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Consultation – Summary of responses

Proposals for Legislation on Organ and Tissue Donation

Date of issue: 8 March 2012



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Introduction

The Welsh Government White Paper “Proposals for Legislation on Organ and Tissue donation” was published on 7 November 2011, opening a twelve week consultation.

The consultation ended on 31 January 2012. A total of 1,234 responses were received. The consultation document set out 9 questions, and question 9 was an open invitation to make any related comment not covered by the other questions.

All responses received a standard acknowledgement letter confirming that the response would be published together with the identity of the respondent unless they contacted the Welsh Government requesting anonymity. The complete list of respondents is at Annex A, with anonymity protected where requested.

During the consultation period the Welsh Government organised 13 public meetings across Wales. The dates and locations of these meetings are at Annex B. In total, 166 people attended these meetings. In addition we held eight meetings with key stakeholder groups.

This report summarises the responses to each of the consultation document’s questions, together with an analysis of the themes raised that did not refer to our questions. It also summarises the discussions at the public meetings.

Next Steps

In June 2012 we will publish a draft Bill for consultation, together with a draft Explanatory Memorandum. The Explanatory Memorandum will explain the contents of the Bill and also indicate how the Welsh Government is proposing to respond to the views summarised here. We will consult on the draft Bill for twelve weeks.

Overview

The Welsh Government White Paper “Proposals for Legislation on Organ and Tissue Donation” was published on 7 November 2011, opening a twelve week consultation period that ended on 31 January 2012. An Easy Read version, aimed at people with Learning Disabilities, was published on 15 December 2011.

The First Minister and Minister for Health and Social Services spoke at a launch event for the consultation on 8 November 2011, held at the Renal Unit of the University Hospital Wales. The publication of the White Paper received considerable media interest, including coverage on UK television news bulletins.

In the week immediately after publication, the White Paper received press coverage from both Welsh and UK titles. As the consultation period continued, regional and national press interest gained momentum around each public meeting and culminated with a live broadcast on BBC Wales Today from the Swansea meeting towards the end of January. Not only did the issue attract interest from the media, but Sir Richard Branson noted his support on the social media site Twitter. This prompted further media coverage, including the front page coverage in the Western Mail on 20 December 2011.

Annex C shows the actions taken by the Welsh Government to promote awareness of the consultation and the public meetings.

In addition to the launch event and associated media coverage, we emailed a wide range of interested parties to draw their attention to the consultation. The list of organisations that were sent this email notice is at Annex D.

The respondents to the consultation included both organisations and individuals, as follows:

Health-related organisations	33
Individuals indicating a health interest (eg GP)	14
Political interests: eg town councils, MP	14
Religious, humanist or ethical interests	14
Voluntary sector organisations	9
Academic bodies	4
Statutory Commissioners	2
Individuals not otherwise classified	1,144

The White Paper took forward a manifesto commitment to introduce legislation on a soft opt-out system organ donation. Given the support shown by the Welsh public for changing the law in a consultation held in 2008-9, the White Paper posed questions relating to the arrangements to make the system work. It did not explicitly invite respondents to state whether they supported the proposals. However, 91% **(1,124)** of the responses we received did indicate an overall view, with 52% **(642)** of respondents supporting the proposals and 39% **(482)** opposed.

Responses varied in how they were submitted; while 376 used the form provided by the Welsh Government, and one used the form on the Easy Read version, many others were letters where respondents made points in their own way. Some of these were quite lengthy submissions. One respondent, Cartrefi Cymru, provided a DVD of a facilitated session with some of their tenants with learning disabilities discussing the proposals. 485 responses were in the form of a standard letter circulated by the Opt for Life campaign, an alliance of charities supportive of the proposals. A further 35 responses were in the form of a standard e-mail circulated by the British Heart Foundation. The text of these is within Part 2 of this report. The Albany Road Baptist Church in Cardiff provided a petition of 45 names in support of the proposals – we have counted this as a single response.

In the summaries that follow, each of these standard responses is included with equal weight to other individual responses. For example, the Opt for Life campaign letter supports option C within the options for a register, so each letter along these lines is included in the total supporting option C under Question 5.

13 public meetings were held, organised in conjunction with the Community Health Councils in Wales.

The discussions at the public meetings served to explain the current process, answer questions on how the proposal would work, and provided the opportunity for attendees to explain why they supported or opposed the legislation.

Eight meetings with key stakeholders were held during the consultation period, as follows: three meetings with the NHS in Wales and meetings with Specialist Nurses and Clinical Leads on Organ Donation, Professional Bodies, the Voluntary Sector and with faith groups. Largely discussions with stakeholders focused on the practical issues surrounding the implementation of the policy such as:

- The need for clarity about the role of the family and the need to ensure the best interest of the deceased and the family are kept at the heart of the proposals.
- Determining Welsh residency.
- Critical care capacity.

The Expert Reference Group established to inform the Welsh Government's policy thinking in relation to the Organ and Tissue Donation Bill also met during the consultation period.

In addition Welsh Government officials met with the office of the Children's Commissioner for Wales; the Newport and Monmouthshire region of One Voice Wales; a group of clinicians in Hywel Dda Health Board; and we spoke with Shelter Cymru to consider the implications of the policy for homeless people. Shortly after the end of the consultation we discussed the proposals with the Funky Dragon Grand Council, representing young people in Wales.

The remainder of this document is structured in three parts:

Part 1 summarises the responses to each of the questions in the consultation document, apart from question 9 which asked the respondent whether they wished to raise any issues not covered by the other questions. These summaries take into account points received that relate to each question whether or not the consultation form was used. For example, if a person responded with a letter that raised an issue relating to the role of the family, it is taken into account in the summary of responses to question 6 which relates to the role of the family.

Part 2 summarises the points made in written responses that did not relate to the consultation questions or that were in response to question 9 on the form.

Part 3 summarises the points made and questions asked in the 13 public meetings.

Inevitably, a summary of such a large number of responses cannot capture accurately every issue raised in writing or made in public meetings. Nor can the responses be interpreted as a representative sample of public opinion. However, every contribution that was made is welcome, has been read and is being taken into account in developing the policy further.

Shortly after the publication of this report we will publish in full all written responses received, maintaining anonymity where this was requested by the respondent.

Part 1 – Questions 1 to 8 in the White Paper

Question 1: The White Paper sets out individuals must have lived in Wales for a sufficient period of time before being included within the soft opt-out system.

a) What factors should be taken into account when determining whether an individual ‘lives in Wales’?

b) What should that period of time be?

314 responses (25%) answered this question.

While the responses to part a) were varied, a number of common replies emerged. Some respondents made several suggestions.

The main factor suggested to take into account was simply the individual’s permanent and main address, and whether that was situated in Wales. The postcode could be used to verify this. 129 responses were along these lines.

The other main factors mentioned were whether an individual was recorded on the electoral register (76 responses) or whether they were registered with a GP in Wales (40 responses).

Other ideas that recurred in more than five responses were:

- Rejecting the question due to opposition to the proposals **(31)**
- Whether registered for Council Tax **(27)**
- Whether employed within Wales **(16)**
- Residence impractical or too difficult to ascertain **(15)**
- How long an individual has lived in Wales **(14)**
- Students from outside Wales should be exempt **(10)**
- In receipt of benefits or full time education in Wales **(10)**
- There should be a qualifying period of residence **(8)**
- Where person lives for majority of time **(7)**
- Uses the public services of Wales / free prescriptions **(6)**

Answers to part b) generally provided a specific period of time, as the question asked.

The following shows the popularity of differing time periods, taking suggestions made more by more than five respondents:

- As soon as resident - **17**
- As soon as on the electoral roll - **14**
- 3 months – **6**
- 6 months – **17**
- 12 months – **42**
- 2 years – **31**
- 3 years – **25**
- 5 years – **27**
- 10 years – **13**

24 respondents who answered this part of the question indicated that in their view the question illustrated the impracticality of the proposal or that they rejected the question since they were opposed to the policy.

The standard Opt for Life letter that was sent in by 485 respondents suggested that all Welsh residents should be included, perhaps implying that there should be no qualifying period in the view of these respondents.

Question 2: Do you agree discussions between clinicians and family in the event of an individual's death, will identify and safeguard those who lack capacity?

Of those that provided a response to this question:

196 replied "Yes"

134 replied "No"

14 replied "Yes and No" or provided comments without a "yes" or "no" answer.

Many of those that provided a "yes" or "no" response also provided comments.

The comments on this question were very wide ranging and thoughtful, and a summary cannot do many of them justice. However, there were recurrent themes.

Among those who responded "yes", and commented, many (50 responses) generally explained why they supported the proposal in the White Paper, expressing for example that people who lack capacity to be able to adequately make the decision about whether to donate or not, need family members to express their wishes, because they may have indicated their wishes to someone in the family.

Among those who responded "no", recurring comments related to whether the family were the right people to ask or would know the deceased's wishes (34 responses); putting pressure on the family at a traumatic time (28 responses); and some respondents mistrusted the possible motives of clinicians within such a conversation (22 responses). These concerns were echoed by some respondents replying "yes" to this question.

Other themes that occurred in more than five responses were:

- Querying what happens if the deceased has no family **(7)**
- The question reinforces opposition to the proposals **(14)**
- The proposed approach is not compatible with good practice under the Mental Capacity Act 2005 **(10)**
- An opt-out system is inappropriate for people that lack mental capacity **(11)**
- Agree with the safeguard proposed while opposed to opt-out system **(10)**

Question 3: Do you agree that the soft opt-out system for Wales should only apply to persons aged 18 years and over? If not, why?

Of those that provided a response to this question:

166 replied "Yes"

165 replied "No"

1 replied "probably", 1 replied "no clear view" and 1 replied "totally irrelevant question"

Comments were received from around 18% (**219**) of the respondents.

Disagreement with the principle of soft opt-out

A significant proportion of those who commented (around 52% **115**) used the answer to express disagreement with the principle of the policy and expressed the view that children should be "protected" from this idea. This group also felt that organ donation should always be subject to parental consent or that the existing Organ Donor Register arrangements should remain.

Those in favour of under 18 age limit

A relatively large proportion of those who commented (around 29% **63**) felt that people below the age of 18 could take decisions relating to organ donation and should be allowed to express a wish in some way or another. Around half of this group felt the arrangements should apply to all, irrespective of age, with appropriate safeguards, such as parents being able to agree to their children opting out. About 36% of this group thought that the soft opt-out system should apply to young people from the age of 16 because they felt people of that age were entirely capable of understanding the issues and making their own decisions.

Those in favour of 18 or over age limit

Around 17% (**32**) of people who commented felt that the system should apply from the age of 18, linked to the voting age or the age of legal responsibility or even that it should start at 18 and be reviewed as the system embeds.

Question 4: Do you agree with the retention of the existing Organ Donor Register to be operated in conjunction with the soft opt-out system?

Generally answers to this question simply recorded a choice between Yes, No, or no response with additional comments. Some respondents supplemented their answers to indicate the strength of their views; others were unsure and responded accordingly.

Of those who responded:

208 replied "Yes"

117 replied "No"

2 replied "Yes – strongly", 1 replied "probably yes", and 1 replied "totally irrelevant question"

327 (26.5%) of the respondents responded to this question.

Disagreement with the principle of soft opt-out

A significant proportion of those who commented (31%, **103**) used the question to express disagreement with the principle of the policy. More than half of these (**57**) explicitly requested that the existing arrangements continue without an additional register.

Those in favour of keeping the ODR

The majority of respondents (65%, **210**) who answered the question were in favour of keeping the existing ODR alongside the new register. The main reasons stated for keeping the register were:

- Should a person from the rest of the UK die in Wales, then their wishes could still be followed (**24**)
- To reinforce the person's wishes that they actively wanted to donate (**23**)
- Should a person from Wales die in England, Scotland, or Ireland, their wishes could still be acknowledged (**8**)
- To allow those under the opt-out age to record their wishes and be participate in the process (**6**)

In favour of a single opt-out register

A small minority (**18**) were in favour of discontinuing the existing ODR in Wales as they felt the Opt-Out register would make the ODR redundant. Some (**7**) respondents stated that the existing ODR should be phased out over a period of time.

Concerns

Some of the respondents **(28)** used the question to raise concerns regarding potential confusion, additional bureaucracy, or inaccuracies as a result of administering two registers.

Other respondents **(9)** questioned the costs of an opt- out system.

Role of the Family

A small number of the respondents **(6)** commented that the family should not over-rule the deceased person's wishes and that the wishes of the deceased should be paramount.

Question 5: In relation to the record keeping options for the soft opt-out system –

a) Which of the suggested options do you prefer?

b) Are there other options you feel would provide an effective and secure system?

689 (56%) of the written responses provided a response to part a) of this question.
178 (14%) of the written responses provided a response to part b) of this question.

Part a)

The majority of answers to part a) simply recorded a choice between the options presented.

These were:

Option A – a register for Wales of persons who have not objected, and a register of persons who have objected.

Option B – a register for Wales of only those persons who have not objected.

Option C – a register for Wales of only those persons who have objected.

Option D – no register(s) but a record of objection given to and held by a person's general practitioner.

Of those who responded to the question:

- 83 supported option A
- 23 supported option B
- 550 supported option C
- 17 supported option D
- 2 supported option A and C
- 2 supported option A or C
- 1 supported option B or D
- 1 supported option C or D

It should be noted that each individual signing the standard letter circulated by the Opt for Life campaign supported Option C.

The comments provided on part a) were varied, but a number of common themes emerged and some respondents used the comments section to explain their

thoughts regarding different systems. The three most commonly recurring themes for each option is given below.

Option A

20 respondents felt this provided the best for integrity and clarity because the registers can be cross-checked for duplication.
9 respondents were not in favour of this option.
5 stated it would be too bureaucratic and confusing.

Option B

Elicited a comparatively small number of comments (11 in total).
4 respondents felt that Option B would be the most compatible with the existing ODR.
3 respondents stated it would be difficult to work out who has opted out.
3 stated it would be difficult to operate and would require more work.

Option C

This was the most popular option among respondents.
479 respondents stated that this would be the best option for ensuring that those who have objected to being an organ donor are formally recorded as such.
14 felt this option would be the least confusing and the simplest or safest.
6 respondents felt that this would provide the smallest list and thus be easier to manage.

Option D

11 respondents were concerned that the GP information wouldn't be available on a 24 hour basis thus leading to delays in obtaining information about the donor's wishes.
6 felt it would be difficult to operate because the GP needed to be involved.
3 said it would be an unacceptable option.

Other themes from the comments:

Of the respondents, a significant proportion used this section to object to the overall proposals **(43)**.

Concerns were raised relating to the ability to keep an accurate register, and that any system needs to be failsafe, secure, reliable and robust **(27)**.

Some of the respondents could not agree with any of the options and felt that the existing organ donation register arrangements should continue **(21)**.

There were concerns expressed that maintaining two or more registers could result in more errors, which in turn could affect public trust **(12)**.

Some of the respondents were concerned about the costs of setting up and running a new system **(6)**.

Part b)

Some of the respondents proposed alternative systems, while others suggested how the current system could work better. These are typical responses raised by more than five respondents:

- Use the existing system as it already works and we have one of the highest donation rates in Europe **(10)**.
- Using medical records or using GPs to create living wills was proposed as an alternative option **(10)**.
- Make it easy to change options and to allow choice as to what to donate or not donate. It was stated that the register should also be regularly updated within a specified timeframe **(10)**.
- To persuade people to register their wishes, use something similar to the electoral register or driving licence renewals with conditions attached i.e. if you don't register the right to vote is lost, or you won't receive a licence on renewal **(7)**.
- Driving licences, mobile phone contracts, passport applications, credit cards, ID Cards, and census forms could be possible tools for asking people to express their wishes and to state if they want to opt-out of the donation system **(7)**.
- As with part a), some of the respondents used this question to register a general objection **(24)**.
- It is not possible to build a safe and secure IT system for this purpose **(18)**.

Question 6: What is the role of the family in safeguarding the wishes of the deceased?

807 (65%) of the responses provided a reply to this question, taking into account that the 485 Opt for Life Campaign letters addressed this issue.

In particular it is worth mentioning the standard letters from Opt for Life campaign supporters which said that “Welsh residents should be presumed to be organ donors unless the wishes of the deceased can be proven contrary after relatives have been contacted” (i.e. a rebuttal) but these letters also said that immediate relatives should be able to object to donation.

Around 6 per cent (**50**) of all those who responded used the question as an opportunity to disagree with the policy altogether or to say that the current system should be retained.

Family as decision-maker/with rights

Some 74 per cent (**599**) of those who made comments said that families should be the ultimate decision-makers/safeguard or felt that the family’s view was very important or essential (many respondents did not go on to amplify this point). Almost 83 per cent of this group felt that immediate family should be able to object or veto the deceased’s consent being presumed.

Family having limited or no role

Around 72 per cent (**584**) of those who commented felt that the family should have no role or at least only a limited one in deciding whether or not donation should go ahead. A majority of this group (**506**) felt that the only role of the family should be to confirm whether they knew if the deceased would have objected. A separate, small number of respondents (**6**) were concerned about how relatives could provide proof, if the deceased had not opted out, that they did not in fact wish to donate their organs, and what form such proof would take. Others in this group of respondents made statements suggesting that families should be consulted but that the final decision should not be theirs and should be taken in accordance with the best interests of the patient. Further responses said that families would have to accept whatever law was put in place.

Miscellaneous comments

Just under 3 per cent of those who commented (**22**) said that the new system might encourage more people to discuss their views with their family and that this would help with decisions about donation. One respondent said that a soft opt-out system would inevitably mean families having little or no influence over decisions. Several respondents (**10**) expressed the view that families were not always the best people to decide these questions because of the potential for disagreement/family rifts/conflicting views. A number of people (**8**) felt there was a lack of clarity about what would happen in the event of a person having no family, or whose family lived away.

Question 7: How can the Welsh Government ensure that the public awareness campaign is effective?

308 (25%) of the responses answered this question.

Answers to this question were varied and covered the following themes:

- Communication channels.
- Messages and content of communication.
- Audience groups that need to be targeted.
- Stakeholders to engage.
- Reach of communications.
- Research and Training.
- Communication issues.
- Responses not related to the question or unclear.

Many responses put forward more than one suggestion which may have covered a range of the themes, therefore the following breakdown rates suggestions on how many times they were featured throughout all responses to the question. Unless stated, only suggestions mentioned more than five times have been included in the summary.

Communication Channels

- Advertising campaign (including references to TV, radio, print, billboards) **(71)**
- Leaflets/posters in relevant locations (inc. GP's, hospitals, pharmacies, dentists, supermarkets, libraries, council owned properties) **(56)**
- Leaflet drop/direct mail to all households in Wales **(33)**
- Use of social media (Facebook, Twitter, Myspace, Bebo, Youtube, forums) **(30)**
- Pro-active/reactive PR (inc. responses where TV, radio or newspapers were mentioned but not used the term 'advertising') **(29)**
- To be included on school curriculum / discussions in school **(22)**
- Regular annual mail-outs alongside council tax/electoral roll/census communications or via benefit applications/P60 **(18)**
- Digital communications/Internet search advertising **(11)**
- Through schools (inc. PTA's), universities or college enrolment **(11)**

- TV/radio discussion or debates with professionals, members of the public, charities and media **(8)**
- Via DVLA driving applications/ car tax renewal or passports **(6)**

Messages and/or Content of Communication

The following answers were identified as suggestions for how the communications should be presented or the messages that should be included:

- Use of language – needs to be clear, transparent and avoid ‘Government speak’ **(15)**
- Messages must include clarity on the role of the family – will their decision be overridden. Legality versus what happens in practice **(8)**
- Public information needs to be balanced, unbiased and address concerns and objections **(8)**
- Communications needs to be honest, truthful and the implications of the legislation need to be clear **(7)**
- The process of organ donation needs to be clear - all facts need to be communicated e.g. definition of brain death, death normally in ICU, separation of clinical care and organ donation team **(6)**

Specific Audience Groups that Communications needs to Target

In this section all responses including those mentioned just once have been listed:

- Ongoing campaign required to reach those who move to Wales post legislation and children who turn 18 yrs old **(10)**
- Hard to reach groups **(4)**
- Ethnic groups **(4)**
- Disabled people **(3)**
- Information should be available in all appropriate formats for disabled people **(4)**
- Faith Groups **(3)**
- Those who don’t speak English but live/work/study in Wales **(2)**
- Prisons/Probation service **(2)**
- Through residential homes for the Elderly **(2)**
- Apathetic/Disorganised **(1)**
- Those who are less well educated or informed **(1)**
- Children and young people – age appropriate information **(1)**
- Families **(1)**
- Homeless workers **(1)**

- Theologians **(1)**
- Homeowners and Tenants **(1)**

Stakeholders to Engage and/or to Disseminate Information

In this section all responses including those mentioned just once have been listed:

- Awareness raised through GPs via one-to-one discussions with patients **(11)**
- Major employers **(3)**
- Local authorities **(2)**
- Trained GP receptionists or front facing NHS staff to communicate the issue **(2)**
- Public sector – communication to all staff via payslips **(2)**
- Third sector including carers **(2)**
- Work closely with stakeholders **(2)**
- Health professionals to disseminate information following initial launch **(2)**
- Community Health Councils **(1)**
- Community councils **(1)**
- Community organisations **(1)**
- Healthcare services **(1)**
- Local Health Boards **(1)**
- Development of an Organ Donation Wales Group to look at communications for the whole of Wales **(1)**
- Human Tissue Authority **(1)**

Awareness or Reach of Communications

The two main issues that addressed this theme are as follows:

- Communication needs to be comprehensive and repeated regularly post consultation so that informed decisions can be made **(25)**
- Awareness needs to be raised on the new opt-out system applies to everyone, ensure that everyone is aware and understands their options/the implications/opt-out procedures **(11)**

Research and Training

- Use of representative pre and post surveys of public awareness to measure impact and impact of legislation as well as regular measurement of public opinion **(9)**

Responses not related to a Public Awareness Campaign

- Criticism on publicity for the consultation **(35)**
- General opposition to the proposed legislation **(27)**
- Communications should focus on promoting the current system rather than introduce the legislation **(16)**
- Referendum or vote should be held on the issue **(9)**

Question 8: The Welsh Government would welcome your views on the potential impact of the proposed soft opt-out system for the Welsh Language, race, faith, disability, age, sexual orientation, gender, gender reassignment, marriage or civil partnership.

235 (19%) of the responses provided a response to this question.

The question provided 9 possible demographics with options for the respondents to add other areas that may not have been covered. The 9 areas are as follows:

1. Welsh Language.
2. Race.
3. Faith.
4. Disability.
5. Age.
6. Sexual Orientation.
7. Gender.
8. Gender reassignment.
9. Marriage or Civil Partnership.

Some respondents only covered one area, while other covered more than one area. Below are the common statements for each of the areas followed by common themes.

Welsh Language

Respondents felt this was covered by the Welsh Language Act **(5)**

Some of the respondents felt there would be no impact in this area **(4)**

A small group felt this shouldn't translate into Welsh due to cost and that every Welsh speaker can speak English **(4)**

Race

Some of the respondents felt there will/could be an impact on race grounds, but did not provide details. **(6)**

Due to the low contribution from ethnic minorities respondents felt there should be increasing appropriate awareness in specific groups. **(6)**

Some respondents felt minority groups would benefit from the new policy as there would be increased provision. **(3)**

Faith

Of the respondents a significant number felt there will or could be an impact for faith groups. **(22)**

Respondents felt some religious families may be upset that the deceased didn't opt-out on grounds of faith and that possibly the families will ignore the deceased wishes on grounds of faith. **(4)**

Respondents felt some faiths groups such Muslims and Hindus may need additional resources and engagement to ensure their awareness of how this policy may affect them. **(4)**

One person felt Faith is the wrong phrase to use to describe this category. "Religion or Beliefs" would have been a better title to cover those who are non-religious.

Disability

Respondents felt this group will have extra requirements and may require additional assistance, and concerns over their ability to understand the opt-out system. **(10)**

Some respondents felt that potentially disabled people will be discriminated against by various people i.e. the medical professionals, families, etc. **(7)**

Age

The respondents generally mentioned two groups, the elderly and the under 18s.

For the elderly the respondents felt extra resources are need to ensure the elderly are kept informed of the opt-out as this may not use the internet. Additionally as this is a venerable demographic they may require extra help and let them know they can donate as there is no age limit. **(8)**.

When a child reaches 18, information should be sent to them to make them aware of the opt-out system. **(3)**

Sexual Orientation, Gender and Gender reassignment

Generally the respondents felt the opt-out system would have no impact in this area, however one respondent did raise the question whether gay men can donate organs as they can't currently donate blood.

Marriage or Civil Partnership

Several respondents mentioned that Marriage and Civil Partnerships both should be given equal status as next of kin. **(5)**

Respondents wondered about the role of the common law partner and should be given consideration. One suggestion was maybe to name the next of kin on the register. **(4)**

A small group felt there shouldn't be any impact. **(4)**

Other Common Themes

The following themes were in a number of responses:

- Registering general objections to the proposals. **(44)**
- Cannot foresee any issues or impacts the proposals would have on different groups. **(38)**
- General statement that all equality strands must be taken in to account when delivery the proposal. **(24)**
- Because eventually everybody dies that equality issues are not relevant to Organ and Tissue Donation. **(20)**
- People who don't use the internet or have limited English or maybe English not as first language minority languages. This could affect the elderly, disabled and Deaf people and immigrants or minority cultures in Wales. **(12)**
- Everyone is an individual and is entitled to a choice. **(8)**

Part 2 – Question 9 in the White Paper and other comments received

Question 9 on the White Paper's response form was:

The Welsh Government has asked a number of specific questions; if you have any related issues which have not been specifically addressed, please record them here.

This section of the report summarises responses received to this question, together with comments from those that did not use the form and which do not relate to any of questions 1 to 8.

Almost all responses made some comment to be summarised here; if only to state support for or opposition to the proposals. 642 respondents indicated support for the proposals and 482 were opposed.

485 respondents signed individual letters with identical wording circulated by the Opt for Life campaign. The letters read as follows:

I welcome the Welsh Government's proactive measures to save lives and fully support its plans to change the law on organ donation by introducing a system of 'soft opt-out' in Wales.

I believe that under system of Opt Out, Welsh residents should be presumed to be organ donors unless:

- *They have joined an Opt-out register.*
- *They cannot be identified.*
- *The person's place of residence cannot be identified.*
- *The wishes of the deceased can be proven contrary after relatives have been contacted.*
- *Immediate relative object.*

Under 'soft' opt out there should be no compulsion. I believe that a register in Wales of only those persons who have objected (Option C, paragraph 56 of the Welsh Government White Paper on Organ and Tissue Donation) will ensure that those who object can be assured that their views are formally recorded.

35 respondents sent an email with wording circulated by the British Heart Foundation:

Heart transplants offer the best chance of long term survival for critically ill heart failure patients. Unfortunately there is a shortage of donor hearts and other organs meaning that many people wait years for a transplant. Sadly the wait means many people die whilst waiting on the list, or become too ill to

receive a transplant. In Wales around one person on the transplant waiting list dies every week.

While 9 out of 10 people in the UK support organ donation, fewer than 3 in 10 are signed up to the register. A soft opt-out system will better reflect the wishes of the majority of the Welsh population, increase the number of organs available for donation and ultimately, help save lives.

The system must be sufficiently robust to ensure that everyone who wishes to opt out has an opportunity to do so and there are safeguards to ensure that an individual's wish to opt out is respected and honoured. Close relatives should be able to refuse permission at the time of request.

I welcome the Welsh Government's proactive measures to save lives and fully support its plans to change the law on organ donation by introducing a system of 'soft opt-out' in Wales.

Apart from these, the great majority of comments received unrelated to the other questions were arguments opposed to the policy.

The most frequent theme emerging from such comments was the argument that organs belong to the individual and not the state **(183)**, often combined with the comment that donation of organs should be a gift from the individual **(110)**. 115 respondents argued that the resources planned to be used for an opt-out system should be redirected to improve awareness of the current system, or used for another government priority.

73 respondents gave notice that they would opt-out if the new system came in, and of those 29 said that they were currently on the Organ Donor Register or carried a Donor Card.

64 respondents were aggrieved that the White Paper was consulting on the implementation detail rather than the principle, 53 felt "presumed consent" was not true consent and unethical or immoral, and 51 expressed doubts that the proposals would provide additional organs.

Other arguments expressed by more than five respondents were:

- Fears that clinicians would put need for organs before care for patients. **(48)**
- Proposal is an infringement of Human Rights. **(35)**
- Risk of error if system comes in. **(30)**
- Concerns relating to diagnosis of death. **(21)**
- There should be more critical care capacity. **(18)**
- Criticism of publicity given to consultation. **(18)**
- The challenge of the whole population having sufficient awareness. **(18)**

- Organ Donation Task Force/Assembly Committee considered and did not support opt-out system. **(14)**
- Experience of Spain does not make case for opt-out system. **(14)**
- The proposal means that Wales is providing organs for the rest of the UK. **(12)**
- Proposal could ultimately lead to organs for sale. **(12)**
- Statements of support from those affected by waiting list or transplant. **(11)**
- Opt-out system will make those objecting look selfish. **(11)**
- Wrong to place an onus on people to opt-out. **(11)**
- Supporting mandated choice system. **(10)**
- Glad Wales is leading the way; could be catalyst for rest of UK. **(10)**
- Those opposed will be able to opt-out. **(9)**
- Not right for Wales to introduce alone in UK. **(9)**
- Queries Assembly competence to legislate on this. **(8)**
- Statements of opposition from those affected by waiting list or transplant. **(8)**
- Querying what happens when family absent at death. **(8)**
- Will increase stress on family. **(8)**
- There should be comprehensive evaluation. **(8)**
- Cannot infer those not on ODR support donation. **(7)**
- Disagree with statements of church leaders opposing proposal. **(7)**
- There should be a referendum on this. **(7)**
- Sweden has an opt-out system and low donation rate. **(6)**

Part 3 – Summary of questions asked in public meetings

Each of the 13 public meetings was led by Dr Chris Jones, Medical Director of NHS Wales. They opened with a DVD showing part of the launch event together with interviews with some of those affected by organ transplantation. Dr Jones or Dr Grant Duncan, Deputy Director then made a presentation explaining the contents of the White Paper, and opened the discussion inviting questions. A Clinical Lead for Organ Donation or Specialist Nurse for Organ Donation was present at all but one event to answer questions about the current process of organ retrieval and transplantation.

Many of the discussions explored the way the current system worked as well as the change proposed. Others present took the opportunity to make statements of support or opposition to the proposals in principle, often with similar themes to those outlined in Part 2 of this report.

The following grid shows themes that recurred in more than one public meeting, in order of frequency. As with the earlier sections, this cannot necessarily capture comprehensively every point that was made.

Issue	Aberavon	Merthyr	Cwmbran	Llandrindod	Clyderwen	Aberystwyth	Bangor	Barry	Cardiff	Wrexham	Swansea	Newport	Llandudno
Challenge of population having sufficient awareness; public apathy; publicity campaign critical	•	•			•	•		•		•	•	•	•
Criticism of publicity/timing for public meeting	•		•	•	•	•		•		•	•	•	
The state taking organs vs donation as a gift	•			•	•		•	•			•	•	•

Testimony of benefits to recipient of transplant		•	•		•					•	•	•	•
Concerns relating to diagnosis of death	•			•	•	•	•				•	•	
Since current system works well, why change/ use resources for current system	•			•	•		•		•		•	•	
How many additional organs with opt-out policy/sufficient?	•		•		•			•			•	•	
Wales providing organs for rest of UK and beyond	•		•		•					•	•	•	
Position of those that die in England after opt-out system		•		•	•	•				•			•
Any register system must be simple/avoiding people both opting in and out/not just online/do need a register		•	•		•	•		•				•	
Will you be able to object to donating some organs and not others?		•			•	•	•				•		•
What if no family is present at time of death?			•		•	•		•		•		•	
Issues relating to mental capacity eg learning disability, dementia		•	•			•			•			•	•
Is there an upper age limit for donation?		•	•	•		•							•

Queries relating to current process for retrieval of organs eg time limits				•	•	•					•		•
Need to integrate more with education system			•					•		•		•	•
Need to consult with & reach out to religious groups and minority groups such as deaf community			•			•		•	•				•
Who owns the body after death?		•					•			•		•	•
Surprise/concern that in current system relatives can override person who has said they wish to donate	•	•								•	•		
If a person has opted-out, family should not override	•			•		•					•		
Wales introducing this system when rest of UK is not	•				•						•	•	
Human Rights issues	•							•			•	•	
Consider a mandated choice system (where citizens legally required to state wishes)				•					•			•	•
Use of electoral register to prove residence or link with opt-out register		•	•		•					•			

Mistrust of safeguards and controls/may change over time/"thin end of wedge"			•				•		•		•		
Risk of administrative or IT error/mistrust of IT			•		•		•					•	
Need for increased critical care capacity/as in Spain					•				•	•			•
Concerns relating to persons in vegetative state					•	•	•						•
"Presumed consent" isn't informed consent as generally accepted							•	•			•	•	
What if you die at home?					•		•				•		
If so little is changing, why change the law?							•				•	•	
Concern that needs of recipient override care for donor									•		•		•
Queries about current donor card/ODR system		•							•		•		•
What if consultation shows opposition to principle/not consultation on principle		•						•				•	
Lack of evidence that a legislative change will lead to increased donation rates					•			•				•	

There should be a referendum on this				•				•				•	
Family must be given full information when asked for consent	•										•	•	
Any effect on funeral arrangements?		•											•
Risk of organs for sale		•		•									
Query regarding use of organs for research	•											•	
Temporary residents such as students	•										•		
Brings in a new option for people – to opt-out				•									•
UK Organ Donation Task Force considered presumed consent and didn't support it								•				•	
White Paper unclear about role of family					•			•					
Support proposal, but concerned people will be antagonised										•			•
Spain doesn't make case for opt-out system			•							•			
Opt-out system allows doctors to retrieve organs, doesn't mandate them to										•			•
Need to educate clinical staff										•			•
Wales can be catalyst for					•					•			

rest of UK													
Issues of religions that don't tend to donate										•			•
Is Organ Donation a permanent solution or a temporary solution i.e. will stem cell treatment help the treatment of people with organ failure					•			•					

Annex A – List of Consultation Responses

This document will be republished with a list of consultation respondents by the end of March 2012. The delay is to ensure all those wishing to request anonymity have a reasonable time to do so.

Annex B – List of Public Meetings

Wednesday, 16 November – Aberavon
Thursday, 17 November – Merthyr Tydfil
Thursday, 17 November – Cwmbrân
Thursday 24 November – Llandrindod Wells

Monday, 5 December – Clynderwen
Tuesday, 6 December – Aberystwyth
Thursday, 8 December – Bangor
Tuesday, 13 December – Barry
Tuesday, 13 December – Cardiff
Tuesday, 20 December – Wrexham

Tuesday, 17 January – Swansea
Wednesday, 18 January – Newport
Wednesday, 25 January – Llandudno

Annex C – Publicity for the Welsh Government Consultation Events on the Organ Donation White Paper

All public meetings were advertised in the following ways:

- Press Notices were released specifically to highlight the meeting at the beginning of the series in November and again when additional meetings were announced in January. Individual Press notices were also issued in advance of each meeting. As a result articles appeared in the Western Mail, Daily Post and local press.
- The meetings were also referenced in other press notices and lines issued in connection with the organ donation consultation.
- Local radio –The Medical Director has undertaken interviews with local radio stations.
- Welsh Government’s website – links to the consultation regularly featured on the home page. Press notice about public meetings also featured as WG news.
- Welsh Government’s social network sites – Facebook and Twitter
- Website and social network sites of the Board of Community Health Councils.
- The Board of Community Health Council’s sent posters to each venue for distribution in the surrounding area.
- Members of the Community Health Councils were given details to announce at their meeting and for inclusion in newsletters.
- Welsh Government’s stakeholders in the public (including CLODs and SNODs) and third sector organisations were sent information for wider circulation.

Following disappointing attendance at the first four events, the following publicity methods were added:

- Additional posters were developed to advertise the events in December and January. These were distributed to libraries and GP surgeries in each area.
- Public service Communicators were contacted through the ‘Comms Cymru’ network and asked to disseminate information through their local networks.
- The Aberystwyth, Cardiff and Wrexham events were advertised as being accessible for the deaf community in Wales. Deaf Access Cymru advertised those events via their twitter and Facebook feeds and The British Deaf Association informed their members via e-mail.
- The Welsh Government tweeted at Wrexham FC’s supporters club to advertise the public meeting at Wrexham.

- Local Authorities and Local Health Boards were also asked to publicise the meetings to their staff via their intranets.

In January, in an attempt to increase attendance further

- Welsh Government Officials distributed posters by hand in Newport, Swansea and Llandudno to supermarkets and shops within the locality.
- Posters were emailed to major public sector employers in each area in order to publicise to staff.

Media coverage:

- Press notices sent to relevant local and national publications and broadcast media for each event (list below)
- Media invited to attend events and several journalists attended meetings.
- Regular coverage in the Western Mail and Daily Post as well as regional newspapers
- The Medical Director undertook interviews with all the major radio stations across Wales, apart from Heart FM.
- Radio Wales were asked to mention the meetings wherever possible -Roy Noble gave a mention to the Merthyr and Cwmbran meetings.
- As well as newspaper coverage in national and regional press, both before and after the events, there was live coverage on BBC Wales Today from the event in Swansea on 17January.

Media sent details of all events:

BBC Wales
 ITV Wales
 Radio Wales/Radio Cymru.
 Real Radio
 Western Mail
 Daily Post
 Press Association
 Golwg
 Bridge FM

Regional news invited:

Aberavon
 Afan FM
 Neath Guardian
 SW Evening Post
 South Wales Guardian
 Tribune

Cwmbran

Pontypool Free Press
South Wales Argus
Gwent Gazette
Abergavenny Chronicle
Chepstow Free Press
Monmouthshire Beacon
Monmouthshire Free Press
Capital FM

Newport

South Wales Argus
Gwent Gazette
Abergavenny Chronicle
Chepstow Free Press
Monmouthshire Beacon
Monmouthshire Free Press
Capital FM

Swansea

Radio Tircoed
South Wales Evening Post
Swansea Bay Radio
Swansea Sound
The Wave
Carmarthen Journal
Llanelli Star
Radio Carmarthenshire
Scarlet FM
South Wales Guardian

Cardiff

South Wales Echo

Barry

Barry and District News
South Wales Echo
Glamorgan Gazette
Penarth Times

Clynderwen

County Echo
Milford Mercury
Western Telegraph
Observer Series
Radio Pembrokeshire
Tivyside Advertiser

Aberystwyth

Cambrian News
County Echo
Tivyside Advertiser
Radio Ceredigion

Llandrindod

Border Counties Advertiser
Brecon and Radnor Express
County Times
Radio Hafren
Radio Shropshire
Shropshire Star

Bangor

Anglesey Mail
Bangor and Anglesey Mail
Bangor Chronicle
Caernarfon Herald
Cambrian News
Champion 103
Coast 96.3 FM
Holyhead and Anglesey Mail
North Wales Chronicle
North Wales Pioneer

Llandudno

Abergele Visitor
Rhyl/Prestatyn Journal
Champion FM
North Wales Pioneer
North Wales Weekly News
Tudno FM

Merthyr

Merthyr Express
Cynon Valley Leader
Rhondda Leader

Wrexham

Calon FM
Wrexham Leader
Wrexham Mail
Flintshire Leader
Flintshire Chronicle
Mold and Buckley
North Wales Pioneer
Caernarfon and Denbigh Herald
Denbighshire Free Press
Rhyl and Prestatyn Visitor
Rhyl Journal

Annex D – List of Organisations notified of White Paper Consultation

NHS Interest

Local Health Boards/NHS Trusts

- Abertawe Bro Morgannwg University LHB
- Aneurin Bevan LHB
- Betsi Cadwaladr LHB
- Cardiff & Vale University LHB
- Cwm Taf LHB
- Hywel Dda
- Powys
- Velindre NHS Trust
- Welsh Ambulance Service
- Public Health Wales
- WHSCC

NHS Blood and Transplant

Clinical Leads on Organ Donation at each LHB

Specialist Nurses for Organ Donation at each LHB

Transplant Centres

Retrival Teams

All Wales Renal Network

Critical Care Network

Cardiac Network

Board of Community Health Councils

Professional Bodies

Royal College of Surgeons

Royal College of Physicians

Welsh Intensive Care Society

British Transplant Society

College of Emergency Medicine

Welsh NHS Confederation

Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of Nursing
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Midwives
Royal College of Ophthalmologists
Welsh Intensive Care Society
Paediatric Intensive Care Society
Faculty of Intensive Care Medicine
British Medical Association
Academy of Royal Colleges
Royal College of Radiologists

Voluntary Sector

Kidney Wales
Welsh Kidney Patients Association
Transplant 2013
Diabetes UK
British Heart Foundation
Epilepsy Action
Anthony Nolan Bone Marrow Trust
Patient Concern
Age Concern
Welsh Mental Health Alliance
Children in Wales
Welsh Neurological Alliance
British Lung Foundation
Cystic Fibrosis Trust
British Liver Trust
Live Life then Give Life
RNIB
Disability Wales
British Organ Donor Society

Kidney Research UK
National Kidney Federation
Haemophilia Society
Patient Association
British Humanist Association
Donor Family Network

Faith and BME Organisations

Cytun
Archbishop of Wales
Roman Catholic
Evangelic Alliance Wales
Free Church Council of Wales
Baha'I Faith
Buddhist Council of Wales
Shree Swaminarayan Temple
Hindu Temple Whitchurch
Reform Judaism
Muslim Council for Wales
ABCD Cymru – Access for Black Children with Disabilities
African Community Centre
AWEMA – All Wales Ethnic Minority Association
Banardos Neville Street Project
BAWSO – Black Association of Women Step Out
Black Voluntary Sector Network Wales (BVSNW)
Cardiff Gypsy and Traveller Project
Cardiff Traveller Education Service
Ethnic Youth Support Team
North Wales Equality Network
Race Equality First
SEWREC
Somali Integration Society
Somali Progressive Society
South East Wales Race Equality Council

Swansea Bay Race Equality Council
Tai Pawb
Valleys Equality Council
Wales Strategic Migration Partnership
Welsh Refugee Council

Government and Government Agencies

Human Tissue Authority
Department of Health
Northern Ireland Executive
Scottish Government
Wales Office
Ministry of Justice

Other Sectors

Coroners
Police Forces in Wales
Trade Unions

- PCS
- Unite The Union
- Wales TUC
- The GMB

Children's Commissioner for Wales
Older People's Commissioner
Equality and Human Rights Commission
Welsh Independent Healthcare Association
Members of the Welsh Government's Expert Reference Group on Organ and Tissue Donation
Welsh Organ Donation Implementation Group