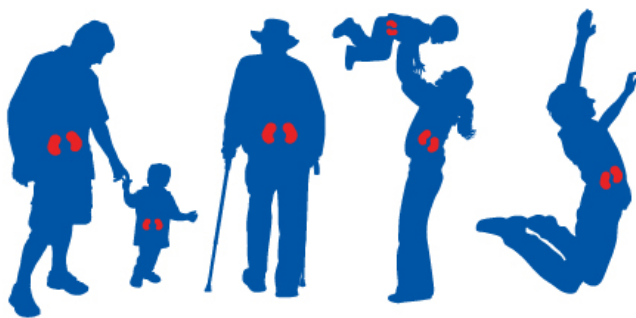




Kidney Wales Foundation
Sefydliad Aren Cymru

Charity Number 700396

The Human Transplantation (Wales) Bill

Evidence to the National Assembly for Wales

Health & Social Care Committee

Supplementary Evidence by Kidney Wales Foundation

On European Convention on Human Rights and European Community Law

Following our evidence to the Committee on 21 of January and Oral Evidence on 24th of January we set out below our views on Human Rights and European Community Law.

European Convention on Human Rights

The core European Convention on Human Rights provisions falling for consideration in relation to deemed consent are

- Articles 8 (right to respect for private life); and
- Article 9 (freedom of religion).

We have focused on the principles that would need to underpin any deemed consent system as outlined in the Bill following our analysis and advice taken over time.

We hold the view contained in the 17 November 2008 Independent Report by “*Organ Donation Taskforce*” entitled “*The Potential Impact of An Opt Out System for Organ Donation in the UK*”.

The Report summarised its views in the following way: “*a system that was based on a presumption of consent or authorisation that allowed adequate provisions for a person to opt out would be compatible with the ECHR. Such a system would need to allow a person to indicate their wishes (such as on a register) during their lifetime and also to allow for evidence from family members about the person’s wishes and beliefs after their death. Particular consideration would be needed for some groups of people, in particular children, people who lack the mental capacity to make a decision to opt out and those whose identity was unknown at the time of their death.*”

Annex C to that report contained a careful analysis of the potential Convention issues arising in respect of any opt out system adopted focusing, in particular, on the concept of presumed consent. The analysis was prepared by the Legal Working Group to the Taskforce.

The Working Group's most important conclusion was that there was no necessary incompatibility problem with a deemed consent system such as to make any assertion of legislative competence illegitimate.

We agree with this view and have taken Counsel Opinion and believe it is further justified by the following considerations:

- (a) Opt out systems operate in a substantial number of European Union and Council of Europe countries and they have never, so far as I am aware, led to any challenge before the European Court of Human Rights¹;
- (b) The Additional Protocol to the Council of Europe's *European Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin* (ETS No. 186)² provides at least some insight into the core standards which the European Court might expect to be respected in this field. It includes the following key provisions, none of which preclude the existence of an opt out system:
 - Signatory States must have a clear legally recognised system specifying the conditions under which removal of organs or tissues is authorised (Article 17);
 - The only absolute bar to organ and tissue removal concerning a deceased person is presented if that person had objected to it (Article 17);
 - The human body must be treated with respect and all reasonable measures must be taken to preserve the appearance of the donor corpse (Article 18);

¹ Spain, Austria and Belgium are the most prominent examples but they are not alone: see e.g. S Gevers, A Janssen and R Friele "Consent Systems for Post Mortem Organ Donation in Europe" *European Journal of Health Law* 11 (2004) 176-177; *New York Times* 23 April 2010; Impact of presumed consent for organ donation on donation rates: a systematic review *BMJ* 2009 338: a3162; The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross Country Study (December 2005) – Alberto Abadie & Sebastian Gaye.

² Although the United Kingdom has not signed or ratified this Convention it has been ratified by 12 member States of the Council of Europe. The Convention has only been referred to in the case law of the European Court of Human Rights in an unrelated context (see e.g. *SH & Others v Austria* Application No. 57813/00 1 April 2010 relating to the availability of fertility treatments).

- Signatory States are obliged to take “*all appropriate measures to promote the donation of organs and tissues*” (Article 19);
 - The Convention requires adequate measures for the protection of the confidentiality of any donor (Article 23).
- (c) There is no indication in the approach of the European Commission of the European Community to the issue of transplantation that it considers that such a system would be incompatible with fundamental rights. This is of at least some significance, even having regard to limitations on European Union competence in this area, (see further below).
13. In view of the care of the analysis set out, and to avoid unnecessary repetition, we strongly urge you to bring a copy of the Working Group’s report dated 11 April 2008 and published as Annex C into your evidence.

European Community Law

14. A helpful summary of recent developments in European Union governance over organ donation and transplantation, focusing on the Commission’s action plan and the Organs Directive (subsequently Directive 2010/45/EU 7 July 2010) is set out in the article “*Adding Value? EU Governance of Organ Donation and Transplantation*” Ann Maree Farrell, EJHL 17 (2010) 51-79. This article makes the following important points each of which support our views that a **deemed consent system would be compatible with European Community law**:
- (a) The Commission and the Directive allow for flexibility on the part of Member States in relation to the meeting of obligations with respect to e.g. donor consent (see paragraph 4.3 & Directive Article 14);
 - (b) As Farrell explains “*in relation to regulatory requirements covering consent to organ donation, the EU’s competence to act on this issue is circumscribed by Article 168(7) TFEU which states that national provisions regarding the donation or medical use of organs shall not be affected by the adoption of minimum harmonisation measures under Article 168(4)(a) TFEU*” (p. 73);

- (c) The Commission has expressly acknowledged that there is a “*degree of variation as between Member States in relation to the consent regimes that have been adopted in relation to deceased organ donation, reflecting the national specificities of historical, socio cultural protection and political flexibility*” (p. 73 citing Commission Impact Assessment accompanying Communication 30.5.02007 SEC (207) 704 at 24-27).

Roy J Thomas

14 February 2013