Consultation Paper on Options for Changes to the Organ Donation System in Wales

Local Health Boards, NHS Trusts, Local Authorities, Community Health Councils, County Voluntary Councils, Health Commission Wales, Members of the Public, and a number of individuals and organisations with an interest in these proposals.

This document sets out options for changes to the organ donation system in Wales following the Welsh Public Debate on Organ Donation held between 27\textsuperscript{th} October 2008 and 23\textsuperscript{rd} January 2009. The options included potential changes to the organ donation consent system and other changes to improve organ donation rates such as increased public education and publicity and involvement of primary care.

Please respond by: 3\textsuperscript{rd} August 2009

Response forms can be sent to the following address:

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Or completed electronically and sent to:
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An Opt-out System for Organ Donation Consent

Full report from the Welsh Public Debate
held 27th October 2008 to 23rd January 2009
1. Background and objectives

In October 2008 the Minister for Health and Social Services initiated a public debate to capture opinion on whether Wales should become the first UK country to introduce an opt-out system, also known as presumed consent, to increase the number of organ donors. The ultimate purpose of the debate being to inform decisions by the Assembly Government on whether it should seek a legislative change.

The public debate was held from 27th October 2008 and concluded on 23rd January 2009. The debate involved various methods of stimulating discussion and gathering the views of the Welsh public. A discussion document to guide the debate was commissioned from Professor Steve Edwards, Swansea University. A website was set up which provided information about how to participate in the debate. An on-line poll was provided on the website to capture people’s preference for alternative consent systems. The public were encouraged to use the freepost address and email address provided to collect additional views on the matter. Unsolicited correspondence received during the period of the debate was also analysed. Opinion Research Service, from Swansea University was commissioned to conduct a telephone survey using structured questions to a representative sample of the population. 11 public meetings were held around Wales to provide interactive discussion and debate on the matter. In addition to the public meetings, a meeting was held specifically for faith leaders in Wales to explore religious and faith views. Clinical experts in the field of organ donation were recruited to participate in the public meetings and the faith meeting to guide the discussion.
2. Methodology

Methodology
The debate aimed to capture people's perceptions about organ donation, find out from them how organ donation rates might be improved and explore their views and feeling towards alternative systems of consent for organ donation such as the opt-out or presumed consent system.

The approach chosen was to employ various methods of engaging with the public and collecting both qualitative and quantitative feedback data:

- Public meetings / faith leaders meeting
- Inviting written views
- Analysis of unsolicited correspondence
- Online poll
- Telephone interviews

It was felt that this approach would provide a wider range of opportunities for the Welsh public to join in the debate. It was recognised that public meetings would offer a feel for Welsh opinion on the subject but this was from a self selecting group of the population and so could not entirely be interpreted as full engagement or consultation representative of all of Wales. It was felt that the additional means of seeking public views, such as the telephone interviews, would further enhance this understanding of the public view in Wales.

All contributions to the public debate have been anonymised and have not been attributed to any one individual.

Public Meetings
Meeting venues were selected by the Community Health Council (CHC). The CHC encouraged attendance at the meetings through their network of local CHCs and their voluntary sector network. Local and National media were contacted to publicise the meetings with features appearing in newspapers, radio and television. In addition the Minister for Health and Social Service wrote to a wide range of Welsh public and voluntary sector organisations asking them to participate in the debate.

The public meetings were held in different locations throughout Wales, selected by the Community Health Council, from 27th October 2008 to 20th January 2009:

- Cardiff - Monday 27 October, Taff Conference Centre, Sophia Gardens, Welsh Institute of Sport, from 6:15pm - 9:00pm;
- Brecon - Tuesday 28 October, Bishop Meadow Hotel, Brecon, from 12:00pm - 3:00pm;
- Haverfordwest - Wednesday 29 October, Nant-y-Ffin Hotel, Llandissilio, from 10:00am - 1:00pm
- Caernarfon - Friday 31 October, Siambr Dafydd Orwig, Gwynedd Council from 1:00pm - 4:00pm
- Aberystwyth - Monday 3 November, Parc Lodge Hotel, Parc y Llun, from 7:00pm - 10:00pm
- Wrexham - Tuesday 4 November, Nick Whitehead Theatre, Main Foyer, Glyndwr University, from 6:30pm - 9:00pm
- Newtown - Thursday 6 November, Ladywell House, Newtown, from 10:00am - 1:00pm
- Anglesey - Thursday 13 November, Main Chamber at YMCC offices, Llangefi from 6:00pm - 9:00pm
- Newport, Gwent - Monday 12 January 2009, St Woolos Hospital Chapel from 6:00pm - 9:00pm
- Neath - Tuesday 13 January 2009, Neath Civic Centre from 6:00pm - 9:00pm
- Merthyr Tydfil - Tuesday 20th January 2009, Post Graduate Centre, Prince Charles Hospital from 6:00pm - 9:00pm

It was felt that holding the meetings at different times of the day would encourage a range of participants to attend. All meeting venues selected had full disabled access and all had Welsh translation services provided. In addition those attending the meetings were asked to notify the Community Health Council in advance with any specific requirements, such as audio typing or sign language interpretation.

All participants attending the public meetings were given the discussion document to read in advance, this was also available on the website to download for any members of the public who wished to see it and an audio-CD version made available for those requesting it.

Each meeting lasted for between 2-3 hours, and involved short informative presentations followed by group discussions then followed by question and answer sessions. Each meeting was supported by a panel of expert clinicians. The clinicians included Intensive Care Consultants, Renal Consultants, Donor Transplant Coordinators and a Transplant Surgeon. During the course of the debate 14 different clinicians offered their time to support the public meetings.

The objectives of the public debate were first explained to the participants. At the start of the meeting it was be made clear that there is no intention to change the current UK wide organ allocation system once organs are donated, that is all organs donated in Wales will still be allocated to the UK wide pool. It was also made clear at the start of the meeting that the debate was concerned with donation after death and organ donations for transplant, not organ donations for medical research. It was also explained that the public debate was a means of gauging public views and should not be considered as a formal consultation on legislative change.

The meeting was broken up into four discussion sessions. In each session the participants were provided with information and then asked to discuss the subject in small groups. Then the discussion was opened up to the whole group. During the sessions, the expert clinicians guided the discussion and answered any questions that arose. Participants were asked to record their own views at each stage of the discussion on sheets provided, plus views discussed with the whole group where recorded on flip charts.
The four discussion sessions were:

**Discussion session 1: What are your initial views on organ donation?**
A short presentation was given by one of the clinicians which provided background information and education about organ donation and how the current system works.

**Discussion session 2: What are your ideas for improving organ donation rates within the current legal system?**
A short presentation was given by one of the clinicians which explained some of the challenges with organ donation such as the shortage of available organs with an explanation of what is happening already in Wales to increase organ donation within the current system.

**Discussion session 3: What are your initial views on the various alternative systems for organ donation consent?**
The participants were provided with information about the range of alternative systems that can be used for donation consent (listed below) and asked about their views on these:

- **A soft opt in (The current system in the UK)**
  Doctors can remove organs from adults that have opted in. It is up to each person to decide if they want to opt in. It is normal practice to let relatives know if the person has opted in and doctors can decide not to proceed if faced with opposition from the families

- **A hard opt out system**
  Doctors can remove organs from every adult who dies unless a person has registered to opt-out. This applies even if relatives know that the deceased would object to donation but had failed to register during life. Example: Austria

- **A ‘hard’ opt-out system which does not cover some groups**
  Doctors can remove organs from every adult who dies unless a person has registered to opt-out or the person belongs to a group that is defined by law as being against an opt-out system. Example: Singapore where Muslims choose to opt-out as a group.

- **A soft opt out system**
  Relatives should be consulted: Doctors can remove organs from every adult who dies unless the person has registered to opt-out. It is good practice for doctors to ask the relatives for their agreement at the time of death. Example: Spain

- **A ‘hard’ opt-in system:**
  Doctors can remove organs from adults who have opted in. It is up to each person to decide if they want to opt in. Relatives are not able to oppose the person’s wishes

- **A choice to opt in or opt out:**
  (a) People can choose to register to opt in or opt out (both options are available).
(b) Legally Mandated: People must register their choice to opt in or opt out (both options are available).

Discussion session 4: What practical issues must we consider if the organ donation system is changed?
Participants were asked to consider the practical implications of changing the consent system, also any communication issues and any possible exclusions or exemptions that might need to apply.

At the end of the meeting the participants were asked to “vote” for their preferred consent system.

All participants were also asked to complete a post meeting evaluation form. These were analysed after each meeting and used to improve subsequent meetings. Examples of improvements made to the public meetings included providing roving microphones to help participant hear the discussions better, also altering the pace and length of the discussion sessions.

In total 235 participants attended the 11 public meetings, with the meeting numbers ranging from 49 to 5 participants.

Faith Meeting
The meeting of faith leaders held was held on 14th January 2009, Chaired by Lord Dafydd Elis-Thomas. The meeting included representation from the Inter-Faith Council of Wales with representation from the following faith groups:

- Buddhist
- Christian, Church in Wales
- Christian, Free Church
- Christian, Roman Catholic
- Jewish
- Muslim
The meeting was also supported by clinical experts in the field of organ donation and contributions were made by a donor recipient, a patient waiting for a transplant and from a donor family.

Written contributions
The public and a wide range of public and voluntary sector organisations were invited to contribute to the debate, with the option of sending in written contributions by email or freepost address. All contributions received were provided with confirmation of receipt and informed that their contribution would feed into the debate findings. During the period of the public debate 32 separate pieces of correspondence were received. Of these 12 were received from organisations which presented the views of their members:

- Welsh Kidney Patients Association
- Kidney Wales Foundation
- RNIB Cymru
- Monmouthshire County Council
- Torfaen County Borough Council
- Plaid Cymru, Ynys Mon Constituency
- The NHS Centre for Equality and Human Rights
Telephone Survey

Opinion Research Service, from Swansea University was commissioned to conduct a telephone survey using structured questions to a representative sample of the population.

The survey was conducted by telephone between 14th November and 8th December 2008. A total of 385 interviews were completed.

The achieved sample had been compared to the Welsh population profile and weighted marginally by Working Status. A fully random sample of 384 cases would yield results accurate to within +/-5% points at the 95% level of confidence. The telephone survey results can be said to be soundly indicative of Welsh public opinion.
3. Findings from the Public Meetings, the Faith Leaders Meeting and the written contributions

Awareness and views on Organ Donation

**Attitudes to Organ Donation**

The majority of participants attending the public meetings and sending in written views indicated their support for organ donation. Some participants explained that they supported organ donation but were concerned about potential changes to the consent arrangements. There were a number of participants at the public meeting who were unsure about the matter of organ donation. At some, but not all, public meetings a very small minority expressed a view against organ donation. Also, objections to organ donation were raised in 1 written contributions out of the 32 received.

“I do not support organ donation; organs should last a lifetime, abuse such as smoking causes organs to fail” (public meeting participant, Cardiff)

_In favour of transplantation… there are many people who have had their lives greatly enhanced by transplantation” (public meeting participant, Cardiff)_

“Organ donation is an essential thing to help other people overcome diseases” (public meeting participant, Brecon)

“I feel that overall; organ donation is a good thing” (public meeting participant, Wrexham)

“Support with reservations about meeting the needs of separate cultures and faiths” (public meeting participant, Newport)

A small minority of participants at the public meetings explained that they supported organ donation for others but didn’t feel that they wanted to donate their own organs or be responsible for agreeing the donation from members of their family.

Some participants at the public meetings explained that organ donation was a difficult subject to discuss because of its association with death. A small number of participants felt that talking about organ donation with their family, and even registering on the organ donor register, would somehow bring forward their death. There was also a view that different generations approached death and organ donation in a different way; that the older generation were less comfortable in discussing the subject of death and organ donation.
“Need to overcome attitudes towards death and related fears” (public meeting participant, Anglesey)

Some participants at the public meeting explained that they were happy to donate certain organs but not others, for example some participants would be happy to donate their kidney, heart or livers but not their eyes. Some participants explained that with the current donor card they could indicate which organs they wished to donate; they appeared to like this ability to choose between different organs.

There was some discussion at the public meetings and in the written contributions about the allocation of organs. Whilst an explanation was given at the public meetings that the Public Debate was not looking at any change in the way that organs are allocated in UK, there were views expressed about this. Discussions and some written contributions suggested that there was a poor understanding of the way in which organs are currently allocated. Many people did not realise that organs are allocated to recipients on a UK-wide and sometimes EU waiting list according to clinical priority and best clinical match. Whilst some participants appeared to be reassured to learn about the strict regulation and governance around this process and the benefits that come from being part of a bigger “pool”, a very small minority expressed views that they would only want their organs to be used for people in Wales.

Initial discussion at the public meetings revealed some confusion about the difference between organ donations for the purpose of transplants and for the purpose of research. The clinicians at the public meetings explained that the focus of the Public Debate was about organ donation for transplantation into another person suffering from organ failure, not for research purposes. Many participants explained that whilst they supported organ donation for transplant they did not support organ donation for research.

For those expressing views in support of organ donation, there appeared to be two view points: One, rather pragmatic view was that when a person has died then their organs may as well be used rather than “go to waste”. A slightly different view, in support of organ donation was that it was an opportunity to “do some good” and these people perceived organ donation as a “positive gift to help others”.

“It’s a great idea. If you lose your life you could save somebody else’s, it’s not like you need them after dying” (written contribution)

“the ill need organs, the dead don’t” (written contribution)

“If you accept an organ you should be prepared to donate” (public meeting participant, Aberystwyth)

The view that organ donation was a positive gift that could do some good for others, emerged very strongly from the meeting of Faith Leaders. All Faith Leaders at the meeting personally supported
organ donation; there was a consensus view that within most faiths organ donation is supported but that it is also a matter of personal choice.

The public meeting discussions revealed that the participants were surprised to find out that most faith groups supported organ donation.

For some participants at the public meetings and with some of the written contributions, their views about organ donation had been shaped by personal experience. The views of these individuals were that there is a desperate need for organs for transplant, they had seen first-hand the effects of waiting for a transplant or had seen the benefits that a transplant could bring. The evidence from these individuals was compelling and emotive and it brought into focus other motives for becoming an organ donor, taking it from an abstract altruistic act (yes, I support organ donation as good thing, but it will probably never effect me) to it having a real, first-hand relevance. There was considerable discussion at the public meetings about the need to highlight this to the wider public, to bring greater public awareness about the need for and the benefits of organ donation; they felt this would have resonance with the public and could greatly increase organ donations rates.

**Awareness and views on the process of organ donation**

With the Organ Donor Card, many participants explained that they were unsure where to find a card and suggested that the cards were not easy to find nor widely available. Similarly there was poor knowledge about how to use or find the NHS Organ Donor Register, whilst some participants had an awareness of the paper forms, much fewer were aware of the internet or telephone registration process. Many participants were not aware that although a person may have a Donor Card they may not be on the NHS Organ Donor Register.

“**Public education is vital, many people would like to be donors and don’t know where to start**” (public meeting participant, Newport)

There were a number of participants who were not sure if they were on the NHS Organ Donor Register and commented that they had picked up a card many years previously and were unsure about how they could update their status.

“**Stop the confusion between carrying a card and being on the register, the public may think after carrying a card they are on the register when they are not**” (public meeting participant, Anglesey)

A common misconception that became apparent at all the public meetings was that when a person gets older or has a chronic illness they are no longer suitable to become organ donors. It was reported that for this reason, many people were not registering on the organ donor register because they believed they were not clinically eligible. The clinical experts at the public meetings explained that almost all
people would be considered as potential donors and that organs are only transplanted following a rigorous clinical assessment.

There was also a misconception that gay men cannot be organ donors; this appeared to have been influenced by the rules restricting gay men from donating blood. The clinical experts explained that there are no restrictions on gay men becoming organ donors.

“Totally in favour of donation but you currently exclude me from making this gift as I am a gay man.” (public meeting participant, Cardiff)

Misconceptions about who can and cannot donate appear to mean that many people had unnecessarily discounted themselves as potential organ donors.

The discussions at the public meetings revealed a level of concern about the process of identifying a potential donor, particularly about the process of defining death. The clinical experts at the public meetings explained how a person might become an organ donor and that, usually, this follows a diagnosis of brain stem death whilst in a critical care unit. Many participants did not understand what brain stem death meant.

A minority were concerned about whether brain stem death meant a person was really dead. Also some expressed concern about whether the level of care received was influenced by the opportunity to retrieve a person’s organs. Many of the participants in the public meeting did not realise that the clinicians caring for sick person in critical care are not the same clinicians who then go onto organise a donation. The participants at the public meetings appeared to be reassured by this and felt that this arrangement, especially the role of the Donor Transplant Coordinator, should be made clearer to the public. Some participants explained that their misconceptions had come from watching television programmes such as “Holby City”.

Participants at the public meetings suggested that more people would likely register as organ donors if more effort was made to build their trust in the clinical processes; they felt that lack of trust or confidence in the clinical process was acting as a barrier to organ donation.

“Some people are unclear about definitions of brain stem death and more publicity is needed to allay people’s fears” (public meeting participant, Wrexham)

“Need a better understanding of what the process is” (public meeting participant, Anglesey)

A small number of participants at the public meetings were concerned about treating the deceased person with respect, especially that organ donation might limit the ability of families to view the deceased person’s body or have a normal funeral. Again, the clinical experts at the public meetings
were able to offer reassurance that viewing of the body and a funeral are not affected or delayed by organ donation. Also that the deceased person’s body stays in the hospital where they died and that organs are retrieved and taken to the recipient; there had been the misconception expressed that the deceased person’s body is transported to the place of the transplant.

The role of family and loved ones in organ donation

Discussion at the public meetings suggested a poor understanding of how the Donor Card and NHS Organ Donor Register is used in the event that a deceased person is identified as a potential donor. Many participants were surprised to learn that that at this stage the clinicians would approach the family and next of kin to seek consent; there was a general belief that having a Donor Card and being on the NHS Organ Donor Register provided the consent and meant the family were then not asked.

There were a number of participants at the public meetings who thought that by carrying a Donor Card this meant they didn’t have to discuss the matter of organ donation with their loved ones and that the Donor Card and NHS Organ Donor Register removed the burden of consent from the family. The public meetings revealed a poor understanding of the differences between a hard and soft consent system. Many participants wrongly believed that the current UK system was a hard system and that families were not able to veto the decision to donate a deceased person’s organs.

At the public meetings, the realisation that the current UK system is a soft system that involved the family in the consent process, created a strong and often polarised response from the participants. Some felt aggrieved that their own family or next of kin had the opportunity to veto a decision they had made in life, especially if they had formally registered their views. For others, the explanation by the clinicians at the public meetings appeared to create a new understanding or appreciation of why the families are involved in the consent process, with some participants attaching importance to this.

“I think it is important that people should register their choice (and be made to do so) but this choice should not be allowed to be overridden by family or the medical profession”. (written contribution)

“If the person has given their consent and carries a donor card, surely their wishes should be carried out” (public meeting participant, Brecon)

“I would expect my wishes to be carried out by family – they should not be able to go against my wishes“ (public meeting participant, Merthyr)
Ideas for Improving Donation Rates within the Current System

*Lack of awareness about organ donation*

The participants at the public meetings and the written contributions presented a wide range of ideas about how best to raise public awareness and education.

As highlighted above, the participants at the public meetings felt that public support for organ donation would increase if they were made more aware of the plight of those waiting for a transplant and the benefits that a transplant can bring. They felt that public awareness campaigns should focus on this.

“More campaigns on successes… how people’s lives have been enhanced and saved” (public meeting participant, Cardiff)

“Improve the focus of public awareness to a more positive approach – saving lives” (public meeting participant, Newport)

“Use the people’s stories to illustrate and influence the people’s decision making” (public meeting participant, Merthyr)

A common view was that more should be done in schools to educate children about organ donation. Also that we need to get into communities and raise awareness directly, suggestions included meeting directly with community groups such as the Young Farmers Association, Women’s Institute, Merched y Wawr, church groups etc. Many participants noted that the Welsh culture had a strong tradition of community spirit and there was huge potential in Wales to get communities talking about organ donation and raising awareness by word of mouth.

“Education – part of PSE curriculum – healthy schools initiative” (public meeting participant, Llandissilio)

“Voluntary and community organisations should be targeted” (public meeting participant, Caernarfon)

Many felt that television and the internet offered powerful means of reaching the public, but there were some concerns that this needed to be tightly managed to ensure the correct messages are given out.

“target young people via You Tube” (public meeting participant, Cardiff)

A popular view was that GPs should be utilised to educate people about organ donation. There was also a suggestion that awareness raising about organ donation should be linked into other health strategies and the 1000 Lives Campaign was mentioned. Many participants suggested raising awareness and encouraging registration at blood donation sessions.
Better Public Education: Overcoming misconceptions and poor understanding of the processes involved

As highlighted above, the participants at the public meetings felt that the public needed to have more information about the processes involved in organ donation, especially about the hospital processes, to help overcome some of the myths and misconceptions and increase public confidence.

Process of registering as an organ donor

As highlighted above, the participants at the public meetings felt that organ donor registration process could be made easier. They felt that more publicity needed to be given to the existence of the NHS Organ Donor Register so that everybody knows about it and that the opportunity to register be built into other forms of registering - suggestions included registering with a GP, completing the electoral register or when signing up for store loyalty cards.

“Still think GPs / Primary Care is the best vehicle to impart knowledge and allow registration” (public meeting participant, Merthyr)

There was some discussion at the public meetings about the need to ensure any register or database was secure and reliable. Many participants felt that once a person had registered it was important to receive some form of acknowledgement.

End of Life Care

Making organ donation a normal part of end of life care was a theme that emerged from the public meetings, from the written contributions and the meeting of Faith Leaders. Suggestions were made that more should be done to educate clinicians about how to approach the subject of organ donation and that there was an opportunity to change the way that death was handled and the family expectations. There was recognition of the importance of the role of the Donor Transplant Coordinator in sensitively managing the process of organ donation and helping the family through the process. Some participants at the public meetings also suggested the hospital chaplain had a useful role to play in supporting families through the organ donation process.

“Hospital staff need to be fully informed and educated so that they are comfortable to raise the topic of organ/tissue donation, and improve the current hospital culture around the issue”(written contribution)

Knowing the wishes of loved ones and the role of the family

As highlighted above, the family expectations around what happens when a loved one dies featured in many of the discussions. There was recognition that such events are incredibly stressful and difficult and there is almost a reluctance to put any further burden on a grieving family. There was a view expressed in many of the public meetings that organ donation should become the accepted norm, that it is something that all families should expect to have discussed with them.
Related to this theme, there were strong views that individuals had a personal responsibility to let their loved ones know their wishes, to effectively remove the burden of families having to make the decision at the time of death without any prior knowledge of the deceased person’s wishes.

“death is the wrong time to first consider organ donation” (public meeting participant, Cardiff)

“People have responsibilities in life, and one of them is to provide their wishes to be known in death” (public meeting participant, Anglesey)

The participants in the public meetings and the written contributions suggested better public education could assist in improving this situation. The recent “Tell a Loved One” campaign in Wales was noted as good example of how this message could be given to the public.

“In the cases where the loved one has already agreed to be on the register, many family members choose to respect that the decision has already been made by the donor and take comfort that so many others will benefit” (written contribution)

Views on the alternative systems for organ donation consent

**A soft opt in (The current system in the UK)**

Doctors can remove organs from adults that have opted in. It is up to each person to decide if they want to opt in. It is normal practice to let relatives know if the person has opted in and doctors can decide not to proceed if faced with opposition from the families

Whilst many participants at the public meetings and in the written contributions supported a change to current consent system, there was also a view that more needed to be done to implement infrastructure improvements within the current system; some cited the Organ Donation Taskforce recommendations. Some expressed a view that there needed to be time given to implementing the infrastructure changes before changing the consent system, whilst some felt that both could be pursued together. Many participants valued the current system and did not want to see a change; this appeared to be related to the concept of an opt-in system representing a positive choice.

“The opt-in system is a positive system relying on goodwill and altruism” (public meeting participant, Neath)

“There is a register already so why change this?” (written contribution)

“We have a system of organ donation in place that should be built upon” (public meeting participant, Cardiff)
“The current system could be improved with easier means to record your wishes and enough money being put into the system for education” (public meeting participant, Brecon)

“I think that more creative methods of getting people to opt-in is the solution” (public meeting participant, Anglesey)

“The present system protects and respects the rights of the individual conscience” (public meeting participant, Wrexham)

A hard opt out system
Doctors can remove organs from every adult who dies unless a person has registered to opt-out. This applies even if relatives know that the deceased would object to donation but had failed to register during life. Example: Austria

The Faith Leaders explained that their faith communities supported organ donation because it was something that a person could choose to do that would help others. The Faith Leaders did not consider that an opt-out system (hard or soft) allowed people to make a positive decision about organ donation, and any measure by the state to make decisions or “presume consent” about organ donation eroded the concept of organ donations as a “gift” for the good of others.

Concerns were raised that if the State were perceived to be introducing a system that moved away from organ donation being a positive personal choice, then there was a risk that the public would react against this and opt-out in protest. There was a view that the public don’t like to be told what to do or have any presumptions made about their wishes.

“It is important that any policy is perceived as supporting the voluntary nature of an altruistic act of organ donation. Care needs to be taken to avoid any perception of “mandatory obligation” which may result in unfortunate public abreaction.” (written contribution)

“An opt-out system will introduce fear and have an adverse effect” (public meeting participant, Wrexham)

Some participants at the public meeting and in the written contributions argued that by not opting-out, a person had still made a conscious decision that they wished to become an organ donor. Then there were counter arguments that the State could not “presume” that those people who had not opted-out had given the matter any thought and actively made a decision about organ donation.

“Consent must be fully informed, individual choice and never presumed” (written contribution)
“An uncast vote is always a no” (written contribution)
“Failure to register an opt-out is not an implied permission and must never be seen as such” (written contribution)

There was concern from some, that an opt-out system could erode public trust in clinicians.

“I worry about the long term effects on the trust the public affords to doctors and nurses if a non-consenting presumption becomes law” (public meeting participant, Anglesey)

The discussions in the public meetings, and in the written contributions, highlighted “apathy” as a concern with both the opt-out and opt-in systems; it was suggested that all systems relied on the public considering the issues and acting on their intentions by registering their views. There was also the view that the opt-out system would take advantage of the less well informed members of the public or those who have other priorities.

“Legislation for opt-out system would be obtaining organs by default in many cases – taking advantage of less well informed members of the public” (public meeting participant, Neath)

There was view presented that an opt-out system would increase the pool of potential donors, on the basis that some public surveys suggest up to 90% of the population support organ donation but that many had not got around to registering.

“It would increase the organs available and spare people the hassle of registering” (written contribution)

The hard opt-out system as opposed to a soft opt-out system appeared to appeal to those who felt that families should not be allowed to veto the wishes of the deceased person. Also, some participants felt that that a hard system offered the benefit of taking away the burden from families of making a decision during the time of bereavement.

“Firmly in favour of automatic donation; this would ease the point of death stress as it would be the norm” (public meeting participant, Cardiff)

A ‘hard’ opt-out system which does not cover some groups

Doctors can remove organs from every adult who dies unless a person has registered to opt-out or the person belongs to a group that is defined by law as being against an opt-out system. Example: Singapore where Muslims choose to opt-out as a group.

There was little support for this option at the public meetings. The participants felt that a decision to opt-out should be a personal one and that any group making a decision on behalf of its members was not helpful and could confuse the public.
A soft opt out system
Relatives should be consulted: Doctors can remove organs from every adult who dies unless the person has registered to opt-out. It is good practice for doctors to ask the relatives for their agreement at the time of death. Example: Spain

As set out above with the hard opt-out system there were similar concerns about the opt-out nature of this system, but despite this and the detailed debate about the pros and cons there was ultimately strong support for this soft option at the public meetings. It appeared that the participants felt more comfortable with the option to include relatives in the decision about organ donation.

“If people feel strongly enough they should say so; in that case we should move to an opt-out system, but soft” (public meeting participant, Cardiff)

“Important to refer to relatives” (public meeting participant, Newtown)

“Relatives should be listened to; they have to live with the outcome” (public meeting participant, Anglesey)

“Must care for concerns of donor families to ensure least stress and pain” (public meeting participant, Neath)

A ‘hard’ opt-in system:
Doctors can remove organs from adults who have opted in. It is up to each person to decide if they want to opt in. Relatives are not able to oppose the person’s wishes

This option appeared to appeal to those participants that did not want to change from the current opt-in system but did feel that families should not be able to oppose the deceased person’s wishes or that they shouldn’t be given the burden of having to make a decision at a time of bereavement. Interestingly this option was marginally more popular than the current soft opt-in system.

“I think it recognises individual’s choice and the rights of an individual to choose without fear of relatives overturning their preferred choice” (public meeting participant, Llandissilio)

A choice to opt in or opt out:

(a) People can choose to register to opt in or opt out (both options are available).

(b) Legally Mandated: People must register their choice to opt in or opt out (both options are available).
A mandated choice option was very popular with participants; they felt that it was sure way of knowing everybody’s wishes and removed any doubt or ambiguity. However there was considerable debate about how such a system could be implemented. Some participants suggested using the electoral role as a means of registering everybody’s views. The idea of using GPs to register people’s wishes was very popular and whilst it was recognised that this wasn’t legally mandated it would capture the views of a large section of the population.

There was some concern raised at the public meetings with regard to the mandated choice option, that if a person was asked to decide and they had received enough information and couldn’t make their mind up at that time, they may opt-out. There was general agreement that such a system would need to have some means of allowing individuals to update their status on the register and if necessary change their mind.

“The only fair system is to make it compulsory for all people to express their view” (written contribution)

“Mandated choice seems to bring the best balance between ethical considerations and patient choice” (public meeting participant, Cardiff)

“A mandatory opt-in and opt-out system would relieve the anxiety for relatives as wishes are clearly indicated” (public meeting participant, Wrexham)

Voting preference on the consent systems from the Public Meetings and Online Poll
A total of 74 people used the online poll to indicate their preference of an organ donation consent system and 242 participants at the public meetings used the voting sheet to indicate their preference. There were some participants at the public meetings that did not indicate their preference.

The most preferred system was a mandated choice system, where people must (by law) register their choice to either opt in or opt out. 27% preferred this system. This was followed by the soft opt-out system. 22% preferred this option. Only 10% preferred the current soft opt-in system.
The results of the online poll and the public meeting preference vote are shown below:

**Practicalities of Changing the Consent System**

*The cost of changing the system*

Some participants at the public meetings were concerned about the potential cost of changing the consent system and building a new register. Even though some of these participants felt that a different consent system (such as opt-out) would be better, they felt that any resources available should be directed towards increasing public education and awareness.

“How would it be financed and what effect would this have on other health services?” (written contribution)

“Money better spent on existing system, to promote” (public meeting participant, Caernarfon)

Some participants at the public meetings expressed concern that if a change in the system increased organ donation rates then there wouldn’t be enough critical care beds. The clinical experts explained that a change to the consent system for organ donation would not mean any change to the clinical protocols for admitting patients to critical care and so under any system the same number of patients would be admitted into critical care beds.

**Publicising a new process / Public Education and awareness**

A clear message provided by the public meetings and written contribution was that any change to the system could only work if accompanied by robust public education, not just about organ donation but about the process of registering your wishes.
“I fully support the opt-out system, with the proviso of a comprehensive education package which caters for all levels of understanding” (written contribution).

“Wide and extensive publicity would be required to encourage participation under any of the options” (public meeting participant, Aberystwyth)

“Organ donation must be an informed choice and must be a personal choice” (public meeting participant, Wrexham)

Introducing a change in Wales ahead of the rest of the UK

There were polarised views from both the public meetings and from the written contributions about whether Wales should become the first country in the UK to introduce a change in organ donation consent. Some had the view that there should be no problem with introducing a change in Wales ahead of the rest of the UK and even went so far as to suggest that if successful the other countries could follow, whereas others had reservations.

“I think a lot of people find the current legal differences within the UK with respect to health care confusing, this could be a logistical nightmare. The potential for some very distressing errors would be enormous and I think it could be contentious and divisive within the UK” (written contribution).

“We should fully support Wales taking the initiative to introduce the necessary legislation to introduce presumed consent, thereby giving a lead to the rest of the UK” (written contribution)

There was discussion at the public meetings about who the arrangements would apply to in system that was unique in Wales to the rest of the UK. There was concern about visitors to Wales and whether they would come under a Welsh system

Exclusions and exemptions

There was recognition in the public meetings and written contributions that certain groups of society may wish to opt-out of organ donation as a group; this didn’t appear to cause concern about implementing a change to the consent system.

“If a minority group does not wish to participate, it would be possible for those groups to carry cards that indicate they do not wish to donate at the time of death” (written contribution)

Some participants at the public meetings were keen to ensure that any new consent or registration system had the facility to allow individuals to indicate which organs they wished to donate and which ones they didn’t want to donate (as with the current system). There was concern about how an opt-out system would facilitate this option – would they have to opt-out altogether or could they simply opt-out for certain organs?
There was also concern about how any consent system might respond to emerging medical advances in transplantation. Some participants raised concern about face transplants. There was discussion about how the consent system and relevant organ donor register might be updated as these medical advances emerged, for example some participants said they would be happy to register as an organ donor now with the current list of organs, but may change their mind if in the future face transplants were occurring.

There was a general view amongst the participants that the Organ Donor Register (whatever the consent system) should be regularly updated. The suggestion that GPs be used to update the register of people’s wishes was popular and they felt that the GP registration process provided an opportunity to routinely update the information.

“Make it easy for people to register and importantly quickly remove themselves off the register if they choose to revoke their consent, without making them feel guilty” (public meeting participant, Anglesey)

The issue of children and organ donation was raised and the general consensus was that the organ donation consent system (whichever system) should apply only to adults. Similarly there was discussion about those who did not have the capacity to consent and there was general agreement that exclusions would have to be made in such circumstances.

“Children should be a separate issue due to the sensitive nature and each case would have to be taken individually” (written contribution).

“Children should not be asked for consent, parental consent only for the under 18s” (public meeting participant, Llandissilio)
4. Findings from the Telephone Survey

Those people surveyed where asked a series of questions about organ donation and the responses are summarise below.

Did you know that organs may not be removed for transplantation unless patients give consent before they die – for example, by registering as a donor and / or carrying a donor card OR unless their relatives give consent after death?

96% of respondents said yes and 4 % said no. This result suggests a good awareness amongst the public of the current organ donation system.

Thinking about those who have consented to donate their organs to people in need, should their families be able to stop (veto) their relatives’ organs being used for transplant surgery?

66% said definitely no and a further 18% said probably no. Only 7% said definitely yes and another 7% probably yes. This result suggests the public might be supportive of a hard consent system rather than a soft system. This differs significantly from the public meetings, where participants seemed to have more of a preference for soft consent systems than those in the telephone survey.

Do you agree or disagree that doctors should be able to presume consent by removing organs from the dead person unless they had previously opted out?

39% said they strongly agreed with presumed consent and a further 18% said they tended to agree with presumed consent. 24% said they strongly disagreed with presumed consent and a further 15% said they tended to disagree with presumed consent. 4% said they do not know.

If the law was changed to allow presumed consent by doctors, should families of dead patients nonetheless be able to stop (veto) their relatives’ organs being used in transplant surgery?

27% said definitely yes and a further 21% said probably yes. 34% said definitely no and a further 13% said probably no. 4% said they do not know. The result suggests the public are evenly split in the preference between a hard and soft opt-out system.

Assuming the law was changed to allow presumed consent by doctors, do you think that you personally would opt out by registering as a non-donor?

11% said they would definitely opt out and a further 7% said they would probably opt out. 60% said they would definitely not opt out and a further 16% said they would be unlikely to opt out. 6% said they do not know.
Overall, do you think that the law should be changed so that doctors could presume patients’ consent and remove organs from dead patients unless they had explicitly opted out?

44% said that the law should definitely be changed and a further 15% said it should probably be changed. 25% said the law should definitely not be changed and a further 11% said the law should probably not be changed. 5% said they do not know.
5. Conclusions

The views expressed in the public meetings and written contributions about organ donation revealed a significant lack of public knowledge about organ donation, the processes of registering and the process involved in organising organ donation; many misconceptions were also revealed. This feedback provides a useful understanding of the some of the barriers to increasing organ donation rates and offers useful ideas for improvement – key messages are:

- Participants, on the whole, felt that any resources available should be directed towards improving education and public awareness about organ donation rather than spent on changing the consent system
- GPs and primary care should be utilised to register people’s organ donation wishes and to increase public education
- Public awareness campaigns should communicate the plight of those waiting for transplant and show the positive benefits a transplant can bring
- Better public awareness is required about who is eligible to be an organ donor and how to go about registering
- Better public awareness is required about the processes involved in organ donation to tackle the misconceptions and concerns about organ donation
- Whatever consent system is in place, individuals should be able to select which organs they wish to donate

Regarding the public appetite for a change to the organ donation consent system, this appears to be clouded by concerns of the cost of implementation and the need for good public education. There is clearly a public preference for either an opt-out system or for a mandated choice system, above sticking with the current system. There is also a preference for a soft rather than a hard opt-out system.
CONSULTATION RESPONSE FORM

Consultation on options for changes to the organ donation system in Wales.

Deadline for responses: 3rd August 2009

Please use this proforma to respond to the consultation.

Name: ....................................................................................................................

Organisation: ........................................................................................................

Address (including postcode): ...............................................................................

...............................................................................................................................

E-Mail address:.......................................................................................................

Are you responding as an individual?  Yes/No

If no, on behalf of which organisation are you responding?

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If you are responding on behalf of your organisation how were the views of your colleagues ascertained?

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The Welsh Assembly Government intends to publish the responses to this document in full on its website. Normally, the name and address of its author are published along with the response, as this gives credibility to the consultation exercise. If you do not wish to be identified as the author of your response, please state this expressly in writing to us.

Please return completed proforma to:

Organ Donation Consultation
Major Health Conditions and Clinical Support Services Team
FREEPOST NAT8910
CARDIFF
CF10 3BR

Electronic versions may be returned to: organdonation@wales.gsi.gov.uk

Thank you for taking the time responding to the consultation.
Consultation Scope:

This consultation exercise is seeking views on three possible options:

1. Do nothing - leave the current organ donation consent system as it is and focus on awareness campaigns and implementing the UK Organ Donation Taskforce recommendations.

2. In addition to focussing on awareness campaigns and implementing the UK Organ Donation Taskforce recommendations, consider legislative options to change the organ donation consent system in Wales to a soft opt-out system.

3. No legal change but implement a system of obtaining and recording consent involving primary care (in addition to focussing on awareness campaigns and implementing the UK Organ Donation Taskforce recommendations).

Consultation Questions

| Question 1: Should the Welsh Assembly Government leave the current organ donation consent system as it is and rely on annual awareness campaigns and implementing the UK Organ Donation Taskforce recommendations? |
| Question 2: Should the Welsh Assembly Government look at legislative options to change the organ donation consent system in Wales to a soft opt-out system? |
**Question 3:** Do you have any suggestions about what the Welsh Assembly Government should consider if a legislative options where taken forward to introduce a soft opt-out system in Wales?

**Question 4:** Should the Welsh Assembly Government look at implementing a system of obtaining and recording consent involving primary care?

**Any other comments:**