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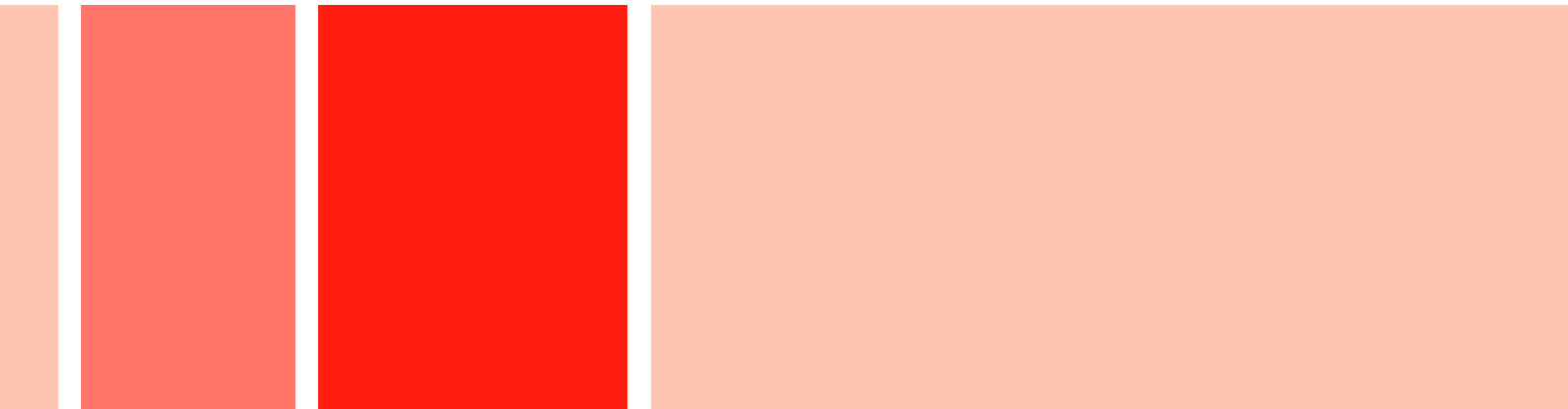
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# Evaluation of the Human Transplantation (Wales) Act: Qualitative Study of Public Attitudes



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

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

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# **1. Executive Summary**

## **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.

The insights from this research will be used to inform and improve Welsh Government communication activities specifically in preparation for the Human Transplantation (Wales) Act taking full effect from 1st December 2015.

## **Design**

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 10<sup>th</sup> and 17<sup>th</sup> March 2014.

A purposive sample design approach was taken whereby groups were convened according to their attitudes to the new organ donation system. This was partly to facilitate good group dynamics and partly to allow some

comparison between those who were positive, negative or undecided about the introduction of the soft opt out system in Wales.

In terms of locations, participants were recruited from:

- Aberdare
- Aberystwyth
- Cardiff
- Caernarfon
- Swansea

## **Key Findings**

### *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 out-reach 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 thoughts on 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.

However, some raised the issue of the costs of setting up and managing the new system. This was raised mainly by those negative or undecided about the soft opt out system.



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.

The research sessions generated much discussion on information needs as well as how the messages should be conveyed. It was clear that participants 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?*'

When asked about whether they would prefer to see actors or people who have experienced organ donation in real life in any television adverts about the new soft opt out system, responses were mixed with people open to either option.

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:

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"How can they assume consent?"

Male, Aberystwyth, Positive, aged 40-59

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### 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 (as in message 2);
- 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
- Softer tone similar to message 2.

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.

## 2. Context

In setting out the context for this research and the main issues, it is important to appreciate the broader policy. The Welsh Government will introduce a soft opt-out system of organ donation through the Human Transplantation (Wales) Act. The legislation means that a person's consent to donation will be deemed to have been given unless they objected during their lifetime – a process called opting out – but where those closest to the deceased will still have an important role to play in the process. The Welsh Government obtained Royal Assent for the Bill in September 2013 and will bring the main provisions of the Act into effect on 1st December 2015.

By increasing the number of organs and tissues available for transplant, the Act aims to reduce the number of people dying whilst waiting for a suitable organ and improve the lives of others. Evidence suggests donation rates could increase by 25-30% under an opt-out system<sup>1</sup>.

In order to assess the implementation of the soft opt-out system of organ donation and the impact it has on donation rates in Wales, the Welsh Government is carrying out a research and evaluation programme for the Human Transplantation (Wales) Act. A communications campaign is being undertaken by the Welsh Government to ensure the population of Wales are aware of and understand the new law and know how to opt out if desired. In order to monitor the effectiveness of the campaign, regular information is required on public awareness and understanding of organ donation law, and attitudes to changes in the legislation in Wales.

To meet these research needs, the Welsh Government has already commissioned quantitative surveys of the adult population in Wales, taking place at regular intervals between 2012 and 2016. In addition, the Welsh Government commissioned qualitative research with members of the public in

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<sup>1</sup> Abadie A, Gay G, The impact of presumed consent legislation on cadaveric organ donation: A cross-country study, Journal of Health Economics, 2006.

2012 to explore attitudes towards organ donation in general, and on changing the organ donation system in Wales.

This research report details the findings from qualitative research conducted in March 2014 prior to any communications campaign to explore emerging findings before the legislation comes into force on 1<sup>st</sup> December 2015.

### **3. Aims and Objectives**

The overarching aims for the research were 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.

The insights from this research will be used to inform and improve Welsh Government communication activities specifically in preparation for the Human Transplantation (Wales) Act taking full effect from 1st December 2015.

#### **3.1 Structure of the Report**

Following this overview of the aims and objectives, the findings from the research are discussed as follows:

- **Chapter 4** – Explains the method and sampling strategy
- **Chapter 5** – examines the main findings
- **Chapter 6** – draws together findings and presents a set of concluding comments
- **Chapter 7** – contains annexes such as the discussion guide and other research tools.



## 4. Research Approach and Methods

### 4.1 Methodology

#### *Primary qualitative research*

The qualitative approach included a combination of **ten** focus groups and **seven** face to face in-depth interviews. The mixed method approach was designed to maximise participants' comfort in the research process, and to encourage participants to contribute fully without feeling inhibited by the format of the discussion. The focus groups encouraged a debate among people in similar circumstances, while depth interviews navigated more sensitive issues that may not have surfaced easily in a group setting. Participants were also pre-tasked with some homework prior to attending the focus groups or interviews. This involved answering some questions about organ donation and their understanding of the current and proposed system.

#### *Focus groups*

The focus groups provided an interactive forum where participants were able to share their views and experiences in their own words. They created a comfortable setting for people to really consider, question and share their views on organ donation and the new soft opt out system. Each group lasted 1.5 hours and included up to 8 participants. Two of the groups were conducted in Welsh.

#### *Individual depth interviews*

Individual depth interviews were conducted with members of Black and Ethnic minority communities in Wales. These in-depth interviews provided a private, one to one engagement with participants, where they could open up about issues that are important to them and discuss ideas they may have been more reticent to talk about in a group setting. The individual depth interview approach enabled the researcher to understand an individual's religious and cultural bearing on organ donation and to try and understand barriers for the

wider communities. Each individual depth interview was conducted face to face and lasted 60 minutes.

### *Homework diaries*

All participants were asked to complete a short written exercise prior to attending a focus group or interview session. The homework was set to ensure that participants were engaged with the issues from the outset and more importantly, that the participants had a chance to consider the barriers and motivations to organ donation by recording their experiences ahead of the interview session. An example of a homework diary can be found in the Appendices.

A key element of the design was to ensure that a wide range of views were captured, both in terms of initial attitudes to the soft opt out process, as well as different age groups, gender and a wide geographic spread to capture any variations in views and opinions. Therefore research took place across Wales, covering North, Mid and South:

- Aberdare (Valleys)
- Aberystwyth (Mid Wales)
- Caernarfon (North)
- Cardiff (South)
- Swansea (South West)

The fieldwork was conducted in March 2014 prior to any major campaign about the new system of organ donation registration, although some participants mentioned coming across information in local media.

## **4.2 Sample**

The research is based on 10 focus groups and seven in depth interviews. Participants were recruited in each of the locations using a 'free-find' recruitment method, which involved networking, street recruitment and 'snowballing'. Participants' eligibility to take part was established by the use of a recruitment screening questionnaire, administered by the recruiter to each

individual participant. The screening questionnaire included a verification of attitudes to the soft opt out system, demographic characteristics (including gender, age and socio-economic group). During recruitment those who may have a heightened awareness of organ donation, such as clinicians or those working in hospitals and GP surgeries were excluded from the research.

A recruitment questionnaire was developed to fill purposive quotas, alongside others based on geographic region and attitudes to the soft opt out system. A copy of the recruitment questionnaire is provided in the Appendices.

Table 1: Sample structure by location

<b>Cardiff</b>	<b>Valleys (Aberdare)</b>	<b>Swansea</b>	<b>North (Caernarfon)</b>	<b>Mid Wales (Aberystwyth)</b>
Undecided 25-39 years C2DE	Negative 25-39 years BC1	Positive 18 – 24 years BC1	Positive 25-39 years BC1	Positive 40-59 years C2DE
Positive 40-59 years BC1	Positive 40-59 years C2DE	Negative 25-39 years C2DE	Negative 40-59 years C2DE Welsh language	Undecided 60+ years BC1 Welsh language

The sampling framework was designed to provide a wide spread of people in Wales taking in to account the variation in attitudes likely to come about because of how old they are, where they live and their socio-economic profile.

The tables below provide actual numbers for the 80 focus group participants.

Table 2: Sample breakdown by attitudes to soft opt out

<b>Sample details</b>	<b>Positive to soft opt out</b>	<b>Negative to soft opt out</b>	<b>Undecided about soft opt out</b>
<b>Area</b>			
Cardiff	8	-	8
Aberystwyth	8	-	8
Aberdare	8	8	-
Caernarfon	8	8	-
Swansea	8	8	-
<b>Gender</b>			
Male	18	13	8
Female	22	11	8
<b>Age</b>			
18-29	9	6	6
30-39	8	8	2
40-59	23	9	-
60+	-	1	8
<b>SEG</b>			
BC1	24	1	7
C2	5	8	7
DE	11	15	1
<b>Healthy Foundations<sup>2</sup></b>			
Balanced Risk takers	12	10	7
Health Conscious Realists	14	2	-
Live for today	7	7	8
Hedonistic Immortals	5	2	-
Unconfident Fatalists	2	2	1

<sup>2</sup> Healthy Foundations is a segmentation tool that provides a holistic and evidenced based insight into what motivates people and how these motivations are affected by people's social and material circumstances.  
[http://www.thensmc.com/sites/default/files/301846\\_HFLS%20Report%20No1\\_ACC.pdf](http://www.thensmc.com/sites/default/files/301846_HFLS%20Report%20No1_ACC.pdf)

Table 3: Sample breakdown by region

Sample details	Total	Cardiff	Aberystwyth	Aberdare	Swansea	Caernarfon
<b>Attitudes to Soft opt out</b>						
Positive	<b>40</b>	8	8	8	8	8
Negative	<b>24</b>	-	-	8	8	8
Undecided	<b>16</b>	8	8	-	-	-
<b>Gender</b>						
Male	<b>39</b>	8	8	9	6	8
Female	<b>41</b>	8	8	7	10	8
<b>Age</b>						
18-29	<b>21</b>	6	-	3	10	2
30-39	<b>18</b>	2	1	2	6	7
40-59	<b>32</b>	8	7	11	-	6
60+	<b>9</b>	-	8	-	-	1
<b>SEG</b>						
BC1	<b>32</b>	8	7	-	8	9
C2	<b>20</b>	7	2	5	2	4
DE	<b>28</b>	2	6	11	6	3
<b>Healthy Foundations</b>						
Balanced Risk takers	<b>29</b>	6	6	7	6	4
Health Conscious Realists	<b>16</b>	2	4	4	5	1
Live for today	<b>22</b>	4	6	4	1	7
Hedonistic Immortals	<b>7</b>	2	-	-	3	2
Unconfident Fatalists	<b>5</b>	2	-	1	1	1

### **4.3 Data collection and analysis**

A discussion guide was designed to capture attitudes to the new system of soft opt out as well as their thoughts around ideal communication messages and channels. All research sessions were recorded and transcribed verbatim for subsequent analysis. The transcribed interviews were subject to a rigorous content analysis (Matrix Mapping), which involved systematically sifting, summarising and sorting the verbatim material according to key issues and themes within a thematic framework.

### **4.4 Strengths and limitations of qualitative research**

Using a qualitative methodology to explore peoples' attitudes towards organ donation and the soft opt out system allowed researchers to gather rich insights regarding the motivations and barriers around organ donation and the implications for communicating the changes in light of the Human Transplantation (Wales) Act. This qualitative approach created a discursive and enabling forum where people could describe, discuss and debate their attitudes and feelings towards organ donation.

The main strength of this approach was that it allowed participants to give their views in an open and spontaneous way. While the groups and individual depth interviews followed a clear structure, participants were able to provide as much information as they wished, and responses were therefore full, rich and nuanced.

However, there are limitations to the approach used. Qualitative research emphasises self-expression and insight over numerical outcomes and therefore relies on detailed discussion with a relatively small sample. Although the research was carried out with a range of people this sample cannot be considered statistically representative of the general public in Wales.

The findings have been illustrated with the use of verbatim quotations. The quotations have been edited for clarity but care has been taken not to change

the respondents' meaning in any way. Any alterations are shown using parenthesis and ellipses. Quotations attributions will include the participant's attitude to the soft opt out system according to the response they gave at recruitment, age, gender as well as their location.

#### **4.5 Note regarding the insights and sub-group differences**

It should be emphasised that the structure of the sample means that we are often reporting on two focus groups per location. To ensure the validity of our findings the data were analysed using a process of triangulation where all of the interview notes have been studied and we have compared the findings from each to establish common themes in the data. Where common themes are established, this demonstrates evidence of some consensus and we are able to report on this as an overall finding.

However, when looking at the sub-groups, it should be stressed that there are fewer sources to compare with, which means that it is not always possible to deliver the same level of validation. Consequently there may not be any noteworthy or valid sub group differences to report in some of the sections. This explains why only differences for some sub groups are cited throughout the report.

## 5. Main Findings

### 5.1 Awareness, attitudes and behaviour in relation to organ donation

There was general awareness of the current system of organ donation and this appears to be consistent across all demographic groups.

It was evident that there was a strong consensus around the importance of organ donation, regardless of whether they were already registered organ donors.

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.

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“The first I knew about it was on the driving licence form. I didn’t realise I could go and say I wanted to be a donor”

Female, Cardiff, Undecided, 25-39

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“It’s an ‘opt in’ not an ‘opt out’ system”

Male, Aberdare, Negative, 25-39

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“All I know is, people who want to donate usually have a donor card and it is basically an ‘opt in’ system”

Female, Cardiff, Undecided, 25-39

---

When asked about what was good or bad about the current system, views tended to vary.



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.

Another criticism of the current system is that it relies on people making an active decision to opt in. While this was considered an advantage for some, others felt that it was too easy for people to put off.

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"You need to be passionate about it to make a decision"

Female, Swansea, Positive, 18-24

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"When you're signing up for something like that you're admitting you're not going to live forever"

Male, Swansea, Negative, 25-39

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Another potential disadvantage of the current system is that a lack of discussion with family members can mean that wishes regarding organ donation are not known, which can lead to difficult decisions being made suddenly and reactively.

.....  
“I’ve got a card but I haven’t discussed it with anyone.”  
.....

Female, Aberdare, Positive, 40-59  
.....

Some mentioned that a lack of information about the current system was perhaps a reason why there were few donors.

.....  
“I’ve never seen an ad for it yet you see loads for blood donations”  
.....

Female, Swansea, Negative, 25-39  
.....

In terms of the process, there was some sense that the current system was neither modern nor simple and did not allow people to update their details on the donor card.

.....  
“It’s not very modern. They’re not bothered about simplifying the system”  
.....

Male, Aberdare, Negative, 25-39  
.....

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

It was expected that all participants would have some awareness of the soft opt out legislation as the research sessions were convened according to how they felt about the soft opt out system. The box below shows the words used in the recruitment questionnaire to explain the introduction of the soft opt out system and the question asked to ascertain their position.

*The National Assembly for Wales has passed a law to change the organ donation procedure to a 'soft opt out' system. From December 2015, people will be given the opportunity to formally 'opt out' of organ donation by placing their name on a register. If they choose not to do so, having had the opportunity, then this will be treated as a decision to be a donor, and one which families will be sensitively encouraged to accept. The law will allow family members to object to donation on the basis that they know the deceased person would not have wished to consent. The opportunity to 'opt in' and register a decision to be a donor will continue.*

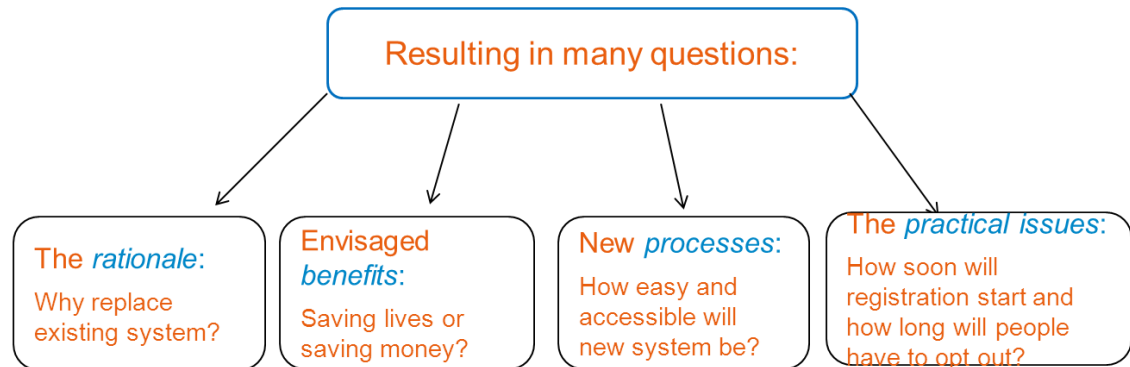
**Q8** Can you tell me which of the following statement best describes your view on this change?

- I am in favour of this change to legislation
- I am against this change in legislation
- I need more time to decide
- I don't know at all

However, it should be noted that prior to the recruitment exercise for this research, some had already heard about the proposed changes to the system of organ donation.

While most were able to say that the new system would be based on people opting out, often this was all they knew. This generated many questions during the research session which are documented further on in this report. A few are shown in the chart below.

While awareness of the new system was high, knowledge of the detail was low.



Many of the issues raised were common across all groups but assumptions differed according to whether they were undecided, positive or negative towards the new system.

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.

The following statements taken from the participants' homework provide some interesting insights on opinions and concerns prior to any advertising campaign.

*"How easy will be for all age groups to opt out? What if you wish to be excluded but forget? Will everybody get annual reminders?"*

*"I think it will make more people discuss the organ donation more together and will give families a better idea of what that person wants when they pass away".*

*"I think it's a good thing mainly because people won't bother to opt out. Family will expect their deceased member to be a donor."*

*“My initial thought is it is a good idea but needs a little more thought on how sensitively the families will be talked to”*

*“I am in firm favour of the new system. I feel that any idea that will potentially increase the numbers of transplants from organ donation is a valuable discussion.”*

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.

There were questions around whether registration for opt out would start on 1st December 2015. This led some to enquire about the likely traffic to the website on the first day and to imagine that the online system could go down as many attempt to opt out. So they suggest that registration to opt out starts as soon as possible, ideally 6 - 12 months before.

While questions about the new system were raised by all participants, regardless of their attitudes towards it, the assumptions regarding how the change would be managed differed according to whether they supported or opposed it.

Undecided	Positive	Negative
<ul style="list-style-type: none"><li>• Assumed the worst</li><li>• Thought introduction would be badly executed</li><li>• Expected poor government response</li></ul>	<ul style="list-style-type: none"><li>• Assumed there would be further questions</li><li>• However, any issues would be investigated and any problems solved in due course</li></ul>	<ul style="list-style-type: none"><li>• General lack of information has left a vacuum which this group have tended to fill with negative assumptions e.g. harvesting of organs, malpractice fears and black market of organ donors</li></ul>

A sense of coercion or a perceived lack of consent can be regarded as the main reasons for negative attitudes towards the new system.

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“I feel like I am being coerced into something. I want my choice. Give me my choice.....spend the money on telling people about how the system is now. This just makes me angry this whole thing.”

Male, Swansea, Negative, 25-39

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The quote below demonstrates that those who have already registered are just as likely to have strong opinions about this.

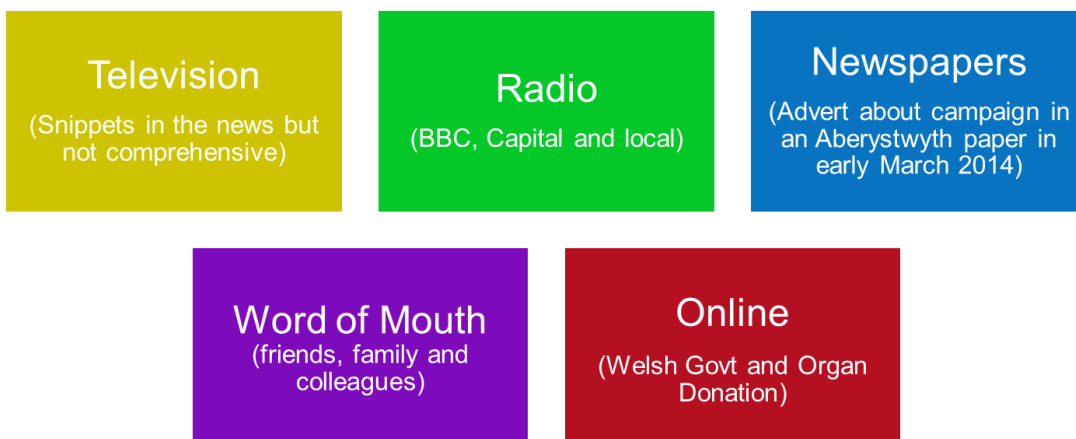
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“I am quite pro, because I’ve signed it. But this makes me angry that somebody can take that because nobody can perform an operation on me without my consent. So why on earth is it ok to give my organs without my consent? You can’t assume consent to go and have an operation or to go under general anaesthetic. So why is it ok to take my organs out when I am dead?.”

Female, Swansea, Negative, 25-39

---

When asked about where they had heard about the new system, prior to attending the research session, responses were many and varied.



### **5.3 Attitudes to the role of the family in organ donation**

The family has an important role to play under the current opt-in system and the new soft opt-out system. Under both systems, the family needs to be present to give important medical information regarding possible donation. In addition, under the new system, the family will have to confirm whether the deceased was 'ordinarily resident' in Wales.

Furthermore, the role of the family under the new law is to be the final safety check. If a relative dies in a way they can donate, the family would be asked if they have any evidence that the deceased did not want to be a donor, or to give any evidence to say they have recently changed their minds if they are either opted in or out. This has to be the deceased's decision, not the family member.

Telling close family about wishes relating to organ donation will be one of the key messages of the education campaign which will accompany the new legislation, since uncertainty about what their relative would have wanted is what prevents many families engaging with the organ donation process. This is borne out by the qualitative research findings where many 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.

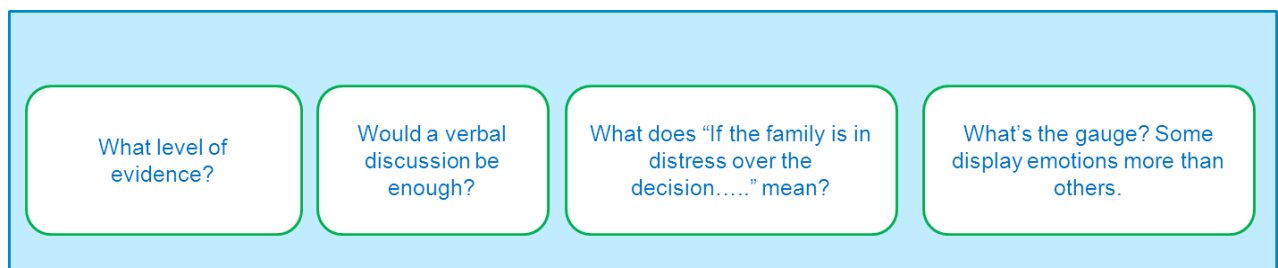
However, once briefed on the new soft opt out system all agreed that it would become important to discuss this issue with their family to ensure that they had the final say about organ donation.

Participants were shown some true and false statements about the role of the family, which generated further debate, particularly with regards to the type of evidence that they would need to provide to halt an organ donation procedure.

- *The family have no role to play in organ donation (FALSE)*
- *The family can provide evidence that the deceased objected to donating their organs but did not get round to registering during their life time (TRUE)*
- *The family can override the wishes of the deceased (FALSE)*
- *If the family is in distress over the decision to donate, clinicians will not proceed with organ donation (TRUE)*

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 the issue of distress and how this could be gauged.





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

Amongst all participants, whether registered or not, 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.

The barriers as they understood them were due to:

- Religious belief and an expectation that their faith would not accept organ donation;
- Perceived family opposition, particularly where there is little or no understanding of organ donation;
- Lack of information about the donor registration process.

Participants thought those least likely to be on the organ donor register include:

- Older people
- People with learning difficulties
- People with mental health problems
- Low income families
- Homeless
- Faith groups including: Muslims, Jehovah's Witnesses and Christians.<sup>3</sup>

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.

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<sup>3</sup> All the major religions of the UK support the principles of organ donation and transplantation. However, within each religion there are different schools of thought, which mean that views may differ. All the major religions accept that organ donation is an individual choice. More information is available here:  
<http://organdonationwales.org/FAQs/Religious-perspectives/?lang=en>

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.

However some argued there was nothing in scriptures against organ donation as it would not have been considered then and that it was probably the way in which the religious texts were interpreted.

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"I can't see there being any problem with Christians and Muslims because there's not going to be any scripture that's saying you're not supposed to do it is there?"

Male, Cardiff, Positive, aged 40-59

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Those who followed a religion or had close family members who were particularly religious felt that it is important to communicate the changes around organ donor registration so that they know whether or not to opt out. They also wanted to see clear instructions on how to opt out because some envisaged that their more observant relatives would want to opt out in the first instance.

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"I think it is a good idea but some people who are quite religious may decide not to and they may not be happy if one of their family members decides to stay in."

Male, Cardiff, Positive, BME Muslim aged 25-39

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"Blood transfusions, donating an organ, that would be against their religion (about Jehovah's witnesses and Muslims)."

Female, Cardiff, Undecided, BME Christian aged 25-39

---

Some Muslim and Catholic participants believed that their relatives would want the body to stay intact and therefore would oppose any form of organ extraction.

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“...my father’s Roman Catholic and he thinks you should be buried whole to go to the afterlife”

Female, Cardiff, Undecided, aged 25-39

---

While some Hindu and Sikh participants felt that as the body was cremated they envisaged low resistance to organ donation provided the system was communicated effectively and in a culturally sensitive way e.g. at Temples and Gurdwaras.

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“We get cremated. So if someone did need something of mine and I’m dead, why not give it to them?”

Male, Cardiff, Positive, BME Sikh aged 25-39

---

It should be stressed that this sample is too small to extrapolate and these views are not necessarily ones held by the wider Catholic, Muslim, Sikh or Hindu communities. It should also be stressed that some of the Muslim and Catholic participants were already registered organ donors.

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 out-reach programme, perhaps via people explaining the law to them in their own language at community centres.

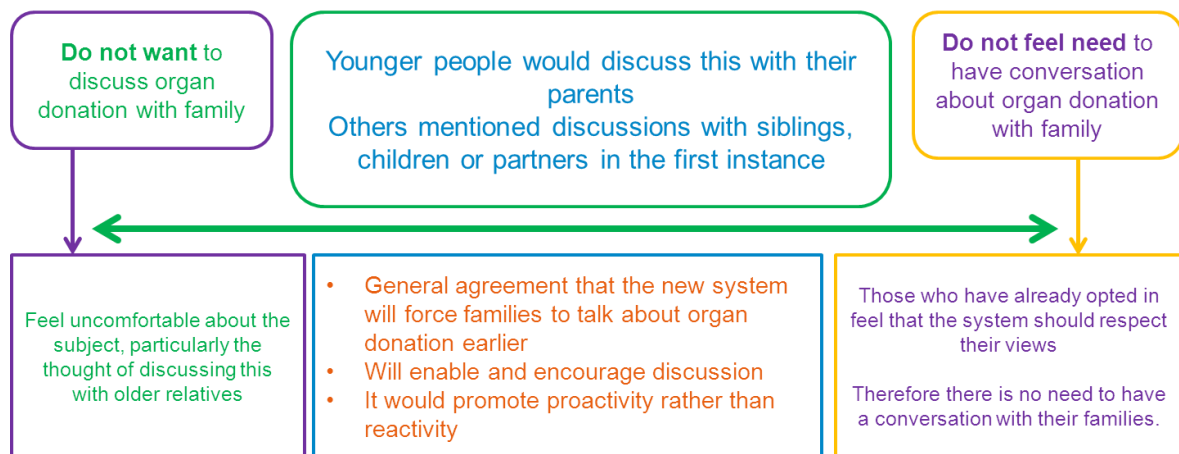
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“There’s lots of people within society who don’t get to make their own decisions, they still live life under the decision of their partner or their family so I think that could affect things as well and that could be linked to religion.”

Male, Cardiff, Undecided, 25-39

---

It was widely accepted that under the new system it will be important for families to discuss their organ donation wishes . 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.

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“It will make people talk about it but it’s not a conversation you want to have”

Swansea, Negative, aged 25-39

---

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.

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“If you’re going to give up organs what’s the point of having this system if family can overturn it?”

Male, Cardiff, Positive, aged 40-59

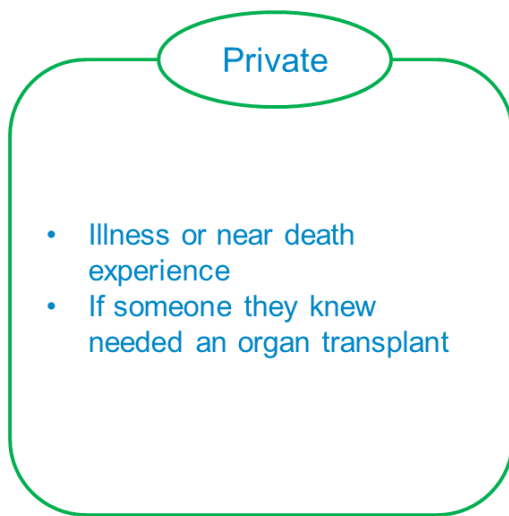
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Although it was seen as a very important issue to discuss with the family, there was general consensus that it was also difficult to raise. However, there was some confidence that future campaigns could help to facilitate conversation and discussion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

Triggers to future discussions appear to fall in to either public or private arenas. The public arena which offers a more proactive approach to family discussions includes:

Public

- Television advertising campaign
- Storylines in soap operas: Emmerdale and Casualty mentioned as recent examples which helped to raise awareness and prompt discussion amongst friends and family
- Public information messages after soaps and dramas that provide helpline details for those affected by the storyline



While the private arena appears to instigate a more reactive approach to discussion with the family.

That said, some envisaged problems with families holding differing views on organ donation.

Those who had already opted in, knowing that their parents might

disagree, believe that the new system would make it easier to discuss their decision about organ donation as they could tell their parents they're thinking about staying in and not have to tell them that they're already in.

---

"I know I have to tell them because it has been in the press recently, so I will imagine there will be a time where we will discuss it..... saying you know, 'have you opted-out or not?' I am hoping it may just be 'yes, I have stayed in, brilliant me too'. I can just say I have stayed in rather than, 'oh yes, I have been in it for years',"

Male, Cardiff, Positive, 25-39

---

## 5.5 Informing and improving communication activities for organ donation

As well as generating insights on attitudes to the soft opt out system and thoughts on the role of the family it became clear that there were gaps in knowledge and understanding of the new system. Some of the most frequently cited questions and concerns shown below, illustrate the existing information gap and should help to inform the public communications campaign.



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.

However, some raised the issue of costs of setting up and managing the new system. This was raised mainly by those negative or undecided about the soft opt out system.

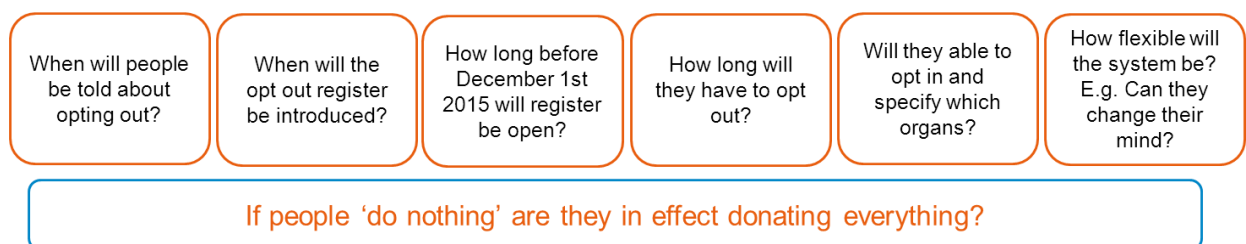
Those who were undecided questioned how cost effective the new system would be, whether or not the IT systems would be able to cope with the

(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. They envisaged big increases in donors so were concerned whether there were adequate resources in the health service to cope with this.

### *Information needs*

It was clear that everyone wanted more information on the soft opt out process. Specifically,



Therefore, 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 opt 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.

During the groups it was evident that how the message is conveyed in a hospital setting would play an important role in how the family respond to organ donation requests. They stressed that the way in which clinical staff approached organ donation with families was very important. Ideally the request for organ/s should be personalised so that it is focused on saving a life rather than taking an organ. The following quote captures this sentiment well.

---

"If somebody approached me in a hospital and said 'we want to use your son's or daughter's, organs, do you consent?' I'd probably say absolutely not. If they said 'we've got a boy who's two wards down who is literally still alive, your son's a match, we need his organs now and we can save this boy's life' it completely changes it whereas if they say 'oh we just want his organs just in case somebody needs them and they're going to be frozen' I'd say don't touch him."

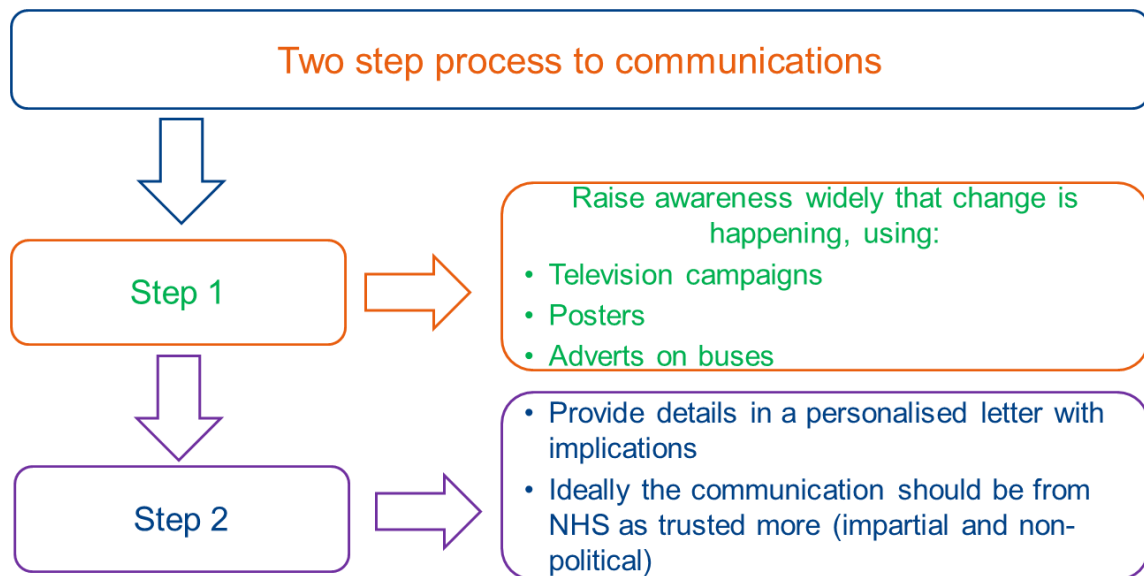
Cardiff, Undecided aged 25-39

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They also wanted to be reassured about what would happen to the organs once they had given their permission, e.g. a guarantee that any organs would be used for saving a life as opposed to being stored for medical research purposes.

## Communication Preferences

The research sessions generated much discussion on information needs as well as how the messages should be conveyed. It was clear from the discussions that participants said 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?'*. The chart below illustrates a two-step process to the communications as described by the participants:



There was also some appetite for reminders to ensure that everyone was kept updated of their registration status.

---

"What if you forget? Do you get annual reminders to say 'look you're on the list and you haven't chosen to opt out, do you want to opt out?'. That's potentially an option because at least if you opt in which is the current system then you've sat down and you've thought long and hard about it and you've made the decision."

Cardiff, Undecided, aged 25-39

---

### *Television advertising preferences*

When asked about whether they would prefer to see actors or people who have experienced organ donation in real life in any television adverts about the new soft opt out system, responses were mixed with people open to either option.

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.

Some cited that the abundance of overseas aid and cancer charity campaigns on television has had a de-sensitising effect. Therefore, on balance, real people and real events would deliver the most impactful message i.e. those who have received or made a decision to donate their organs/family member's organs.

---

"The actors are there to perform. The real people will not perform. You can make out from the face and the character...they [actors] don't know the pain, they don't know the wait. Real people...know how important it was for them."

Cardiff, Positive, aged 25-39

---

There were those who interpreted the word 'actors' as celebrities and famous people. In this instance they felt the message would be more powerful if a famous person was a registered donor, a recipient or a close family member of a recipient or donor.

Those who were positive towards the new system felt that any advertising should be hard hitting and focus on the consequences of not having enough organs to save lives.

They wanted the advertising to be more direct and based on asking the question “*would you accept an organ if you needed one? If yes, you should be a donor.*” They felt that this would help to persuade people to stay in rather than opt out.

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“Might encourage more people to stay in than opt out”

Female, Aberdare, Positive, aged 40-59

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---

“I’d prefer real people. TV isn’t always real anyway.”

Male, Aberystwyth, Positive, aged 40-59

---

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.

## Message Testing

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."*

### 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."*

### Message 2

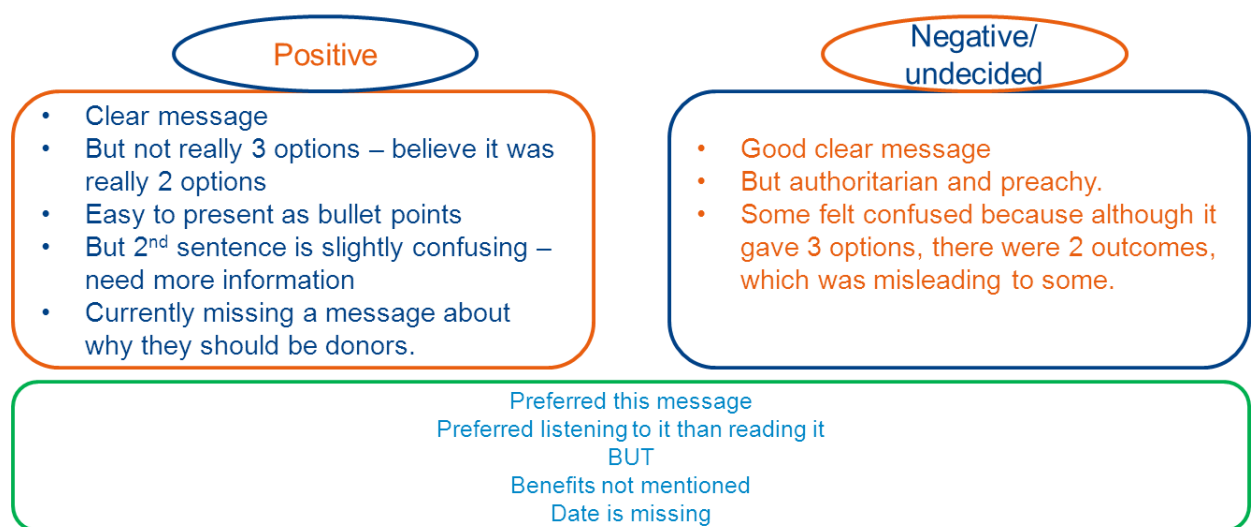
*"Families are always involved in the decision around organ donation, so it is important that you discuss your decision with loved ones. Too many life saving donations are missed because families are unsure of what their loved ones will have wanted. That's why on 1 December 2015, Wales will be changing 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"*

## 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.

The chart below shows the variation in opinions across the sample



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".

.....  
"....I feel more like I don't want it. I feel coerced. I already have a choice.  
This makes me angry"

Male, Swansea, Negative, aged 25-39  
.....

.....  
"If you opt in you can choose what to donate, but if you do nothing at all they can take what they want."

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

## 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'

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"There's too many opt-ins and opt-outs. I had to read it several times"

Male, Aberystwyth, Positive, aged 40-59

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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:

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"How can they assume consent?"

Male, Aberystwyth, Positive, aged 40-59

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- This message did not work for the vast majority of participants because it was too long.
- Many felt that this was too wordy and confusing
- Some needed to read this multiple times to absorb the message fully
- There was resistance to the phrase “consent may be deemed”
  - Some found the phrase difficult to understand
  - Others felt the phrase may be too inaccessible for others
  - Some wondered how this would be translated in Welsh

A few preferred this message because it issued an introductory statement about a new system.

However, they preferred reading it to listening to it

## Message 2

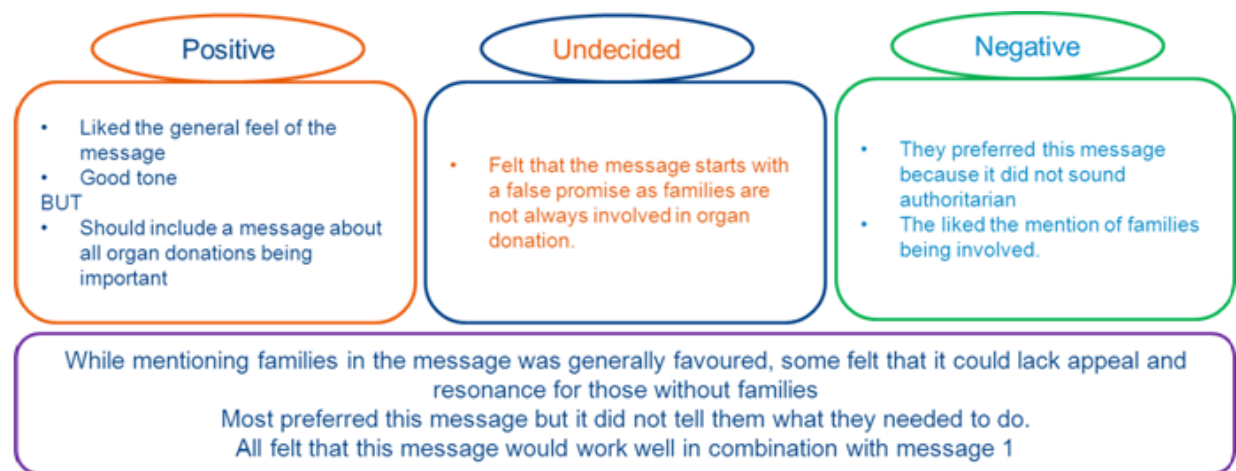
*“Families are always involved in the decision around organ donation, so it is important that you discuss your decision with loved ones. Too many life saving donations are missed because families are unsure of what their loved ones will have wanted. That’s why on 1 December 2015, Wales will be changing 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.



The chart below shows the variation in opinions across the sample.



### *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 (as in message 2);
- 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;
- Softer tone similar to message 2.

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 law will get everyone talking”

Female, Swansea, Positive, aged 18-24  
.....

## 6. Conclusions

The overarching aims for the research were to explore the views of the public with regards to the introduction of the soft opt out system in Wales. In particular, 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;
- 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.

The insights will be used to inform the Welsh Government's communication activities for organ donation, and so far it is evident that further clarity is needed, particularly with regards to how '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. It is interesting to note that no-one changed their opinions as a result of taking part in the research groups and depth interviews.

Advertising is seen as a key factor in initiating and generating discussion amongst families. Therefore, the tone of advertising is important as well as how people relate to the characters involved and the scenario. Participants believed that any advertising should be continuous so that everyone has a chance to see it and act on it. The message should be simple and clear, ideally with signposting to a helpline or website with further support.

If there are any exclusions to the soft opt out then this needs to be clarified as soon as possible before any information vacuum is created for negative assumptions to take hold and gain traction. There were no discernable differences across the 5 locations in this wholly qualitative study given the small sample size and the purposive nature of the sample design.

Those who were positive said that they would be likely to stay in and not opt out. However, they left feeling concerned about what they perceived as the 'increasing' role of families under the new system.

Those who were undecided remained sceptical and needed more answers before they would make their minds up about whether to opt out or stay in.

Those who were negative wanted more information about the registration process and some also stated that they needed more information before they could decide whether to stay in or opt out.

## 7. Annexes

### Recruitment screener

Good morning/afternoon/evening. My name is <insert name> and I am from Criteria Fieldwork, a market research company. We are working on some research with GfK NOP and independent research agency. We are currently working together on a research study exploring the views about government policies and are looking for people to take part in a group discussion/one-to-one interview. As a token of our appreciation for participation eligible attendees will receive a cash thank you for their time. I just need to ask a few questions first...

### DEMOGRAPHICS

**Q1a** Code Gender:

Male	1
Female	2

#### Groups:

X4 per group to be male at Q1a

X4 per group to be female at Q1a

#### Depths:

Spread of gender across depths 1-7 AND across depths 8-14 at Q1a

**Q1b** Age: \_\_\_\_\_

#### Group 5 & Depth 5:

All to be aged 18-24 years (spread in each group and across depths) at Q1b

#### Group 1, 3, 6 & 7 & Depths 1, 2 & 6:

All to be aged 25-39 years (spread in each group and across depths) at Q1b

#### Group 2, 4 8 & 9 & Depths 3 & 7:

All to be aged 40-59 years (spread in each group and across depths) at Q1b

#### Group 10:

All to be aged 60-75 years (spread) at Q1b

#### Depths 8-14:

Spread of ages across depths (spread across depths) at Q1b

**Q1c** Are you at present (code all that apply):

Married/civil partnership	1	Single	2	Divorced	3
Widowed	4	Separated	5	Cohabiting	6
Living with parents	7	Sharing with friends	8	Living alone	9

**Q1d** Do you have children or are you expecting your first child?

<b>guidance</b>	Yes, I have children	1	<b>Complete grid below</b>
	Yes, expecting first child	2	<b>Refer to office for</b>
	No	3	<b>Continue to Q1e</b>

Respondents children:

	Gender	Age
Living at Home		
Away from home		

**Group 1, 3, 6 & 7 & Depths 1, 2 & 6:**

**Spread of pre-family and family (have at least X1 child living at home) in each group at Q1d**

**Group 2, 4 8 & 9 & Depths 3 & 7:**

**Spread of family (have at least X1 child living at home) and empty nesters in each group at Q1d**

**Q1e** Occupation of Chief Income Earner (*Probe fully*):

\_\_\_\_\_

Qualifications: \_\_\_\_\_

Number in Charge of: \_\_\_\_\_ SOCIAL GRADE: \_\_\_\_\_

**Groups 1, 4, 6, 8 & 9:**

**All to be C2DE at Q1e**

**Groups 2, 3, 5, 7 & 10:**

**All to be BC1 at Q1e**

**Depths:**

**Spread of SEG across depths 1-7 AND across depths 8-14 at Q1e**

**Q1f** If respondent NOT Chief Income Earner ask if:

Working full time (30+ Hours per week)	1
Working part time (6-29 Hours per week)	2
Working less than 6 hours	3
Education (GCSE or pre-GCSE)	4
Education (A-level or equivalent)	5
Education (Vocational - <i>write in</i> ):	6
Education (Degree or equivalent)	7
Education (Post-graduate)	8
Non-Working	9
Retired	10
Other	11
( <i>write in</i> ): _____	

**Q1g** Occupation of respondent if not Chief Income Earner:

\_\_\_\_\_

**Q1h** Can you tell me which of the following best describes your ethnicity?

British	1
Irish	2
Any other white background	3
White and Black Caribbean	4
White and Asian	5
Any other mixed background	6
Indian	7
Pakistani	8
Bangladeshi	9
Afghan	10
Bhutanese	11
Nepalese	12
Sri Lankan	13
Maldivian	14
Other Asian background	15
Black Caribbean	16
African	17
Any other black background	18
Chinese	19
Any other background	20

**Depths 1-4:**

All to be South Asian (Indian, Pakistani, Bangladeshi, Afghan, Bhutanese, Nepalese, Sri Lankan, Maldivian) at Q1h

**Depths 5-7:**

All to be Black Caribbean at Q1h

**Groups 1-10 & Depths 8-14:**

Please ensure a representative mix of ethnicity based on location at Q1h

## OCCUPATION/INDUSTRY EXCLUSIONS

**Q2** Thinking about the following occupations, can you tell me which, if any:

- a) you currently work in or have worked in the past?
- b) any member of your family or close friends currently work in?

<b><u>Read out:</u></b>	<b>a)</b>	<b>b)</b>
Advertising	<b>X</b>	<b>X</b>
Market Research	<b>X</b>	<b>X</b>
Public Relations	<b>X</b>	<b>X</b>
Journalism	<b>X</b>	<b>X</b>
Marketing	<b>X</b>	<b>X</b>
Local Government	<b>X</b>	<b>X</b>
National Government	<b>X</b>	<b>X</b>
Political Party Administration	<b>X</b>	<b>X</b>
Doctors/Nurses/Healthcare profession	<b>X</b>	<b>X</b>
<hr/>		
None of the above	<b>0</b>	<b>0</b>

**If yes to any responses above the line, close interview**  
**All to code None of the above at Q2a and Q2b**

**Q2c** Do you intend to work in any of those occupations in the next 6 months?

Yes	<b>X</b>	<b>Close</b>
No	<b>2</b>	<b>Continue</b>

## PREVIOUS ATTENDANCE

**Q3a** Are you scheduled to participate in a market research group discussion/depth interview in the near future?

Yes	<b>X</b>	<b>Close</b>
No	2	<b>Continue</b>

**Q3b** Have you ever attended a market research group discussion/depth interview?

Yes	1	<b>Ask Q3c</b>
No	2	<b>Go to Q4</b>

**Q3c** How long ago did you last attend a market research group discussion/depth interview?

In the last 6 months	<b>X</b>	<b>Close</b>
6 Months-3 years ago	2	<b>Ask Q3d</b>
More than 3 years ago	3	<b>Ask Q3d</b>

**None to have attended in the last 6 months**

**Q3d** How many market research group discussions/depth interviews have you attended in total?

---

**If more than 3 market research group discussions/depth interviews attended in total close**

**Q3e** What was each of those market research group discussions/depth interviews about?

Interviewer write in:

---

**If on a similar subject as this survey, close interview**



Now I would like to ask you some questions about the subject we are conducting the research on. The research is on behalf of the Welsh government to understand people's views on organ donation. First of all....

**Q4** Can I ask, how much do you know about how the current system of organ donation works – i.e. how organs get donated?

- |   |   |
|---|---|
| I feel I know quite a lot about the current system                            | 1 |
| I feel I know a fair amount about the current system, but not too much detail | 2 |
| I don't think I know very much about the current system, only basic knowledge | 3 |
| I don't think I know anything at all about the current system                 | 4 |

**Record for information purposes at Q4**

**Q5** And can I ask, have you ever had any experience with organ donation?

- |   |   |
|---|---|
| Yes, I have personally donated an organ/organs  | 1 |
| Yes, I have personally received a donated organ   | 2 |
| Yes, I have a close friend or family member who has donated organs                      | 3 |
| Yes, I have a close friend or family member who has received a donated organ            | 4 |
| Yes, I have had to decide on behalf of a loved on whether or not to donate their organs | 5 |
| No, I have no experience with this  | 6 |

**Depths 8-14:**

**All to have had some experience with organ donation (code 1 -5) at Q5**

**Q6** Are you aware of any proposed changes to the current organ donation system?

- |        |   |
|--------|---|
| Yes    | 1 |
| No     | 2 |
| Unsure | 3 |

**Record for information purposes at Q6**

**Please Read to Respondents:**

*The National Assembly for Wales has passed a law to change the organ donation procedure to a 'soft opt out' system. From December 2015, people will be given the opportunity to formally 'opt out' of organ donation by placing their name on a register. If they choose not to do so, having had the opportunity, then this will be treated as a decision to be a donor, and one which families will be sensitively encouraged to accept. The law will allow family members to object to donation on the basis that they know the deceased person would not have wished to consent. The opportunity to 'opt in' and register a decision to be a donor will continue.*

**Q7** Can you tell me if you have heard anything about this already, before today?

- |        |   |
|--------|---|
| Yes    | 1 |
| No     | 2 |
| Unsure | 3 |

**Record for information purposes at Q7**

**Q8** Can you tell me which of the following statement best describes your view on this change?

- |  |   |
|--|---|
| I am in favour of this change to legislation | 1 |
| I am against this change in legislation      | 2 |
| I need more time to decide                   | 3 |
| I don't know at all                          | 4 |

**Groups 2, 4, 5, 7, 9 & Depths 2, 4 & 5 - POSITIVE:**

**All to agree with the statement 'I am in favour of this change to legislation' at Q8**

**Groups 3, 6 & 8 & Depths 3 & 6 - NEGATIVE:**

**All to agree with the statement 'I am against this change in legislation' at Q8**

**Groups 1 & 10 & Depth 1 - UNDECIDED:**

**All to agree with the statement 'I need more time to decide' or 'I don't know at all' at Q8**

**Ask Groups 2 & 8:**  
**WELSH LANGUAGE**

**Q9a** Would you say you are.....?

Fluent in Welsh	1	<b>Continue</b>
Can speak a fair amount of Welsh	2	
Can only speak a little Welsh	3	
Can only say a few words in Welsh	4	
Not able to speak any Welsh	5	

**Q9b** Would you say that you can.....?

Read Welsh fluently	1	<b>Continue</b>
Read a fair amount of Welsh	2	
Only read a little Welsh	3	
Only read a few words in Welsh	4	
Are not able to read any Welsh	5	

**Groups 2 & 8:**  
**All to be fluent in Welsh at Q9a/b**

**Ask All:**

**Q10** We would like you to complete a short exercise either before or after attending the group. Is this something you are happy to do?

Yes	1	
No	<b>X</b>	<b>Close</b>

**Q11** It may be necessary for the research team to contact you by email or telephone after the research has taken place to follow up on ideas generated during the discussion. You would only be contacted if strictly necessary and only in connection with this research. Are you happy to agree to be re-contacted on this basis, and for us to pass your email address to the research team?

Yes	1	<b>Continue</b>
No	2	<b>Refer to the office</b>

**INVITE TO PARTICIPATE IF RESPONDENT MEETS ALL QUOTAS**

## Topic guide

### National Assembly for Wales Welsh Government: Human Transplantation (Wales) Act Discussion Guide – FINAL

#### Objectives:

- 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 findings that emerge from the on-going quantitative surveys.
- 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.
- Inform and improve Welsh Government communication activities for organ donation.

#### Notes:

*This guide is intended to guide the discussion however; the exact flow and question wording will be tailored by the moderator to best fit the group. Resultantly, not all questions may be asked in the order below, or in the wording below.*

*This discussion guide will be used for focus groups and individual depth interviews. The timings are colour-coded for these as follows:*

- *Focus group timings are in blue.*
- *Individual depth interview timings are in green.*

#### Moderator background:

“The Welsh Government will introduce a soft opt-out system of organ donation through the Human Transplantation (Wales) Act. The legislation means that a person’s consent to donation will be deemed to have been given unless they objected during their lifetime – a process called opting out – but where those closest to the deceased will still have an important role to play in the process. The Welsh Government obtained Royal Assent for the Bill in September 2013 and will bring the main provisions of the Act into effect on 1<sup>st</sup> December 2015. In order to assess the implementation of the soft opt-out system of organ donation and the impact it has on donation rates in Wales, the Welsh Government wishes to evaluate the Human Transplantation (Wales) Bill. A communications campaign is being undertaken by the Welsh Government to ensure the population of Wales are aware of and understand the new law and know how to opt out if desired. In order to monitor the effectiveness of the campaign, regular information is required on public awareness and understanding of organ donation law, and attitudes to changes in the legislation in Wales. To meet these research needs, the Welsh Government has already commissioned quantitative surveys of the adult population in Wales, taking place at regular intervals between 2012 and 2016. In addition, the Welsh Government commissioned qualitative research with members of the public in 2012 to explore attitudes towards organ donation in general, and

on changing the organ donation system in Wales. In order to further explore public attitudes, and gain a deeper understanding of findings emerging from the on-going quantitative surveys, the Welsh Government has commissioned qualitative research with members of the public.” This discussion guide deals with gaining a deeper understanding of general public views and opinions.

## **1. Introduction**

**10 mins | 5 mins**

(Aim: to introduce participants to the research and each other)

- Thank you for agreeing to take part in this research.
- Introduce self and GfK NOP.
- Explain purpose of the research: We are carrying out the research on behalf of the Welsh Government who are interested in knowing what people think about organ donation and the proposed changes to the system. I'll explain more about this throughout the course of our discussion, and I will be showing you some information and asking for your comments on these. .
- Explain audio recording.
- Reassure participants that the discussion is confidential, and that it complies with the Market Research Society Code of Conduct.
- Explain the discussion will last for **1 ½ hours | 1 hour**.
- Explain the importance of being able to say what you think, there are no right or wrong answers and please be honest.
- Any questions?

## **Participant introductions**

- Please tell me a little bit about yourself...
  - First name, age, who you live with
  - Where do you spend most of your time?
  - Who do you spend the most time with?

## **2. General awareness of and attitudes to organ donation** **10 mins | 10 mins**

(Aim: to understand levels of awareness and knowledge of organ donation)

Today we are going to be talking about organ donation and the processes around donation currently and in the future, but first of all – what comes to mind when you think about organ donation?

### **EXERCISE: word association**

- Flip chart responses to ‘what comes to mind when you think about organ donation?’
- What do you know about the current system of organ donation?
- What do you think about organ donation in general?
- Have you ever discussed organ donation with anyone?
  - Who have you discussed this with?
    - What aspects did you discuss?
- Where have you heard/read about organ donation?

- How does the current system of organ donation work? (if nec. Prompt: opt in/register, carry donor card, permission from the family/family decide)
- According to a recent survey in Wales, 40% said that the current system of organ donation works by an opt in/registration system (i.e. people need to opt in or register) and 36% said it worked with an organ donor card (i.e. that people had to carry a donor card). Does this surprise you at all? Why?
- What would you say is good about the current system?
  - Why do you say that?
- What's not so good about it?
  - Why do you say that?
- As far as you know is there anything that makes it difficult for some people to donate or receive organs?
  - What makes it difficult for them?
  - Why is that?
  - Which groups of people are particularly affected by this?

### **3. Attitudes to introduction of soft opt out system 20 mins |15 mins**

(Aim: explore understanding of and attitudes to soft out system)

- When we invited you to the group/interview we asked you about how much you knew about the new system of organ donation And we asked you to answer some questions. Do you have the completed exercise sheets with you? (Gather these).
- How did you find answering the questions?
- Any problems/difficulties? What were they?
- Prior to doing this exercise how much did you know about it?
- What had you heard?
  - Probe for key words used and phrases that come to mind
- Where did you hear about the change from?
- How do you feel about the change? (moderator to capture initial reactions at this stage)

If not mentioned spontaneously ASK:

- Have you thought about what you might do?
  - Opt out
  - Do nothing
  - Opt in

Now I'm going to read out some information about the changes to the system of organ donation:

*"The National Assembly for Wales has passed a law to change the organ donation procedure to a 'soft opt out' system. From December 2015, people will be given the opportunity to formally 'opt out' of organ donation by placing their name on a register. If they choose not to do so, having had the opportunity, then this will be treated as a decision to be a donor, and one which families will be sensitively encouraged to accept. The law will allow family members to object to donation on the basis that they know the deceased person would not have wished to consent. The opportunity to 'opt in' and register a decision to be a donor will continue."*

- What do you think of this system?

- **EXERCISE 1: hand out Exercise 1 sheet and ask them to write down what their initial thoughts about the system, what they think is good about it and what they think is not so good about it.**
- Gather up the sheets and then discuss the positives and negatives of the new system as a group:
  - What do you see as the benefits of the new system
  - What do you see as the drawbacks of the new system
- As far as you can tell is there anything about this new system that makes it difficult for some people to donate or receive organs in this way?
  - What makes it difficult for them?
    - **PROBE:** is it the process? Or something else? What is that?
  - Why is that?
  - Which groups of people will be particularly affected by this? Why do you say that?
- **EXERCISE 2: For each statement ask participants whether they agree or disagree and why?** Here are things that some people have said about the new system (written on cards), for each I'd like you to tell me what you think about each and why you feel that way.....
  - The proposed soft opt out system for wales will result in more lives being saved
  - Organ donation is a gift which the soft opt out system will take away
  - The soft opt out system maintains freedom of choice because anyone can opt out from organ donation if they want to
  - The soft opt out system gives the government too much control
- You might have heard others discussing the new system before coming to this group/interview, what other things have you heard people say about it?
  - What else?
- **EXERCISE 3: What questions do you have about the new system once it becomes law in December 2015? Hand out exercise sheets and ask participants to complete. Once they have finished gather up the sheets and ask:**
  - What concerns do you have about the new system of organ donation before it becomes law in 2015?
  - In what way could it change the way people think about organ donation?
  - How will it change people's behaviour?
    - In what way?
  - What impact do you think it could have on you and your family?
    - Why do you say that?

#### **4. Attitudes regarding the role of family in organ donation 20 mins |10 mins**

*(Aim: explore attitudes to role of family in the new soft opt out system)*

- Thinking a bit more about the impact on families now....
  - Will it make things easier or harder for families?
    - In what way?

- How important do you think it is to discuss the issue of organ donation, given the introduction of the soft opt out system, with family now?
- Supposing you were to raise the issue of organ donation with family, who in your family would you talk to about this?
- What would prompt you to discuss it?
- What might you prefer not to discuss?
- When do you think most people would be likely to discuss it with family?
  - Explore trigger points.
- What challenges do you envisage some families could face as a result of this new system becoming law from 2015?
  - Why do you say that?
- I'm going to read out some statements and I'd like you to tell me which you think are true and which are false. **Moderator: Read out each statement from a card and place on table then ask participants to sort in to true and false piles.**
  - The family will have no role to play in the organ donation process (FALSE)
  - The family can provide evidence that the deceased objected to donating their organs but did not get around to registering during their lifetime (TRUE)
  - The family can override the wishes of the deceased (FALSE)
  - If the family is in distress over the decision to donate, clinicians will not proceed with organ donation (TRUE)

**Once they have sorted the cards reveal which are true and which are false and gather reactions.**

- For the true statements in the recent survey around a quarter thought that *"If the family is in distress over the decision to donate, clinicians will not proceed with organ donation"* was false and a fifth thought that *"The family can provide evidence that the deceased objected to donating their organs but did not get around to registering during their lifetime"* was false.
  - Why do you think they thought that?
- For the false statements around a third thought that *"The family will have no role to play in the organ donation process"* and *"The family can override the wishes of the deceased"* were true.
  - Why do you think they thought that?
- Now that you know which are false and which are true, what do you think about the role of families?
- How does this make you feel?
- What other concerns do you have?
- How could the role of families be made clearer?

### **5a. Communications**

**15 mins | 10 mins**

(Aim: to inform and improve communication activities for organ donation)

- What have you seen about organ donation recently?
- Have you seen any advertising? Where
  - TV
  - Radio
  - Newspaper/press



- Online
- What did you think about it?
- What was it telling you?
- What do you think would be the best way to make people aware of the proposed changes to the organ donation system?
- What are the important things to tell people?
  - What else will people want to know?
- How should they be told about putting their name on the register to opt out?
- What information should they be told about the registration process?
- Who should tell them?
  - Who are people likely to trust to tell them the truth about it?
- What is the best way to reach people about registration?
  - Television (news programme)
  - Radio
  - Local newspaper
  - Television advert
  - Leaflet/poster
  - National wales newspaper
  - National UK newspaper
  - What else?
- Thinking about television adverts specifically, how would you feel about actors being used in TV adverts that promote organ donation?
  - Why do you like/dislike this?
  - What else?
- How would you feel if TV adverts used 'real' people who have benefitted from organ donation(either themselves or their families) or family members who had to make the decision about organ donation following the loss of a loved one
  - Why do you like/dislike this
  - What else?
- Can you think of any reasons why...
  - Someone would want to go the register?
  - Someone would not want to go on the register?
    - Why is that?

### **5b. Message testing**

**10 mins | 5 mins**

(Aim to test whether message on publicity materials is clear)

Now I'd like to ask you about the actual words that could be used to tell people about the new system. Essentially the messages about the new system needs to be clear so that it easy for people to make a decision about organ donation. I am going to read out the message that could go on the publicity material and I'd like you to tell me whether you think this is easy or difficult to understand. **NB: Moderator hand out showcards for message 1.** I am also going to hand out some sheets with the message typed on so that you can read it as well.

#### **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."*

ASK:

- Content: Clear what the message is about?
- Clarity: how easy/difficult is it to understand?
- Visual/aural impact: Is it easier to understand when you hear it or read it? Why is that?
- Tone: How is it coming across to you?
- What would make it easier for people to make their decision with confidence?
- What else would you change about it? Why is that?
- (ASK IF RESPONSES NEGATIVE: How would you improve it / alternative suggestions?)

### **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."*

ASK:

- Content: Clear what the message is about?
  - Clarity: how easy/difficult is it to understand?
  - Visual/aural impact: Is it easier to understand when you hear it or read it? Why is that?
  - Tone: How is it coming across to you?
  - What would make it easier for people to make their decision with confidence?
  - What else would you change about it? Why is that?
  - (ASK IF RESPONSES NEGATIVE: How would you improve it / alternative suggestions?)
- How do the two messages compare?
  - Which is easier to understand the first one (1a) or the second one (1b)?
    - Why is that?

### **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"*

ASK:

- Content: Clear what the message is about?
- Clarity: how easy/difficult is it to understand?
- Visual/aural impact: Is it easier to understand when you hear it or read it? Why is that?
- Tone: How is it coming across to you?

- What would make it easier for people to make their decision with confidence?
- What else would you change about it? Why is that?
- (ASK IF RESPONSES NEGATIVE: How would you improve it / alternative suggestions?)

## **6. Summary and Close**

**5 mins | 5 mins**

(Aim: to finish up the discussion and thank participants)

You very kindly completed the exercise and came along to this session to answer questions around organ donation and the new proposed system. I'm very interested to know if anyone's views have changed since completing the written exercise? (show of hands)

- What was it that made you change your views?

To finish, I'd like to ask each person for an answer to the following two questions:

- What would encourage you to discuss the issue of organ donation with family?
- What would put you off discussing the issue of organ donation with family?
- Any final questions?

## **Thank and Close**

## Pretask

# Research Pre-task

Name

- Thank you for agreeing to take part in the research.
- The research is about understanding how people feel about changes to the organ donation system in Wales and what they know about it. We hope that you will find it interesting and thought provoking.
- Before you come along to the research session we'd like you to complete this short task.
- There are **four** questions to answer so please provide as much detail as possible.

# Awareness and understanding

**Q1. What have you heard about changes in the organ donation system in Wales?**

## **Sources of information**

**Q2. Where did you hear about these changes to the organ donation system?**

## Speaking to others

**Q3. Have you spoken to anyone about these changes taking place?  
Who did you speak to and what kind of issues came up during the conversation?**

# Questions

**Q4. Do you have any questions about the changes taking place? What kind of questions?**



**Thank you for completing this short task.  
Please remember to bring it with you when you attend the session.**