

Review of National Statement
NHMRC (MDP 24)
GPO Box 9848
Canberra ACT 2601

8 March 2005

To the Review Committee,

Thank you for the opportunity to submit further comments on the draft *National Statement on Ethical Conduct in Research Involving Humans*. The Research Network of the Diversity Health Institute wishes to emphasise the following two issues for consideration.

Issues pertaining to obtaining Informed Consent

1. PRINCIPLES OF ETHICAL CONDUCT – CONSENT

The history and circumstance of some members of the Australian population give rise to a wariness or mistrust of authority. Little distinction is drawn between the tiers of government, powerful private sector bodies, welfare and other non-government organisations, and authoritative individuals. Those with a personal or cultural heritage of political or civil strife, who have family members in precarious situations in other countries, or who come from smaller communities within the broader population, may have an adaptive reticence to disclosure or participation in research, in particular to signing official – looking documents. Therefore, to extend the benefits of research outcomes to these persons and to satisfy the principle of 'justice in research', point 1.1.8 (e), provision should be made to accept verbal consent in a variety of forms, rather than requiring a rigid approach that *a priori* excludes people from participation due to the misapplication of a legal tradition.

Issues pertaining to situations of power imbalance

7. RESEARCH INVOLVING PERSONS IN DEPENDANT OR UNEQUAL RELATIONSHIPS

Within some communities, and particularly for recently arrived members of these communities, health providers and other authority figures occupy rigidly defined positions that are due significant respect. Parallel to this, in some communities agreeableness is an obligation rather than a free will option, especially towards persons in honourable positions. Expressing negative decisions may not be permissible in a personal encounter. As such, the notion of consent involves less free will than may be presumed within mainstream Australia. Consideration for this situation should be specifically addressed in the methodology of obtaining Informed Consent for participation.

Assumptions about the nature of power balances and their potential impact upon the research process and the ethics of that process require consideration of each situation. In some approaches, particularly ethnographic paradigms and research conducted in collaboration with communities, the participants may hold the balance of power, or the power balance may shift in the course of the investigation. Committees should be encouraged to examine the potential variations in power relationships, particularly in non-clinical research. A corollary is that a collective may grant consent, placing a reluctant individual member of that collective in a coerced situation.

We hope that these suggestions are helpful to the revision of the *National Statement on Ethical Conduct in Research Involving Humans*.

Respectfully,

Professor George Rubin
Professor of Public Health
School of Public Health, University of Sydney
Director, Centre for Health Services Research, Sydney West Area Health Service
Director, Effective Healthcare Australia, University of Sydney

Acting Chair, Research Network
Diversity Health Institute

Prepared by:

Dr Ilse Blignault
School of Public Health & Community Medicine
University of NSW

Roy Laube
Research Coordinator
Diversity Health Institute

Dr Maureen Fitzgerald
School of Occupation and Leisure Sciences
University of Sydney

Jan Kang
Planning and Operations Manager
Diversity Health Institute