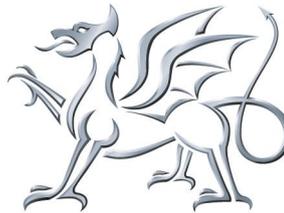


WELSH ASSEMBLY GOVERNMENT

**OPTIONS FOR CHANGES TO THE
ORGAN DONATION SYSTEM IN
WALES**

CONSULTATION REPORT



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

SEPTEMBER 2009

OPTIONS FOR CHANGES TO THE ORGAN DONATION SYSTEM IN WALES

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INTRODUCTION

On 8 May 2009 the Minister for Health and Social Services published the consultation paper 'Options for changes to the organ donation system in Wales'.

The consultation followed an earlier Welsh public debate held during October 2008 to January 2009 with purpose of gauging public views in Wales on organ donation and different options for consent. Feedback from the public debate was used as the basis of the consultation document.

The consultation exercise sought 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).

These options form the basis for the summary of responses which follows at page 5.

RESPONSE TO THE CONSULTATION BY MRS EDWINA HART AM OStJ MBE, MINISTER FOR HEALTH AND SOCIAL SERVICES

In October 2008, I launched a public debate in Wales to gauge public views about organ donation and possible changes to the consent system. In response to the public debate, I launched a 12 week public consultation in May 2009 to find out if the Welsh public would support the Assembly Government in proposing a legislative change to introduce an opt-out organ donation system in Wales.

It is encouraging to see that so many people in Wales have engaged on this matter through this consultation and by participating in the earlier public debate; organ donation is clearly an important issue for the Welsh public.

The public debate and views offered in this consultation about an opt-out system are complex and highly emotive and I have considered all the contributions and responses very carefully. The consultation shows strong public support for pursuing a legislative change that would ensure the default position is changed in favour of organ donation but with appropriate safeguards to ensure that those who do not wish to donate have the opportunity to register their wishes and opt-out. On this basis I will be advising the Assembly Government to propose a legislative change to introduce an opt-out organ donation system in Wales.

I also recognise the strong public support in Wales for implementing the Organ Donation Taskforce recommendations and continuing our efforts to raise public awareness about organ donation. Any change in organ donation consent will not distract from this important work.

Finally, I am very grateful for the varied and insightful practical suggestions offered in the consultation, many of which will be considered as we pursue a change to the consent system. In particular, I will be looking to explore further how we can involve primary care in both engaging with their patients on organ donation and registering their views.

I am grateful once again to those who responded and let me have their views.

SUMMARY OF RESPONSES

1. We received 68 written responses to the consultation. One response from the Clwyd Community Health Council included results from a public survey with 287 individual views specifically on the consultation questions. Also a response from the Kidney Wales Foundation included the views of 39 individuals presented in anonymised consultation forms and also included 272 separate petition style letters also giving a view on the consultation questions. In total the views of 664 separate individuals / organisations have been considered and included in this consultation report.
2. Many of the responses provided by organisations represent the views of lots of individual members who contributed to that organisation's summarised response. Where an organisation has provided an indication of the number of its members that held a particular view then each individual view is counted. If the organisation presented a single view and did not indicate how many of its members contributed to this, then that is counted as one single view.
3. Three late responses were received; these views were not included in the consultation report but were noted by the Minister.
4. None of the respondents requested that their names and address and response should not be published. All respondents received an acknowledgement.
5. Throughout this summary of responses; all consultation contributors, whether they be individuals, who responded in a personal capacity, or organisations are all referred to as "respondents".
6. Not every respondent answered every consultation question and so in some cases there are more views provided concerning one area of the consultation than in other areas. Also, some respondents did not structure their responses around the consultation questions but instead provided general views or information on the matter.

7. The summary of responses does not attempt to provide a detailed reproduction of all responses and comments but to summarise them and provide a small sample of some of the comments made. Copies of the full responses received can be viewed at:

<http://wales.gov.uk/consultations/healthsocialcare/organadonation/?lang=en>

8. The majority of responses supported a change to the organ donation consent system in Wales to a soft opt-out system. 538 respondents out of the total 664 specifically agreed that the Welsh Assembly Government should look at legislative options to change the organ donation consent system in Wales to a soft opt-out system.
9. Summary of responses received to the 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 (ODTF)

107 respondents specifically agreed that the Welsh Assembly Government should leave the current organ donation consent system as it is.

Many of the respondents who supported keeping the current system highlighted the need to focus efforts on implementing the ODTF recommendations:

“...WAG should focus the majority of its energy on this matter to implementing the ODTF recommendations whilst supporting regular and sustained publicity and communications.”

“WAG must assure itself that the current system is working to its optimal efficiency before seeking to change. That is the basis of the ODTF recommendations.”

“More transplant coordinators are needed and doctors need to be properly trained to help the family decide whether or not to let their loved ones organs go forward for donation.”

Some respondents highlighted evidence from other countries with an opt-out system, that their higher rate of organ donation cannot be necessarily attributed to just their consent system but is influenced by other factors, in particular by the service infrastructure that supports organ donation.

Some respondents also presented views about how attitudes and culture impacts on donation rates rather than the consent system:

“The experience from Spain in particular shows that the way that the transplant system and its coordinators work is the key to increasing organ donation rates...”

The UK organ donation taskforce report also recognises that the transplant coordinator network needs to be strengthened to ensure that there are local champions in each hospital, particularly working closely with those areas where patients who die from extensive brain trauma are likely to be admitted. In addition, the training and ongoing support of transplant staff needs to ensure that they work within an environment where organ donation is culturally supported....

This cultural change in Spain is thought to be behind the increased organ donation rates, as there is an attitude within Spanish society that people would expect their family to give consent on their behalf for organ donation. Thus it has been the cultural change, rather than the legislative framework that has made the difference. This seems to be little evidence from Spain that legislation per se has been responsible for the improved donation figures.”

There were a number of respondents who wanted to see a change to introduce an opt-out system but who also emphasised the need to implement the ODTF recommendations; they felt that both could be done together and were not mutually exclusive.

Many of the respondents who supported keeping the current system highlighted the need to increase public awareness:

“The consultation document highlights the current lack of understanding and trust in the clinical process associated with organ donation. This must be challenged as a priority.”

One respondent suggested that confusion over the current system of the National register and the carrying of cards is an example of where education is required.

“There is an overwhelming need for better education, public awareness and understanding of organ donation which needs to reach beyond an annual awareness campaign.”

“The knowledge gained from the public’s input during the consultation should be utilised to help devise new and improved awareness campaigns”.

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?

538 respondents specifically agreed that the Welsh Assembly Government should look at legislative options to change the organ donation consent system in Wales to a soft opt-out system.

“A soft opt-out consent system should be led by Wales”

“We have complete faith in the ability of the NHS to ensure the wellbeing and care of all patients ... we support the introduction of a soft opt-out system of organ donation in wales with the confidence that it will be administered with integrity.”

Some of the key themes that emerged from the consultation in relation to Question 2 are set out below:

Overcoming the issue of individuals who support organ donation but do not register

Some respondents felt that current awareness and publicity campaigns were not entirely effective because of individuals not taking the trouble to register as donors rather than not being prepared to donate and for this reason supported an opt-out system.

Shifting the default position to one of donation

Some respondents also offered the view that under the current system, donation often doesn't happen because if the potential donor is not registered then those responsible for making a decision opt for the default position which is not to donate:

“Making donation the default position reflects a positive view of organ donation, reflecting the very strong support for it within society”

Building on this, there was also a view that an opt-out system would make it easier for clinicians to approach bereaved families and discuss organ donation.

An opportunity to respect wishes of the family

The soft opt-out system rather than the hard opt-out system was recognised by some respondents as being more acceptable in so far as it acknowledges the position of bereaved families:

“I agree with concern that a hard opt-out would lead to the less well informed members of the public being less able to have their wishes respected. Whilst it can be said the same is true of the soft opt-out option, it does offer some safeguards by looking at the wishes of relatives.”

Objections to an opt-out system

94 respondents specifically expressed a view that they do not agree that the Welsh Assembly Government should look at legislative options to change the organ donation consent system in Wales to a soft opt-out system.

A small minority of respondents explained that they did not support organ donation under any system.

“If we continue to extend life beyond natural limits the NHS will never be able to sustain the eventual number of old people.”

A small minority of respondents also expressed views that introducing an opt-out system would be counterproductive and carried a risk of making the current situation worse.

Maintaining a UK-wide system

Some respondents felt that any changes should be UK-wide and not confined to Wales and on that basis they did not support a change to the law in Wales alone.

“I think it is impossible for Wales to go it alone without the other UK countries.”

Potential to damage trust between public and clinicians

Comments provided highlighted concern that an opt-out system had the potential to damage the relationship of trust between clinicians caring for people at the end of their life.

Principle of donated organs being freely given

Many of those respondents who opposed an opt-out system commented that organ donation would no longer be seen as a “positive act of giving” for which they attached importance.

Some respondents suggested that recipients of donated organs need to know that organs have been given freely by donors and their families. There was also a view that donor families find comfort in being an active part of the decision to donate.

Some respondents suggested that an opt-out system represented a more paternalistic approach to healthcare in contrast to the current emphasis on choice and responsiveness.

Question 3: Do you have any suggestions about what the Welsh Assembly Government should consider if legislative options were taken forward to introduce a soft opt-out system in Wales?

Suggestions are summarised below under key themes:

Public education

A large number of responses highlighted concern about how the public would be made aware that they had to opt-out of the system if they did not want to be a donor and how they would do it and the implications of doing so.

“Ensure that all sections of the population regardless of social class, ethnicity, religion, language spoken were aware of the implications of a soft opt-out system”

A large majority of respondents specifically highlighted that for the soft opt-out system to work, then it has to be brought in with a planned, structured and high profile public education and media strategy. Also, the need to get people to discuss their wishes openly must also be part of the strategy. Any information must be tailored to the needs of hard to reach groups such as those who have impaired capacity or are socially isolated. The publicity needs to be repeated at intervals.

Timescale for implementing a change to an opt-out system

One respondent suggested that there would need to be a time delay between the passage of the legislation and it coming into force (as much as two or three years) to ensure that the publicity campaign has been properly planned and executed and so that people have time to consider the issues and opportunity to opt-out if that is their wish.

Language and literacy provisions

One respondent advised that with any campaigns, education and implementation plans, in any medium, language should be a key consideration and that they are bilingual English and Welsh.

It was also advised that there is a duty to ensure that the language of choice of the patient and bilingual provision is an integral part of any considerations, whether it is within the current system or in a changed system; in particular the need to ensure NHS staff, such as Donor Transplant Coordinators, have the linguistic skills to discuss matter of organ donation with patients, their families and loved ones in their language of choice. This needed specific consideration in workforce planning.

It was also noted that internet organ donation registration should be possible in Welsh.

It was also suggested that consideration was needed about how best to provide organ donation information to those with low levels of literacy.

The opt-out register

One respondent felt that further clarity was required about how information on a separate Welsh register might be communicated into the existing UK systems for organ donation and transplantation.

“the Welsh Assembly Government must set out how any logistical problems of having a different organ donation system within the UK will be addressed satisfactory.”

The need for a central computerised opt-out register was highlighted by a number of respondents:

“..this must be easily accessible to authorised personnel in hospitals and it should allow individuals to add or remove their names at any time in a variety of ways and locations.”

Some respondents raised concern about the likely financial costs of putting in place a separate organ donation register and system in Wales.

Ability to review an opt-out decision after a period of time

Some respondents suggested that opting out should require renewal after a set period of time and should not be considered a life long position.

Ability to opt out of donating particular organs or tissues

A small number of respondents highlighted the need to ensure that individuals are able to opt out of donating particular organs or tissues (as they do currently with the opt-in system).

Similarly the respondents asked that special consideration be given to the handling of new forms of donation such as limbs and face.

Religious considerations

A number of respondents also asked that consideration be given to how religious beliefs are be respected with any consent system introduced.

Considerations of competency

A number of respondents raised the matter of how any system would consider matters of competence and deal with vulnerable adults and those with impaired mental capacity.

“Expert opinion should be sought to determine matters of competence both for minors and for vulnerable adults, where the continued involvement of relatives may be necessary.”

A number of recipients specifically welcomed the acknowledgement that any opt-out system would only relate to competent adults, and therefore exclude patients with capacity issues as well as excluding children (under the age of 16). It was also suggested that consideration would need to be given to advice on the management of Gillick competent children.

NHS staff education

The need to ensure appropriate level of training and education for clinicians to support increases in organ donation was common theme for respondents who both wished to retain the current system and those who wished to see an opt-out system.

Some respondents noted the need to ensure that Donor Transplant Coordinators are suitably trained to understand issues of concern to certain religious groups, with Jews and Muslims being specifically referred to.

One respondent highlighted the need to ensure that discussions about organ donation become a normal part of end of life care.

“It is essential that these crucial staff members feel at ease with the soft opt-out system”

Dealing with situations of uncertain consent

One respondent noted that under a soft opt-out system there must be clarity about who has the final decision about proceeding with the donation. In cases where a person hadn't opted out but had informally expressed a wish not to donate, then a framework would be required to manage such cases on an individual basis. It was suggested that, like in Spain, a person similar to a magistrate would be required to lead the parties to a decision; legal responsibility and powers, authority

and training and education of the appropriate parties would need to be addressed.

Considerations of how an opt-out system relates to the Human Tissue Act (2004).

One respondent highlighted that an opt-out system is out of line with public opinion on organ retention after post mortem and two respondents noted that an opt-system would be out of line with the Human Tissue Act (2004); it was suggested that the act would need to be revised if Wales pursued an opt-out system of consent for organ donation.

Impact of a Welsh system in a UK context

Some respondents noted that organs retrieved in Wales would still become part of the UK-wide pool of organs available for transplant and the positive impact of a change to the consent system in Wales would be diluted by the system in the rest of the UK.

In addition, one respondent suggested that Wales would need to work closely with NHS Blood and Transplant to ensure that organs continue to be offered for transplant across the UK on the basis of a good match and considering the potential benefit to the patient.

Potentially negative perception of “Welsh Organs for Welsh People”

One respondent also suggested that the Assembly Government needed to consider how it would manage any negative response that might arise from the population and media in Wales if as a result of an opt-out system, an increase in donation from Wales was disproportionately benefiting transplant patients from other parts of the UK and possibly EU.

Disparity of systems between Wales and the rest of the UK

A small number of respondents highlighted the potential negative impact because of the disparity of systems between Wales and the rest of the UK if Wales were to pursue a legislative change. Practical issues were raised in relation to this, including how to deal with English people who die in Wales and Welsh people who die in England.

There was also concern about the current UK Organ Donation Register and whether this would be retained in Wales and whether a change in the law in Wales would undermine the register.

Coping with the extra transplant capacity that an opt-out system might require

Two respondents made the point that if a change to an opt-out system delivers an increase in organs available for transplant then Wales must be in a position to facilitate these additional donations and transplants.

“The Organ Donation Taskforce recommendations need to be implemented to cater for the potential increase in organs made available.”

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

46 respondents specifically expressed a view that they do agree that the Welsh Assembly Government should look at implementing a system of obtaining and recording consent involving primary care.

One respondent suggested that the process of legislative change could be lengthy and so there was an urgent need for more organ donors and that primary care presented an opportunity to increase donors.

A number of respondents noted that primary care should be considered if it can be done in a sensitive way.

Some respondents felt that whilst primary care had a role it shouldn't be the only means of obtaining and recording organ donation consent:

“Primary care is a useful way of capturing the views of people in the healthcare system but this may need to be supplemented by other opportunities to ensure that as many people as possible are reached.”

A number of respondents suggested that primary care would need to be supported in this role in terms of staff education, resources and time.

It was also highlighted that if involving primary care then the public would need to be made aware of this arrangement through publicity campaigns.

One respondent highlighted the merits of such a system of obtaining informed consent using primary care and this response provided a useful description of how it might be implemented:

“There is merit in trying to raise awareness of organ donation in the population via primary care. Until now GPs have been urged to display organ donor cards but have not had a requirement to record patients’ wishes. In any record of wishes, it will be important to record those who want to register as potential donors, those who do not, and those who are undecided or with whom discussions are ongoing. Such a decision might have a time limit so that it becomes reviewed after, for example, five years. A clear statement of the wish to be a potential donor should be accompanied by giving the patient a donor card, marked with the name and contact details of the GP with whom the discussion has been held. The GPs would then be responsible for verifying this was a voluntary, informed and competent decision. All those approached must be encouraged to inform their family / next of kin of their wishes.

Informed consent would require a detailed discussion with each patient; this could not be done within one or two minutes in the context of a routine consultation.

It may therefore be more practical to ask GPs to raise the question with patients & signpost them to sources of further discussion. Simply raising the question may be enough to prompt those who have thought the issue through, but not yet registered, to register as donors. But for those with strong views against donation, this would also emerge and could be documented on the patient's record.”

12 respondents specifically expressed a view that they do not agree that the Welsh Assembly Government should look at implementing a system of obtaining and recording consent involving primary care

One respondent felt that patients using primary care services might not be in the mental or emotional position appropriate to make an informed decision regarding donation.

There was concern that primary care register may not be complete because some people do not register with primary care or move away. Some respondents also felt that this arrangement would probably not reach important groups such as healthy young adults.

There was also concern that a primary care register would be expensive to put in place.

Whilst some respondents felt that primary care should not be used to obtain and record consent, they did feel that primary care had a role in increasing public awareness and understanding of organ donation issues.

Additional comments

Many respondents commented on the consultation exercise itself:

“This is a fundamentally important decision and I welcome the fact that it appears to have undergone a lengthy and in depth consultation process to gauge the views of those in Wales”

“it is great that I feel able to contribute to a consultation document with some views on a subject that could effect me, or a friend or member of my family”

“Well done for leading on this issue. It is a sensitive area but we all need to face up to certain issues and think of others before ourselves.”

One respondent provided a positive comment about the “plain English” of the consultation discussion document.

One respondent presented a concern that this consultation hadn't addressed the range of evidence examined by previous enquiries on this matter and that the consultation seems to be based on the assumption that changing the law would lead to a significant rise in donation.

The consultation highlighted that there are still concerns about the role of the deceased person's next of kin in providing the consent for organ donation. Whilst not a specific part of this consultation, some respondents took the opportunity to indicate their support for a hard rather than soft opt-out system whereby the wishes of the deceased person could not be overruled by the next of kin. In addition, some respondents also indicated preference for a mandated system whereby all individuals must either opt in or out.

One response which did not support an opt-out system expressed a preference for a system of "required referral" which involves critical care areas having to refer all potential donors to the transplant coordinators, i.e. all patients from whom treatment is to be withdrawn and those who are considered to be brain stem dead. This would avoid potential donors being missed and therefore increase the donor pool.

List of consultees

NHS Trusts
Local Health Boards
Welsh NHS Confederation
Board of Community Health Councils in Wales
Welsh Local Authorities
University of Wales, Bangor
Equality & Human Rights Commission
NLIAH
British Dental Association (Wales)
Cardiff University School of Postgraduate
Medical & Dental Education
Cardiff University School of Postgraduate
Medical & Dental Education
Cardiff University School of Medicine
University of Glamorgan
British Medical Association (Wales)
UNISON
Royal College of Nursing (Wales)
British Orthoptic Society
Optometry Wales
AMICUS MSF
The GMB
Transport & General Workers Union
Community Pharmacy Wales
Royal College of General Practitioners
Wales TUC
Chartered Society of Physiotherapy
College of Occupational Therapists
Society of Radiographers
Society of Chiropractors and Podiatrists
Union of Construction Allied Trades and
Technicians
Royal College of Midwives
Royal Pharmaceutical Society of Great Britain
Wales Council for Voluntary Action
Denbighshire Voluntary Services Council
Association of Optometrists
Business Service Partnership
Wales Audit Office
Statutory Health Advisory Committees
Academy of Royal Colleges Wales
NHS Wales Regional Offices
Health Commission Wales (Specialist Services)
National Public Health Service
Welsh Language Board / Bwrdd yr Iaith
Gymraeg
Healthcare Inspectorate Wales

Capital Audit Team
Welsh Pharmaceutical Quality Assurance
Children's Commission
Royal College of Speech and Language
Therapists
Community Health Councils
Police Authorities
Welsh Coroners
NHS Wales
Business Service Centres
NHS Trusts
NHS Blood and Transplant
Human Tissue Authority
Policy Leads for Organ Donation and Transplant
- UK Health Departments
ABCD – Access for Black Children with
Disabilities
ACCAC
Age Concern Cymru
A:Gender
Area Diversity Manager South Wales
AFASIC Cymru
African Community Centre
AWEMA - All Wales Ethnic Minority Association
All Wales Saheli Association
Baha'i Representative
Baha'i Representative
Barnardos Neville Street Project
Bangladesh Association Cardiff
Bangladesh Welfare Association
Bangladesh Welfare Association
BAWSO
Black Voluntary Sector Network Wales
Bobath Children's Therapy Centre Wales
British Heart Foundation
British Liver Trust
Buddhist
Cardiff Gypsy and Traveller Project
Cardiff & Vale Coalition of Disabled People
Cardiff Women's Safety Unit
Carers Wales
Careers Wales
Children In Wales
Christian (Church In Wales)
Christian (CYTUN)
Churches National Assembly Liason Officer
Christian Evangelical
Christian (Free Church)
Christian (Roman Catholic)
Chwarae Teg

City and County of Swansea
Communications Workers Union
Community Regeneration Unit CCS
Community Services
Cross Roads Association
Cymroth I Ferched De Gwynedd
Cystic Fibrosis Trust
Diabetes Cymru
Disability Wales
Displaced People In Action
East London Somali Association
Education Leisure and Community Services
EHRC
Equalta
Estyn
Estyn
Friends and Neighbours
Funky Dragon
Help the Aged
Hindu Representative
Hindu Representative
HMP Swansea
Independent Councillor
Jewish Representative
Jewish Representative
Kidney Wales Foundation
LBT Excellence Centre (Wales Ltd)
Learning Disability Wales
Leonard Cheshire Wales & West Region
Live Life and then Give Life
Llandidloes High School
Mencap Cymru
Men's Health Forum
Merched Y Wawr
Merthyr Local Health Board
MEWN Cymru
MEWN Cymru
Mind Cymru
Mothers Union
Muslim
NASEN
National Association of Principle Education
Psychologists (NAPEP)
National Asylum Support Service (NASS) Wales
National Council ELWa
National Union Of Students Wales
Neath Port Talbot CB Council
New Link Wales
NFWI Wales
NHSCEHR

North Wales Deaf Association
North Wales Lesbian Line
North Wales Race Equality Network
NWFA
North Wales Race Equality Network (NWREN)
NFWI Wales
Oxfam
Patients Association
Race Equality First
Refuge Liason Office
Refugee Voice Wales
Royal College Of Nursing Wales
Royal National Institute of blind people
RNID Head Office
Safer Cardiff
Save The Children
Sense Cymru
South East Wales Race Equality Council
(SEWREC)
Scope Cwmpas Cymru
Shekina
Shelter Cymru
Sikh Cultural Association for South Wales
SNAP Cymru
Somali Intergration Society
Soroptomist International
Stonewall Cymru
Supporting Others Through Volenteer Action
(SOVA)
Swansea Bay Race Equality Council
Swansea CC
Swansea CC
Swansea College
NHS Centre for Equality and Human Rights
Valleys Race Equality Council
Wales Council For Voluntary Action
Wales Women's European Network
Wales TUC Cymru
Wales Assembly of Women
Welsh Consortium For Refugees and Asylum
Seekers
Welsh Language Board
Welsh Kidney Patient Association
Welsh Refugee Council
Welsh Women's Aid
Women's Aid
WOMEN CONNECT FIRST
Women's Food and Farming Union
Women in Agriculture
Women Making A Difference

Wales Women's National Coalition (WWNC)
Women's Voice/Llais Merched
Young Disabled People
Ysgol Hen Felin
Ysgol Y Drindod

List of respondents

Individuals in a personal capacity

Alex Down
Andrew Evans
Celia Cox
Christine Blackwood
Christine Thomas
Claire Stephens
Dai Treharne
David Evans
Dennis J Harrett
Don Brown
Dr Iain Robbe
Dr M Wulf Stratling
Dr Medwyn Williams
Dr Peter Drew
Dr Sahir Rassam
E M Cooper
Gareth Castle
Gareth Jones
Gloria Owens
Helen Jones
Jackie Irwin
Janet Meredith
Janet Williams
Jean R Graham
John Chapple
Keshav Singhal
Llinos Roberts
Mathew Millar
Professor Gurch Randhawa
Professor the Baroness Finlay of Llandaff
R Clements
Rhiannon Garnett
Robin Stimpson
Roy J Thomas
Sarah MgGuire
Susan Bendle-Jones
Tim Edwards
Vivien and Mike Stoddart
Will R Thomas

Assembly Members in a personal capacity

Peter Black AM
Bethan Jenkins AM
Dr Dai Lloyd AM
Jenny Randerson AM

Community Health Councils

Board of Community Health Councils in Wales (including the E-Citizen Panel)
Cardiff Community Health Council
Clwyd Community Health Council (including a public survey with 287 individual views)
Conwy Federation of Community Health Councils

Patient Associations / Groups

People Like Us Council
Welsh Kidney Patient Association (providing responses of its members but specific numbers not provided)

NHS Organisations

Abertawe Bro Morgannwg University NHS Trust (Organ Donation Committee)
Cardiff and Vale NHS Trust (Including responses from the Cardiff Donor Transplant Coordinator Team and Intensive Care teams)
Caerphilly Teaching Local Health Board
Hywel Dda NHS Trust
Mid and West Wales Critical Care Network Board
National Public Health Service
North Wales NHS Trust Organ Donation Committee
North West Wales NHS Trust

Professional organisations

Academy of Royal Colleges Wales
Association for Perioperative Practice
British Medical Association Cymru
Royal College of Nursing Wales
Welsh Intensive Care Society
Welsh Nursing and Midwifery Committee

Public Organisations

Welsh Language Board

Third sector organisations

British Heart Foundation Cymru
Kidney Wales Foundation (included 39 anonymised consultation forms and 272 letters)

Faith Groups

Archdiocese of Cardiff
Board of the Deputies of British Jews