



australian
nursing federation

Submission to the Review *Recommendations for the donation of cadaveric organs and tissues for transplantation* (NH&MRC 1996) – Call for initial comments

March 2005

1. Introduction

- 1.1 The Australian Nursing Federation (ANF) is the national union for nurses in Australia with branches in each state and territory. The ANF is also the largest professional nursing organisation in Australia. The ANF's core business is the industrial and professional representation of nurses and nursing in Australia.
- 1.2 The ANF's 145,000 members are employed in a wide range of enterprises in urban, rural and remote locations in the public, private and aged care sectors, including hospitals, health services, schools, universities, the armed forces, statutory authorities, local government, offshore territories and industries.
- 1.3 The ANF participates in the development of policy in nursing, nursing regulation, health, community services, veterans' affairs, education and training, occupational health and safety, industrial relations, immigration and law reform.
- 1.4 The ANF recognises that the ethical, social and clinical issues around organ and tissue donation and transplantation remain as challenging in 2005 as they were in 1996 for both the community and health professionals and welcome the opportunity to participate in the review, both at this initial stage and as it progresses.
- 1.5 This submission will cover the major issues of interest to the community, the ANF, nurses and nursing and attempt to address the specific questions raised by the Australian Health Ethics Committee (AHEC) on the document *Recommendations for the donation of cadaveric organs and tissues for transplantation* (National Health and Medical Research Council, 1996) as well as making some brief comments about the four other AHEC booklets on organ donation and where they fit with the *Recommendations* document (National Health and Medical Research Council, 1997, 1997, 1997, 1997).

1.6. The issues covered include:

- Updating the information in each of the five documents under review to reflect the current prevailing ethical views and legislative arrangements in relation to organ and tissue transplantation.
- Making the documents more accessible to the audiences to which they are directed, in terms of:
 - more clearly articulating the purpose, principles, components and linkages of the whole framework made up by the suite of statements, guidelines and discourses;
 - availability in the popular and professional media using a range of mechanisms which are culturally relevant and meet the diverse audiences' needs for information;
 - making the language and writing style more user-friendly and comprehensible; and
 - ensuring their relevance to the purposes for which they have been prepared.

2. Ongoing relevance and utility of the document

2.1 Ongoing innovation in health technology in areas such as immunology, micro-surgery, pharmacology and areas of critical care are increasing the scope in the health care system for organ and tissue donation and transplantation for managing chronic and debilitating illness and the effects of serious injury. Importantly, this is enabling people to move from an often painful and burdensome existence to achieving a better quality of life.

- 2.2 Therefore it is vital that there is national consistency in policy and legislation around the profoundly challenging ethical issues that confront the community at large and, most particularly the recipients and donors of tissues and organs and to those 'significant others' in their lives such as family, carers and close friends, as well as the health professionals who are involved in the care of each of the people involved.
- 2.3 The *Recommendations for the donation of cadaveric organs and tissues for transplantation* was a document that was clearly developed in an effort to obtain some consensus in approach. The ANF has no doubt that there is an ongoing need to have a strong statement of policy to provide consistent guidance for all. This statement must be further developed with input from relevant and expert stakeholders, and must be broadly promulgated to ensure that it is well known: across the community; for those involved in donation, receiving or awaiting receipt of organs or tissue from another person; health professionals; and all those involved in any way with organ and tissue donation and transplantation.
- 2.4 Therefore the ANF is strongly of the view that there is great value in updating the information in each of the five documents under review to reflect the current prevailing ethical views and legislative arrangements in relation to organ and tissue donation and transplantation, including the important recent policy position taken by Australian Health Minister's Conference (AHMC) (Australian Health Ministers Conference, 2005). Whether they remain as five separate documents requires further debate and discussion among stakeholders.

3. Areas for revision and rewriting

3.1 *Making the documents more accessible to the audiences to which they are directed*

As indicated above, the ANF is of the view that the information contained in the documents is worth updating to reflect the progress that has been made in the community and health systems' thinking and action on the ethical and legislative arrangements around tissue and organ donation and transplantation in the almost nine years since the recommendations were endorsed by the NH&MRC in June 1996.

3.2 The current documents do have some significant structural and substantive areas for improvement that will enhance their accessibility for all stakeholders. For example, currently there is no real clarity around which audiences the documents are aimed at. Their style and layout make them forbidding except to the hardened reader of Government policy.

3.3 The ANF is of the view that there needs to be further broad consultation across the community and health sectors to ensure that any revised statements on these important issues outline contemporary thinking as well as the areas of continuing controversy and tension.

3.4 We would suggest that it is critical in the first instance to more clearly articulate the purpose, principles, components and linkages of the whole framework made up by the suite of statements, guidelines and discourses. The new draft *National Statement on Ethical Conduct in Research Involving Humans* that is currently undergoing review and consultation may be a useful model to use (National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellors's Committee, 2004).

It is also critical that there is a process to test the relevance of any information published against the purposes for which they have been prepared.

- 3.5 As well as updating and improving the quality of the information provided, there is also a great need to make such information more available using the popular and professional media using multiple mechanisms designed to be culturally relevant and meet the diverse audiences' needs for information. There is no doubt that the internet is being used increasingly by a broad range of people in the community and the health system. Ensuring that the home page for such information is designed to ensure easy and intuitive navigation is certainly reducing the need for huge quantities of print material having to be designed, printed and circulated at great cost. This is especially so when translation into community languages is undertaken, which, given the issues of sensitivity around organ donation and transplantation among different cultural groups, is a very important consideration. There is certainly scope for making the language and writing style more user-friendly and comprehensible.

4. Gaps in the document

- 4.1 The governance and ethical framework that provides the infrastructure for the issues pertaining to the rights of the parties, and for caring and clinical management are not well articulated in the 1996 document. While the principles are evident in the different sections, it is telling that there is little reference to the 'person' donor and the 'person' recipient in the table of contents, although families, the Coroner and staff do get specifically mentioned.

4.2 The language around the donor, especially if a donor who is 'dead' in terms of the human tissue legislation making it possible for their organs and tissues to be donated to a person in need of these, is euphemistic and scientifically sterile. Many of the difficulties in trying to improve the donation rate of organs and tissues goes to the humanness of the response from individuals, families and loved ones, so stronger acknowledgement of the humanness of the donor person may assist in addressing some of the very sensitive issues.

4.3 The document could be divided into sections around:

- the person donating organs or tissue - the ethical, legal, social and clinical aspects of care; and
- the person receiving donated organs and tissues – the ethical, legal, social and clinical aspects of care.

4.4 The document is very medico-centric and makes minimal reference to the important roles that other members of the clinical team have in the organ and tissue donation and transplantation processes.

5. Areas for omission

5.1 No areas should be omitted though some of the clinical information may be better contained in a set of accompanying clinical practice guidelines.

7.

6. Other issues relating to organ and tissue donation and transplantation warranting comment

- 6.1 The ANF is keen to be involved in the broader consultation around a draft revised document (or documents) that has had the input from individuals with specific expertise in this area, such as consumers, ethicists, clinicians and lawyers. The ANF is willing to recommend expert nurses who could assist the Council once a decision is made on 'where to from here'.

REFERENCES:

Australian Health Ministers Conference (2005) *Joint Communiqué: Transplant donors' wishes to prevail.*

National Health and Medical Research Council (1996) *Recommendations for the donation of cadaveric organs and tissues for transplantation.*

National Health and Medical Research Council (1997) *Certifying death: The brain function criterion: Ethical issues in organ donation - Discussion paper No 4.*

National Health and Medical Research Council (1997) *Donating organs after death: ethical issues: Ethical issues in organ donation - Discussion paper No 1.*

National Health and Medical Research Council (1997) *Ethical issues in donation of organs or tissues by living donors: Ethical issues in organ donation - Discussion paper No 2.*

National Health and Medical Research Council (1997) *Ethical issues raised by allocation of transplant resources: Ethical issues in organ donation - Discussion paper No 3.*

National Health and Medical Research Council, Australian Research Council & Australian Vice-Chancellor's Committee (2004) *Review of the National Statement on Ethical Conduct in Research Involving Humans: First Consultation Draft, Australian Government.*

*Submission prepared by:
Amanda Adrian of Amanda Adrian & Associates
on behalf of the Australian Nursing Federation*