

## SPUC Consultation Briefing: Human Transplantation (Wales) Bill

**Start of consultation:** 18/06/2012

**End of consultation:** 10/09/2012

### Key documents:

- Draft Bill <http://wales.gov.uk/docs/dhss/consultation/120618billen.pdf>
- Explanatory Memo <http://wales.gov.uk/docs/dhss/consultation/120618memoen.pdf>
- Consultation document: <http://wales.gov.uk/docs/dhss/consultation/120618documenten.pdf>
- Response form (scroll down to bottom of page. Response form is the Word document)  
<http://wales.gov.uk/consultations/healthsocialcare/organbill/?lang=en>

### How to respond:

#### Online:

<https://secure.wales.gov.uk/consultations/forms/organ1/:jsessionid=1KTVQRKXHz2npfnhkN2j9wj8XhLPHjJDwpGJ5TyTjCs9Lhq1GnS!545803488?lang=en>

**Email:** Fill in the consultation response form (above) and email it to [organdonation@wales.gsi.gov.uk](mailto:organdonation@wales.gsi.gov.uk). Please mark the subject of your email: Consultation on the Draft Human Transplantation (Wales) Bill

**Post:** Print out the consultation response form (above), fill it in, and post it to:

Organ Donation Legislation Team  
Medical Directorate, 4th Floor  
Welsh Government  
Cathays Park  
Cardiff  
CF10 3NQ

**Telephone:** Call the following number and ask for a response form to be posted to you. Large print, Braille, and alternative language versions are available. **029 2037 0011**

**Question 1: Have the concepts of deemed consent and express consent been explained clearly enough? No (see below).**

**Question 2: Is the role of the family clear? No (see below).**

**Question 3: Are the arrangements for the registration of wishes clear? No.**

**Question 4: Are the arrangements for establishing residency clear? No.**

**Question 5: Does the Equality Impact Assessment properly set out how the legislation will affect different sections of society, including children and people who lack capacity?**

No. Since unfortunately the Equality Impact Assessment neglects to address crucial scientific and ethical issues surrounding organ donation it cannot give a realistic account of how different sections of society will be affected by legislation.

### Society for the Protection of Unborn Children

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**Question 6: The outline for the communication plan is shown in the Explanatory Memorandum. Do you feel reassured that the Welsh Government is planning the public information campaign thoroughly?**

No. Any public information campaign must address crucial ethical issues surrounding organ donation; most importantly, current controversies surrounding the definition of death.

**Question 7: Any other comments not addressed by the questions above**

There are many and serious objections to the proposals that are not addressed at all (or only inadequately) in setting out these proposals; most importantly the question of whether so-called ‘brain-death’ or ‘brain stem death’ is actual death. As David W Evans MD, FRCP has noted:

“the basis upon which a mortally sick patient is declared “deceased” – for the purpose of acquiring his or her organs for transplantation without legal difficulties – is very different from the basis upon which death is ordinarily diagnosed and certified and that highly relevant fact is not fully and generally understood.”

The proposals ignore the facts concerning this area of scientific dispute, yet this is a question with enormous ethical implications. Most organ donors are unaware that their hearts may be beating when their organs are taken, and that they may be pink, warm, able to heal wounds, fight infections, respond to stimuli, etc. They are also unaware of common practices of paralysing and (sometimes) anaesthetising supposedly brain dead donors before their organs are taken. Simply signing a donor card does not in any way indicate that the prospective consenting donor understands what will be involved, and those who are merely ‘presumed to consent’ are likely to know even less.

It is extraordinary that the issue of determination of death, which must govern consideration of so many other issues in organ donation, is so often ignored, in spite of the US President’s Council findings (see appendix) and the growing scholarly literature on the question. That the public are not made aware of the controversy, even in a consultation on organ donation, is deeply regrettable. Notions of informed consent, let alone presumed consent, are meaningless unless the facts of the matter are openly discussed and considered. So too are impact assessments.

A presumed consent system could also place relatives and loved ones under great pressure, with insufficient regard for their wishes and feelings, at a time when they may be at their most vulnerable. Even if they give consent ‘on behalf of’ the patient, and are given an opportunity to veto organ harvesting under a ‘soft’ system, they may come to regret this at a later time; for example, if they become aware of controversies about the determination of death.

Another ethically significant issue that has received insufficient attention is the different significance of organs and other body parts that can be transplanted or may be transplanted in the near future. A presumed consent system that effectively transfers ownership of the body to the state could mean that *any* organ or tissue might be used for transplant in the future. There are some important nuances here that relate to identifiability of the deceased (for example, limb transplants) or to reproductive continuity. The purposes for which a transplant could be used may raise serious ethical questions. New transplant techniques may, if future legislation permits, allow gonadal tissue to be transplanted, leading to the potential for children to be born whose biological parents are deceased. Another

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example: would the public be untroubled if wombs or genitalia from deceased people were transplanted – for example, in sex change operations? At present it is unclear whether body cells might not be used for purposes of therapeutic cloning, leading to the creation of an early human being destined for destruction. While a discussion about the ethics of these matters should take place sooner rather than later, as far as the issue of consent is concerned, ethically more contentious transplantation could become more common, though no less problematic, under a presumed consent system.

The implementation of presumed consent is driven by the desire to increase organ donation rates. Whilst this is certainly a good goal in principle, if ethical conditions are met, there is no definitive evidence that presumed consent actually increases the availability of organs (see the documentation produced by the independent report of the Organ Donation Taskforce: *The potential impact of an opt out system for organ donation in the UK*, and their conclusion; “...after examining the evidence, the Taskforce reached a clear consensus in recommending that an opt out system should not be introduced in the UK at the present time. The Taskforce concluded that such a system has the potential to undermine the concept of donation as a gift, to erode trust in NHS professionals and the Government, and negatively impact on organ donation numbers. It would distract attention away from essential improvements to systems and infrastructure and from the urgent need to improve public awareness and understanding of organ donation. Furthermore, it would be challenging and costly to implement successfully. Most compelling of all, we found no convincing evidence that it would deliver significant increases in the number of donated organs.”

Moreover, in other medical contexts, informed consent is the gold standard. So it really must be asked why in this particular setting informed consent is being set aside. Perhaps it is because presumed consent is outcome driven and therefore primarily justified on utilitarian grounds.

Given the already numerous questions that surround organ donation (even aside from questions surrounding brain-death), this ethically sensitive area needs the careful attention of those who are not only committed to assisting potential organ and tissue recipients to achieve better health, but also to ensuring that an ethically sound system is in place that protects human life and well-being.

Finally it is worth noting that organ ‘donation’ is about the giving of a ‘gift’. Yes, the idea of donation as a free gift is essential to the use of human remains in transplantation. Presumed consent dispenses entirely with this notion, and with it, one of the strongest rationales against trafficking in organs for financial rewards.

## **APPENDIX: Brain Death Controversies**

The US President’s Council on Bioethics in December 2008 was highly critical of current UK practice of seeking to identify ‘brain-stem death’ as a sufficient basis for the diagnosis and certification of death for transplant purposes. (President’s Council on Bioethics, *Controversies in the Determination of Death* (Washington, D.C.: President’s Council on Bioethics, 2008)). An influential recent paper on the subject by D. Alan Shewmon (“Brain Death: Can it be Resuscitated” *Hastings Centre Report* 39.2 (2009): 18-24) critically assesses the Council’s work and makes a

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strong case against current UK practice in relation to ‘brain stem death’, as well as US practice in relation to ‘whole brain death’. As Shewmon notes in the paper:

“Just as cigarette ads are required to contain a footnote warning of health risks, ads promoting organ donation should contain a footnote along these lines: “Warning: It remains controversial whether you will actually be dead at the time of the removal of your organs. This depends on the conceptual validity of ‘position two’ in the analysis of the determination of death conducted by the President’s Council of Bioethics. You should study it carefully and decide for yourself before signing an organ donor card.” Similarly, in conversations with families of patients in total brain failure, representatives of organ procurement organisations should frankly disclose the existence of ongoing controversies over whether their loved one is dead or in a deep, irreversible coma. Of course such information is never given, neither to the public nor to individuals, because it would likely decrease the number of donated organs.”

There have been documented cases of ‘brain dead’ patients maintaining bodily functions for months or even years; for example, growing up and passing through puberty in the case of a child, or sustaining a pregnancy and giving birth to a baby in the case of a pregnant woman. See D. Alan Shewmon, “The Brain and Somatic Integration: Insights Into the Standard Biological Rationale for Equating ‘Brain Death’ With Death”, *Journal of Medicine and Philosophy* 26.5 (2001): 457-478. Moreover, it is well-known to transplant teams that heartbeating donors move when organs are taken, unless they are paralysed by drugs, and that their blood pressure goes up when the incision is made. It is worth noting that some anaesthetists recommend that the supposed ‘cadaver’ be anaesthetised when his/her organs are retrieved.

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