



Organ donation legislation: discussing decisions with family

Executive Summary

1. Background and method

1.1 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).

1.2 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

2. Defining discussions about organ donation

2.1 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

3. Barriers to discussing organ donation decisions

3.1 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

4. Benefits to discussing organ donation decisions

4.1 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

4.2 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)

4.3 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.

5. Organ donation media activity

- 5.1 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.
- 5.2 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.

6. Suggestions for encouraging discussions

- 6.1 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](#).

<i>Element of the EAST framework to encourage behaviour change</i>		<i>Research findings</i>
E	Make discussing organ donation decisions easy	Encourage and support organ donation decisions discussions by: <ul style="list-style-type: none"> • Providing a stepping stone to broach the topic. • Tips to encourage people to start the topic. • Modelling the conversation.
A	Make discussing organ donation decisions attractive	Use a positive tone and real life stories to promote the benefits of discussing organ donation decisions: <p>Personal benefits:</p> <ul style="list-style-type: none"> • 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. <p>Family benefits:</p> <ul style="list-style-type: none"> • 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.
S	Make discussing organ donation decisions social	Highlight the social benefit of organ donation as a 'heroic' act, making it easier to broach and discuss the topic and decisions with family.
T	Make discussing organ donation decisions timely	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.

7. Conclusions and recommendations

7.1 The diagram below summarises the factors that are likely to help encourage participants discuss organ donation decisions with family:



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Available at: <http://gov.wales/statistics-and-research/evaluation-human-transplantation-wales-act/?lang=en>

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