

Draft Human Transplantation (Wales) Bill

This paper is offered as a guide to issues raised by the Bill (& its memorandum of explanation) ahead of the meeting at the National Assembly on February 7.

The Welsh Assembly Government has bent over backwards to consult on these proposals: with its specialist advisory groups, its public consultation and its active programme of local opinion finding. (The latter was well intentioned, but the numbers too small to be reliable. As its report makes clear some of the findings were contradictory. Nevertheless, it was a good effort).

On the central issue, let me reiterate that I strongly support the intention of the Bill. Transplants save lives; transplants enhance lives. They are also cost effective: transplantation is cheaper than dialysis, for example.

The draft Bill and its explanatory memorandum are, in the main, well written and understandable. The term ‘presumed consent’ has, mercifully, been expunged. What now appears is ‘deemed consent’. I interpret this to mean that the person from whom organs will be removed has not consented but will be treated as if they have. (It might be helpful to acknowledge that in the Memorandum). That is now correct; ‘presumed consent’ (despite its previous use in the Health, Well Being and Local Government Report) was wrong. Consent, to repeat, can never be presumed: that is definitional of consent. Similarly the term ‘donation’ or ‘donor’ implies giving. Giving is voluntary. If there is no knowledge that someone wanted to give, then it is not a gift. It is something removed, not donated. That does not make it morally objectionable, merely inappropriate and – in an extreme view – coercive use of language.

The chief problem with this Bill remains its underlying justification. Organ donation has risen by about 50% since the UK Organ Donation Task Force Report. In Wales 37% are now on the register, an achievement of which Wales should be proud. It is not “only” 37%. There is nothing in the Explanatory Memorandum to the Bill to suggest that a further significant improvement can be achieved by this legislation. We know that Spain, in particular, has the best record in Europe for transplants and we also know that it is not the result of its opt out system.

Para 13 of the Explanatory Memorandum states that “nothing could be further from the truth” that organs will be taken compulsorily or automatically. If there are no family members available to act as advocates against, then the organs will be taken. I have no moral difficulty with that: but I also don’t think it is ‘nothing further from the truth’. It strikes me as pretty close to the truth! The problem with soft opt out is that it is very close to what currently happens when consulting the potential source patient’s family. Insofar as the possible patient’s wishes are downgraded, it is not difficult to understand how some will construe this as the person’s body becoming the property of government: even though it doesn’t. It is legitimate for the state to act on the basis of the best interests of society while protecting minority beliefs. Given the balance of benefit, perhaps the memorandum should make the case for the Bill with greater moral force about the contrast between organs transforming lives, on the one hand; and organs being eaten by worms or burned to ashes on the other. Failure to maximise benefit when the personal cost (i.e. by the source patient) is so minimal (actually nil, as they are then dead) and the potential for good so high makes the moral calculus, in my view, clear.

The problems with the Bill are the hazards it creates for damaging the present programme of transplantation. That damage will be contingent on certain practicalities and how they are handled. A single mishandled opportunity in the hands of a critical media could create havoc with donation numbers; a vociferous opposition could prime the public in a negative manner if practical issues are not addressed. Among these are the way the modified Register is operated. There is a substantial potential for confusion in the single opt in/opt out register. 'Opting in' could fall, while 'opting out' would take us little further on than where matters stand at present. The practicalities of constant reminders of the system will be challenging. It will require different materials compared to England and Scotland: for example, the invitation on Boots Advantage Card membership may require amending. In principle this represents no problem, but practice may be more difficult.

The biggest single problem with the Bill is the lack of data to predict (or even make probable) its success. The Bill has been introduced in the face of two expert inquiries: one UK wide which was unanimous despite starting with divided opinions; and one in Wales with a 2:1 majority against. It is nowhere adequately explained why these two expert groups got it wrong. After all, the Task Force's other recommendations have surely been responsible for rising rates of donation across the UK. The track record of the Task Force has been good so far on the other issues.

Given the manifesto commitment and the advanced stage of planning, this point may be considered a battle lost for opponents of the Bill; and I would tend to agree with that. However it does emphasise the importance of agreeing what would constitute success. Politicians do not have a high place in public esteem. (I personally think that is overall rather unfair, but that is beside the point). The risk is that if donation continues to rise at the same rate as it is currently rising, there will be a political incentive to now claim that it results from the Bill, when it would have happened anyway. Whether we like it or not, Wales is a pilot project for the rest of the UK. If it can be clearly demonstrated that the Bill really has made a difference, then England and Scotland and Northern Ireland will follow suit, to the great benefit of thousands of patients. If the numbers transplanted falls then the reverse applies. It is therefore critical that what constitutes success is set out in advance and not the subject of argument afterwards. I appreciate the difficulties of creating 'counterfactuals' as discussed at paragraph 93 and the section on Regulatory Impact Assessment is short on detail. It would be helpful to discuss how this might be improved.

This paper emphasises issues previously articulated in the paper submitted by the Royal College of Physicians of London. I declare an interest as the main contributor to that paper and continue to hold the views in it. You may wish to consider queries and opinions arising from it alongside this briefer submission.

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