

Evidence to Health and Social Care Committee

Human Transplantation (Wales) Bill

Further suggestions from Professor Vivienne Harpwood

The Bill would benefit from clarification in a number of ways, as the people who will need to interpret and act upon the proposed legislation will be clinicians and families of donors, all of whom have a right to expect that the language used will be accessible. The Welsh public at large, and those who come to live in Wales, some of whom do not have English or Welsh as their first language, will be educated about the important social and practical matters proposed in the Bill, and will need to understand its provisions. Greater clarity of language will facilitate realistic opportunities for publicity and discussion. Some suggestions are outlined below:

Deemed or presumed?

The central focus of the Human Transplant (Wales) Bill is on the provision of a “soft” opt-out system, in which consent is presumed in certain circumstances. However, this is not immediately obvious on the face of the Bill, which uses the word *deemed* – a term that is difficult for non-lawyers to understand. The history of the use of *deemed* indicates that it can be a complex and difficult word even for lawyers.

- It is a word that can be used in many different ways, and has different meanings and interpretations according to the context.
- It is a legal expression that has no clear meaning in ordinary discourse, and its use often leaves important details to be worked out by the reader.
- There are many different sorts of deeming – e.g. conferring a discretion; adding in something that is otherwise excluded.
- Deeming clauses are commonly found in technical areas of law such as planning Regulations, and have been under sustained criticism for some time in academic and other discussion fora.
- The current legal language in the Bill is a perpetuation of an opaque and problematic position.
- The word *deemed* is used in the Human Tissue Act 2004, which probably accounts for the decision of those who drafted the Welsh Bill. However, that Act has itself been much criticised for its lack of clarity.
- There may not be an equivalent Welsh term to *deemed*, and it is important that there should be no linguistic disjunction between the terms used in the English and Welsh versions of the Bill.

In my view there is a strong case for grasping the opportunity that we have now in Wales to produce clear legislation which can readily be understood by the majority of the population. We have tabula rasa in this respect, and clarity is particularly important in legislation that directly affects such a deeply personal and sensitive matter as consent in medicine.

Since the use of the word *deemed* in connection with what is generally understood as *presumed* consent, could be seen as a deliberate attempt to obfuscate one of the main objectives of the Bill, why not be honest with the people of Wales? This is a Bill aimed at winning hearts and minds, accompanied by a publicity campaign entitled “Heart to Heart”, encouraging families and friends to express make their wishes about organ donation known to those close to them. This reinforces the argument in favour of clarity. The position is that *consent may be presumed in the absence of compelling evidence to the contrary*, and everyone affected by the legislation needs to know that.

Why not make the most important point in the Bill as close to the start as possible? In the preamble, perhaps, by adding the words “*and for the introduction of the concept of presumed consent in certain circumstances*”.

Clumsy use of language in parts

e.g. Clause 1 (e) (i): It is not usual to use “*that*” in connection with “*persons*”. The clumsy use of language in the statement “*persons that do transplantation activities*” is almost ungrammatical. Would not “*persons who carry out transplantation activities*” be preferable? Throughout the Bill, “*carry out*” is clearer than “*do*” in relation to transplant activities.

Clause 8 (2) is ungrammatical. “*P’s consent to the activity is deemed*” does not make sense. Is it meant to read “*P’s consent to the activity is deemed to have been given*”? (but as already indicated, I would favour *presumed to have been given*).

Clarification of the difference between donation after circulatory death (DCD) and donation after brainstem death (DBD).

It would be helpful if the expressions *DCD* and *DBD* were defined in the Bill.

Clause 5 refers to *excepted patients* and does not therefore refer to DCD patients. Section 8 does refer to DCD patients, but the distinction is not clear on the face of the Bill. Also, the word *deceased* needs to be removed from Clause 12, as it does not currently take account of DCD patients. The same applies to Clause 6, which is opaque because of the lack of these definitions.

Donors of tissue who are located in the community

The Bill appears to assume that all patients from whom material is taken for the purposes of donation will be in hospital. However, tissue (e.g. corneas) is taken from donors at home.

Conjunction with the Mental Capacity Act 2005

Where a patient has issued an advance refusal of treatment, that decision needs to be taken into account when considering the various processes that might need to be carried out in relation to DCD patients close to death. Has the relationship between the Bill and the MCA and its Code of Practice been taken into account?

An additional chart would add clarity

Why not add a chart to cover all categories of patients?

Proposed duty on Welsh Ministers to promote organ donation.

At present, donors are being lost because there are insufficient numbers of critical care beds. Will the new duty on Ministers result in an increase in the number of critical care beds as part of the restructuring of healthcare services in Wales? Have the financial implications of this been taken into account?