Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill
UK Donation Ethics Committee

I set out below a response from the UK Donation Ethics Committee (UKDEC) to the call for views, in the form of answers to the questions posted on the website.

By way of background, UKDEC was formed to consider ethical issues, both general and specific, relating to the field of organ donation and transplantation and provide independent advice to clinicians, policy leads and others. Further details about the Committee, including its full terms of reference and current membership, can be found at:

http://www.aomrc.org.uk/committees/uk-donation-ethics-committee.html

Do you support the Bill?

1. Do you think the Bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland? Please provide an explanation for your answer.

The Committee thought that the Bill was unlikely to achieve this aim for a number of reasons.

The procedures for determining the wishes of the potential donor are so elaborate that organs may be lost or degraded due to the passage of time.

Because of the complexity of the checking process, much greater resources of staff and equipment are likely to be necessary than at present. It would be understandable if staff felt their time and resources were better applied to the care of other patients at a time when resources are tight.

The Bill proposes a change from a system where authorisation is explicitly given, to an opt-out system where it would be indicated by doing nothing. For an opt-out system to be ethically sound, the public must be adequately informed of all aspects of the system. The proposals for keeping the public informed are not convincing – in particular any information programme will need to be permanent (because the resident population ages and changes). If the information programme is inadequate, confidence in organ donation might well fall.

The likely public perception that it is no longer necessary to state formally a desire to donate may reduce the number of potential donors on the Organ Donor Register (ODR), thus limiting the number of potential donors whose wishes are clearly understood at an early stage.
There would seem to be merit in waiting for an analysis of the effectiveness of the Welsh public information programme before formulating a Scottish model.

2. Do you support the proposal of appointing a proxy? Please provide an explanation for your answer

No. It is too complex, and implies too close an interest and involvement in this issue by the general public. The provisions for appointing anything up to three proxies are confusing and the system for recording the appointment of a proxy is unclear. There is considerable potential for confusion and losing precious time while the existence or otherwise of a proxy is investigated. The danger is that, far from increasing the supply of organs, such a system may well end up losing organs while the wishes of the potential donor are investigated.

3. Do you have any comments on the role of “authorised investigating persons” as provided for in the Bill?

This is not properly explained. It is unclear who this person is, how they are trained, where they fit into the clinical hierarchy, or whether they are outside it. It is also unclear whether their prime duty of care is to the potential donor and their family or to potential recipients, or to a more nebulous concept such as the transplant programme overall.

If it is envisaged that the Authorised Investigating Person is the Specialist Nurse for Organ Donation (SNOD), the Bill as currently drafted would lay a further substantial burden on the SNODs at a time when their primary focus should be on supporting the family and enabling the donation process to proceed as efficiently as possible.

4. Is there anything in the Bill you would change? If yes, please provide more details.

All definitions in the Bill need to be more precise.

The Bill proposes a profound shift in the relationship between the state and its citizens’ bodies. As well as moving from explicit authorisation to an opt-out system, it appears to dilute, if not do away with, the idea of ‘donation’ - substituting for ‘donated’ the word ‘removed’. The tenor of the revisions is all about *taking* and *removing* organs rather than *giving* and *donating* them. This would seem to be a fundamental shift rather than just a change of emphasis.
The Committee believes that such a big change deserves standalone primary legislation after a period of extensive public consultation, rather than a series of complex amendments to existing legislation.

Given that Wales is about to implement its own scheme, there may be merit in waiting to see if there are any lessons to be learnt from the Welsh experience.

In particular, the assumption that a shift to a system of deemed consent automatically leads to more donations needs to be tested. Any additional donations attributed to the change need to be costed in the light of the public information campaign and the increased administration required to run the 'proxy' and ‘authorised investigating person’ schemes. These costs need to be weighed against other possible uses for the money.

Yours sincerely,

Peter Jones  
UKDEC Secretary