

31 12 2012

Re: Consultation on the Human Transplantation (Wales) Bill

Dear Mr Drakeford,

Above all I want to emphasise the vital need to maximise organ donation. The concerns expressed below are entirely directed at the proposed bill which is unlikely to increase donation rates, a point now tacitly admitted by the minister concerned, and may well make matters worse. My intention is to avoid damage to the donation process which has seen a great advance in the last few years..

Although I am both the Chairman of the Abertawe Bro Morgannwg Organ Donation Committee and Vice Chair of the Clinical Ethics Committee I am responding to the request for consultation in a personal capacity. I am doing this in part because of previous arithmetical arguments as to the level of support for the bill being based on the number of returns for and against. It was clear that if an organisation provided proforma letters to its members to sign individually those letters would be counted as individual submissions whereas the considered opinion of a large group with special expertise which provided one submission via its chairman would be counted as one submission.

1. a. The “elephant in the room” which continues to be ignored is that both presumed and deemed consent are oxymorons. Consent can only be legally and ethically meaningful if it is contemporaneously informed. However much publicity is given informed consent can never be assumed for an individual. This bill is in fact proposing non consensual donation. The name of the process is therefore mendacious and manipulative. It sets out to mislead the public from the outset and therefore cannot have public confidence except by way of ignorance.
 - b. The notion that government can proceed by deemed or presumed consent is very dangerous ; for instance why not presume if a voter does not attend a ballot then it be assumed that they accept the status quo?
2. Contrary to that stated by Welsh Government there is not robust data to support the concept of presumed consent as a route to increased donation. Indeed in their own publications they refer to robust data in the same paper as that giving different levels of expected benefit. This is an intrinsic contradiction inconsistent with “robust” data. There is an increasing appreciation that data from the Spanish presumed consent process has been widely misquoted. The increase in donation rates in Spain occurred about ten years after the bill was introduced and followed extensive investment in the donation process. The demographics of the health service, ITU bed numbers and head injuries are very different in Spain and in fact vary across Europe. In this context it is essential to note that the UK has an appalling record in the number of ITU beds per head and as increased donor numbers will put extra pressure on those beds other patient categories will suffer. No allowance has been made for this need. It is all too easy to assume

post hoc propter hoc, and if this bill had been introduced in 2007 then the efforts of the organ donation taskforce in raising the donation rate by 48% in four years would have been ignored and the increase ascribed to the bill not to other more pertinent measures including increased publicity. This increase has taken up a lot of “slack in the system” and any further increase will be correspondingly more difficult to achieve.

3. NHSBT has identified areas within Wales where there is a significant failure to identify donors. If the money set aside for the Principality wide mechanism now proposed was concentrated in those areas the expected outcome would be reached sooner and more effectively.
4. There is an increasing swell of concerned public opinion about the bill’s proposals with many anecdotes (some of which fall within my direct personal experience) that potential donors are withdrawing from the organ donation register. NHSBT organ donation register data on this are difficult to interpret as the reporting process altered about the time of the bill’s announcement but they can be interpreted as supporting this anxiety . There is understandable concern that what was previously considered as a gift similar to blood transfusion has now, at the state’s behest, become a right of the state to take not a choice of the donor to give. A major part of the increase in donation rates is due to the inception of donation after cardiac death. This process only applies in 4 countries of the EU and is illegal in many . It has been difficult enough to ensure that clinical staff understand and support the concept . When the general public become more aware of it , especially in the context of assumed consent , disquiet will be become still stronger. Although some organisations notably the BMA have been seen to support the bill nationally there is clear evidence that within Wales that support is not shared and an informal poll of 18 renal specialists in Wales revealed only one in favour. It is unfortunate that it was at the national BMA meeting held in Cardiff when the supporting vote was proposed by a Welsh doctor and then announced. This gave a spurious validity to positive feeling amongst Welsh doctors.
5. The Human Transplantation (Wales) Bill includes the following provision at its sub-clause 5(3) in respect of an ‘excepted adult’, i.e. a deceased person to whose mortal remains the law, if enacted, will not apply:

‘(b) an adult who has died and who for a significant period before dying lacked capacity to understand the notion that consent to transplantation activities can be deemed to be given; and for this purpose a significant period means a sufficiently long period as to lead a reasonable person to conclude that it would be inappropriate for consent to be deemed to be given’

A rational adult being, by virtue of their rationality, unable to understand the notion of an oxymoron such as "deemed consent" (except as an intellectually invalid abstraction) the bodies of the majority of potential ‘donors’ would automatically be made unavailable for transplantation purposes by the

wording quoted. My own body would certainly be unavailable under such wording.

- 6 The estimated costs of the scheme have varied depending on what is included, but do not include the costs of inevitable challenges all the way to the Supreme Court. The sequential subjectivity of the definition of 'excepted adult' that is quoted above is itself remarkable, quite unusually vague, and open to challenge accordingly in almost all conceivable circumstances. We fear that, as a consequence only the lawyers will benefit.

In summary the bill is defective in many ways, it is the consequence of political initiative in the face of professional and public disquiet. There is little evidence that it will increase donation rates and the strong negative publicity it has already attracted gives cause to expect the opposite. There are also better and cheaper ways to go forward.

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