

Consultation on the Human Transplantation (Wales) Bill

I am responding as a Consultant Transplant Surgeon in Nottingham who has been involved in transplantation for 25 years. I am a member of the Human Tissue Authority, Past-President of the British Transplantation and Chair of Transplant 2013, but I respond with my own personal view.

1. The individual provisions set out in the Bill

Section 2, relating to the promotion of transplantation

Whilst it is important for Welsh Ministers to promote the benefits of transplantation, it would seem more important under 2(b) and 2(c) for Ministers to specifically provide information and increased awareness about organ and tissue donation, as this is what is actually required. I recognize that organ and tissue donation are included under the umbrella term of transplantation activities for the benefit of this Bill under section 3(2), but I still feel it important that organ and tissue donation are specifically mentioned at this point of the Bill.

Section 3, relating to lawful transplantation activities

Could section 3(3) (and 9(2)(b)) be taken to read that primary consent was not required when transplantable material was removed outside Wales? I'm sure this is not what is intended and may just be the way the Bill is worded, but should be considered at this stage to ensure.

Sections 4-8, relating to consent

No comments

Sections 9-11, relating to offences

No comments

Sections 12-20, which make general provision

Can I suggest that 17(2) includes aunt and uncle (particularly as niece and nephews are included), as this seems to have been omitted from the Human Tissue Act 2004?

2. Any potential barriers to the implementation of these provisions and whether the Bill takes account of them.

Currently the rate of relative refusal when an individual is not on the Organ Donor Register across the UK is of the order of 56%. Whilst the approach to families under the proposed system of deemed consent will be different, there is no evidence to show whether families will be more likely to give consent if they didn't actively know what their loved one would have wished. So whilst individuals may have been deemed to have given consent if a) they had not registered an objection or b) previously registered on the Organ Donor Register – in reality despite any

communication plan many individuals will not have had a conversation with the family in life about their wishes after death and therefore consent will not have been given and families may still refuse to give consent to similar rates as at present.

3. Whether there are any unintended consequences arising from the Bill.

See comments under 1 above about potential unintended consequences namely:

- i) the need to express clearly the responsibility of Welsh Ministers to promote both organ/tissue donation and transplantation
- ii) to ensure that primary consent is given under the Human Tissue Act 2004 or Human Tissue (Scotland) Act 2006 for tissue removed and stored outside Wales and then imported into Wales.

It is still unclear to me as to how much public support there is within Wales for these changes. It appears that two public opinion polls have been skewed by organized campaigns – one in favour and one against, so the real view of the people of Wales may not be as clear. Whilst opting out/presumed consent legislation has been accepted in Europe, the effect in Brazil and Chile has been to reduce organ donation rates and legislation has subsequently been repealed. The European countries with the highest organ donation rates are Spain, Coatia and Portugal and it is changes in the infrastructure that have resulted in these improvements. Even though Spain has an opt-out law they do not attribute their high organ donation rate to it – see Fabre J, Murphy P, Matesanz R. Presumed consent is unnecessary. *BMJ* 2010; 341: 922.

4. The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the Bill).

No comment

5. The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Part 1, paragraph 90 of the Explanatory Memorandum, which contains a table summarising the powers for Welsh Ministers to make subordinate legislation).

No comment

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