

SPUC consultation summary: Human Transplantation (Wales) Bill

August 2012

(You can also read the SPUC briefing <http://www.spuc.org.uk/campaigns/alerts/2012/walesorgansbriefing201207> for lots of good points you can include as you fill in the consultation.)

The Welsh Assembly has introduced a draft bill for presumed consent for organ donation. This is a serious danger and effectively abolishes organ donation as a free gift: a person's organs will automatically become the property of the State. The new system would opt-in as donors those who have been living in Wales for a period of six months or more. These measures could negatively impact on the seriously ill and dying and their families, who may not be aware of medical controversies surrounding the determination of death which, if known to them, might make some reluctant to donate their organs. The evidence seems mixed about whether such a change would increase the number of organs available. Some countries with presumed consent systems do worse than the UK but some do better, suggesting that other factors may be more important.

Question 1: Have the concepts of deemed consent and express consent been explained clearly enough?

No. Deemed consent is not a readily understandable concept. Deemed consent and presumed consent is the same thing, yet a new word has been used. This is confusing. Concepts such as opt-in and opt-out are also open to misinterpretation. It is also misleading to include the word consent, when no true consent is given in the case of deemed (presumed) consent.

Question 2: Is the role of the family clear?

No. Difficulties will arise regarding parents and children, carers of adults who lack capacity, and the role of family members appointed to act on behalf of the deceased. For example, there could be difficulties when a family member believes they have evidence that proves the deceased would have objected to having their organs taken but others in the family disagree.

Question 3: Are the arrangements for the registration of wishes clear?

No. Many problems will arise with people being automatically be opted-in. This will be a shock for those not aware of this policy. There will be language barrier problems for those from overseas. Deregistering will be burdensome if the person is elderly, disabled, lives in a rural area, or lacks internet or telephone, for example.

Question 4: Are the arrangements for establishing residency clear?

No. The application of the proposed bill is confusing regarding a person living outside of Wales. It is unacceptable that everyone is opted-in, included those living in Wales for 6+ months.

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. Unfortunately the Equality Impact Assessment neglects to address crucial scientific and ethical issues surrounding organ donation and therefore cannot give a realistic account of how different sections of society will be affected by legislation.

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. This consultation itself has not been properly advertised, considering the importance of the issue.

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

The very serious issue of how death is determined has not been addressed. The medical literature points to evidence that brain death, particularly as diagnosed in the UK, may not be an accurate guide for determining death. Potential donors are not informed about what will be done to them in terms of common practices like paralysing and (sometimes) anaesthetising supposedly brain dead donors before their organs are taken. 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.