Inquiry into the Charter of Human Rights and Responsibilities

Submission from the Alfred Health Human Research Ethics Committee

5 July 2011

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Alfred Health

Alfred Health incorporates The Alfred, Caulfield Hospital and Sandringham Hospital
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Submission by the Alfred Hospital Ethics Committee (General Ethical Issues Sub-Committee) on the Inquiry into the Charter of Human Rights and Responsibilities Act 2006 (Vic)

The Alfred Hospital Ethics Committee ("the Alfred Ethics Committee") has been advised of the call by the Victorian Parliament for submissions to the Inquiry into the Charter of Human Rights and Responsibilities Act 2006 (Vic) ("the Charter").

The Alfred Hospital is public authority and as such is regulated, in part, by the terms of the Charter. The Alfred Ethics Committee perceives a duty, as a public authority, to provide information to the Inquiry on "the effects of the Charter on ... the provision of services, and the performance of other functions by, public authorities", this being one of the Terms of Reference of the Inquiry.

Of particular relevance to the Alfred Ethics Committee is subsection 10(c) of the Charter, which provides as follows:

"A person must not be ... 
(c) subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent."

One of the Alfred Ethics Committee's primary roles is to ensure that people are given the opportunity to make their own decisions about research participation - to exercise a voluntary and informed choice. Another of its roles is to help facilitate research that is of benefit, whether to the community in general or to particular patient populations. For the majority of research, these two roles align. In some cases, however, research will necessarily involve people unable to exercise their right to give full, free and informed consent, by reason of some incapacity. Furthermore, it is important that people who are unable to exercise this right are not excluded from research which may be of benefit to them, their cohort, and/or the community generally, and that particular conditions or patient populations are not under-researched because of the requirement for consent.

Certain Alfred Health patients (e.g. trauma, intensive care, acute psychiatry, dementia) would not of themselves have the capacity to give full, free and informed consent to take part in medical research, and hence s.10(c) of the Charter is not apt to that patient cohort. The National Statement on Ethical Conduct in Human Research 2007 guides the committee in assessing risk and determining how this inherent tension is managed.

The Charter is by necessity an aspirational piece of legislation designed to ensure that fundamental human rights are safeguarded and protected. In the setting of the field in which the Alfred Ethics Committee operates, those rights are well protected with the existing provisions of the Guardianship and Administration Act 1986 and the National Statement to resolve inevitable tensions that arise when assessing research projects affecting some vulnerable participants.

1 Guardianship and Administration Act 1986 (Vic), Part 4A-Medical and other treatment (and in particular Division 6-Medical research procedures)
2 National Statement on Ethical Conduct in Human Research 2007 (in particular Chapter 4.4 'People highly dependent on medical care who may be unable to give consent', Chapter 4.5 'People with a cognitive impairment, an intellectual disability, or a mental illness', Chapter 2.2 'General requirements
Finally, the Alfred Ethics Committee is also concerned that the terms of subsection 10(c) of the Charter may complicate possible reforms to the medical research provisions\(^3\) in the *Guardianship and Administration Act 1986*, which is currently being reviewed by the Victorian Law Reform Commission.

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\(^{3}\) *Guardianship and Administration Act 1986* (Vic), Part 4A-Medical and other treatment, Division 6-Medical research procedures