

HEALTH AND SPORT COMMITTEE

HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

SUBMISSION FROM GILLIAN E HOLLIS

Q1 - What do you think are the key strengths and weaknesses of the proposals to introduce 'deemed authorisation' for those who have not made their wishes on organ donation known?

Key weakness – Presumed consent is presumptuous, and risks alienating people who would have opted to donate freely but not when forced, presumed or expected to donate.

The element of gift that characterises the existing system of organ donation – and is so important to potential donors, donor families and recipients - would be diminished under the proposals. There is a potential backlash from people who object to the state having assumed rights over their bodies. Thus, the proposals may lead to a negative shift in public perception about organ donation, and possibly create a new category of people who would have opted in under the old system but would opt out under the new.

Key weakness – Lack of public trust in the security and accuracy of personal data being held by third parties.

The proposals place greater reliance on the recording of wishes on the organ donor register than the current system, particularly if a person does not wish to donate. Public trust in the security and accuracy of personal data held by third parties has eroded recently. This may lead some people to worry that their wishes may not be followed.

Key weakness – The message is complicated.

As I detail in my response to Q3, I believe the communication of any change in the default position will be crucial to successful implementation. However, I think both the message and language are complicated, offering a significant challenge to the team assigned to raising awareness. “Tell us if you want to donate, tell us if you don’t want to donate, and if you don’t tell us anything we’ll presume you have authorised donation.” “Deemed authorisation” is not an intuitive description, and the use of the phrases opt-in and opt-out invites double negatives. The percentage of Scots signed up to the Organ Donor Register is the highest in the UK, thanks to a combination of Scottish Government funding for awareness raising, excellent campaigns and the generosity of the Scots. However, replacing a simple message with a complicated one risks confusing the public and undermining the good work achieved.

Q2 - What do you think are the key strengths and weaknesses of the plans for authorisation of pre-death procedures?

Key strength – Transparency.

Specifically obtaining authorisation for such procedures ensures that families understand exactly what is going to happen to their loved one, to allow donation to take place.

Key weakness – Quite technical, and risks information overload for donor families at a difficult time.

It increases the burden of information and decision-making on families at a very sensitive time. Most other laypeople to whom I've talked assume that the decision to donate is a simple one; the myriad of subsequent information and questions following an initial decision to go ahead comes as a surprise. Adding to this burden should be avoided.

Q3 - Do you have any other comments to make on the Bill?

The importance of raising public awareness and communicating any change in default position, without alienating people already sympathetic to organ donation.

The overall thrust of the Bill is a significant change in the default position. How that message is conveyed to people, should it be necessary, will be extremely important. I think it's crucial that the element of gift, so central to organ donation under the current system, is maintained.