

Health Ethics Section
NHMRC (MDP 24)
GPO Box 9848
Canberra ACT 2601

9 August 2004

Dear Dr Breen:

Thank you for the opportunity to make early comments on the *National Statement on Ethical Conduct in Research Involving Humans*. The Research Network of the Diversity Health Institute (DHI) is pleased to submit the following concerns for consideration. In this submission we address the need for a greater emphasis on culture in the *National Statement*. The issues canvassed here regard the ethical review of applications pertaining to research directed towards cultural or ethnicity issues and research that deals with culturally or linguistically diverse populations.

The Research Network is interested in participating in the revision process for the *National Statement*; we would be pleased to discuss how we may best contribute in a significant role. This includes coordinating relevant submissions and consultations in the area of culture and language, and extends to development of supplemental documentation, such as a body of "best practice" guidance papers. The DHI is in a unique position to coordinate this activity and to develop such papers, given its partnerships with a range of individuals and organisations with particular knowledge and expertise in these areas.

Without being prescriptive, we believe the National Statement for multicultural Australia should provide leadership in highlighting cultural issues that are not only relevant to work within Australia, but the growing body of international research in which Australian researchers and institutions are involved. We urge that the document as a whole should be used to encourage cultural sensitivity and competency in research, not only among culturally diverse populations, but for all people as cultural beings. Cultural diversity is a specific area where Australia can lead world opinion in an evolving aspect of research ethics.

The points raised here are based on the idea that cultural beliefs and assumptions are an inherent part of all research and that research ethics are cultural. What may be appropriate for one cultural context or population may not be appropriate in another context or population. The issues and the way to address them vary across contexts and cultures. Cultural sensitivity, relevance and competence are always important, but they may be manifestly different across situations and groups. These points become more complex when we consider the range of paradigms used in such research and, thus, the need for methodological expertise that is culturally and linguistically astute. In particular, we highlight the following points;

- All cross-cultural research must consider cultural and linguistic issues.
- All research that involves people from culturally and linguistically diverse populations must consider cultural and linguistic issues.
- These issues must be addressed not only in relation to the principles of autonomy, beneficence and justice, but also in relation to methodological integrity.
- There needs to be recognition of the cultural diversity within as well as across populations. Thus, there is no one culturally appropriate model for research in any population. In some cases, the population can be viewed as a "collectivity" with identifiable leaders or spokespersons, but not all cultural or linguistic groups represent organised collectivities and there can be problems if a collectivity is too narrowly defined.
- Ethical reviews must consider research with specific populations based on information that is culturally appropriate for that population.
- No one person or group of persons is likely to possess all the necessary knowledge to develop culturally sensitive and appropriate research for all populations. There are, however, people who have enough relevant information and expertise to be considered "experts." These experts include people from the cultural or linguistic group and scholars with extensive expertise with a particular group. Ethics committees and researchers should be encouraged to consult with such people, but committees must also be able to recognise when applicants and their collaborators have the necessary knowledge and expertise.
- Ethics committees that deal with a number of applications for work with particular cultural or linguistic groups should be encouraged to either include members with appropriate expertise or to use an identified panel of relevant experts as consultants.
- There needs to be a clear understanding and appropriate use of relevant terms. For example, there should not be a confounding of the concepts of culture and ethnicity. The use of the term race should be discouraged unless it can be justified in relation to the topic of the research (i.e., an exploration of the concept as a socio-political term and not as a label for populations).
- The importance of language cannot be stressed too strongly. This includes, for example, using the appropriate language or languages for the population involved (the level of language expertise may vary within a population and some groups use more than one language or level of language for different purposes, e.g., written vs. verbal communication), a recognition of the issues related to translation of information sheets, consent form, and research instruments. Reviews of such documents will often require the use of outside evaluators or a clear identification by the researchers of the steps taken to develop the materials in the appropriate languages. There also needs to be recognition that this is a time intensive and often costly process and every effort should be made by committees to not increase the burden of this work by making unnecessary requests for changes that might not be relevant in documents in another language.

- As a review of the literature demonstrates, there are many issues related to the informed consent process that are culturally and linguistically related. Consent processes common for some kinds of research are inappropriate for other kinds of research and processes appropriate for some cultural groups are inappropriate for others. Cultural issues related to such things as power, language, and forms and the process of consent must be considered. Again, no one model is appropriate for all cultural groups.
- There are some populations that require particular cultural and psychological sensitivity and this need should be highlighted. This includes people who have experienced torture and trauma, those who have experienced mental illness, been the subject of discrimination or oppression, etc. The ethical issues related to research with these potentially vulnerable populations take on particular importance if people involved are from a cultural group different from those of the researchers.
- Issues of confidentiality and anonymity are not only cultural constructs, but they can have different forms of significance in some population and may present different issues to be addressed.
- There are special concerns in relation to clinical research. This includes:
 - Issues that may not be the same in relation to work considered quality assurance or quality audit.
 - Power relations that may take on particular importance with some groups because of courtesy bias, feelings of powerlessness with people in authority, or ideas about trust.
- Issues related to privacy can vary across cultural groups.
- Issues related to confidentiality and anonymity may vary across groups and may take on particular significance in small populations or research using some paradigms.
- Complaint mechanisms need to consider cross-cultural differences in the way complaints are expressed and whether the methods available for dealing with any potential problems or concerns are culturally and linguistically sensitive and appropriate. These mechanisms need to be easily understood and initiated.
- The capacity for understanding information presented in common consent processes must be considered from both cultural and linguistic perspectives. The processes should not end up being coercive because they use an inappropriate approach or do not take into consideration cultural issues related to intercultural interactions.
- Issues associated with ideas about public vs. private domains can vary across cultural groups. What may be considered public may not be so considered in some groups and issues normally considered private might not be so considered.
- Ideas about autonomy can vary, particularly because the construct is based on individuated concepts of self that are not relevant in some cultural groups, particularly those from collectivist cultures, but the variability can be extensive within some populations in the process of culture change or acculturation.

- Issues related to ownership of data and what constitutes data need to be considered from a cultural perspective. This needs to take into consideration issues of the multivocality inherent in research data and interpretations, and issues related to academic freedom, that at the same time considers issues of potential benefit and harm for all the people involved.
- Such research needs to consider issues associated with gate-keeping by individuals, groups, and organisations, including the role of ethics committees as potential gatekeepers.
- Guidelines regarding reporting cultural or ethnic self-identity of research participants in the report of findings, to assist the interpretation of data and outcomes.

We thank you for the opportunity to raise these issues for consideration in the revision of the *National Statement* or any documentation that may accompany the new *Statement*. Given the complexity of these issues as identified in our own research experiences and those raised in the literature, we encourage the development of a set of “best practice” documents, or a handbook to accompany a straight-forward, succinct *Statement*. The most important issue to be included in the new *Statement* is the concept of cultural consciousness in relation to all aspects of the research process, particularly when it involves an overt focus on culture, ethnicity, or pertains to identifiable cultural communities.

Yours sincerely,

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