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Research to support Wales' organ donation opt-out proposal consultation

***Qualitative research report
Executive summary***



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proposal consultation***

Qualitative research report

Fiona McAllister/Adam Blunt
Beaufort Research
2 Museum Place
Cardiff
CF10 3BG

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

For further information please contact:

Name: Janine Hale

Department: Health Social Services and Children

Welsh Assembly Government

Cathays Park

Cardiff

CF10 3NQ

Tel: 029 282 6539

Fax:

Email: janine.hale@wales.gsi.gov.uk

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1. Research findings: executive summary

Introduction

- The overall aim of this qualitative research study was to explore attitudes towards organ donation in general, and the Welsh Government's organ donation opt-out proposal. The research consisted of six discussion groups and seven in-depth interviews with range of people across six locations in Wales.
- Quotas were set on age and socio-economic grouping to ensure a spread within the sample and each group contained a small number who were on the NHS Organ Donor Register. The sample also included Black and Minority Ethnic participants.

Attitudes towards organ donation in general

- In keeping with figures available on UK views, participants in this research were mostly very much in favour of the principle of organ donation. They believed that organ transplantation saved and prolonged lives, improved quality of life for the patient and those close to the individual.
- Some, however, were uncomfortable thinking about the subject in too much detail.
- Overall, participants felt that there was a lack of communication on organ donation, and some reported that they knew very little about how the current system worked, including those who were on the Organ Donor Register, some of whom did not know if they were still registered.
- The role and influence of the family with the opt-in system was rarely noted spontaneously, and it was often assumed that the donor's wish was final. The procedures at the point of death were unclear.
- On hearing of the influence the family could have at the point of death, participants regularly took issue with the realisation that doctors would not proceed with organ donation if families asked them not to. There was a strong belief that the individual's choice to opt in should be respected, and that no-one else should be able to object to that choice.
- The perceived importance of family discussions about organ donation tended to grow during the research discussions as participants spent more time considering the subject.

Motivations for joining the NHS Organ Donor Register

- Reflecting overall attitudes towards organ donation among this sample, those who thought that they had joined the Organ Donor Register did so ultimately to help others.
- Specific triggers to sign up to the Register included: being asked about donation when giving blood; completing a driving licence application form; as a result of family health experiences; seeing information in the GP's surgery; and first thinking about it when becoming a mother.

Barriers to joining the NHS Organ Donor Register

- Passive barriers to joining the Register were more prevalent with this sample than active decisions not to join: they included the lack of prominence the subject had in day-to-day life, busy routines, and anticipating that it would probably be a 'hassle' to do so.
- Participants who had taken a more conscious decision not to join the Register referred to cultural and religious reasons (for example a desire to return to the earth whole) and personal beliefs. These reasons for not joining the Register were sometimes influenced by the belief of participants' parents.

Discussing organ donation with family

- Across this qualitative sample, participants tended not to have discussed with family their wishes regarding organ donation. The general consensus was that it was not a top-of-mind subject and that it could also be a 'difficult' topic to casually touch upon, especially when facing religious or cultural influences.
- Some believed it was a personal decision and did not need to be discussed with others.
- Prompts to discuss organ donation with the family included completing a DVLA form, experiencing serious ill-health in the family or among friends, wanting to be organised and generally believing strongly in the process.

Finding out about the opt-out proposal

- In general, those taking part in the discussions tended to be unaware of the proposal although people aged 45 or over were more likely than others to have heard about it.

Spontaneous understanding of the opt-out proposal

- Understanding of the opt-out system was limited among those already aware of the proposed change. Little thought had been given to how it would work in practice other than if an individual had not opted out, that person's organs would be available for transplant.
- There was clearly a lack of knowledge of the detail of the proposal and some misunderstandings existed about how the system would work. Some assumed that it would be 'legally binding' and that the family of the deceased would not be able to have a final say on donation.

Reactions to the organ donor opt-out proposal

- Participants sometimes confused the existing system with the opt-out proposal, and it was not always easy for them to grasp how the two systems worked. Contradictions in views occurred from time to time.
- Spontaneous comments were obtained first, followed by reactions to a number of statements which referenced arguments for and against the opt-out proposal.
- Across the discussions, participants regularly highlighted spontaneously the expected increase in organ availability as a convincing reason for

changing to an opt-out system. It was envisaged that this would lead to shorter waiting lists and, ultimately, more lives saved.

- In broad terms, participants found the anticipated figure of a 25 to 30 per cent increase in organ donations reasonably persuasive although the context for this figure was not necessarily clear.
- A second, common positive theme to emerge spontaneously was that the opt-out system would mean those who were in favour, but cited passive barriers to joining the Register such as not getting around to it, would become donors.
- The statistic provided by the Welsh Government that 31 per cent of population of Wales were on the Register drew more mixed responses; for example, some deemed it unacceptably low, but some were prompted to wonder why more could not be done to promote the existing system and encourage engagement, before attempting such a significant change to the process.
- Some stated spontaneously that the move to an opt-out system would encourage people to consider their own wishes and have those important conversations with family.
- Some participants, however, were uncertain how exactly the opt-out system would lead to more discussions among family and close relatives (other than via initial communications campaigns) and that it still relied upon members of the public knowing about the system in the first place, and wanting to discuss it.
- Most of the negative comments voiced by participants in relation to the opt-out proposal concerned the role of the family, rather than any specific issue associated with the concept of opting out.
- As with the current system, participants were frequently dismayed to find out that a family member or close relative could object to the deceased's personal choice on organ donation. Some therefore questioned the whole point of expressing a wish on organ donation.
- Some also foresaw complications with the family's influence because of differences in opinion on organ donation. The need for family conversations about organ donation became even more important, in some participants' minds.
- From time to time, participants spontaneously referred to how they were uncomfortable with the idea of presumed consent, which did not sound 'very democratic'. However, when the argument was prompted of losing rights over your own body, it received little further support.
- A small number of participants spontaneously wondered whether doctors would make as much effort to save a patient if they knew the patient had not opted out. When prompted, this topic sometimes sowed seeds of doubt in participants' minds although, on balance, it was felt that doctors were bound by a duty of care.
- The potential cost of moving to an opt-out system was rarely raised and the benefits of an increase in organs available were believed to outweigh

the financial cost (e.g. saving lives; long-term financial savings on care provision).

- The general consensus was that the opt-out system should only apply to those aged 18 or over who live permanently in Wales. Complications arose for some participants when they considered what would happen if they died outside Wales.
- For those moving to settle in Wales, participants spontaneously suggested that they could be informed of the opt-out system when registering with their GP; and that they should be eligible from that point onwards.
- The opt-out proposal prompted some queries from participants, including: what the implications were for members of the public who might not have the mental capacity to decide whether or not to opt out; how the opt-out system would apply to children; how simple it would be to opt out; and why it was that other parts of the UK were not proposing a change to the opt-out system.
- Towards the end of the discussions, participants were briefly asked to argue for and against the proposed legislation change on organ donation. They generally found it easier to put the case for, rather than against, the proposal by focusing on how it would lead to more lives being saved.