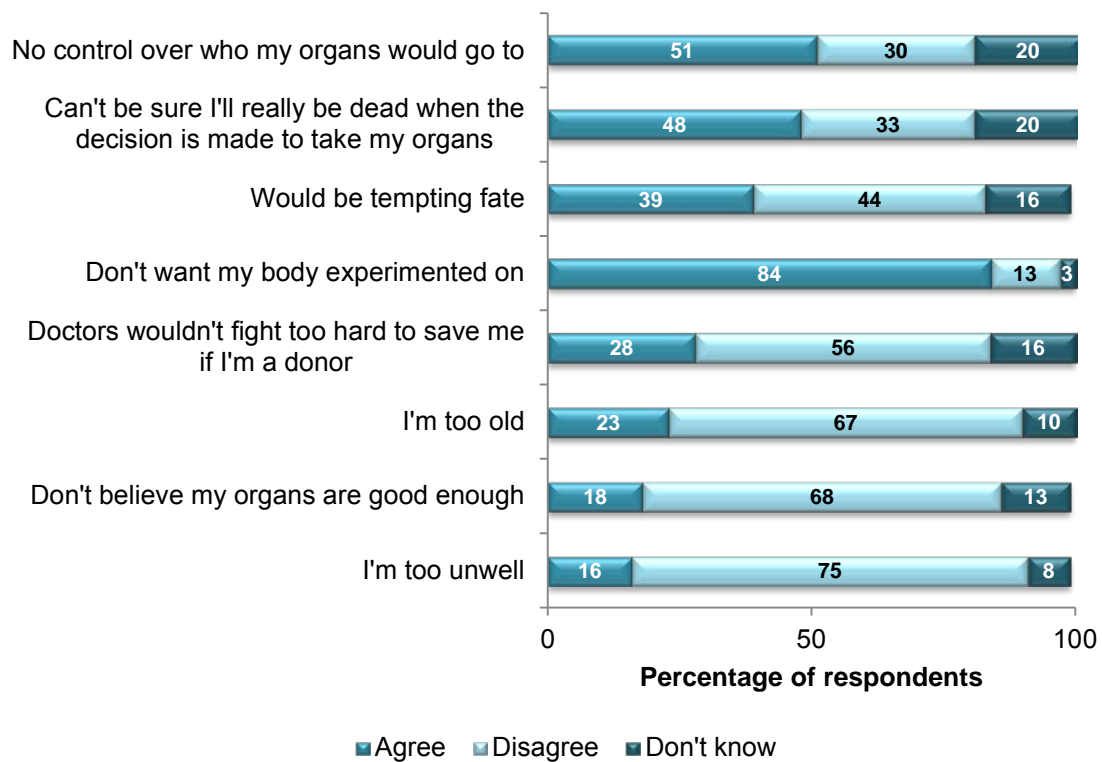
These respondents were asked why they were unlikely to put their name on the ODR (Figure 5). Just over a third of respondents (35%) said they did not want their organs donated. However, just under a third (31%) said they had not really thought about organ donation, 3% said they would like to donate but had not yet got around to registering, and 2% said they would like to register but did not know how. This indicates that there is some potential to mobilise approximately 36% of respondents who said they were unlikely to sign the ODR in the near future.

Figure 5: Reasons for being unlikely to register on the ODR in the near future (unprompted, n=174)



Analysis continued to further investigate why some respondents would be unlikely to sign the ODR. Those who said they did not want their organs donated (n=60) were asked to rate the extent to which they agreed with eight potential reasons why someone would not want their organs donated (Figure 6). The majority of these respondents (84%) did not want their body experimented on. Approximately half (51%) said they did not want to donate because they had no control over who would receive their organs and 48% said they could not be sure that they would really be dead when the decision for organ retrieval was made.

Figure 6: Reasons for not wanting to donate (prompted, n=60)

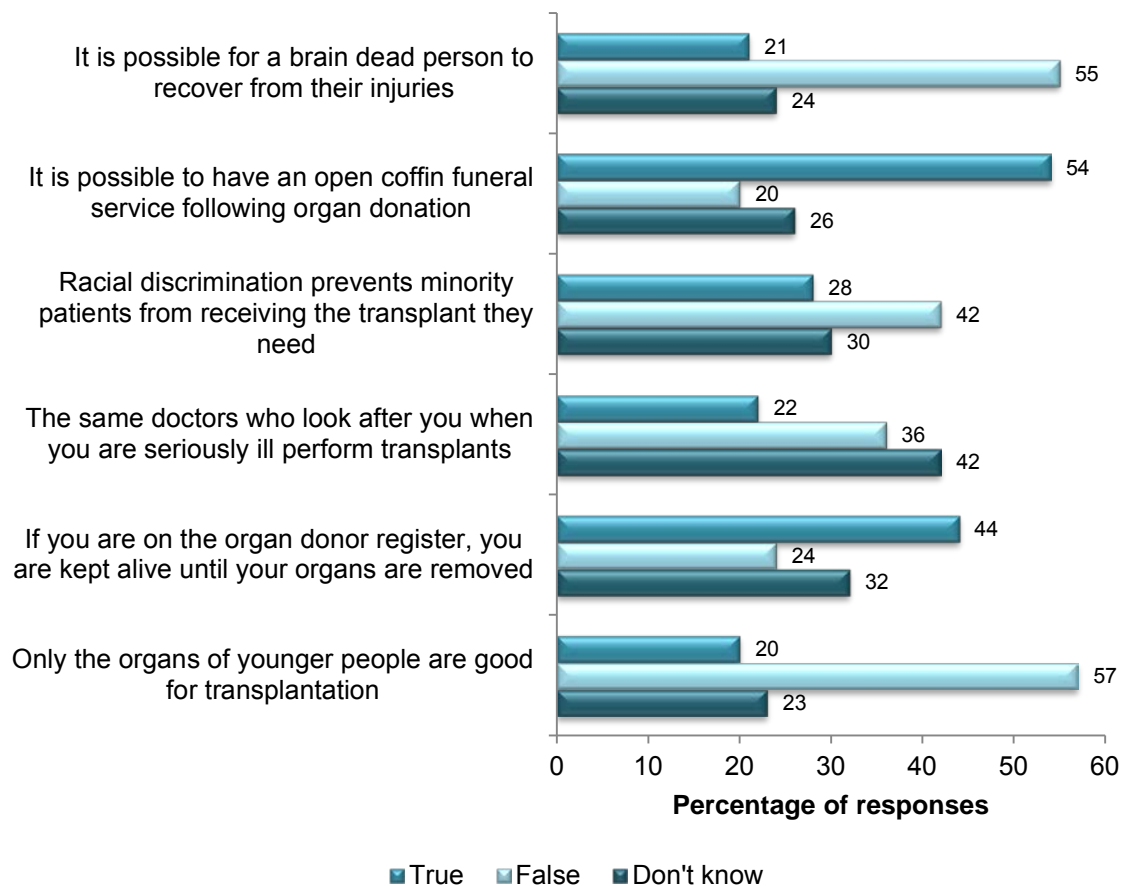


3.2 Knowledge of organ donation

Seven items included in the public attitudes survey were designed to assess respondents' knowledge about organ donation. Respondents were asked to indicate whether they thought six knowledge items were true or false (Figure 7). The correct response for item 'It is possible to have an open coffin funeral service following organ donation' was 'true', and the correct responses for all other items were 'false'.

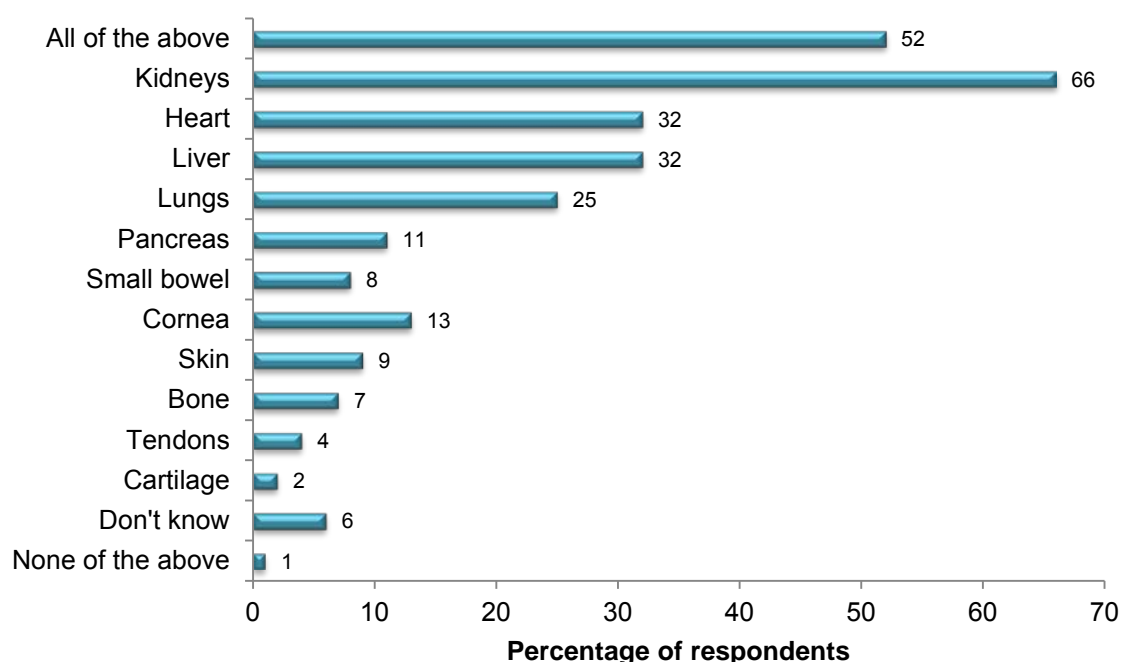
Figure 7 shows that approximately half of respondents provided correct responses for 'It is possible for a brain dead person to recover from their injuries' (55% false) and 'It is possible to have an open coffin funeral service following organ donation' (54% true). Nearly three in five respondents (57%) correctly said the statement 'Only the organs of younger people are good for transplantation' was false. Forty two per cent of respondents correctly said that 'Racial discrimination prevents minority patients from receiving the transplant they need' was false. However, responses to questions that were more technically framed were more likely to be answered incorrectly ('The same doctors who look after you when you are seriously ill perform transplants' 36% false; 'If you are on the organ donor register, you are kept alive until your organs are removed' 24% false).

Figure 7: Responses to six knowledge items (n=1,012)



In addition to responding to these six statements, respondents were presented with a list of organs/tissue and asked which of these they thought could be used for transplantation purposes, with the correct response being 'all of the above'. As can be seen in Figure 8, approximately half of the sample (52%) said all the organs and tissue presented could be donated. From the remaining 48% of respondents, the most common answers were kidneys (66%), heart (32%), liver (32%), and lungs (25%).

Figure 8: Respondents' views of organs/tissue that can be transplanted (n=1,012)



Correct responses to the seven knowledge items were scored to give an overall knowledge score ranging from 0–7, with higher scores indicating higher levels of knowledge about organ donation. Average knowledge score was 3.2, with 57% scoring 3 or less (Table 3).

Table 3: Number of correct knowledge items

Number of knowledge items answered correctly	%	n
0	6	61
1	12	124
2	18	181
3	21	213
4	20	207
5	12	119
6	6	60
7	5	47
Total	100	1012

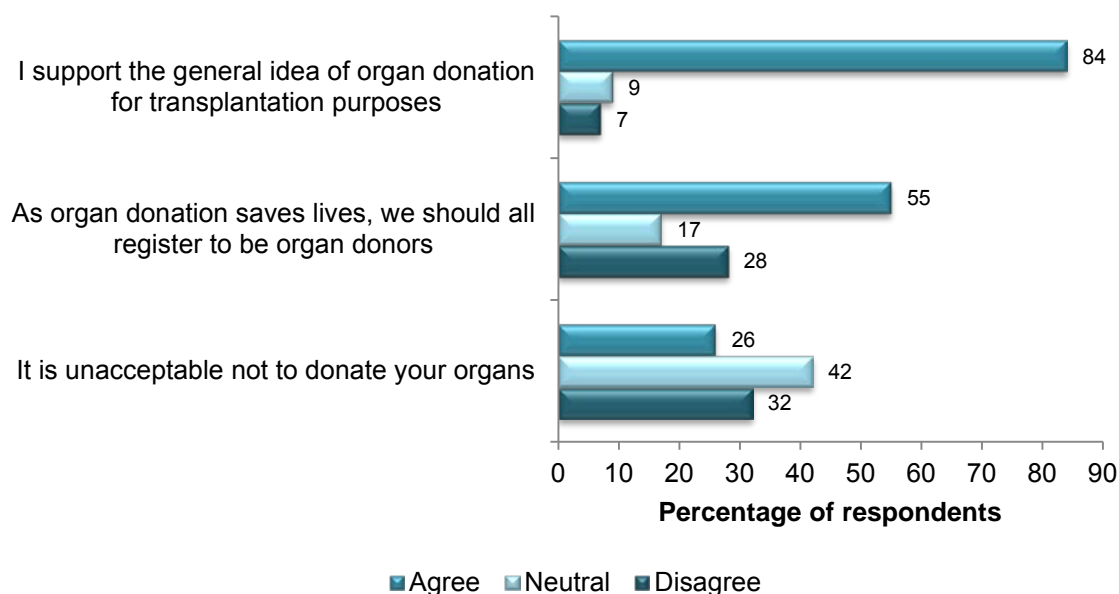
Higher knowledge scores were associated with being aged between 30 and 64 years, being in socioeconomic groups ABC1, living in the Western and Southern Health and Social Care Trust areas, living in rural areas, having no religious affiliation, having no limiting long-term illness or disability, being in excellent/good health, being on the ODR, and being exposed to organ donation (see Appendix B, Table 7).

Knowledge about organ donation was significantly associated with the factors underlying attitudes towards organ donation. High knowledge scores were associated with low scores on spiritual (traditional) beliefs ($p \leq 0.001$), medical distrust ($p \leq 0.001$) and the 'ick' factor ($p \leq 0.001$), and high scores on perceived benefits ($p \leq 0.001$).

3.3 Attitudes towards organ donation

Attitudes towards organ donation in Northern Ireland were generally positive, with 84% of respondents agreeing with the statement 'I support the general idea of organ donation for transplantation purposes'. However, fewer respondents agreed with the additional two statements in Figure 9, namely that 'We should all register to be organ donors' and 'It is unacceptable not to donate your organs'.

Figure 9: Attitudinal items indicating support for organ donation



When analysed by key demographic variables, support for organ donation was consistently and significantly higher among those aged between 16–64 years, who were in socioeconomic groups ABC1, who didn't have a limiting long-term illness or disability, who had a self-rating health status of excellent/good, who were on the ODR, and who had been exposed to organ donation (Table 4).¹⁵

Respondents were presented with 22 statements about organ donation and asked to rate on a seven point scale (ranging from 'strongly disagree' to 'strongly agree') the

¹⁵ This refers to anyone who had a close family member/relation/friend who had been the recipient of an organ, was on the waiting list, or had donated.

extent to which they agreed with each of the statements. The statements form a scale of attitudes towards organ donation that have been validated elsewhere.^{16,17,18}

According to O'Carroll et al, the organ donation attitudes scale has five subscales, which are labelled 'perceived benefit', 'ick', 'jinx', 'bodily integrity' and 'medical distrust'.^{13,15} However, analysis for the Northern Ireland population indicated four subscales, which are listed in order of importance and labelled 'spiritual (traditional) beliefs', 'medical distrust', 'the 'ick' factor' and 'perceived benefits'. While the original scale was validated for use in the UK, the Northern Ireland culture is unique in relation to death and funeral rituals, and this seems to be apparent in the current analysis. This difference highlights that the donation attitudes scale is sensitive to cultural variations.

Items in each of the subscales described above were summed to give an overall score for each of the factors. The scores for each of the subscales were then used to identify significant associations with key variables.

Table 4: Support for organ donation by key variables

Significant associations with key variables	Statement		
	I support the idea of organ donation for transplantation purposes	It is unacceptable not to donate your organs	As organ donation saves lives, we should all register as organ donors
Gender	NS	NS	NS
Socioeconomic group	ABC1***	ABC1*	ABC1**
Age	<65***	<65**	<65***
Religious affiliation	None**	None**	NS
HSC Trust	Southern South Eastern*	Belfast***	South Eastern***
Urban/rural	NS	Urban**	Urban**
Limiting long-term illness or disability	None***	None*	None***
Health status	Excellent/good***	Excellent/good***	Excellent/good***
ODR registration	On ODR***	On ODR***	On ODR***
Exposure to donation	Exposed*	Exposed**	Exposed**

***p≤0.001; **p≤0.01; *p≤0.05; NS denotes not significant

¹⁶ O'Carroll, R.E., Foster, C., McGeechan, G., & Sandford, K. (2011). The "ick" factor, anticipated regret, and willingness to become an organ donor. *Health Psychology, 30*(2), 236-245.

¹⁷ Morgan, S.E., Stephenson, M.T., Harrison, T.R., Affi, W.A., & Long, S.D. (2008). Fact versus 'feelings': How rational is the decision to become an organ donor? *Journal of Health Psychology, 13*(5), 644-658.

¹⁸ O'Carroll, R.E., Dryden, J., Hamilton-Barclay, T., & Ferguson, E. (2011). Anticipated regret and organ donor registration – a pilot study. *Health Psychology, 30*(5), 661-664.

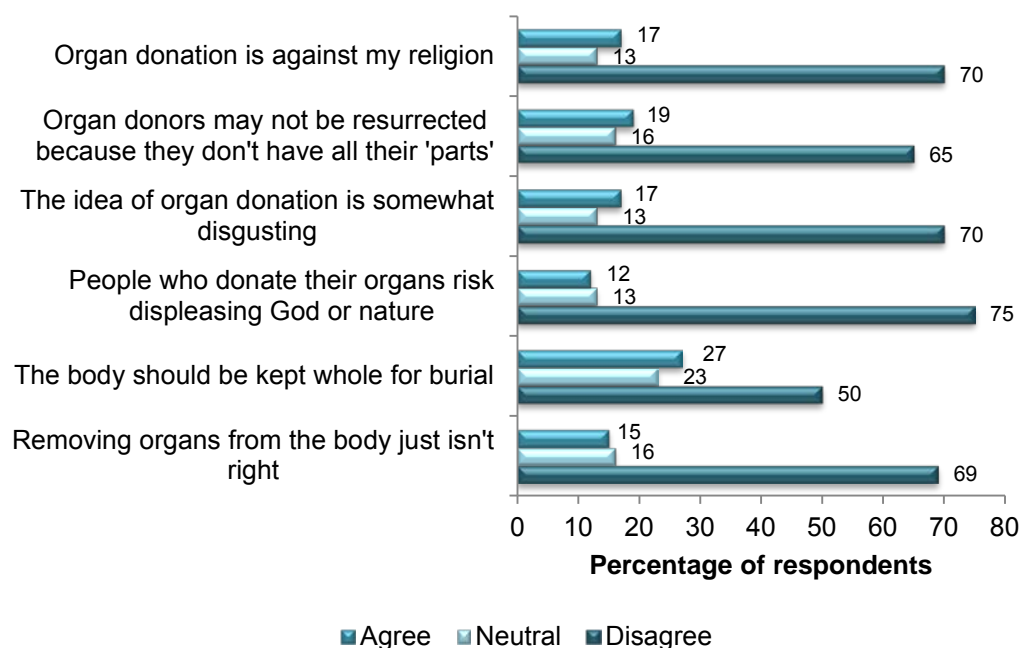
3.3.1 Spiritual (traditional) beliefs

'Spiritual (traditional) beliefs' explained the greatest variance in attitudes towards organ donation, with higher scores on this subscale indicating higher levels of 'spiritual (traditional) beliefs'. Figure 10 shows the frequency of responses to each individual item on this subscale. As can be seen from Figure 10, the majority of respondents disagreed with all of the statements. However, high scores on 'spiritual (traditional) beliefs' represented more negative attitudes towards organ donation.

'Spiritual (traditional) beliefs' scores ranged from 6–42, with an average score (M) of 16.7. Analysis indicated that higher scores were associated with:

- being over 65 years of age – the mean score for the oldest age group was 18.6 compared with 16 for the other age groups (16–29 years, M=16.3; 30–44 years, M=16.0; 45–64 years, M=16.5; 65+ years, M=18.6; $p \leq 0.01$);
- socioeconomic groups C2DE (M=17.7 v ABC1, M=15.5; $p \leq 0.001$);
- living in the Western Health and Social Care Trust area (Belfast, M=17.5; Northern, M=16.8; South Eastern, M=15.4; Southern, M=15.8; Western, M=18.0; $p \leq 0.01$);
- Catholics (Catholics, M=17.1; Protestants, M=16.7; no religious affiliation, M=15.1; $p \leq 0.01$);
- nationalists (nationalists, M=18.0; unionists, M=16.0; other, M=14.9; refused to answer, M=17.0; $p \leq 0.001$);
- having a limiting long-term illness or disability (M=18.6 v M=16.0; $p \leq 0.001$);
- a self-reported health status of poor (poor, M=19.8; fair, M=18.6; excellent/good, M=15.7; $p \leq 0.001$);
- not being on the ODR (M=17.7 v M=14.0; $p \leq 0.001$).

Figure 10: Frequency of responses for each item on the 'spiritual (traditional) beliefs' subscale (n=1,012)



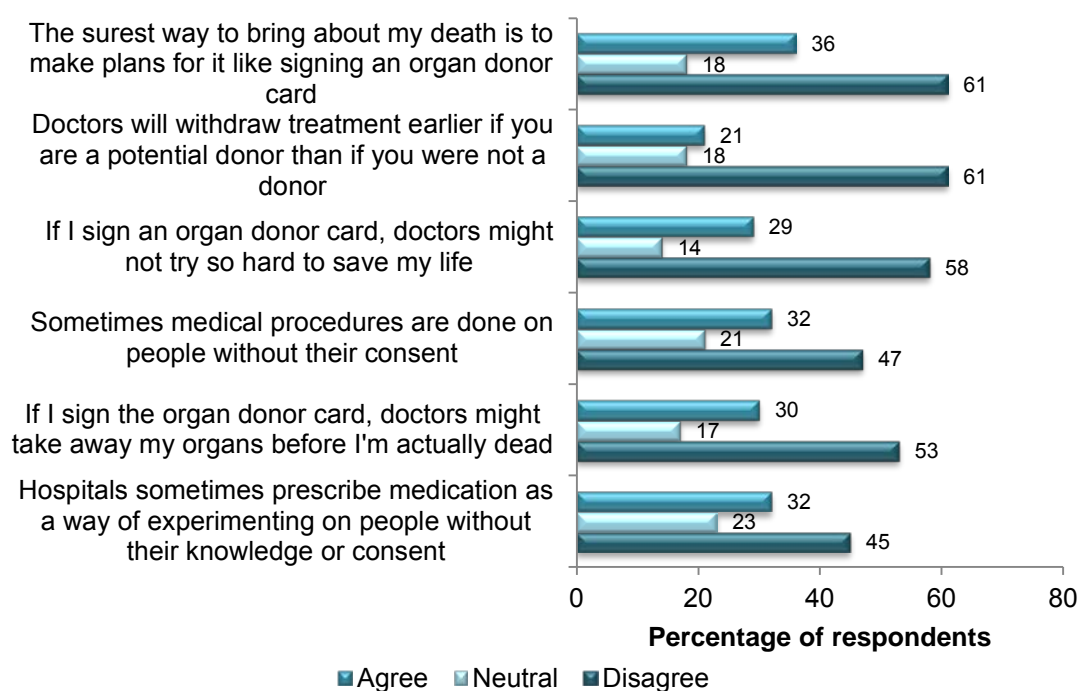
3.3.2 Medical distrust

'Medical distrust' was the second most common consideration for attitudes towards organ donation, with higher scores indicating higher levels of medical distrust. Figure 11 shows the frequency of responses to each individual item on this subscale. As with 'spiritual (traditional) beliefs', the majority of respondents disagreed with each of the statements, indicating that attitudes towards organ donation were generally positive.

'Medical distrust' scores ranged from 6–42, with an average score (M) of 20.7. Analysis indicated that higher scores were associated with:

- being over 65 years of age (16–29 years, M=20.5; 30–44 years, M=20.3; 45–64 years, M=20.0; 65+ years, M=22.5; $p \leq 0.01$);
- socioeconomic groups C2DE (M=21.5 v ABC1, M=19.7; $p \leq 0.001$);
- living in the Belfast and South Eastern Health and Social Care Trust areas (Belfast, M=23.1; Northern, M=19.3; South Eastern, M=22.5; Southern, M=19.7; Western, M=20.7; $p \leq 0.001$);
- Catholics and Protestants (Catholics, M=20.9; Protestants, M=20.9; no religious affiliation, M=19.5; $p \leq 0.05$);
- nationalists (nationalists, M=22.1; unionists, M=21.0; other, M=19.0; refused to answer, M=19.8; $p \leq 0.001$);
- having a limiting long-term illness or disability (M=22.6 v M=20.0; $p \leq 0.001$);
- a self-reported health status of poor or fair (poor, M=23.6; fair, M=23.0; excellent/good, M=19.6; $p \leq 0.001$);
- not being on the ODR (M=21.8 v M=17.4; $p \leq 0.001$);
- not being exposed to organ donation (M=7.7 v M=6.8; $p \leq 0.01$).

Figure 11: Frequency of responses for each item on the 'medical distrust' subscale (n=1,012)



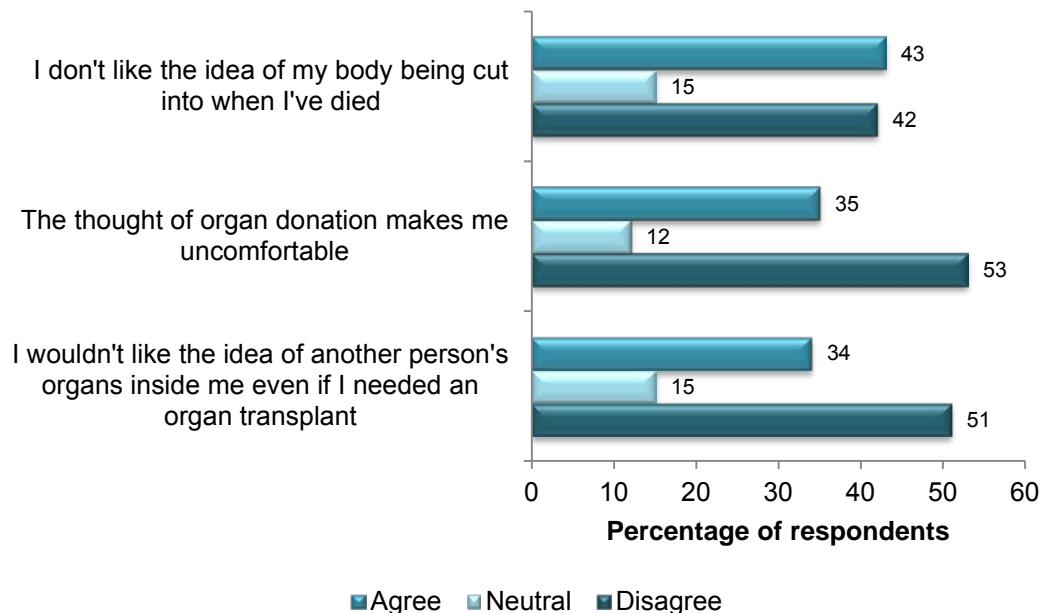
3.3.3 The ick factor

Figure 12 shows the frequency of responses to each individual item on the ick factor subscale. Higher scores indicate higher levels of disgust towards organ donation.

'Ick' factor scores ranged from 3–12, with an average score (M) of 10.9. Analysis indicated that higher scores were associated with:

- being over 65 years of age (16–29 years, M=10.8; 30–44 years, M=10.2; 45–64 years, M=10.8; 65+ years, M=12.4; $p \leq 0.001$);
- socioeconomic groups C2DE (M=11.7 v ABC1, M=10.1; $p \leq 0.001$);
- living in the Northern and Western Health and Social Care Trust areas (Belfast, M=10.9; Northern, M=11.6; South Eastern, M=10.4; Southern, M=10.2; Western, M=11.2; $p \leq 0.01$);
- living in rural areas (M=11.4 v urban, M=10.7; $p \leq 0.05$);
- Catholics and Protestants (Catholics, M=11.2; Protestants, M=10.9; no religious affiliation, M=10.1; $p \leq 0.05$);
- having a limiting long-term illness or disability (M=12.4 v M=10.4; $p \leq 0.001$);
- a self-reported health status of poor (poor, M=13.1; fair, M=12.3; excellent/good, M=10.2; $p \leq 0.001$);
- not being on the ODR (M=11.7 v M=8.6; $p \leq 0.001$).

Figure 12: Frequency of responses for each item on 'the ick factor' subscale (n=1,012)



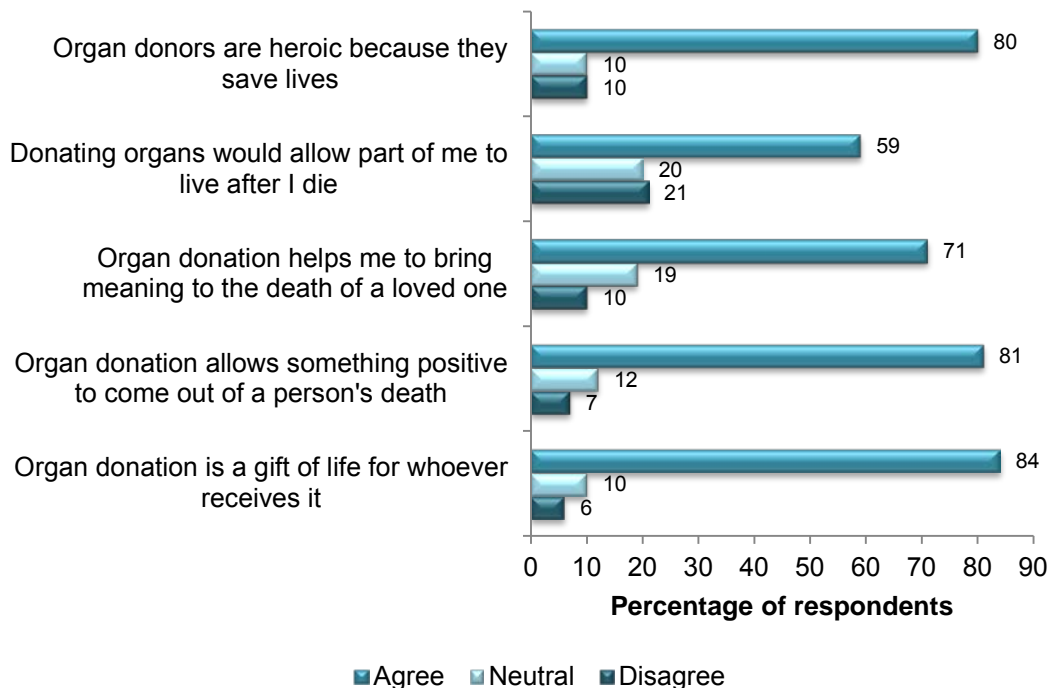
3.3.4 Perceived benefits

Figure 13 shows the frequency of responses to each individual item on the 'perceived benefits' subscale. This subscale indicates positive attitudes towards organ donation and higher scores indicate respondents perceiving more benefits to organ donation.

'Perceived benefits' scores ranged from 5–35, with an average score (M) of 27.1. Analysis indicated that higher scores were associated with:

- females (M=27.5 v M=26.8; $p \leq 0.05$);
- being aged 16–64 years (16–29 years, M=27.6; 30–44 years, M=27.6; 45–64 years, M=27.1; 65+ years, M=25.8; $p \leq 0.01$);
- socioeconomic groups ABC1 (M=27.9 v C2DE, M=26.5, $p \leq 0.001$);
- living in the Southern and South Eastern Health and Social Care Trust areas (Belfast, M=26.1; Northern, M=27.1; South Eastern, M=27.8; Southern, M=28.6; Western, M=26.0; $p \leq 0.001$);
- having no religious affiliation (Catholics, M=26.7; Protestants, M=27.4; no religious affiliation, M=27.8; $p \leq 0.05$);
- having some 'other' political affiliation (nationalists, M=26.2; unionists, M=27.8; other, M=28.1; refused to answer, M=26.9; $p \leq 0.01$);
- not having a limiting long-term illness or disability (M=27.4 v M=26.3; $p \leq 0.01$);
- a self-reported health status of excellent/good (poor, M=26.3; fair, M=25.5; excellent/good, M=27.8; $p \leq 0.001$);
- being on the ODR (M=28.8 v M=26.5; $p \leq 0.001$).

Figure 13: Frequency of responses for each item on 'perceived benefits' subscale (n=1,012)

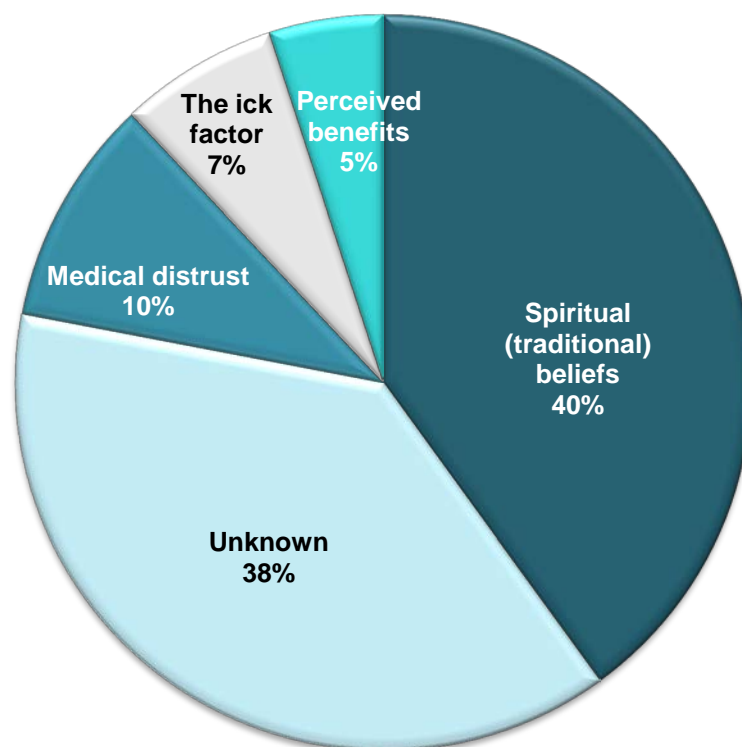


3.3.5 What drives people's attitudes towards organ donation?

Figure 14 provides some context to the factors underlying attitudes towards organ donation. The most powerful single driver behind attitudes towards organ donation in the Northern Ireland population is 'spiritual (traditional) beliefs', which accounts for 40% of the variance. It is important to note that this factor may not relate to the perception that organ donation is against people's religion per se. This factor may also include people's attitudes towards burial and funeral rituals that once had religious significance but have now become ingrained in Northern Ireland culture and traditions.

The driver behind a further 38% of the variance is currently unknown but may include factors such as anxiety, fear of death etc, which were not measured in the current survey. 'Medical distrust' accounted for 10% of the variance, the 'ick' factor accounted for 7% and 'perceived benefits' accounted for 5%.

Figure 14: What drives attitudes about organ donation? (n=1,012)



3.3.6 Summary of factors underlying attitudes towards organ donation

Table 5 offers a summary of the associations between key variables and the factors underlying attitudes towards organ donation. Although there was some variation in significant relationships between some variables (such as Health and Social Care Trust area, political affiliation and gender), a consistent pattern emerged. Positive attitudes towards organ donation (ie scoring high on 'perceived benefits' and scoring low on 'spiritual (traditional) beliefs', 'medical distrust' and the 'ick' factor) were consistently associated with:

- being aged 16–64 years;
- belonging to socioeconomic groups ABC1;
- having no religious affiliation;
- being in excellent/good health;
- having no limiting long-term illness or disability;
- being registered on the ODR.

Table 5: Summary of associations between attitudes towards organ donation and key variables

Key variable	Factors underlying attitudes towards organ donation			
	Spiritual (traditional) beliefs	Medical distrust	The ick factor	Perceived benefits
Gender	NS	NS	NS	Females*
Age	>65**	>65**	>65***	16-64**
Socioeconomic group	C2DE***	C2DE***	C2DE***	ABC1***
HSC Trust	Western**	Belfast*** South Eastern	Northern** Western	Southern*** South Eastern
Urban/rural	NS	NS	Rural*	NS
Religious affiliation	Catholic	NS	Catholic* Protestant	None*
Political affiliation	Nationalist***	Nationalist***	NS	Other**
Limiting long-term illness or disability	Disabled***	Disabled***	Disabled***	None**
Health status	Poor***	Fair*** Poor	Poor***	Excellent/good***
ODR status	Not registered***	Not registered***	Not registered***	Registered***
Exposure	NS	None**	NS	NS

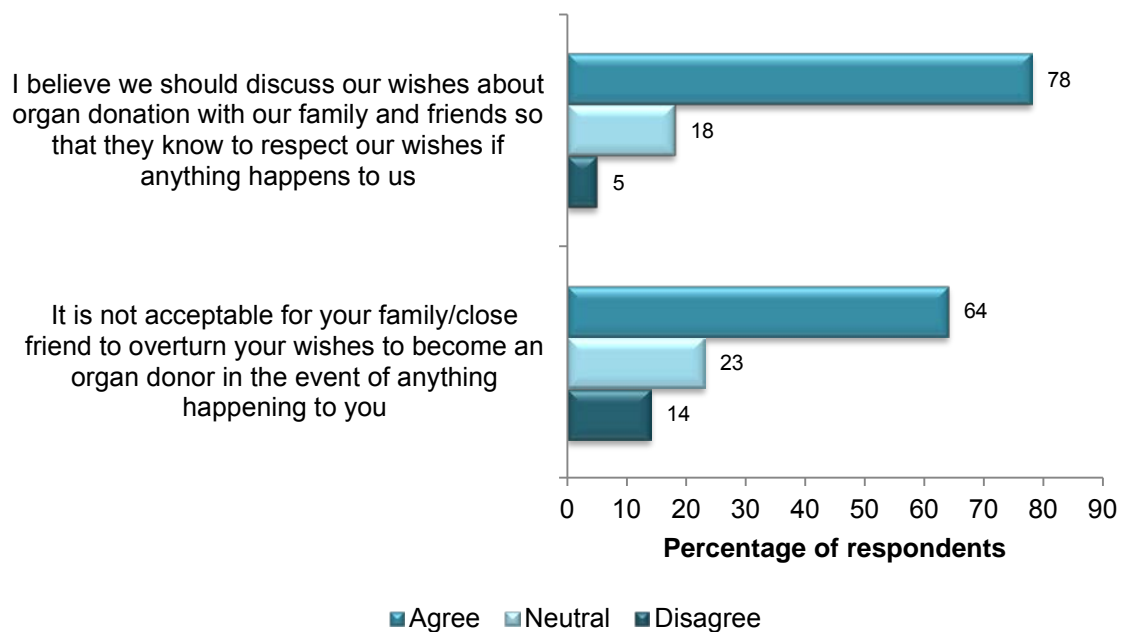
***p≤0.001; **p≤0.01; *p≤0.05; NS denotes not significant

3.4 Discussing donation wishes

The majority of respondents (78%) agreed that discussing your donation wishes with your family and/or friends is important (Figure 15). Agreeing with the statement 'I believe we should discuss our wishes about organ donation with our family and friends so that they know to respect our wishes if anything happens to us' was significantly associated with being aged 16–64 years, belonging to socioeconomic groups ABC1, living in rural areas, being in excellent/good health, being on the ODR, and being exposed to organ donation.

Two thirds of respondents (64%) agreed that 'it is not acceptable for your family/close friend to overturn your wishes to become an organ donor in the event of anything happening to you'. Those more likely to agree with this statement were in good health and registered on the ODR.

Figure 15: Attitudes towards discussing organ donation wishes with family/close friends (n=1,012)

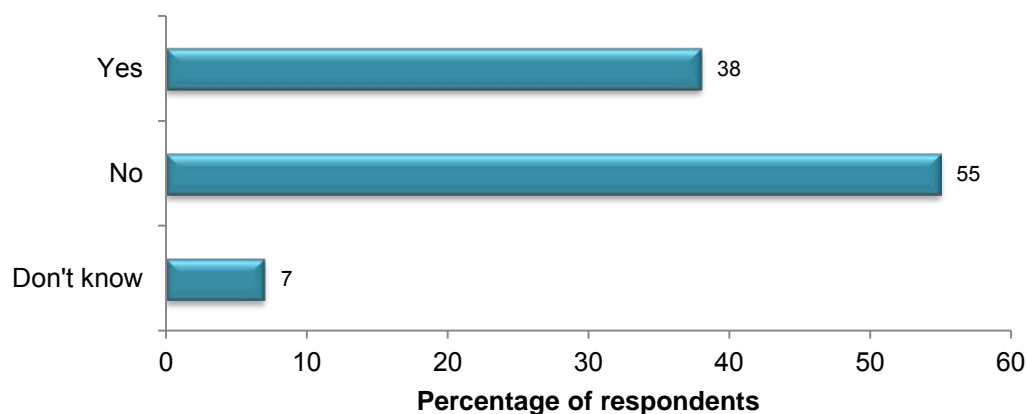


Despite the majority of respondents being supportive of having a discussion with your family/close friends about your donation wishes, only 38% of the full sample had discussed their donation wishes with their family (Figure 16). Having discussed donation wishes with your family/friends was associated with females, being aged 16–64 years, belonging to socioeconomic groups ABC1, not having a limiting long-term illness or disability, being in excellent/good health, being on the ODR, and being exposed to organ donation.

Having discussed donation wishes with your family/close friends was also associated with:

- low 'spiritual (traditional) beliefs' (M=14.9; not having discussed, M=17.4; didn't know, M=20.6; $p \leq 0.001$);
- low 'medical distrust' (M=18.6; not having discussed, M=21.8; didn't know, M=23.0; $p \leq 0.001$);
- low scores on 'the ick factor' (M=9.3; not having discussed, M=11.8; didn't know, M=12.4; $p \leq 0.001$);
- high scores on 'perceived benefits' (M=28.1; not having discussed, M=27.0; didn't know, M=22.9; $p \leq 0.001$).

Figure 16: Percentage of respondents who had talked to their family/close friends about donation wishes (n=1,012)

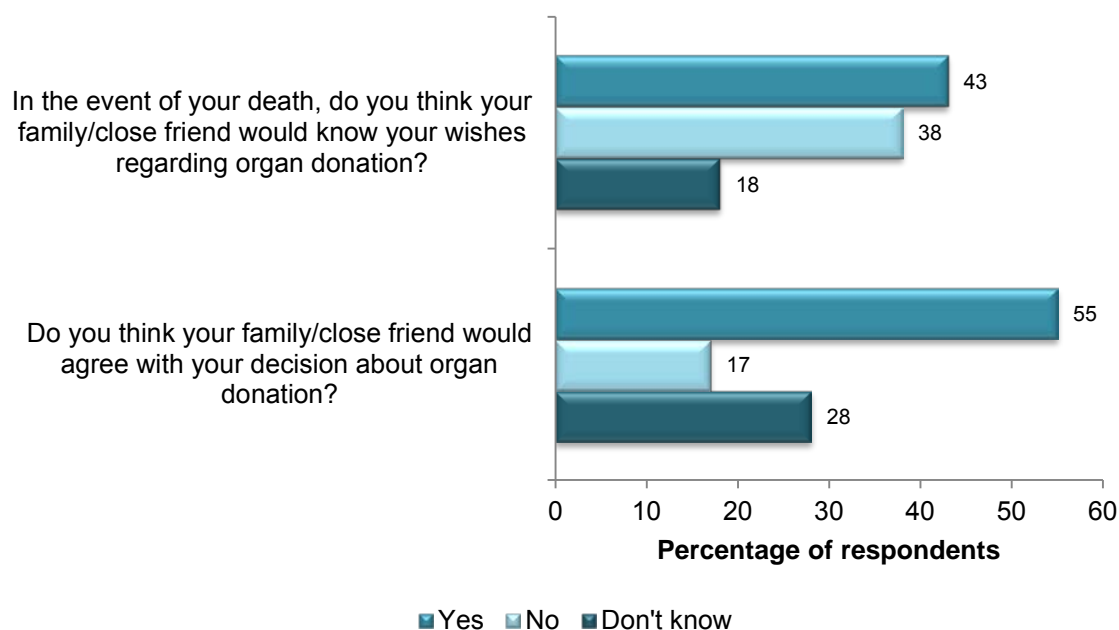


Another indication of discussing organ donation wishes within families was assessed by asking respondents whether they thought their family would know their wishes about organ donation. Approximately two out of five respondents (43%) believed their family/close friends would know their donation wishes (Figure 17) and just over half (55%) said they thought their family/close friend would agree with their donation wishes.

Agreeing that a family member/close friend would know your donation wishes was significantly associated with:

- being aged 16–64 years;
- belonging to socioeconomic groups ABC1;
- having no limiting long-term illness or disability;
- reporting excellent/good health;
- being on the ODR;
- having been exposed to organ donation;
- living in rural areas.

Figure 17: Family's/close friends' knowledge of, and agreement with, donation wishes (n=1,012)

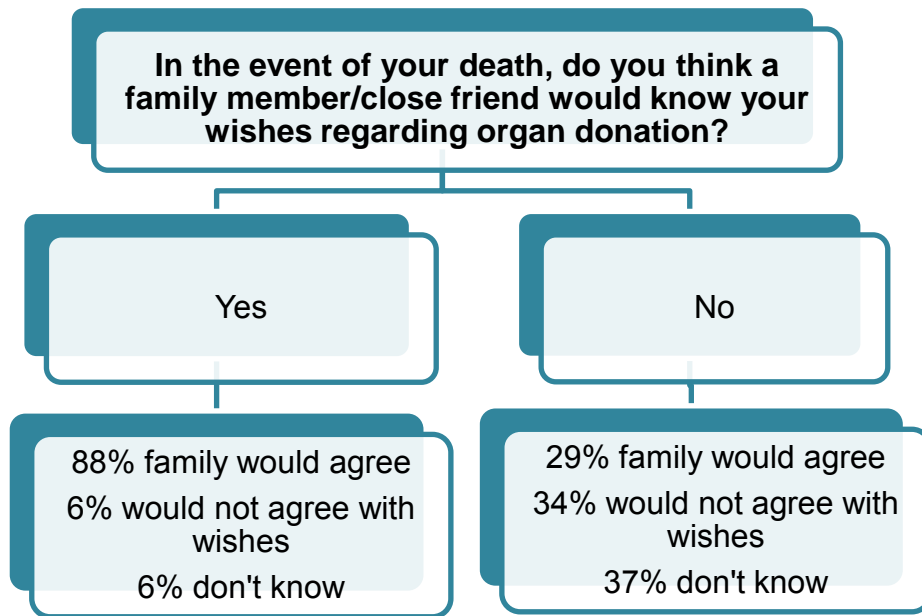


Eighty eight per cent of respondents who said they thought their family/close friend would know their donation wishes said they thought their family/close friend would agree with their decision (Figure 18). However, the proportion of respondents who said they thought their family/close friend would agree with their decision decreased to 29% in instances where they did not think their family/close friend knew their decision.

Whether respondents thought their family/close friend would know their wishes was significantly associated with:

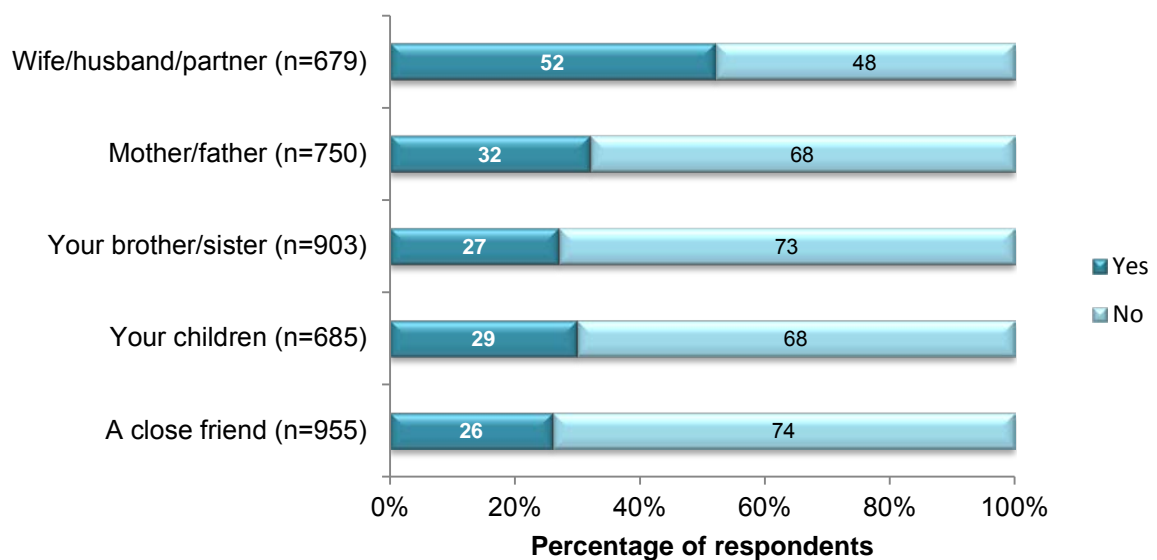
- low 'spiritual (traditional) beliefs' (M=15.0, wouldn't know, M=17.8; don't know, M=18.3; $p \leq 0.001$);
- low 'medical distrust' (M=18.6; wouldn't know, M=22.7; don't know, M=21.4; $p \leq 0.001$);
- low scores on 'the ick factor' (M=9.6; wouldn't know, M=11.7; don't know, M=12.4; $p \leq 0.001$);
- high scores on 'perceived benefits' (M=28.2; wouldn't know, M=26.6; don't know, M=26.0; $p \leq 0.001$).

Figure 18: Family's/close friends' awareness of, and agreement with, donation wishes (n=1,012)



Another measure used to provide some indication about whether family members discuss organ donation was to ask respondents whether they knew the donation wishes of their family/close friend. Figure 19 shows that just over half of respondents (52%) were aware of their wife/husband/partner's donation wishes, and a quarter (26%) were aware of their close friend's donation wishes.

Figure 19: Awareness of donation wishes of family/close friends



3.5 Willingness to accept organs

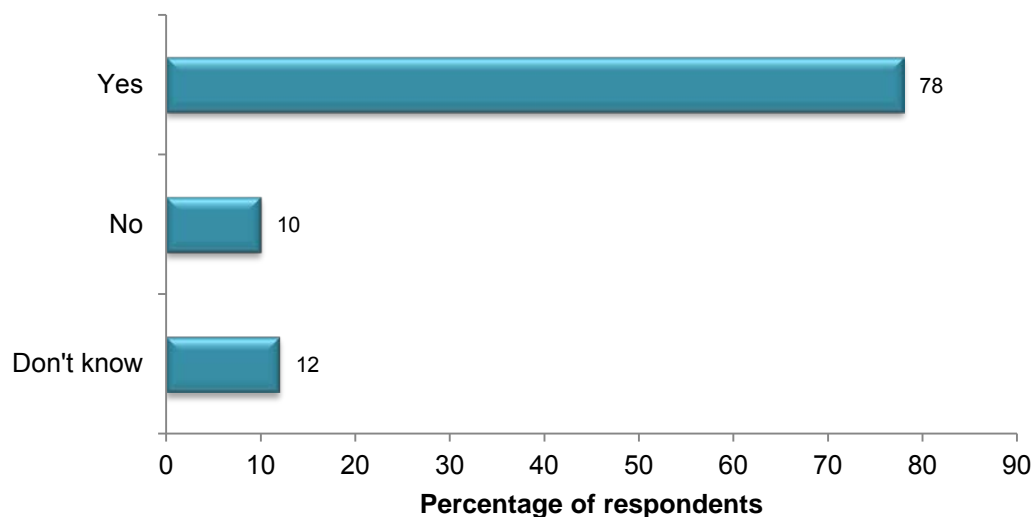
More than three quarters of respondents (78%) said they would be willing to accept an organ if they needed one (Figure 20). Willingness to accept an organ was associated with:

- being aged 16–64 years;
- belonging to socioeconomic groups ABC1;
- having no limiting long-term illness or disability;
- reporting excellent/good health;
- living in rural areas;
- living in all Health and Social Care Trust areas except Belfast;
- being on the ODR.

Willingness to accept an organ was also associated with the following attitudes towards organ donation:

- low 'spiritual (traditional) beliefs' (M=14.8; would not, M=26.9; don't know, M=20.9; $p \leq 0.001$);
- low 'medical distrust' (M=19.0; would not, M=27.9; don't know, M=25.4; $p \leq 0.001$);
- low scores on 'the ick factor' (M=9.9; would not, M=15.2; don't know, M=13.7; $p \leq 0.001$);
- high scores on 'perceived benefits' (M=28.4; would not, M=21.0; don't know, M=23.9; $p \leq 0.001$).

Figure 20: Willingness to accept an organ



3.6 Summary: Behaviours/attitudes and key variables

Table 6 summarises significant associations between key variables and behaviours/attitudes towards organ donation. Positive behaviours (including awareness of the ODR, being registered on the ODR, discussion of wishes, willingness to accept an organ) were consistently associated with younger ages (ranging from 30 to 64 years), socioeconomic groups ABC1, having no limiting long-term illness or disability, reporting excellent/good health, and being exposed to organ donation.

Table 6: Summary of behaviours/attitudes towards organ donation and key variables

Relationships between behaviours/attitudes and key variables						
Key variable	Awareness n=1012	Registered n=1012	Unlikely to sign n=174	Having discussed wishes n=1012	Family would know wishes n=1012	Willingness to accept an organ n=1012
Gender	NS	NS	NS	NS	NS	NS
Age	30–44**	30–44***	65+***	30–64***	30–64**	16–64***
Socioeconomic group	ABC1***	ABC1***	C2DE***	ABC1***	ABC1***	ABC1***
HSC Trust	Southern**	Belfast** South Eastern Western Southern	Western** Northern	NS	South*** Eastern Southern Northern Western	Southern***
Urban/rural	NS	NS	NS	NS	Rural***	Rural**
Religious affiliation	Protestant**	NS	Catholic*	NS	NS	NS
Political affiliation	Unionist***	NS	NS	NS	Unionist*	NS
Limiting long-term illness or disability	NS	None***	Disabled***	None**	None*	None***
Health status	NS	Excellent/ good*	Poor/ Fair***	Excellent/ good***	Excellent/ good**	Excellent/ good***
ODR status	N/A	N/A	N/A	Registered ***	Registered ***	Registered ***
Exposure	Exposed***	Exposed***	NS	Exposed ***	Exposed ***	Exposed**

***p≤0.001; **p≤0.01; *p≤0.05; NS denotes not significant

4 Public attitudes survey: registration systems

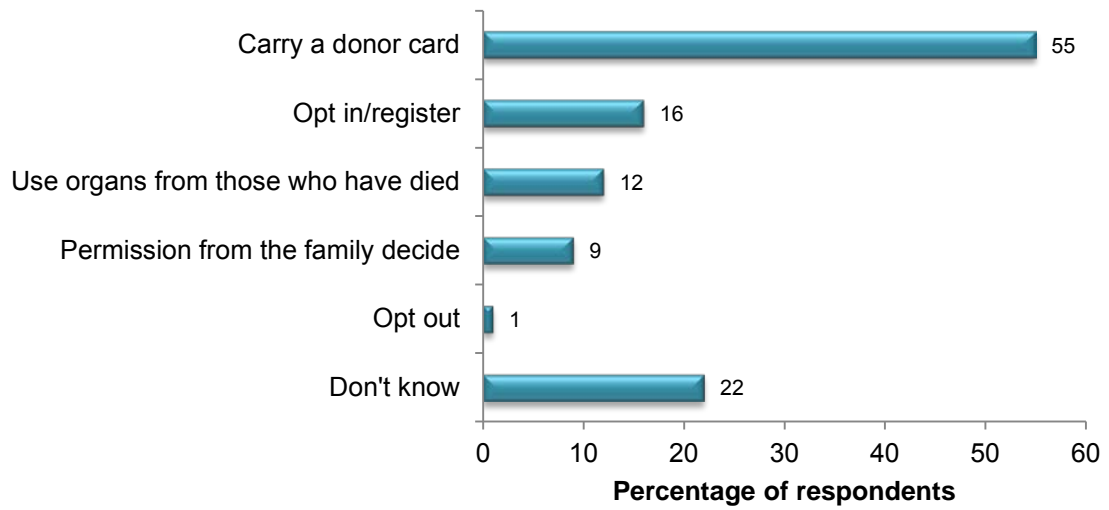
There are four different registration systems for organ donation that may be implemented. Each system is briefly described as follows:

Opt-in (informed consent):	Individuals actively put their name on a donation system to explicitly provide consent (or opt-in) that they are willing for their organs to be used after their death.
Soft opt-out (presumed consent):	Individuals are presumed to have consented to organ donation after their death unless they have actively registered their objections by opting out of the system. However, the family of the potential donor will be consulted to obtain final consent before organ retrieval.
Hard opt-out (mandated consent):	Individuals are presumed to have consented to organ donation after their death unless they have actively registered their objections by opting out of the system. In this case, family members are NOT consulted before organ retrieval.
Mandated choice:	Individuals are required by law to register their wishes or objections to organ donation (similar to completing the Census).

In conjunction with understanding respondents' attitudes and behaviours towards organ donation, the public attitudes survey also focused on gaining insight on respondents' understanding about registration systems. This included awareness of, and thoughts about, the current debate on the possibility of introducing a system of presumed consent (soft opt-out) as well as the current opt-in system.

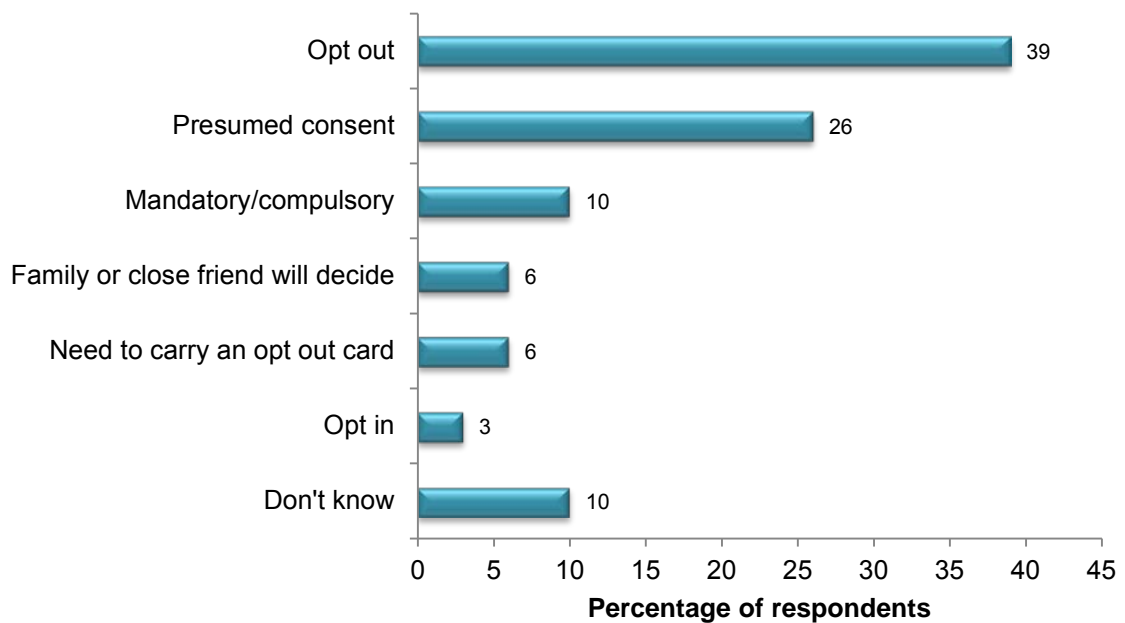
Figure 21 shows the variety of responses that respondents gave when asked, unprompted, about their understanding of the current registration system. The majority of respondents (55%) said you carry a donor card and 16% said you opt-in or register. Notably, 22% said they did not know and 1% thought the current system was opt-out. The variety of responses highlight that the public do not fully understand the current system for organ donation in Northern Ireland.

Figure 21: Understanding of the current registration system used in Northern Ireland (n=1,012)



Fewer than a third of respondents (29%) were aware of a current debate on the system of organ donation in Northern Ireland. Among those respondents who were aware of a current debate, 39% thought the system would change to an opt-out system and a further 26% thought presumed consent would be introduced (unprompted). Figure 22 shows other unprompted responses.

Figure 22: Ways in which respondents think the registration system in Northern Ireland will change (n=290)



4.1 Support for soft opt-out

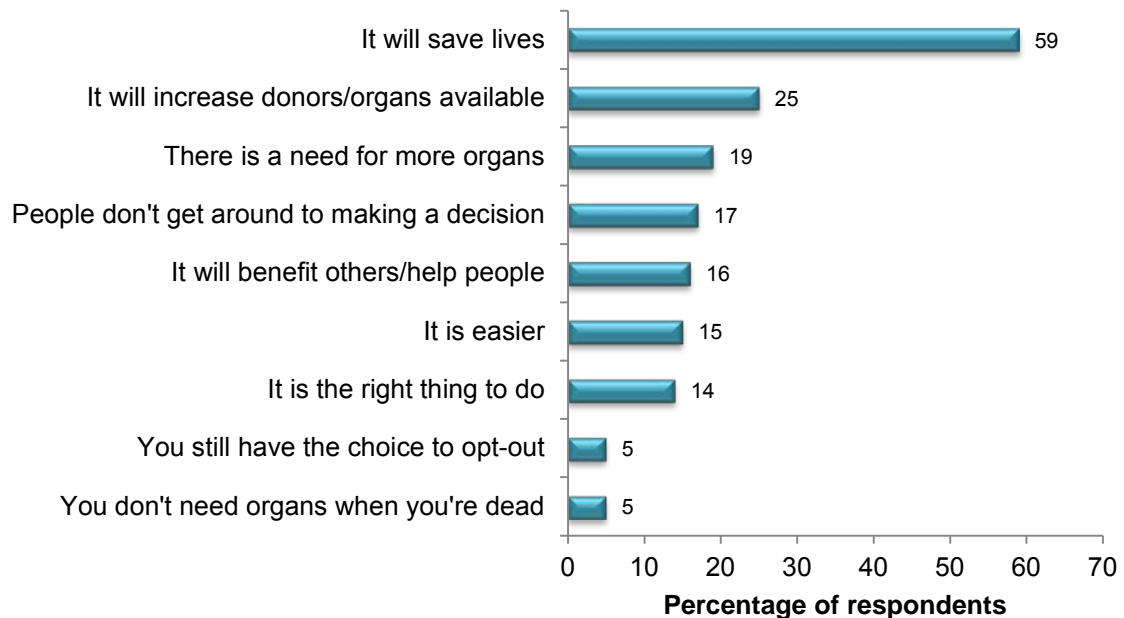
All respondents were presented with a statement describing the soft opt-out (presumed consent) system and asked to indicate whether they would support this type of system being introduced in Northern Ireland. Fifty six per cent of respondents said they were in favour of changing to a soft opt-out system, 18% said they were against, 8% said they needed more information to decide, and 18% said they did not know.

Being in favour of changing to a soft opt-out system was associated with:

- being aged 16–44 years;
- belonging to socioeconomic groups ABC1;
- having no limiting long-term illness or disability;
- reporting excellent/good health;
- being unionist;
- living in the South Eastern Health and Social Care Trust area (with Belfast being most opposed);
- being on the ODR;
- having been exposed to organ donation;
- scoring low on 'spiritual (traditional) beliefs', 'medical distrust' and 'the ick factor', and scoring high on 'perceived benefits'.

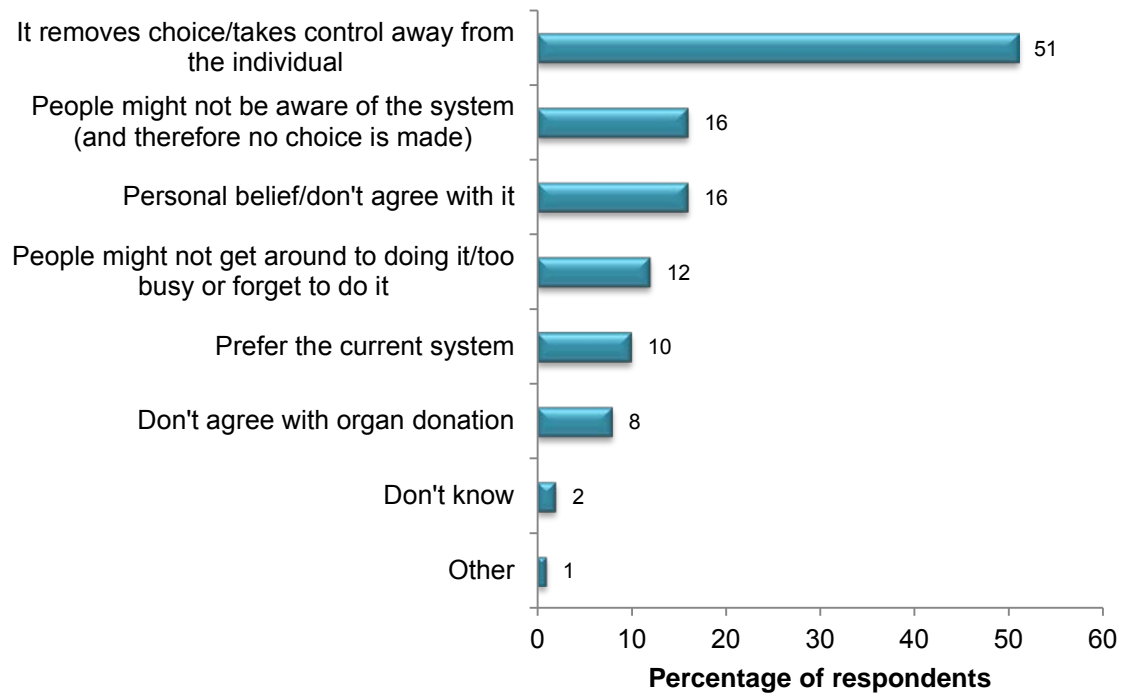
Figure 23 shows that the most common reason why 59% of respondents were in favour of changing to the soft opt-out system was because they thought it would save lives.

Figure 23: Reasons for being in favour of the introduction of a soft opt-out system (unprompted, n=570)



Of those who were against the introduction of a soft opt-out system, 51% felt it would remove choice/take away control from the individual (Figure 24).

Figure 24: Reasons for being against a soft opt-out system (unprompted, n=178)



However, the proportion of respondents who were supportive of changing to a soft opt-out system differed depending on how they were asked (Figures 25 and 26). Two questions in the public attitudes survey indicated support for changing to a soft opt-out system. Fifty six per cent of respondents said they 'would be in favour of changing to a system where it is presumed that I have consented to donation'. However, this decreased to 49% when respondents were asked to rate the extent to which they agreed with the statement 'everyone should be presumed to be an organ donor unless they register a wish otherwise'.

Figure 25: Proportion of respondents who were supportive of changing to a soft opt-out system (n=1,012)

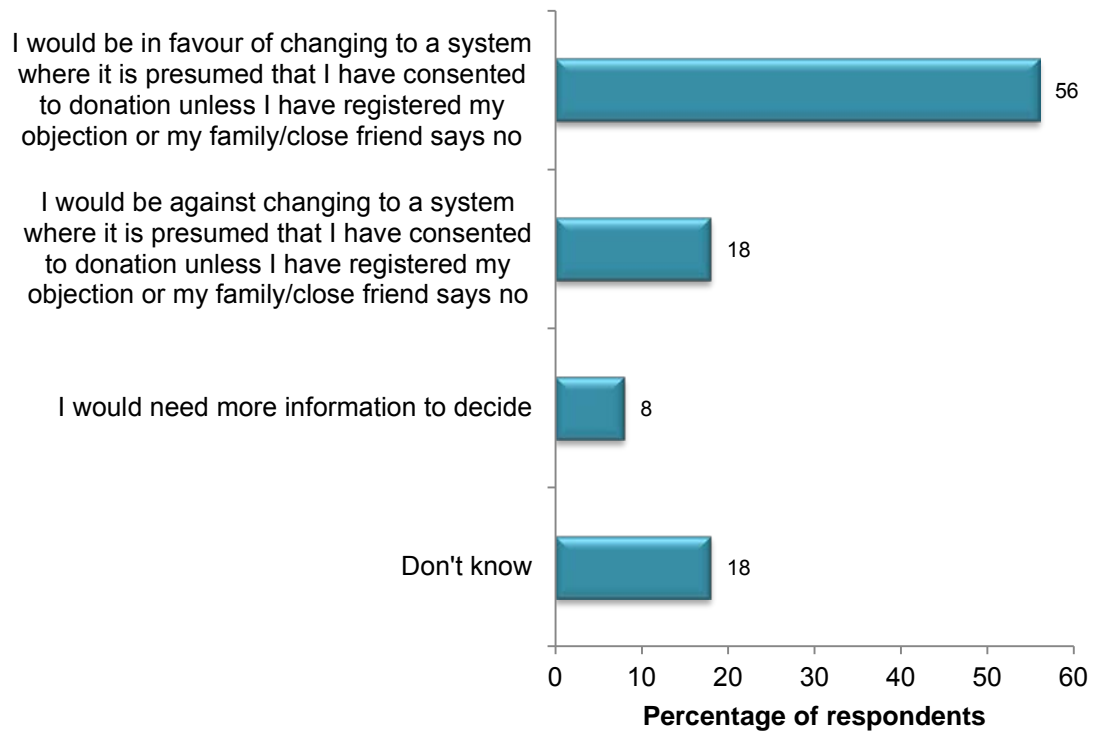
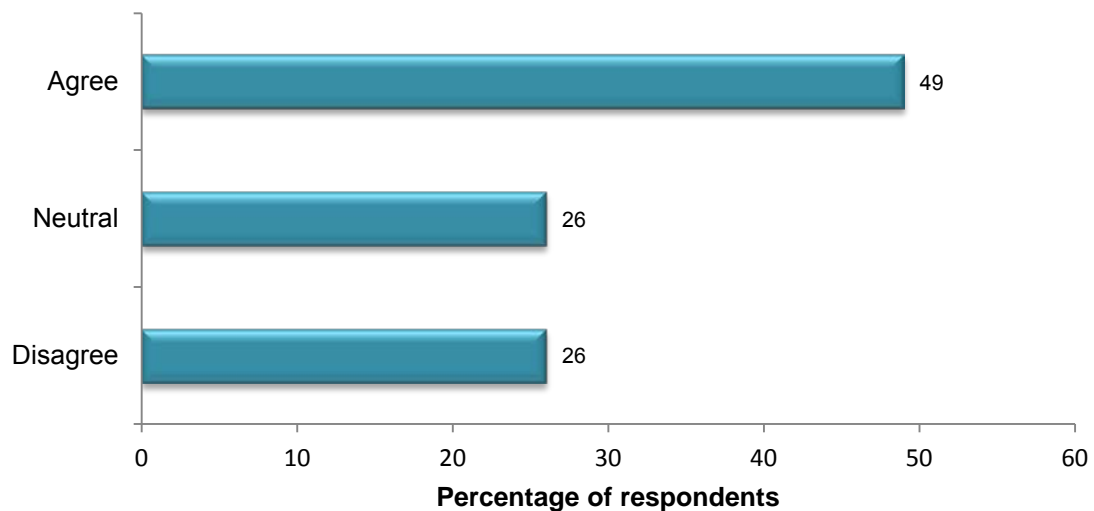


Figure 26: Proportion of respondents who agreed that 'everyone should be presumed to be an organ donor unless they register a wish otherwise' (n=1,012)



As well as being asked about support for changing to a soft opt-out system, respondents were asked whether they agreed with attitudinal statements relating to registration systems. The statements relating specifically to the introduction of a soft opt-out system are presented in Figure 27 (significant associations with key demographic variables are included in the SMR report).

Figure 27: Attitudinal statements relating to the introduction of a soft opt-out system

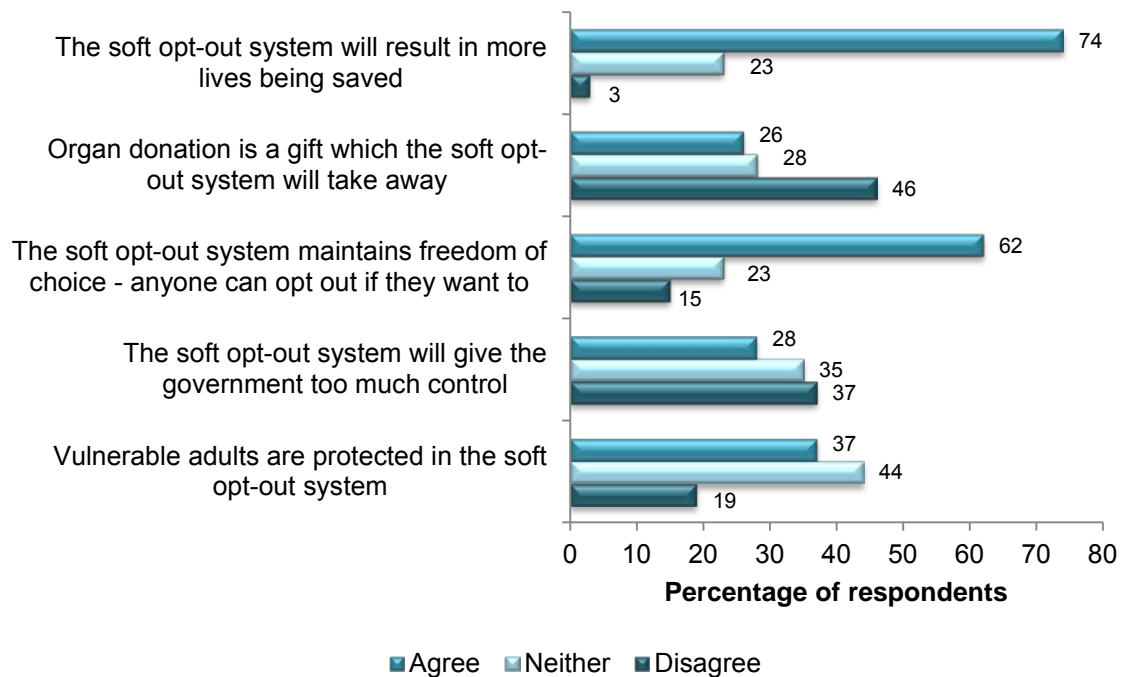
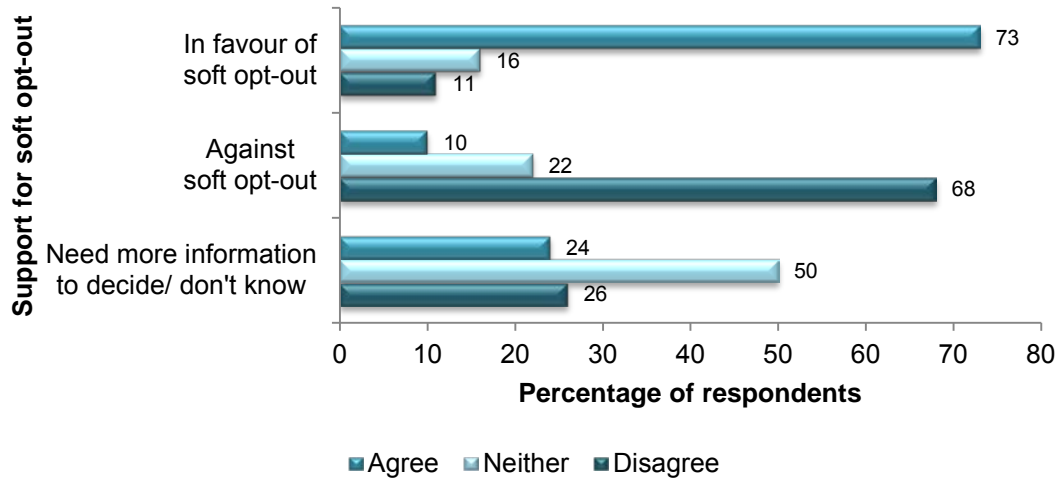


Figure 28 compares those who said they were in favour, or against, or needed more information/did not know about changing to a soft opt-out system, and those who agreed with an attitudinal statement that 'everyone should be presumed to be an organ donor unless they register a wish otherwise'. As can be seen below, 11% of those who said they were in favour of changing to a soft opt-out system disagreed with the statement, and a further 16% neither agreed nor disagreed. Conversely, 10% of those who said they were against changing to a soft opt-out system agreed with the statement, and a further 22% neither agreed nor disagreed. Similar patterns were also found among those who said they needed more information or did not know about changing to a soft opt-out system.

Figure 28: Agreement with 'Everyone should be presumed to be an organ donor unless they register a wish otherwise' (n=1,012)

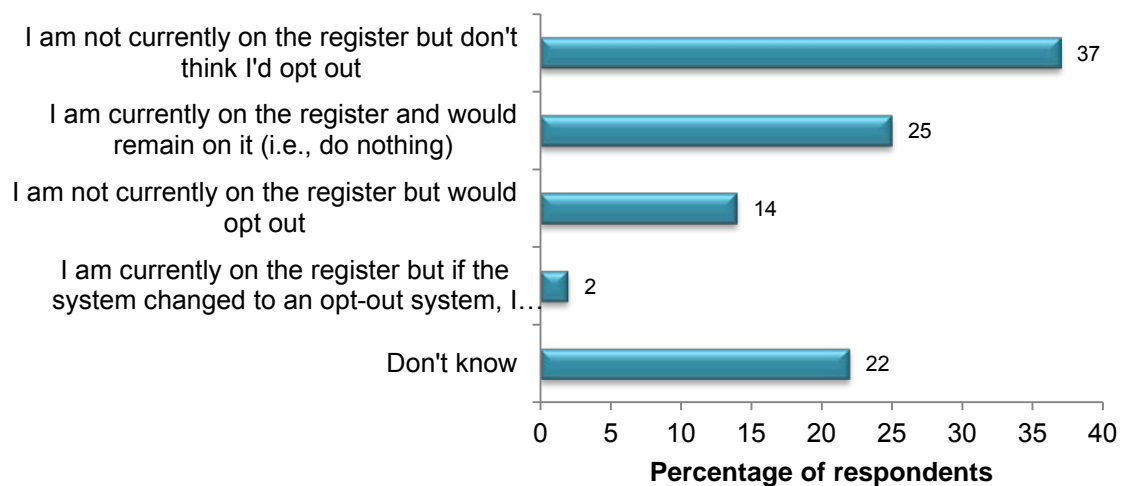


Of the full sample, 43% agreed with the statement 'more should be done with the current opt-in system before the government should change to an opt-out system' (38% neutral and 19% disagreed). Of note, 35% of those who said they were in favour of changing to a soft opt-out system also agreed with this statement.

4.2 Anticipated response if soft opt-out is introduced

In total, approximately 62% of the full sample said they would not register an objection if the soft opt-out system was introduced (Figure 29). Approximately 22% did not know what they would do and 16% indicated they would register an objection to donation if the soft opt-out system was introduced. This latter group included 2% who said they were currently on the ODR but would not provide consent if the legislation was introduced.

Figure 29: Respondents' anticipated reaction if the soft opt-out system is introduced (n=1,012)



4.3 Support for a mandatory system

The majority of respondents (54%) said they would be in favour of a mandatory system of registration being introduced in Northern Ireland and 59% thought GPs should collect this information when new patients register with them (Figures 30 and 31).

Figure 30: Support for mandatory registration system (n=1,012)

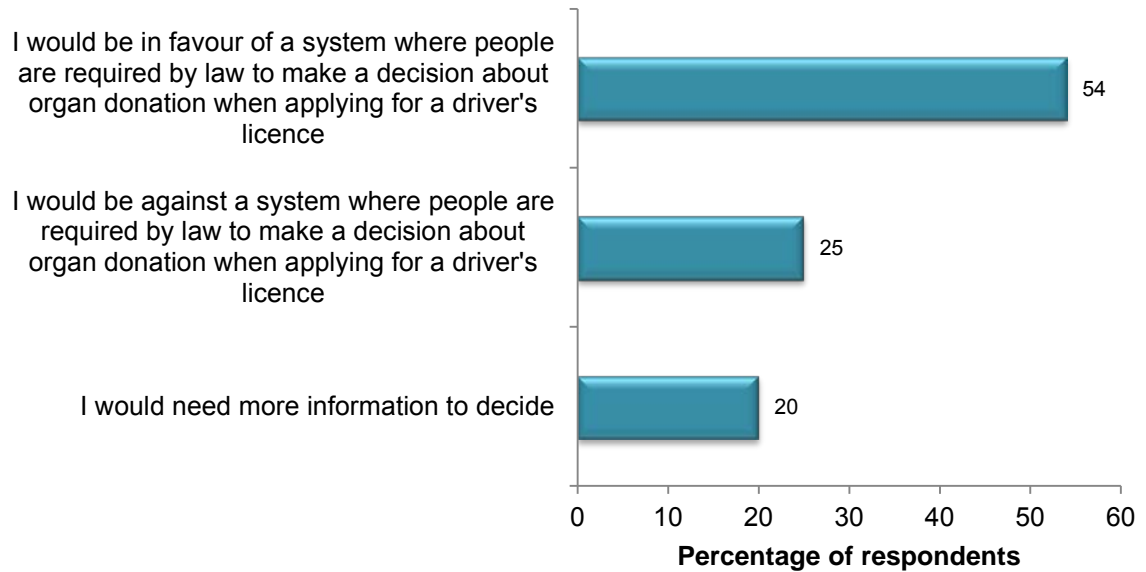
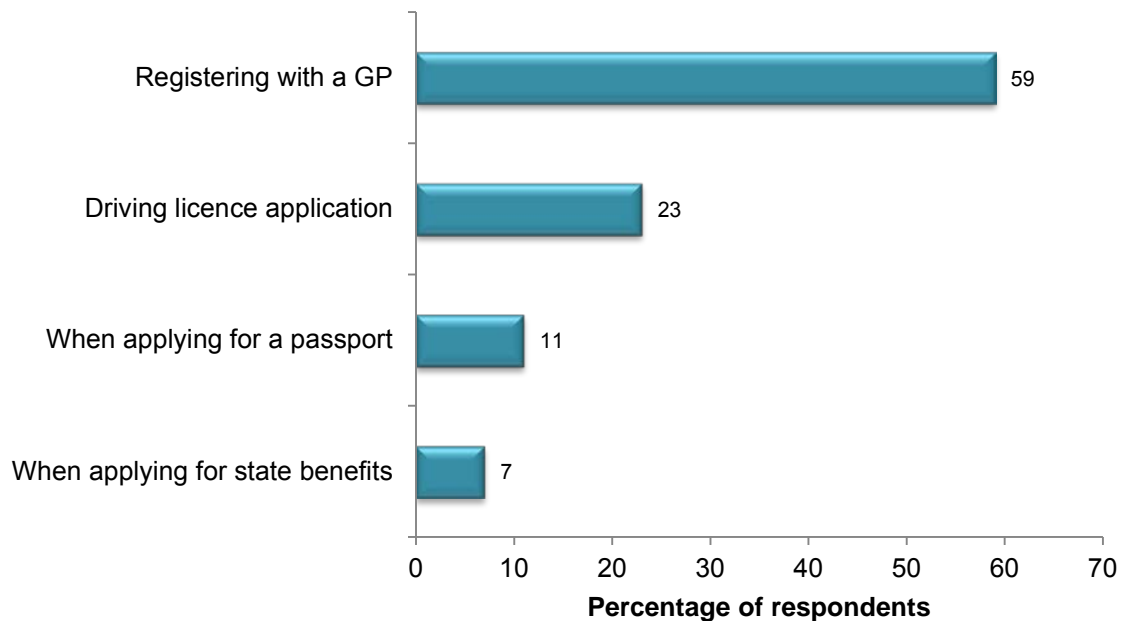


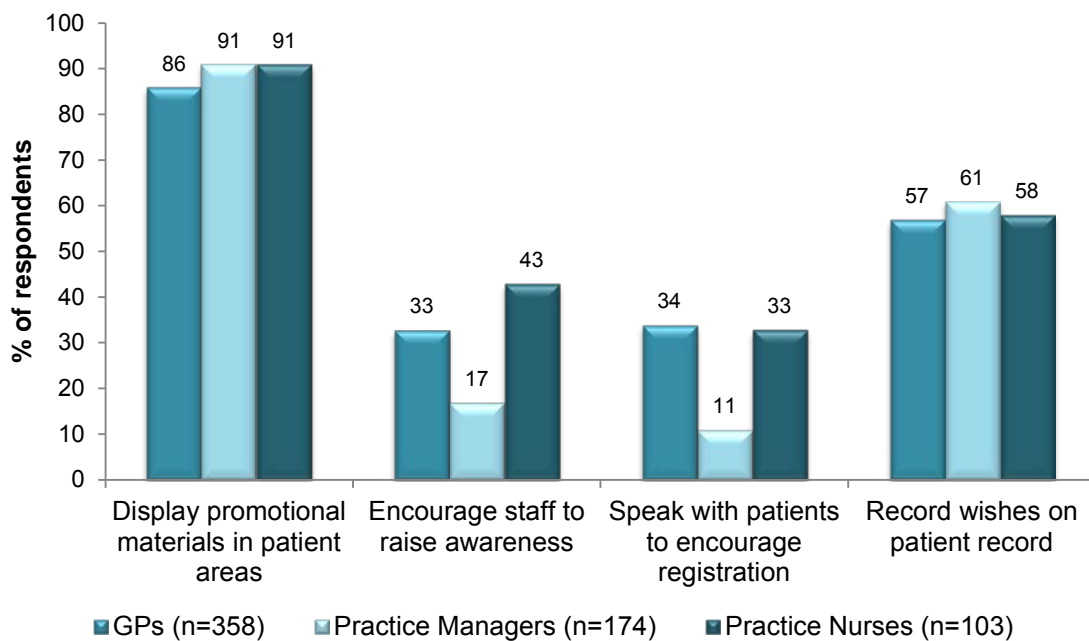
Figure 31: Respondents' preferred way to register their donation wishes if a mandatory system was to be introduced in Northern Ireland (n=1,012)



5 Willingness in GP practices to become more involved in promoting organ donation

In a recent PHA commissioned survey (unpublished), GPs, practice managers and practice nurses provided some indication of what they would be willing to do in their practice to help increase donation rates in Northern Ireland. Figure 32 shows the proportion of GPs, practice managers and practice nurses who responded positively to each of the options mentioned. Of note, they were willing to record wishes on patients' records and particularly willing to display promotional materials.

Figure 32: Willingness in GP surgeries for staff to become more involved in organ donation



6 Stakeholder engagement findings

This section presents key findings from discussion groups with stakeholders that sought their views and ideas about how organ donation can be improved in Northern Ireland. These groups were:

- charities, transplant recipients and those on the waiting lists;
- donor families;
- Health and Social Care (HSC) staff and the BMA.

Discussions included views on support for a public information campaign and also asked for views on legislation and presumed consent (see Appendix A).

6.1 Improving organ donation

Discussion groups initially considered how organ donation can be improved in Northern Ireland. There was consensus across all groups that organ donation needs to be normalised in Northern Ireland, and that it is important to provide the public with correct information, educating the general population about donation and dispelling myths.

6.1.1 Normalising organ donation

There was consensus that the key to improving organ donation is to break the taboo surrounding the topic of death and organ donation. This could be achieved by using sustained public information campaigns to educate the public, with particular focus on educating the younger generation. There was an expectation that normalising organ donation will result in greater discussion within families about donation and individuals' wishes as a result of reduced disgust or fear about the donation process. During discussions, participants provided the examples of Canada and Spain where organ donation is a cultural norm and noted that donation is higher in both countries than in Northern Ireland.

"It's about changing the perception of organ donation, it is a taboo subject so people do shy away from it and actually it is something we should take pride in!"

Stakeholders felt it is important to educate the public, particularly the younger generation, to ensure organ donation is a cultural norm in the future. Within groups, individuals differed in how they felt the younger generation could be educated. Some felt this should be included as a topic within the school curriculum. Others felt a range of social media targeting the younger generation would be more appropriate. Some felt organ donation should be discussed with secondary school aged children while others felt primary school aged children could be approached. However, all agreed the younger generation should be approached before they start applying for provisional driving licences, as this is a method used to register on the ODR. Any approach to children and/or young people should be handled sensitively and carefully, allowing for questions to be openly discussed and answered. The immediate outcomes of educating the younger generation would include: raising awareness of the ODR, encouraging registrations, and stimulating discussion about donation wishes within families.

Normalising organ donation within Northern Ireland was seen as an important step in preparing potential donor families before they are in the situation where they are being asked to provide consent to donation. There was recognition that making such a decision when in crisis or when distressed about losing a loved one is harder to deal with if the request for consent is unexpected.

There was consensus that normalising organ donation and breaking taboos surrounding death will result in higher rates of consent to organ donation and more lives being improved.

6.1.2 Provide correct information and dispel myths

There was a general feeling among stakeholders that knowledge about organ donation among the general public is generally low and needs to be improved. Stakeholders felt it is necessary to provide the public with accurate information to correct misconceptions and dispel myths about organ donation. It was noted that if organ donation is misunderstood, individuals cannot make informed decisions about whether they would like to donate and this increases the likelihood of declining to give consent to donation.

The following is information compiled from discussion groups that stakeholders felt it was important for the public to know:

- organ donation is a modern miracle that saves the HSC money (in comparison to treating those waiting for a transplant);
- the number of people waiting on a transplant;
- the number of lives that can be saved or improved from one person donating their organs;
- children who require a transplant are likely to need more than one in their lifetime;
- the length of time people can wait for an organ – there is not an endless supply of organs;
- you are more likely to need an organ than be a donor, and if you are willing to accept an organ then you should sign the register;
- family consent is required after death before donation occurs;
- the length of time taken for donation to ensure expectations are managed before potential donor families are in crisis;
- the treatment of the body after organ retrieval has taken place;
- the range of organs/tissue that can be used for transplantation and how different organs are used, especially the cornea.

In conjunction with providing more information about donation, stakeholders reiterated the importance of dispelling myths or addressing negative beliefs about donation. Some of the myths or beliefs were also cited as reasons for potential donor families to decline to give consent to donation. These include:

- signing the ODR means that you will be given poor quality treatment if you are admitted to hospital;
- signing the ODR means that treatment could be withdrawn early;
- organ retrieval means the body will be butchered/mutilated;
- donation is just for the young (you can actually donate organs until you are 80 years old);
- donation is just for those who are healthy;

- people are still alive when the decision about donation is made in cases of donation following brain death (donation is actually only considered when all treatment options are exhausted and the person has died);
- the heart/eyes are part of the soul;
- transplants are just for adults (people forget children also may need organs);
- the person suffers further by donating;
- not everyone who needs an organ should get a transplant because they have abused their bodies.

6.1.3 Other suggestions

In order to cope with the increase in transplant operations assumed to result from improving organ donation, stakeholders commented that it is necessary to improve infrastructure within Health and Social Care. This included making more resources available to help cope with more retrievals. Such resources included:

- improving facilities in ICUs to ensure they are comfortable and provide potential donor families with privacy;
- having more specialised staff to deal with donation;
- increasing capacity (theatres, ICU beds, staffing);
- quicker access to retrieval teams (via working with the Republic of Ireland) or having retrieval teams based in Northern Ireland.

Many were keen that registering on the ODR should be made easier. Whilst there are many ways to currently sign, there was some confusion about where and how to sign. As a means of raising awareness, many felt the ODR should have more identifiable branding or visibility (eg a badge or the donor card could be reintroduced as this association is still prevalent). Some felt that it would be beneficial for GPs to register patients' wishes at routine appointments, registration with the practice, or built into the Quality and Outcomes Framework. Other contact points with Health and Social Care (such as emergency departments, inpatient/outpatient appointments, etc.) were seen as further opportunities to ask people about donation. More shops and high street stores could adopt the approach used by Boots by encouraging people to register when obtaining loyalty cards and finally, making better use of social media.

A high proportion of potential donor families who do not consent to donation do so because they did not know their loved one's wishes. Consequently, some felt the ODR should request the signature/contact details of the next of kin who the person signing has discussed their wishes with. The act of giving another person's contact information could act as a way for individuals to initiate the conversation about donation.

In addition to making registration easier, some feel it should be easier to check the details held with NHSBT as some people do not know if they are registered or not.

Members of HSC staff in particular felt that public support for organ donation from key churches/religions would be useful in helping the public to understand the religious position and dispel myths.

6.2 A public information campaign: support and key messages

There was unanimous support among stakeholders for a public information campaign (PIC) to be conducted in Northern Ireland. However, all agreed that serious commitment needs to be devoted to a PIC and it needs to be well funded and sustained. The key aim of a PIC was perceived to be making organ donation a cultural norm.

6.2.1 Key messages

The key message of a PIC was simply to:

Consider your donation wishes and then tell your family

The family discussion was regarded as the most important message for a PIC because the family/close friend of all potential donors are currently asked to consent to donation regardless of whether the potential donor is on the ODR. A common reason for families of potential donors not consenting to donation in Northern Ireland is because they did not know their loved one's wishes. Having the family discussion removes the decision-making burden from the family, which reduces the likelihood of further distress if they are asked to consent to donation. It also ensures an individual's donation wishes are fulfilled. Finally, family discussion transcends registration systems which reduces confusion should legislation be enacted in Northern Ireland to introduce presumed consent.

While the family discussion was the preferred and key message, other suggestions included:

- advising individuals on how and where to sign on the ODR;
- asking people to consider the possibility that they might need an organ;
- providing factual information about donation (eg the number of people waiting for organs);
- messages to educate the public about the practical processes involved in donation;
- messages to dispel the myths associated with donation.

6.2.2 The approach

There was consensus that a PIC must have a positive focus, with any facts and figures being positively framed. For example, the number of lives that can be improved from a single donor should be the focus, rather than the number of people dying while waiting on a transplant.

Positive messaging should include the benefits to donor families in conjunction with recipients. Telling the personal stories of recipients and donor families and focusing on the benefits of donation was considered a worthwhile approach that would resonate well with the public and be memorable.

The benefits to recipients are well known, with their health and quality of life improving following a successful transplantation; but personal stories may add depth.

Benefits to the donor families were considered to be less well known among the general public. All donor families talked about the immense sense of pride they feel in knowing the positive impact their loved one had on the lives of so many others. Several participants felt that the testimony of comfort and pride felt by grieving families through their gift is a powerful tool. The public may also be more able to identify with the donor family story as the public are not required to think about the possibility of being sick and in need of a transplant.

Participants felt that the key to a testimonial approach was to use local people, some of which could be high profile to ensure public engagement with the messages. As the testimonial approach was considered memorable, it was envisaged that the PIC should be like the Northern Ireland Road Safety advertisements: sustained and well known.

6.3 Registration systems

All stakeholders emphasised that all registration systems aim to maximise the number of organs available for transplantation purposes. Many felt that there have been improvements in organ donation in Northern Ireland over recent years. This was considered to result from the implementations of the Taskforce Report 2008, and in particular the introduction of Clinical Leads in Organ Donation and Specialist Nurses in Organ Donation (SNODs) into all ICUs in Northern Ireland. HSC staff commented on how SNODs are invaluable in liaising with potential donor families and working with them to maximise consent for donation. Furthermore, their presence in ICUs serves as a constant reminder of organ donation for other staff members. Donor families commented on how SNODs helped them to consider donation with minimum distress when they were approached.

6.3.1 The proposal to introduce soft opt-out/presumed consent

Discussion about the proposal to introduce a soft opt-out/presumed consent registration system in Northern Ireland was the only issue that resulted in differences between, and within, groups. All agreed that the current debate about the presumed consent system is successful in raising awareness about organ donation. However, many were confused about how the change would be implemented and the impact it would have.

Considering the differences that arose during discussions about the proposal to change to a soft opt-out/presumed consent system, stakeholders could be divided into the following groups (although some within group differences remained):

- charities, recipients and those on the waiting list;
- donor families;
- HSC staff;
- BMA.

Support for the proposed changes was highest among the BMA, charities, some transplant recipients and those on the waiting list. However, with the exception of the BMA, some individuals within discussion groups disagreed with the overall support for the proposed changes.

Whilst there was some support for the proposed changes among HSC staff, the majority were opposed to the introduction of a soft opt-out system in Northern Ireland. Notably, the greatest hesitation appeared to be associated with those who work closest to or directly with potential donors and their families. Some emphasised that they were not strictly opposed to soft opt-out legislation but felt it was not the right time.

6.3.2 Advantages of soft opt-out/presumed consent

Despite the concerns raised by stakeholders outlined above, some explained that soft opt-out/presumed consent legislation marks a cultural change for Northern Ireland that would encourage altruistic behaviour among the general population. For these stakeholders, a legislative change could only result in an increase in potential donors and therefore organs available for transplantation as it captures ambivalent individuals who never get around to signing the ODR. For those who were less certain about the increases in available organs but who fully supported soft opt-out/presumed consent, the proposed changes are better than not doing anything to raise the profile of organ donation.

Some stakeholders believed a change to soft opt-out/presumed consent will make it easier for HSC staff to approach the potential donor family and removes the decision-making burden from the family. Finally, it was noted by charities, recipients and those on the waiting list that increases in organ availability would result in significant economic savings for Health and Social Care.

6.3.3 Concerns about soft opt-out/presumed consent

All stakeholders whether or not they were supportive of soft opt-out/presumed consent identified a number of risks they associated with the introduction of soft opt-out/presumed consent system if it is not implemented carefully. If the risks are realised, stakeholders expressed concern that the change in legislation could result in a reduction in the number of donors and increase the risk of potential donor families declining consent to donation.

The risks identified included:

- feeding into medical distrust;
- gaining family consent;
- creating public confusion;
- making organ donation a political football.

6.3.4 Medical distrust

'Feeding into medical distrust' was a theme identified in the stakeholder engagement exercise that strongly echoed the findings from the public attitudes survey. It was noted particularly by medical staff that individuals have become less trusting and respectful towards members of the medical profession over recent years. As such, the public are increasingly likely to question the judgement of medical staff. This has been confounded by news reports of scandals about hospitals keeping tissue and other body parts and other scandals relating to incompetency and/or negligence. HSC staff in particular was concerned that the introduction of soft opt-out/presumed

consent could ultimately result in more conflict between medical staff and potential donor families. They noted that they were dealing with families in a highly emotionally charged situation and there can be complex family structures and within family conflict. HSC staff were concerned about a public perception that the focus for medical staff will be on 'harvesting organs' and the difficulty families have in accepting brain death may exacerbate difficulties associated with accepting end of life status and the withdrawal of therapy, which may, in turn, result in refusals. Furthermore, HSC staff expressed ethical concerns about end of life care and a perceived conflict of interest regarding patient care and death, particularly when dealing with donation following cardiac death (DCD).

HSC staff commented that recent scandals (such as Mid Staffordshire hospital, issues around the Liverpool Care Pathway) have focused on family dissatisfaction and a feeling that people had not been appropriately consulted or included in decisions made about their loved one's care. Some commented that a move to soft opt-out/presumed consent would result in further dissatisfaction and is a return to a paternalistic approach that Health and Social Care has moved away from.

Some stakeholders (donor families and HSC staff) expressed concern about an increase in litigation and particularly about the media publicity that could result from the first complaint from a family that may have had the slightest perception that their loved one wasn't given the appropriate care. Ultimately, this could have long-lasting devastating consequences for the credibility of organ donation.

6.3.5 Family consent

Family consent was perceived to be the most fundamental issue for increasing donation rates in Northern Ireland regardless of the registration system used. In the current opt-in system, the families of all potential donors are approached by HSC staff to seek consent for donation when medically appropriate. In the event of a soft opt-out/presumed consent system being introduced, it is unclear if this would still be the case, but from their own perspective, some staff said they would feel reluctant to approach a family where the loved one had opted out. Consequently, the pool of potential donor families who are approached could reduce from 100%, as is currently the case.

HSC staff (in particular) seemed to be of the view that the current ODR would not be used by the public in the soft opt-out/presumed consent system. They were also of the view that people who are ambivalent about organ donation would be unlikely to actively seek out an 'opt-out' register. This gave them the perception that they would not be able to provide families with any information about their loved one's donation wishes. They felt that this would increase the decision-making burden placed on families, increase the likelihood of conflict within the family and with HSC staff, and increase the numbers of families refusing to consent to donation. In contrast, other stakeholders (BMA, charities recipients and those on the waiting list) felt that those who do not want to donate would be highly motivated to register their objections to donation in a soft opt-out/presumed consent system. Consequently, they felt that a soft opt-out/presumed consent system would capture those who do not 'get around' to signing the ODR, which would decrease the burden on the family and make consent easier.

Some stakeholders (particularly HSC staff, donor families and some recipients) felt that a soft opt-out/presumed consent system reduces the likelihood that individuals

will discuss their donation wishes. Some feel that signing the ODR is a proactive declaration of wishes which may stimulate conversation among families.

Stakeholders who directly work with potential donor families were concerned that soft opt-out/presumed consent is a difficult concept to explain and understand. These stakeholders felt that explaining presumed consent may cause complications and increase tensions between family members and HSC staff at a time when emotions are running high. Their concern was that a lack of understanding and/or confusion about the consent system, confounded with grief, would increase the likelihood of refusals to donate while contributing also to feelings of medical distrust.

Finally, HSC staff considered the ODR to be a positive aid to initiating a conversation about donation with the potential donor family. They explained they could use the ODR as a softer way of asking about donation wishes if the potential donor was registered. These stakeholders felt that where wishes are clearly known through the ODR, it reduces the decision making burden on the family and makes it more difficult to go against their loved one's wishes. However, with the legislation change the family could potentially be approached by explaining that their loved one did not actively make a decision not to donate. So, their views about organ donation may be unknown, making the choice more difficult for the potential donor family.

“Approaching the [donor] family with the message that their loved one didn’t opt out is useless ... the response could be ‘they didn’t do lots of things doesn’t mean they agree with it.’”

“At the end of the day it’s not about [HSC staff], it’s about the donor family and opt-out makes it more difficult for the family to come to a decision.”

6.3.6 Loss of the notion that donation is a gift

All stakeholders considered that the notion that donation is a gift holds strongly for many, and is particularly important for both donor families and recipients. Donor families associated their sense of pride with the idea of donation being a gift that their loved one had given others. Recipients and those on the waiting list also spoke of the importance of donation being a gift. Some explained that it is psychologically difficult for some recipients to cope with the integration of someone else's organ into their bodies and this is confounded with the knowledge that someone had to die for their life to be saved or improved. The knowledge that donation is a gift that someone actively considered and decided to do helped them to cope with and accept the donation. Many stakeholders felt that soft opt-out/presumed consent is passive and may not require a donor to make a decision. They felt that a gift cannot be presumed and raises questions about whether donation is a gift or a duty and that it 'is hard to celebrate not signing a form'.

6.3.7 Creating public confusion

There was concern that discussion about changing the registration system to soft opt-out/presumed consent would cause confusion among the general public. Some reflected on the confusion within the organ donation community and felt that if those who are involved with organ donation are confused, then the general public must be

confused. In particular, stakeholders were concerned about the public understanding of what the soft opt-out/presumed consent system is, how it will work, whether the system has already changed, what will happen to organs, how to register objections, and how conflicts between registration systems used in Northern Ireland and other parts of the UK will be resolved. A major concern was that increases in public confusion may undo the work that has been done over recent years to increase ODR registration and donation rates and result in higher rates of refusals. Some felt that in the time between the discussions about proposed changes and the implementation of said changes (if the system is changed in the future) there may be reduced numbers of people signing the ODR as some already think the changes have been implemented.

6.3.8 Political football

The majority of stakeholders were concerned that the topic of organ donation and the possibility of introducing soft opt-out/presumed consent legislation was becoming a 'political football'. Introducing new legislation was perceived by some as a method by which politicians were making it look like they were taking action and public point scoring.

Some were concerned that introducing the legislation may invoke stubbornness among some of the public who may have been previously ambivalent about donating. Such individuals may react negatively to being told (rather than asked) to donate, this may antagonise them and increase the likelihood of them registering their objections to donate.

In addition to this, a small number raised the idea that some individuals may politicise soft opt-out/presumed consent legislation. Some individuals may perceive soft opt-out to mean that after death the body is 'state owned' but may not affiliate with the United Kingdom. This complication was perceived to be unique to Northern Ireland.

6.3.9 Changing opinions

Some stakeholders spoke about their changing attitudes towards the proposed legislative changes. Changes in attitudes were also noted to occur during the discussion groups when some individuals within the groups spoke of their concerns associated with the introduction of soft opt-out/presumed consent. Some explained that they were initially in full support of the proposed changes but their attitudes changed when they had further considered the implications and were more cautious about soft opt-out/presumed consent. This shift in attitudes resulted from consideration of issues around medical distrust and family consent, with many concluding they needed further evidence of effectiveness before the changes should be implemented in Northern Ireland. Some commented that soft opt-out/presumed consent legislation will be introduced in Wales and that there should be a delay in the system being changed in Northern Ireland to give time to assess its impact in Wales.

Some stakeholders were eager to find out more about how the soft opt-out/presumed consent system had worked in other countries. Some reflected on the use of Spain as an example of success for the soft opt-out/presumed consent system. However, other stakeholders (especially HSC staff) cautioned that donation in Spain is higher due to structural and cultural differences (a higher level of trust in the medical profession, and organ donation is accepted as the cultural norm) and differences between the health services (such as attitudes to 'medical futility', number of ICU

beds and different infrastructure). Such discussions led many to conclude that soft opt-out/presumed consent legislation will not make any difference to organ donation unless other changes are implemented.

6.3.10 Can more be done with the current system?

All stakeholders noted that a change in legislation would require awareness campaigns and education to ensure the public is well informed about how and when the change would be implemented, and how to register their objections if they wish to do so. Some stakeholders suggested that the resources required to do this could be directed to improving the current system. It was regarded that the latter option would cost less as the cost of legislation change would be avoided.

7 Discussion

7.1 Gaining support for organ donation – high potential to mobilise

Support for organ donation was high among the general population, with 84% supporting the general idea of organ donation for transplantation purposes. However, approximately one quarter of respondents reported having registered on the Organ Donor Register (ODR) (24%). Therefore, it is important to maximise support for donation by examining how to mobilise support into action.

One important finding from the public attitudes survey (PAS) is that one in three of those surveyed were not aware of the ODR. There was a high proportion of people in favour of organ donation who had either no awareness of the ODR or had not yet registered. Theoretically, it should be possible to mobilise this group of people and encourage them to register on the ODR. This means there is potential to encourage the majority of the Northern Ireland population to register as only 16% said they were not likely to sign the ODR. However, even within this latter group, there is potential to mobilise them into action by addressing their concerns about donation.

Awareness of the ODR was poorest among the youngest and the oldest age groups (ie 16–29 year olds and over 65 year olds). Analysis showed the youngest group being strongly in favour of organ donation. Therefore, addressing the simple issue of awareness of the ODR among young people may lead to quick gains in registration and ensuing promotion of the issue between friends and family members.

Mobilising some groups may be a simple matter of correcting some misinformation. For example, those who are over 65 years old, those who have a long-term illness/disability, and those who rate their health as fair/poor are among those least likely to have registered. This may be associated with the prevalence of myths surrounding organ donation. Dispelling the idea that organs from older people or from someone who has been sick or disabled are of no value may be encouragement alone.

For others, deeper held attitudes (including spiritual [traditional] beliefs, medical distrust, the 'ick' factor and perceived benefits) may shape their willingness to donate. With the exception of perceived benefits, the factors identified in the PAS reflected negative attitudes underlying the public's perceptions relating to organ donation. The negative attitudes were strongly associated with those in the C2DE socioeconomic groups, the over 65s, those with any kind of religious affiliation (compared with no beliefs), and those with a disability or in poor health.

Factors underlying attitudes towards organ donation were also significantly associated with knowledge about organ donation. High scores in knowledge were associated with low scores on spiritual (traditional) beliefs, medical distrust, the ick factor, and high scores on perceived benefits. Improving knowledge could help to shift attitudes and have a positive impact on donation-related behaviours. For example, increasing public knowledge about brain death or that doctors who deal with donation are not the same doctors that look after you if you are ill, may help to counter negative beliefs such as doctors 'will withdraw treatment earlier if you are a potential donor' and reduce medical distrust that impacts on positive donation-related behaviours.

Despite the fact that all major religions in the UK openly support organ donation and transplantation, some of the Northern Ireland population believe that organ donation is against their religion. Furthermore, some also believe that organ donation would 'displease God' and that the body needs to be 'kept whole for resurrection'. In discussions with HSC staff, potential donor families consider the state of the body following retrieval, whether it is possible to have an open coffin wake, and also the time it takes to get the body home, before providing consent to donation.

It is important to note that the spiritual (traditional) belief factor does not necessarily reflect spiritual beliefs per se. The majority responded that organ donation was not against their religious beliefs, yet this factor yielded the greatest explanatory power in relation to organ donation. This may reflect spiritual beliefs and traditions around burial rituals that have become ingrained in the Northern Ireland culture, as was highlighted during discussions with stakeholders.

Participants reflected that making organ donation a cultural norm in Northern Ireland would take time, especially considering cultural norms and spiritual (traditional) beliefs relating to death and burial rituals. Some spiritual (traditional) beliefs are unique to Northern Ireland making it difficult to compare Northern Ireland with other parts of the UK. Specifically, it was noted that burials are expected to take place within two/three days, with deviations from this being seen as unusual. Many felt that support from churches in Northern Ireland would be useful in helping individuals to understand the religious position regarding organ donation and in dispelling myths relating to the soul and burial. However, such beliefs were regarded as being deeply ingrained in our culture, meaning that making organ donation a cultural norm will require consistent and sustained effort.

The PAS suggests the need for public information and discussions with stakeholders highlighted unanimous support for a public information campaign which must be sustained and carry positive messaging. It is clear from PAS findings that there are different messages for different sections of the public. However many felt that the key message to get across to the public, aside from correcting misinformation and addressing attitude, is not just about the ODR but about discussion. Letting each other know our wishes, particularly among family members, is felt to be the key to gaining consent to donate, no matter what legislation is in place.

7.2 Opt-in or soft opt-out/presumed consent system

While there was unanimous agreement between various stakeholder groups on the need to improve organ donation in Northern Ireland and the need for a sustained public information campaign and education, views diverged on the issue of legislation and the proposal of a soft-opt out/presumed consent for Northern Ireland.

The majority of charity representatives were in support for a change to soft opt-out/presumed consent, feeling that it would signal a cultural change to the general public on the issue of organ donation. However, HSC staff in the Intensive Care Unit (ICU) setting and closest to the donor family scenario were least supportive of a change to soft opt-out/presumed consent, at the current time. There is a general feeling that presumed consent legislation will not change their current practice, however there are fears that a change to presumed consent will make approaching the family more difficult, it could risk trust with health care staff, lose organ donation credibility and risk gains that have been made in organ donation over the last five years.

The issue of medical distrust was a significant issue for HSC staff in the ICU setting, these include ethical concerns or concerns about a conflict of interest regarding end of life care, the perception that the public may have that the medical focus will be on harvesting organs and the perception that the public have much less respect for the health service and medical staff. This corresponds with findings from the PAS with regard to medical distrust and as such is something that needs careful consideration.

The issue of approaching the potential donor family is also important. HSC staff explained that currently families get asked about organ donation (where medically appropriate) if their loved one is on the ODR or not. This seems to be something not understood by other stakeholders or perhaps the general public. When this was explained to some stakeholders they wondered why there would be a need for change if this indeed is currently the case.

It seemed to be presumed by stakeholders that people would no longer feel the need to sign the ODR and there was some debate whether people would be more or less likely to sign an opt-out register. Those HSC staff members who feel that people would be less likely to sign an opt-out register feel that families are left with no record of wishes at all –making the burden of family decision making more difficult.

The idea of organ donation being a ‘gift’ was extremely important to some recipients, to some HSC staff, and particularly to the donor families. For some, the idea of a ‘gift’ is taken away with presumed consent.

Findings from the PAS and stakeholder engagement suggest that there is difficulty in understanding the concept of ‘soft opt-out/presumed consent’ and there are issues regarding the language used to explain legislation. A deeper consideration of presumed consent changed some people’s views in both the PAS and in some stakeholder discussion.

Support for organ donation is high among the general population, but the level of agreement declines with statements that suggest obligation, for example we ‘should’ all register or it’s ‘unacceptable’ not to donate. This suggests that a substantial proportion of the general public, while supportive of organ donation, may be in favour of donation being a personal choice. While 56% were in favour of a system in which ‘it is presumed that I have consented to donation unless I have registered my objection or my family or close friend says no’, fewer (49%) agreed with the statement ‘everyone should be presumed to be an organ donor unless they register a wish otherwise’, with some who agreed with the former statement then disagreeing with the latter statement.

This apparent contradiction may be explained by the wording in the first statement that shows family agreement is needed (soft opt-out). However, it is the family consent aspect that health care stakeholders particularly those in ICU (ie closest to the donation scenario) are concerned with if people no longer register their wishes.

In addition some stakeholders (particularly HSC staff, donor families and some recipients) felt that a soft opt-out/presumed consent system reduces the likelihood that individuals will discuss their donation wishes. Again, this might only be the case if use of the ODR also falls off. Findings from the PAS show that those who have signed the ODR are most likely to know and accept their family member’s wishes, suggesting that proactive signing of the ODR does encourage some family discussion.

Those who did not support soft opt-out/presumed consent were not necessarily of the opinion that it would not increase donation, but were concerned that the Northern Ireland public are not yet ready for it. There is a risk with soft opt-out/presumed consent that those who are currently ambivalent (haven't given it much thought/maybes) could take an oppositional stance, leading to a potential reduction in the availability of organs for donation.

In the PAS, 43% of respondents felt more could be done with the current system before there is need for change. Stakeholders were also of this opinion and felt that much would still need to be done to encourage organ donation with legislation change.

7.3 Implications for public information campaign

A well-resourced and sustained public information campaign was highly supported and welcomed by all of the key stakeholders. The public attitudes survey also indicated several objectives for a campaign that would ultimately increase donation in Northern Ireland. These include:

- increase awareness and knowledge of organ donation;
- increase awareness of the ODR;
- mobilise people who are currently ambivalent about donation;
- encourage people to discuss their donation wishes with their family/friends.

Both the public attitudes survey and the stakeholder engagement process highlight that a key focus of a campaign should be to encourage the public to discuss their donation wishes with their family/close friends. This clear message transcends any registration system likely to be used in Northern Ireland where family consent is crucial to donation.

Appendix A: Topic guide used for stakeholder engagement discussion groups

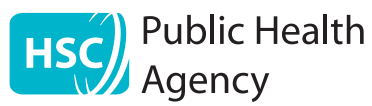
Organ donation stakeholder engagement Discussion guide June 2013
Introductions
What do you think could be done, and by whom, to improve organ donation in Northern Ireland? Prompts: <ul style="list-style-type: none">- By Government, HSC, public, media etc.- What do you feel are the main issues for the public and why?- How could the public be better informed about organ donation?
Would you be supportive of a public information campaign for organ donation? Why do you say this? What do you think should be included in a public information campaign on organ donation? Prompts: <ul style="list-style-type: none">- What should be the key message(s) of a PIC?- Approach?
What are your views about the current registration system for organ donation in UK? What do you think are the main influences for potential donor families when they are considering consent? Prompts: <ul style="list-style-type: none">- What would make the consent choice easier? What are your views about a soft opt-out/presumed consent registration system for organ donation? What do you think the impact would be of introducing a presumed consent (soft opt-out) system in Northern Ireland? Prompts: <ul style="list-style-type: none">- On the number of available donors- Number of available organs for transplant

Appendix B: Additional tables

Table 7: Knowledge score by key variables in public attitudes survey (n=1,012)

		Knowledge score	
		M	n
All		3.3	1,012
Gender	Male	3.1	495
	Female	3.3	517
Age***	16–29	3.0	275
	30–44	3.4	265
	45–64	3.4	289
	65+	2.9	183
Socioeconomic group***	ABC1	3.5	466
	C2DE	2.9	546
Trust area***	Belfast	2.9	200
	Northern	3.2	273
	South Eastern	2.9	190
	Southern	3.5	182
	Western	3.7	167
Urban/rural***	Urban	3.1	728
	Rural	3.6	283
Religious affiliation*	Catholic	3.2	354
	Protestant	3.1	441
	None	3.5	190
Political affiliation	Nationalist	3.1	209
	Unionist	3.0	370
	Other	3.1	68
	Refused to answer	3.5	365
Limiting long-term illness or disability***	Yes	2.9	265
	No	3.3	747
Self-reported health status***	Excellent / Good	3.3	708
	Fair	2.9	224
	Poor / Very Poor	3.0	80
Registered on Organ Donor Register***	Yes	3.9	269
	No	3.0	743
Family/friend organ recipient, on waiting list or have you donated an organ*	Yes	3.5	229
	No	3.1	783

***p≤0.001; **p≤0.01; *p≤0.05; NS denotes not significant



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