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Organ and Tissue Donation After Death: Ethical Guidelines for Health Professionals
Public Consultation Feedback Template

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Name: Tony McBride **Organisation:** Health Issues Centre

Page	Chapter	Paragraph	Comments
	Introduction		HIC welcomes the Working Party's acknowledgment that there is a need for further research into why rates of organ and tissue donation and transplantation are particularly low among Aboriginal and Torres Strait Islander peoples. HIC urges the initiation of this research as a priority, especially given the high rate of diabetes and renal failure in these communities. Research into why many culturally and linguistically diverse communities have low donation rates should also be undertaken.
	1.1-1.2		HIC advocates the addition of further background context to the guidelines. For example, it would be helpful for readers to know why the donation rate is so much higher in South Australia, and whether the contributing factors have any relevance to attempts to raise the rates in other states and territories. If this is not known, further research would be useful. There is a similar issue with regard to Tasmania's comparatively high percentage of its population registered on the Australian Organ Donor Register, and yet its comparatively low rate of donation.

			Even if these points are obvious to some professionals in the field of organ and tissue donation, they would be useful to explain for other professionals who will be following the guidelines and perhaps having input into public education processes and materials.
	1.3	Opting out / opting in systems	HIC has strong reservations about any attempt to replace the current ‘opting in’ model of donation with an ‘opting out’ model. HIC’s experience of working to improve health outcomes for Australians, especially those who are disadvantaged, suggests that such a change risks further alienating those consumers already marginalised in the health system. Overseas literature further supports this conclusion, with minority communities often found to have high levels of distrust of the health system (see Appendix in **General Comments** below). As implied in our response to 2.1, 2.2, 4.3 and Appendix D, many members of ATSI and CALD communities would be highly unlikely to register their unwillingness to donate. Even if the ‘soft’ system was favoured in relation to the deceased person’s families (in our view, the better of the two options under the opting out approach), this is unlikely to achieve high rates of donation without the availability of earlier, culturally appropriate information. While the Draft notes the necessity of ensuring that the relatives of potential organ donors are always approached by someone with sufficient experience or specific training for the purpose, it is not clear that at present appropriately culturally qualified personnel are in place for this. The ‘opting out’ approach is therefore also likely to further reduce the future pool of donors from these communities. We also note that under the ‘soft’ option, family members effectively become the safety net for the presumption of

			consent to donation by the deceased. However, it is unclear how this would work for individuals with no close ties, or what checks and balances would exist if relatives were difficult to locate.
		Contact between donor families and transplant recipients	While HIC does not have sufficient information to comment specifically on the mutual consent register proposal, it is unclear how such a register will resolve the problem of donor families and recipients making contact via information gleaned from the internet and the media. To avoid situations where such contact is unwanted, or is distressing in the absence of professional assistance, there may be need for specific strategies such as legal reform (eg analogous to the present situation where if media publish adoption details they risk a contempt of court action).
	2.1		The research into why rates of organ and tissue donation and transplantation are particularly low among Aboriginal and Torres Strait Islander peoples, and into why many culturally and linguistically diverse communities have low donation rates, should aim to produce more culturally appropriate materials to assist members of all of these communities to make informed decisions about organ and tissue donation. This must go further than the acknowledgment in 2.1 ie it is not simply about translating materials from English.
	2.2		There needs to be more specific content in the guidelines in relation to the types of beliefs and practices which help to influence the low rates of ATSI and CALD donation.
	4.3		HIC agrees that the production of culturally specific materials must work in tandem with appropriate education and processes at the local community level – not just in relation to organ/tissue donation, but with the aim of fostering increased confidence and trust in the health system by ATSI and CALD communities.
	Appendix D		Appropriate cultural training should also be an essential part of the training options.

General Comments

HIC draws the attention of the Working Party to the bibiliography below which represents the results of a brief search of the international literature on some of these issues. If these references have not already been surveyed, they may be a useful starting point for further Australian work.

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