

Draft Human Transplantation (Wales) Bill

Consent to organ and tissue donation in Wales Consultation response form Christian Medical Fellowship

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Responding as Health- related organisation

Question 1

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

No

Comments

The change in terminology from 'presumed consent' to 'deemed consent' is new and the term is ambiguous. Deemed consent is a legal expression that does not have any clear meaning in ordinary conversation. It is not a readily understandable concept. Moreover, it is not clear from this term whether a conclusive or rebuttable presumption is created ie. 'conclusively presumed' or 'presumed in the absence of evidence to the contrary'.

The change in term appears to be an attempt to play down the reality that 'deemed' - and 'presumed' - consent are both misnomers. This proposed change involves neither donation nor consent by the individual. Silence does not amount to consent.

While the (competent and properly informed) express wish of a donor should trump the views of the next of kin, the mere fact of not registering an objection is not equivalent to express consent and it is a legal fiction to deem it to be so.

Question 2

Is the role of the family clear?

No

Comments

There must be an amendment to the Bill clearly stating that where the deceased has not given express consent for their organs to be taken, they shall not be removed if the surviving family objects.

The Bristol and Alder Hey controversies were fuelled by the perception that families had no real power in decision-making with respect to what happened to their loved one's body parts. They also showed how crucially important the body is to bereaved parents and friends, and illustrated the need to respect the human body, even in death, and not cause unnecessary distress to the mourners.

In this draft Bill, the opportunity for the deceased's family to veto organ donation if they hold strong objections and/or concerns with it, and where no explicit consent was given by the deceased, is very unclear, despite the claim that this Bill introduces 'soft' consent (ie. involving relatives in the decision-making). There is no provision in the draft Bill to veto the removal of organs.

The consultation memorandum states that in the context of very strong objections or distress, the taking of organs is 'unlikely' to happen. It does not state that it will not happen. Moreover, it says that the objections have to be 'very strong' or that people must be 'distressed.' However, consent underlies the relationship between a doctor and patients *and* their families. Where no view was stated when the deceased was alive, unless the State wishes to suggest that the deceased now belongs to the State, and not the family, the family must have some right to become his/her spokesperson. It would be concerning for medical practice if doctors were encouraged to disregard consent in dealing with the immediate family in this context.

Paragraph 12 of the memorandum states that: *'we believe the fact a person had chosen not to opt out, will help relieve the burden on families at the most difficult of times by giving them more confidence of their loved one's wishes'*. However this 'confidence' could only be reasonable if it were grounded in evidence, and lack of formal objection is very weak as evidence of consent. The fact that the State 'deems' the person to have consented, in the absence of any evidence other than lack of formal objection, is not grounds for confidence.

Therefore the Bill must, at the very least, make plain that where the deceased has not given express consent, clinicians should not be able to take organs if the family object.

Question 3

Are the arrangements for the registration of wishes clear?

N/A

Question 4

Are the arrangements for establishing residency clear?

N/A

Question 5

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

N/A

Question 6

Do you feel reassured that the Welsh Government is planning the public information campaign thoroughly?

No

Comments

If an opt-out system is introduced to Wales, it is essential for the Welsh Government to be able to state that they have done their utmost to ensure that every person in

Wales has had the opportunity to hear about their right to opt out of the new proposals, otherwise consent cannot be presumed or 'deemed'.

Yet even with a major - and costly - public awareness campaign, it will be almost impossible to guarantee that everyone is informed and understanding of the situation, knows their options and can easily and simply opt out.

The groups most likely to fail to express their views by signing up to a register, or removing their name from one, even if they hold personal views on this, will include those who are disorganised, apathetic, disabled, less well educated or informed, isolated, lacking full capacity, of different languages and race, suffering from mental illness, dependent, those who have less ready access to information and those changing their minds. We are concerned that the proposals as they stand cannot guarantee reaching all these marginal groups.

Additionally, the public information campaign does not appear to have engaged at all with current controversies surrounding the definition of death,¹ which is clearly a central part of the donation process and one that potential 'donors' and their families need to be informed about and aware of.

Question 7

We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them:

CMF has over 4,000 British doctors and 1,000 medical students as members. We have members in all branches of the profession, and through the International Christian Medical and Dental Association are linked with like-minded colleagues in more than 90 other countries.²

As a representative body, we are very concerned that there is no provision in the draft Bill for conscientious objection for clinicians who have ethical reservations about participating in this process, despite their key role in many of the decisions that will need to be made around donation. For example, in establishing what constitutes a reasonable effort to establish a lack of objection, ensuring that family members correctly represent and honour the views of the deceased (not voicing their own), and assessing evidence from various family members in cases of disagreement. Some clinicians will be required to identify and define those who lack capacity. Legislation or guidance may also be required to enforce a certain level of duty for clinicians to seek information about a deceased person's views.

Conscience legislation or guarantees will be essential to protect clinicians who do not wish to be part of this process, particularly where consent has not been expressly given or where the family objects.

It is interesting to note that concerns have been expressed in a recent issue of 'Transplantation' about the potential to damage the vital trust between clinicians

¹ Stammers, T.'Brain Death'. 2012.CMF File 48.

<http://www.cmf.org.uk/publications/content.asp?context=article&id=25894>

² See, for example: <http://www.cmf.org.uk/publicpolicy/submissions/?id=142>

<http://www.cmf.org.uk/publicpolicy/submissions/?id=134>

<http://www.cmfblog.org.uk/2012/03/15/limited-consent-for-presumed-consent-legislation/>

<http://www.cmfblog.org.uk/2012/01/16/welsh-plans-to-increase-organ-donation-are-a-costly-waste-of-time-and-money-and-are-ethically-tricky/>

caring for people at the end of life (their patients) and their families, leading to intensive care practitioners opting out of participation in donation programs:

*'Some intensive care staff fear that a move to an opting-out system would make critical care more difficult and could lead to some intensive care practitioners themselves opting out of participation in donation programs. This would be disastrous for the future of organ donation, which is dependent on the active support of intensive care practitioners.'*³ These concerns must be fully and properly addressed through effective conscientious objection provision.

³ Rudge, C & Buggins, E. 27 January 2012. 'How to Increase Organ Donation: Does Opting Out Have a Role?' *Transplantation* 2012;93: 141–144. <http://bit.ly/z4Q8F0>.