

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)17 - Dr Hefin Jones

Dear HSCCommittee

I write, again, in response to the Consultation on Presumed Organ Donation and as someone who has carried an Organ Donation Card since 1979, to register my deep concern regarding this legislation.

Firstly, I do so as a practising Christian and without repeating his words, highlight the thoughtful response of the Archbishop of Wales on this matter. I also note that a large number of my Islamic (Muslim) friends share very similar and strong concerns regarding this proposed legislation.

I also seriously question, the ethical justification for the fundamental correctness of the assumption that consent can be presumed. I would argue that *presumed consent in effect equals no consent*, unless there is an extensive public information programme, which would need to capture *the entire adult population* including those on the margins of society. Only this would ensure that those who do not opt out of donation have made an explicit choice, rather than doing so by default, by ignorance or by a lack of knowledge or understanding. This, to me, makes the whole concept of 'presumed', or 'deemed', consent ethically problematic, as well as complex, and very costly, to administer. There is, as you will be aware, considerable evidence in peer-reviewed literature that it is not even the most effective way to increase organ donor numbers.

I have read the various documentation associated with this debate and unless I am totally mistaken it appears to me that it has been said all along that 'soft' opt-out legislation will be introduced, allowing the family of the deceased a role in the final decision, **the Bill as it stands does not in fact allow for this**. While provision is made on page 20 of the draft memorandum, there is, again as far as I can determine, no provision in the Bill itself for providing distressed relatives with a right to object to the removal of organs when no consent was given by the deceased.

I again register my deep concerns and inability to support this legislation.

Yours sincerely

Hefin Jones (Dr)