

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)52 - Anonymous

Dear Sirs

Thank you for the opportunity to respond to the above consultation.

Although the proposed legislation appears, on the surface, to be an ingenious and attractive solution to the problem of inadequate donor supply - unfortunately, I believe it to be a seriously misguided and unnecessarily draconian response to that issue and indeed, that it raises more fundamental and far-reaching concerns than those that it may seek to address.

The principle of *informed* patient consent is fundamental to the position of trust between clinician and patient (and indeed, with regard to the status of the person, between the patient and the State). The principle of deemed consent, in the form that underpins the draft legislation, is anything but that. It is not consent at all, even if it may be couched in those terms by way of legal fiction or in media-friendly terms such as a 'soft opt-in'.

It seems to me that the potential effect of deemed consent in the legislation is that, inter alia, the State in effect owns a person's body after death, regardless of that person's individual wishes or convictions (religious or otherwise), with the very real risk that a citizen may simply be regarded as a 'resource' - and that the dignity of that person, and indeed all citizens, is eroded. This seriously undermines what many would regard to be a fundamental human right - that donation should, as now, be a gift freely given. A State should not assume the rights or freedom of conscience of its citizens if it is to call itself democratic nor should it dictate, as it seems to in this draft legislation, that ministers be propagandists for transplantation in this form (and therefore the questionable ideology behind it) irrespective of their personal views or those of the citizens that they are democratically charged to represent. The imposition of a 'duty' upon ministers to promote transplantation in this way is a dangerous legal precedent in general terms and, more specifically, could also suppress objective and necessary review of these policies in future - for fear of breach of duty. In particular, it may suppress any sensible debate about any other alternatives to, or means of, increasing the donor pool in an ethical, democratic and clinically beneficial way.

The draft legislation also raises the issue of consent more generally. I query whether those who are generous enough to consent to organ/tissue donation, even now, are aware of what precisely they are consenting to upon their death. Many will not know that the bar for determining death for the purposes of organ and tissue donation is, I understand, set much lower than perhaps they would understand. Many, perhaps most, are not aware of the significant concerns that exist within the medical community whether, say, brain-stem death is actual death, and that potentially a donor could have organs removed in circumstances when their heart is still beating and when they could give birth or feel pain/be deemed to require anaesthesia, i.e. when most of us might consider ourselves still to be alive. This raises serious ethical issues, which I do not believe are addressed.

I would urge, therefore, that the proposed legislation be rejected for the reasons stated, and that time be devoted towards other solutions to clinical need based on real informed patient consent - not least as I am particularly concerned that such legislation might be regarded as some form of 'pilot' for the wider UK.

Please acknowledge safe receipt.