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Welsh Government

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Evaluation of the Human Transplantation (Wales) Act: Qualitative Study of Public Attitudes

Research Summary

Social research

Number: 87/2014

Research Approach

The research used a qualitative interview approach with a wide range of members of the general public across Wales. A total of 10 focus groups and seven in-depth interviews were conducted resulting in 87 participants taking part.

Interviews were conducted between 10th and 17th March 2014.

Research was conducted in:

- Aberdare
- Aberystwyth
- Cardiff
- Caernarfon
- Swansea

Research Aims

The key aim of the research was to explore the views of the public with regards to the introduction of the soft opt out system of organ donation in Wales.

Specific objectives were to:

- Investigate awareness, attitudes and behaviour of individuals in relation to organ donation and the introduction of a soft opt-out system in Wales.
- Explore in greater depth the findings emerging from the on-going quantitative surveys of public attitudes.
- Build on findings from initial qualitative research with members of the public conducted in 2012.
- Elicit and investigate attitudes regarding the role of the family in organ donation.
- Explore motivations for, and barriers to, organ donation; opting in or out; and discussing wishes regarding organ donation with family members.

Dadansoddi ar gyfer Polisi



Analysis for Policy

Executive Summary

Awareness, attitudes and behaviour in relation to organ donation

It was evident that there was a strong consensus around the importance of organ donation.

All participants claimed to understand the current organ donation process and believed that one could become a donor by ticking a box on a driving licence or registering and carrying a card.

One perceived advantage of the current system is that it is based on a positive decision to opt in which, in turn implies that the donor's decision is final i.e. there is no room for doubt after their death. This is a particularly compelling argument for those not wishing to discuss their decision to register as an organ donor with their family members.

Another advantage of the current system according to participants is that registered donors can choose which organs they want to donate.

However, there was general agreement that the current system does not yield enough donors, leaving many patients to wait a long time for organ transplant operations.

Awareness and attitudes to introduction of soft opt out system in Wales

Most were able to say that the new system would be based on people opting out rather than opting in. However, often this was all they knew, generating many questions during the research sessions. Most cite that the main benefit of the new system is that it will ensure more organs are available, reduce waiting lists and help to save more lives.

Participants were generally positive towards the soft opt out system because they believed it will help to save lives. However, there are still concerns around how the new system will be communicated and when. There was a strong desire for good levels of publicity to allow time for people to opt out if and when they want to.

Attitudes to the role of the family in organ donation

Many participants felt their decision to register as an organ donor was a private matter that did not require discussion with family members. Often this was because of a lack of context or suitable opportunity to raise the subject, while for some it was to avoid confrontation with family members who might disagree. However, once briefed on the new soft opt out system all agreed that it would become important to discuss this issue with their family to ensure that family members were aware of and understood their wishes about organ donation.

Some perceived that the new system was giving more decision making powers to families of the deceased which would have the effect of diminishing the original decision to opt in. It became clear that the role of the family needs to be clarified further, specifically that clinicians would not go ahead if family are in distress; participants had concerns about how this would be gauged in practice.

Motivations and barriers to organ donation, opting in or out and discussing wishes regarding organ donation with family members

Amongst all participants there was strong motivation to register as an organ donor because they believed that this can help to save lives. However, it was widely believed that barriers remain for some members of society, including:

- Older people
- People with learning difficulties
- People with mental health problems
- Low income families
- Homeless
- Faith groups including: Muslims, Jehovah's Witnesses and Christians.

There was a strong sense that some of these groups may not feel empowered enough to exercise their rights and as such they should be excluded from the soft opt out system.

With regards to faith groups, the strength of opposition varied by adherence to faith or whether they were restricted by cultural

influences. While not religious themselves, some participants envisaged barriers for others on the basis of religion and also cultural norms.

Some cited challenges for members of some Black and Minority Ethnic communities who may have insufficient English language skills so they may miss any communications about the change unless they are targeted through a community based outreach programme, perhaps via people explaining the law to them in their own language at community centres.

It was widely accepted that under the new system it will be important to talk about organ donation with families. However, there were some mixed feelings about whether they would discuss it and with whom.

Those who were against the new system accepted the need for a conversation with family members but anticipated this with a degree of anxiety. They feared that it could cause conflict within families of the deceased because of differing

positions on organ donation. There were some who felt that the new system could stigmatise those who wanted to opt out and that this could lead to difficult conversations amongst family members.

Those who were positive about the soft opt out legislation were less favourable about the role of the family under the new system. They perceived that the new system gave the family a greater role, which may be explained by a general lack of understanding about the role of the family under the current system. They felt that organ donation was their decision alone and that once they consented to be an organ donor (opted in under the current system or not opted out under the new system) then family should not be able to overturn their decision.

Although it was seen as a very important issue to discuss with the family, there was general consensus that it was also difficult to raise. However, there was some confidence that future campaigns could help to facilitate conversation and discussion about organ donation with family and friends.

Informing and improving communication activities for organ donation

As well as generating insights on attitudes to the soft opt out system and the role of the family it became clear that there were gaps in knowledge and understanding of the new system. Everyone agreed that the new system would inevitably lead to reductions in the need for dialysis and treatments and therefore would save costs as well as lives.

Those who were undecided questioned how cost effective the new system would be, whether or not the IT systems would be able to cope with the (perceived) number of people opting out and whether there would be enough staff to deal with the (perceived) increase in work load.

Those who were negative about the new system echoed these concerns but they also wondered whether the change was purely a cost saving exercise for the government. For example, some suggested that the new system would mean little or no need for organ donation advertising and

publicity. Others mentioned that the NHS in Wales would not have to spend as much money on dialysis machines. Some also envisaged big increases in donors so were concerned whether there were adequate resources in the health service to cope with this.

A great deal of importance is placed on detailed and timely information about the registration process to enable people to make an informed decision about whether or not to opt out. There was also anxiety that some sections of society could miss any awareness raising activities unless the messages were widely accessible and also sustained e.g. diverse communication channels including press, TV, radio and outdoor advertising for as long as possible to ensure that as many people as possible are made aware of what is happening.

Their next concern was around communicating the registration process. This was particularly the case for those opposed or undecided about the soft out system. As with the diverse communications channels for

awareness raising, they wanted to see multiple approaches for registration, encompassing:

- An official and personalised letter with information about the change in law and the next steps they can take;
- An online platform with a personal account to enter their details and preferences;
- Information to be available from their GP surgery.

Most importantly, they want to see a specific date to 'act on' or 'act by' as they believe this would prompt people to take action and address any uncertainties. Some wondered whether there would be a time limit to opt out, so this would need to be addressed in any communications.

Participants expressed that they would prefer communications to be accessible and continual. In addition to this, there was also a need for communications which directly address the individual's likely concerns about the new system, along the lines of '*what does this mean for me and what should I do now?*'

Responses were mixed when it came to television adverts about the new soft opt out system and their preferences for actors or people who have experienced organ donation in real life.

Most felt that TV adverts with more information could prompt and help to generate discussions. Amongst some there was a strong feeling that any advertising should feature real people who have donated or received organs as the message would be more powerful.

In Aberystwyth and Caernarfon Welsh speaking participants suggested that a strong storyline in a locally based television drama could be a good way to convey both the message about organ donation and the detail.

Information about the soft opt out process will form an important part of the communications approach. So it is critical that messages about the new system are easily understood and result in a call to action. As part of the research exercise three messages were tested to check for clarity, relevance and resonance.

Message 1a

"You will have three choices. You can be a donor by opting in or by doing nothing. If you do nothing it will be the same as choosing to be a donor. If you don't want to be a donor you will be able to register a decision to opt out."

For most, Message 1a was seen as clear, concise, unambiguous and most importantly short.

However, the tone was not right for some people, particularly by those who felt that they were being pressured to 'conform' via the use of "you will", "you can" and "if you do nothing".

Message 1b

"Under the new system you can agree to being a donor by either registering a decision to opt in or by doing nothing at all, in which case your consent may be deemed. By doing nothing it will be the same as agreeing to be a donor and you will be treated in the same way as those who have registered an opt-in decision. If you don't want to be a donor you will also be able to register a decision to opt-out."

This was considered by some to be a longer version of the first message. The main difference being that it appeared to clearly present three choices, as opposed to two in the first message. The overall message appeared confusing and repetitive with overuse of 'opt in' and 'opt out'. Others felt that the use of complex words such as 'deem', would leave many people confused. Some interpreted 'deemed' as 'assumed' and elicited the following response:

.....
"How can they assume consent?"

Male, Aberystwyth, Positive, aged 40-59
.....

Message 2

“Families are always involved in the decision around organ donation, so it is important that you discuss your decision with loved ones. Too many life saving donations are missed because families are unsure of what their loved ones will have wanted. That’s why on 1 December 2015, Wales will be changing the way organs are donated. The new system will make it easier for you to make a clear decision on whether or not you want to become an organ donor”

This message was positively received by everyone, regardless of how they felt about the introduction of the soft opt out system. They felt that this was a softer message, which was emotive as well as informative about the importance of organ donation. The language was considered less authoritarian and evocative of compassion and empathy.

There was a strong reason behind the message which resonated well with everyone i.e. “Too many life saving donations are missed because families are unsure”. To many it felt like a real choice as it provided the right context to discuss this with their families.

Improving the message

Ideally the message should be clear and short with signposting to further information prominently displayed. Other improvements suggested include:

- Make it clearer that a change is happening and the reason for this before explaining the options and what they need to do;
- Including the date
- Further information about “do nothing” option, how this differs from opting in and the implications;
- More of a focus on families so as to make it easier to raise the subject with family members;
- Clearer presentation of the choices as opposed to the outcomes and a softer tone.

There was general agreement that any communications around the soft opt out system in the coming months would generate interest and make it easier to discuss this with family and friends.

The research insights so far indicate that further clarity is needed around ‘opt in’ and ‘do nothing’ differ. The research sessions generated many questions which demonstrate the existing knowledge gap and current information needs which should therefore inform any education programme issues.

Author: Rezina Chowdhury
GfK NOP
Welsh Government Social
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