Organ donation legislation: discussing decisions with family
Organ donation legislation: discussing decisions with family

A qualitative study

Polly Hollings, GfK UK

Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government.

For further information please contact:
Janine Hale
Social Research and Information Division
Welsh Government
Cathays Park
Cardiff
CF10 3NQ
Tel: 0300 025 6539
Email: janine.hale@gov.wales
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1. Executive Summary

**Background and method**
This research set out to explore:
- Whether people understand the importance of discussing organ donation decisions with family.
- Barriers to discussing organ donation decisions with family.
- Potential role for communications in overcoming barriers to discussing organ donation with family.
- Reactions to existing organ donation legislation communications (two bus adverts used during 2016).

Eight mini-group discussions were carried out. Each lasted up to 90 minutes, and six participants were recruited to each session. The sample was designed to include:
- Those who had discussed their organ donation decision with family
- Those who had not discussed their organ donation decision with family
- Those who were happy for presumed consent
- Those who had opted in for organ donation
- A range of demographics

**Defining discussions about organ donation**
Across the research it was clear that having a ‘discussion’ about organ donation decisions with family could mean different things to different people including:
- Discussed, but a long time ago
- Discussed with some family members but not others
- Discussed in passing, but not conclusive or in-depth

**Barriers to discussing organ donation decisions**
Five key barriers (including rational and emotional barriers) emerged to discussing decisions with family:
- The topic has not come up in conversation
- No sense of immediacy to discuss the topic
- Misperceptions of the legislation
- Not an easy topic to bring up
- Misperceptions of who can be a donor

**Benefits to discussing organ donation decisions**
Those that had discussed their organ donation decision with family were typically driven by one or more of the following three factors:
- Recognising the positive outcome of organ donation (the positive impact that organ donation could have on individuals waiting for an organ transplant)
- After seeing media coverage regarding the change in legislation
- Personal experiences of friends/family dying which had highlighted the importance of discussing decisions with family

Whilst these were the core reasons for participants who had discussed organ donation decisions, across the research as a whole, a range of other potential benefits were identified:
- Ensuring that family decisions are respected; making sure that family know my decision, and I understand their decisions.
- Making things easier for next of kin if I become a potential organ donor
• More broadly encouraging more open family discussions (although this was cited by a minority of participants)

The role of the family, and making things easier for next of kin had often not previously been considered by most participants. Thinking about this was a key turning point for many and confirmed the benefit of discussing organ donation decisions.

Organ donation media activity
Across the research there was low recall of advertising regarding organ donation legislation although there was appetite for information about the impact of the change in legislation.

Participants were shown two recent communications, used on public buses during 2016. Overall participants felt that the posters were a little ‘bland’ and were not eye-catching. They were most positive towards communications that they felt conveyed a real life positive story demonstrating the positive outcome of having a conversation about organ donation decisions with family.

Suggestions for encouraging discussions
Participants were asked to generate suggestions for how to encourage people to discuss organ donation decisions with family. These ideas, alongside insights generated during analysis are reported using the behaviour change framework EAST.

<table>
<thead>
<tr>
<th>Element of the EAST framework to encourage behaviour change</th>
<th>Research findings</th>
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</thead>
<tbody>
<tr>
<td>E Make discussing organ donation decisions easy</td>
<td>Encourage and support organ donation decisions discussions by:</td>
</tr>
<tr>
<td></td>
<td>• Providing a stepping stone to broach the topic.</td>
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<td></td>
<td>• Tips to encourage people to start the topic.</td>
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<td></td>
<td>• Modelling the conversation.</td>
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<tr>
<td>A Make discussing organ donation decisions attractive</td>
<td>Use a positive tone and real life stories to promote the benefits of discussing organ donation decisions:</td>
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<td></td>
<td>Personal benefits:</td>
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<td></td>
<td>• Being confident that your decision is clear.</td>
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<td></td>
<td>• Peace of mind that your family would not be left in a difficult situation of having to make a decision when they were unclear on what you wanted.</td>
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<td>• Peace of mind that you know your family’s decision.</td>
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<td></td>
<td>• Those in favour of organ donation further noted the benefit that being clear on your decision could make a positive impact on someone else’s life should you ever become a potential organ donor.</td>
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<td>Family benefits:</td>
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<td>• Respecting each other’s wishes.</td>
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<td>• Making it easy for family should you ever become a potential organ donor.</td>
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<td></td>
<td>• Avoid shocking family members who were not aware of your decision.</td>
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<td></td>
<td>• Avoiding family arguments where family members are not aware of your decision.</td>
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</tbody>
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Conclusions and recommendations
The diagram below summarises the factors that are likely to help encourage participants discuss organ donation decisions with family:

<table>
<thead>
<tr>
<th>S</th>
<th>Make discussing organ donation decisions social</th>
<th>Highlight the social benefit of organ donation as a ‘heroic’ act, making it easier to broach and discuss the topic and decisions with family.</th>
</tr>
</thead>
<tbody>
<tr>
<td>T</td>
<td>Make discussing organ donation decisions timely</td>
<td>Reflect that thinking about when to bring up the topic of organ donation is a difficult decisions by encouraging people not to leave it too late whilst avoiding a pressurised feel.</td>
</tr>
</tbody>
</table>

![Diagram summary of factors]

- **Create a ‘stepping stone’ for people**
- **Tips and encouragement to have the conversation**
- **Model the conversation for people to copy**
- **Frame the conversation in a positive way (peace of mind, respect, sharing)**
- **Highlight personal benefits: my wishes are known**
- **Highlight family benefits: making it easier for next of kin**
- **Highlight societal benefits of organ donation (for those in favour)**
- **Focus on the benefits of a two-way conversation – making your views concrete**
- **Show real life examples**
- **Build on the positivity felt around blood donation and living organ donation**
- **Show public debates/discussions**
- **Don’t pressurise people but encourage a ‘don’t leave it too late’ or ‘now is as good as ever’ feel**
2. Background and objectives

The new organ donation system came into effect in Wales on 1st December 2015. If people have not registered a decision to be a donor (opted in) or not to be a donor (opted out), their consent may be deemed (if criteria apply). This means they are treated as having no objection to organ donation.

This new system is called a soft opt-out system. Family will always be involved in all discussions about donation. They will need to be present to answer questions about the person’s health, lifestyle and where they lived. Family could also say if they knew that the individual wanted to be or did not want to be an organ donor. Therefore, it is important that people talk to family about their organ donation decisions.

This research set out to explore:

- Whether people understand the importance of discussing organ donation decisions with family.
- Barriers to discussing organ donation decisions with family.
- Potential role for communications in overcoming barriers to discussing organ donation with family.
- Reactions to existing organ donation legislation communications (two bus adverts used during 2016).

3. Method and sample

Given the exploratory nature of the research objectives, a qualitative approach was employed. This allowed participants to speak openly about their views and feelings regarding discussing organ donation with family, using their own words. Mini-group discussions were chosen to bring people together to share their opinions, encourage debate and to support the creation of ideas for how communications could best encourage people to discuss their organ donation decisions with family.

Eight mini-group discussions were carried out. Each lasted up to 90 minutes, and six participants were recruited to each session.

The sample for the mini-group discussions was designed using existing Welsh Government data from the Beaufort Wales omnibus survey. This survey provided statistics regarding awareness of the change in organ donation legislation, and steps taken by individuals since the change in legislation had come into force. The data identified the following groups of interest that were considered key in understanding how to encourage people to discuss decisions with family:

- Those who have not registered to opt-in or opt-out of organ donation but are happy for presumed consent and have discussed their decision with family.
- Those who have not registered to opt-in or opt-out for organ donation but are happy for presumed consent and have not discussed their decision with family (in one research location this was broadened out to include those who were considering their options to reflect the survey data for the region).
- Those who have registered an opt-in decision on the organ donation register and have not discussed their decision with family.

The mini-group discussions were also sampled based on demographics to ensure a good spread of different people and circumstances across the research. This included a mix of gender, age and socio-economic group. Four locations were included across the research ensuring a spread of regions across Wales, and in two of these, one mini-group discussion was carried out in Welsh language.
The sample table is provided below:

<table>
<thead>
<tr>
<th>Location</th>
<th>Status</th>
<th>Gender/ Age/ Language Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiff</td>
<td>Done nothing/ happy for presumed consent and discussed</td>
<td>Male, 18-34 years, C1C2</td>
</tr>
<tr>
<td></td>
<td>Registered a decision to opt-in to the organ donor register/ not discussed</td>
<td>Mix male/ female, 35-54 years, BC1C2</td>
</tr>
<tr>
<td>Aberdare</td>
<td>Done nothing/ happy for presumed consent and discussed</td>
<td>Mix male/ female, 45+ years, BC1C2</td>
</tr>
<tr>
<td></td>
<td>Done nothing/ considering options/ not thought about it yet and not discussed</td>
<td>Mix male/ female, 18-44 years, C2DE</td>
</tr>
<tr>
<td>Machynlleth</td>
<td>Done nothing/ happy for presumed consent and discussed</td>
<td>Mix male/ female, 18-44 years, C1C2</td>
</tr>
<tr>
<td></td>
<td>Registered a decision to opt-in to the organ donor register/ not discussed</td>
<td>Mix male/ female, 45+ years, BC1C2, Welsh language group</td>
</tr>
<tr>
<td>Colwyn Bay</td>
<td>Done nothing/ happy for presumed consent and discussed</td>
<td>Mix male/ female, 45+ years, BC1C2, Welsh language group</td>
</tr>
<tr>
<td></td>
<td>Done nothing/ happy for presumed consent and not discussed</td>
<td>Mix male/ female, 18-44 years, C1C2</td>
</tr>
</tbody>
</table>

Quotes included in the report are taken from across the mini-group discussions and include written verbatim as well as responses to written tasks participants were asked to complete during the research session.

4. Defining ‘discussions’ about organ donation

Across the research it was clear that having a ‘discussion’ about organ donation decisions with family could mean different things to different people. A range of definitions and thoughts emerged across the mini-group sessions as summarised in the diagram below.

**Discussed but a long time ago**
Some reflected that they had discussed their organ donation decision many years ago, usually when they had originally registered to be an organ donor. However, these participants often commented that they had not had more recent discussions with family. In some instances family make-up had changed in subsequent years meaning that some had not had the discussion with people that would now be considered their next of kin. Others mentioned that they had not discussed decisions with family since the change in legislation assuming that they had no cause to do so because they were a registered donor.
Discussed with some family members but not others
Some participants noted that they had discussed their organ donation decision, and organ donation more widely with some family members but not others. For example, some had discussed with their partner or spouse but not their children. This was particularly the case where participants felt that this type of discussion could upset their children and included participants with both younger and older grown up children.

Discussed in passing but not conclusive or in-depth
The depth and decisive nature of conversations and discussions with family was also varied across participants. Some noted that they had touched on the topic of organ donation in passing and not all of these participants felt confident that they had fully concluded these discussions. Others described more in-depth discussions with family which had been conclusive and clear.

5. Barriers to discussing decisions
Five key barriers (including rational and emotional barriers) emerged to discussing decisions with family:

- **Has not come up in conversation**
- **No sense of immediacy**
- **Misperceptions of the legislation**
- **Not an easy topic to bring up**
- **Misperceptions of who can be a donor**

Rational barriers
For many, organ donation decisions simply had not come up in day-to-day conversation. This was not based on a positive or negative reaction to having the conversation but based on the fact that it was typically not seen as a general topic of conversation.

“It’s not that it’s a forbidden topic, it’s just not something you talk about in general conversation.”

Participants felt that fitting this type of discussion into day-to-day life could be difficult where competing priorities existed.

The relationship with family members also impacted on whether organ donation decisions were likely to come up in conversation. Some saw their family often but fleetingly, and noted that organ donation felt too serious a topic for a quick ‘on the move’ discussion.

“It’s one of them subjects, a bit awkward to slip into the conversation – how would you start? When’s the right time to bring it up…I don’t really see it as something to bring up over Sunday dinner.”

Others lived some distance from family and commented that bringing up the topic over the telephone felt ‘odd’.
The types of words and phrases that participants used are shown in the diagram below and highlight that for many there lacked the impetus or trigger to have the conversation.

For these participants there was no sense of immediacy for having the conversation.

Other barriers to discussing decisions with family were based on misperceptions of the legislation.

Whilst most were aware of the change in legislation there were some queries around how presumed consent worked. Some assumed that presumed consent was automatic and were surprised that next of kin would be asked. Further to this a few participants noted that when the legislation had changed they had assumed that they did not need to think any further about organ donation; as long as they were content with presumed consent they need to do nothing further. These participants were not clear on the role of the family and were surprised to hear about the practicalities of family involvement.

When discussing the role of family a few other participants commented that they had not discussed their organ donation decision with their family because they assumed that their family would feel the same way as they did. These participants felt confident that they knew how their family would feel about the issue.

“We had a brief conversation because of this [mini-group discussion]…I made light of it as I do with anything serious, but I knew already my partner would say yes to organ donation.”

Those who had registered a decision to opt-in on the organ donation register were also unsure whether they needed to discuss their decision with their family; most assumed that they did not need to.

Across the research there were also misperceptions of who can be an organ donor. A couple of participants who lived rurally queried whether they lived near enough to a hospital to be a donor if anything should happen whilst they were at home/ in their local area. Older participants also queried whether there was an age limit on being an organ donor. Those who assumed they would be too old to be a donor (most likely to be those aged 60+ years) cited this as a reason for not discussing organ donation decisions with family.

Whilst older participants sometimes held these misperceptions, a few younger participants reflected that organ donation discussions held limited personal relevance as they did not anticipate being in the situation where this type of discussion would be drawn upon.

“I know it could happen to anybody but, being quite young, it seems a bit, not unnecessary but, it’s not the first thing on your mind.”

**Emotional barriers**

Emotional barriers tended to focus on the idea that discussing organ donation decisions could elicit negative reaction from family. These emotional fears meant that organ donation was not an easy topic to broach or consider discussing. Overall, participants
aligned organ donation with other end of life topics and therefore felt discomfort in bringing it up and discussing it with family. Some felt that bringing up organ donation could encourage family members to think that there was a bigger issue prompting the discussion (e.g. ill health) which could cause unnecessary worry.

Participants agreed that discomfort associated with discussing organ donation would increase in the following situations:

- Where there had been recent deaths in the family: there were concerns that discussing organ donation could ‘stir up’ sensitive emotions.
  
  “I don’t want to stir up a hornet’s nest of grief.”

- Where members of the family had mental health conditions or depression: there were concerns that discussing organ donation introduced a negative topic of conversation.

- Where children were sensitive towards discussing the mortality of their parents: parents anticipated that even if they tried to start a conversation about organ donation decisions, their children would ‘shut down’ the conversation. This was more often associated with daughters than sons.
  
  “They [my daughters] would go ‘oh mum, there’s no need to talk about things like that.”

- Where differences in opinion were anticipated: there was concern that discussion of organ donation decisions could lead to arguments.

- Where there were concerns that bringing up the topic could be construed as insensitive or driven by a ‘hidden agenda’: participants were concerned that bringing up organ donation with older family members could be misconstrued as an attempt to encourage these family members to consider or reveal details about wills and bequeaths.

- Where the participant personally cited a spiritual reason for not discussing organ donation e.g. on the basis of faith or through fear of ‘tempting fate’. It should be noted that this was only mentioned by a couple of participants.
  
  “I feel like I was tempting fate by discussing this with my son. I prefer to put it in a box.”

- Where the participant personally felt squeamish about the idea of organ donation and the imagery associated with this made it a difficult topic to personally discuss and bring up.

Participants agreed that a ‘stepping stone’ to having the conversation was needed; something that would enable them to easily begin the conversation. For most, attending the research session was considered a ‘stepping stone’. Participants suggested that when they went home they could more easily bring up the topic of organ donation decisions, starting the conversation by talking more broadly about taking part in the research.

Overall it was clear that at a spontaneous level, participants thought about organ donation decisions from a negative and emotional mind set. Some noted that it was a ‘doom and gloom’ subject.

However, participants also reflected that the outcome of organ donation is very positive. Where participants had discussed organ donation with family, thinking about the benefits of organ donation had been a key reason for initiating the discussion.

This suggests that there is scope to broaden the positive association with organ donation to encompass organ donation discussions.
6. Benefits of discussing decisions

Those that had discussed their organ donation decision with family were typically driven by one or more of the following three factors:

- The positive outcome of organ donation
- The change in legislation (media coverage)
- Personal experiences of family/friends dying highlighting the importance of discussing decisions with family

“I don’t often discuss this [organ donation] but have had a discussion about it when the law changed.”

“Having three grandchildren I feel it’s important to discuss organ donation and would like to think that if you should ever need an organ, you should also be responsible enough to donate.”

Whilst these were the core reasons for participants who had discussed organ donation decisions, across the research as a whole, a range of other benefits were generated. Overall, participants felt that discussing organ donation decisions would have a number of positive outcomes:

- Respect my decision
- Respect my family’s decision
- Encouraging more open family discussions
- Making things easier for next of kin

Many participants noted that they had not initially thought about finding out about their family’s organ donation decisions. When they considered the discussion from this perspective they agreed that it was important to share decisions. This would mean that things were agreed so that if the need arose, it would be possible to respect each other’s decision.

“It’s important that people know what…you want so that they can carry out your final wishes.”

“I haven’t really discussed it with my wife because we both have similar views on health and I feel that we would make similar choices for each other if we die – I feel we should have a more concrete understanding of where we stand on the subject.”

This led participants to reflect that they could be in a difficult position if they did not know their family’s decision and vice versa.

“I felt quite relaxed about the law change because to me it meant that my mind had been made for me. However now I’m thinking I should really be having this discussion with my wife so that she knows for sure what I think.”
Thinking about organ donation discussions as having a two-way benefit (making your decision clear, and finding out the decision of your family) was motivating for many. It was clear that most participants had not thought about the discussion from this perspective before.

However, a few older participants queried with whom they should have two-way conversations. For example, would the next of kin for their grown up child be themselves or their child’s spouse or partner.

More generally, there was some push-back across participants when thinking about organ donation decisions for young children and grandchildren; participants felt uncomfortable thinking about this.

Many participants had also not previously considered the role that family would play should they become a potential organ donor. Once they considered this, they felt that a clear benefit of discussing organ donation decisions was making things easier for next of kin. Participants felt that having a discussion about organ donation decisions would:

- Ensure peace of mind that family members were clear on organ donation decisions.
  
  “It’s important for everyone to know your feelings on it. Otherwise you’re in a no-man’s land really aren’t you.”

- Eliminate feelings of guilt that family could feel if they were asked to make a decision and were not aware of your wishes.

- Ensure family were not left to make a difficult decision at what would already be a difficult time.
  
  “I didn’t realise that the family that’s left behind…make the awkward decision without me.”

  “I sort of assumed that it would just happen, I didn’t realise that they’d have to be checked with them [family].”

- Avoid potential family arguments or shock if they were unaware of your decision.
  
  “Where I was a bit blasé about it, thinking – oh, it’s not my problem – it [the research session] has made me think well, it can cause problems with families at a time when they don’t need that extra hassle.”

  “It would be less of a shock to your family if you told them what you wanted before you die.”

  “I haven’t told my family as yet but am starting to think that maybe I should, as I wouldn’t want it to be a shock.”

Because the role of the family, and making things easier for next of kin had often not previously been considered by most participants, thinking about this was a key turning point for many and confirmed the benefit of discussing decisions.

Whilst not mentioned by all, some participants felt that a consequential benefit of discussion organ donation decisions with family could be an increased openness to discuss other sensitive topics. For example, some felt that it could ‘pave the way’ for talking about topics such as wills, power of attorneys and funeral plans. Whilst this was
considered a positive by some participants others felt some discomfort in opening the door to these types of topics.

7. Organ donation media activity

Recall of media activity
Across research participants there was low recall of advertising. Some did recall television and radio coverage, posters and news articles about the change in legislation during the time when the legislation came into force. However few could recall seeing any information or coverage specifically about the legislation since this time. Some participants did mention seeing local news articles about local people being an organ donor/ benefitting from organ donation. These stories had typically engendered a positive reaction, highlighting to people the value and importance of organ donation (rather than encouraging them to discuss decisions with family). A few participants recalled national media coverage of more sensationalised stories e.g. head transplants. These types of stories were met with mixed response, with some participants expressing interest whilst others noting that they felt very squeamish when they saw these types of articles. In a couple of cases thinking about these stories led to participants querying how processes for organ donation differed to organ donation for medical research.

Overall participants reflected that they would be interested to know more about the impact of the change in legislation. Some noted that they would be interested to hear about the benefits of the change including statistics regarding the number of organ donors and donations compared to numbers before the change in legislation.

Reaction to recent communications
Participants were shown two recent communications, used on public buses during 2016. Both English and Welsh language speakers reviewed these communications. A few Welsh language speakers commented that the translation was a ‘formal’ translation – this was more of a passing comment rather than a criticism of the communications. It is interesting to note that a couple of participants on first glance assumed that the communications were only in Welsh language.

Overall participants felt that the posters were a little ‘bland’ and were not eye-catching.

Poster displayed on the outside of a bus:

Participants felt that on first glance, this poster was not clearly about organ donation or the change in legislation, only once they read the text did the topic become clear. When reviewing the text some participants felt that the tone was ‘demanding’ which was disengaging. These participants felt that the poster was trying to ‘shame’ people into becoming an organ donor and there was push-back to this communications approach. Participants also felt that the poster lacked a ‘conversational’ element which would make the poster feel friendlier, and could encourage broader discussion and conversation.

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1 Head transplants were the topic of media coverage in September 2016. Whilst participants did not mention a specific media source, an example of the type of coverage is provided here: http://www.bbc.co.uk/newsbeat/article/37420905/the-surgeon-who-wants-to-perform-a-head-transplant-by-2017
Poster displayed on the inside of a bus:

Participants were much more positive towards this poster because they felt it conveyed a positive story. Resultantly the ‘feel’ of this poster was liked. Participants also reacted positively because they felt that the poster clearly demonstrated the positive outcome of having a conversation about organ donation decisions with family.

However, some felt that the image was ‘generic’ in feel. These participants noted that the image could be applied to a range of advertisements, and could be equally used in an advert for a product such as butter, or for a new local café.

In one group discussion, this poster led participants to talk about a similar local story they had heard of. When participants considered that the story described in the advert could be true - and that the woman shown was the real person involved - they felt dramatically more positive about the advert. The idea of hearing real life stories from real life people was appealing and engaging.

Across both communications, some participants queried the lack of a website link, as this was something that they had typically come to expect and look for on advertising in general. However, younger participants were very positive toward the inclusion of social media links.

8. Suggestions for encouraging discussions

Across the research sessions participants were asked to generate suggestions for how to encourage people to discuss organ donation decisions with family. These ideas, alongside insights generated during analysis are reported in this section using the behaviour change framework EAST.

The EAST framework, developed by the Behavioural Insights Team in partnership with the Cabinet Office\(^2\), provides a useful way to categorise strategic ideas for encouraging discussions.

An overview of the EAST framework is provided below. The remainder of this chapter structures findings for encouraging people to discuss organ donation decisions against these four categories. A separate section on messenger is also provided to report participant views regarding who they felt was best placed to provide information about having organ donation decision discussions.

Making discussing organ donation decisions easy:
Across the research most participants felt that having a discussion about organ donation decisions with family would not be easy but could be encouraged and supported by:

- Providing a stepping stone to help broach the topic. Those who had discussed organ donation decisions with family often noted that an external prompt had encouraged them to do so. This included finding out about the change in legislation, family circumstances (e.g. a death in the family) or feeling strongly about the benefits of organ donation. It was clear that an external prompt would help participants bring up the topic. Suggestions included adverts, news articles or a storyline in a television soap.
- Tips to encourage people to start the conversation. This included suggestions that any communications could encourage people to turn to the person next to them and start the discussion. Others suggested that people be encouraged to think about who they personally feel most comfortable talking to, and talk to them first about organ donation decisions.
- Modelling the conversation. Participants reflected that it can be easier to have a conversation if you see other people and families doing the same thing. Participants suggested that showing real life families sharing and debating their decisions could empower others to do the same.

Making discussing organ donation decisions attractive:
Across the research participants cited a range of personal and family related benefits that would encourage them to discuss organ donation with their family.

Personal benefits included:
- Being confident that your decision is clear.
- Peace of mind that your family would not be left in a difficult situation of having to make a decision when they were unclear on what you wanted.
- Peace of mind that you know your family’s decision.
- Those in favour of organ donation further noted the benefit that being clear on your decision could make a positive impact on someone else’s life should you ever become a potential organ donor.

Family benefits included:
- Being open and sharing your decisions.
- Respecting each other’s’ wishes.
- Making it easy for family should you ever become a potential organ donor.
- Avoid shocking family members who were not aware of your decision.
- Avoiding family arguments where family members are not aware of your decision.

Participants felt that these benefits could be communicated in an attractive way. Overall it was agreed that a positive approach to information and communications was important to help mitigate the ‘morbid’ feel often associated with organ donation. Light feel
communications and a ‘softly, softly’ approach was considered an appropriate tone, and some further suggested that humour could be used to further lighten the topic (although this was not appealing to all). Others – often male participants - suggested that it could be useful to make people aware of statistics and numbers that demonstrated the positive impact of the change in legislation. They felt that this could bring your own decision to the forefront.

In addition to adopting a positive tone, participants also felt that providing real life examples could help people engage with the issue and discussing decisions. For example, participants felt that it would be motivating to see families sharing their decisions. Participants often suggested information that provided dual storylines, where in one story family had discussed decisions so were clear on what to do when someone became a potential organ donor whilst the other family had not discussed decisions and faced problems when someone became a potential organ donor.

Across the research participants were asked to consider some illustrative case studies of families that had not discussed their decisions. These case studies encouraged participants to think about the impact on families more so than they had done before. Thinking about the discussion - and impact of having or not having this - from the perspective of a real life family helped participants think about how their family would be affected.

Making discussing organ donation decisions social:
The social benefit of organ donation was often mentioned as a reason to discuss organ donation decisions with family. This was particularly the case for those who were personally in favour of organ donation.

Participants felt that donating was a positive thing to do. Some reflected that giving blood or being a living organ donor was often framed as a ‘gift’ and in a more positive light than organ donation. A couple noted that being a living organ donor was a ‘heroic’ thing to do, and felt that aligning this positivity with organ donation could help make it an easier topic to discuss and therefore make it easier to discuss with family.

“Thinking of it as a gift takes the morbid side out of it.”

“[Thinking about] Giving blood makes it easier to think about this [topic].”

It was clear that normalising the discussion in society could also help participants feel more confident and comfortable in having discussions with family. There was a suggestion that local debates could be helpful.

Making discussing organ donation decisions timely:
Thinking about ‘when’ to have the discussion with family about organ donation decisions was a key barrier for participants across the research. Many were simply unsure when would be appropriate to bring up the topic. Participants agreed that they did not want to feel pressurised into having a conversation but equally felt that it was important that people did not leave the discussion too late. Some suggested that communications could adopt the following approaches:

“Now is as good a time as ever.”

3 See discussion guide in the appendix.
“Get it done and out of the way.”

“It’s a ‘just in case’ conversation isn’t it.”

“I’d be more relaxed if I’d had that discussion.”

**Messenger:**
When thinking about who this information should come from most participants agreed that hearing from real life people about real life stories would be engaging. Participants felt that they could best relate to real life examples, and thinking about how real life people have been impacted helped them think about how their own family would be affected.

A few participants also felt that celebrity endorsement could be eye-grabbing and make people take notice. There was no strong preference over which celebrity would be most appropriate, and suggestions from participants tended to focus on those they anticipated would be high profile and engaging and/or had a Welsh link. This included Tom Jones, Michael Sheen, David Beckham and Morgan Freeman.

**9. Conclusions and recommendations**
Overall, across the research, organ donation was often negatively framed by participants who thought about having discussions with family from an emotional viewpoint rather than with a practical mind-set. A number of core barriers to discussing organ donation decisions with family were identified.

It is likely that some core barriers can be over-come by providing people with more information about the role of family and highlighting the benefits of discussing organ donation decisions:
- Lack of certainty regarding the role of the family.
- Fear of having an awkward discussion with family members.
- Fear of upsetting family members because organ donation is typically aligned with ‘end of life’ topics.

Other core barriers are less likely to be easily over-come and support or encouragement is likely to be needed to help people introduce the topic to family:
- Organ donation decisions are not a typical topic of conversation.
- Organ donation decisions are not an easy topic to bring up.

It was clear across the research that most participants had not previously fully considered the importance of discussing organ donation decisions with family. Taking part in the research and debating why these discussions might be useful provided a forum for participants to consider these in more detail. It was clear that views shifted during the discussions. This is illustrated by a task participants were asked to complete in the research which is described in the case study below.
Case study: participant exercise
Participants were asked to complete an exercise at the beginning of the research session asking on a scale of 1-10 how likely they would be to talk to their family about their organ donation decision. The exercise was repeated at the end of the focus group to see if opinions had changed.

Amongst those that originally gave a higher score (were likely to discuss their organ donation decisions with family) some participants maintained their high score, giving the same score at the end of the discussion. This suggests that thinking more about discussing organ donation decisions did not have a negative impact on views for these participants.

Amongst those that originally gave a higher score (were likely to discuss their organ donation decisions with family) some participants increased their score to a higher likelihood. These participants reflected that the group discussions had given them opportunity to further consider and cement their views that it was important to discuss organ donation decisions.

Amongst those that originally gave a lower score (were unlikely to discuss their organ donation decisions with family) some participants slightly increased their score indicating that they were slightly more likely to discuss their decisions with family. Whilst these participants felt that they better understood the benefits of having discussions they still expressed reticence in how best to broach the topic with family, and when to bring it up.

Amongst those that originally gave a lower score (were unlikely to discuss their organ donation decisions with family) many participants greatly increased their score indicating that they were much more likely to discuss their decisions with family. These participants noted that they had not previously considered the impact that not having the discussion could have on their own family should they become a potential organ donor. They had also not previously considered that it would be important that they equally understood their family’s decision.

The following core benefits are likely to encourage people to discuss organ donation decisions with family:

- Understanding the role that family play.
- Peace of mind: family know my decisions.
- Peace of mind: I know my family’s decisions.
- Making things easier for next of kin.

Benefits for family were a strong motivator for many – especially those who had not felt positively towards talking to family previously. Even those who were open to the idea of discussing organ donation decisions with family had simply not always thought about or considered the role that family would play. However, once they had considered this they often felt more strongly that there were benefits to having discussions.
The diagram below summarises the factors that are likely to help encourage participants discuss organ donation decisions with family:

- **Create a ‘stepping stone’ for people**
- **Tips and encouragement to have the conversation**
- **Model the conversation for people to copy**
- **Frame the conversation in a positive way (peace of mind, respect, sharing)**
- **Highlight personal benefits: my wishes are known**
- **Highlight family benefits: making it easier for next of kin**
- **Highlight societal benefits of organ donation (for those in favour)**
- **Focus on the benefits of a two-way conversation – making your views concrete**
- **Show real life examples**
- **Build on the positivity felt around blood donation and living organ donation**
- **Show public debates/discussions**
- **Don’t pressurise people but encourage a ‘don’t leave it too late’ or ‘now is as good as ever’ feel**

Finally, below are some comments from participants who after the mini-group discussion felt motivated to talk to family about organ donation decisions.

“I haven’t really given my family’s views on this subject much thought until today.”

“Our family need to know my views especially if I don’t do anything about it.”

“Following this meeting I feel it’s very important to discuss organ donation with my family, as it’s important they understand my wishes.”

“I think that my resistance is ridiculous, it needs to get out there.”

“I’ve never given it more than two minutes discussions…now having talked about it, it’s become a lot clearer.”

“Something I didn’t consider before – my children’s wishes…it’s something I’ve never really thought about…because in my mind as a parent I’ll go first…but I don’t know whether they’d want to donate or wouldn’t.”

“I have never given this window to discuss with family. Given today’s discussions I would now discuss it further with my wife.”

“Temporary squeamishness is no barrier to getting it resolved.”
“I thought it was highly likely it was going to come up after discussing where I’ve been tonight and easier given the conversation started.”

“Following tonight’s discussion I need to be more positive and discuss this with my husband.”