



Ipsos MORI
Social Research Institute

Focus group consultation

Opt-out system for Organ Donation

A report prepared for NHS Blood and Transplant

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(March 2018)

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Executive Summary

In 2017 the British Government announced its plans to change the legal basis for organ donation in England to an 'opt-out' system, whereby it will be presumed that an individual has consented to be an organ donor after their death unless they have specifically recorded a decision on the Organ Donor Register to refuse to donate. This builds on similar changes introduced in Wales in December 2015, and alongside Scotland who is also consulting on developing opt-out legislation.

NHS Blood and Transplant commissioned Ipsos MORI to conduct qualitative research with the public and groups who may be less likely to engage in the formal written consultation process, and/or more likely to raise issues with the assumed consent model to seek their views on the best ways to implement the move to opt-out.

Alongside the Department of Health and Social Care's consultation on the opt-out system, Ipsos MORI conducted 26 focus groups across England over February and March 2018 with a number of Black and Asian Minority Ethnic (BAME) groups, faith groups, parents of children under 18 years old, and people temporarily resident in the country. Research participants were asked about their views of the current (opt-in) system, and then about what they thought about the proposed opt-out system, including the role of the family. Fictional case studies, in the form of short stories about hypothetical people, were used to stimulate discussion. Participants were also asked about any groups or individuals they thought should be excluded from the opt-out system, what the legal basis should be for visitors and temporary residents, and about the implementation of the system (communications, how decisions should be recorded etc).

General attitudes towards organ donation

- Participants were **generally supportive of organ donation**, recognising that it saves lives. Some expressed more willingness to donate if they knew their organs would go to a family member, whilst others raised concerns about donating to people who had abused their bodies.
- Several faith groups were unclear on their respective official teachings and felt **religion could act as a barrier to donation**. Reservations were raised with regards to:
 - Judaism: the belief the body should be buried whole;

- Christianity: Catholic funerals often require an open casket and burial within 3-4 days; and,
 - Islam: the need for the family to seek support from an Iman.
- Another barrier, related this time to tradition passed down through generations and expressed in the Black African and Afro-Caribbean groups, was the belief that you arrive in the world with all your organs and you should not leave without them.
- Focus group participants acknowledged that organ donation is a morbid topic, and one that people are typically uncomfortable discussing. There was a **broad lack of awareness about the organ donation process**, particularly in respect to the donor having to die in specific circumstances (i.e. in hospital, in intensive care) which surprised most.
- There were also a number of **common misperceptions** across the groups: that the body would be rushed away from the grieving family; that the donation process would slow down funeral arrangements; that organs would be retrieved, stored up and sold on the black market; that the body would not be treated with dignity; and that organs would be used for research. Additionally, within the Black African and Black Afro-Caribbean groups, there was a feeling that doctors are less likely to help you if you have decided to donate your organs.

Opt in vs Opt-out

- Across the groups there was **awareness of the existence of the Organ Donor Register**, with the exception of the Black Afro-Caribbean groups and those with international students. However, participants in most groups **lacked an understanding of the role of the family at the time of death**. Only a minority of participants were certain that they were actually registered on the Organ Donor Register, with participants often acknowledging that they had not encountered organ donor communications previously.
- There were a number of widely recognised **merits of the current system, including its simplicity as well as the choice and control** it promotes and provides. Additionally, the opt-in system was seen to give **the individual priority in any decision making**, much the same as in the creation of a will. To this extent, **participants struggled to see how family members *could* override an individual's decision to opt-in**. However, the current system was recognised as failing to address the lack of donors, and in particular within certain communities, due to the fact that **it relies on individuals being proactive and finding the time and mind-set to opt-in**.

- **Awareness of the proposed opt-out system**, and the fact it has been introduced already in Wales, **was low** and it was common for **participants to struggle to understand the concept of deemed consent**, where people will need to *actively decide to do nothing*. However, **the proposed opt-out system** – compared the current opt-in system - to some, **felt simple and was welcomed for having less onus on the role of the family** (with the possibility flagged of completing removing them). Participants **struggled to understand how people will still be able to opt-in under an opt-out system**, and some important suggestions were made around the phrasing of this message.
- The **opt-out system was seen to be a positive step with regards to increasing the number of donors**, and by shifting the responsibility to the minority who are not in favour of organ donation. It was also seen to **tackle a major flaw in the current (opt-in) system**: people putting off or forgetting to register to donate their organs. People who are strongly opposed to organ donation will make the effort to opt-out.
- It was also recognised that the **system itself will be a means for encouraging people to discuss their organ donation wishes with their family**, meaning that families will become more aware of what their loved ones would have wanted. These discussions, too, will **eventually normalise organ donation** as a topic.
- A number of concerns were raised about the proposed opt-out system, however. These included the **lack of choice**, which was sometimes linked to a distrust in government and questions over the government's true motivations. There was a feeling, too, that **the individuals' decision under deemed consent would be less clear** – whether they would have wanted to donate their organs or not. This “grey area”, as it was often described, was seen to place more onus on the family and healthcare providers.
- Some participants questioned whether it was necessary to move to an opt-out system, suggesting that an extensive communications campaign around the current system might achieve the same desired outcomes. Nonetheless communications and campaigns were seen as crucial under the proposed opt-out system, to ensure that people will not be donating their organs under the circumstances of deemed consent but out of ignorance.

The role of the family

- Participants spoke of the **difficulty of involving family members in decisions about organ donation**. Families will be in very distressed and devastated situations which may mean that they are not thinking straight or clearly, and **could make decisions that they later regret**. Several other issues were associated

with involving families. The fact that families may not have discussed their wishes with one another could result in families being unaware of what the individual would have wanted. Families, too, might not get along with each other and some worried about the negative implications of this. It was also felt that family members won't always agree with the decision of the deceased or they will assume that they held the same attitudes towards organ donation to those of their own.

- These concerns over the role of the family meant that **some participants called for a system which does not request the family members to be involved in the decision**. A suggestion, under a similar vein, was that families should only ever be informed but not asked.
- A general point made, however, was the **importance of encouraging conversations to be had within families**. This would mean that families are informed about each other's wishes so that these can be honoured, especially given that death is such an emotional time for a family to have to make that choice on the individual's behalf. A few **suggestions were made for how an individual's decision could be validated**, thus easing the pressure on families. For example, **including signatures on the Organ Donor Register alongside either an opt-in or an opt-out, and/or having a family member witness the decision**.

In the presence of an expressed decision

- On the whole, **in the presence of an expressed decision (either an opt-in or an opt-out), it was felt that the individuals' wishes should be honoured**, and that family members should not be able to override the decision. Whilst this view was not entirely universal, it was common and **participants often questioned the premise of the proposed opt-out system if families will still be able to override recorded decisions**. Some groups cautioned allowing the family too much power in the proposed opt-out system, which could run the risk that the system won't necessarily solve the current problem of the lack of organs on the register.
- Participants often talked about **an individual's expressed decision being binding**, much like the case would be if the person had made a will or expressed their funeral wishes. However, this assumed a number of important conditions that would need to be present at the time they made that choice. It was felt that the **individual would have had to have been in a fit state and were thus making an informed choice**; that **they would have had to have been aware of the new opt-in system**, understanding the requirement to opt-out if they did not wish to donate their organs; **they would have to have been old enough to**

decide for themselves; and enough time would have had to have passed under the new opt-out system to give them the opportunity to opt-out if they wanted to.

- In the **male Pakistani and Muslim groups**, there was an **additional assumption that the family would need to be involved in the individual's decision, for it to be binding** – and families probably would be involved anyway so would have previously approved it. For these participants, the family should only be able to override an individual's expressed decision if they were not aware of it.
- For some, the **recentness of an expressed decision, carried more weight** – and this was linked to a suggestion that the government should remind people to regularly update their decision. To others, however, the length of time that may have passed since the decision was recorded was irrelevant and it was the fact it was recorded/expressed that surpassed anything else.
- To some extent, **an opt-out was seen by some to be even more binding than an opt-in** – thus it was **even more important that a family should not be allowed to overturn the decision**. This was linked to the feeling that people who opt-out are likely to feel very strongly about it, and this could be for moral or religious reasons. Some participants were of the opinion that a family should be able to override an opt-in expressed decision, assuming they simply could not cope with donation going ahead, but they should not be able to override an opt-out decision.
- The involvement of the family, across some groups however, was more nuanced. **Participants in the Black Afro-Caribbean groups, for example, spoke of how the 'next of kin' should have the final say** even in the presence of expressed decision. This was because they were seen to be knowledgeable of the person's most recent wishes, with concern that some time could have passed since the decision was made. **Participants in other groups called for a means for individuals to be able to hand over authority to a family member once they pass**, even where they had opted in or out, giving them peace of mind that their family would not have to go ahead with a decision they were extremely uncomfortable with. And **whilst rare, there were occasions where participants suggested that families could override decisions so that organ donation could proceed for the greater good and so that a life could be saved**.

In the absence of an expressed decision

- Across all groups **participants struggled with the role of the family in the absence of an expressed decision**, and in particular where deemed consent would apply. Thus (though not universal) they argued for a greater role of the family in the proposed opt-out system under these circumstances. Families were seen to need to be consulted more in the absence of an expressed decision, therefore the opt-out system was seen to place more pressure on families.
- The reason why it was assumed that families would need to be more involved was because participants were **fundamentally concerned that individuals may not have been aware of the ‘automatic opt-in’, they may have been undecided (and so did nothing), or they may not have got round to opting out before they died**. Some **participants in the Black Afro-Caribbean groups were very clear that the family should always have the final say in the absence of an expressed decision**, because there was a **general distrust in the government** and a belief that the government will just remove organs otherwise.
- Not all who called for a greater involvement of the family went as far as to say that they should have the final say. Some indicated that they were happy for the **family to instead be consulted about any evidence which would suggest that the individual would not have wanted organ donation to proceed**. Assuming there were no grounds for objection from the family, in these circumstances, it was felt organ donation should go ahead.

Choice in an opt-out system?

- Whilst in some groups participants recognised that by not opting out, an individual would be making a choice (hence it was not the family’s role to override this), in most groups there was at least some failure to recognise the choice that the opt-out system will offer. Participants often spoke of a ‘grey area’ in the absence of an expressed decision, or referred to the individual being “in the middle” (i.e. they had neither opted in, or opted out).
- Across the groups participants came up with **a number of suggestions for ways in which an extra layer could be added, in the new opt-out system, that would help families be assured that organ donation was what the individual wanted** (i.e. where deemed consent would apply). These included providing a means for individuals to record their signature (electronically or physically), somewhere, to state that they had *not* opted out. In addition, participants thought of other ways that an individual could verify that they had not opted out, for example carrying a card around and using social media (such as Facebook) to

state that they had not opted out. Participants, too, thought it was important that the communications campaign was clear that individuals will still be able to opt-in. Another suggestion was the idea that, if they wanted to, **people could nominate someone else, a family member for example, to make the decision for them** where deemed consent would apply.

Exclusions and safeguarding

- Participants believed that **some exceptions to the general rule would also need to exist in the proposed opt-out system**, and particularly under the circumstances where deemed consent would apply. It was generally agreed that explicit consent should be required for:
 - all children under 16 or 18 (either through self-authorisation or parental consent), and that deemed consent should apply to young people aged 16 or 18.
 - People lacking mental capacity, unless they had legal capacity after the date of the opt-out system.
 - Temporary residents who have been in England for less than 12 months.
- It was felt that **those entering the country for periods of less than 12 months should have the option to opt-in to the register** for the duration of their stay, either as part of the process of applying for a visa or by specifically applying to the register, however they should *not* be included under the conditions of the opt-out system.
- A number of **concerns around older people** were raised too, relating to the extent to which older people can be considered capable of making a decision about organ donation because of possible loss of mental capacity. It was, acknowledged, too, that older people might not be as likely to be exposed to media campaigns around the proposed opt-out system and may, therefore, be unaware of a change taking place and what this will mean for them.
- There was a perception, albeit rare, that **those who die in England, and have agreed to organ donation, should be able to donate their organs to somebody in their home countries**. However, most non-resident participants disagreed, naming practical issues around the repatriation of organs and the nationality of organ receivers was irrelevant to them.

Implementing the opt-out system

- Overall, participants believed that, for the launch of the opt-out system to be successful and for organ donation to increase, the Government has to conduct a thorough public information campaign focus on:
 - o the new regulations
 - o the vital need for more organs
 - o the need to discuss organ donation with family members
 - o the possibility to formally opt out if they do not wish to donate their organs
- Such campaign should focus on people still have the freedom to make their own choices regarding organ donation.
- Participants agreed that **widespread campaigns could open a dialogue, and ultimately normalise discussions around organ donation** so that people feel comfortable talking about it and making their loved ones know about their decision to donate, or not donate.
- A number of methods were suggested to increase the awareness of marginalised groups, and participants highlighted the key role community and faith organisations, schools and GPs in raising awareness about the move to opt-out and organ donation in general.

1 Introduction

Last year, the Government announced plans to change the legal basis for organ donation in England to an ‘opt-out’ system, whereby it will be presumed that an individual has consented to be an organ donor after their death unless they have specifically recorded a decision on the Organ Donor Register to refuse to donate. This system, also referred to as “deemed consent”, builds on similar changes to legislation in Wales in December 2015. Scotland is also consulting on developing opt-out legislation.

The main rationale for introducing this change is that there is good evidence that over 80% of the population support organ donation and would be willing to be a donor after their death, but only 30% have signed on to the Organ Donor Register and/ or spoken to their family about their decision. Whilst most people say that they would be willing to donate their organs and tissue after death, comparatively few people record their decision on the Organ Donor Register. Families often refuse to allow donation to proceed if their loved one’s decision is not known and as a result, many people’s decisions regarding organ donation are not honoured. In 2016 3,144 families were asked to agree to organ donation. Although 1,972 supported donation, 1,172 families said decided not to allow organ donation because they were unsure, or did not know whether their relatives would have wanted to donate an organ or not (NHSBT, 2017)¹.

The Department of Health and Social Care launched a consultation last December aiming to gather people’s views on the opt-out system. The consultation asked three questions: ‘How much say should families have in their deceased relative’s decision to donate their organs? When would exemptions to “opt-out” be needed, and what safeguards will be necessary? How might a new system affect certain groups depending on age, disability, race or faith’.

1.1 Research aims and objectives

Alongside this wider consultation, NHS Blood and Transplant, the authority with the responsibility for organ donation in the UK, commissioned Ipsos MORI to undertake a series of focus groups with the general public and groups who may be less likely to engage in the formal written consultation process or more likely to raise issues with the assumed consent models to seek their views on the best ways to implement the move to opt-out. These groups were defined as follows:

¹ https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/4657/activity_report_2016_17.pdf

British and Asian Minority Ethnic (BAME) groups: As people from black and Asian communities are more likely to need an organ transplant, but are less likely to be organ donors and have a longer average wait for an appropriate organ to be found², it was particularly important that BAME communities were engaged with and any specific barriers to registration or donation found and understood.

Faith groups: Engaging with religious communities was also important to understanding any specific religious barriers to organ donation, and ways that these can potentially be overcome. Ipsos Mori's research for the Human Transplant Association in 2013, found that "religious considerations" was the second most common reason given for not wanting to donate any tissues or organs after death for use in medical research, mentioned by 11% of those who said they were unlikely to donate³. As religious perspectives on organ donation can vary, including within a religious group, understanding ways people from different faiths engage with and understand organ donation is important, particularly with variation of what is considered "death", and what should happen to a body following death.

Parents of children aged up to 18⁴: Where children are eligible to be organ donors, particularly young children, the decision of whether their organs can be donated will normally be made either entirely by, or in communication with, a parent or both parents. Therefore, any implications of changes to consent rules needed to consider how they would impact on this group.

People temporarily resident in England (e.g. overseas students, overseas temporary workers who would be resident in England for less than 12 months): As any change in the structure around consent could also potentially impact non-permanent residents, it was important to consult people from these groups are consulted.

The **aim of this research** was to explore the views on what more could be done in England to ensure that the overwhelming public support for organ donation is supported both within the legal system and in the NHS and that a person's decision to donate is supported whenever possible, covering both the general public and the specific groups discussed above.

More specifically, this research project sought to uncover the views and attitudes towards organ donation in England, covering the following questions:

² <http://www.nbta-uk.org.uk/why-should-i-register-as-a-donor/>

³ https://www.hta.gov.uk/sites/default/files/HTA_Stakeholder_Evaluation_Report_2013_Final_-_Public_Release.pdf

⁴ As this research is to be carried out in England, parents of children under 18 need to consent to organ donation. This varies in other areas of the UK.

- What are people's understanding and views of the current opt-in system;
- What are people's views of the opt-out system;
- What should be the role of the next of kin in decisions regarding organ donation and how can the burden on distressed families be reduced;
- Whether people think there are any exclusions and safeguards to the general rule of consent in future;
- What's the most important thing they think NHS need to think about when communicating the change and why;
- What are the barriers or enablers to better support people from black and Asian and faith communities;
- How to make it easy for people to make their decision known and keep it up to date.

1.2 Methodology

To meet these research aims, a qualitative approach was adopted, consisting of 26 discussion/focus groups with 7 to 10 participants each. Groups were carried out across England (see table below) over a six-week period. Each group lasted two hours in order to adequately explore the issues around consent (see the discussion guide in Appendix 1).

Participants were recruited to ensure that a range of demographic characteristics were represented within each group of interest including gender, age, and social grade. It was assumed that people who were strongly opposed to organ donation, and people (albeit rare) who had either direct experience of involvement in a decision around the organ donation for a deceased family member, or were organ transplant recipients, would have very specific, and different, views about organ donation and the consent process to the general public. They were therefore excluded from the recruitment process.

Fictional case studies, in the form of short stories about hypothetical people, were used to stimulate discussion. Participants were asked to comment on how they think the characters in the stories would feel or act in the given situation, what they would do themselves or what they think about the scenarios given. Slightly different scenarios were posed to parents, overseas students and temporary workers.

All participants were recruited by face-to-face on street recruiters using a screening questionnaire to identify the target groups, apart from temporary workers who were recruited through gatekeepers and support organisations. Recruitment screeners, participant information leaflets, and consent forms were provided to participants where appropriate. All participants were offered a financial incentive as a thank you for taking part.

Focus group consultation on the opt-out system proposed for organ donation

	Primary Respondent Quota	Location	Number of participants
1	African	Leeds	10
2	African	London	10
3	Afro-Caribbean	Manchester	8
4	Afro-Caribbean	London	9
5	Bangladeshi/ Pakistani- female	Luton	8
6	Bangladeshi/ Pakistani- male	Luton	7
7	Christian	Bradford	9
8	Christian	Brighton	10
9	Hindu/Sikh/Buddhist	Manchester	8
10	Hindu/Sikh/Buddhist	London	9
11	Indian	Bradford	9
12	Indian	London	7
13	Jewish	Manchester	8
14	Jewish	London	8
15	Muslim Male	London	9
16	Muslim Female	Birmingham	10
17	Overseas students studying in the UK	Manchester	8
18	Overseas students studying in the UK	London	10
19	Parents of children aged 0-17	Nottingham	10
20	Parents of children aged 0-17	Brighton	10
21	White British	London	9
22	White British	Birmingham	9
23	White Other	Nottingham	10
24	White Other	Leeds	9
25	Workers on temporary visas	London	8
26	Workers on temporary visas	London	10
Total number of participants			232

1.3 Presentation of the data

It is important to note that qualitative research is used to explore why people hold particular views, rather than to estimate or quantify how many people hold those views. Such research is intended to be illustrative rather than statistically representative of a wider population and, as such, does not permit conclusions to be drawn about the extent to which findings can be generalised to the wider population. When interpreting the findings from this research, it should be remembered that the results are based on a small number of people who have discussed the relevant issues in depth; the views stated here are not facts, rather they are the participants' perceptions and the truth as they see it.

1.4 Structure of the report

The report is structured around the topic guide used during the groups. The report presents findings around four main themes, namely:

1. Participants' perceptions on organ donation, and **views on the opt-in and opt-out systems**;
2. Participants' attitudes towards **the role of the family**, and especially their general expectations of their role as a close family member;
3. Participants' **views on the 'excepted' categories** of people for whom explicit authorisation;
4. And participants' **recommendations on how to successfully implement** the opt-out system.

1.5 Acknowledgements

Ipsos MORI would like to thank the team at NHS Blood and Transplant for their help and guidance with this study, as well as all of the volunteer nurses and other experts who gave up their time to attend the groups and help with field clinical queries. We would also like to thank all of those who participated in the research and shared their views with us. The research would not have been possible without them.

2 Opt-in vs Opt-out

This section explores attitudes towards organ donation, including awareness of the organ donation process and common misconceptions. Furthermore, it provides participants' views on the advantages and disadvantages of both the current opt-in system and proposed opt-out system.

2.1 Attitudes towards organ donation

For this research, participants were screened on the basis of support for organ donation, thus none of the recruited participants were **against organ donation in principle**. Overall, participants were very positive about organ donation and the most common reason for this support was because it **saves lives**.

If you don't need them [your organs], you've passed on and they can save someone's life, I think "Take it. I don't need it".

(Male, Black Afro-Caribbean group, Manchester)

You are going to give your organs to save someone's life and how amazing that would be.

(Female, Jewish group, Manchester)

You're going to die at some point, so you might as well help some people along the way. For me it's a positive choice, even though it's a negative subject.

(Female, Temporary workers group, London)

Some exceptions to this strong support were as follows:

1. For some participants, willingness to donate was linked with being able to choose who the organs go to. For example, several groups mentioned they would be **more willing to donate to a family member** and occasionally participants raised **concerns about donating organs to someone who had abused their body**.

Do you get to hear why that person needs that organ? That could be someone who abused their liver, alcoholic, and then you give that to someone and they destroy it.
(Male, Black Afro-Caribbean group, Manchester)

You think about a stranger, don't you, when you want to donate an organ? It might be different when it's within your family.
(Female, Indian group, Leeds)

2. Some parents were emotional about the idea of their **children donating organs**. However, they recognised they would likely proceed if in that situation on the basis that if their own children were ill they would accept another child's organs.

I think it'd be different if it was my children. I don't know why, I can't explain why. I suppose emotional, you don't want any of their body removed. I think eventually I would agree.
(Female, White Other group, Nottingham)

3. Although all major religions in the UK support the idea of organ donation⁵, several groups were unclear on their respective official teachings and felt **religion could act as a barrier to donation**. Within certain religious groups there was debate about whether organ donation was accepted or not.

Religious and cultural issues

Judaism

Some participants had reservations about organ donation as they believed the Jewish Law states you should be buried whole.

It's a grey area, you're not allowed to pre-plan [donation] in the Jewish religion. If it's life or death and you have to give a family member something, it's okay. But I think you need to be buried whole.
(Male, Jewish group, Manchester)

In contrast, others felt Judaism had progressed with the times, with one overriding rule that Jewish Law is subservient to the law of the land.

It's more modern now, the law has changed.
(Female, Jewish group, London)

⁵ <https://www.organdonation.nhs.uk/about-donation/what-does-my-religion-say/>

According to Jewish law, you can break the rules of Judaism if you are saving a life.
(Female, Jewish group, London)

Christianity

Though most participants agreed that the Catholic church supports organ donation, it was noted that Catholic funerals often require an open casket and burial within 3-4 days, both of which they felt were barriers to donation. However, similarly to the Jewish groups, some participants recognised the ability to save a life was more important.

Religion can come into it because in our religion [Catholicism] we're buried within 3 or 4 days, there isn't that window of opportunity. People come to sympathise with the loss of a loved one, two of those days that coffin is still open. After going through surgery for organ donation, you may not look your best.
(Male, White Other group, Nottingham)

I'm a Christian and it does say that we're supposed to be buried with all of our organs, but with this day and age and the society we live in, there are so many people we can help so I don't think that applies to me anymore. Yes, the Bible doesn't support that, but we live in a different world.
(Female, Black Afro-Caribbean group, London)

Islam

Some Muslim participants supported organ donation for ethical reasons, but felt unclear on the position of Islam and the views of their more traditional families. Although religion may not contribute to the opt-in decision, they felt their family would seek the support of an Imam at the point of donation which may act as a barrier.

When we look into it, religion doesn't tell you how to go about it ... As a human being, I would want to help someone and that's what it says in the script.
(Female, Pakistani/Bangladeshi group, Luton)

Tradition

Some Black African and Afro-Caribbean participants discussed some views commonly shared in their respective communities that because you arrive in the world with all your organs, you should not leave without them. Although the participants did not necessarily agree with this, they noted it was a tradition passed on by older generations and community members.

The BME community donate less ... you came whole, you die whole and that's the principle of Black people.

(Female, Black Afro-Caribbean group, Manchester)

Awareness and misconceptions

Most groups acknowledged that organ donation is a **morbid topic**, and that people are not typically comfortable discussing it. Possibly for this reason, there was a **broad lack of awareness about the organ donation process**, particularly in respect to the donor having to die in specific circumstances (in hospital, in intensive care) which surprised most participants.

It's interesting, why is it so important that you have to die in a certain way? I understand if you were to be poisoned or crushed your organs aren't going to work or they'll be contaminated. Is that the only couple of ways, or is there more?

(Male, Black Afro-Caribbean group, Manchester)

One of the more common misconceptions in the **Black African and Black Afro-Caribbean** groups was that **doctors are less likely to help you if you have decided to donate your organs**. This distrust applied to the government as well as doctors. This view was shared by some participants in other groups (e.g. White British) though not as strongly.

There is stigma involved in the Black community. It's the elephant in the room that no one wants to discuss. There's something we get from the generation above about mistrust, like if I was in an accident, the hospital wouldn't look after me as well because they want my organs. There is misinformation around some of the areas.

(Male, Black African group, London)

When I think about organ donation, I always think about doctors turning off machines and the 'let's grab what we can get' approach. Someone must have said it to me when I was really young but it's a negative thing that a lot of people think. So there's the idea that if you're not on the list, then maybe you'll be spared.

(Female, White British group, London)

The lack of awareness among participants led to a number of other **misconceptions** across groups, including:

- that the body would be rushed away from the family during their grieving time;
- that the donation process would slow down funeral arrangements or burial;
- that organs would be retrieved, stored up and sold on the black market;

- that the body would not be treated with dignity; and
- that donated organs would be used for research.

There was something on the news about that 3 or 4 years ago, a problem in how the bodies were treated afterwards. That's something else to think about, what happens once they've got what they want.

(Female, Black Afro-Caribbean, London).

Generally, participants were happy to discuss these misconceptions, and were reassured by the answers provided. Some participants recognised that it was a lack of information and misconceptions (particularly within certain religions and cultures) which created a barrier to organ donation.

It comes back to misinformation. Many people think that if you donate then they will take some bits and the rest will be put in the trash, but this isn't correct. They may just take one organ.

(Female, International students group, Manchester)

You need to know the right information. It's scary. Some of my family would tell me your body is going to be cut and my body parts are going all over the country.

(Female, Bangladeshi/Pakistani group, Luton)

2.2 Opt-in

Awareness and understanding

Levels of awareness and understanding of the current opt-in system were varied. In many of the groups, participants were aware that the existence of the Organ Donor Register and were **knowledgeable about how to sign-up** (i.e. driving license, boots card, GP surgery, cycling helmet, online). But in some groups (those with international students and Black Afro-Caribbean participants), there was a notable lack of awareness. Most groups **lacked an understanding of the decision-making process and role of the family at the time of death** (discussed further in section 3).

Even where participants were aware of the opt-in process, and supported organ donation, **only a minority were certain they were actually registered on the Organ Donor Register**. It was only in the Black Afro-Caribbean groups where there appeared to be a subtle reluctance to being on the register.

Where people were not registered as donors, it was mostly because they had not thought about it or got around to it, not that they were opposed to it. Often

participants thought they had opted-in earlier in life but could not specifically remember.

Most surprise arose from the fact that there is not a means for increasing awareness of the opt-in system, considering the demand for organs. Participants generally agreed they had **not encountered organ donation communications in the past**.

When you see how many people need [organ donation], you think they would make it a bigger deal, because it's weird that none of us know about it.

(Female, Jewish group, Manchester).

Advantages and disadvantages

Advantages

When explained how the current opt-in system works, participants were generally happy with the premise and thought it was a simple concept. A general theme across groups was that a **merit of the current opt-in system is the choice and feeling of the control** it provides. Participants were reassured that the system allows you to **explicitly state your desire**.

When you do register, you're making a very conscious decision, so you know exactly why you're doing it and for what, that's a big advantage.

(Female, International students group, London)

Participants felt the **clear opt-in decision** would ensure the individual has priority in any decision making, with some comparing the opt-in decision to creating a **will**. Linked to this was the common misperception that the family do not play a role in the decision, and most participants **struggled to understand why family members could override their decision** to opt-in (discussed further in section 3).

As long as you're of a sane mind when you make the decision, that's it. It's the same as a will. What's the point in writing a will, if it's not going to be enacted? Ultimately, as an individual, you've made the decision.

(Male, Indian group, Bradford)

Disadvantages

Some participants recognised that the **current system fails to address the crux of the problem which is a lack of organs**, and there were links made to a lack of donors and a high demand within certain communities.

We don't have enough [organs], there's still a shortage, it needs to be improved or changed.

(Male, Jewish group, Manchester)

I was in favour of the opt in system until different sets of friends needed organ donations, and I've recently become a dad. Now I think that if someone feels so strongly about not giving their organs then they can take 15 minutes to fill in a form to opt out. A lot of people I've spoken to about it can't really be fussed to fill out the forms, or they don't know where to get them.

(Male, Black African group, London)

Most commonly, the conversation returned to the fact that an **opt-in system relies on individuals being proactive, finding the time and mindset to opt-in.**

Participants identified a **passive barrier** to this, as it is often something which goes to the bottom of your 'to-do' list.

People who desperately need organs are dying, and some people just haven't signed up because they haven't thought about it or don't have access to registering. Lives could be saved.

(Female, International students group, London)

So many people are passive, not against organ donation and probably leaning towards doing it but it takes the extra effort to opt-in. I think we're losing out on a lot of people who would be perfect for that.

(Female, White Other group, Nottingham)

2.3 Opt-out

Awareness and understanding

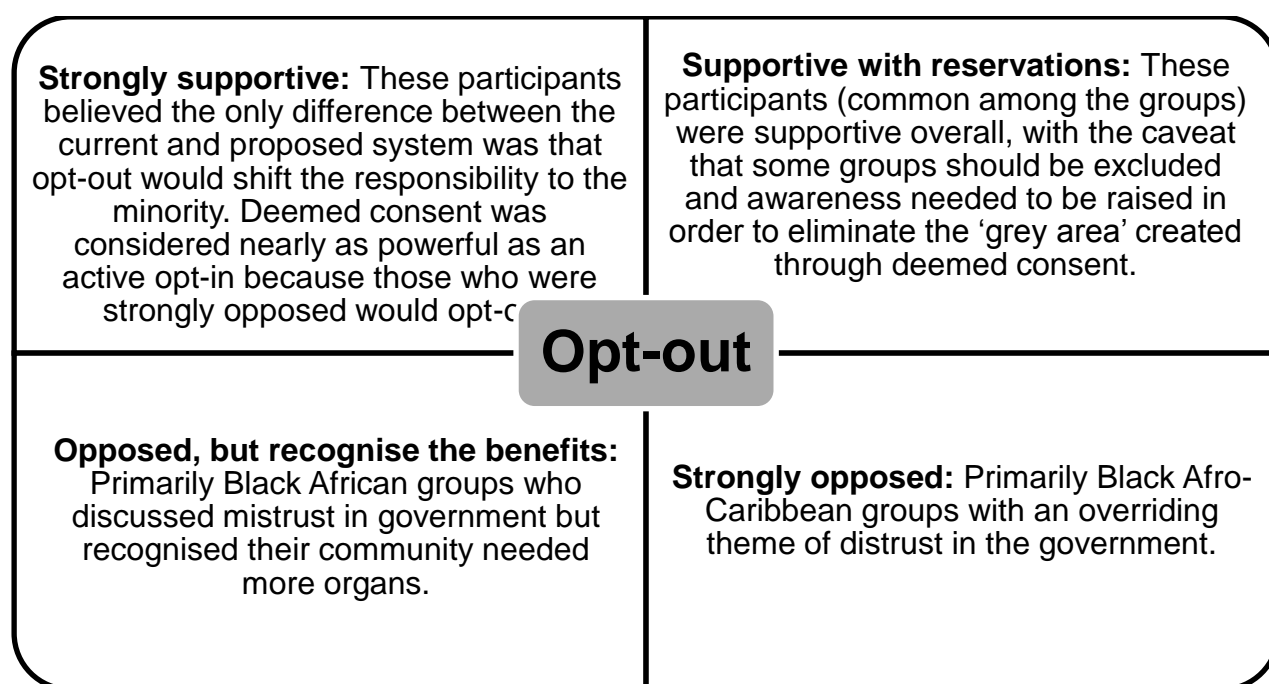
The majority of participants had not heard of the opt-out system and were not aware it had been introduced in Wales. However, some **spontaneously suggested a move to an opt-out system** before it was introduced by the moderator. Once introduced, **it was common for participants to struggle to understand the concept of 'deemed consent' and that you actively decide to do nothing.**

Others initially thought the **proposed system sounded simple**, compared to the current system, with **less onus (and even the potential removal) of the role of the family**, indicating the reality that the family will likely remain to be involved in discussions was not immediately acknowledged. Participants **particularly struggled to understand that you could continue to opt-in within the opt-out system.**

Importantly, suggestions for phrasing this more clearly during implementation were provided (discussed further in section 5).

Broadly, **most of the groups were in favour of the opt-out system** and could see the value in that it would increase the number of donors and save lives, targeting those people who were in favour of donation but too busy to opt-in. However, support for the proposed system was varied, ranging from strongly supportive to strong opposition. A typology emerged from the data, which is shown in the image below.

Table 1.1: A typology of support for the opt-out system



Advantages and disadvantages

Advantages

The obvious advantage that came to mind for participants was that **the number of donors would increase by shifting the responsibility to the minority** who are not in favour of organ donation. This will increase the availability of organs. Although some participants queried the origin of the figures provided by NHS Blood and Transplant (i.e. 85% of people are in favour of organ donation), most saw these figures as a compelling reason for the proposed opt-out system and often held onto these statistics throughout their discussions.

There would be a larger group of organ donors. As we saw, 85% of people are in favour of it. It would be more benefit to us and you don't have to do anything. People don't have to remember to go online. Puts the responsibility on the minority, as you said. That's a big advantage.

(Female, White Other group, Nottingham)

The new system will eliminate the group of people who haven't opted in because they don't know about organ donation or just haven't registered but who would be happy to donate their organs. The new system is more inclusive.

(Female, International students group, London)

I think it's inherently a good thing to get it changed, because it can save people's lives.

(Male, White Other group, Leeds)

Some participants recognised an opt-out system would tackle a major disadvantage of the opt-in system whereby people put off, forget or don't consider registering to donate: this was described by one participant in the Black African group in Leeds as the “*tomorrow syndrome*”. For those in favour of organ donation, an opt-out system would make it **easier to become a donor**.

I would probably support the opt-out system more, I think it's much more efficient. It's also a conscious decision to opt out, a lot of people actually die in hospitals and they could help somebody else but they just haven't thought about it before. If you opt out, then you have some reasons for doing so. But if you don't opt in, then maybe you're just reckless or didn't think about it, or it's not on your priority list.

(Male, International students group, London)

Participants often noted that those who were **strongly opposed to organ donation would make the effort to opt-out**. For some participants, this meant they still had **choice in the system going forward**. For others it meant that they **considered deemed consent to be nearly as powerful as an active opt-in**.

People are going to fight it, but then there's an easy solution. You can tell them to opt out.

(Male, Temporary workers group, London)

I think this is still an active consent, not a deemed consent, because if you didn't want to do it, you would opt out. These days people make their passions known, if they don't want to do something. So, I think not opting out should be considered as actual consent, not deemed consent.

(Female, Black African group, Leeds)

The more opinionated people are the ones that are more likely to say no, and they will still be within their right to do that. They are a minority.

(Male, White British group, London)

Most participants felt the move to an opt-out system would encourage people **to discuss their organ donation preferences with family which would eventually normalise organ donation, and also enable families to better understand what their loved ones would have wanted.** Others thought the large-scale awareness campaign accompanying the move to opt-out which would be the impetus to stimulate discussion.

A minority of participants felt that opt-in requires you to think about donation and make a decision, whereas in an opt-out system, the decision is taken away from you which is actually preferable. This is more inclusive and makes it easier for family (and medical staff) to make a decision at time of death.

I would be happy to not know about it and not have to think about it. I would never opt out, I love the thought of doing it and hope everyone would do it for me, but I don't want to talk about it, it makes me feel sick, I'm so squeamish. It would be good for someone like me.

(Female, White British group, London)

It'd take the pressure off families, as well. It's such a difficult time for people to make the decision, and I think it'll make it easier.

(Female, White Other group, Leeds)

Disadvantages

Three main disadvantages concerning the opt-out system were discussed by participants:

1. Choice

Some groups shared a feeling of **distrust in government** and believed their **personal choice was being taken away**, struggling with the perception that society makes the decision on your behalf. Although others understood the move to opt-out

would save lives, they **questioned the governments' true motivations**. Some groups didn't agree with the government making the decision for everyone as some people would not have the **capacity to understand the new system**.

Fundamentally the reason why the government is doing this is to save more lives, or I would hope so. I don't trust this government.

(Male, parents group, Brighton)

I do struggle with the idea of opting out, because when society becomes prescriptive about what you should do, that's a struggle for me. If you are on life support and there are organs needed desperately, then are there barriers to doctors turning off life support machines for the sake of getting organs? I disagree with the idea of society knowing what's best, especially when so many people are disenfranchised.

(Male, White British group, London)

A common theme of distrust came up in **Black Afro-Caribbean groups who strongly opposed the opt-out system**. They felt the move was a “**stitch-up**” by **government** wanting to **own their bodies**, ‘harvest’ organs and sell them on the black market abroad. They noted that others in their community would share these suspicions and disapprove of the government making decisions for them. Although these groups recognised their organs are in greater demand, there was a lack of a feeling that moving to opt-out would be for the greater good.

There's going to be a certain pushback, for one because of our understanding of the benefits of transplantation and life extension, that's not natural to everybody and doesn't lend itself to everybody's beliefs ... In a sense, this being rolled out would have benefits to the wider community, but I think people in our community would opt out because of their reservations about the system.

(Male, Black Afro-Caribbean group, London)

They'll [the government] take your organs, you need to be informed, and that's why I think it's an uncomfortable situation. They haven't pushed people to be a part of the register, but they'll skirt it, and it'll be the same blasé attitude that they won't tell you about it.

(Female, Black Afro-Caribbean group, Manchester)

They're still not advertising it, that this day is coming when you'll be opted in. I believe that they don't want people to know, they want to sneak it in.

(Female, Black Afro-Caribbean, Manchester)

That's a stitch-up then, because they're not giving people that option.

(Male, Black Afro-Caribbean, London)

You should have to opt in, because if it was legal without opting in, you would feel that you're owned by the government, that at any point you could be summoned to give an organ away. Pressured into it.

(Male, Black Afro-Caribbean, Manchester)

Some participants from the Black African groups shared similar views but remained overall in favour of the move to opt-out as they recognised the benefit of having more donors.

My friend was waiting for an organ and the percentage of Afro-Caribbean donors was really low. This would increase the chance of minority ethnic patients getting an organ.

(Male, Black African group, London)

2. Deemed consent creates a 'grey area'

Most groups felt that under deemed consent the decision would be less black and white, creating a 'grey area' where you **cannot be certain if an individual wanted to donate or not**. This was often linked to **lack of awareness and lack of mental capacity**. It was also frequently raised that participants might want to opt-out but forget to do so. Most participants felt this grey area would place **more onus on the family and healthcare providers**, as discussed in section 3.

As someone who isn't decided, whether I want to be a donor, it's like the decision's being made for me. I might not have time to opt out. I know my family will be asked, but I feel like the decision's been made for me.

(Female, Indian group, Bradford)

In principle, the opt-out system seems a good idea. On the basis that the government are trying to get that bigger subset of people who don't actually register. In practice, though, the cons will still be there. It's not on the top of everyone's to-do list. 'Bread, milk, opt-out.' It's one of those things you'll never get round to. The opt-out process may not hit communities that don't fully understand the processes.

(Male, Indian group, Bradford)

3. Lack of awareness

Some participants questioned whether it was necessary to move to an opt-out system, given that an extensive awareness campaign of the current system might achieve the same outcome.

It seems like they're looking at an easy option to get the number of donors up, rather than promoting the opt-in, and getting more people to sign up, so that it's definite that they wanted to give their organs. That's what it feels like. It's positive for people on the waiting list for organs, but, I don't know.

(Male, Christian group, Bradford)

Instead of having the automatic opt-in, why not educate people? Don't roll out the new system, stick with the old system, and that will bring people in droves to become organ donors. Just educate people on things like that.

(Female, Muslim group, Birmingham)

What's the saying, 'If it ain't broke, don't fix it.' The only thing that we should do is raise awareness of the opt-in. The problem isn't the system. It's the amount of awareness.

(Female, Bangladeshi/Pakistani group, Luton)

Nonetheless, the lack of information underpinned some of the scepticism about the circumstances where deemed consent would apply, as participants knew so little about the current system. Participants frequently highlighted the need for increased campaigning in the new system, to ensure people were not donating under deemed consent through ignorance (discussed further in section 5).

I think if the government are going to start making that choice for you, there has to be a lot more out there...Then, if you don't, it's your own fault. You've had the opportunity.

(Male, Christian group, Bradford)

I'm wondering how I didn't know about such an important issue, why people haven't been speaking about it more. As long as you are informing people, that's key.

(Female, White British group, London)

[For deemed consent to be the same as opting in] it has to be beyond reasonable doubt that the person had the information.

(Male, Christian group, Bradford)

2.4 Chapter summary

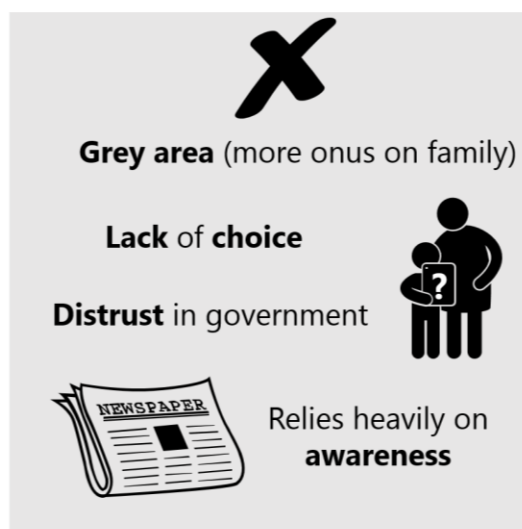
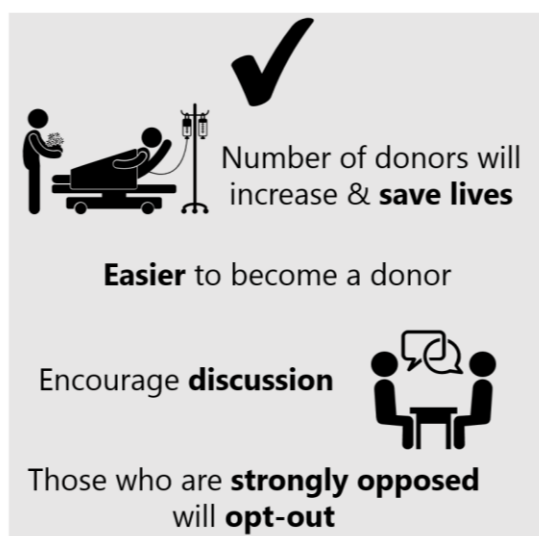
Participants were **supportive of organ donation**, although there was a **broad lack of awareness about the organ donation process**. It was also felt that **religion and a range of misconceptions**, especially prevalent in the Black African and Black Afro-Caribbean communities could act as barriers to donation.

While most participants knew of the Organ Donor Register, **only a minority were registered**, with participants often acknowledging that they had not encountered organ donor communications previously. There were a number of widely recognised **merits of the current system, including its simplicity as well as the choice and control** it promotes and provides. However, participants recognised that it is failing to address the lack of donors, especially within certain communities, because **it relies on individuals being proactive and finding the time and mind-set to opt-in**.

Awareness of the proposed opt-out system was quite low and it was common for participants to struggle to understand the concept of deemed consent. Yet, on the whole, the opt-out system was seen to be a positive step with regards to increasing the number of donors, and by shifting the responsibility to the minority who are not in favour of organ donation, as it was believed that people who are strongly opposed to organ donation will make the effort to opt-out. It was also recognised that the system itself will be a means for encouraging people to discuss their organ donation wishes with their family and eventually normalise organ donation as a topic.

However, a number of concerns were raised about the proposed opt-out system, including the **lack of choice** (sometimes linked to a distrust in government) and the fact that **individuals' decision under deemed consent could be less clear** and therefore place more onus on the family and healthcare providers.

Opt-out



3 The role of the family

This section explores a key part of the research carried out, and goes some way to answering a number of important questions: what should be the role of the next of kin in decisions regarding organ donation, and how can the burden on distressed families be reduced?

In line with the Department of Health and Social Care's public consultation, and using a number of different scenarios as stimulus to generate discussion (see Appendix 2), we asked focus group participants about the role of the family both:

1. in the presence of an expressed decision, and
2. in the absence of an expressed decision.

The role of the family in both circumstances is discussed in detail within this section.

3.1 The role of the family in general – Consenting adults

Participants spoke of the **general difficulties of involving family members** in decisions about organ donation. They recognised that families will be in **very distressed and devastated situations**, and may not be thinking straight or clearly. Therefore, there is a **risk that families could make a decision (on behalf of the deceased) that they later regret**.

I'm all for a hard opt-out, families will not be thinking rationally when they're grieving. If it was the wish of the person who has died to donate their organs, then they will donate their organs.

(Male, Jewish group, London)

Participants also spoke of how **families may not have discussed their wishes with each other**, meaning family members could be unaware of what an individual wanted – and therefore making it hard for them if/when they are asked.

It was also suggested that **families may not get on with each other**, and participants raised concerns about the implications of this, such as a family's motive, on such a huge decision.

You might not get on with your family. What would be the motive for the family's decision?

(Male, Black African group, London)

Say you've fallen out with your family and there are deep rifts and they do it to spite you.

(Male, Christian group, Brighton)

Finally, participants raised the point that **family members won't always agree with the decision of the deceased**, likely on moral or religious grounds, and/or they may assume that the individual held the same attitudes towards organ donation to those of their own. They recognised, too, that some families are large and may disagree among themselves, hence coming to such a decision could create internal problems within families.

You don't know what the relationship is either. My mother might relay things to the doctors that don't reflect my decisions. The donation should go ahead regardless.

(Female, Hindu, Sikh and Buddhist group, London)

Some participants (for example those in the White British groups), spoke of the **need for a system which does not request family members to make the decision**. Similarly, but with less strength, in other groups, there were suggestions that the **family should always be informed, rather than asked**.

Participants, in general, voiced **the importance of encouraging conversations to be had within families**, so that people are informed about each other's wishes, meaning that these can then be honoured. Individuals should be encouraged to make their wishes known to their family, given that death is far too emotional a time for a family to have to make the choice on the individual's behalf.

That's the importance of the discussion with your family, that you have to have, so there are no blurred lines. It's there in black and white, and they have to honour it.

(Female, Black African group, Leeds).

Various other suggestions were made to ensure that an individual's wishes could be honoured, and to **validate the individual's expressed decision**. For example:

- including a signature on the Organ Donor Register, alongside an opt-in or an opt-out, to legitimise the decision; and
- requiring a witness signature (handwritten, or electronic which could simply be a tick-box) or ideally from a family member, at the time an individual either opts-in or opts-out.

In the presence of an expressed decision

A key finding, across all groups, was that **where a decision has been expressed – either an opt-in or an opt-out – the individual's wishes should be honoured**. Whilst this view was not entirely universal – and participants contradicted themselves when discussing the role of the family in some of the scenarios – in most of the groups, it was felt that **family members should not be able to override a decision in the presence of an expressed decision**.

It's wrong for the parents to get involved. Whoever opted in, or opted out, it should be up to them.

(Female, Hindu, Sikh, Buddhist group, Manchester)

Before you've passed away, you've made the decision that you want to help people. Your family shouldn't stand in between that. It's your choice. It's your body. Your family shouldn't make that decision for you.

(Female, Pakistani group, Luton)

It was common, too, for **participants to question the premise of the proposed opt-out system, if families will still be able to override (recorded) decisions**. This was particularly the case when they discussed the hypothetical situations where individuals had opted out.

What's the point in doing it, if you can opt out, and people can change your mind for you? There needs to be legislation to say that once you've opted in or out, your decision stays.

(Female, Black African group, Leeds)

If there was no explicit objection, that's the whole point of the system. There's no point in the new system or not as much point if the family can change it.

(Female, White Other group, Nottingham)

During some groups, for example in the group with parents in Nottingham, **a link was made between allowing families too much power in the proposed opt-out system, and the risk that the new system won't necessarily be the solution to the current problem: the lack of organs on the register**.

Participants often talked about an **individual's decision being (legally) binding**, much like the case would be if the person had made a will or expressed their funeral wishes. An organ donation decision was even described as, and likened to, a human right. The right to vote for example.

It's like having the right to vote and then your Mum can come along and change it.
(Female, White British Group, Birmingham)

When you think about your will, that stands after you've passed, and that's just material things. So your decision about your body should stand as well.
(Female, Black African group, London)

That's like voting for Labour, and then someone saying: 'Why's he voted of Labour? I thought he would have voted Conservative.' Why are they going round the houses? You've ticked the box.
(Male, Indian group, Bradford)

As long as you're of a sane mind when you make the decision, that's it. It's the same as a will. What's the point in writing a will, if it's not going to be enacted? Ultimately, as an individual, you've made the decision. You're supposed to respect the wishes of someone.
(Male, Indian group, Bradford)

Again, across most groups there were a number of important conditions associated with situations where an individual's decision, or 'choice', should always have the final say, even if the family disagrees with it. For an expressed decision to be respected, it was assumed that:

- the individual **would have had to have been in a fit state** when they opted in or out / they understood what they were doing: **an informed choice**.
- the individual **would have had to have been aware of the new (opt-out) system**, and would have understood the requirement to opt-out if they did not want to donate their organs.
- the individual **would have had to have been old enough** to decide for themselves (see next chapter).
- **enough time would have had to have passed under the new (opt-out) system** to give the individual the opportunity to opt-out if they wanted to.

[When discussing one of the scenarios where the person had opted out] *She made her decision when she was rational. She wasn't impaired, in any way. It should be honoured.*

(Female, Black African group, Leeds)

[When discussing one of the scenarios where the person had opted out] *At the end of the day, he's had the facts, and made the decision, so it should be respected.*

(Male, Indian group, Bradford)

[When discussing one of the scenarios where the person had opted in] *If she's fully sane, she knows what she's doing, she's agreed. It's like writing your will.*

(Female, Black Afro-Caribbean, Manchester)

Once you're an adult, whether you're alive or dead you should have your choice.

Otherwise it's not really a choice

(Male, Hindu, Sikh and Buddhist group, London)

For some participants, for example those in the Pakistani Male group in Luton and those in the Muslim male group in London, **there was an additional assumption that the family should only be able to override the decision – and this was mostly where an opt-in applied - if they *did not know* about the expressed decision.** It was assumed, among members of this group, that family members *would* be aware of the expressed decision, thus this would not be a problem. There were some who talked about how the family would have been involved in the decision, thus they would have previously “approved it” anyway.

I would have consulted my family. They would've approved beforehand and stick to that.

(Pakistani male group, Luton)

You must say to your family that after your death your organs should be donated, otherwise they are likely to say no.

(Muslim male group, London)

The recentness of an expressed decision

For some participants, **the recentness of an expressed decision also came into play.** Particularly when they were discussing one of the scenarios where the deceased (Karen) had registered to be an organ donor five years ago (see Appendix 2, Description 1), participants often spoke of how **a recent decision should have**

added weight. There were suggestions put forward that the government should remind us to update our decision, every five years for example.

For others, however, the length of time that may have passed since the decision was recorded was irrelevant. It was the expressed, and recorded, decision which surpassed anything else.

Opt-out carrying more weight

To some degree, **an opt-out was seen (by some) to be even more binding than any other expressed decision.** In the Jewish group in Manchester, and the Christian group in Brighton for example, participants raised the point that **people who opt-out are likely to feel very strongly about it, and this may actually be for moral or religious reasons.** Hence this was even more of a reason as to why the decision should not be allowed to be overturned by the family.

Otherwise having the opt-out system is completely redundant. If somebody has taken the time to opt-out, you shouldn't be able to overrule their decision
(Male, Jewish group, London)

In this case I think opting out is more meaningful.
(Female, Indian group, London)

Related to this, and in particular when discussing the scenarios, **some participants were of the opinion that a family *should* be able to override an opt-in** (assuming they simply could not cope with donation going ahead), **but they *should not* be able to override a recorded opt-out.**

Exceptions to the rules

As suggested, **the involvement of family members in relation to being able to override an expressed decision was, in some groups, more nuanced.** There were a number of quite different views put across, each potentially placing more of a role on the family than we have already highlighted.

1. Participants in the Black Afro-Caribbean group in Manchester spoke of **how the 'next of kin' should have the final say even where there was an expressed decision.** The reasons given for this were that some time could have passed since the person expressed their decision, and they could have since changed their mind. There was a feeling that the family would know their most recent wishes.

2. Participants in some of the groups (one of the White British groups, the Christian group in Brighton and the Hindu, Sikh and Buddhist group in London) called for **a means for individuals to hand the authority to a family member once they pass, even where they had opted in or opted out**. This would give the individual “peace of the mind” that the family would not have to go along with a decision they were extremely uncomfortable with.

I think there should be a middle ground option. 'I'm happy for someone else to decide.'

(Male, Christian group, Brighton)

I don't mind. They've given me life, so I don't mind them having that choice.

(Female, Hindu, Sikh and Buddhist group, London)

3. Whilst rare, and appearing to be unrelated to religion or ethnic background, there were occasions where participants suggested that **if families were able to override decisions so that organ donation can proceed, even in the presence of an expressed decision, this could save a life and benefit society and the “greater good”**. It was here that some participants expressed how they personally would want the power to change an organ donation decision to ensure that another family member's life could be saved⁶.

[When discussing a scenario where the person had opted out] *She's dead so she won't know. If the daughter gives the organs and it saves a life then it balances out as better.*

(Female, Black African group, London)

[In response to a question from the moderator about whether the family should be able to override an opt-out, when discussing one of the scenarios] *Yes. We make mistakes. We can say, 'She opted-out.' At the end of the day, from her perspective, another life can go. One individual has passed away but another can live on. It sometimes comes down to the family.*

(Female, Pakistani group, Luton)

If it were my two sons, and he's opted out, and I knew I could save the other one by overriding the decision, I'd do it.

(Male, Christian group, Bradford)

⁶ Although participants were reminded that donated organs are given to those in the greatest need, this misperception was a view held by some participants.

I suppose it's always a question of the greater good for society. It's the individual's choice but it might not be best for society. Someone's decision could be overturned if there was a greater societal need.

(Male, Hindu, Sikh and Buddhist group, London)

In the absence of an expressed decision

Participants, across all groups, **struggled with the role of the family in the absence of an expressed decision – in other words when deemed consent would apply.**

There was a view point, observed across all groups - however this was by no means universal - that **argued for a greater role of the family in the proposed opt-out system, and *in particular* in circumstances where deemed consent would apply.** It was for this reason that the opt-out system was seen to place more pressure on families, on the assumption that many will need to be consulted and asked in the absence of an expressed decision.

I think it'd cause more confusion with families, the new system. They haven't actually done anything [referring to not opting out], so they'd be like, 'Well, actually, they didn't want it anyway.' So there'd be more disagreements.

(Female, Indian group, Bradford)

Participants who raised these concerns – suggesting that the family would need to be more involved – were fundamentally **concerned that individuals may not have been aware of the “automatic opt-in”, they may be undecided and so did nothing, or they may not have got round to opting out.** Because of this risk, it was assumed that the role of the family would be greater.

This problem's going to be reoccurring. People might just put off [opting out] like they put off opting in in the current system. They might just never get around to it.

(Male, Hindu, Sikh and Buddhist group, London)

[When discussing one of the scenarios where deemed consent would apply, but where the individual was an adult] *The final say is the parents because we don't know.*

(Pakistani Male group, Luton)

Some participants in a Black Afro-Caribbean groups were very clear that families should have the final say in the absence of an expressed decision. The reasoning of this particular group, however, related to a general distrust in the government, and a belief that it has made that choice for everyone and will just “take” organs otherwise.

A similar vein of thought was occasionally expressed in other groups too, though with less unity.

Who would you rather make the decision: the government or your family?
(Female, Hindu, Sikh, Buddhist group, Manchester)

Not all participants who called for this greater role of the family (in circumstances where deemed consent would apply), however, went as far as to say that families should have the final say. Some indicated that they were happy for **families to instead be consulted about any evidence which would suggest that the individual would not have wanted organ donation to proceed**, in the absence of an expressed decision. For those that held this view, and assuming there were no grounds for objection from the family, organ donation should proceed.

He might have been lazy. There might have been evidence that he wanted to opt out but never got around to it, in which case the family should have the final say.
(Male, Muslim group, London)

Choice in an opt-out system

During some groups (for example the White British group in Birmingham, the Black African group in Leeds and the Hindu, Sikh, Buddhist group in Manchester), participants recognised that **by not opting-out, an individual would be making a choice**. It was therefore not the family's role to override this decision and to stop donation from proceeding.

The idea that just opting in is the only moral decision is flawed. People are still being asked a question, it's a legal decision that's been made at the end of the day. Everyone will have the decision to opt out, so if you don't opt out, you're in.
(Male, White British group, London)

[When discussing a scenario where deemed consent would apply] *In either case, you have a choice. With the opt-in system, we're automatically opted out. In the new system, we're automatically in but we can opt out. So, either way, you have a choice. What I'm saying is, you were saying Wales had a gap. I assume there would be a gap here, as well. She did have a choice, and she didn't make it.*
(Male, Black African group, Leeds)

[When discussing a scenario where deemed consent would apply] *I don't think the family should have a decision. When everyone is opted in, and you have to opt out, she would have been told and so she has made a decision. I probably wouldn't tell anyone if I chose to not opt out.*
(Female, Hindu, Sikh, Buddhist group, Manchester)

The 'grey' area concerning choice

Across most groups, however, there was at least some **failure to recognise the choice people will have in an opt-out system**, and particularly in circumstances where deemed consent would apply. Participants often spoke of a 'grey area' in the absence of an expressed decision, or referred to the individual being "in the middle" (i.e. they had neither opted in, or opted out).

The grey area is where a decision hasn't been made. Where the choice has been made, respect the choice. Grey area, that's where the family's influence comes in.
(Black Afro-Caribbean, Manchester)

[When discussing a scenario where deemed consent would apply, and comparing it to a scenario where the person had opted in as well as one where the person had opted out] *In the previous two scenarios, the individuals have made a conscious decision. I think the family's decision should be considered.*
(Male, Indian group, London)

[When discussing a scenario where deemed consent would apply] *He hasn't made the decision, has he?*
(Female, Christian group, Bradford)

[When discussing a scenario where deemed consent would apply] *Because she's forced into it, then it should be the family's decision.*
(Male, Hindu, Sikh, Buddhist group, Manchester)

The husband and daughter should have the final say and should come up with a joint decision because it's such a grey area. She has opted in automatically, but she might not have known that she could opt out.
(Male, Muslim group, London)

[When discussing a scenario where deemed consent would apply, but where the individual was an adult] *This new system leaves no choice. Personally, I'd leave it to the parents, give the choice to the parents, because at the end of the day it was their son. The doctors are professionals, they don't know [the person] more than the parents do.*
(Female, Muslim group, Birmingham)

Across the groups participants came up with **a number of suggestions for ways in which an extra layer could be added in the new opt-out system. Those would help families be assured that organ donation was what the individual wanted** (i.e. where deemed consent would apply). These included:

1. A **recorded signature** (handwritten or electronic) of the individual, somewhere, to state that they had *not* opted out;
2. Individuals being able to, and encouraged to, **carry a card** around with them which proves that they have *not* opted out, or one which states that they have opted in;
3. Individuals **using social media, such as Facebook**, to vocalise that they have *not* opted out;
4. Adding **clarity to the communications campaign**, and making it clear that **individuals can still opt-in**; and
5. **Using GPs**, and recording on individual's health records that they have *not* opted out.

Couldn't you let your GP know that you want to donate? They would be able to say what you wanted, regardless of whether your family disagreed. It's a grey area if you haven't opted out, but you can help that by making sure that your doctor knows.

(Male, Black African group, London)

There was another suggestion, put forward by those discussing the perceived ambiguity around the circumstances where deemed consent would apply, which allowed **people to be able to nominate someone else, a family member for example, to make the decision for them.**

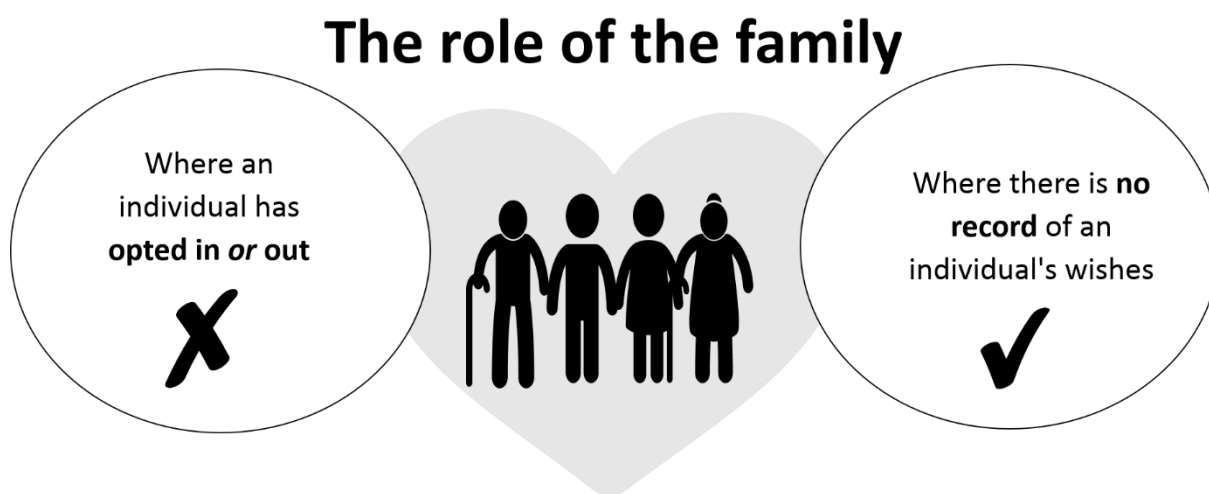
3.2 Chapter summary

Participants spoke of the **difficulty of involving family members in decisions about organ donation** in a range of situations:

- **In the presence of an expressed decision:** it was felt that the individuals' wishes should be honoured and that family members should not be able to override the decision.
- **In the absence of an expressed decision:** participants struggled with the role of the family in the absence of an expressed decision, and in particular where deemed consent would apply. Families were often seen to need to be consulted more in the absence of an expressed decision, therefore the opt-out system was seen to place more pressure on families.

- **Choice in an opt-out system:** participants often spoke of a ‘grey area’ in the absence of an expressed decision, or referred to the individual being “in the middle” (i.e. they had neither opted in, or opted out).

All groups highlighted the **importance of encouraging conversations to be had within families**. This would mean that families are informed about each other’s wishes so that these can be honoured, especially given that death is such an emotional time for a family to have to make that choice on the individual’s behalf.



3.3 Recommendations and suggestions

- Legislation needs to protect the decision of someone who has either opted in or opted out.
- A means for recording signatures on the Organ Donor Register, which would legitimise an opt-in or an opt-out, and could be shown to families.
- In the absence of an expressed decision, and where deemed consent would apply, consider consulting families to see whether they have any evidence to suggest that the individual would not have wanted donation to proceed.
- Consider ways in which individuals could make the fact that they have not opted-out known.
- Consider a means for reminding individuals so that people regularly make their wishes known, by opting-in or opting-out. As well, a recent record will be better evidence to use when discussing the person’s wishes with the family.

4 Exclusions and safeguarding

While the topic guide explicitly sought views about the **‘excepted’ categories of people for whom explicit consent** – either from the person themselves or from their family – would still be required in an opt out system, participants often raised this spontaneously when discussing their impression of the proposed changes at the beginning of the groups. Discussing the opt-out proposal, its merits and disadvantages, often prompted some queries around how the system would apply to certain groups such as children or people lacking mental capacity.

Participants believed that **some exceptions to the general rule would also need to exist in the proposed opt-out system**. A range of views were however expressed about the extent to which certain groups should be excluded. While a minority felt the current proposal was too restrictive, the majority of participants felt that the inclusion of certain groups was unethical.

I'd say, maybe, if they don't understand what it means, they should be excluded. Just, in general, I would say the same thing about voting. There has to be a level of understanding, before you can make a valid decision.

(Male, White Other group, Leeds)

The following section discusses participants' views on the proposed exceptions that would apply in relation to three specific groups:

- **children**, the age under which donation would only be able to take place with explicit authorisation – and above which deemed authorisation would apply;
- **people viewed as ‘not having capacity’** to make their own decisions about donation;
- and people resident in England for less than 12 months.

4.1 Children

Participants discussed, often unprompted, how children also required transplants, but it was not always clear how they would be affected by the proposed legislative change. When debating exemptions of children under a certain age, a range of views on the following topics were exchanged.

The age at which a child can consent

There was a general agreement that **children over a certain age should have the choice and opportunity to opt in**. However, participants acknowledged that the age at which this is appropriate may vary from one child to another.

Participants discussed how **a young person under the age of 16 or 18 may have the capacity to consent**, depending on their maturity and ability to understand what is involved. However, there was no clear consensus about which age children should be able to consent. While some participants commented on how 12 was too young for a child to make their own decision to donate their organs or tissue, others disagreed. Less commonly, respondents suggested that children should only be able to opt-in at a later age (14, 16 or 18), or they argued that it was not possible to specify an age for consent given the wide variability in maturity and understanding that there may be among children of the same age.

I think my 12-year-old would make an informed decision.

(Male, Parents group, Nottingham)

My 12-year-old can't sign a form to say she's going on a school trip. She sure as hell isn't signing a form to say what part of her body she's giving away

(Female, Parents Group, Brighton)

Across several few groups, there was a view that children could consent at the same age they have criminal capacity, which in England is 10.

When kids commit crime, there's a certain age when you can say the child is fully aware, and so he or she will be punished. If at that age you're aware when you are doing something wrong, then you can be aware of organ donation too.

(Female, International students group, London)

All in all, it was believed that **much more is needed to educate children about organ donation** so they are able to, if they wish, to opt-in to the Organ Donor Register themselves. Yet, it is important to note that a **majority of participants, and more particularly participants who were parents, considered that parental consent should be required for children up to age 16 or 18, regardless of the child's wish to opt in**.

At 12, if they've had this conversation at school, the parents should have to countersign. Say I've had this discussion, I authorise.

(Male, Parents group, Nottingham)

I think it should be the choice of the parent, until the age of 16. Children are extremely conscientious. I think they're a highly underrated group of people. They're intelligent. They can be spoken to. It's about how you speak to them, and fire up their passion. I think you can allow the parent to put them on until 16, but when they're in high school and they become socially conscious, then they should be able to do it with their parents' consent. Then after 16, they can do their own.

(Female, African group, Leeds)

I think the parents should play more of an active role when it's a child. It should definitely be just the parents' decision.

(Female, Indian group, Bradford)

The contrasting view, expressed less commonly, was that parental consent should not be required at all for a child over the age of 12 where the child had opted in to the Organ Donor Register, or otherwise explicitly expressed a wish to donate their organs or tissue.

The age at which deemed consent would apply

Participants were asked to consider age at which deemed consent should apply in an opt-out system. Overall, participants agreed that **deemed consent should apply to children from either age 16 or age 18**, however there was no clear consensus about which age was most appropriate (only one participant, in the male Muslim group, thought that deemed consent should be increased to 21 as he considered 18-year olds 'reckless').

I think 16. You pay National Insurance at 16. If they are going to make that the threshold, though, they need to go into schools and make sure they're aware.

(Male, Christian group, Bradford)

Less commonly, there was also a view, especially among younger participants, that children of all ages should be included in the opt-out system and deemed consent should apply in all cases- unless their parents had previously opted out on their behalf. For example, some participants suggested that women could be informed in hospitals, when they give birth, that their child will automatically be on the Organ Donor Register (unless they opt-out for them on their behalf).

I think children these days are more with it, and more aware of it. Age doesn't matter as long as they understand it, and you discuss it with them. There's that much media, and things going on, so I think they are more aware of it than we were at their age.

(Female, Hindu/Sikh/Buddhist group, Manchester)

Overall, **there was a clear view observed across all groups that promoted and involved a discussion with the child's parents** where a child had expressed a desire to donate their organs after death (see the section about the role of schools and education in the next chapter).

4.2 People who lack capacity

Participants were asked their views about the circumstances in which an adult should be viewed as 'not having capacity' to make their own decisions about organ donation; and whether people in this group should be excluded from the opt-out system.

Because participants agreed that the opt-out system is premised on the principle that the potential donor has been given an opportunity to decide if they do not wish to donate, **there was an overwhelming consensus that adults who lack the capacity to consent to organ donation should be excluded from any new legislation concerning organ donation.**

Participants generally agreed about the circumstances in which a person would be seen as lacking capacity. Dementia and other similar conditions (including Alzheimer's disease) and severe learning disabilities were particularly prevalent in people's discussions around this group.

There were some discussions around the degree of mental incapacity and that some people defined as such might still understand how the opt-out system works and more generally what organ donation entailed. **There were some concerns shared across many groups about what would happen if someone never had legal capacity to make decisions** around organ donation, or did not have capacity any time after the introduction of the opt-out system. The worry here was that these people would never have had the opportunity to make an informed choice to opt-out.

However, some participants also thought that deemed consent could apply depending on the degree to which a person lacked capacity. Some people in that group could be included in the opt-out system as long as measures were taken to ensure they were aware and understood how opt out works.

There are people with mental illnesses that may not understand that they have to opt out. I think medical staff have a duty of care to tell people that they have a choice.

(Female, Afro-Caribbean group, London)

However, views were more nuanced when it came to people with a long-term incapacity: the vast majority of participants agreed that if such a person had made an

earlier decision to opt-in, this earlier decision should continue to be respected even if the person had a long-term incapacity at the time of death.

Not all people with mental incapacity make wrong decisions. What if someone, 10 years ago said, in their sober state, that they want to donate, and then they get dementia and say that they've changed their mind, they've still made that decision.

(Male, Black African group, Leeds)

Some participant specifically commented on the issue of the period of time before death. In most cases, participants thought that if an individual chose not to opt-out during a period of years after the new system was introduced, then, even if they later lost the capacity to make decisions, deemed consent should continue to apply.

I could have dementia in 20 years, but I've made the decision now. In 20 years' time, I'd like for them to still honour that.

(Female, Black African group, Leeds)

Alongside this, it was believed that only people who had lost the capacity to make decisions *before* the system came into operation should require explicit consent. For those who lose capacity *after* the implementation of the opt-out system, it was felt that **the appointment of someone as a nominated representative to take that decision for a person was a good compromise** to ensure people lacking capacity are not excluded outright from organ donation.

I think people who are mentally incapacitated would have a legal guardian anyway, so the consent would be there. They could opt the person in or out depending on the circumstances. It's the same with elderly people, they have the power of attorney. It's the same with people with Alzheimer's or Dementia.

(Female, Temporary workers group, London)

4.3 Older people

Concerns around older people were also raised in a number of groups as participants often associated the loss of mental capacity with old age. There were

some questions around the extent to which older people can be considered capable at making a decision about organ donation for these reasons.

[Talking about the age limit for which deemed consent should apply] *If it's that under-16s can't, then it's got to be over 80, as well, hasn't it? You can lose your marbles at that age*

(Male, Christian group, Bradford)

Participants, too, believed that older people might not be as likely to be exposed to media campaigns around the proposed opt-out system and may, therefore, be unaware of a change taking place and what this will mean for them. As such, some groups concluded that it was safer to exclude people over a certain age when the proposed system is introduced. A range of ages were mentioned, from 65 to 80.

Others were less extreme on this, and instead voiced the importance of ensuring that far reaching communications – which rely less on digital methods - are targeted at the older population, and that they explain the system and its implications in a way that people will understand (see next chapter).

4.4 Non-residents

Participants were asked to consider how the legalities of the proposed opt-out system should deal with **visitors to England and those living in England for less than 12 months**.

Overall, while non-resident groups tended to think they *should* be included in the opt-out system, **resident groups felt the organs of non-residents should not be donated unless they have expressed a clear wish to donate their organs or their families have given consent**.

Foreign nationals need to opt in, you can't just say to people, 'As long as you're here, we're taking your organs.' You can probably check if they've opted in somewhere else.

(Male, Jewish group, London)

A range of views were expressed about the period of residence, how to bring awareness of the opt-out system and where organ donation could/should occur.

There were participants (in both resident and non-resident groups) who commented on the amount of time someone would have to be living here for under which the opt-out system to apply to them. There were a range of views, with some **thinking 12 months was a good timeframe**, while others wanted a shorter or longer timeframe (from 3 months to several years).

Interestingly, **in the non-resident groups with international students and workers on temporary visas, there was a common view that this period of restriction could be shorter than 12 months.** In some instances, some participants in the non-resident groups felt that they should be **part of the opt-out system as soon as they arrive in England** as long as they are made aware of its existence beforehand (see next chapter).

As long as they're aware, I don't think it matters if it's 6 months or 12 months. You could be an organ donor from day 1.

(Male, International students group, Manchester)

In the resident groups, it was felt that **those entering the country for periods of less than 12 months should have the option to opt in to the register** for the duration of their stay (but not be included under the conditions of the opt-out system). This could be done either as part of the process of applying for a visa or by specifically applying to the register.

Finally, there was a less common view that the residency check was unnecessary, and that deemed consent should apply for any individual who dies in England (including someone visiting as a tourist).

Awareness of the opt-out system

There were also suggestions in both the resident and non-resident groups that the introduction of the opt-out system will require a **mechanism for proactively informing** all new English residents about the need to explicitly opt out if they do not want their organs or tissue to be donated.

Participants in the non-resident groups discussed how there needs to be **something built in with the opt-out system to the VISA application process** in order to inform people on how donation works in England, and at which point in time they have to expect to be automatically opted in (unless they have already opted out).

It takes so long to get a VISA. They could ask if you wanted to be a donor after 12 months, or straight away. You have a face to face interview with someone, it takes 10 or 15 minutes.

(Male, Temporary workers group, London)

In the international students' groups, it was felt that **English universities and UCAS should play a key role** in providing information about how the proposed legislation may affect them, and how this process could be incorporated into the admission/matriculation process.

Overall, it was felt that there were many options at different points in time to bring awareness of the new system.

There's so many points you can do it. When they're getting the visa in their country, when you pick the VISA up, when you meet the biometrics people, when you get bank accounts.

(Male, Temporary workers group, London)

Where the organs should go

There was a perception, albeit rare, that **those who die in England, and have agreed to organ donation, should be able to donate their organs to somebody in their home countries**. However, most non-resident participants disagreed, naming practical issues around the repatriation of organs and how the nationality of organ receivers was irrelevant to them.

I think it makes sense to donate in the country that you die in, it's already very complex and it would just be making it even more complex, especially when more than one country is involved and different policies come into play.

(Female, International students group, London)

Geographical location doesn't matter much, it's still a life you're saving.

(Female, International students group, London)

However, there was some agreement that the idea of donating organs to people who need them in England could be problematic for some international families, who might struggle with the concept of deemed consent.

While acknowledging that this would probably be relevant to only a handful of people, some participants wondered whether they could somewhat prioritise their organs going to their family members abroad and whether they could go online and sign some sort of clause stating 'if possible please favour family members'.

In some crazy scenario where a family member abroad is in need of an organ, and where the relative who has died is a very good match, that situation should be prioritised.

(Male, International students group, London)

4.5 Chapter summary

In line with the DHSC consultation question “When exemptions to ‘opt-out’ would be needed, and what safeguards would be necessary”, participants were asked, what sort of groups of people, if any, should be excluded by the model of “deemed consent”.

The majority of participants agreed that explicit consent should be required for:

- all children under 16 or 18 (either through self-authorisation or parental consent), and that deemed consent should apply to young people aged 16 or 18.
- People lacking mental capacity, unless they had legal capacity after the date of the opt-out system.
- Temporary residents who have been in England for less than 12 months.

However, views were a bit more nuanced regarding non-residents with some participants believing that awareness of the opt-out system rather than length of residency should be taken into account when taking the decision to include this group or not.

Exclusions



4.6 Recommendations and suggestions

- The following groups should be excluded from the opt-out system:
 - all children under 16 or 18;
 - those who are elderly/ incapacitated at the time of introducing the legislation; and
 - temporary residents who have been in England for less than 12 months.
- Information around how organ donation works in England, and the option to opt-in should be included the VISA application process.
- UCAS and English universities should promote and raise awareness around organ donation among international students after their arrival.

5 Implementing the opt-out system

This section explores participants' views around what could be done to make the implementation of opt-out as successful as possible. In discussing this, participants identified four necessities:

- **Informing** English people that organ donation system is changing and why, through a range of campaigns;
- **Explaining** which options have under the future legislation and signposting opportunities on how to register an opt-out (or opt-in) decision should people wish to do so;
- **Ensuring** there is a sufficient transition period between the start of the awareness campaign and the implementation date for opt-out, so that people have a chance to opt-out if they wish to do so before the proposed system comes into play; and
- **Increasing knowledge** of the general public around organ donation and opt-out.

In line with the DHSC consultation, participants were asked what could be done to make people aware about the new rules for organ donation. Overall, **increasing awareness and understanding of the opt-out system** were viewed as absolutely key by participants who came up with a number of suggestions around what to drive communication going forward.

I think opt-out is a good system, but the education and discussion need to be there.
(Female, Temporary workers group, London)

[When asked what the NHS should think about when communicating the move to opt-out] I think it's about awareness, that's what [the NHS] need to think about (...) do [people] know the system is changing, and do they know what the system is now? Do they even know that?
(Male, Afro-Caribbean group, Manchester)

Interestingly, participants initially reluctant to the change of legislation tended to feel positive about the change by the end of the groups, suggesting how **increasing knowledge around opt-out - and also challenging myths around organ donation - is prerequisite to the successful implementation of the new system.**

Overall, participants felt that increasing knowledge could help create a favourable attitude towards opt-out. It was believed that doing so could **reduce potential barriers to organ donation** (such confusion about brain death or uncertainty about religious support), so that a more favourable attitude can be created.

Increasing knowledge and awareness for the people [is key]. It is about clearness of the situation. Basically, knowledge about the circumstances where they will remove your organs. So that they know in what circumstances they will have things removed. So that when you're definitely dead, and not when you're maybe dying.

(Male, International students group, Manchester)

5.1 What information and which messages

To increase awareness, but also ensure wide support for the opt-out system, effective campaigning would mean **sharing key facts and statistics about organ donation** such as the number of donors on the transplant waiting list.

Whether it's opt in or opt out, they need to give people the facts. Emphasise how many lives are saved.

(Male, Parents group, Brighton)

To inform people with statistics and choices, and to reach every single person in the country by one way or another, and that nobody slips through the net, you know? Then to be more aware of decisions and informing your family of your choices, for friends and family.

(Female, Jewish group, Manchester)

It is also good to give some information and statistical data about transplantation, why it's an issue and why you're being asked about it at such an early stage, because as it has been said, it's not on many people's list of priorities. Knowing will have an impact on decision-making.

(Female, International students group, London)

In addition to statistics around organ donation, it was thought that **the use of real life stories** could be particularly effective in highlighting how organ donation can save lives and why the move to opt out is taking place.

I think real people work much better than actors. You can have supporting people like role models.

(Male, Hindu/Sikh/Buddhist group, London)

However, it is important to point out that some caution was expressed, and to avoid the risk of campaigning having the negative effect, the audiences should not be 'pushed' too much.

The information provided should be very objective and not manipulative, because it's a very personal choice, and saying no should be just as ok as saying yes (...) [Do] not manipulate people on an emotional level by saying things like 'With one body, you can save 9 lives'. They (the NHS) should focus more on the system and how it's going to work.

(Female, International students group, London)

At the beginning of the groups, but also later on when they were discussing the role of the family, some participants struggled sometimes to grasp the concept of deemed consent, and felt the choice to donate their organs will be somewhat taken away from them. This challenged their assumptions about consent and individual decision-making. After discussions about how opt-out will work in practice, they often came around to agreeing that this was a good model to have in place. In particular, and importantly in terms of the terminology to avoid, one of the Jewish groups were opposed to the term 'assumed consent' as this portrayed a feeling that the choice has been made for people.

Overall it was felt that, when communicating the change in legislation, **it was crucial to stress to the general public that moving to opt-out would still give them the opportunity to express freedom of choice** This should be done simply, with straightforward messages which could be grasped by a variety of audiences.

I think that the NHS should highlight that you still have a choice, you have to actively opt out but it is still your choice.

(Male, International students group, Manchester)

Alongside this point, participants were insistent that it was crucial to clearly explain the options under the new legislation and to **signpost so that people know how to register an opt-in or an opt-out** decision, should they wish to do so.

The NHS needs to make any advertisement in clear English, make sure the message is clear and easy to understand, don't fill it with jargon, think about your audience, and clearly identify the requirement to opt out and what it means if you don't opt out. To take away, I'll articulate my decision, so that my family and friends know my position, and encourage them to have the conversation with their families. The decision is being taken away from you ultimately.

(Female, Afro-Caribbean group, Manchester)

The most important thing the NHS needs to communicate, how to opt out, if it's an automatic opt in, it needs to be extremely clear.

(Male, Jewish group, Manchester)

Make it clear how to opt out, and what I would tell my family, would be to remind them that I am a donor.

(Male, International students group, Manchester)

Linked to this, participants discussed how **several different channels should be made available to those who choose to opt-out**, for example via their GP or other face-to-face interactions with the NHS; online, or via text message.

5.2 Targeting the general public and specific groups

Participants discussed how the communication strategy should be delivered over two levels: mass media advertising, and targeted interventions.

Mass media advertising campaign

In line with the evidence suggesting that public information campaigns substantially increase the number of organs donated and the willingness of people to donate both their own and the organs of their relatives (Mossialos et al, 2008), participants felt that **some campaigns should be run extensively in the run-up to the system change**. These included **radio, television and social media adverts, as well as adverts on transport advertising spaces and billboards**. One female Muslim participant mentioned the stroke awareness 'act F.A.S.T' as an example of effective campaigning, where the message was well absorbed.

Other methods mentioned included:

- TV shows with participating experts
- information published in daily newspapers
- storylines in soaps and magazines and documentary TV shows
- roadshows and public events across the country

These were viewed as an effective range of tools to ensure the public engagement is as wide reaching as possible. Going further, a group suggested holding a polling day when people could vote whether they want to opt-out or not.

[The NHS] should 'drench' [people] with every means.

(Female, Black African group, Leeds)

There was an assumption among participants that **a move to opt-out would necessitate considerable financial investment in the appropriate communications**. Some participants were therefore keen to suggest that the budget dedicated to the promotion of introduction of the opt-out system **should come from Central Government and not the NHS** (highlighting some common misconceptions around government spending).

Overall, participants believed that widespread campaigns around organ donation could not only encourage clarification of organ donation decisions but will **also inspire people to share these decisions with family and friends**, so that talking about organ donation becomes normalised. To highlight this point, several participants mentioned the smoking ban and how quickly people adapted to the changes it entailed.

As we move on through generations, [being an organ donor] will become the norm.

(Male, Parents group, Brighton)

Bespoke work with specific audience groups who may not be engaged in mass media

Older people

To reach out to older people, whom participants felt were more likely marginalised, **the role of GPs was widely discussed**. Across all groups, participants talked about how the positive and trustworthy role played by GPs should be utilised to increase the awareness of the new system among the elderly (as well as among other marginalised groups). In addition, it was widely acknowledged that GPs had fairly high level of contact with all groups.

Some suggested educating GPs about opt-out, and also training other staff such as practice nurses and receptionists, so they could inform and answer to their patients' queries around organ donation.

I think it could be done via the GP system. Particularly for older people, who might not have access to the internet. There's probably someone who can do it for them. That discussion with your doctor, which, to generalise, older people are more likely to have. The whole system need to be made very easy for everyone. For elderly people, that is a really good way. Not just for elderly people, everyone should have

the option to do that (...) The GP system is the ideal way for them to opt you in and out on their system.

(Female, Black African group, Leeds)

Most people see GPs at least once a year, so the GP could explain the new system to them when they do. That's a way to protect older people as well, because a medical professional has had the discussion with them and that medical professional will know if a person has dementia and needs to be excluded from the system.

(Female, Jewish group, London)

It may be down to the GPs, who have people that age. It might be down to them, to personally get in contact with them. Send a letter out. They're all under some sort of care. They're a major population. They probably don't watch TV.

(Female, Black African group, Leeds)

Some participants went further, suggesting that GP surgeries should mail out and/or text their patients in order to inform them about the opt-out system and its launch date. However, concerns were raised about the extra work and time this would impose on already overworked and time-pressured GPs.

Don't forget, a lot of the GPs are private practices under the NHS, but the NHS don't pay them enough. Then you're going to add this on top of it? It should be up to the government's pocket, to provide it to the public, to respond back.

(Female, Jewish group, London)

BAME and faith groups

There was a general view that there should be some specific work undertaken to target specific on BAME and Faith groups. In order to achieve better engagement on organ donation with members of faith and BAME groups, participants felt that some work should be done at **grass roots level within their communities** to encourage donation, and that a range of methods should be used such as events, talks by faith leaders etc.

There should be a huge drive to make it more grass-roots and information-led.

(Female, Black African group, Leeds)

Have scholars or someone who can put it directly to our community, not beating around the bush and diverting it.

(Female, Pakistani/Bangladeshi group, Luton)

Approach Islamic community centres, mosques, and the person in charge. Get them to do the research. Loads of people come in the mosque all the time. There are seminars and gatherings.

(Female, Pakistani/Bangladeshi group, Luton)

Overall, it was believed that providing **targeted education about opt-out and the benefits of organ donation** may clarify ambiguities surrounding cultural and religious-based views on organ donation, challenge misconceptions and suspicion towards donation, and in turn, lead to increased organ donation rates.

Children

While it was agreed that the opt-out system should not cover children under a certain age, there was a widespread consensus among participants that organ donation and **the move to opt-out should be covered within schools**, with many acknowledging that **it could be part of the curriculum**. It was felt critical to give children the facts around donation so they can become equipped to make a decision when the time comes.

I was thinking about how we talk about sexual health and drug abuse all the time when we're at school, but organ donation is never mentioned, and I'm not sure why it can't be discussed at a young age.

(Female, International student, London)

You need to make it clear to kids by going into schools, so they can learn what they can do by opting in.

(Male, Black African group, London)

It's on the government. If they haven't put out there in schools, it's like politics, you don't know nothing about politics until you get to 18. You don't know enough about it, you have to go and learn about it, so then you're automatically opting in.

(Male, Afro-Caribbean group, Manchester)

Furthermore, it was believed that talking about donation at schools could encourage children and their parents to start discussions about organ donation at home.

Non-residents

As mentioned in section 4, there was a general agreement that **providing information, and an option, during the visa application process** was an effective way to communicate information about organ donation in England.

International students also mentioned the role of UCAS and English universities in promoting and raising awareness around organ donation after arrival.

In my school a lot of people applied to English universities so we had to do it through UCAS, and I think there should be an extra thing on UCAS that tells you how it works, I was really confused about how the NHS worked when I got here. I came from a completely different background, especially in terms of organ donation.
(Female, International students group, London)

When I was registering for my student ID at [English university], we had a very long questionnaire to fill in. Some of the questions were really interesting and I enjoyed answering them, and I thought it was good to ask these questions, because it sounds like the university is paying attention to your personal life. Adding questions about organ donation would be good.
(Female, International students group, London)

5.3 The transition period

Ensuring the transition period (between the start of awareness campaigning and the implementation date for opt-out) is long enough so that people have a chance to opt-out before the system comes into play, was considered critical for participants across all groups. However, views varied widely about how long the period should be, with some participants citing any time period from 6 months to 3 years. **Two years was commonly reported.**

The big disadvantage of the new system is that the state is taking away control from you, so in the transition period people need to be made aware of how they can opt out. It is your body and you should still be in control of it, even after you die. People need to be aware of their options, it's even more important with the new system that this is the case.
(Female, International students group, London)

Even though, leading up to it, everyone knows next year September 14th, this is going to come underway. You can opt out whenever. You have to really know about it.
(Female, Christian group, Brighton)

While it was agreed that most of the communication campaigns should take place through the transition period, participants also strongly felt that efforts to raise understanding and awareness of organ donation should be on-going and go beyond the launch date of the opt-out system.

It needs to be a continuous process. Not just 6 months and they forget.

(Male, Christian group, Brighton)

I feel like there hasn't been an organ donation drive for a long time (...) Every 6 months I could get a text, 'Come in, get your blood pressure checked.' If after that, those numbers were the same, 'We need to look at it.' In the 80's there was a bit of a thing about it, everyone opting in (...) People feel they are opted in but they can't remember.

(Female, Parents group, Brighton)

5.4 A period of grace

As mentioned earlier in this report, a big concern to participants was that individuals might die without knowing about the opt-out system (and the implications of deemed consent), or they may not have got round to opting out (if they wanted to) before they died. As discussed already, for some this meant that families would need to be more involved in the decision around whether organ donation could proceed.

Whilst participants did not explicitly, themselves, come up with the idea of a period of grace, where it was suggested (either by the moderator or by the expert), they found this particularly reassuring.

5.5 Chapter summary

Overall, participants believed that, for the launch of the opt-out system to be successful and for organ donation to increase, the Government has to conduct a thorough public information campaign focus on:

- the new regulations
- the vital need for more organs
- the need to discuss organ donation with family members
- the possibility to formally opt out if they do not wish to donate their organs.

Such campaign should focus on people still have the freedom to make their own choices regarding organ donation.

Participants agreed that **widespread campaigns could open a dialogue, and ultimately normalise discussions around organ donation** so that people feel comfortable talking about it, and making their loved ones know about their decision to donate, or not donate.

A number of methods were suggested to increase the awareness of marginalised groups, and participants highlighted the key role community and faith organisations, schools and GPs in raising awareness about the move to opt-out and organ donation in general.

Which information and messages

Share **key facts** and **statistics**

Use **real life stories**

Do not use expression 'assumed consent'

Opportunity to express own's **freedom of choice**

Signpost how to **opt-in** and **opt-out**

Transition period

Period of grace



Results

Increase in **awareness**

Increase in **discussions in families** around organ donation

Increase in **donations**

Organ donation becomes part of the **social norm**

5.6 Recommendations and suggestions

- Use mixed communication channels to reach a broad audience.
- Identify and address your target groups. One should take into account specific requirements for communicating with different age, language, religion or ethnic groups.
- GP surgeries should be used to reach marginalised groups.
- Children should receive information about donation at school.
- Information around how organ donation works in England, and the option to opt-in should be included the VISA application process.
- Media campaigns around the new system should make clear that individuals would still have the freedom to make their own choice.

6 Conclusion

This research project has sought to explore the views of the general public, and of different ethnic and faith groups on the best ways to implement the proposed opt-out system for organ donation. Alongside the Department of Health and Social Care's consultation, this research aims to inform final policy decisions with regards to how the opt-out system will work going forward.

It is important to note that the findings should be treated with caution because of the qualitative research approach. They are based on a small number of people who have discussed the relevant issues in depth. The views stated here are not facts, rather they are the participants' perceptions and the truth as they see it. Additionally, people who strongly opposed organ donation were excluded from the recruitment process.

Awareness and understanding of the proposed opt-out system was low prior to the groups, suggesting some communication challenges ahead, especially around the concept of deemed consent. However, by the end of the discussions, participants tended to be in favour of the opt-out proposal, and how it shifts the responsibility to the minority of people to record a decision to opt out of organ donation, rather than the majority, who are happy to donate their organs. They also felt that the move could act as a catalyst for family conversations, and help normalising organ donation as a topic of discussion.

However, a number of concerns were raised about the proposed opt-out system, namely the perceived lack of choice, and the lack of clarity over the role played by family members at the point of organ donation. Participants felt that the individuals' decision under deemed consent would be less clear-cut. This "grey area", as it was often described, was seen to place more onus on the family and healthcare providers.

Overall, participants believed that, for the launch of the opt-out system to be successful and for organ donation to increase, the Government has to conduct a thorough public information campaign aiming to: inform people that the legislation is changing and why; clearly explain the options under the new legislation and signpost opportunities on how to register an opt-in or opt-out; and encourage people to discuss organ donation decisions with their family and friends so that doing so becomes the 'norm'.

7 Appendices

Appendix 1. Discussion Guide for Moderators

Background

- *The Government recently announced plans to change the legal basis for organ donation in England to an 'opt-out' system, whereby it will be presumed that an individual has consented to be an organ donor after their death unless they have specifically recorded a decision on the Organ Donor Register to refuse to donate.*
- *The main rationale for introducing this change is that there is good evidence that over 80% of the population support organ donation and would be willing to be a donor after their death, but only 30% have signed on to the Organ Donor Register and/ or spoken to their family about their decision. This means that many people risk not having their decision honoured, as it is not clear what they wanted to happen.*
- *This system, also referred to as "deemed consent", builds on similar changes to legislation in Wales two years ago. Scotland is also consulting on developing opt-out legislation. The current system in England that the Government is proposing to change is referred to as "opt-in", because people who want to be organ donors have to specifically register their wish on the Organ Donor Register or have expressed a positive desire to donate to a qualifying relationship (e.g. next of kin).*
- *NHS Blood and Transplant is the authority with the responsibility for organ donation in the UK. They manage the NHS Organ Donor Register and National Transplant Waiting List, which allows them to match organs from deceased donors to people who are waiting for a transplant.*
- *The Department of Health and Social Care and NHSBT are working collaboratively to seek views on the move to opt-out, via a series of focus groups.*

Research Aims

The objectives of the focus groups are to develop a deeper and more nuanced evidence base, especially among the different ethnic and faith groups, to be looked at alongside the online consultation the Government are undertaking at the same time. Both consultations will inform final Department of Health and Social Care policy decisions and eventual legislative change with regards to how the opt-out system will work going forward.

1. Introduction

(5 Minutes)

- **Research introduction**
 - Introduce moderator
 - Research on behalf of NHS Blood and Transplant
 - Aim of the discussion is to consult on changes to the legislation relating to consent to organ donation

- Introduce Ipsos MORI staff and their roles
- Role of Ipsos MORI – independent research organisation, here to gather your opinions.
- No right or wrong answers and all opinions are valid – ground rules, allow everyone to speak, but do feel free to (politely) disagree.
- Group length – 120 minutes
- Comments are anonymous, participants are not identified/ Information gained will be used for research purpose only
- Ask permission for recording. Explain MRS and anonymity, right to stop at any time, **it is ok not to answer questions they don't like.**
- Client observation (if applicable)
- Housekeeping – food, drink, toilets, mobile phones
- Any questions?

2. Participants introduction **(5 Minutes)**

Paired introduction: moderator to ask respondents to introduce themselves to one another.

- Ask the person next to you what they would be doing today if they weren't attending this event.
- Introduce your partner to the rest of the group.

3. Main Discussion **(105 Minutes)**

3.1 Opt in vs. Opt out **(20 minutes)**

MODERATOR – *please show Video 1. Please make sure that you explain to the participants that while the video we're going to show them promote organ donation, we're only showing it to them so they can understand how the current 'opt-in' system works. Please re-stress that the aim of the group is not to discuss whether people should donate their organs or not.*

Main views of current opt-in system

- General views/basic acceptance of concept of donating organs after death (NB respondents to be pre-screened to exclude outright rejectors)
- Understanding of how the current system works
 - Knowledge of organ donation system and Organ Donor Register
- Are they donors or have they thought about donating their organs
 - What about discussing their intention with their friends or family
 - What are the merits or otherwise of the opt in system?
PROBE: Reliance on the effort of individuals, not a nice thing for healthy people to have to do, perception that probably already on the register (either through actively registering at some point or because it's initiated as part of something else – applying for a driving licence for example).
 - Does the opt-in system create problems/barriers to donating?
 - Could it be changed/improved and how
- **The opt-out system**

MODERATOR – briefly explain the Government’s proposed change to “opt-out” or “deemed consent” concept and the basics of the change, what it will mean to the participants. **Show video 2**

Ask people if they understand opt-out. It might be helpful to read the points below:

- Nearly 85% of the UK population say that they would be willing to donate their organs after they have died, but only around 35% of the population has actually signed on to the Organ Donor Register. This means that 50% of people run the risk of not having their decision about organ donation honoured, as the decision has to be made by their family instead. This also places a lot of pressure on family members at a time when they are grieving for their loved one.
- Under the new system, it will be assumed that everyone would be willing to be an organ donor unless they have opted out. The Government believes that system better reflects what most people want to happen. It shifts the responsibility to the minority of people to record a decision to opt out of organ donation, rather than the majority, who are happy to donate their organs.
- The family will always be involved in the organ donation discussion.

Impression of proposed changes

- What are the merits or otherwise of the opt out system?
 - PROBE: Govt intrusion, extending powers, perception that Govt “owns my body” or other negatives
 - What about people who in their lifetime may be unaware that they have to opt-out?
 - Will this help to ensure that the NHS honours the decision of those who would have wanted to donate, but had not signed on to the Organ Donor Register?
- What personal impact would this change have on them and their families?
 - What sort of influence would this have on their view of donating organs?

3.2 Role of the Family (General) (10 minutes)

- **General role of the family**
 - What is the role of the family in principle overall, i.e. excluding any specific circumstances for now.
 - What would be your general expectations of your role as a close family member if your spouse/siblings/children asked you to support their wish to be organ donors
 - PROBE: How would you feel if you had told your family that you wished to donate your organs, but they were so distraught at your death that they don’t want donation to proceed.

3.3 Role of the Family (Specific Scenarios) (60 minutes)

MODERATOR – Give Description 1 (2) to the respondents and allow a few minutes for them to read.

After they have read it, ask either Scenario 1, 2 or 3 at random. Cycle through the Scenarios in turn until all 3 have been discussed. **(approx. 30 minutes)**

Now, Give Description 2 (1) to the respondents and allow a few minutes for them to read.

After they have read it, ask either Scenario 1, 2 or 3 at random. Cycle through the Scenarios in turn until all 3 have been discussed. **(approx. 30 minutes)**

NB – Descriptions 1 and 2 to be rotated among groups of the same, main demographic (e.g. Faith, Ethnicity etc.)

3.4 Exceptions **(10 minutes)**

[NOTE: THIS SECTION MAY NOT BE NEEDED FOR THE PARENTS/NON-RESIDENTS GROUPS IF COVERED BY SPECIFIC SCENARIOS IN PREVIOUS SECTION – IPSOS TO ADVISE]

- **Exclusions & Safeguards**

- Assuming the Government moves to an Opt-out system, what sort of groups of people, if any, should be excluded by the model of “deemed consent”?
- PROBE: Children? People with mental disabilities? People who cannot look after themselves, e.g. old and infirm?
 - Should consent continue to be obtained from a parent, guardian or family member as at present or should it come from the individual themselves?
 - When do you think the level of competence to make this decision begin?
- At what age should children be considered adult enough to make an informed decision on opting in or out of the Donor Register?
- What about foreign students and temporary workers?
 - Should they be eligible for donation if they happened to die in this country?

3.5 How to Record Decision (IF NEEDED) **(5 minutes)**

- **Method of Recording**

- Which is the best way to record people’s intention to donate their organs or not to?
- Who should have access to that data? The family, the Government, the NHS or only the donor?
- What is the role of technology in this, how can it help?

4. Final Reflections & Close **(5 Minutes)**

So finally, after all you have heard and discussed today:

- What’s the most important thing they think NHS need to think about when communicating the change? Why?

- What's the one thing they'd tell family and friends about what we've discussed tonight?

Additional areas for discussion

Should the following issues arise, the moderator should explore people views and then move on to the next scenario:

- IF SPARE TIME ONLY: Novel transplantation – There are some forms of donation that are very unusual, such as limb or face transplants. These all have the ability to dramatically improve a person's life and are provided on the NHS, but are very rare. Is it reasonable to assume that either opt in or a decision to not opt out would cover these forms of donation?

THANK & CLOSE

Appendix 2. Descriptions and Scenarios

Description 1

Karen is a 52-year-old lady who works at a local Primary School, where she supports children who have special needs. She is married to David who is five years older than her and who is a motor mechanic. They have a daughter called Louise who is a nurse. Louise is very close to her mother and is currently on maternity leave, having had her first baby three months ago.

One morning Karen goes off to work as normal. However, mid-morning she collapses suddenly after complaining of a terrible headache. She is rushed to hospital where a head CT scan shows that she has had a massive brain haemorrhage. Karen is unconscious and admitted to an intensive care unit where she is placed on a ventilator. There is nothing that can be done to save her and the doctors explain to David and Louise that Karen is brain-stem dead. This means that she has lost all brain function permanently and that it is impossible for her to make any recovery.

David and Louise accept that they have lost Karen and that nothing can be done to save her. After speaking to the doctors they are introduced to a specialist nurse who raises the possibility of organ donation. Louise is very upset and is also struggling to look after her baby. However, she knows her mum is a very kind person who would do anything to help people in need.

Scenario 1

From the perspective of David (husband) and Louise (daughter):

- Karen registered to be an organ donor when she renewed her passport five years ago. Who should have the final say? What about if David and Louise's decision is different to that of Karen's?

Scenario 2

From the perspective of David (husband) and Louise (daughter):

- Karen was always very squeamish about the subject of organ donation and when the new system came into play, opted out of organ donation (i.e. registered that she did not want to be an organ donor). Louise did not know about this. In fact, Louise works in a transplant unit and thinks her mother *would* want to be a donor. Who should have the final say? What would you think if David and Louise were allowed to reverse Karen's decision and allow donation to go ahead even though she had opted out?

Scenario 3

From the perspective of David (husband) and Louise (daughter):

- Karen had never opted-in to organ donation, nor did she opt out when the new system came into play hence the circumstances of deemed consent would apply. This means that because she had not opted-out, it will be assumed that she wanted to be a donor. What should David and Louise do? Should they assume that because Karen hadn't opted out, she would have been ok with it, or should they have the final say? What do you think the decision to donate is based upon? What do you think about the absence of saying no as a donation decision? What about David and Louise's final say in these circumstances compared to Scenario 1?

Description 2

Deepak is a 22-year-old medical student at Sheffield University. His parents live in London with his younger brother and sister. Deepak's father is a pharmacist and he is incredibly proud that his son will soon become a doctor.

Deepak is a keen rock climber and is secretary of the University Mountaineering Society. He is involved in an accident whilst climbing in the Peak District and is rushed to a hospital in Sheffield with very serious head injuries.

Deepak has been on a mechanical ventilator in intensive care for five days and his parents have hardly left his bedside. His girlfriend Carla, who is a fellow student at Sheffield University, is also there. Deepak is not waking up and doctors decide to do another head scan. The scan shows terrible brain damage from which Deepak cannot recover. Deepak is brain dead and only the ventilator keeps his heart beating and blood circulating. The doctors have several discussions with Deepak's parents about how bad things are and during the latest one says that the time has come to stop and let Deepak die. Deepak's father knows in his heart that the doctors are right and he agrees to what they are saying. The doctors console the family and tell them about organ donation. They explain that an organ donation nurse is waiting in the room next door if they would like to have a chat with her.

Scenario 1

From Deepak's perspective:

- You registered to be a donor when you applied for your first driver's licence four years ago. However, you never discussed your donation wish with your parents because you thought they might disapprove. Who should have the final say? What about if your parents' decision is different from yours?

Scenario 2

From Deepak's perspective:

- You opt-ed out of organ donation when the new system came into play (i.e. registered your decision not to be a donor). However, you didn't discuss this

with anyone for fear of what others might think. What would you think if your parents were allowed to override your wishes and let organ donation go ahead?

Scenario 3

From Deepak's perspective:

- You had not opted-out since the new system came into play, because you want to be a donor and understand that doing nothing means that this will happen. Who should have the final say in these circumstances? What about your rights and your family rights? Whether/ How is it different from Scenario 1 because you have not actively opted-out of organ donation? Whether/ how the donation decision based on the absence of an opt-out have the same authority as one based upon having opted-in during your lifetime.

Description 3 (only discussed in the non-residents groups)

-
- Piotr is a 28-year-old man from Poland who has been living in England for around six months, working on a building site. One afternoon he is involved in an accident at work, falling from scaffolding onto a hard-concrete surface. He is unconscious and taken to hospital, where a head scan shows that he has terrible head injuries. He is taken to intensive care and put onto life-support, although the doctors don't think he has much chance of survival. A colleague from the building site tells staff that Piotr has recently started seeing an English girl but lives alone in a small flat. Piotr's girlfriend is contacted and informed about what has happened.

Two days later, doctors examine Piotr very carefully and reach the conclusion that he is brain-stem dead. They recognise that he was a healthy young man and that several of his organs are suitable for transplantation. Piotr is referred as a potential donor to the organ donation nurse.

- **Scenario 1**
The organ donation nurse checks the donor register and discovers that he has recently registered as an organ donor when he taxed his car. His girlfriend has only known Piotr for a couple of months and doesn't feel able to be comfortable about being involved in the decision. Should donation be allowed to go ahead?
- **Scenario 2**
The organ donation nurse checks the donor register and tells the medical staff Piotr has not opted out of organ donation. However, she goes on to explain that his consent to be a donor cannot be deemed – as it would if he were English – because the law does not apply to foreign nationals living in England for less than twelve months. Instead, she says that consent is required from his next of kin. Is it right for opt-out not to be applied in such circumstances?

Should the law of the land not apply automatically or should temporary residents be protected from deemed consent?

Description 4 (only discussed in the parents' groups)

Phoebe is a 12-year-old girl who is in year 8 at her local High School. She lives with her mother and father and has two younger brothers – Joseph who is 9 and Tom who is 7 years old. Phoebe's mother Jennie works in a nearby supermarket and her father Bruce works in a bank. Phoebe is doing really well at school and her teachers have recently remarked upon how mature she is for her age, particularly in the PHSE lessons.

Phoebe wakes up one Saturday morning with a sore throat and a bit of stomach ache. Jennie gives her some paracetamol before going off to work. A few hours later Bruce rings her at work to say that he has had to call an ambulance for Phoebe because he can't wake her up and she is covered in a rash.

Phoebe is rushed to hospital and admitted to a children's intensive care unit. She is deeply unconscious and doctors tell Jennie and Bruce that their daughter has meningitis. They go on to explain her brain is very swollen and to treat this she needs to be put into an induced coma and placed on a mechanical ventilator. Unfortunately, her condition gets worse over the following two days and doctors explain that Phoebe is now brain-stem dead.

Although the doctors say it would not have made any difference, all Jennie can think about is how things might have been different if she had stayed at home with Phoebe rather than going off to work. The doctors and nurses are very kind and supportive, but tell her that Phoebe has gone. They also ask Jennie and Bruce to think about organ donation and introduce them to the organ donation nurse.

Scenario 1

The organ donation nurse tells Jennie and Bruce that Phoebe recently registered on line as an organ donor. Jennie remembers that Phoebe had talked about a recent discussion at school about transplantation and that she had decided that she would want her organs used for transplantation after her death. Bruce did not know anything about this and although he accepts that Phoebe has died, he cannot bear the idea of his daughter having surgery.

What should Jennie and Bruce do? Twelve-year olds are allowed to register as donors and there seems little doubt that Phoebe made an informed decision about organ donation. Should they – as her parents - be allowed to overrule her decision, even though it was her last known wish?

Scenario 2

The organ donation nurse tells Jennie and Bruce that opt-out has now been introduced into England and that anyone aged 12 years or more will be assumed to be an organ donor unless they have said they didn't want to. The nurse has checked the donor register and tells Jennie and Bruce that Phoebe has not opted out and for this reason should be considered as a donor. Is this the right way to go about things or should her parents, Jennie and Bruce, have the final say? If 12 years of age is too young, at what age do you think opt-out should be applied? Should it be 16 years of age? Should it be 18 years of age?

Scenario 3

The organ donation nurse meets with Jennie and Bruce and tells them that Phoebe opted out as an organ donor just a few months ago. Jennie and Bruce are really surprised about this as Phoebe was such a kind and generous girl and they wonder whether she has made a mistake. Furthermore, they had already discussed organ donation and were keen to consider it. Should they, as her parents, be allowed to over-rule her stated wishes? If so, would it be different if Phoebe was 14 years old, 16 years old? How old does Phoebe have to be for her views to be more important than her parents?