

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)75- Anonymous

Dear Mr Drakeford,

I am writing to engage with the latest round of consultation on the Human Transplantation (Wales) Bill. I do so despite the response of the Welsh Government (WG) to previous consultations to which I have submitted evidence, where the WG has consistently failed to acknowledge the level of disquiet about this bill. While the transplant community in Wales has made great progress in increasing the level of donation over the past two years, assisted no doubt by the controversy over this bill, the case for changing the law has not been made.

In the face of opposition the WG has turned to evidence ostensibly showing that an opt-out system will increase donation, and to opinion polls showing support for the legislation. However the very report the WG cites states explicitly that "it cannot be inferred that this association means that presumed consent *causes* increased organ donation" (emphasis in the original). At the same time support for the legislation has declined over the period of engagement with the public and has now fallen below 50%. The results of the most recent consultation showed more opposition than support from those who engaged, not only from identical submissions (which generally reflect campaigns for or against legislation) but from those, such as myself, who took trouble to write individual responses. It is also very evident that the process of engagement has significantly alienated certain minorities within Wales. This opposition also seems to have increased over the period of engagement with the public. "Consultation" without listening generates frustration and anger.

My greatest concern about this bill remains the key idea that someone who has never expressed any view can be "deemed" to give consent. This act of deeming is a legal fiction which perhaps does no harm when the relatives are also supportive, but where relatives object, there is the prospect of the body being effectively confiscated by the state on the basis of a legal fiction. Even where someone has signed the donor register there is no way to assess if this consent is informed or if it is consent to donate in the face of serious opposition from close relatives. No donor is ever asked if they consent to use of organs *in these circumstances* (which they may do, but it may be that they would not wish to upset the people they leave behind and have not considered the possibility of such opposition).

Clearly the best case is where people think about this issue and discuss it while they are alive (as I have discussed it with my wife, as well as signing the register) but in the absence of such *knowledge of the actual wishes of the deceased*, some consideration must be given to the feelings of the bereaved. People have a right to bury their wives, husbands, parents and siblings, and to give to them the respect due by the rites of their religion and tradition. This is quite compatible with a system of organ donation where it is voluntary and respects the feelings of those left behind. The greatest flaw in the draft bill is section 4 subsection (4) which includes no qualification of deemed consent ***in cases where there is no evidence of prior express consent and a person who stood in a qualifying relationship to the deceased has a strong objection to the removal of organs***. Not to include such a qualification is inhumane and risks undermining long term support for organ donation. Such a qualification is of course compatible with an opt-out system (as in Belgium).