



Australian Government  
National Health and Medical Research Council

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

**Closing Date for Comments: Monday 24 April 2006**

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Page	Chapter	Paragraph	Comments
5		1	A wonderful expression, 'social capital' but not well understood. It may need a brief definition as a footnote.
5		a) in box	'Solidarity' is not a word that lends itself to use in this context. Perhaps 'humanity' may be a better word.
12->	2 ->		The use of the word 'patient(s)' should be diluted and interspersed with the use of person or people. It is a term not well supported by health consumer organisations and has some negative ethical connotations. While it continues to be widely used by health professionals, this document is an opportunity to reduce its increasingly outdated usage and educate health professionals subtly in terminology that is more contemporary and better suited to the notion of some level of partnership in treatment and care.
16	3	Title 3.1	Suggest a change to <i>Care of people who are organ donors</i> to put the humanity back into the definition, rather than defining the person by their catastrophe only ie <i>Care of Potential Organ Donors</i> .

17	3	c) in box	The notion of the health provider ‘allowing’ family members to be present is improper. Perhaps the use of the term ‘enabling’ in its place may give a more appropriate ethical balance to the relationship and reduce the rather paternalistic connotations of the notion of ‘permitting’ and the accompanying power imbalance.
26 +	3 +	In box +	Use of the term ‘the body’ is both insensitive and reductionist. Suggest that ‘the person’s body’ introduces the humanity back into the descriptor.

## General Comments

### 1 Terminology:

- 1.1 The terms around brain death and cardiac death and others used in the document are acceptable. There are a number of terms and as long as they are explained or self-evident, there should be no imperative about using only one.
- 1.2 ‘Sincerely held objection’ is about as good as you can get without sounding paternalistic or obsequious.
- 1.3 ‘Controlled circumstances’ is not particularly intuitive but with adequate explanation can adequately describe the defined procedures that occur in the period after cardiac death.

### 2 Issues for further community discussions:

- 2.1 **Opt in/Opt out Systems:** While the more cautious ‘opt in’ system has some merit, it may be time to set a sunset period (eg 5 years) before moving to an ‘opt out’ system for the following reasons:
  - 2.1.1 Effectively, the capacity for family to overrule the considered choice of a person who has registered themselves on the Register or left a clear statement of desire and consent through some form of enduring power of attorney is legally and ethically improper. The current position is inconsistent with the notion of autonomy and a person’s right to make choices about their bodies and health.
  - 2.1.2 Five years hence, it is to be hoped (and earnestly committed to, resourced and worked toward) that there is: wide community understanding of the role and availability of the Register; the publicity concerning the pros and cons of organ donation should be promulgated much more extensively throughout the community; opportunistic discussions with health providers about organ donation; and open discussions in families. This should all go to making the discussion about organ donation at the emotional and critical time near-death with family less fraught.

- 3 **Contact between donor families and recipients:** The capacity for this contact to be facilitated through a process of ensuring mutual consent is supported. A controlled and appropriate process that ensures that there are no inadvertent breaches of confidentiality or privacy and safeguards in support has the potential to avert the distress and impropriety if people take the investigation and contact upon themselves. If families are adequately and sensitively informed about the possible consequences in relation to the use or not of the donated organs or tissue then the risks are potentially less, including that they will not be misled as to the outcomes.

- 4 Composite tissue allotransplantation:** If people are desperate enough to need such transplants they will often go to great lengths to obtain them, including seeking the surgery in other locations off-shore where the quality of the personnel, techniques and support may be questionable and place them at risk both physically and psychologically. By applying the safeguards around ensuring: an understanding that the treatment is currently largely experimental (hence would need to be constructed as a formal clinical trial); provision of comprehensive information and consent; and ongoing support, the potential benefits may be great. People make difficult choices about treatment and care every day eg to have chemotherapy or not. If the quality of their life is significantly compromised because of a disability that may be remedied or partially remedied by composite tissue allotransplantation then they may regard the risks as worthwhile.
- 5 Family presence at clinical tests for brain function:** This is a decision that should be made after discussion and information with the family, donor support personnel and clinicians. To make a blanket rule is inappropriate and has the potential to lead to the development of conspiracy theories that will prevent the continuation of a relationship of mutual trust, free exchange of information and understanding.
- 6 Citations for additional guidelines and resources:** It would be useful to provide citations for some of the key ethical and legal literature that can give some background to health professionals in this area such as: Kerridge I, Lowe M and McPhee J (2005) *Ethics and law for the health professions*, as well as the very specific literature already cited. Context is important and there are benefits if people can obtain that context by reading more widely.
- 7 Relevant training programs:** A number of the universities and health services have vibrant and well respected bioethics departments, institutes or centres that would be well equipped to develop a custom designed program for a health professional organisation, health department, health service or other organisation in this area.
- 8. Implementation of the Guidelines:** This is the sort of information that should be a ‘pop-up’ on the websites of health professional organisations, health services, departments of health, as well as being widely advertised and available: in the professional literature; hospital and other health service libraries and educational centres; through health professional development programs, universities etc. Electronic accessibility as part of clinical information access hubs available locally and links from health professional sites are probably key means of communication.

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