QUEENSLAND COUNCIL FOR CIVIL LIBERTIES

G.P.O. Box 2281 Brisbane 4001

Submission for the Queensland Council for Civil Liberties

Overview

The Queensland Council for Civil Liberties (QCCL) accepts the importance of increasing the availability of organs for transplantation (and therefore the number of donors) ideally so that no potential recipient will die or be unduly delayed before a transplant is available.

However, QCCL attaches great importance to the need for informed consent by or for each donor. It respectfully urges the Select Committee to come to the view that a presumed consent system:

- is not ethically acceptable;
- does not balance individual and family rights with community need so well as an opt-in system does;
- is not indicated by any strong evidence;
- should not be introduced by any one State if Australia as a whole continues to apply an opt-in system; and
- would create too many problems or exceptions if minors and the impaired are to be catered for properly.

QCCL sees great merit in the NHMRC guidelines set out in 2.5.3 of the Issues Paper particularly, in the context of the Select Committee's terms of reference, to giving precedence to the needs of the potential donor and family over the interests of organ procurement.

QCCL notes that the "strongest" system described in the Issues Paper is that of Austria but Austria's dpmp is not included in Figure 1. It will be apparent that QCCL would be strongly against a comparable system in Queensland (particularly the idea that opting out might adversely affect priority as a recipient) and suggests that, unless the dpmp is very high, the Austrian example provides strong support for the view that opt-out systems do not of themselves lead to high donation rates.

QCCL notes the importance of the aphorism "think nationally, act locally" and suggests the Select Committee should draw three conclusions from it. First, Queensland should attach great importance to positive efforts to maximise its involvement in national initiatives like the National Organ Donation Collaborative and the smoothest possible transfer of organs across state borders so they are

available Australia-wide to recipients in greatest need. Secondly, Queensland should only adopt approaches that are fully compatible with any proposed national system. Thirdly, that Queensland should establish a system that optimises the role of each hospital and its practitioners in identifying, supporting and guiding potential donors and families.

Issues for Comment

QCCL will comment only on the issues that are of concern to it or about which it believes it possess some understanding. In this submission each issue will be identified by the page of the Issues Paper on which it appears and its dot point. For example P18, dot 4 is: Do you support introduction of an opt-out or presumed consent system?

P 18, dot 1

The system should be an opt-in one for reasons given above. It need not require signed written consent. For example, an email should suffice or electronic entry on the National Register if that is available.

P18, dot 2

Yes, if a person has given written consent, next of kin should be consulted (a) to learn if the donor had made known a wish to withdraw and (b) to provide a chance for an active objection to be voiced. There should be no need for a further written consent.

QCCL recognises the great sensitivity involved if a potential donor has given consent but family object. Is it practicable for donor decisions to be recorded in different categories? For example:

1. No
2. Yes if family agrees
3. Yes
4. Yes despite family objection

QCCL supports freedom of individual choice and suggests the 4 categories above could carry the following consequences:

1. No: Family cannot then consent.
2. Yes if family agrees: There would be a need for active written consent.
3. Yes: Family to be consulted as in the first paragraph under this issue.
4. Yes, despite family objection: Family should not be consulted and objection should carry no weight. Those involved in a transplantation should have statutory indemnity for carrying out the individual's wish.

P18, dot 4

QCCL is against an opt-out system. It opposes mandated choice (3.2.4); any strong opt-out system; and any adverse consequence for opting out.

P18, dot 5

QCCL is much more persuaded by the arguments in 3.5 than those in 3.4.

P19, dot 3 Yes.

P19, dot 4 No.

P 19, dot 5 Yes. This clearly follows from the answer to dot 4. QCCL believes, however, that it will prove extremely difficult to draw up a truly appropriate division between those who should be excluded and those who should not. For example, what does "impaired decision making capacity" entail? Is it to be decided on purely medical grounds or can cultural and educational issues be considered? This is a major reason why QCCL opposes the opt-out system

P21, dot 1

In considering this issue, QCCL believes it is worth distinguishing between research (and perhaps other purposes) that is closely related to the transplantation and other essentially separate uses. In this submission the former is called "related research" and the latter "other uses".

By way of example, in the case of a lung transplant, once the transplant is complete there will be tissue left (trimming from connective tissue, and fluids). Using that tissue for research would be related research. If an organ were removed but transplantation could not proceed for some reason and the organ were then used to research the effect of introducing a tumour to it or how it reacted to specific stimulae, that would be "other uses".

QCCL believes informed consent should always be required before the removal of organs. QCCL also believes consent, whether actual or presumed, to removal for transplantation should not be presumed to extend to other uses. Explicit consent even if broadly expressed – for example "teaching and/or research" – should be required for other uses.

By contrast, QCCL believes that actual consent to transplantation should carry with it presumed consent to related research. It is hard to imagine that anyone prepared to consent to their lungs being transplanted would object to residual tissue being used for related research. On the other hand, it might be unnecessarily stressful as well as impractical to require explicit consent be obtained from a potential donor and their family before undertaking related research.

P21, dot 2

Yes. There may well be potential donors or their families who would be prepared to consent to transplantation for the good of another individual but who would not wish to donate organs for other uses. If no opt-out for specific

uses was possible, this might result in a total opt-out which would defeat the aim of maximising the number of willing transplant donors.

P22, dot 1

Broadly speaking, yes.

P22, dot 2

a) QCCL believes consideration should be given to including presumed consent to related research when actual consent to transplantation is given.

b) QCCL understands that under the present system, when a potential donor has given full consent and the family has indicated agreement during the donor's life, it is still necessary to gain written confirmation from next of kin after the potential donor is declared brain dead. This should be changed so that it is possible to finalise all required consents before death.

P27, dot 1

Since there were 360 tissue donors compared to 39 organ donors in 2007, consideration should be given to ensuring the maximum proportion of donors provide organs as well as tissue. This may focus on increasing the proportion of cardiac death donors who provide organs as well as tissue.

P27, dot 2

The penultimate paragraph of 4.7 of the Discussion Paper states that in Spain presumed consent allows intervention before discussion with family thus maintaining a cardiac dead person's organs. QCCL requests the Select Committee to consider whether there are hospital-based strategies that can be undertaken, pending any required family decision over donation, to preserve the organs of cardiac-dead potential donors that would still leave a later refusal possible. If so, QCCL would not oppose a system of presumed consent to the preservation of a potential donor's organs pending the family decision.

P27, dot 3

QCCL believes the law should continue to prohibit the sale of organs. Incentives to potential donors to actually donate, such as assistance with funeral expenses appear to QCCL to carry similar if less acute dangers and to be open to the same ethical criticism as organ sale. Providing priority to someone registering consent who later needs a transplant disturbs what QCCL sees as the important principle that organs should go to those in greatest need. It should not be used as an incentive.

However, the proportion of those registered as having consented to donation that actually become donors will always be very low. It will occur only after a series of chance events that lead to someone registered suffering brain or

cardiac death in or close to hospital. As a result QCCL does not see a danger in or an ethical objection to a modest incentive to those who register on the Australian Organ Donor Register and maintain their consent to donation.

P27, dot 4

QCCL suggests the Select Committee consider the feasibility of some modest on-going incentive to those on the Register such as a tax rebate in the year of registration and every complete year in which they remain on the register.

Yours faithfully

Michael Cope
President
For and on behalf of the
Queensland Council for Civil Liberties
20 August 2008