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

Qualitative research report



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proposal consultation***

Qualitative research report

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

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1. Research findings: executive summary

Introduction

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

Attitudes towards organ donation in general

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

Motivations for joining the NHS Organ Donor Register

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

Barriers to joining the NHS Organ Donor Register

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

Discussing organ donation with family

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

Finding out about the opt-out proposal

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

Spontaneous understanding of the opt-out proposal

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

Reactions to the organ donor opt-out proposal

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

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

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

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

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

2. Introduction: situation, research objectives and methodology

2.1 Situation

Organ and tissue transplantation is considered one of the most effective forms of medical treatment that saves lives and improves quality of life for patients with organ failure¹. Members of the UK population can currently opt in to the NHS Organ Donor Register and this will be taken as appropriate consent should that individual go on to die in circumstances that make organ donation a possibility. Health professionals should still consult with relatives to find out if the deceased had spoken about their wishes and to encourage them to be respected, but it is possible, if relatives object, that the donation may not go ahead. People who are not on the Organ Donor Register may also become donors (in fact the majority of donations are from people who have never registered) but in these cases consent is given by family members on behalf of the deceased.

Previous research² has found that most people support organ donation but only one third have registered their wishes to be a donor, despite a number of high profile campaigns in recent years. Approximately 50 people died in Wales in 2010-2011 while waiting for an organ donation, and there are around 300 people at any given time on the active waiting list for a transplant.

The Welsh Government is therefore committed to continuing efforts to increase organ donation rates. It states that previous consultation and research on this topic in 2008-09 'confirmed significant support for increasing donation rates'³.

The Welsh Government reports that research from other European countries, where an opt-out system has been implemented, suggests a consequent organ donation rate increase of around 25 to 30 per cent⁴.

At the time of this study, and as part of its ongoing efforts to increase rates, The Welsh Government was undertaking a consultation exercise on 'Proposals for Legislation on Organ and Tissue Donation', which was drawing to a close at the time this project was commissioned. The Organ Donation Bill would create a soft opt-out system of organ donation for adults aged 18+ who live and die in Wales. This means that unless an individual makes an objection their organs and tissues will be available for donation after their death. Families will be involved in the decision-making process around donation, after death.

¹ Welsh Government White Paper November 2011, <http://bit.ly/t8rPV2>

² Organ Donation Taskforce report November 2008 on moving to a presumed consent system, <http://bit.ly/uwLpAe>

³ Welsh Government, August 2009 consultation, <http://bit.ly/w0QCG4>

⁴ Abadie and Gay, 2006, 'The impact of presumed consent legislation on cadaveric organ donation: A cross-country study': available to view online at: <http://hvr.d.me/uRx43G>

2.2 Research objectives

The Welsh Government wished to include a qualitative research component to support the consultation process by exploring attitudes to organ donation, and the consultation proposals. The research specification set the following main objectives for the project:

- To use qualitative research techniques to elicit attitudes towards organ donation in general and the opt-out proposals in particular across the general population
- To use qualitative research techniques to discuss responses to the key issues raised in the consultation document

The detail of the objectives was expanded upon commission to cover the following topics:

- To explore motivations for, and barriers to, joining the current NHS Organ Donor Register
- To understand to what extent organ donation is a subject ever discussed with family or friends
- To gauge levels of awareness of the organ donation opt-out proposals

2.3 Research methodology

The research used a qualitative approach to better understand what lies behind opinions on organ donation and the soft opt-out proposal.

The research consisted of six discussion groups and seven qualitative face-to-face interviews. Each group was recruited to include a mix of people in terms of awareness of the NHS Organ Donor Register and included some who had joined the Register and / or carried a donor card.

Black and Minority Ethnic (BME) people formed part of the research sample and included Pakistani, African Caribbean, Nigerian and Chinese participants.

Each group contained a mix of men and women and the sample was broadly stratified by age and socio-economic grouping (SEG). Two groups were conducted in the Welsh language.

The table below summarises the overall group composition. In total, 52 participants took part in the research. The fieldwork took place between 8 and 14 February 2012 across Wales in Cardiff, Newport, Carmarthen, Treorchy, Caernarfon and Wrexham.

	Age	Additional criteria	SEG
1	16-25	<ul style="list-style-type: none"> ▪ Approx. 1-2 to be on NHS ODR ▪ To include c.50% BME people 	ABC1
2	26-44	<ul style="list-style-type: none"> ▪ Approx. 1-2 to be on NHS ODR ▪ Discussion in medium of Welsh 	ABC1
3	45-70	<ul style="list-style-type: none"> ▪ Approx. 1-2 to be on NHS ODR 	ABC1
4	16-25	<ul style="list-style-type: none"> ▪ Approx. 1-2 to be on NHS ODR 	C2DE
5	26-44	<ul style="list-style-type: none"> ▪ Approx. 1-2 to be on NHS ODR ▪ To include c.50% BME people 	C2DE
6	45-70	<ul style="list-style-type: none"> ▪ Approx. 1-2 to be on NHS ODR ▪ Discussion in medium of Welsh 	C2DE

Participants were given a short information sheet prior to taking part in the groups to note down any thoughts they had on organ donation. The aim of this exercise was to give participants the opportunity to record initial, uninfluenced views including any they preferred not to share in the group environment.

This report contains verbatim comments from the discussions with participants as well as from their written information sheets. Each comment is attributed according to gender, socio-economic grouping and age.

The qualitative research approach and sample size means that the findings should be treated as indicative rather than conclusive, and are not intended to reflect overall on whether or not the nation supports the soft opt-out proposal on organ donation for Wales.

3. Attitudes to organ donation in general

3.1 Top of mind thoughts on organ donation

In keeping with figures available on UK views, participants in this research were mostly very much in favour of the principle of organ donation. At the start of the discussions, they were asked for immediate associations with the topic.

Their main spontaneous focus was on the end benefit of the process for the individual receiving the organ or tissue, and also for the patient's family. They used terms such as 'saving lives', 'hope', 'help', 'from sadness comes life', 'good thing', 'beneficial', 'second chance' and 'miracle' to describe the impact of the process. Participants believed that organ transplantation saved and prolonged lives, improved quality of life for the patient and those close to the individual.

You are essentially extending somebody else's life. As you say, it's not just the benefit to them but the family as well, and their friends. (Male, C2DE, 16-25)

It gives someone a chance to live after you die. (Male, ABC1, 26-44)

I've believed in the principle of donating organs since schooldays. One of my peers suffered from kidney disease and his life was transformed when he had a new kidney. (Female, 45-70, C2DE)

There was an additional view expressed that it made sense to donate organs rather than allow them to go to waste.

Because you're able to help someone if you no longer need your organs then I don't see why they should go to waste. (Male, C2DE, 26-44)

Some also spontaneously considered organ donation from the perspective of the (potential) would-be donor and used phrases such as 'selfless', 'choice', 'humanitarian', 'moral obligation', 'comfortable', and 'big decision'. Some personal doubts emerged within this theme as terms like 'nervous', 'scared', 'uncomfortable', 'difficult', and 'don't like to think about it' were volunteered.

I'm not comfortable with it at all. It does bring goodness if a young person is killed and seven or eight people benefit from that, but I'm not comfortable with it. (Female, 45-70, C2DE)

I can see the overwhelming benefits of donating organs but still haven't signed up to the donor register. . . . I have a strange feeling about donating blood, organs, quite a selfish feeling. My blood, skin, organs, brain make up who I am and so I have reservations about belonging to someone else in the future. (Male, ABC1, 16-25)

A further theme to surface among initial associations centred on a lack of familiarity with the current system: 'unknown', 'lack of information', and 'not much information' were phrases used.

There's been no campaigns recently. I haven't seen anything for years I feel. (Female, ABC1, 26-44)

Less often, participants referred spontaneously to the opt-out proposal in their top-of-mind associations with organ donation, using phrases such as 'new system', 'the way forward', 'not enough publicity', and 'controversial'.

As the contextual discussion unfolded, it became apparent that some participants were uncomfortable thinking about the actual organ transplant process, particularly as it was not clear what this entailed.

Pretty nervous. I know you're not going to know anything about it but I'd like to know more about what goes on. (Female, ABC1, 45-70)

The only thing that plays on my mind is how they would cut me open in the event of my death. (Female, C2DE, 26-44)

Other concerns voiced included the impact of religious and cultural issues, the effect of the beliefs of other family members and, occasionally, whether those currently on the Organ Donor Register would receive the best quality care should they find themselves in hospital with a critical condition. These subjects are covered in more detail later in the report.

In very isolated cases, participants were against the principle of organ donation.

I'm against donating organs. After the organs have come to an end, the body is ready to say it's over. (Female, C2DE, 45-70)

3.2 Awareness and understanding of the current opt-in system

On the whole, participants tended to be aware that there was currently an opt-in system in place in Wales. Some older people in the sample had carried a donor card for many years, and some younger participants had become aware of the process more recently when applying for a driving licence. There was a general view that the donor's wish was final whereas the need for family consent was only mentioned infrequently and became a significant issue once prompted in the discussion (see section 3.3).

Well, you carry a card and they take you away and obviously take your organs out. They don't even have to contact the family. That's what you sign that card for. (Male, ABC1, 45-70)

You sign on when you get your driving licence, don't you? You have to sign something. You have to opt in to it at the moment and then on

death they ring the family and they can say, yeah, take it. That's what I understand it to be. (Male, ABC1, 16-25)

However, there was a good deal of uncertainty about the current system and a widespread lack of familiarity with what the process of becoming a donor entailed, together with the decision-making process at the point of death. In isolated cases, participants believed that Wales had already switched to an opt-out system.

I'm not too aware about donating and how you go about it to become a donor. It's not something I have ever thought about. (Male, ABC1, 16-25)

When it actually happens, the procedure they go through before they take your organs that bit I'm totally blurred. (Female, C2DE, 26-44)

Those who carried a donor card were often uncertain whether or not they were still on the Register, whether the card was still valid, and even whether or not they had sent off a form to join the Register in the first place. They reported having never received any communication relating to organ donation since joining the Register.

I was [on the Register] but I don't know if I'm still registered because the purse I had with the card in I've lost. (Female, ABC1, 45-70)

I'm actually a donor. I used to carry a card. I joined when I was in my 20s and I'm 42 now, so I don't even know if I'm still on the Register – would I be on the Register? (Female, C2DE, 26-44)

Participants as a whole, therefore, concurred that they rarely encountered communication on the subject of organ donation. For those involved in giving blood, this lack of communication compared unfavourably with regular communications experienced relating to this other form of donation.

I don't think it's spoken about enough, people aren't as aware of it these days. It's not as common as it used to be. Because I've not seen it advertised for years. The only time I see it is when my Mum opens her purse and I see [the donor card]. (Female, C2DE, 16-25)

Especially compared to the Welsh blood service I think because you always see adverts for that, all the time everywhere, especially in universities or if you're out and about, the posters, and emails as well. Because once they have you on the list you're constantly getting things through the post as reminders and text messages as well. But compared to that I think there's very little information about organ donation. (Male, ABC1, 16-25)

3.3 Reactions to an overview of the current opt-in system

Having obtained spontaneous comments on perceptions of the current opt-in system, participants were provided with a brief summary of the system as follows:

Currently, people in Wales have to opt in to join the NHS Organ Donor Register if they wish to donate their organs after death. It's normal practice for doctors to let relatives know if the person has opted in and doctors will not proceed if families ask them not to. If you have not joined the Register, your family can consent to donate your organs after your death.

On hearing the summary, participants regularly took issue with the realisation that doctors would not proceed if families asked them not to. There was a strong belief that the individual's choice to opt in should be respected, and that it was 'no-one's choice but yours'. The surprise with which some participants met this news was highlighted by responses like 'very wrong', and thinking it 'so bad' that the individual's wishes could be overruled. This led some to question the point of having the Register as it apparently relied on having the 'family behind you'.

F: So it's up to the people who are left behind then basically, even if you've opted-in.

F: That's wrong, though, isn't it?

F: And they decide no. That's not fair because they're going against your wish. (Female, C2DE, 26-44)

So what you're saying, then, it's a waste of time registering unless you get your family behind you. (Male, ABC1, 45-70)

That's so bad. It's your own personal choice. That's double standards. (Male, C2DE, 16-25)

Some envisaged that the current onus on the family to give consent would only add to the distress of families at what would already be a very difficult time for them. Also, some thought that it would be an awkward conversation to have immediately on the death of a loved one, especially if they did not know the deceased's wishes in relation to organ donation. In addition, a number of participants felt that this would cause problems within their own family given strong differences in opinion on organ donation.

But it's a hell of a thing to raise when they're grieving, . . . 'listen, we're also taking so-and-so's organs as well'. (Male, ABC1, 26-44)

It also puts pressure on the relatives. My friend's Mum, her Dad was a donor, card and everything, but she couldn't go through thinking that her Dad was being cut up. So she said 'I can't physically say yes', but she's an organ donor herself, but at that moment, there was so much pressure, she couldn't say yes. (Female, C2DE, 16-25)

My mother will say 'no'. That would be against my will wouldn't it? . . . [Dad] might be too upset [to discuss it]. (Female, C2DE, 26-44)

I know if I died, my Mum would give everything of me away! But my Dad would be well against it. Same religion, but my Mum's dead for it and my dad's really against it. (Female, C2DE, 16-25)

Less often, participants recognised that the family's feelings should be taken into account given that close relatives would have to live with the outcome of any decision on organ donation. There was also recognition from time to time that it might be necessary for the family of the deceased to have the final say if the deceased's wishes were not known.

I think at that point my Mum and Dad might come in and say, 'well, she might have wanted this but we don't feel very comfortable'. . . . I could understand where they were coming from as well. I do respect my parents a lot and I do think that it is such a difficult decision for them because they've got to live with it as well. (Female, ABC1, 16-25)

The perceived importance of family discussions about organ donation tended to grow during the research discussions as participants spent more time considering the subject, the role of the deceased's family, and the potential scenarios that could arise with either an opt-in or opt-out system for organ donation.

4. Motivations for, and barriers to, joining the NHS Organ Donor Register

4.1 Motivations for joining the NHS Organ Donor Register

Reflecting overall attitudes towards organ donation among this sample, those who thought that they had joined the NHS Organ Donor Register did so ultimately to help others. (Some older participants who carried a donor card were not always sure they were on the Register.)

I feel that it is important to donate organs if in my death I could save a life then that would be for me helping someone to live life to the full. (Female, C2DE, 26-44)

They realised the good transplants could do, and often stated that it was simply part of their 'nature' to be on the Register. Some also commented that there was no point in letting organs be wasted, that it was only right an individual should be a donor if they were happy to receive an organ, and that it would avoid adding to family distress at the time of their death by making their wishes clear.

It should be an easy decision because I feel like if I . . . needed a transplant then I would, like, hope that I would get one so I feel like it's an easy decision for me to say that I would definitely give my organs to someone. (Female, ABC1, 16-25)

It's to relieve [family] of making a decision at what will obviously be a difficult time. (Male, ABC1, 45-70)

Specific triggers to sign up to the Register were varied. They included: being asked about donation when giving blood; completing a DVLA form; deciding to sign up during a first aid course as a student; as a result of family health experiences; seeing information in the GP's surgery; and first thinking about it when becoming a mother.

I gave blood, and there was a question saying would you like to donate organs, that's the only way I knew about it. (Male, C2DE, 16-25)

When I did my driving licence [I applied]. I don't think I'd have bothered otherwise although I'd always have said that I would be happy to donate my organs. I think if it wasn't so easy, you know, just tick this, I probably wouldn't have bothered. (Female, ABC1, 16-25)

I just wanted to help someone else, someone who's ill. I've got a nephew, five years old with a serious heart defect, and maybe he'll need one some day, and it's no use to me when I'm dead, so I'll give it to someone else. As soon as I was 18, I filled in the form and told my family, and it's been in my purse since then. (Female, ABC1, 26-44)

I had a friend who was waiting for a kidney transplant which prompted me to be a donor. (Female, ABC1, 45-70)

4.2 Barriers to joining the NHS Organ Donor Register

The reasons for not signing up to the Register given by these participants were divided between passive barriers, which were more prevalent, and those where people had taken more of a conscious decision not to be on the Register.

Those expressing passive barriers to joining explained how it was not a top-of-mind subject and that they lived busy lives with other, more pressing and immediate things to consider. Some acknowledged that they had never thought about joining the Register before, while others rationalised that they would not know how to sign up and that it would probably be a 'hassle' to do so. The perceived absence of regular interventions or calls to join the Register was also thought to compound the passive obstacles raised.

It's like, oh yeah, I'd like to do that, but then you just forget. (Male, ABC1, 26-44)

Well for me I just, it's really lazy and not being bothered because I've informed the family of my wishes. (Male, ABC1, 45-70)

You know unless you're in the circumstance where something happens in your family, you don't tend to think of it do you? (Female, 26-44, C2DE)

For some participants, however, cultural and religious issues caused complications when considering whether or not to opt in to being a donor. Some older participants across different cultures referred to a desire to return to the earth whole either because of a religious belief or custom. A handful also expressed a belief in the afterlife and a concern over how organ donation might in some way affect it. The views of other family members based on culture or religion posed a further issue for some, often younger participants.

It's not so easy, it depends what my [Muslim] family wants to do with me. (Male, 26-44, C2DE)

I don't know whether it's just me but I actually think if you go to the other world you should go with all your parts. (Female, Christian, ABC1, 45-70)

My one family member in particular is strongly opposed to organ donation because of her Christian faith; she believes that what God has given when people were born depending on health they should die with all their organs in tact. (Female, 16-25, ABC1)

Examples included one Muslim participant who described how a sibling found out that this individual carried a donor card. The sibling mentioned the card to

the parents who were distressed at the news because of their religious beliefs. In another case, a participant explained how the individual's partner had strongly stated that they did not want the participant to be on the Register, which the participant believed was a cultural issue.

I used to carry a card but then found out my [Muslim] family were very against it. It upset a lot of members of my family so for that reason I said, fine. . . . To keep the family happy and to avoid any conflict or upsetting them further. (Male, 26-44, C2DE)

[My husband] said 'if you die, no-one's going to touch you, as you are'. There's something in the culture as well, a lot of Black Caribbean people are like that, they just don't like the idea of bits of the body, especially the older generation, being used. (Female, 26-44, C2DE)

A final cultural barrier centred on a strong sense of 'bad luck' should death be discussed or considered and that it would be tempting fate to join the Register.

The cultural and religious barriers to agreeing to organ donation meant that a small number of participants were left with dilemmas because they wanted to join the Register. In the first example below, a Muslim participant who wanted to be able to donate felt that he would need to discuss the issue with a scholar but that he might ask for advice from more than one scholar should he be informed in the first instance that he could not be a donor.

I'd seek advice from another scholar. I want to support this initiative so I have to seek more than one advice. One may not be well educated even in religious issues. I opt for a second opinion. (Male, ABC1, 45-70)

I think maybe if I knew more about it and I was more educated in everything else, maybe a little older, I could decide. It's still my body at the end of the day so I could donate but it is really against my religion so I don't think I would go against it. (Male, ABC1, 16-25)

5. Discussing organ donation with family

Across this qualitative sample, participants tended not to have discussed with family their wishes regarding organ donation. The importance of family discussions, at least in the early parts of the research groups, had not been considered. This mindset included some of those who carried a donor card and even one or two participants who had family or friends with experience of transplants.

I have also lost a relative in the past but neither I nor my family had ever thought of donating an organ. I think this was because of the feeling of loss and grief and not many adverts about. (Male, ABC1, 26-44)

[A friend] was near to death at one stage and she was on dialysis and everything – but not [discussed] about myself and my wishes; so I need to really sit and talk to [family] about it, don't I? (Female, C2DE, 26-44)

The general consensus was that it was not a top-of-mind subject and that it could also be a 'difficult' topic to casually touch upon. Some wondered whether there was ever an appropriate time to have such a 'morbid' and 'taboo' conversation, especially when facing religious or cultural influences, and when realising that a parent or partner was strongly opposed to opting to become a donor.

It's not a subject that comes up every day and you think about. (Male, ABC1, 16-25)

I've just never really got round to it but after today I will have a chat to [my sons]. Let them know my wishes and what I want and chat with them just in case anything should happen to them and find out their wishes because I wouldn't want to give their parts of the body if they didn't want it. (Male, ABC1, 45-70)

No [not discussed] . . . Maybe superstitious, thinking if it happens it happens, . . . Chinese people say if you talk about this death then you'll be [pause] . . . these things are changing but yeah [this occurs among older people]. (Female, C2DE, 26-44)

Some also expressed the view that making the decision on whether or not be a donor was a personal, individual choice and did not need to be discussed with family.

I've never spoken to my family about it. . . . I think it's my decision. If I want to do it I should be able to do it. (Male, ABC1, 45-70)

No, not discussed with the family. It's something personal. (Female, C2DE, 45-70)

Those who had discussed organ donation with family had done so for a number of reasons which included:

- A lifestyle change – reaching 60 years of age and deciding to plan ahead which incorporated mentioning the individual's organ donation wishes to family members
- Completing a driving licence application form at home and being prompted by the organ donor question on the form to raise the topic with family who were in the room (a number of younger participants also described how they had discussed with friends at school the option of donating corneas as some could not bring themselves to agree to donate this tissue)

Well, me and all my friends talked about it because loads of my friends didn't want to give their eyes, like they were really funny. . . . But it's weird because they do actually put it as a separate question. (Female, ABC1, 16-25)

- Having experienced serious ill-health or bereavement in the family

I've got to be honest what prompted me was the fact that my father, . . . he was an ex-miner but he was fit as a fiddle and then ten o'clock in the morning he phoned the ambulance, rushed him in, two hours later he was dead. And that's why I discussed [organ donation] with my brothers because it could happen that way and just go, like. (Male, ABC1, 45-70)

- Simply being an organised individual and wanting to minimise family distress when the individual died, or having parents who were comfortable and open with discussing the subject

I'm willing to donate [and the family knows]. I'm all for helping people, really. We're quite open as to what we want. They'll know if I want to be cremated or whatever, very organised because it's a hard decision for your family to take, 'oh she didn't say', so I've stated categorically what I want. Accidents can happen. (Female, C2DE, 26-44)

My Dad [is on the Register and] calls himself a mobile organ donor. He's a biker, so I'm sure he goes too fast! (Male, C2DE, 16-25)

- Having seen a TV programme which involved organ donation
- Having heard about the opt-out proposal and discussing it further with family

Attempts to bring up the conversation, however, were not always positive because other family members did not want to discuss the matter for the reasons already described in this report.

When I discuss it with people that are close to me they go to me 'don't talk about death; God, you're not going to die tomorrow'. (Female, ABC1, 45-70)

Having discussed it with my brothers, my one brother's not very happy because you know he's of an opinion that you should go in one piece. Well I said, 'why'? (Male, ABC1, 45-70)

Some participants commented that taking part in this research had stimulated constructive conversations with family and friends, for example finding that all shared the same positive view on organ donation and that none had registered.

Before [being asked to take part in the research], I hadn't discussed with friends or family. After talking to them, the interesting thing was nobody was against it, my family, my husband or friends, yet none had actually registered. It was something they'd thought about but never got round to it. (Female, C2DE, 45-70)

6. Levels of awareness and understanding of the organ donor opt-out proposal

6.1 Finding out about the opt-out proposal

In general, those taking part in the discussions tended to be unaware of the proposal. (Level of awareness of the proposal did not form part of the selection process for the research.) Older people in the sample (aged 45+) were more likely to be aware of the proposal although there was a scattering of awareness among younger people in the sample.

*I don't read newspapers and watch grown-up TV, I'm too busy.
(Female, C2DE, 26-44)*

There has been a consultation; I think it's just finished. (Female, C2DE, 45-70)

In a couple of cases, participants were annoyed that they had not heard about the opt-out proposal and therefore assumed that it was a done deal.

*This is why I'm shocked nothing's really been said. I think the decision's been made to be honest with you – I think they've already got the Register set up with everybody's name on it, you know you're just bringing this to light now just to make people aware. . . You're just listening to us now to give them our views, but it don't mean nothing to them really I don't think. I think the decision's already been made, I do.
(Female, C2DE, 26-44)*

Those who were aware of the proposal prior to taking part in the research had encountered information in the local press (e.g. Western Mail), on TV and radio news, and via word of mouth, for example chatting on the bus. A small number of participants recalled comment in the media from the Church in Wales which had occurred shortly before the research took place.

[The Archbishop of Wales] was giving his personal views, not the view of the Church. (Male, C2DE, 45-70)

*It's such a topical issue and there's been lots of press recently about it, especially from the Church in Wales as well where you know they're obviously vehemently against the whole idea of an opt out system, and that's why I think it's particularly controversial. It's not necessarily a bad thing, I just think it is everyone seems to have an opinion about it.
(Female, ABC1, 16-25)*

6.2 Spontaneous understanding of the opt-out proposal

Understanding of the opt-out system among those already aware of the proposed change was limited. Little thought had been given to how it would work in practice other than if an individual had not opted out, that person's

organs would be available for transplant. There was clearly a lack of knowledge of the detail of the proposal and some misunderstandings existed about how the system would work.

The terms 'presumed' or 'assumed' consent were used to describe it from time to time, and some acknowledged that the change would be aimed at those people who were too busy to get around to opting in to organ donation. Some felt that the proposal sounded straightforward and 'simple' with no room for ambiguity which indicated that the 'soft' opt-out element to the proposal had not been noted, for example describing it as 'legally binding', 'compulsory', and a system where the family could not 'dispute it' thus removing the need to discuss it.

If you ask people to sign the forms to donate they might be busy, put it off, they may want to give the organs when they pass away but if they're busy they put it off. (Female, C2DE, 26-44)

If you don't decide to opt out of the system, you're in it. It makes it easy for everyone. (Female, C2DE, 45-70)

Normally families don't talk about death. If it's legally, then no family member can refuse organ donation and it means you have a lot more organs available for people needing it. (Male, C2DE, 26-44)

Well, [I'm aware] that you're automatically going to be on there and it's up to you to opt out. (Female, C2DE, 26-44)

I've just heard that you've got to opt out if you don't want to donate, instead of the other way around. (Male, ABC1, 26-44)

As with the current opt-in system, therefore, participants who were aware of the proposal were not familiar with the envisaged role of the family.

I did see something on the news. Was it the Welsh Assembly were on about making it compulsory or something like that? I can't remember. I didn't really take much note of it. Isn't it something to do with opting out and everyone's in and you have to say you don't want to – something like that! (Female, ABC1, 26-44)

Occasionally, participants referred to how the proposal meant that, in their minds, the element of choice was removed from the individual; these participants maintained this argument throughout the discussion.

The only I thing I can say anything about really is I don't agree with this compulsory bit. . . . I believe we should be, you know, allowed to give but not just take it because you're there. (Male, ABC1, 45-70)

The lack of clarity around the opt-out proposal was highlighted by how some participants believed that there would be a new register consisting of the

entire adult population, from which people would have to opt out; and a small number assumed that it would apply to the UK, rather than Wales.

I think it's the UK, that their name is automatically registered. . . .And I think the family can't dispute it or something; that was in the newspaper. Which I remember thinking, what? Which is quite interesting for the opt-out system because it's not exactly informed consent, it's assumed consent. (Female, ABC1, 16-25)

On occasion, participants demonstrated a more detailed understanding of the opt-out proposal for organ donation: a couple of participants remarked how this system was working successfully in other countries (e.g. in Sweden, having reportedly seen the subject covered on TV), while another had read how Spain's improvements in increasing the number of donors arose from an increase in road accidents in the country. In a final example of a more detailed comprehension of the topic, one participant stated that the opt-out process would never be compulsory, that family would be involved in decision-making, and that it was aimed at 'catching fence-sitters' who wanted to donate but had not got around to registering or expressing this wish.

There's no compulsory, this is down to deemed consent isn't it and they're trying to just . . . catch the fence-sitters really. (Male, ABC1, 45-70)

7. Reactions to the organ donor opt-out proposal

7.1 Introducing the subject to participants

Once participants had discussed their awareness and understanding of the organ donor opt-out proposal, they were presented with the following summary description of the proposal in order to explore more informed reactions to the proposal.

Your organs will be available for transplantation when you die unless you have registered to opt out. Your family will be involved in the discussion at the time of death.

Having discussed the proposal based on this description, a range of positive and less positive statements relating to the opt-out system were posed to participants for further reaction, together with more detail on aspects of the proposal. The statements and aspects tested are provided below.

Statements

- *The opt-out system is likely to result in more lives being saved – on average in Wales one person per week dies waiting for a transplant*
- *Opt-out systems in other European countries have resulted in an organ donation increase of around 25-30% (e.g. Spain)*
- *Most people support organ donation and many more would be willing to donate than are on the Organ Donor Register (31% of population of Wales are on the Register)*
- *The opt-out system may encourage more families to discuss organ donation preferences and wishes*
- *After death relatives will be involved in the decision making process around donation*
- *This means that people automatically lose rights over their own bodies*
- *The positive action of organ donation as a gift is taken away from people*
- *How can people be sure that the NHS's information on people's choices about organ donation is up to date and accurate?*
- *The opt-out system might change the way people who are very ill are cared for*
- *The opt-out system may cost a lot of money to introduce that could be better spent elsewhere in the NHS*

Detail on aspects of the opt-out proposal

- *Only people aged 18 or over who both live and die in Wales would be included under the system*
- *People would be able to change their minds about opting out*

- *People would still be able to choose which of their organs they wanted to donate*

In this section, the report distinguishes between points made spontaneously by participants, and where the point was prompted in the discussion using the statements above. The order in which the statements were introduced in the discussions varied.

It should be noted that participants sometimes confused the existing system with the opt-out proposal, for example stating that it should be 'legally binding if I've signed up' when supporting the opt-out system and discussing the role of family. It was not always easy for them to grasp how the two systems worked, and contradictions in views occurred from time to time.

7.2 Increasing organ availability for transplant, saving lives

Across the discussions, participants regularly highlighted spontaneously the expected increase in organ availability as a convincing reason for changing to an opt-out system. It was envisaged that this would lead to shorter waiting lists and, ultimately, more lives saved. Similarly, when prompted with the statement: 'The opt-out system is likely to result in more lives being saved – on average in Wales one person per week dies waiting for a transplant', participants generally considered it a strong argument for the change and assumed it was the whole point of why the Welsh Government wanted the opt-out approach.

Well, basically it's giving more people the chance of living isn't it because obviously the numbers are going to treble and, you know, that's the whole reason why they're probably going to do it because they need organs don't they, desperately. There are so many people on the waiting list. (Female, C2DE, 26-44)

I'm in favour of the opt-out, because there are more organs to be had then. (Female, ABC1, 26-44)

People who are suffering and on the waiting list. The impact. More lives saved. (Male, 26-44, C2DE)

There's the number of organs that will be available will be dramatically increased. (Female, 26-44, C2DE)

Well that is a good argument, it's getting to the core of the matter, you're talking about lives even though a person could reject an organ they could also save quite a few lives, you'd have more matches. (Female, 26-44, C2DE)

Personally, I think it's a great thing; it makes sense, especially in a world with people on waiting lists. (Male, 26-44, C2DE)

On hearing that, on average, one person per week dies in Wales waiting for a transplant, some participants reacted emotionally, for example describing it as 'heart-breaking' and 'sad'. Very occasionally, however, this statement prompted less positive reactions: the figure was not as much as expected; and it was felt that the aim was to give people a 'guilt trip'.

*F: Is that a fact [one person a week dies on average in Wales]? Wow!
M: It's a shame really isn't it? It's sad really. (ABC1, 26-44)*

Participants were also presented with the statement that 'Opt-out systems in other European countries have resulted in an organ donation increase of around 25-30 per cent (e.g. Spain)'. In broad terms, participants found this figure reasonably persuasive. For some, it demonstrated that the opt-out system works and that more lives will be saved. It also highlighted on occasion that the system encouraged discussion among families because it appeared individuals were making the effort to opt out.

I think it looks like a good thing because it means it's obviously stimulating people to talk about it and still opt out, so it's a good thing. (Female, ABC1, 16-25)

F: it doesn't surprise me.

M: I'm convinced because with presumed consent you'd have a lot more people.

F: It's realistic to think that. It would increase the number of organs. (C2DE, 26-44)

Less often, participants were not sure how emphatic the figure of 25 – 30 per cent was. It did not sound like a large increase to a few participants and it was meaningless to one or two others because of the absence of any context. Very occasionally, it was argued that an increase in road accidents in Spain was the real source of its improved organ donation levels, and that the opt-out system had not worked so well in other countries where it had been implemented.

7.3 Making it easier to become a donor

A second common, positive theme to emerge across the groups was that an opt-out system would make it simpler for those in favour of organ donation, but who had not joined the Organ Donor Register or expressed a wish to donate, to become donors. Some participants conceded that they and sometimes their friends had not taken this step because they were too busy, did not know how to register, assumed it would be a 'hassle' to do, or were too lazy. This view was slightly more prevalent among male participants. These participants believed that the choice was still there, and expected that those who were against organ donation would make the effort to opt out.

If you don't get many people donating at the moment, maybe this is a better way of doing it. Like your family [another participant in the

group], seven have said they're willing, but only one has registered, the other seven are in limbo. (Male, ABC1, 16-25)

If you turned that on its head, and say that people who opt out, if they are genuinely against giving their organs, they'll go to the effort to say 'I don't want to'. With the need for organs at the moment, it's pathetic we're behaving the way we are. It should be an opt-out system. (Male, ABC1, 26-44)

With so many people on the waiting list for organ donation, it seems like it makes more sense to opt out, because as you said, a lot of people can't be bothered to opt in, it's too much hassle, or they forget, but if you really don't want to do it, you have that choice. (Male, C2DE, 16-25)

I probably would be on the organ donor list but I've just never really been prompted to be on the organ donor list. So at the moment it requires effort on my part to go to the website and sign up and all that kind of stuff. (Male, ABC1, 16-25)

Basically if it comes into action, everyone is a donor unless you have strong views to opt out, because some people don't want to opt in because it's too much hassle. . . . If you had that such strong views against it you would opt out. (Female, C2DE, 16-25)

The notion that 'Most people support organ donation and many more would be willing to donate than are on the Organ Donor Register' was therefore not disputed by participants overall and supported the spontaneously voiced argument described above. When given the statistic that 31 per cent of population of Wales are on the Register, some felt that this was an unacceptably low figure and that it demonstrated the current opt-in approach was not working effectively.

We're lazy, it's not there in front of you. (Female, ABC1, 26-44)

That's a shocking number, 69 per cent not on the Register. (Male, C2DE, 16-25)

On seeing this figure, however, participants on occasion wondered why more could not be done to promote the existing system more effectively and encourage engagement, before attempting such a significant change to the process. A number of participants in the sample gave blood and felt that the perceived absence of any communication around organ donation compared unfavourably with the regular communication they encountered on blood donation. Also, in a small number of cases, participants were surprised by how high, rather than how low, the opt-in rate was in Wales.

[Communication on blood donation] works really well and I think they should at least try it with the organ donation system before, you know, implementing something this big because this is almost a top-down

approach as opposed to getting people more engaged. (Female, ABC1, 16-25)

But if you put the same effort into the opt-in, if you had a big campaign, and all their efforts put into a campaign, I think, I'd hope they'd see the same results. (Male, C2DE, 16-25)

I didn't expect it to be that high [31% on the Register in Wales]. (Female, 45-70)

7.4 The potential to encourage more family discussion on organ donation

As the discussions progressed, participants tended to become more aware of the importance of discussing their wishes regarding organ donation with family members, as well as finding out the wishes of others in the family. Some believed that the move to an opt-out system would essentially 'force' people to consider their own wishes and have those conversations with family.

If you make your wishes plain before you die and then you die that's your wish. But if you die unexpectedly and your organs are available I think it should be down to the family then. (Female, ABC1, 45-70)

I think with the opt-out system you're forced to talk about it. (Male, ABC1, 16-25)

In isolated cases, however, some envisaged that there would be no need to have such a discussion with family because it was assumed that the ultimate decision would lie with the deceased.

The introduction of the topic of encouraging family discussions during the groups was generally met with agreement, reinforcing the view that people would need to make a decision on their preferences concerning organ donation. There was also occasional reference to the importance of ensuring family members were not left in an even more distressing situation where the wishes of the deceased were unknown. One BME participant thought that the opt-out system might act as a catalyst for discussions on the subject within Muslim communities.

The change is a step forward and a chance for more people [in the Muslim community] to be involved so this is the advantage of the change. (Male, ABC1, 45-70)

Families will sit up and talk then. (Male, ABC1, 45-70)

I think it will always be talked about when this is brought in because it wasn't an issue before, you either put yourself on it or you didn't, it's neither here nor there. But now you've got to decide, you know,

whether you're on it or not, for everybody – so it's always going to be discussed I think for years and years to come. (Female, C2DE, 26-44)

It needs to be an open discussion that all families need to do. If you have an open discussion everyone will know where they stand, and the decision is there. (Male, ABC1, 26-44)

A number of additional points emerged when this subject was raised. Some participants were uncertain how exactly the opt-out would lead to more discussions among family and close relatives and that it still relied upon members of the public knowing about the system in the first place. Some therefore assumed that these family conversations would be as a result of the anticipated communication campaign accompanying the legislation change rather than specific elements of the opt-out system.

The publicity around the opt-out system will make people talk about it. There'll be TV campaigns or whatever getting people to talk about it. (Female, ABC1, 26-44)

It might encourage more people but I'm not sure how much, I wouldn't put it at the top of the list [of arguments for moving to an opt-out system]. (Female, C2DE, 26-44)

Furthermore, a handful maintained that death and organ donation were still not topics to bring up with the family, for the kinds of reason described in sections 4.2 and 5 of this report.

I think it depends on the individual. Some will plan for their death. (Male, C2DE, 45-70)

7.5 Concerns over the role of the family

Most of the negative comments voiced by participants in relation to the opt-out proposal concerned the role of the family at the point of death, rather than any specific issue associated with the concept of opting out. As with the current system, participants were frequently dismayed that a family member or close relative could object to the deceased's personal choice on organ donation. One or two likened it to attempting to change a family member's will.

It's nothing to do with the family. I know it's hard for them but you have made that decision. (Female, ABC1, 45-70)

I don't think that families should have the right to dispute the dead person's own wishes. (Male, ABC1, 16-25)

Why does the family need to be involved? It's your body, your choice. . . . It also puts a lot of pressure on your family. (Female, C2DE, 16-25)

It hasn't got anything to do with the family. If you include the family, it causes more trouble in the end. If I've signed and agreed to it, it's legally binding. (Male, ABC1, 26-44)

Family involvement in the final decision led some to wonder what the point was, therefore, of making any choice on organ donation at all and that it seemed to 'defeat the object' of increasing the number of donors. With this in mind, some envisaged that it would be 'so easy to say no' to donation because of the emotional distress at the time, even if they knew the deceased's wishes. Also, it was often not clear to participants why it was necessary to involve the family in a discussion on organ donation.

If it's the choice of the family in the end, what's the point of the donor card? (Male, ABC1, 26-44)

It's also pointless in having your own opinion if they can change it. (Female, C2DE, 16-25)

Participants identified a number of further potential issues with the family's involvement: it would over-complicate the system and render it harder to understand; it might add to the pain of the deceased's family because they would need to be involved in a difficult decision at an emotional time; some families would not wish to discuss organ donation at any time, and especially on the death of a loved one; and there would be some family members who would object to organ donation regardless of the deceased's wishes, for example the deceased's side of the family, from a cultural perspective.

I need time to think about it because there's a lot of [Chinese] culture. Have I got the right to say on behalf of my husband what his wish is? I don't think so. . . . If I had to make the decision I don't know what my husband really thinks, what he wants us to do. If I did it, I don't know what his side of the family will say when they find out he hasn't got a heart! Then they might blame me for the rest of my life. No, I wouldn't [want that]. (Female, C2DE, 26-44)

Say I gave the presumed consent, well my Dad's not for it really so if the family can get involved and my Dad will think, oh, my little girl I don't want that to happen to her, just leave her be, it's not my last wishes is it? (Female, C2DE, 26-44)

The description given to participants was that 'Your family will be involved in the discussion at the time of death'. Some found the use of the word 'involved' ambiguous: how much of a say would family have, and would clinicians listen to them in any case?

It implies that they might just phone up and say 'we're going to take your guy's organs'. You know, 'involved' doesn't necessarily mean they're actually going to listen; it just means that they must just inform them. (Female, ABC1, 16-25)

What do you mean by 'involved'? Do you mean they will have veto over it or they'll just be involved in being told what's going to be happening? Being informed and having the last word is not necessarily the same thing. (Male, ABC1, 45-70)

Occasionally, the point was made that the opt-out system would be even less clear than the opt-in system for the deceased's family because they would not necessarily know the deceased's wishes. The opt-in approach, it was felt, might be more 'decisive' in this respect because the individual could express their choice through the Organ Donor Register.

I'm somewhat confused at the moment. This opt-in opt-out business . . . after thinking about the fact that family can change your wishes and influence the decision of doctors, maybe it would be better with the opt-in system. There's no doubt if you have a donor card under the current system. (Male, C2DE, 45-70)

Strength of opinion, therefore, lay against allowing the family to have a final say on whether or not the deceased became a donor. However, it was apparent that the subtleties of what would happen in practice were difficult to grasp, and that participants had not given a great deal of thought to the potential consequences for the deceased's family.

After further thought on this subject, some participants acknowledged that family discussions were therefore even more important given family involvement at the point of death, and that the individual would need to trust that family would respect their wishes. A small number of participants ultimately accepted that the family should be involved. For example, if the family did not know the deceased's wishes, they might still want to have a say on organ donation; a 'hard' opt-out system might add to further distress on the deceased's death; and family involvement would be necessary in recognition of how strongly certain family members felt on the subject of donation (for example one participant's Muslim family).

That's why I think it should be discussed with the family beforehand. That's all I can say to that. (Female, C2DE, 26-44)

But there may be cases where the family that are left, for whatever reason may find it so distressing that they just couldn't live with that. And I think the rights of the survivors have to be considered. (Male, ABC1, 45-70)

I think if you don't make, if you don't say before you die then that's what you want, it should be up to the relatives. (Female, ABC1, 45-70)

The example below sums up one participant's confused position, having discussed the proposal in detail, and a feeling that whether or not to donate was best left to the deceased's family to decide.

I think I'm more confused [now]. I think the best thing is ask your relatives' permission because they're the ones who have to live afterwards. . . . Once you're gone, you're gone. It's the living that's got to make the decision, now I'm thinking about it. (Female, C2DE, 70+)

Other than the issues surrounding family involvement, no other single concern with the opt-out proposal was prevalent across the groups. The report now focuses on the remaining negative opinions which emerged.

7.6 Losing automatic rights to your own body

From time to time, participants spontaneously referred to how they were uncomfortable with the idea of presumed consent, rather than being given the choice to opt in on what was regarded by some as a 'big decision'. There were references to 'Government control', a 'nanny state', and to an approach which felt 'authoritarian' and 'not very democratic'. The small number of participants who voiced this concern maintained this argument throughout the discussion.

I'm pro donation, but on the idea that everybody has opted in, compulsory from birth, and you have to opt out, and that makes me really annoyed. I find it really authoritarian, like the nanny state, it's a personal choice to give organs. It's a personal thing, it's your organs, your body, and I think the presumption that you're opted in from birth, it's like your body is not your own, it's part of the state's. That really puts my guard up. (Male, C2DE, 16-25)

Because informed consent implies that you actually have all the facts and you've made the decision, you're old enough, you know what it involves. But assumed consent is just, well, go for it, have my body, which is not quite . . . I don't know, doesn't sit very well with me at all. (Female A, ABC1, 16-25)

I've changed my mind a little – I was for the opt-out register coming here, but now I'm thinking opting in is more of a choice for me now. (Male, ABC1, 26-44)

There were occasional concerns that organs would be removed from people who did not wish to have them removed (for example for religious reasons) and that the system could also be 'open to abuse' with doctors removing organs without any family involvement.

When the topic was prompted using the statement, 'This means that people automatically lose rights over their own bodies', the argument received little further support. Participants tended to feel that the option to make a choice was still available, and that those feeling strongly enough about it would just need to make the effort to opt out. It was also felt that it would be particularly important to educate the general public on the value of family discussions on organ donation preferences, and on how to opt out of organ donation.

How can you lose rights if you've got the option to sign out? If the option wasn't there . . . then you lose your right but because there's an opt-out section I don't see how you can lose any rights. (Female, C2DE, 26-44)

It's not really [an argument] because they still have the option to opt out. (Male, ABC1, 26-44)

The thing is, if they were educated properly and it was discussed in places and families then they wouldn't lose the right over their own bodies. (Male, ABC1, 45-70)

Very occasionally, however, participants reiterated the point that it would be more appropriate to focus efforts on encouraging members of the public to join the current register so that it was based on informed consent and it was clear that those on the Register wished to be donors.

The idea of placing everyone on the system is against the individual's rights. If they want more to register, they must spend more money to give people information, and then you will only have people who want to be on the Register on it. This is much easier. (Female, C2DE, 45-70)

7.7 The possible impact on care received in hospital

A small number of participants spontaneously raised this concern in relation to a move to an opt-out system for organ donation. They wondered whether doctors would make as much effort to save a patient if they knew the patient had not opted out. Alternatively, as a couple of participants pointed out, doctors might focus on preserving the condition of the organs (i.e. the patient being kept artificially live) rather than the appropriate care for the individual.

You know someone could be in a car crash and they could be on a life support machine and they say to you there really is no hope for you. But I have actually seen people come back off these life support machines so it makes me think twice then, is he really dead or is he not really dead? (Male, ABC1, 45-70)

I watch a lot of medical programmes and there was one in America where the doctor deliberately kept the patient alive for four days because they couldn't get the person who wanted an organ there. (Male, ABC1, 45-70)

One participant felt very strongly about this issue and stated that she would opt out if the system changed and rely on family to inform doctors of her wishes once deceased. It emerged that this concern was not unique to the opt-out proposal as the participant had taken a conscious decision not to opt in to the current system, for the same reason.

I think it will have an effect personally; if I'm very ill the chances are they want my organs. (Female, C2DE, 26-44)

On balance, participants tended to doubt that a move to an opt-out system would affect care for the critically ill in reality when prompted with the issue. They countered that doctors were bound by a duty of care and were only interested in saving lives.

If you're a doctor or nurse you're going to try and save lives. (Female, C2DE, 26-44)

The NHS, the doctors they are doing their job and whether you are opt out or not, still you will receive the same treatment. (Male, C2DE, 45-70)

I don't think they'd play God. Doctor's are there to save lives. (Male, ABC1, 26-44)

No, the professionals should be well educated. I still believe they would do everything they could. (Female, C2DE, 26-44)

However, the potential issue did sow occasional seeds of doubt among participants and media stories on poor care were mentioned. It was also suggested that an increase in the number potential donors might lead to an increase in activity where the quality of care was affected and that, according to one participant, it already sometimes happened with the way in which older people were cared for in hospitals.

The concern I have is, is it open to abuse? Because you hear all these horror stories, Dr Death stories where someone is ill, on the verge of death and you think, how well is that doc going to perform to sustain that person's life, knowing this person's organ matches perfectly? (Male, C2DE, 26-44)

Would they worry about you so much if you was dying anyway? I get scared of that. You know if you was ill would they try that much harder to save you knowing your organs were going to go to somebody else – you haven't got long left anyway so they're not going to fight too hard for you because your organs. (Female, C2DE, 26-44)

It might be happening now but I'd be worried if the opt out system came into effect then it might be happening even more. (Female, ABC1, 16-25)

They do it with the elderly now, they don't care for them as much as the young. (Female, C2DE, 16-25)

7.8 Additional concerns with the opt-out proposal

The remaining issues given below attracted isolated mentions across the groups:

- *Potential cost of moving to an opt-out system:* believing that promoting the current system more effectively could yield similar results, and be less expensive.

Why are we entertaining the idea of this opting-out thing? It's like all this effort, when it could be done for the opt-in, and all this money to do the whole databases. Opting out is a stupid thing to do. There's a system that works, OK not effectively, but none of us knew [about the current system] before we started talking about it really, so put the effort into the opting in. (Male, C2DE, 16-25)

This subject was also prompted with participants and, in the main, they believed that the end benefit of increasing the number of organs available – and saving lives - outweighed any costs associated with the change in legislation. The anticipated long-term savings on care provision for those waiting for a donor was also highlighted. Furthermore, some could not envisage how the legislation change would prove to be especially costly.

At the end of the day, there is no cost on life. (Male, ABC1, 26-44)

What would you better spend it on in the NHS? More organs, more lives saved. (Female, ABC1, 16-25)

But there would be larger savings made in chronic care at the moment if all this became available. So you've got to balance that up. (Male, ABC1, 45-70)

Would it cost a lot of money? It's a register isn't it, a computer system. Excel files. I don't know but I wouldn't expect it. (Female, C2DE, 26-44)

- *Opt-out register data accuracy:* whether or not NHS records of who had opted out would be accurate and up to date. When prompted, participants tended to assume that there would be a number of opportunities for people to review or update their choice if necessary, for example via their GP, during hospital visits, and via their dentist. Only very occasionally did participants describe negative experiences with the NHS on this topic, such as their 'notes' being lost between hospitals. NHS IT programme issues were also mentioned in this respect.

Any time I've been to hospital, they know all the hospitals in the past, where I've been and what treatment I've had. (Male, ABC1, 45-70)

The suggestion was made that it would be useful to receive a confirmation letter if an individual chose to opt out, as a reassurance that their wish had been recorded.

I know it takes time and money but it is a big decision so some sort of, you know, confirmation. (Female, ABC1, 16-25)

- *Commercialisation of organs*: a concern among a couple of BME participants that a surplus of organs might lead to the selling of organs

Could they sell some of the excess organs to overseas? Would they exchange? What they've got here is that only for the UK user? . . . You hear in the news organs can be sold in other countries, I start to worry about a lot of things, I don't believe people watch out and care enough. In China they sell organs so it's a question of have you got money or not. (Female, C2DE, 26-44)

- *Imposing a moral obligation to opt out*: giving people the impression that in order to receive an organ they should be prepared to be a donor themselves, when they might have a strong reason for not donating, such as a faith related reason. It was felt that this might result in a sense of 'stigma' for those who did opt out.

I think many people might consider the fact that there's some sort of moral obligation, if you want to receive you ought to give. And I don't see that people ought to feel compelled in that way. There are many people perhaps would need a donation but for some other reasons either religious or personal reasons might not want to donate. (Male, ABC1, 45-70)

The concept that 'The positive action of organ donation as a gift is taken away from people' did not arise spontaneously among participants. When prompted, most participants disagreed with this argument. They believed that the choice could still be made and organs could still be donated, and felt that 'donation as a gift' sounded as though the individual was seeking thanks of some sort by donating.

I don't really think that matters because I mean whether they take it or I give it they're still using the organs and I'm happy enough on that. (Male, ABC1, 45-70)

So receive praise for opting in, then, is it? (Female, ABC1, 26-44)

It's kind of like you're up yourself a bit, 'I'm a donor, I'm better than you'. (Male, C2DE, 16-25)

If you're just doing it to get self gratification then [that] defeats the object doesn't it? (Male, ABC1, 16-25)

In isolated cases, the view was supported in that an individual wishing to be a donor loses the opportunity of feeling that they have done something positive.

You feel good giving your organs as a gift, yes. So it will be a negative thing to take that away from people. (Male, C2DE, 45-70)

7.9 Detail on aspects of the opt-out proposal

Participants were asked to comment on the following three statements which described aspects of how the opt-out proposal would work.

Only people aged 18 or over who both live and die in Wales would be included under the system

The general consensus was that the opt-out system should only apply to those aged 18 or over who live permanently in Wales. In rare instances, participants felt that minors should also be automatically covered by the legislation because they agreed with donation but doubted they would be able to agree when faced with a child's death.

It's brilliant because if anything happened to my child there's no way I'd be in a state to be able to make that decision anyway because I would just be completely, like a vegetable. So if that choice is already made for me . . . (Female, C2DE, 26-44)

Students from outside Wales, it was felt, should not be affected by the change in legislation because Wales was not considered their permanent residence.

[Students] don't enjoy the benefits of being subsidised by the Assembly for their tuition fees because they are resident elsewhere. And I think there are resident where their family is (Male, ABC1, 45-70)

Complications arose for some participants when they considered what would happen if they died outside Wales. Some acknowledged that the legislation could only apply to those who died in Wales but a handful of participants expected it to apply to the individual wherever the person was, and also that 'Welsh' organs should be used for 'Welsh people'.

No, that doesn't make sense. What happens if I'm run over in England, in Bristol? So it wouldn't apply? That's ridiculous! (Female, C2DE, 26-44)

That's too complicated. If someone dies while on holiday in Bristol, they can take them to Cardiff! (Female, ABC1, 45-70)

Further queries and issues on this subject included:

- A participant in North Wales who wanted to know what the implications were, given the nearest hospital was over the border in England
- A BME participant querying whether nationality would affect eligibility for the legislation change

I live in Wales but I'm not Welsh, or English, or British; what does that mean for me then? (Female, ABC1, 16-25)

For those moving to settle in Wales, participants spontaneously suggested that they could be informed of the opt-out system when registering with their GP; and that they should be eligible from that point onwards.

[They should be eligible] as soon as they register with a doctor. And when they go to register, you've got to register with your doctor, and they go register and that's one of the questions on that registration form. (Female, C2DE, 26-44)

People would be able to change their minds about opting out, and would still be able to choose which of their organs they wanted to donate

Participants agreed that the ability to change one's mind, and to choose which organs they wished to donate were both important components to maintain with the system. Some commented how they disliked the idea of donating corneas and had chosen not to donate this tissue.

Well I think it's just the thought of people going round with my eyes, it sounds stupid I know, but that's what's in my head. (Female, C2DE, 26-44)

Both these points were raised spontaneously as queries. The remaining questions participants raised which were specific to the opt-out proposal are described below. It is worth noting that participants also mentioned other queries which related to organ donation in general, rather than the proposed legislation change (for example what exactly happens at the point of death).

7.10 Queries about the opt-out proposal

Participants asked the following questions about the organ donation opt-out proposal:

- *What were the implications for members of the public who might not have the mental capacity to decide whether or not to opt out? Some participants felt that this might be a negative aspect of the proposal because not everyone with a mental health illness, or who was vulnerable, had the support of family to help with decision-making. It was assumed that a discussion between next of kin and doctors would be necessary.*

[The opt-out system] is better for me, because it means I don't have to bother registering, but then what about the elderly, they will want to opt-out. Who's going to help them do it? And you've got people with learning difficulties; do they have the mental competency to make a decision? (Male, ABC1, 26-44)

But what about these people who want to opt out but can't, like the elderly? (Female, C2DE, 45-70)

I don't agree with it either because I think for people who have mental illness, who've got issues, disabilities, . . . If they haven't got no family

around them, how on earth are they going to manage to turn around and say they don't want that? They can't. (Female, ABC1, 16-25)

- *How would the opt-out system apply to children?* It was noted that children also required transplants but it was not always clear how they would be affected by the proposed legislation change.

What's the age limit? If something happens to a child, what happens to the organs of the child? Are they in this opting-in, opting-out? (Male, ABC1, 26-44)

- *Why were other parts of the UK not proposing a change to the opt-out system?* Prior to being prompted with the Spain example, a small number of participants wanted to know where else the opt-out system was implemented and how successful it had been. One person believed that the Welsh Government's desire to change to the opt-out system indicated that Wales was particularly short of donors.
- *How simple would it be to opt out of organ donation?* Participants thought that several different channels should be made available to those who wished to opt-out, for example via their GP or other face-to-face interactions with the NHS; online, or via text message.
- *Could the family of the deceased reverse the individual's choice to opt out?*
- *Would the opt-out system save money overall?*
- *Would people be given the choice of where their organs went, for example only to those who had not opted out?* One or two participants felt strongly that they only wanted their organs to go to those who had not opted out of the organ donation system

I wouldn't want it to go somewhere else, especially to a person who wasn't prepared to give their organs themselves. If you aren't prepared to give your organs you aren't having mine. (Female, C2DE, 26-44)

- *Has the role of the family definitely been decided?* A small number queried whether the proposed legislation had in fact set out how exactly the family would be involved.

Well, you'd hope that they'd listen to your family obviously [that wanted to opt out] but what would actually happen? Has that not been decided? (Female, ABC1, 16-25)

7.11 Putting the case for or against the opt-out proposal

Towards the end of the discussions, participants were briefly asked to argue for and against the proposed legislation change on organ donation. They generally found it easier to put the case for, rather than against, the proposal.

The key aspects they focused on in favour of the proposal were the envisaged end benefits described in section 7.2: increasing the number of organs available for transplant, shorter waiting lists and saving more lives. There were also references to stressing how individuals were still able to make a choice on organ donation, highlighting how the opt-out system might encourage more discussion, and emphasising how people would be informed and educated on the proposed legislation change.

Talk about all the positives, . . . the increase, and the amount of lives that'll be saved and the fact that it will stimulate people to talk about it a lot more. (Female, ABC1, 16-25)

It will save more lives, maybe someone close to you. (Female, C2DE, 26-44)

That you've still got like the choice of what happens. It's not just like it's going to happen, deal with it. It's like you can still choose to opt out, and then you can still choose what organs will be donated and all that. (Male, ABC1, 16-25)

Participants identified several possible information channels to ensure that the general public were made aware of the change, were it to be made law. GPs were a popular suggestion because of the appropriate setting for a conversation on organ donation, along with hospital interactions. Other suggestions included information sent with any official letters such as council tax or utility bills, benefits documentation, when first receiving a National Insurance number, with payslips from employers, and via education in schools.

Because if say every single doctor now in Wales has to say to their patients . . . the next time they see them, you know, "Do you realise you're on the Donor Register?" And you know you have a chance to opt out, then those people [will be aware]. (Female, C2DE, 26-44)

Male: Why don't doctors ask their patients if they want to donate? I've never been asked.

Female: You wouldn't feel awkward if he asked. (ABC1, 26-44)

There was less of a clear-cut argument put forward against the move to an opt-out system. Some participants suggested highlighting how it was not, in fact, an informed choice that people would make, that it did not necessarily inform loved ones of the deceased's wishes, that it relied on people having discussed organ donation with their family - and that it was effectively 'forced on you'.

I don't think someone coming to me and saying your loved one didn't opt out therefore they're a donor, that doesn't give me their wishes. So it doesn't relieve me from any decision making and that would leave me exactly the same as I would feel now. (Male, ABC1, 45-70)

There was also a view that the whole process could be challenged on the basis that there was little point in changing to an opt-out system if the family of the deceased was able to influence the final decision on organ donation.

I just think the main [argument against] would be what's the point because the family will always have the end say and it's going to stand isn't it? (Female, C2DE, 26-44)

8. Research conclusions

Awareness and understanding of the current organ donation opt-in system was limited at best which meant that non-proposal specific issues often came to the fore during opt-out proposal discussions, both as straightforward queries but also as concerns.

Awareness of, and familiarity with, the opt-out proposal was also quite low, especially among younger participants which compounds the communication challenges ahead, should the change in legislation take place. However, awareness related findings and other inferences from this study should be treated with caution because of the qualitative research approach.

The most pressing concern from participants' perspective was the lack of clarity over the influence of (and role played by) family members at the point of organ donation, and the realisation that family members could effectively 'overturn' the wishes of the deceased. The need for family involvement was not widely understood. Clearly this is a topic that spans both the current opt-in system and the opt-out proposal. Similarly, the cultural and religious issues voiced in relation to organ donation and the current system would still apply to the opt-out proposal.

The research indicates that the opt-out proposal may help to address the inertia to which participants often referred when describing how they had not got around to joining the current Organ Donor Register. The findings also suggest that the opt-out proposal may act as a catalyst for family conversations on the topic which, currently, were not widespread.

The view was not so prevalent that the current system allowed for an informed choice to opt in whereas the opt-out approach removed this choice and affected an individual's rights over their body; but it was strongly felt by those who held this opinion.

Regardless of whichever system is in place, the importance of family discussion needs to be raised, with clear explanations of why it is necessary and why families need to be involved in the final decision-making process. The research suggests that this lack of awareness also needs to be addressed among those who are currently on the Organ Donor Register, as some had not started such conversations despite being registered or carrying a donor card.

For this qualitative research audience, the potential arguments against the opt-out proposal were not as compelling as the expectation of increasing the number of donors and saving more lives, provided that there was high awareness of the opt-out system and family discussions had taken place.

By the end of the discussions, participants tended to be in favour of the opt-out proposal, on reflection. However, some remained undecided on what was the best way forward and, infrequently, some maintained that it would be against their rights if an opt-out system was adopted. A handful conceded that

they were somewhat confused by it all as the discussions concluded; and occasionally, one or two participants admitted that they were unlikely to give the subject any further thought.

The qualitative nature of these findings means that they cannot be used to evaluate whether or not the general public overall are in favour of the move to an opt-out system, or to draw conclusions by demographic attributes. Robust quantitative research amongst a representative sample of the Welsh population is required in order to meet these aims, so that a clear picture of the view in Wales is available. This will provide an invaluable baseline against which changes in opinion can be tracked over time, and the impact of Welsh Government communications activity assessed.

APPENDIX: DISCUSSION GUIDE

A. INTRODUCTION (10 MINS)

1. *Thank participants for attending. Introduce self and Beaufort Research.*
2. *Explain purpose of discussion is to allow them to express their own views – there are no right or wrong answers.*
3. *Explain MRS Code of Conduct: reassure about confidentiality and obtain permission to audio record – to aid analysis.*
4. *Explain aims of research: to find out their views on organ donation.*
5. *Participant introductions. Tell us a little about yourself? E.g.*
 - *First name, area live in*
 - *Family / work situation*
 - *The highlight of their week*

B. PERCEPTIONS OF ORGAN DONATION AND CURRENT OPT-IN SYSTEM (25 MINS)

Capture on flipchart

1. To begin with, what words or phrases would you use to sum up how you feel about the idea of organ donation? You may want to refer to some of your notes from the information sheet we gave you.
 - *Group suggestions on the flipchart as they are made*
2. *Probe words and phrases suggested: Tell me more about what you mean by this phrase?*
 - *Open up discussion and ask for the groups' views*
3. How familiar are you with the current organ donation system?
 - *Focus first on those who appear less familiar – what do they know?*
 - *How clear is it to you how the current system works? Probe for interpretations.*
4. *Prompt current system summary: Currently, people in Wales have to opt in to join the NHS Organ Donor Register if they wish to donate their organs after death. It's normal practice for doctors to let relatives know if the person has opted in and doctors will not proceed if families ask them not to. If you have not joined the Register, your family can consent to donate your organs after your death.*

Note if asked: while doctors have the legal right to proceed if a person has opted-in and a family refusal goes against the wishes of the

deceased, in practice they will not proceed without the cooperation of the family.

- What further thoughts do you have on hearing this summary?

If not already covered

5. *Those who have joined the Register:* what prompted you to sign up to the Organ Donor Register?
6. *Those aware but haven't joined:* What are your views on signing up to the Organ Donor Register?
7. Changing the subject slightly, tell me about organ donation and the rest of your family? *Allow for spontaneous comments / referrals to notes; probe whatever emerges, then ask if not already covered:*
 - How often, if ever, have you talked about organ donation with family members? *Probe any circumstances/ reasons why not*
 - Is anyone in your family aware of your views on the subject?
 - *Probe:* tell me more about that?
 - Are you aware of the views of any of your family members?
 - *Probe as above*

C. OPT-OUT PROPOSALS (55 MINS)

1. In the information sheet we gave you, we asked you about the idea of registering to opt out of donating your organs if you wish to, rather than the current system where you opt in and register to donate your organs, or the family consents on your behalf after your death.

Before we talk about it in detail, were any of you aware of this proposal from the Welsh Government before being invited to take part in this focus group? *Probe:*

- *Sources of information*
 - *What they know about the proposal*
2. What are your initial thoughts on this idea? *Probe whatever emerges, and cover:*
 - At this point what, if anything, sounds positive about this opt-out proposal? *Probe*
 - At this point what, if anything, sounds less positive about this opt-out proposal? *Probe*
 3. What are the things you would want to know more about, in relation to the opt-out proposal? *Probe*

Hand out pens and image of person reading paper with thought bubble.

4. Let's imagine the person has just read about this new opt-out proposal for Wales which says your organs will be available for transplantation when you die unless you have registered to opt out. Your family will be involved in the discussion at the time of death.

Please note down / think about anything that might go through someone's mind on reading this – positive, neutral or negative. You can write down as many possible thoughts as you want.

Capture on flipchart

5. Tell me what you've written down? *Probe for each point raised:*
 - Is this a point that anyone here can relate to? *Probe*
6. So, at this stage, how do you feel about this opt-out proposal for Wales? *Probe*
7. Let's now look at what some of the reasons for this proposal and how it would work. I'm interested in your views on these points. *Read out each, pausing for discussion on each point, and probing:*
 - How does this make you feel about the proposal?
 - How much impact do you think this point would have on people's perceptions of the new opt-out proposal?
 - *(If negatives mentioned at Q4-6)* Thinking about the negative points we came up with earlier, what difference do you think this reason / benefit would make to people with those perceptions?

Benefits / rationales to cover (rotate order in which introduced across groups):

- *Opt-out systems in other European countries have resulted in an organ donation increase of around 25-30% (e.g. Spain)*
- *The opt-out system is likely to result in more lives being saved – on average in Wales one person per week dies waiting for a transplant*
- *Most people support organ donation and many more would be willing to donate than are on the Organ Donor Register (31% of population of Wales are on the Register)*
- *After death relatives will be involved in the decision making process around donation (ensure this statement is probed for understanding and opinion):*
 - How do you see this working?
 - No organs would be taken if the family object, even if the deceased wanted to donate (*probe reactions, including*)
 - How clear does this approach sound to you?
 - Do you think the family of the deceased should have the final say? *Probe*

Moderator note: families having the final say may not be the legal position, but clinicians say they could not proceed without family cooperation. The discussion between the medical team and the family will be about making sure the wishes of the deceased are respected.

- *Only people aged 18 or over who both live and die in Wales would be included under the system*
- *People would be able to change their minds about opting out*
- *People would still be able to choose which of their organs they wanted to donate*
- *The opt-out system may encourage more families to discuss organ donation preferences and wishes*

8. *Repeat Q7 but with focus on potential issues with the op-out proposal*
Let's now look at what are sometimes put forward as potential arguments against this proposal. I'm interested in your views on these points. *Read out each, pausing for discussion on each point, and probing:*

- *How does this make you feel about the proposal?*
- *How much impact do you think this point would have on people's perceptions of the new opt-out proposal?*
- *(If positives mentioned at Q4-6) Thinking about the positive points we came up with earlier, what difference do you think this issue would make to people with those perceptions?*

Potential perception issues to cover (rotate order):

- *This means that people automatically lose rights over their own bodies*
- *The positive action of organ donation as a gift is taken away from people*
- *How can people be sure that the NHS's information on people's choices about organ donation is up to date and accurate?*
- *The opt-out system might change the way people who are very ill are cared for*
- *The opt-out system may cost a lot of money to introduce that could be better spent elsewhere in the NHS*

9. To sum up, now that we've discussed this proposal in more depth, how do you feel about it? *Probe:*

- *Has anyone's view changed during the course of the discussion?*
Probe what prompted change

10. If you were responsible for convincing people to support the proposal, what would you talk about?

11. And if you wanted to try and deter people from supporting the proposal, what would you focus on?

If time available and not already covered

12. Earlier we considered the point that only people aged 18 or over who both live and die in Wales would be included under the system. For people moving to Wales, at what point do you think this potential new law should apply to them? *After spontaneous comments probe reactions to:*
- As soon as the individual registers with a GP?
 - When they register to vote?
 - After 6 months, 1 year, 2 years?
 - What about students studying in Wales who are not from Wales?
 - How should people be made aware of the new law when they move to Wales?
13. Before we finish, is there anything else you'd like to add on this subject?