



Cynulliad National  
Cenedlaethol Assembly for  
Cymru Wales

## Health, Wellbeing and Local Government Committee

Inquiry into Presumed Consent for Organ Donation

July 2008

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# Contents

Committee Members

Chair's Foreword

<b>Main Report</b>		<b>Page</b>
Section 1	- Summary of Recommendations	1
Section 2	- Introduction	3
Section 3	- The Legal Position	5
Section 4	- Current Capacity and Infrastructure	7
Section 5	- International Perspective	12
Section 6	- Public Views on Presumed Consent	17
Section 7	- Raising Public Awareness	24
Section 8	- The Work of the UK Organ Donation Task Force	27
Section 9	- Could Presumed Consent be introduced in Wales alone?	29
Section 10	- The Committee's Conclusions	32
Section 11	- Monitoring	34
<b>Annexes</b>		
A.	Analysis of Public Questionnaire and Website Data	35
B.	Analysis of Written Evidence	47
C.	UK Organ Donation Task Force Recommendations	55
D.	International Comparisons - Deceased Organ Donation Rates - 2006	57
E.	Organisations and individuals who gave evidence in person	59
F.	Schedule of Published Committee Papers and Transcripts	61
G.	Responses to Call for Evidence	62
H.	Glossary of Terms	63





# Health, Wellbeing and Local Government Committee



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## Chair's Foreword

Transplants save and transform lives. Sadly, the gift that brings about this transformation often follows the death of a fellow human being, perhaps in tragic circumstances.

Asking grieving people for their consent to remove part of their loved ones, even if it is to save the life of another, is not an easy task. It is a job that few of us would want to undertake, particularly only a few hours after the death of a beloved child or partner; father or mother.

It is perhaps not surprising therefore, that 4 out of 10 families currently refuse consent for their loved ones' organs to be donated. Improving the consent rate would go a long way to help meet the shortage of organs available for transplant and so help save and transform more lives.

There is broad agreement on some of the steps that might help. Carrying a donor card and registering on the organ donor register will help. Talking to your loved ones will help; so that they know what your wishes are should the worst happen.

We can help by providing the right training and support for the highly committed and skilled staff who have the difficult job of approaching recently bereaved loved ones. Perhaps most importantly, we can help by improving the organisation of transplant services, so that as many potential donors as possible actually become donors.

This Inquiry set out to look at one specific way that many people think might help - presumed consent. Presumed consent means that instead of having to opt-in, by carrying a donor card or joining the organ donor register, you would have to opt-out by registering that you don't want your organs used.

Some people are concerned that presumed consent means that there will be no real consent or that it is an unwarranted intrusion by the state. Others believe these concerns are overstated and that presumed consent can make a real difference to the organs available for transplant. Some believe that presumed consent may divert attention from other steps that can have a greater effect more quickly.

This is an extremely sensitive issue. The events at Alder Hey and elsewhere, where the organs of loved ones were taken without proper consent, coloured the views of many. The public consultations we carried out and the evidence we took from individuals brought home to us the need for great care if public opinion is not to be alienated from organ donation itself.

I would therefore, like to place on record my thanks to every Member of the Committee for the way they have approached such a sensitive issue. There are sincerely held views on both sides of the debate on presumed consent. I believe the mature and balanced way that Committee Members have

approached this matter reflects great credit on them and has showed the new scrutiny arrangements in the third Assembly at their best.

We have agreed on most things. We are certainly all agreed on the benefits of organ donation and transplantation and that more needs to be done to ensure that more organs are available for transplant. However, we could not agree unanimously on whether to move ahead with presumed consent legislation in Wales.

This should not be seen as a failing. I believe the open and transparent way that we have dealt with this shows that Members of the Committee accept that there is not a monopoly of wisdom in this area. I also believe that the sincere and honestly held views expressed in this report, even if they are not in complete agreement, will help stimulate public debate. That can only help raise public awareness of the great good that organ donation does.

I would like to thank all those who gave often very powerful, evidence to the Committee as well as our Clerking, Research and Legal team for their hard work in producing this report.

Finally, I would like to thank all those professionals working in the field who, in often traumatic circumstances, help transform lives through their work. Most of all, I thank donors for their gift of life to others.



Jonathan Morgan AM  
Chair, Health, Wellbeing and Local Government Committee

July 2008



## Section 1 - Summary of Recommendations

### Summary

- 1.1 Transplants save, prolong and in many cases transform the lives of those who benefit from them. Much more can and needs to be done to improve organ donation rates in Wales.
- 1.2 The most urgent and productive steps for improving donation rates rest with the early implementation in Wales of the UK Organ Donation Task Force<sup>1</sup> (ODTF) recommendations. We do not rule out introducing presumed consent in Wales at some point in the future. However, we do not believe that it is currently the most urgent priority and believe that it could be a distraction from other more productive actions.
- 1.3 We have agreed the following recommendations. It is important to note that, with the exception of the first, all have been agreed unanimously by the Committee. It is also important to note that, whatever our views on Presumed Consent, we are all agreed that there is a pressing need for more organ donors in Wales.

### Recommendations

#### Presumed Consent

We recommend that the Assembly should not at this stage seek a Legislative Competence Order, to allow the introduction of a system of presumed consent in Wales.<sup>2</sup> *(See page 33)*

We recommend that in any future detailed consideration of legislation to introduce presumed consent in Wales or in the UK a “soft” system should be used, where loved ones are consulted and their views taken into account. *(page 22)*

#### Capacity Issues

We recommend, in anticipation of increased donations flowing from the UK Organ Donation Task Force (ODTF) recommendations, that the Assembly Government should review transplant capacity within Wales to see whether further expansion is justified. Any review should consider the possible viability of facilities located regionally in addition to Cardiff. *(page 10)*

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<sup>1</sup> *Organs for Transplant: A report from the Organ Donation Task Force.* Department of Health 2008

<sup>2</sup> This is the majority view on the Committee supported by Jonathan Morgan AM, Lorraine Barrett AM, Irene James AM, Ann Jones AM, Val Lloyd AM and Nick Ramsay AM. See section 10.4 for the minority view, supported by Helen Mary Jones AM, Dai Lloyd AM and Jenny Randerson AM.

We recommend that the Assembly Government should consider an increase in the number of ICU beds in Wales in order to help increase the number of organs available for transplant alongside the wider implications of such a move. *(page 16)*

We recommend that, as far as it is responsible for doing so, the Assembly Government should implement the ODTF recommendations in full in Wales as a matter of urgency. *(page 28)*

We recommend that the Assembly Government ensures that a comprehensive training programme is developed to make the improvements needed to the training for healthcare professionals to ensure that the ODTF recommendations are implemented properly. *(page 28)*

### Operational Issues

We recommend that the Assembly Government names UK Transplant (UKT) as a body required to prepare a Welsh Language Scheme under the Welsh Language Act 1993. *(page 9)*

We recommend that the Assembly Government should review with UKT how it operates to ensure that it has a clear focus in Wales and on issues specific to Wales. *(page 9)*

We recommend that the Assembly Government should review its financial contribution to UKT to ensure that funding is clearly aligned with service delivery that is responsive to the needs of Wales. *(page 9)*

### Public Awareness Raising

We recommend that the Assembly Government carries out a full evaluation of the *Tell a Loved One* publicity campaign with a view to either extending the campaign or building on it through a consistent programme of public awareness-raising campaigns. *(page 24)*

We recommend that in future publicity campaigns particular attention should be paid to the needs of ethnic minority communities in Wales and how the donation rate among ethnic minorities might be improved. *(page 25)*

We recommend that the Assembly Government explores how public sector bodies in Wales can publicise the Organ Donation Register and Donor Cards in the normal course of their work, including the possibility that their websites include a prominent link to the Organ Donation Register website. *(page 25)*

## Section 2 - Introduction

### Background

2.1 Presumed consent for organ donation was considered by the Committee in November 2007 following a referral from the Petitions Committee of a petition from Kidney Foundation Wales. The petition aimed for a campaign to increase awareness of the need for more organ donors in Wales. However, the Petitions Committee asked us to look at the issue of presumed consent, which Kidney Foundation Wales had highlighted specifically while presenting their petition.

### Terms of Reference

2.2 Given the importance of organ donation and presumed consent and the current active public debate on the issue we were happy to agree that this would be a suitable subject for a Committee inquiry. After receiving advice on the scope of the inquiry we agreed the following terms of reference:

*To examine arrangements for organ donation in Wales and to make recommendations on whether a system of presumed consent should be introduced in Wales with reference to:*

- *Moral, ethical, religious and social views on presumed consent*
- *The potential legal framework for such a system*
- *Examples of weak and strong systems of presumed consent*
- *Existing infrastructure, resources and organisations*
- *Additional resources and infrastructure that would be needed*
- *The interaction between Welsh and UK Transplant arrangements*
- *The views of the public, including minority groups.*
- *Options for improving levels of organ donation without introducing presumed consent.*

### The Inquiry

2.3 We conducted ten oral evidence sessions between March and June 2008 during which we took direct evidence from 19 individuals representing 13 organisations. We received 25 written submissions including 7 from individuals.

- 2.4 We were aware from the outset that this was a very sensitive issue for a range of reasons. We were, therefore, very keen to get the widest possible direct input from the public in Wales. As a result, we held three “open mike sessions” with the public in meetings at locations across Wales. Although the number of people who attended these sessions was disappointing, a range of views were brought to our direct attention as a result. We would like to place on record our thanks to those who attended and gave us the benefit of their views and experiences.
- 2.5 We also looked at other more innovative ways in which we could engage with the public in Wales and encourage participation from a wider range of people in a Committee Inquiry. As a result, Committee Services and the Members’ Research Service compiled a short questionnaire outlining their attitudes to organ donation and presumed consent, which visitors to Assembly public buildings, including the Senedd and the North Wales Office, and the Urdd Eisteddfod were asked to complete. The Assembly’s Education Service also took the questionnaire into schools throughout Wales, as part of their National Assembly awareness-raising with young people. This was combined with results from a website forum and online “quick vote” poll.
- 2.6 The Members’ Research Service analysed the results from these exercises and to the written responses, which are at Annexes A and B.
- 2.7 Spain is acknowledged to have among the most successful organ transplant arrangements in the world with donation rates significantly higher than elsewhere. Spain has introduced presumed consent in relatively recent times. To see what lessons could be learned from their experience, a number of us paid a short visit to Madrid to meet the Director of the Spanish National Transplant Organisation as well as clinicians working in the field. A fuller explanation of arrangements in Spain is in Section 5.
- 2.7 A list of those organisations and individuals who gave evidence in person is at Annex E, a schedule of the papers we considered and a link to transcripts of meetings is at Annex F. Those responding to the call for written evidence are shown at Annex G. These papers and the transcripts of our public meetings are available in full on the Committee’s pages on the National Assembly’s Website [www.assemblywales.org](http://www.assemblywales.org). A glossary of terms used in this report is at Annex H.

## Section 3 - The Legal Position

### Current Legislation

- 3.1 The main legislation covering organ donation in Wales, Northern Ireland and England is the Human Tissue Act 2004<sup>3</sup>. The legislation is based on the principle of appropriate consent and was at least in part a response to the Alder Hey controversy<sup>4</sup>. (The Human Tissue (Scotland) Act 2006<sup>5</sup> governs the law in Scotland but is also based on the same basic principles of informed consent).
- 3.2 This means that consent from an appropriate person (“appropriate consent”) is required before organ donation, can be undertaken. Children who are competent to do so may give their own consent. If they are not competent, or choose not to decide, appropriate consent will be that of a person with parental responsibility for them. Where a child has died, if he or she was competent and made an advance decision to give or refuse consent their wishes will be respected. For certain purposes such as the use of organs for transplantation, the consent of someone with parental responsibility will be appropriate consent provided that the child had not dealt with the issue of consent.
- 3.3 For adults (aged 18 or over), where the person has not made a prior decision, “appropriate consent” is to be given by a person nominated by the deceased or, if no person has been so nominated, by someone in a “qualifying relationship”. Qualifying relationships are: spouse, partner, parent, child, brother, sister, grandparent, grandchild, child of a brother or sister, stepfather, stepmother, half-brother, half-sister and friend of long standing.
- 3.4 The Act deals in the main with matters that are reserved to the UK Government although it did confer upon the Assembly power to appoint a member to the Human Tissue Authority. This power is now exercisable by the Welsh Ministers. The Act also requires the Secretary of State to consult the Welsh Ministers on a range of issues including statutory codes of practice.

### The Assembly’s Competence to Legislate on Presumed Consent

- 3.5 The Government of Wales Act 2006<sup>6</sup> enables the Assembly to pass measures on “Matters” relating to health and social services. At present there is only one such Matter, in the field of health and social services, which relates to redress arrangements. Given this, a Legislative Competence Order (LCO) would need to be agreed giving the Assembly

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<sup>3</sup> Human Tissue Act 2004 c.30

<sup>4</sup> The Royal Liverpool Children’s Inquiry Report - House of Commons 30 January 2001

<sup>5</sup> Human Tissue (Scotland) Act 2006 asp 4

<sup>6</sup> Government of Wales Act 2006 c.32

the legal competence to provide for presumed consent in certain circumstances.

- 3.6 To establish whether a suitable LCO could be framed it would be necessary to establish that the proposal fell within an area in respect of which legislative competence could be conferred on the Assembly. Schedule 7 to the Government of Wales Act 2006, which lists the areas in which the Assembly will be able to pass Acts of the Assembly if there is an affirmative vote in a referendum, is a useful reference point in this respect. Paragraph 9 of Schedule 7 sets out the areas relating to health and health services. It also sets out exceptions in the field of health and social services (essentially those reserved from the devolution settlement) in respect of which legislative competence would not be granted.
- 3.7 Acquiring legislative competence is not therefore a straightforward matter. The legal complexities should not be underestimated and should be approached with caution. Further consideration would need to be given to a number of the factors noted. However, subject to the various caveats referred to earlier, the advice we have received<sup>7</sup> suggests that there appears to be no fundamental legal reason why the Assembly should not seek the power to legislate to introduce presumed consent in Wales if there is the political will to do so.

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<sup>7</sup> *Assembly Parliamentary Legal Service* - Paper to Committee reference HWLG(3)-03-08 (P1): 30 January 2008

## Section 4 - Capacity and infrastructure

### Existing infrastructure, resources and organisations

- 4.1 The Transplant Directorate of the University Hospital of Wales (UHW) in Cardiff is currently the only Transplant organisation within Wales and is responsible for kidney and pancreas transplantation in South West and Mid Wales. It is also responsible for zonal retrieval of pancreata all around Wales and is the zonal retrieval team for non heart beating kidneys for all of South and West Wales<sup>8</sup>.
- 4.2 The Directorate has performed more than 2,100 transplants over 30 years. There has been a significant increase of kidney and pancreas transplants in the last year with 113 transplants being performed, an increase of 22% compared to the previous year. The Minister for Health and Social Services has recently approved a business case for the Transplant Directorate's strategy to increase transplantation in Wales in the next 5-7 years by 50%. A new dedicated Transplant Centre has been built and will be ready in around 18 months. There is a dedicated kidney and pancreas transplant team and new recruitment is taking place for both surgical and nursing staff in order to meet the anticipated new demand<sup>9</sup>.
- 4.3 Kidney transplants for patients in North Wales are carried out mainly in Liverpool in the Royal Liverpool Hospital. Transplants for Welsh patients are also carried out in Bristol and elsewhere, particularly for hearts and lungs. Dr Abdul Hammad<sup>10</sup> of the Royal Liverpool Hospital explained the process to us in this way:

*"The whole process is overseen by UK Transplant. Each organ has its regional donation team. For example, liver retrieval is done by Birmingham for north Wales, while we [Royal Liverpool Hospital] undertake kidney retrieval in Liverpool. Heart retrieval is done by Wythenshawe Hospital in Manchester. Each organ has its regional centre that is responsible for organ retrieval."*

- 4.4 UK Transplant (UKT) is an operating division of NHS Blood and Transplant (NHSBT). Its remit is to manage transplant waiting lists, allocate organs, collect and analyse data for all transplant units in the UK and promote organ donation and the NHS Organ Donor Register.<sup>11</sup> UKT has around half

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<sup>8</sup> Evidence from the Nephrology and Transplant Directorate, University Hospital of Wales - Paper to Committee reference HWLG(3)-07-08 (P1): 9 April 2008.

<sup>9</sup> As above.

<sup>10</sup> National Assembly for Wales Record of Proceedings - Health, Wellbeing and Local Government Committee 19 June 2008 para 150.

<sup>11</sup> Evidence from UK Transplant - Paper to Committee reference HWLG(3)-07-08 (P2): 9 April 2008.

a dozen co-ordinators based in South Wales<sup>12</sup>. In North Wales, co-ordinators cover between them the wider area including Liverpool. This includes one Welsh speaking co-ordinator who lives in North Wales<sup>13</sup>.

4.5 The UK Organ Donation Task Force (ODTF) recommendations mean that the number of co-ordinators seems likely to increase significantly (possibly to around 14 in South Wales). The ODTF has recommended that a single UK Organ Donation Organisation be established and it has been agreed that NHSBT should lead the process of establishing this organisation. The new organisation is likely to be based around UKT's current and increased co-ordinator network. NHSBT would in future employ co-ordinators centrally rather than being employed by individual Trusts.

### Criticisms of UK Transplant

4.6 In their oral evidence Kidney Foundation Wales<sup>14</sup> in particular was critical of UKT's focus on and knowledge of Wales. They raised questions about:

- UKT's record in getting people to register on the Organ Donation Register and its lack of targets for doing so.
- Its knowledge of how the media operates in Wales.
- Leadership within the organisation.
- Its lack of awareness of specific Welsh developments (such as memorials for organ donors) and that it pays insufficient attention to the needs of Welsh speaking families.
- The extent to which the Whitehall agenda sets the direction for its business planning.
- The size of the organisation and whether it has sufficient focus on local issues and campaigns.

4.7 In relation to the Welsh language concerns were confirmed to some extent by the evidence from the UK transplant Co-ordinators Association who said that *"the only literature that is produced in Welsh is the organ donor card. We requested that the consent form be translated into Welsh, but that never happened."*<sup>15</sup>. However, they also made it clear that they believed that co-ordinators had *"been led professionally by UK Transplant in the same way as the rest of the UK. Resources from UK*

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<sup>12</sup> Oral evidence - UK Transplant Co-ordinators Association - National Assembly for Wales Record of Proceedings (RoP)- Health, Wellbeing and Local Government Committee (HWLG) 14 May 2008 - para 31.

<sup>13</sup> Oral evidence - Mr Abdul Hammad, Director, Nephrology and Transplant Directorate, Royal Liverpool Hospital - RoP, HWLG 19 June 2008 - para 160.

<sup>14</sup> Oral Evidence - Kidney Foundation Wales - RoP, HWLG 14 May 2008 paras 154, 170-171, 177-178

<sup>15</sup> Oral evidence UK Transplant Co-ordinators Association - paras 110-116



*Transplant have been put into south Wales in the same way as has been the case in the rest of the UK".<sup>16</sup>*

4.8 We do not doubt that UKT does much excellent work throughout the UK. We were impressed with the professionalism and commitment of the co-ordinators who gave evidence to us as part of the UK Transplant Co-ordinators Association. However, we are concerned at what we heard from Kidney Foundation Wales, which is a well respected organisation in Wales. We doubt that they would have made their criticisms lightly. In the case of the Welsh language, there can be no excuse for not providing at least a minimum level of service to Welsh speakers.

**We recommend that the Assembly Government names UK Transplant (UKT) as a body required to prepare a Welsh Language Scheme under the Welsh Language Act 1993. [Recommendation 1]**

4.9 We understand that the Assembly Government provided UKT with funding of £562,000 in 2007-08<sup>17</sup>. It was unfortunate that we were not made aware of this until after we had completed our evidence gathering for this inquiry. If this information had been available at the time, it might have allowed us to explore further with the Minister what level of service she expected for this not insubstantial amount of funding.

4.10 The fact that the Minister and her senior officials did not have this funding at the forefront of their minds, when giving evidence to the Committee, perhaps shows that the Assembly Government needs to focus more attention in future on its relationship with UKT to ensure that it delivers services appropriately tailored to the needs of Wales.

**We recommend that the Assembly Government should review with UKT how it operates to ensure that it has a clear focus in Wales and on issues specific to Wales. [Recommendation 2]**

**We recommend that the Assembly Government should review its financial contribution to UKT to ensure that funding is clearly aligned with service delivery that is responsive to the needs of Wales. [Recommendation 3]**

## **The interaction between Welsh and UK Transplant arrangements**

4.11 Apart from the common legislative framework, arrangements for co-ordinating transplant arrangements are currently integrated throughout the UK through UK Transplant and the various regional teams. Despite the criticisms of the service provided by UKT in Wales, there have been few suggestions that it should not continue to be the main organisation

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<sup>16</sup> Oral evidence UK Transplant Co-ordinators Association - para 31

<sup>17</sup> Letter to Committee Chair of 30 June 2008 from Professor Mike Harmer, Deputy Chief Medical Officer, Welsh Assembly Government.

responsible for co-ordinating the management of transplant waiting lists and allocating organs. Neither has there been any suggestion that organs harvested in Wales should not continue to be made available across the UK (and more widely) based on clinical need.

- 4.12 As noted above, many Welsh patients receive their transplants in other parts of the UK. There are currently no facilities in Wales to carry out heart, and other specialised transplant surgery, nor does there seem much prospect of this changing in the near future. Whatever happens in future it is accepted that there will be a need for some transplants to continue outside Wales.

### **Future Transplant Capacity**

- 4.13 The ODTF believe that their recommendations can result in a 50% increase in organ donations after death within 5 years. Whether this forecast is accurate or not it seems likely that the number of organs available for transplant is likely to increase significantly.
- 4.14 In our view planning for this likely increase in donations should start now. As welcome as the increased capacity planned for UHW is, consideration needs to be given to whether this increase is sufficient to meet the extra demand likely to be caused by the implementation of the ODTF recommendations.
- 4.15 Currently all transplants in Wales are carried out in UHW in Cardiff. Although we accept that the current level of transplant activity in Wales may make it difficult to demonstrate the viability of transplant centres outside Cardiff, we also believe that consideration needs to be given to whether an increased in donation rates could make centres in other areas more viable.
- 4.16 The planned expansion at UHW will bring the number of transplants performed annually to around 150. On the most recent figures<sup>18</sup> this would make Cardiff one of the biggest kidney transplant centres in the UK. There currently appear to be a number of centres in the UK where the number of kidney transplants each year is only around a third of this level<sup>19</sup> (we assume these centres are viable).
- 4.17 Given the expected increase in demand then it seems to us that it may in future be viable to base new facilities to meet this demand outside of Cardiff. While we have not considered this matter in any detail we believe this is an area that is worthy of further study by the Assembly Government.

**We recommend, in anticipation of increased donations flowing from the UK Organ Donation Task Force (ODTF) recommendations, that the Assembly Government should review transplant capacity within Wales**

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<sup>18</sup> Transplant Activity in the UK 2006-2007 (table 3.1) - UK Transplant August 2007

<sup>19</sup> As above

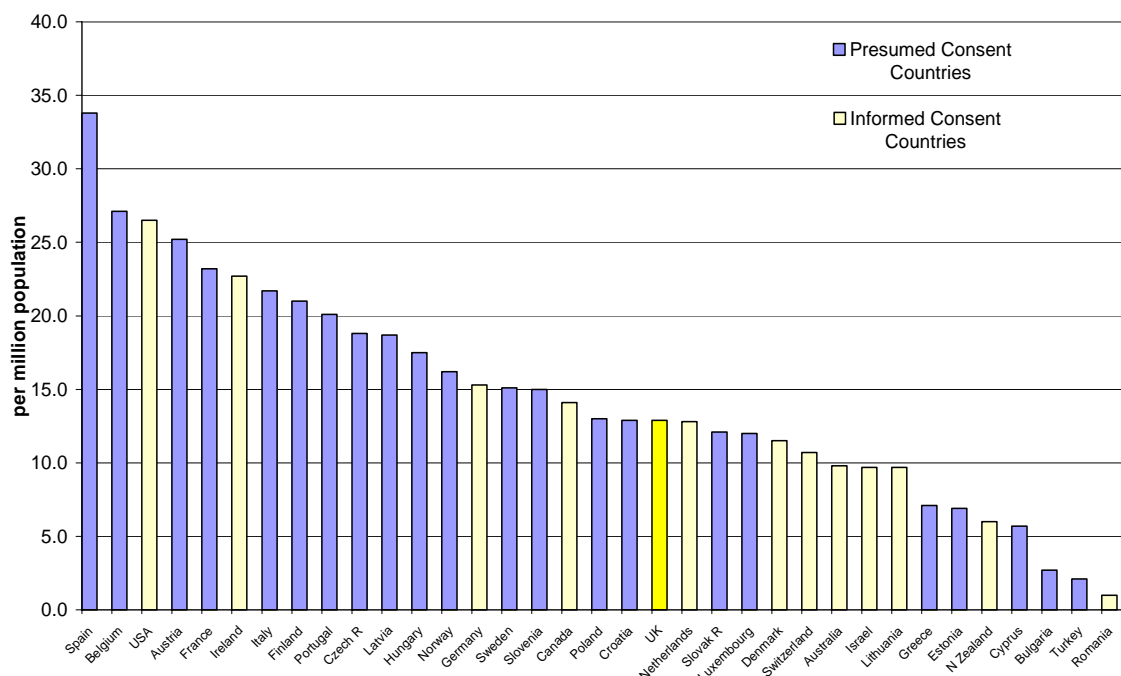
to see whether further expansion is justified. Any review should consider the possible viability of facilities located regionally in addition to Cardiff. *[Recommendation 4]*

## Section 5 - International Perspective

What happens elsewhere?

5.1 The chart below gives an international perspective on presumed consent. The chart includes a range of European countries for which data is available as well as the USA, Canada, Australia and New Zealand. The majority of these countries (60%) have presumed consent but there is a significant number (40%) that operate under informed consent arrangements.

International Deceased Organ Donation Rates 2006<sup>20</sup>



5.2 Most of the countries with relatively high rates of donation have presumed consent but there are notable exceptions such as the USA and Ireland. Similarly, a number of the countries with the lowest donation rates also operate presumed consent. While there may appear to be a correlation between generally higher rates of donation and presumed consent regimes, such comparisons should be treated with considerable caution as there may be a range of other factors that influence donation rates. What is clear is that the existence of presumed consent legislation does not guarantee high donation rates.

<sup>20</sup> Council of Europe Transplant Newsletter: September 2007 - International Figures on Organ Donation and Transplantation - 2006. For precise figures and more information on sources see Annex D.

## Research Evidence

- 5.3 There is little direct research evidence that has been brought to our attention to support the proposition that presumed consent has a positive effect on organ donation rates. However, a study published in the *Journal of Health Economics* in 2006 by Alberto Abadie of Harvard University and Sebastien Gay of the University of Chicago, has been cited by a number of witnesses who favoured presumed consent<sup>21</sup>.
- 5.4 The study drew on data from 22 countries over a 10-year period and analyzed the impact of presumed consent laws on donation rates. It points out that there may be a range of factors that affect organ donation rates and that most previous studies have found that presumed consent countries do not produce significantly higher organ donation rates. It concluded that further research is needed to better understand how societies perceive and respond to legislative changes of this nature. However, once other determinants of organ donation are accounted for, deceased donation rates are 25-30% higher on average in presumed consent countries.

## The Spanish Experience

### Background

- 5.5 Spain is acknowledged to have a highly successful organ transplant organisation. It has the highest organ donation rate from deceased donors in the world at 33.8 per million population (pmp) in 2006. The comparable figure for the UK in 2006 was 12.9 pmp<sup>2223</sup>. Spain also operates under a system of presumed consent, which was introduced there in 1979. In the light of this a number of us paid a short visit to Madrid to meet the Director of the Spanish National Transplant Organisation, Dr Rafael Matesanz, and clinicians working in the field, to see what if any lessons we could learn from the Spanish experience.
- 5.6 We would like to place on record our thanks to Dr Matesanz and his transplant co-ordinator colleagues in the Hospital Clinico San Carlos for their time and courtesy in explaining the Spanish system and answering our questions.

### The Spanish Model

- 5.7 The philosophy behind the Spanish model is that improvements in organ donation are mainly the result of good organisation. Although they

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<sup>21</sup> Abadie A, Gay S. The impact of presumed consent legislation on cadaveric organ donation: a cross-country study. *J Health Econ* 2006;25 :599-620

<sup>22</sup> As Above footnote 20.

<sup>23</sup> Wales has a somewhat higher rate at 17.2 pmp but the significance of this should be treated with some caution. Source: *Transplant Activity in the UK: 2006-07* - NHS Blood and Transplant August 2007

accept that legislative changes, publicity campaigns and promotion of donation have an effect, these are of considerably less importance than ensuring that services are organized to maximize the number of potential donors that become actual donors.

5.8 The Spanish system is headed by the National Transplant Organisation the ONT<sup>24</sup>. This coordinates the activities of a series of regional transplant organisations and a nationwide network of hospital based co-ordinators. The other factors that Dr Matesanz<sup>25</sup> identified as being key to their success were:

- A three level Transplant coordination network organized at national, regional and hospital level with each level having its own distinct responsibilities. There are now more than 150 co-ordinator teams in Spain compared to less than 20 in 1988.
- Hospital co-ordinators based inside hospitals. Co-ordinators are mostly part time (in respect of their co-ordinator role) and are doctors rather than nurses (although nurses are involved in the bigger hospitals).
- Continuous brain death audit
- Central support from the ONT, particularly for small hospitals, including for organ sharing, transport, waiting list management, transplant registries, statistics, general and specialised information and action which can improve the whole process of organ donation and transplantation.
- Great effort in medical training.
- Reimbursement by the regional health administrations, for procurement and transplant activity.
- Proactively engaging with the mass media.

5.9 Although presumed consent was introduced in Spain in 1979, the ONT was not established until 1989. At that stage, organ donation rates in Spain were around the same (approx 14 pmp) as they are currently in the UK. After its initial establishment, there has been a virtually constant rise in rates since the ONT was established.

#### Presumed Consent in Spain

5.10 In addition to the points noted above, one of the other key factors that Dr Matesanz identified as being key to the success in Spain was what he described as “an adequate legal and technical background”. This would include a definition of brain stem death, whether organ retrieval needed family consent and not paying compensation for donation or grafted organs. A clear system of consent would obviously be part of this legal framework.

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<sup>24</sup> Organización Nacional de Trasplantes

<sup>25</sup> A more detailed explanation of these points can be found in an article by Dr Matesanz in issue 62 of the NHS Blood and Transplant Bulletin at [www.uktransplant.org.uk](http://www.uktransplant.org.uk).

- 5.11 As mentioned earlier, Spain has had a system of presumed consent since 1979. However, the law has developed in such a way that that the consent of the family or loved ones is always requested. In fact, a certificate from a judge is needed before organs can be taken and judges very rarely grant certificates without explicit family approval.
- 5.12 It also became clear during the course of our visit that there are no national arrangements for an “organ opt-out register”, or some similar legally mandated device to allow citizens to express their preferences. In practice, although Spain may technically operate under a presumed consent law, it has evolved into a system of “family consent”.
- 5.13 This is not to say that the law on presumed consent has no effect. It may well be that the ability of clinicians to approach relatives on the basis of whether there is any reason not to take organs, rather than whether it is known whether the deceased would have wanted organs to be taken, does make a difference. It may also be that the decision to move to presumed consent helped frame public debate in a way that has led to other changes that have improved donation rates. However, these factors do not seem to adequately explain the huge advances made in Spain since the ONT was established.
- 5.14 Dr Matesanz himself pointed out that the significant increase in organ donation since the ONT was established cannot be attributed to any change in Spanish legislation because this has remained constant since 1979. Despite this he was also very clear that, while presumed consent may not be a significant factor in the recent Spanish success story, he had a clear preference for presumed consent as the default legal position.

### Other Factors

- 5.15 One other factor that Dr Matesanz felt was important in helping Spain increase its donation rates so significantly is the relatively higher number of intensive and critical care adult beds in Spain. Dr Matesanz told us that Spain has 8.5 per 100,000 population (3,736) while the UK has only 6.4 per 100,000 (3,240). In proportional terms this means Spain has around 30% more critical care beds per head of population than the UK.
- 5.16 While Dr Matesanz felt that this was an important factor Dr Mike Harmer in giving evidence with the Minister for Health and Social Services was more sceptical. He said:

*“I am not sure that there is a direct link, because presumed consent is influenced by the whole healthcare system, and the Spanish healthcare system is different to the national health service.”<sup>26</sup>*

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<sup>26</sup> Oral evidence Professor Mike Harmer, Deputy Chief Medical Officer, Assembly Government - RoP, HWLG 19 June para 63.

However, he went on to say:

*“Clearly, the more critical care facilities that you have, the more likely you are to be able to run an appropriate transplant service. You will identify more donors because they will be picked up quicker. We lose some donors because they never make it to critical care. We are certainly reviewing critical care facilities—they are constantly under review. We are also looking at the further development of trauma centres following the National Confidential Enquiry into Patient Outcome and Death report, which stressed the importance of having major centres and super critical care units. So, that is under review as well.”<sup>27</sup>*

5.17 The number of critical care beds is of wider importance and needs to take account of a range of other factors than their impact on organ donation rates. However, given the importance that Dr Matesanz attached to this factor, as well as Dr Harmer’s acceptance that more critical care facilities can help in identifying more donors, we believe that further work needs to be done to establish the impact that the number of ICU beds has on organ donation rates.

5.18 Clearly any work done in this area will need to take account of the other factors that are of equal if not more importance. However, the clear economic case for organ donation, made by the Organ Donation Task Force report, should also be taken into account. The report said<sup>28</sup>:

*The most obvious and significant economic benefits are shown by an analysis of the costs of renal replacement therapy - dialysis - compared with the costs of kidney transplantation. Current indicative costs suggest an average annual cost for dialysis of £23,177, compared with an initial cost of £42,025 for a transplant followed by annual maintenance costs of £6,500.*

**We recommend that the Assembly Government should consider an increase in the number of ICU beds in Wales in order to help increase the number of organs available for transplant alongside the wider implications of such a move. [Recommendation 5]**

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<sup>27</sup> Oral evidence Professor Mike Harmer, Assembly Government - para 63

<sup>28</sup> Organ Donation Task Force Report - Section 5



## Section 6 - Public Views on Presumed Consent

### Polling evidence

- 6.1 A number of witnesses have claimed that opinion polling evidence shows that a large majority of the public in the UK would be prepared to donate their organs. However, only around a quarter of the population have signed up for the Organ Donor Register and the family refusal rate in real situations is over 40%. Even taking opinion polling evidence at face value suggests that there are a very significant number of people who are either not prepared to donate or have real concerns about doing so.
- 6.2 Set against this is the evidence from Spain where public attitudes to donation are not markedly different to the UK (if anything, support for donation is not as strong) yet the numbers donating are much higher and the family refusal rate much lower (around 15%). In fact, UK ex-patriots have a lower refusal rate in Spain than do the Spanish themselves. It seems clear from this that it is not public attitudes to donation that lead to the higher donation rates in Spain but how donation services are organised and delivered there. What is not clear is the extent to which this is due to presumed consent compared to other factors in the Spanish system. Although preferring presumed consent as the default legal position, Dr Matesanz, the head of the Spanish National Transplant Organisation, was very clear that presumed consent was only a small part of the Spanish success story.

### Views among Minority Groups

- 6.3 There appear to be markedly different attitudes to organ donation among non-white minority groups<sup>29</sup> where the family refusal rate can be much higher. The reasons for this are not clear but it may be that improved donation rates can be achieved by placing greater emphasis on linguistic and cultural factors when families are approached.

### Committee Surveys for this Inquiry

- 6.4 As part of the evidence gathering for this Inquiry, visitors to Assembly public buildings including the Senedd, and to the Urdd Eisteddfod, were asked to complete a short questionnaire outlining their attitudes to organ donation and presumed consent. The Assembly's Education Service also took the questionnaire into schools across Wales. We also hosted a website forum and conducted online "quick vote" polls.

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<sup>29</sup> For instance see Organ Donation Task Force Report section 4.48.

6.5 In total almost 900 questionnaires were returned. The results indicate strong support for organ donation. 72% of the questionnaires from the general public and 53% of those from young people indicated views that were clearly supportive of organ donation<sup>30</sup>. On presumed consent the position is less clear cut. 48% of the general public and 30% of young people expressed clear support for presumed consent compared to 47% and 69% respectively who favoured other methods of consent or who did not want their organs removed.

6.6 A more detailed analysis and breakdown of the results of these exercises is in Annex A. We do not claim that this survey was wholly representative of public opinion in Wales. However, the views of a significant number of people were surveyed and the results suggest that public views on presumed consent are not straightforward. If public support is the key to introducing presumed consent, then that support cannot be taken for granted. In the website Quick Vote, for example, 24% of people said they would not want their organs removed (see Annex A).

### Moral and Ethical Arguments

6.7 A range of views have been put to the Committee on these issues and an analysis of the written submissions we have received is in Annex B.

#### Arguments In Favour of Presumed Consent

6.8 In broad terms, most of those who have given evidence support presumed consent and believe that it is a reasonable, moral and ethical way to proceed. They generally believe that presumed consent will make more organs available for transplantation and that this is a clear benefit to those who have transplants - their lives may be saved, prolonged and in many cases transformed by transplants. The claim is also made that presumed consent better reflects the wishes of the majority who, polling evidence suggests, would like their organs to be used after they die. The claim is also made that presumed consent allows the subject of the use of organs to be broached more sensitively with loved ones by clinicians.

#### What the public said:

- *"If you had to opt-out it would force you to think about the subject a bit more."*
- *"People should opt out rather than opt-in. It would increase the amount of organs available."*

<sup>30</sup> The questionnaires from young people were completed following a group discussion of issues.

- *"This is the land of the living. To hoard organs in the dead, preventing them from being reused is the ultimate in selfishness."*
- *"Presumed consent avoids the inevitable delays and distress that inevitably accompany a search for the deceased's wishes. In my experience as a GP, relatives are usually comforted by the fact that their loved one's death has contributed to life for someone else."*
- *"You don't need your organs when you die so they should automatically be given to someone who needs them."*

### Arguments Against Presumed Consent

6.9 Arguments made against presumed consent include that it is essentially the "nationalisation" of organs, that there is no way of knowing in many cases what the wishes of the deceased are (and that, inevitably, organs will be taken from those who would not have wanted them to be taken), that organs will no longer be seen as a "gift" and that presumed consent is no consent at all, or is at best an absence of objection<sup>31</sup>.

#### **What the public said:**

- *It is interfering with people's rights to take their organs when they die without asking.*
- *Everyone should have the right to decide if they wish to donate or not.*
- *I already have a card but if I didn't, I would not be happy for anyone to take my organs automatically unless my family had given permission.*
- *"Presumed consent" is a bit too drastic.*
- *As a nurse I think it should be the individual's choice. Consent should not be assumed, and should still be in writing.*

### Religious Views

6.10 Evidence from religious organisations suggests that there are few fundamental tenets that oppose organ donation or, for that matter,

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<sup>31</sup> For instance, see evidence from Patient Concern - Paper to Committee reference HWLG(3)-09-08 (P3): 23 April 2008.

presumed consent. However, religions and religious belief should not be viewed monolithically and any change to the law on consent would need to take account of different strands of belief, both between and within religions (see Annex B).

### Ethical Issues

6.11 One of the main ethical issues surrounding presumed consent is the potential for conflict between the interests and rights of potential donors compared with those who are waiting for transplants. Simply put, the potential for donation might lead to compromises in the care of potential donors.

6.12 We have heard no evidence that suggests this is the case but around 36% of those who completed our questionnaires cited this as a concern. In our view, a very clear separation of clinical responsibility, well understood by the general public, between the care of the sick person and those who might receive their organs, would need to be considered carefully if presumed consent is to be introduced.

6.13 The ethics and sensitivity of the approach to loved ones following bereavement is also a concern. It is important, under any given system of consent, that loved ones are approached sensitively at what can be a devastating and deeply traumatic time in their lives. We have heard of resistance to approaches being made to relatives about whether their loved ones would have been willing to donate organs. We assume this is in the belief that it will lead to further and unnecessary distress.

6.14 We understand these concerns but believe that if donation rates are to be increased, whether under the current consent arrangements or under presumed consent, there is a need for loved ones to be approached in all cases where donation is a possibility. These approaches clearly need to be sympathetic and understanding of the feelings of loved ones. This means more and better training for both transplant co-ordinators and the clinical and nursing staff who are involved in end of life care. We believe that such training would be beneficial whether or not presumed consent is introduced. We note that the ODTF makes relevant recommendations in these areas and we fully support their early implementation.

### Choosing organs

6.15 The evidence on whether presumed consent should apply to all organs or whether people should be able to choose to donate some and not others is dealt with in Annex B. Although opinion was somewhat divided, it seems clear to us that while presumed consent should apply equally to

all organs, public support is unlikely to be given to any system that forces a straight 'all or nothing choice'. In our view any opt out arrangements should be able to accommodate all shades of consent including consent for some organs to be taken but not others.

**What the public said:**

- *"I would accept compulsory organ donation EXCEPT my eyes."*
- *"I am very for compulsory organ donation, but I would like to have a choice of which organs I would like to donate."*
- *I would be happy to donate my organs but not my eyes. (I would like to keep them just in case I need them in the afterlife.)*

**Soft or Hard Consent?**

6.16 Those who have given evidence have for the most part favoured a "soft" or "weak" system of presumed consent whereby the views of loved ones must be taken into account and there is a strong presumption that their wishes will be respected. We do not believe that there is sufficient public support in Wales or the UK to introduce a "hard" or "strong system where organs are taken even when loved ones have strong objections.

6.17 We accept that there are those who object to their wishes being overridden by relatives, particularly where they hold very strong views on the matter or where family relations may have broken down during life. However, under the Human Tissue Act 2004 donor cards currently provide sufficient consent for organs to be taken even where loved ones object. Despite this there is an understandable reticence for both legal and moral reasons on the part of clinicians to take organs in these circumstances.

**What the public said:**

- I would be worried that my loved ones wouldn't be given enough say in what happened to my body.
- The family would need time to discuss when such a situation arises.
- When someone dies, it's an emotional enough time. The last thing the family needs is to be asked whether to cut up the body.
- I am content for there to be a presumed right to my organs but would still like this discussed with my next of kin.

We recommend that in any future detailed consideration of legislation to introduce presumed consent in Wales or in the UK a “soft” system should be used, where loved ones are consulted and their views taken into account. [Recommendation 6]

### Required Request and Mandated Choice

- 6.18 Apart from presumed consent other possibilities have been suggested as ways of increasing donation rates that do not raise the concerns that many people have about presumed consent. Among these are “required referral” and “mandated choice”.
- 6.19 Required request or required referral operates in the United States of America. Under this system hospitals are required by law to refer all potential donors to their local Organ Procurement Organisation (these are not-for-profit organisations carrying out a broadly similar role to that of UKT in the UK). There is evidence that this system has resulted in fewer opportunities for donations being overlooked. However, although the introduction of this scheme saw an initial increase in the availability of organs, over time the numbers have declined<sup>32</sup>. Given the very different cultural and economic background to the provision of healthcare in the United States, and in the absence of strong evidence that it can make a real and lasting difference, we are not convinced that required request is worth pursuing in our context in Wales.
- 6.20 Mandated Choice would be a legally mandated decision where all adults would be required by law to indicate their wishes regarding use of their organs after death. This could be done through the electoral roll or be mandatory on registering with a general practice or some other mechanism. Individuals would be free to make whatever choices they wanted in relation to the use of their organs but they would, nevertheless be required to make a decision.
- 6.21 The system was advocated by Professor John Saunders<sup>33</sup> the current chair of the Royal College of Physicians’ Committee for Ethical Issues in Medicine. Professor Saunders argued *“this proposal is worthy of examination but it is not yet at the stage at which it should be accepted. However, at the moment, it has not been explored, and I think that that is highly reprehensible. It would be reprehensible if it were not explored.”*<sup>34</sup>

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<sup>32</sup> For further background see- Evidence from UK Transplant - Paper to Committee reference HWLG(3)-07-08 (P2): 9 April 2008.

<sup>33</sup> Oral evidence Professor John Saunders - RoP, HWLG 19 June 2008 - paras 192-260; and Written evidence - Paper to Committee reference HWLG(3)-16-08 (P2): 19 June 2008.

<sup>34</sup> RoP 19 June - para 228.

6.22 Perhaps unfortunately, we did not have the time to explore mandated choice in any great detail. Professor Saunders' views, as eminent as they are, are not mainstream, as he acknowledges. He also acknowledged that there were a number of practical issues that would need greater study before mandated choice could be introduced. In any event, public debate on this issue, rightly or wrongly, seems to have coalesced around presumed consent versus informed consent. Professor Saunders' views deserve further detailed exploration. They illustrate some of the concerns around presumed consent but we are not in a position to take any authoritative position on them at this stage.

## Section 7 - Raising Awareness

### Public Awareness Campaigns

- 7.1 One of the strongest themes running through the evidence we have taken is the need to raise public awareness of organ donation and transplant issues to encourage more people to donate their organs after death. There has also been implicit (and explicit - see Section 4) criticism that not enough is being done to publicise organ donation.
- 7.2 In Wales the Assembly Government has supported The *Donate Wales - Tell a Loved One* campaign with £100,000 of public funding. The campaign is a high profile means of raising awareness of the issue and attempts to encourage people to talk to their families and loved ones about their wishes in respect of organ donation. The campaign aims to encourage an additional 50,000 people to join the organ donation register and features television adverts including stars like James Hook, Connie Fisher and Colin Jackson, who have all joined the register and told their loved ones<sup>35</sup>.
- 7.3 The campaign has been well received as a high profile means of raising awareness of the issue. It is too soon to say yet what success it will have in increasing the number of organs made available from Wales for donation. Evidence from the Minister<sup>36</sup> suggested that 5,385 new donors have signed up to the Register in Wales since the campaign started on 13 May. Kidney Wales Foundation have told us separately that 9,198<sup>37</sup> new donors signed up between 13 May and 9 July but it is not known to what extent the Welsh campaign has contributed to this or whether other factors, such as the Committee Inquiry, TV coverage or other UK campaigns have helped.
- 7.4 The Committee welcomes and strongly supports this initiative. If it proves to be as successful, as initial indications suggest, then it will be money well spent. It is however, important that the impetus is not lost. Organ donation needs to be consistently and regularly put before the public through campaigns such as this one if the initial success is to be lasting.

**We recommend that the Assembly Government carries out a full evaluation of the *Tell a Loved One* publicity campaign with a view to either extending the campaign or building on it through a consistent programme of public awareness-raising campaigns. [Recommendation 7]**

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<sup>35</sup> Evidence from the Minister for Health and Social services - Paper to Committee reference HWLG(3)-16-08 (P1): 19 June 2008

<sup>36</sup> Oral evidence, Minister for Health and Social Services, RoP, HWLG 19 June - para 11

<sup>37</sup> Figures supplied by Kidney Wales Foundation from UK Transplant.



7.5 As mentioned earlier, and acknowledged also by the Organ Donation Task Force<sup>38</sup>, family refusal rates among the Black and Minority Ethnic (BME) population tend to be markedly higher than is generally the case. As well as the research envisaged by the Organ Donation Task Force into how organ donation can best be promoted to the BME population, campaigns in Wales need to ensure that they are promoting messages that are of relevance to minority groups.

**We recommend that in future publicity campaigns particular attention should be paid to the needs of ethnic minority communities in Wales and how the donation rate among ethnic minorities might be improved. [Recommendation 8]**

### The Role of the Public Sector

7.5 Public sector organisations in Wales regularly send information to the public on a variety of issues. From council tax notices and electoral registration sent by local authorities, through car tax and registration documents from central government to consultation exercises run by the Assembly Government, public sector bodies are constantly sending information to the public. It may, therefore, be cost effective to include with these notices information about organ donation and the organ donation register. Some public sector organisations may already be doing this but there is a need for this information to be consistent and regular if the issue is to be kept at the forefront of the public mind.

7.6 All public sector bodies in Wales run websites. A prominent link to the organ donation register website on the home pages of all publicly funded websites in Wales would act as a powerful and cost-effective reminder of the importance of organ donation. Although, it would be for each public body in Wales to look at the implications of these steps the Assembly Government is best placed to help public bodies see how they can make a difference in publicising organ donation. The organ donation website can be found at: <http://www.uktransplant.org.uk>

**We recommend that the Assembly Government explores how public sector bodies in Wales can publicise the Organ Donation Register and Donor Cards in the normal course of their work, including the possibility that their websites include a prominent link to the Organ Donation Register website. [Recommendation 9]**

#### *What the public said:*

- *An advertising campaign with a prominent comedian, for example, waxing lyrical about how various bits of their anatomy might be used for other people might raise public consciousness and a few laughs.*

<sup>38</sup> Organ Donation Task Force Report - Recommendation 13

- *People should be made more aware of the shortage of organs available for donation.*
- *Better marketing.*
- *Let's just make sure that we communicate effectively with the people of Wales and makes it really easy to opt out for anyone who wishes to (a simple website, telephone helpline, through your GP or using the TV remote).*

## Raising Awareness of Presumed Consent

7.7 Set out above are measures aimed at increasing awareness of organ donation under current consent arrangements. The central point of this inquiry however, is to consider arrangements for presumed consent. We hope that this inquiry, the work that is being done by the Organ Donation Task Force, who have now been asked to look at presumed consent, as well as the Assembly Government's plans<sup>39</sup> to consult the public in Wales will lead to a growing and well informed public debate around this issue. We consider this to be essential if presumed consent is ever introduced.

7.8 More specifically, if legislation on presumed consent is to be introduced there would be a need to ensure that there was not an adverse public reaction caused by misunderstanding of what was proposed. This would require a substantial public education campaign to inform people of their right to opt out and robust arrangements to ensure that opt out preferences could be recorded and respected.

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<sup>39</sup> Oral evidence Minister for Health and Social Services RoP 19 June - para 4

## Section 8 - The Work of the Organ Donation Task Force

### Background

8.1 The Organ Donation Task Force (ODTF) was set up by the UK Government in 2006 with the following terms of reference:

- To identify barriers to organ donation and transplantation and recommend solutions within existing operational and legal frameworks.
- To identify barriers to any part of the transplant process and recommend ways to overcome them to support and improve transplant rates<sup>40</sup>.

8.2 In considering this remit, the Task Force was chaired by Elisabeth Buggins the Chair of West Midland Strategic Health Authority and a non-executive director of NHS Blood and Transplant. The membership of the Task Force was mainly drawn from the medical profession and academic institutions but also included lay and donor family representatives<sup>41</sup>. The Task Force did not include anyone with a specific remit to represent Welsh interests but one representative from each of the devolved governments, including the Assembly Government, attended Task Force meetings.

8.3 The Task Force published its report "Organs for Transplant"<sup>42</sup> in January this year. The report made 14 recommendations all of which have been accepted by the UK and Assembly Governments. The Task Force estimates these recommendations could lead to a 50% increase in the number of organ donations across the UK.

8.4 Implementation of the recommendations will be taken forward on a UK-wide basis but the Assembly Government intends to establish an implementation project group in Wales which will include representatives from the clinical, lay and public, and from the voluntary and charitable sectors. The appointed Chair of the implementation project group in Wales will also sit on the UK-wide implementation oversight group<sup>43</sup>.

8.5 The remit we agreed for this inquiry was narrower than that set for the ODTF. Our primary focus has been to look at presumed consent and the contribution that it might make to increasing organ donation rates. Nevertheless, we have looked, albeit in less detail and perhaps from

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<sup>40</sup> *Organs for Transplant: A report from the Organ Donation Task Force*. Department of Health 2008.

<sup>41</sup> As above

<sup>42</sup> As above

<sup>43</sup> Written evidence from the Minister for Health and Social Services - Paper to Committee reference HWLG(3)-167-08 (P1): 19 June 2008.

more of a lay perspective, at many of the same issues that the ODTF has considered.

- 8.6 Many of the recommendations seem familiar to those of us who visited Spain, particularly a UK wide network of trained co-ordinators based in critical care units, seeing donation as a regular part of the hospital's work and the considerable emphasis on training. We were reassured that the Minister and her senior officials, in their oral evidence,<sup>44</sup> believed that Wales would get at least, if not more than, its "fair share" of the additional transplant co-ordinators recommended by the Task Force.
- 8.7 We do not believe that the Task Force's recommendations rely on any particular system of consent, although we note that the ODTF has itself been asked by the UK Health Minister has extended their work to consider whether presumed consent should be introduced throughout the UK. They are scheduled to report later this year.
- 8.8 We have heard little or no opposition to the ODTF's recommendations indeed they have received strong support from most quarters. Neither has any of the evidence presented to us challenged the estimate of a 50% increase in organ donations being possible as a result of the recommendations.

**We recommend that, as far as it is responsible for doing so, the Assembly Government should implement the UK Organ Donation Task Force (ODTF) recommendations in full in Wales as a matter of urgency. [Recommendation 10]**

- 8.8 One of the main factors in Spain's success and one of the key recommendations from the ODTF is that all clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation. There is a need to reinforce training in organ donation and to provide regular refresher training and continuing professional development. This would further support the notion of organ donation being usual rather than unusual. There should also be regular update training.<sup>45</sup> In our view this is essential if the other recommendations are to be successful.

**We recommend that the Assembly Government ensures that a comprehensive training programme is developed to make the improvements needed to the training for healthcare professionals to ensure that the ODTF recommendations are implemented properly. [Recommendation 11]**

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<sup>44</sup> RoP 26 June - paras 19-21

<sup>45</sup> Organ Donation Task Force Report - Recommendation 11

## Section 9 - Could presumed consent be introduced in Wales alone?

### Issues

- 9.1 In section 3 we looked at the current legal position and whether there was any fundamental reason why Wales should not seek the power to legislate to introduce presumed consent in Wales if there is the will to do so. We concluded that there was not.
- 9.2 Many of those who sent us written views did not express a firm opinion on whether Wales should introduce a system of presumed consent on its own and of those who did views were split evenly for and against. Those who gave oral evidence were also divided but although a number of witnesses expressed a preference for UK wide legislation, and voiced concerns that Wales only legislation might cause a degree of confusion, only one witness<sup>46</sup> argued strongly that Wales only legislation presented considerable difficulties.
- 9.3 One of the main issues that concerned witnesses about separate Welsh legislation was the possibility of confusion for the bereaved whose loved ones were only visiting Wales or for healthcare professionals who might not be sure which consent basis might apply. However, we do not believe this is by any means insurmountable since cross border legislation differences between Wales and England already exist in health and other policy areas. Although, there appear to be few examples of different consent arrangements operating within individual countries we were told of evidence from Germany and Austria which shows that it is possible to have different consent systems yet still pool organs for transplant<sup>47</sup>. Any of the millions of UK citizens who travel to Spain on holidays, for instance, would also be subject to different consent arrangements than in the UK but this does not appear to have proved a problem. In any event, one of the consequences of devolution is that different laws will apply on different matters in different parts of the UK. Indeed Scotland already has its own legislation on consent which although not based on presumed consent does nevertheless apply a somewhat different legal framework.
- 9.4 Of perhaps more concern is the practicality of disentangling the current UK based opt-in organ donation register from a Welsh register asking people to opt out. As the UK Transplant Co-ordinators Association pointed out there is *"a register of nearly 14 million people who say that they would become a donor in the event of their death; 700,000 of those are probably from Wales. So, what would you do to transfer those 700,000 people over to an opt-in or an opt-out decision? With the opt-*

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<sup>46</sup> Oral evidence UK Transplant - RoP, HWLG paras 142-157 - 9 April 2008

<sup>47</sup> Written evidence BMA - Paper to Committee ref HWLG(3)-05-08(P1): 5 March 2008.

*out system, you choose not to be a donor and so you would register your name not to be a donor. However, there would be some confusion, because the current system is so different.*"<sup>48</sup> Again, while we accept the scope for some confusion, we do not think the difficulties are insurmountable.

- 9.5 The current highly integrated arrangements for transplantation across the UK are not therefore in our view themselves an argument against Wales introducing presumed consent separately from the rest of the UK.
- 9.6 Set against this are the views of those who felt that Wales should take the lead in this area. They have tended to argue that, whatever scope for confusion there may be, Wales only legislation to introduce presumed consent would send out a positive (as they see it) message that would more than outweigh any possible difficulties.
- 9.7 What is clear is that legislation would be time consuming, may cause some degree of confusion and that even those who advocate Wales leading the way would prefer UK wide legislation if this could be delivered sooner. However, the ability of legislative change to move and shape social attitudes should also not be underestimated. If presumed consent could be shown to make a substantial difference to the number of organs available for transplant and if Wales moving ahead on its own helped lead that improvement then separate legislation for Wales should be considered as a serious option.

#### **What would need to be included in any Assembly Legislation**

- 9.8 If a decision to move ahead in Wales alone were taken and legislative competence in this area agreed, the Assembly would subsequently need to legislate through an Assembly Measure. This would, among other things, need to set out the circumstances, exceptions and other arrangements in relation to organ transplantation in which appropriate consent would be presumed to be given.
- 9.9 There would need to be detailed consideration of these issues at the time. Our consideration of the matter has concentrated mainly on the arguments in principle around the introduction of presumed consent and how donation rates can be improved. Beyond establishing that there appears to be no fundamental reason why the Assembly should not be able to legislate in this area, we have not given further detailed consideration to other points of law and how they might be applied in any future Measure. Nevertheless, the following have emerged as matters that we agree would need to be written into any legislation that did emerge:

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<sup>48</sup> RoP 14 May 2008 - para 4

- A definition of what constitutes consent and the circumstances in which consent cannot be presumed (for instance children and those who are considered not to have the capacity to opt out);
- A clear right to opt out for those who want to;
- Arrangements setting out a clear legal mechanism for individuals to register their wish to opt out, including the right to opt out of all donation for all organs or for some;
- A requirement for loved ones (and defining who these might be) to be consulted;
- The balance between the requirement of loved ones to be consulted and the right of the deceased to have their explicit wishes respected.
- To whom the Measure would apply<sup>49</sup>.

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<sup>49</sup> The assumption is that it would apply territorially to all persons who died in Wales, whether or not they are normally domiciled here. But, this could be a matter of some contention and would need to be more carefully considered at the time.

## Section 10 - The Committee's Conclusions

### Main Conclusions

10.1 From the evidence we have heard we have drawn the following broad conclusions on which we are all agreed:

- There appears to be no fundamental reason why Wales could not seek legal competence to introduce presumed consent separately from the rest of the UK. Thereafter, there is no reason why Wales should not be able to legislate successfully to create a robust and rigorous legal framework for presumed consent.
- Although different systems of consent in the UK may cause some confusion on occasions these difficulties are not insurmountable. However, there is no value in introducing presumed consent in Wales unless it is clear that the benefits of doing so outweigh the difficulties.
- Presumed consent appears to have a positive effect on donation and transplantation rates but the evidence is not overwhelming and there is general agreement that other factors are probably more important in improving donation rates.
- There are a significant number of people, and significant strands of opinion, for whom presumed consent raises difficult ethical issues or causes them concern on matters of principle.
- If presumed consent were introduced there would be a need to ensure that there was not an adverse public reaction caused by misunderstanding of what was proposed. This would require a substantial public education campaign to inform people of their right to opt out and robust arrangements to ensure that opt out preferences could be recorded and respected.
- There is good evidence that more resources, particularly in relation to training, availability of co-ordinators and infrastructure, can have a very significant effect on organ donation rates. These effects may be more marked in the short term than changing the law on presumed consent. This is not to say that presumed consent should not be introduced at some point but that it may not be the immediate priority.

10.2 Despite the broad range of agreement between us, we have not been able to reach unanimous agreement on whether presumed consent for organ donation should now be introduced in Wales. While the case has in our view been made that the Assembly is capable of exercising legal competence in this area, it is less clear whether legislating to introduce presumed consent is a prerequisite to other changes or whether it would be a distraction from them.

10.3 While most of us agree with presumed consent in principle, most of us also believe that organ donation rates can be improved significantly



without introducing presumed consent. More than that, we feel there is a danger that moves to legislate in Wales ahead of the rest of the UK could be a distraction from more productive improvements and could alienate public support for organ donation if not handled properly. The majority<sup>50</sup> of us therefore have come to the view that now is not the right time to take steps to introduce legislation on presumed consent in Wales.

**We recommend that the Assembly should not at this stage seek a Legislative Competence Order, to allow the introduction of a system of presumed consent in Wales. [Recommendation 12]**

### Minority View

10.4 A minority of us<sup>51</sup> take the view that a case has been made to introduce presumed consent. Those of us who take this view believe that it directly affects donation rates and enables a more positive dialogue about organ donation with bereaved relatives and loved ones.

10.5 Although we agree that legislation may not be the most urgent step needed to increase donation rates, the process of seeking legislative competence is likely to be time consuming and it is important that the Assembly has the legislative tools available to it to introduce legislation when the time becomes right to do so.

10.6 We took evidence that suggested that it would be better if legislation in this area were to be implemented on a UK basis, but we do not believe this is a reason not to allow the Assembly the ability to legislate in this area if UK legislation is not forthcoming. We also took evidence that suggested that presumed consent is an issue where the introduction of legislation in Wales could provide a lead for the rest of the UK. For these reasons we believe that a Legislative Competence Order should be sought as soon as possible to allow the option of introducing presumed consent in Wales.

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<sup>50</sup> Jonathan Morgan AM; Lorraine Barrett AM; Irene James AM; Ann Jones AM; Val Lloyd AM; Nick Ramsay AM.

<sup>51</sup> Helen Mary Jones AM; Dai Lloyd AM; Jenny Randerson AM.

## Section 11 - Monitoring

11.1 Where appropriate, we expect the Welsh Assembly Government to report on progress in implementing our recommendations within 12 months of their initial response to this report.

## Annex A

### **PRESUMED CONSENT FOR ORGAN DONATION: ANALYSIS OF QUESTIONNAIRE AND WEBSITE DATA**

#### **Introduction**

This paper contains analysis and data from the following sources:

- Questionnaires that were made available in public buildings and completed by school pupils through the Assembly Education Service;
- The Presumed Consent Inquiry forum on the National Assembly for Wales' website;
- The National Assembly for Wales' website "Quick Vote" poll.

#### **1 QUESTIONNAIRE**

##### *Designing the study*

- 1.1 As a result of discussions in Committee, the Members' Research Service and the clerking team looked at more innovative ways in which we could engage with the general public. Greater public engagement is an aim for Members and Parliamentary Service officials alike and this presented an opportunity to pilot new ways for the Assembly to encourage participation from a wider range of individuals/groups in a Committee Inquiry.
- 1.2 When discussing the questionnaire for the general public with colleagues from the External Communications Division, we were asked whether the questionnaire could be used with school pupils as an engagement tool for the Schools Education Service when they went into classrooms to raise awareness of the National Assembly for Wales. After changing the wording around for some of the statements in view of the sensitivities around Bridgend, a separate questionnaire, without demographic questions, was produced.
- 1.3 Statements were based on the terms of reference and known concerns that had been reported to us and which we had researched during the scoping period. In addition to the content of the statements, their number and length and the information and instructions had to be designed to fit into a manageable-sized format while endeavouring to meet equality needs in terms of print size.

##### *Results*

- 1.4 Number of completed questionnaires received:

Schools	498
General public	373

- 1.5 While undertaking the analysis, an extra value was added to the second set of statements for "no concerns".
- 1.6 There were concerns about how respondents were interpreting Statement 7 "I wouldn't want someone interfering with my or a loved one's body after death" particularly in view of one person having added "without my permission" to it.

1.7 Also of concern was the use of the word “interfering” and what it conveyed, particularly as the proportion of school pupils who circled this statement was twice as high (28%) as among the general public (12%). For those under 17 who completed that questionnaire (40), the percentage was lower (15%).

1.8 The main results were as follows:

- The percentage of school pupils who were “for” organ donation was 53%. Of these, 30% supported presumed consent with 23% preferring informed consent.
- The percentage of the general public who were “for organ donation was 72%. Of these, 48% supported presumed consent with 24% preferring informed consent.
- The percentage who did not want their organs removed were 23% (schools) and 11% (general public).
- Of those who would prefer their families to decide whether or not to donate their organs, the percentage of school children (19%) was higher than the general public (12%).
- Over a third of both school pupils (36%) and the general public (37%) said they would like to donate their organs but would be worried that not enough would be done to save their life.
- More than twice as many school pupils (28%) said they did not want someone interfering with their or a loved one’s body after death compared with the general public (12%).
- Those who did not want their organs donated for religious reasons were 2% for both school pupils and the general public.
- The percentages of those who were worried their loved ones might be able to object to their organs being removed was 14% (school pupils) and 12% (general public).

1.9 Below are all the statements with the numbers and percentages for each.

*NB: The instructions were to select one statement in the first set (Statements 1-5) and then as many as applicable in the second set (Statements 6-10). Therefore, responses to the second set of statements, may add up to more than the total number of questionnaires received as choices have been added together.*

#### Schools

<b>Statements 1-5</b>	<b>Number</b>	<b>Percentage</b>
I would like my organs to be taken automatically when I die to save or improve someone’s life.	148	30%
I would like my organs to be used after I die but want to put my name on the register or carry a donor card.	115	23%
I would not want my organs removed when I die.	115	23%
I would prefer my loved ones to decide whether or not my organs should be donated.	94	19%

None of the above.	22	4%
<b>Statements 6-11</b>		
No concerns.	86	17%
I would like to donate my organs, but would be worried that not enough would be done to save my life.	177	36%
I wouldn't want someone interfering with my or a loved one's body after death.	139	28%
I would not want to donate my organs due to my religious beliefs.	10	2%
I would be worried my loved ones might be able to object to my organs being removed.	69	14%
Other concerns.	13	3%

*General public*

<b>Statements 1-5</b>	<b>Number</b>	<b>Percentage</b>
When I die, I would like my organs to be taken automatically to save or improve someone's life.	178	48%
I would like my organs to be used after I die but want to put my name on the register or carry a donor card.	91	24%
When I die I would not want my organs removed.	39	11%
I would prefer my loved ones to decide whether or not my organs should be donated.	46	12%
None of the above.	14	4%
<b>Statements 6-11</b>		
No concerns.	138	37%
I would like to donate my organs, but would be worried that not enough would be done to save my life.	137	37%
I wouldn't want someone interfering with my or a loved one's body after death.	47	12%
I would not want to donate my organs due to my religious beliefs.	7	2%

I would be worried my loved ones might be able to object to my organs being removed.	46	12%
Other concerns.	18	5%

### *Demographics*

1.10 Below is a table of demographic information:

Live in Wales	Yes	286	(89%)
	No	37	(11%)
Gender	Male	114	(35%)
	Female	214	(65%)
Age	17 or under	40	(12%)
	18-29	52	(15%)
	30-49	116	(34%)
	50-64	82	(24%)
	65 and over	46	(14%)

1.11 We are not able to say whether more women visit Assembly public buildings or whether they are more likely to complete questionnaires.

1.12 Analysis was carried out to see whether there were any differences in responses according to age and gender. The following differences were noted but they were not found to be significant:

People under 17 years of age were more likely to want to register or carry a donor card or to leave it for their family to decide than older people, but were more concerned that family might go against their wishes.

Respondents aged 30-49 years were less likely to be against organ donation but more worried that not enough would be done to save their lives than other age groups.

### **1.13 Comments**

Comments received from the questionnaires have been grouped below under a series of themes, sub-divided by whether they were provided by school pupils or by the general public.

### **1.14 Choosing organs**

#### *Schools*

- I am very for compulsory organ donation, but I would like to have a choice of which organs I would like to donate.
- I would accept compulsory organ donation EXCEPT my eyes.
- It's my choice to opt out of donating certain organs.

- I wouldn't mind them taking some organs but not my skin or eyes. And they should sew me back up.
- I would want to carry a donor card saying this.
- I would not want my eyes to be removed.
- Don't take my eyes and my privates.

*Public Buildings/Urdd*

- I would be happy to donate my organs but not my eyes. I (I would like to keep them just in case I need them in the afterlife).
- I would like to choose which organs I donate.

**1. 15 Choosing who has the organs**

*Schools*

- I'd like my organs to go to someone who doesn't abuse the body, e.g. smoking.
- To save my relative's life I would want my organs removed but otherwise, no.
- Only to save a loved one.
- I would donate organs to one of my family if they need it.
- Would like to choose which organs they take.

*Public Buildings/Urdd*

- My organs would be given to someone who I don't know rather than family who need transplants.
- Organs could be donated provided they go to a vegan.

**1.16 For presumed consent**

*Schools*

- People should not have the choice of whether or not to donate their organs. People should donate every possible organ.
- Ensuring that sick people receive organs is the most important thing.
- You don't need your organs when you die so they should automatically be given to someone who needs them.

*Public Buildings/Urdd*

- Let's be dynamic about saving lives and giving people a chance.

**1.17 For organ donation but against presumed consent**

*Schools*

- It is interfering with people's rights to take their organs when they die without asking.
- I am not sure if I want my organs removed, but I would definitely not want them removed without my consent.
- It's fine to donate or take a person's organs with their consent only.
- I don't agree with the presumed consent system in the first place. I believe that everyone should have the right to decide if they wish to donate or not. If they are not 18, I believe it ought to be a decision of close family.

- I already have a card. However, if I didn't, I would not be happy for anyone to take my organs automatically unless my family had given permission.
- I think it should be easier to sign the organ donation register (better advertising).

*Public Buildings/Urdd*

- "Presumed consent" is a bit too drastic.
- I fully appreciate that presumed consent is a current concern, but I would be totally opposed to it.
- There are too many areas of concern around the emotional matters for me to be convinced it would work.
- I just do not find "presumed consent" appropriate – surely an individual must be allowed to express their own wishes themselves.

**1.18 Against organ removal**

*Schools*

- I wouldn't want my body parts to be taken out: I'd like to be left intact.
- My organs are mine, even if I'm dead.
- I don't like the idea of my body being tampered with after I die.

*Public Buildings/Urdd*

- The fact that the body rejects other's organs should tell us something. What nature rejects, should no man join together.

**1.19 Family consent**

*Schools*

- I would like the chance for my family to know that they are going to remove them.

*Public Buildings/Urdd*

- I would be worried that my loved ones' organs would be rushed away without a thought for the family.
- I would be worried that my loved ones wouldn't be given enough say in what happened to my body.
- I am content for there to be a presumed right to my organs but would still like this discussed with my next of kin.
- It's important to ensure that the family can object – but it ought to be opt-out not as it stands at the moment.
- The family would need time to discuss when such a situation.
- It is difficult to make prior decisions.
- I would want to discuss with my family first for everyone to feel happy (response to registering).



## 1.20 In favour of informed consent but not asking the family at death

### *Schools*

- When someone dies, it's an emotional enough time. The last thing the family needs is to be asked whether to cut up the body.
- It is my decision, my loved ones ought to respect that I am saving someone's life, but if it's possible to rescue the person, you ought to save them.

## 1.21 Safeguards for opt out

### *Schools*

- Need to ensure "opt-out".
- How do you say that you don't want to donate your organs?

### *Public Buildings/Urdd*

- How will it be ensured that those who don't want to donate are protected?
- I do think you should be able to opt out of a presumed consent scheme but it should be carefully policed.

## 1.22 Difficulty making up mind

*A few school pupils, who appeared to be "for" presumed consent, had difficulty making up their minds between statements. They were undecided between presumed and informed consent or between one or the other and leaving such a decision to their families to make.*

- Undecided between 1 and 2. If the "opt-out" system existed, a long term national advertising campaign would be needed to ensure that everybody is aware.
- Either 2 or 4
- Either 1 or 4
- 1 and 2
- 2 and 3

## 1.23 Card Carrying

*Three pupils stated that they already carried a donor card.*

## 1.24 Other concerns

### *Schools*

- I would be worried that the organ removal would be made the priority and not have a dignified and sensitive death.

### *General public/Urdd*

- I do not wish to suffer pain when donating organs. I would wish the donor to receive automatic pain relief. i.e. I want to help someone after my death by my body so my choice.
- Better diet and lifestyle should be promoted (vegan perspective)

- Politicians have interfered enough in my life. There is no need for them to interfere in my death as well.
- Keen to donate, but not sure that hospitals would try to rescue me where possible.
- I would be concerned for young individuals' rights – ensure that information arrives before commencement and a family decision should be made first.
- It would depend on the circumstances of the death.
- They shouldn't wreck their own (organs).

## 1.25 Possible Misconceptions

### *General Public/Urdd*

- I believe individual permission should be sought and details should be kept on a closed database in hospitals.
- I agree completely as I am totally opposed to embryo research. What about tablets taken in life for depression/osteoporosis? As a Christian, I do not believe in euthanasia – support hospice movement.

## 2. QUICK VOTE

Statements	Yes	No
When I die, I would like my organs to be taken automatically to save or improve someone's life.	73%	27%
I would like my organs to be used after I die but want to put my name on the register or carry a donor card.	40%	60%
When I die I would not want my organs removed	24	76
I would prefer my loved ones to decide whether or not my organs should be donated	41	59

- 2.1 The proportions of respondents in favour of presumed consent and who would not want their organs removed concurs with other attitude surveys that have been carried out in the UK.
- 2.2 The following two results are of interest:
  - 59% of respondents said they would not prefer their loved ones to decide whether or not their organs should be donated.
  - 60% of respondents would not want to have to put their name on a register or carry a donor card.

## 3. WEBSITE FORUM

- 3.1 The website forum had 44 comments posted to the five questions although the number of people who used the forum was 18.
- 3.2 Mostly respondents showed a good understanding of the issues around organ donation and were in favour, although not necessarily of presumed consent.
- 3.3 The questions and responses are listed below and it is suggested they along with other comments may illustrate themes in the draft report.

### 3.4 Do you have any moral, ethical or religious views on presumed consent?

<p>As a Humanist I believe that it is morally correct to protect and preserve all human life for as long as reasonably and humanely possible etc.</p> <p>Obviously the emotional needs of relatives of the deceased are important, but I think the needs of the suffering and dying are far more important.</p> <p>Under strict legislation to prevent abuse, I would support presumed donor consent that would put an end to the inevitable suffering caused to young and old when waiting for scarce suitable organs to be found and also the tragic loss of human life when organs turn up too late.</p>
<p>But the sensitivities of very close relatives should be catered for.</p>
<p>Unless you are an ancient Egyptian (or similar), you will appreciate that you can't take your body or your organs with you when you die. The choice we have to make is:</p> <ol style="list-style-type: none"><li>1 Whether we do the right and charitable thing by offering organs to whomever might have a need for them with minimal delay (organs deteriorate quickly) without needing any consultation</li><li>or</li><li>2 We be problematic by having process of consent to go through at the wrong time.</li><li>or</li><li>3 Be selfish and obstructive and prevent others from benefiting.</li></ol> <p>I recommend option 1. Presumed consent will make the whole process of organ donation less emotionally draining and more beneficial to those in need who we should try and help.</p>
<p>In Spain they have had presumed consent for a long time and the refusal rate is about 3%.</p>
<p>If your body is dead, it's dead. Not resting. It doesn't care. Help the living.</p>
<p>Dwi'n credu fod hawl gan unrhyw un optio mas o dan chaniatad Tybiedig</p>
<p>Dim o gwbl. Dwi'n meddwl ei fod en syniad da! O'r diwedd.</p>
<p>I would always want the final say on what happens to my organs after my death. Presumed donation may not be the total answer.</p>

### 3.5 Other than presumed consent, what more can be done to improve transplant rates?

<p>The topic of organ donation frequently focuses on what happens once we've died. Instead the focus should be on those people who are about to die unless they find a suitable donor organ.</p> <p>A positive advertising campaign with this in mind might remind people why they are donating organs.</p> <p>It would do no harm to have relatives of a deceased organ donor discussing</p>
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<p>how they were comforted by the knowledge that there's a part of their loved one helping someone else to live.</p> <p>An advertising campaign with a prominent comedian, for example, waxing lyrical about how various bits of their anatomy might be used for other people might raise public consciousness and a few laughs.</p>
<p>1) Non-heart Beating Donor scheme 2) Cash incentive for Live Relative Donation 3) Allow (state regulated) tissue market (ie sell your own kidney)</p>
<p>Better marketing</p>
<p>People should be made more aware of the shortage of organs available for donation.</p>
<p>Improved marketing, possible cash donations to donor families.</p>

**3.6 Have you or your family had any direct experience of transplant surgery or of needing a transplant?**

<p>No, but I know of other people who have had transplants.</p>
<p>Dwi'n mynhau y fforwm</p>
<p>No, but I imagine it would be a very traumatic experience for all concerned.</p>
<p>No.</p>

**3.7 Do you believe that the choice of donating organs should be left to an individual or their loved ones?**

<p>adults should be presumed to give consent (an opt-out system) but those who remain alive are the ones who carry the consequences, emotional or otherwise, of a decision, so immediate family members should be able to disallow donation - any objection should mean no donation.</p>
<p>Whilst I am in favour of an opt-out system in Wales, there should be a mechanism for the consideration of the wishes of the immediate family (partner, children over 16, parents - in that order of importance) where there are concerns.</p>
<p>Neither. It should be automatic, and either way certainly not to be vetoed by loved ones.</p>
<p>I'm with R, surely it should always be the individual who makes the choice?</p>
<p>the individual should be the one who decides.</p>
<p>Disagree, I think it should be the individual.</p>
<p>...yw fy marn i .</p>

**3.8 Do you believe that when a person dies their organs should automatically be used for transplantation?**

<p>You have asked for a contribution to the debate on Donor Card opt out scheme, first I would like to point out that it makes no difference to me, at 70 years my parts would probably be of no use (worn out).</p> <p>But what about the 20%+ of the population who cannot or are not able to opt out:</p> <ol style="list-style-type: none"> <li>1.Those that are not allowed to smoke, drink or vote through age restrictions.</li> <li>2.Those that have not learned to read or write. (because of their age)</li> <li>3.Those who cannot read or write. (mentally challenged)</li> </ol> <p>I may be wrong but are not the above the biggest contributors to the donor system. It is going to be a big loss to transplants if these are to be excluded because of their inability to opt out. Or is their inability to choose to be taken as permission to remove whatever parts are required.</p> <p>I consider this initiative like all others to be devoid of thought and feeling for the departed, like making arrangements for the dead to pay their dues (poll tax)after they are dead. Is this the future for the 21st Century, your caring society?</p>
<p>A system with safeguards included would help save the lives of many people and release much needed resources (less dialysis costs, more people able to return to work). These savings could be used in other areas of health care. If the public were fully engaged in the law making and a clear method of opting out made available, I am sure that the majority of people would agree to a change in the law to an opt out system. After all, it is a fact, that we are more likely to need a transplant in our life than we are of being in the situation where we would be a potential donor.</p>
<p>I agree with M; whilst I am all in favour my spouse has reservations.</p>
<p>Because there is a lack of donors. Many lives would be saved through the opt out system.</p>
<p>as a nurse I think it should be the individuals choice, that consent should not be assumed, and should still be in writing</p>
<p>I certainly think we should move to an opt-out system in Wales although I think there should be a mechanism for the consideration of the wishes of the immediate family (partner, children over 16, parents - in that order of importance) where there are concerns.</p>
<p>This is the land of the living. To horde organs in the dead, preventing them from being reused is the ultimate in selfishness.</p>
<p>The current system is failing people who are waiting for a kidney transplant. Many of these people need dialysis 2 or 3 times a week to stay alive, simply because someone forgot to fill in their donor card. A significant proportion of these patients die before a suitable matched donor turns up.</p> <p>This is the tip of the iceberg. The humane option is to advertise to the public</p>

<p>that donation is optional but will be presumed unless you carry an opt-out card. Thus those people with strong feelings have their wishes respected.</p> <p>Presumed consent avoids the inevitable delays and distress that inevitably accompany a search for the deceased's wishes.</p> <p>In my experience as a GP, relatives are usually comforted by the fact that their loved one's death has contributed to life for someone else.</p>
<p>The current scheme, that was fit for purpose when launched, is no longer meeting the needs of today's society. There are not enough organs for transplant. How dreadful to lose a loved one and then, in that time of distress, to try to make a rational decision on donating organs. It must be so awful for the doctors too who have to ask the question - at a time when they would want to be offering comfort and support.</p> <p>I think society will be mature and accept that presumed consent is the only way forward and leadership from the Assembly is needed to take this step.</p> <p>Let's just make sure that we communicate effectively with the people of Wales and make it really easy to opt out for anyone who wishes to (a simple website, telephone helpline, in person with your local GP and making the function available by pressing buttons on your TV remote control to ensure that everyone has free access to make their choice).</p>
<p>I can't agree that it's about money or selfishness. I think it's a very easy to ignore the subject at the moment because you have to opt-in. If you had to opt-out if would force you to think about the subject a bit more.</p>
<p>I am of the mind that people should automatically have to donate their organs unless they have formally opted out. I find it strange that individuals are not willing to try and save another persons life upon their death - I think this just shows peoples attitude today and how selfish people are - I bet these same people who opt out would suddenly opt in if the government was to make a payment to them upon agreement of donation.</p>
<p>They should be screened for disease and malfunction first.</p>
<p>Does it necessarily mean that a person is giving his/her consent to the use of their organs if an opt-out system is introduced? Not saying 'no' does not mean you've said 'yes'.</p>
<p>I agree with S.</p>
<p>I think people should be fully aware of the situation especially if they choose not to opt out</p>
<p>I agree, I think people should opt out rather than opt-in. It would increase the amount of organs available.</p>

## **Annex B**

### **PRESUMED CONSENT FOR ORGAN DONATION: ANALYSIS OF WRITTEN CONSULTATION RESPONSES**

#### **1. Introduction**

Twenty five written submissions were received in response to the call for evidence. Of these submissions, 18 were from organisations and 7 from individuals. Few respondents systematically answered the questions posed by the consultation, preferring to submit views in their own way or to write on a specific issue or aspect of the consultation.

The written responses have therefore been analysed according to emerging themes rather than by questions. The text is referenced throughout using the numbers given to each consultation response. Where general views are expressed, some, but not all, submission numbers are given. However, direct quotes or statements, are referenced either by the name of the organisation or individual, or by the submission number from where the text was derived.

The conclusions that can be drawn from the written evidence are:

- There is general agreement and support for policies and actions that will increase the numbers of organs that are donated;
- There was a positive reaction to the 14 recommendations of the Organ Donor Taskforce (ODTF) which many respondents are keen to see implemented in Wales;
- Legislation for presumed consent should be seen in the context of underpinning the ODT improvements or as a means of increasing organ donation if the outcomes of the Taskforce do not meet expectations;
- Much could be done in Wales to raise awareness among the public and healthcare professionals, and to create an environment and infrastructure to increase organ donations.

#### **2. Views on presumed consent**

Submissions which unconditionally supported a change to a system of presumed consent were in the minority. Among those who were not in favour of presumed consent, a number wrote that there was more that could be done without the need for legislation. Most commonly-held views were that the number of donors could be increased more effectively by addressing structural and service issues or by education and awareness-raising than by legislation. The Donor Family Network (6), for example, felt that the 14 recommendations of the Organ Donation Taskforce should be implemented first, then presumed consent introduced only if the numbers of organs available for donation failed to increase.

Some were concerned about increasing state intervention and the potential for invasion of privacy that they felt presumed consent might entail (4) while Mr Argiris Asderakis (12) said that “some professionals have nightmares about negative headlines attributed to presumed consent. From the point of view of getting the general public on board he felt it was better to mount awareness raising campaigns than to legislate for presumed consent.

Patient Concern (3) said that presumed consent was “not a quick fix” nor was it informed. “How can you consent to something by failing to give consent?” Other

views expressed were “Presumed consent is no consent at all” (2), and “presumed” has unfortunate connotations, opt-out would be a better choice of wording”(5). The teachings of the Hindu faith would not support a system of presumed consent because, they say, without consent the organs are regarded as stolen, not donated (23).

One submission (15) felt that mandated choice, where, by law, all adults would have to say whether or not they wished to donate their organs after death, was a better option for increasing the numbers of donors.

Those who did agree with presumed consent were most often in favour of the “soft” or “weak” option where, if a family or loved ones registered a strong objection, a donation will not proceed (12) (14). Few advocated the hard option although the Welsh Kidney Patients Association (5), which as a body supports a soft option, admitted that there was anecdotal evidence from events and clinics where patient groups meet that a “hard” or “strong” system, where the views of loved ones would not carry weight, was the preferred option. The BMA (14), which supports presumed consent, feel that among other benefits, such a system would bring protection for those who did not want to donate because a clear mechanism for opting out would have to be introduced. Having safeguards was also a condition of presumed consent that other supporters felt would need to be in place (8) (6).

The BMA (14) concluded that:

*“We believe that the two-pronged approach of both improving investment and infrastructure around donation alongside implementing a system of presumed consent will have a dramatic effect on the number of organs available for transplantation.”*

The British Heart Foundation Cymru (8) said that “while legislation in favour of presumed consent would not be a “magic bullet” to increase donor rates, a change in the law could help shift social norms and increase support of organ donation”.

Opinions were divided on the weight that should be given to presumed consent legislation as a means of increasing the number of organ donors. Some felt presumed consent should be introduced to underpin any other initiatives that were taken such as the implementation of the Organ Donor Taskforce recommendations. Others suggested that it should be introduced in its own right because there were other important aspects to having the legislation such as easing the path for doctors to talk to patients. Others again felt that it should only be introduced if the impact of the Organ Donor Taskforce recommendations did not increase the number of organs available for transplant (6) (8).

### **3. Should presumed consent be introduced in Wales alone?**

Less than half of the submissions expressed an opinion on whether Wales should introduce a system of presumed consent on its own. Of those who did, views were split evenly between “yes” and “no” with those taking the latter view expressing concerns that it would be problematic. Problems identified included high tourist population and questions of residence (1) (6), the current UK-wide service arrangements for organ donation and transplantation (7), and lack of fixed country boundaries (14).

However, others felt that no problem was insurmountable and that a different consent system would not impinge on UK-wide transplant and coordination. The BMA (14),



for example, cited evidence from Germany and Austria which shows that it is possible to have different consent systems yet still pool organs for transplant.

#### **4. Capacity and infrastructure**

A number of submissions expressed concern that Wales might not have the service capacity, ITU beds, theatres, hospital staff, transplant co-ordinators and training etc., to cope with a significant increase in the number of organs available for transplant and the consequential number of potential transplants if improvements happened in the near future. (1) (5) (25).

The British Heart Foundation Cymru (8) was concerned that the NHS would struggle with heart transplantation if numbers of available organs increased. However, the general view was that the 14 recommendations of the Organ Donation Taskforce together with the investment in the Transplant Unit at the Heath Hospital could have a significant positive impact on capacity and infrastructure (8). Accordingly there is a consensus that it is important in the first instance that the Taskforce recommendations are implemented (6).

The success of the Spanish infrastructure was mentioned by some and the fact that donation rates improved over a decade as the number of transplant co-ordinator teams increased from 25 to 139. The BMA believes that the goals of improving infrastructure and increasing the numbers of donors available through a system of presumed consent are interdependent and should be seen as two sides of the same coin. (14)

In terms of being able to increase the number of available organs, Mr David Crosby (19) pointed out the desirability of having neurosurgery departments, full laboratory services and regular dialysis units on hand where potential donors were being assessed.

#### **5. Raising awareness**

It is claimed that 25% of people in Wales (24% in the UK as a whole) have signed up to the Organ Donor Register (5) (14) (16). Of the percentage of people in the UK, there is higher representation among younger age groups with a marked decrease among people over 41 years of age.

There was a view among respondents that more could be done to encourage people to “opt in” to organ donation (1) (3) (6) (17). It was claimed that not enough people knew about the donor register or how to join it and more awareness-raising and information was therefore needed (6) (7) (18). Mr Paul Thomas felt that kidney donation was not sufficiently widely publicised and that a lot more could be done to increase the number of donors “*why not have high street stalls encouraging people to sign up to be donors?*”(11). Another suggestion was that education, particularly around the issue of opting-in, in the later school years was a way forward (2).

Mr P Davies (24) wrote about how important it was for members of the public to not only register if they wish to donate but to make their family members aware that they have registered and try as far as possible to ensure that their family will respect their wishes. As a recipient of a donated organ, he empathised with the fact that for some families this might be an agonising decision. Some of the organisations described how important it was for recipients to know that organs had been given freely and that donors or their families had chosen to give this “gift of life”.

Figures quoted for refusal from families and loved ones gathered from a UK Transplant audit study suggest that around 40% of families refused to donate the organs of loved ones when asked; for people from non-white backgrounds this percentage rose to around 75% (15). UK Transplant (13), in their written submission, claim that the actual family refusal rate would be higher if the figures had taken account of i) assumptions or prior knowledge by health professionals that the family are likely to refuse donation when approached and ii) the effect of families who subsequently withdraw their initial consent.

The BMA suggests that an explanation for the high rates of refusal may be found in the possible connection between people over 41 years of age, who are more likely to be asked for consent to a donation, and the low level of uptake on the Organ Donor Register by older people.

It was suggested that the processes around organ donation and the term “brain stem death” should also be explained more clearly (5) and that there is possible confusion among the public. Mr Argiris Asderakis from the Nephrology and Transplant Directorate, University Hospital of Wales (12) said that discussions on issues of donation seem to become muddled with issues of retention of organs such as at Alder Hey Hospital.

The British Humanist Society said they supported altruistic organ donation from living donors but that people must have enough information to make a rational choice for themselves about the risks of such procedures to their well-being and life compared with the benefits to the well-being and health of the person needing that organ.

Communication barriers among those whose first language was not English and those who had other difficulties communicating were mentioned (8) as an issue related to awareness-raising.

## **6. Religious considerations**

Whilst Wales has relatively low levels of ethnic and religious diversity overall, some urban areas, e.g. Cardiff, have more mixed communities. The BMA stated:

*“We know that all the major religions in the UK support the principles of organ donation and transplantation and believe that donation is an individual choice. Within every religion, however, views will differ and some communities are opposed to donation.”*

The Kidney Wales Foundation (16) stated that although the leaders of all six major faiths in the UK have endorsed organ donation and transplantation, there may be differences among local faith leaders in Wales. Kidney Wales also made the point that grass roots opinion does not always concur with official views of their faith.

The Committee received a number of submissions which gave information on the views of a range of religions and some of these gave an insight into the problems and complexities of religious and community “labelling”.

The Buddhist Council of Wales, for example, wrote that there are a variety of traditions practising the teachings of the Buddha, each of which differs in its views on body organ donation. These views will vary according to different levels of practice within these traditions. In the light of this diversity, there is a general feeling that in Buddhism each person, during their life and at the time of their death, therefore

makes their own decision as to what action they may wish to take in these matters of donating body organs (20).

The District Manager of the Christian Science Committees on Publication (10) said that while personal decisions including organ donation and transplantation are left to each individual's own prayerful judgement, Christian Scientists most usually prefer prayer-based healing as their primary choice of healthcare.

Swansea Bay Racial Equality Council (9) provided some information on the views of certain sections of Muslim communities who would consider the burial of the body as soon as possible after death as a necessity. For Jehovah's Witnesses, while donation is a matter for individual conscience, there would be a proviso that all organs and tissues are completely drained of blood before transplantation. Further evidence from them suggested that there are some issues for Jews, i.e. the success of a transplant would need to be established before it took place, no vital organ can be removed until death is confirmed by the complex cessation of all spontaneous life functions, and Orthodox Jews object to all forms of organ donation and transplantation.

The Baha'i Council for Wales stated that whether or not presumed consent for organ donation becomes law a Baha'i would be concerned about the proper treatment/burial of the remaining organs according to the faith's guidance. They also said that the teachings of the faith suggest that it would "seem a noble thing to do" to bequeath eyes to another person. (21)

While the Hindu religion sees organ donation under informed consent as a gift given freely, equating with their teachings, they would not support presumed consent (see Section 1). In addition they pointed out that in Singapore, certain groups are exempt from presumed consent which, their submission suggests, may lead to further alienation of a community (23).

The British Secular Society highlighted myths and assumptions that they claim are known to affect donation rates (22):

*"Key barriers to donation among black and Asian communities include assumed cultural or religious objections to donation, confusion about who can donate and receive organs, a reluctance to discuss death, and fear of bodily disfigurement."*

## **7. Choosing organs**

Opinions on whether presumed consent should apply to all organs, or whether people should be able to choose to donate some and not others, was divided. Some advocated that presumed consent should apply to all organs on the grounds that a "restricted" scheme would add an additional level of administrative and IT/database complexity (8), or that *"it should be extended to all organs since, by its very nature, it is not conditional; it is not rational to be restricted a priori to specific only organs"* (12).

Others, however, felt the system could accommodate people's wishes. The BMA, for example, thought that a soft system of presumed consent could still allow for individuals to choose not to donate specific organs (14), and it may be that for some religions, having a choice over which organs to donate might be more acceptable.

## 8. Research

### *Public opinion and presumed consent*

No coherent research has been done among the Welsh public to gauge opinions about their views on the introduction of presumed consent for organ donation (12). Some opinion polls and surveys have been done and were quoted by respondents, but the majority of these are undertaken on a UK-wide basis as opposed to Wales only. There are wide differences, too, between reported attitudes. The Welsh Kidney Patients Association stated that UK Transplant figures suggest 90% of the population have said they would be willing to donate their organs after death. However, a YouGov poll in October 2007 suggested that the figure was 64%.

### *Donation rates and presumed consent*

Kidney Wales recommended a study "*Presumed consent and other predictors of cadaveric organ donation in Europe*" which demonstrated that presumed consent was one of four variables which emerged as a significant predictor of cadaveric organ donation rates.

### *Donor refusal*

Little research has been done to drill down into the reasons why people refuse to donate their loved ones' organs. However, respondents did refer to some work that had been done or provided the Committee with evidence of some small-scale studies or data analysis.

Kidney Wales said that the Co-ordination team in the University of Wales Hospital Cardiff reported that the most common reason for declining organ donation was the need to protect the body of the deceased. This concurred with the findings of a study mentioned by Kidney Wales which looked into the reasons why people who had refused to consent to a donation regretted their decision later.

UK Transplant included a report written for the Scottish Transplant Group which documents the circumstances under which people give or refuse consent and then change their minds. The report highlighted the importance to gathering organs of going back to a family after the initial approach and having a detailed discussion with them.

Kidney Wales went on to say that families sometimes do not want to relinquish the guardianship of the body. Other pertinent factors include circumstances at time of death. People needed to have time to come to terms with the death of their relative, especially if the death was sudden or their body looked normal. Lack of knowledge is a key point.

A list of sources to which written evidence referred is set out below.

## Sources and References used in written submissions

Evidence No.	Source
2	Dr Andrew Murrison MP, Human Tissue Bill Debate HoC Col. 1038 15 January 2004
3	<i>Human Tissue Act 2004</i>
5	Department of Health, <i>Organ Donor Taskforce Organs for Transplants: A report from the Organ Donation Taskforce</i> , January 2008
8	Gimbel RW et al, (2003) <i>Presumed Consent and other predictors of cadaveric organ donation in Europe</i> , Progress in Transplantation 13(1):17-23  Martinez, J et al (2001) <i>Organ donation and family decision-making within the Spanish donation system</i> , Social Science and Medicine 53:405-421
13	Submitted paper –  Appendix 1: <i>Compliance with Human Tissue (Scotland) Act 2006</i> Appendix 2: <i>Potential Donor Audit – summary report for period 1 April 2005 to 31 March 2007</i> Appendix 3: <i>Table showing international Approaches to Organ Donation</i>
14	Abadie, A and Gay, S. <i>The impact of presumed consent legislation on cadaveric organ donation: a cross-country study</i> , J Health Econ 2006; 25:599-620  BBC, May 2005, Sample of 2,067 people age 16+  UK Transplant (2005) <i>General leaflet on religious viewpoints</i> .  Miranda B et al, Organ donation in Spain, Nephrol Dial Transplant 1999; 14 (suppl 3): 15-21.  Human Tissue Authority. (2007) <i>Delivering better regulation in HTA Annual Report and Accounts 2006-07</i> , July. London: The Stationery Office
15	Department of Health and Social Security, 1987, Conference of Medical Royal Colleges: <i>Report of the working party on the supply of donor organs for transplantation</i> (Hoffenberg Report): London.  Riad J and Nicholls A, <i>An ethical debate: elective ventilation of potential organ donors</i> , BMJ 1995; 310:714-5  Council Report, Strategies for Cadaveric Organ Procurement: Mandated Choice and Presumed Consent, JAMA 1994; 272:809-815  Erin C, Harris J. Presumed consent or contracting out? J Med Ethics 1999; 25:365-6

	<p>Mclachlan H. Presumed consent is no consent at all.  <a href="http://www.bmj.com/cgi/eletters/336/7638/230#189028">http://www.bmj.com/cgi/eletters/336/7638/230#189028</a></p> <p>Spital A. Mandated choice: the preferred solution to the organ shortage? Arch Int Med 1992;152:2421-4</p> <p>Chouhan P, Draper H. Modified mandated choice for organ procurement. J Med Ethics 2003;29:157-62</p> <p>Beauchamp TL, Childress J. Principles of Biomedical Ethics. (2<sup>nd</sup> edition). Oxford University Press, New York, 1983. p158</p> <p>Hume D. Of suicide (1784). In: Singer P (ed). Applied ethics. Oxford University Press, Oxford, 1986, 25</p> <p>Saunders J. Asking for organs. Lancet 1988;i:1229-30</p> <p>Anon. The organ debate is long overdue. BMJ 2008;336:278</p>
16	<p>Welsh Assembly Government, Decision Report, 21 February 2008</p> <p>Sque, M et al, (2008) Why relatives do not donate organs for transplants: 'sacrifice' or 'gift of life'? Journal of Advanced Nursing 61(2), 134-144</p>
17	<p>British Medical Association (2007) Organ Donation – presumed consent for organ donation, October</p>
23	<p>Institute of Medicine, Organ donation: opportunities for action, Washington, D.C: National Academies Press, 2006)</p>

## **Annex C**

### **Organ Donation Task Force Recommendations**

#### **Recommendation 1**

A UK-wide Organ Donation Organisation should be established.

#### **Recommendation 2**

The establishment of the Organ Donation Organisation should be the responsibility of NHS Blood and Transplant.

#### **Recommendation 3**

Urgent attention is required to resolve outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice. Additionally, an independent UK-wide Donation Ethics Group should be established.

#### **Recommendation 4**

All parts of the NHS must embrace organ donation as a usual, not an unusual event. Local policies, constructed around national guidelines, should be put in place. Discussions about donation should be part of all end-of-life care when appropriate. Each Trust should have an identified clinical donation champion and a Trust donation committee to help achieve this.

#### **Recommendation 5**

Minimum notification criteria for potential organ donors should be introduced on a UK-wide basis. These criteria should be reviewed after 12 months in the light of evidence of their effect, and the comparative impact of more detailed criteria should also be assessed.

#### **Recommendation 6**

Donation activity in all Trusts should be monitored. Rates of potential donor identification, referral, approach to the family and consent to donation should be reported. The Trust donation committee should report to the Trust Board through the clinical governance process and the medical director, and the reports should be part of the assessment of Trusts through the relevant healthcare regulator. Benchmark data from other Trusts should be made available for comparison.

#### **Recommendation 7**

BSD testing should be carried out in all patients where BSD is a likely diagnosis, even if organ donation is an unlikely outcome.

#### **Recommendation 8**

Financial disincentives to Trusts facilitating donation should be removed through the development and introduction of appropriate reimbursement.

**Recommendation 9**

The current network of DTCs should be expanded and strengthened through central employment by a UK-wide Organ Donation Organisation. Additional co-ordinators, embedded within critical care areas, should be employed to ensure a comprehensive, highly skilled, specialised and robust service. There should be a close and defined collaboration between DTCs, clinical staff and Trust donation champions. Electronic on-line donor registration and organ offering systems should be developed.

**Recommendation 10**

A UK-wide network of dedicated organ retrieval teams should be established to ensure timely, high-quality organ removal from all heartbeating and non-heartbeating donors. The Organ Donation Organisation should be responsible for commissioning the retrieval teams and for audit and performance management.

**Recommendation 11**

All clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation. There should also be regular update training.

**Recommendation 12**

Appropriate ways should be identified of personally and publicly recognising individual organ donors, where desired. These approaches may include national memorials, local initiatives and personal follow-up to donor families.

**Recommendation 13**

There is an urgent requirement to identify and implement the most effective methods through which organ donation and the 'gift of life' can be promoted to the general public, and specifically to the BME population. Research should be commissioned through Department of Health research and development funding.

**Recommendation 14**

The Department of Health and the Ministry of Justice should develop formal guidelines for coroners concerning organ donation.



## Annex D

### International Comparisons - Deceased Organ Donation rates per million population - 2006<sup>52</sup>

<u>Country</u>	<u>Rate (pmp)</u>	<u>Presumed Consent Country?</u> <sup>53</sup>
Spain	33.8	Yes
Belgium	27.1	Yes
USA	26.5	No
Austria	25.2	Yes
France	23.2	Yes
Ireland	22.7	No
Italy	21.7	Yes
Finland	21.0	Yes
Portugal	20.1	Yes
Czech R	18.8	Yes
Latvia	18.7	Yes
Hungary	17.5	Yes
Norway	16.2	Yes
Germany	15.3	No
Sweden	15.1	No
Slovenia	15.0	Yes
Canada	14.1	No
Poland	13.0	Yes
Croatia	12.9	Yes
<b>UK</b>	<b>12.9</b>	<b>No</b>
Netherlands	12.8	No
Slovak R	12.1	Yes
Luxembourg	12.0	Yes
Denmark	11.5	No
Switzerland	10.7	No <sup>54</sup>
Australia	9.8	No
Israel	9.7	No
Lithuania	9.7	No
Greece	7.1	Yes
Estonia	6.9	Yes
N Zealand	6.0	No

<sup>52</sup> Council of Europe Transplant Newsletter: September 2007 - International Figures on Organ Donation and Transplantation - 2006

<sup>53</sup> Abadie A, Gay S. The impact of presumed consent legislation on cadaveric organ donation: a cross-country study. *J Health Econ* 2006;25 :599-620 - Also Global observatory on Donation and & Transplantation.

<sup>54</sup> Informed consent applies at the Federal level. However, the country is divided into Cantons that have their own legislation including a number that have presumed consent legislation. Sources as above.

Cyprus	5.7	Yes
Bulgaria	2.7	Yes
Turkey	2.1	Yes
Romania	1.0	No

## Annex E

### Organisations and individuals who gave evidence in person to the Committee

Those giving evidence	Representing
<b>5 March 2008</b>	
<ul style="list-style-type: none"><li>Dr Richard Lewis, Welsh Secretary</li></ul>	British Medical Association
<b>9 April 2008</b>	
<ul style="list-style-type: none"><li>Mr Argiris Asderakis, Consultant Transplant Surgeon</li></ul>	University Hospital of Wales
<ul style="list-style-type: none"><li>Karen Morgan, Regional Manager Donor Care &amp; Co-ordination</li></ul>	UK Transplant
<b>23 April 2008</b>	
<ul style="list-style-type: none"><li>Joyce Robins</li></ul>	Patient Concern
<b>30 April 2008</b>	
<ul style="list-style-type: none"><li>Greg Pycroft</li></ul>	National Secular Society
<ul style="list-style-type: none"><li>Naomi Phillips</li></ul>	British Humanist Association
<b>7 May 2008</b>	
<ul style="list-style-type: none"><li>Bill Morgan, Secretary</li><li>Gloria Owens, Trustee</li><li>John Reeve, Chair</li></ul>	Welsh Kidney Patients Association
<b>14 May 2008</b>	
<ul style="list-style-type: none"><li>Louise Collar</li><li>Lorraine Hill</li></ul>	UK Transplant Co-ordinators Association
<ul style="list-style-type: none"><li>Allison John, Ambassador</li><li>Roy Thomas, Executive Chair</li></ul>	Kidney Wales Foundation

21 May 2008

▪ Richard Griffith, School of Health Science	Swansea University
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12 June 2008

▪ Delyth Lloyd, Communications & Public Affairs Manager ▪ Betty McBride, Head of Policy	British Heart Foundation
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19 June 2008

▪ Edwina Hart AM, Minister for Health & Social Services ▪ Prof Mike Harmer, Deputy Chief Medical Officer	Welsh Assembly Government
▪ Mr Abdul Hammad, Consultant Transplant Surgeon	Royal Liverpool Hospital
▪ Prof John Saunders	

## Annex F

### Schedule of Committee Papers Provided to Inform Oral Evidence

Date	Name of Paper	Paper Reference Number
5 March 2008	British Medical Association	HWLG(3)-05-08-paper 1
9 April 2008	Transplant Directorate, University Hospital of Wales	HWLG(3)-07-08-paper 1
9 April 2008	UK Transplant	HWLG(3)-07-08-paper 2
23 April 2008	Patient Concern	HWLG(3)-09-08-paper 3
30 April 2008	National Secular Society	HWLG(3)-10-08-paper 2
30 April 2008	British Humanist Association	HWLG(3)-10-08-paper 3
7 May 2008	Welsh Kidney Patients Association	HWLG(3)-11-08-paper 1
14 May 2008	UK Transplant Co-ordinators Association	HWLG(3)-12-08-paper 1
14 May 2008	Kidney Wales Foundation	HWLG(3)-12-08-paper 2
21 May 2008	School of Health Science, Swansea University	HWLG(3)-13-08-paper 1
12 June 2008	British Heart Foundation	HWLG(3)-15-08-paper 1
19 June 2008	Welsh Assembly Government	HWLG(3)-16-08-paper 1
19 June 2008	Transplant Directorate, Royal Liverpool Hospital	HWLG(3)-14-08-paper 1
19 June 2008	Prof John Saunders	HWLG(3)-16-08-paper 2
<b>Additional Written Evidence (following oral evidence session)</b>		
9 April 2008	British Medical Association	HWLG(3)-07-08-paper 8
3 July 2008	Kidney Wales Foundation	HWLG(3)-18-08-paper 3

### Transcripts

Copies of all papers and transcripts of meetings can be found at:

[www.assemblywales.org/bus-home/bus-committees/bus-committees-third-assem/bus-committees-third-hwlg-home.htm](http://www.assemblywales.org/bus-home/bus-committees/bus-committees-third-assem/bus-committees-third-hwlg-home.htm)

## Annex G

### List of Respondents to Call for Written Evidence

The following organisations responded to the call for written evidence

Organisation	Committee Reference
National Kidney Federation	HWLG(3)-07-08-paper 3
Mr Bruce Robins	HWLG(3)-07-08-paper 4
Donor Family Network	HWLG(3)-07-08-paper 5
Mr Hywel Matthews	HWLG(3)-07-08-paper 6
Ynys Môn Community Health Council	HWLG(3)-07-08-paper 7
Swansea Bay Racial Equality Council	HWLG(3)-09-08-paper 4
Christian Science Committees	HWLG(3)-09-08-paper 5
Mr Paul Thomas	HWLG(3)-09-08-paper 6
Mr F.G.N. Morgan	HWLG(3)-09-08-paper 7
Buddhist Council of Wales	HWLG(3)-10-08-paper 4
Bahá'í Council for Wales	HWLG(3)-10-08-paper 5
Shree Swaminarayan Hindu Temple	HWLG(3)-11-08-paper 2
Mr P Davies	HWLG(3)-11-08-paper 3
<b>Additional Written Evidence</b>	
British Medical Association	HWLG(3)-07-08-paper 8

Please note that the above list does not include any organisations or individuals who indicated that they did not wish their details to be published.

## Annex H

### Glossary of Terms

<u>Abbreviation or Acronym</u>	<u>Explanation</u>
BMA	British Medical Association
BME	Black and Minority Ethnic
HWLG	Health, Wellbeing and Local Government Committee
LCO	Legislative Competence Order (A piece of legislation that gives the Assembly wider legislative powers)
NHSBT	National Health Service Blood & Transplant
ODTF	Organ Donation Task Force
pmp	per million population (rate of organ donation)
UHW	University Hospital of Wales
UKT	United Kingdom Transplant