DRAFT SUBMISSION

FROM: RESEARCHERS IN THE HUMANITIES AND SOCIAL SCIENCES

TO: THE AUSTRALIAN HEALTH ETHICS COMMITTEE (AHEC)

FOR: THE REVIEW OF THE *NATIONAL STATEMENT ON ETHICAL CONDUCT IN RESEARCH INVOLVING HUMANS*

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Health Ethics Section
NHMRC (MDP 100)
GPO Box 9848
CANBERRA ACT 2601

The following submission is offered to the AHEC by a number of individuals and organisations in the humanities and social sciences. Those endorsing the submission are responsible for or are carrying out research involving humans. We see the current review as an opportunity for the AHEC to address some of the practical issues that have arisen for research projects in the humanities and social sciences from the implementation of the *National Statement* by Human Research Ethics Committees. We support a revision of the *Statement* that makes it more succinct and accessible to researchers. We also see the review as a reflection of the rapidly changing context for research and as a further development in the commitment of the NH&MRC, the ARC, and the AVCC to address, adequately and appropriately, the complex ethical issues raised by research that involves human subjects.

The submission focuses on a number of key practical issues as follows:
  1. comments on principles set out in the *Statement* in relation to ethics and research;
  2. a recommendation for the inclusion of an alternative research model better suited to the humanities and social sciences;
  3. identification of some of the reasons why current procedures and policies impede rather than facilitate approval for ethical research and the fostering of an ethical approach to research in the humanities and social sciences;
  4. identification of more appropriate means of encouraging and ensuring ethical conduct in research.

1. Principles set out in the *Statement*: The meaning of ethics and of research (Preamble)

Much of the research in the humanities and social sciences is an engagement or partnership with its subjects. This may be over an extended period. An objective of

the researcher in this kind of humanities and social science research is to listen, in a variety of ways, to his or her subjects and give them voice. In these contexts, the humanities or social science researcher is as much a translator as an analyst. We support the *Statement*'s comment about the essential value of the integrity of researchers and take the view that the ultimate responsibility for ethical research lies with the researcher. We also support the principles of respect for persons, beneficence, and justice. The interpretation and application of these principles may, however, differ in different research situations and among different social groups. The research process itself may lead to a better understanding of such differences and their meaning.

We also support the intention of the *Statement* in identifying the need to take into account the relationships between individuals and their communities (or 'collectivities'). However, we suggest that the character of communities or 'collectivities' is problematic and is itself often a focus or part of the research process rather than a point of departure. The pre-identified definition of 'collectivities' (referred to in the Preamble and set out in section 8) is therefore inadequate and unnecessary. It does not reflect the socio-cultural reality of the range of groups, either in Australia or in other countries, that are covered in humanities and social science research. Instead, we suggest that an appropriate model for this kind of research is the *Guidelines for Ethical Research in Indigenous Studies* (Australian Institute of Aboriginal and Torres Strait Islander Studies 2000). These *Guidelines* provide an adequate, accessible, and clear set of principles that are appropriate for research not only with Indigenous peoples but also more broadly to other socio-cultural groups.[1]

2. An alternative research model

The *Statement* (1999: 7) acknowledges that:
> Some research, particularly outside the health and medical fields, is not performed directly on human subjects but rather involves their informed cooperation in the researcher's investigation of some human behaviour or some local knowledge base in, for example, the social, cultural, biological or physical environment. This kind of research involves the exchange of knowledge between the researcher and those with whom he or she interacts.

Nevertheless, the vocabulary of the *Statement* and the examples that it offers tend to assume a research model based on medical and clinical practice. That is, the researcher is assumed to have primary power and authority in the research interaction, with the result that subjects are disempowered and in need of protection. This model does not reflect the general general reality in much contemporary Australian research in the humanities and social sciences. On the contrary, much contemporary research has moved in the direction of being a collaboration or partnership between researcher and subjects that has no immediate parallel in medical or clinical research. This collaborative approach recognises that research is by its nature intrusive, but engages with the research participants in negotiating the extent and character of that intrusion,

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[1] The AIATSIS *Guidelines* also offer more succinct practical guidance for researchers working with Indigenous groups than does the NH&MRC *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (2003).

keeping in mind the principle of benefit to the participants as well as to the researcher and to the general state of knowledge and understanding in the field.

We suggest that a revised *Statement* give explicit recognition to a different model: that of the research conversation or **research collaboration** 'as a distinctive form of investigation, equal in standing to experimentation and survey, and raising different ethical imperatives' (Cribb 2003: 1, 13). The AIATSIS *Guidelines* already offer an example of what the research collaboration means in practice in research with Indigenous peoples. A similar approach is taken in the Australian Anthropological Society's Code of Ethics, which reflects the anthropological practice of extended fieldwork and social participation in the host community, and states, for example, that:

> 3.9…Research should involve an essentially collaborative relationship between anthropologist and the research participants.

There are some exceptions to be noted. These include research with children, or persons with an intellectual or mental impairment (*Statement* s.5); research in situations of abuse of power, conflict, or corruption; or research which actual regimes of power and authority, where the researcher is in fact in a subordinate role. In the first two instances, researchers are clearly dealing with manifestly vulnerable groups in special need of protection. It is therefore appropriate that the *Statement* make special reference to them and to ethical provisions for including them in research. At the same time, this is an area where not all situations are straightforward. In research involving children and young people, the *Statement* (s.4), requires consent not only from the children or young people, but also from either:

> 4.2 (b) the parents/guardian in all but exceptional circumstances; or
>   (c) any organisation or person required by law.

This, like a number of the *Statement*'s requirements, assumes a state of peace, order, and the application of the rule of law. This is not the case in many areas where humanities or social science research is carried out. To take an extreme, but not unusual example, this kind of consent is impossible in research with children who have been trafficked into prostitution or other forms of slavery. Yet research in these areas is regarded by many as urgent. In situations of conflict or corruption, it may not be possible, or even desirable, to 'minimise risks of harm or discomfort to participants in research projects' (1.3). On the contrary, exposure of particular individuals, corrupt practices, or violations of human rights may be the legitimate goal, or even an unintended outcome, of the research.

3. Some of the reasons why current procedures and policies impede rather than facilitate approval for ethical research in the humanities and social sciences

The issues arising from the *Statement* and its implementation by Human Research Ethics Committees, particularly as they affect much humanities and social science research, are set out in dot point form for ease of identification and brevity. They cover the way in which the *Statement*, despite its declared intention of offering 'guidance for rather than prescription of ethically sound research design and practice' (1999: 2), is implemented by Human Research Ethics Committees. Some of these issues have already been touched on in the discussion above.

3.1 Practical

A number of issues arising from the practices of Human Research Ethics Committees are related to the ways in which these Committees interpret their responsibilities under the *National Statement*. These include:

> The lengthy time taken to review applications is an obstacle to the commencement of research. This is especially troublesome for honours students, but also affects time-to-completion for all research students, as well as for academics;
>
> the process is oriented toward catching inadequate proposals, but little advice is available prior to review;
>
> feedback is often unclear in guiding required revisions;
>
> terminology is often inappropriate and is oriented specifically towards experimentation and vulnerable populations;
>
> lengthy reviews provide a significant obstacle to the timely implementation of consultancies and fulfilment of contractual obligations;
>
> for researchers working overseas, the requirements of the Human Research Ethics Committee clearance may be at odds with local and national laws, regulations, and approvals from the foreign state or supervisory research bodies;
>
> the workloads of Human Research Ethics Committees have become untenable.

3.2 Political

> Lengthy reviews and/or highly constrained modes of inquiry discourage research on sensitive issues;
>
> research based solely on published and public sources tends to support rather than question the status quo;
>
> the stifling of research conflicts with the ARC's and other granting agencies' mandate to *facilitate* original research;
>
> concern over protecting vulnerable populations can restrict the aim to expose injustice and to amplify the voices of the oppressed;
>
> concern to spare subjects embarrassment and/or distress potentially leaves public figures and abusers of power free from scrutiny;
>
> the requirement for signed, legalistic permission forms may be culturally inappropriate or politically risky for some subjects, or interpreted as an opportunity to demand a bribe. In authoritarian states, the risk for subjects of signing a form that the researcher will need to keep is even higher;
>
> in some instances, groups that deny access to a field site can and should themselves be studied, with the refusal becoming part of the research.

3.3 Philosophical

> The review process is oriented toward risk management rather than ethical research conduct;
>
> a science-based model of review presupposes a marked power imbalance between researcher and subject, in which the subject lacks the capacity to refuse or limit the effects of research. This may not commonly be the case in humanities and social science research;
>
> unlike the approach in surveys or experimentation, it is often inappropriate to standardise research questions and proposed research populations. The prior approval approach is not well suited to the collaborative research model in the humanities and social sciences. In this model, research questions evolve

during the conduct of research, even during the course of a single discussion, in response to the material encountered. It is not feasible to refer a developing project repeatedly to an HREC;

it is often impossible to foresee the 'human impact' of research outcomes;

it may also be impossible to ensure that the research consequences do not cause any distress to research subjects or wider populations.

3.4 Ethical

The gate-keeping orientation of ethical review is a policing model, not a process designed to foster good conduct;

the current HREC review process encourages researchers to adopt a narrow, legalistic interpretation of research ethics;

there is pressure on supervisors to focus more on getting projects through the HREC review process than on receiving or providing ethics advice;

the frustrations of researchers have produced a culture of cynicism, non-compliance, and evasion.

4. More appropriate means of encouraging and ensuring ethical conduct in research

The complexities of these issues indicate that, in order to encourage and ensure ethical conduct in research in the humanities and social sciences, the *Statement* might better take an approach of limiting itself to a statement of basic principles and approaches, rather than attempting to set out particular procedures for applying those principles. This would assist in shifting the focus of Human Research Ethics Committees from what has in practice become a legalistic approach about management of risk to the university rather than a true fostering of ethical research conduct.

4.1 Code of good conduct

Rather than orienting research ethics towards rules and their possible violation, we suggest that the AHEC review lead, after appropriate consultation, to the adoption of a formal *Code of Good Conduct in Humanities and Social Science Research*. This *Code* would complement professional codes of conduct for the various disciplines and would focus on how best to undertake research. This *Code* would be applicable to all humanities and social science researchers whether they are based in a university or work independently.

The *Code* would underpin the encouragement of compliance in practical as well as ethical ways.

Copies of the *Code of Good Conduct in Humanities and Social Science Research* could be distributed to all researchers as part of the induction package for students, fellows, and faculty;

before undertaking a research project (whether funded or not), individual researchers would sign a form indicating that they have read and understood the*Code*, and that they have complied its provisions;

if researchers consider it inappropriate or impossible to follow the *Code* in any respect, they would be entitled to seek permission from the HREC to follow a different practice.

The *Code* would cover how ethical researchers:

identify themselves;

where feasible and appropriate, include the subjects of research as early as possible in the planning and formulation of the research project;

negotiate the terms and conditions of the research and of the publication of research results with the research participants;

engage their subjects respectfully and inclusively, obtaining their consent in ways appropriate to the culture and the circumstances;

where possible and appropriate, obtain clear permission to access records and research subjects;

respect the intellectual and cultural property rights of subjects and, where appropriate, their rights to be acknowledged as contributors to or collaborators with the research;

work to minimise risks to subjects;

behave in ways appropriate to the conditions and culture;

allow the possibility for subjects to raise questions, and be prepared to renegotiate the terms and conditions of the research, and of the consent of subjects, in response to such questions and issues;

deal fairly with the range of differing or conflicting views the emerge during the research;

avoid posing an unacceptable burden on research subjects or their communities;

maintain a research environment that allows other researchers access to materials and subjects as appropriate;

preserve a faithful record of research, except where it may endanger people;

make agreed arrangements for the research outcomes to be made available to the subjects as and when appropriate;

where and as appropriate, negotiate the conditions of publication of the research, including the possibility of co-authorship with subjects;

offer and, where possible under the law, honour requests for anonymity or disclosure;

where possible under the law, ensure the security of confidential information;

balance the risk of distress against the likely social benefit of publishing research;

comply with local laws, unless such laws are themselves unethical or in breach of human rights.

4.2 Human Research Ethics Committees
The responsibilities of Human Research Ethics Committees for humanities or social science research should be limited to research projects that raise ethical issues beyond those that would be dealt with routinely and competently by departmental or disciplinary ethics committees, for example, research that involves the following:

persons in special need of protection, including children, where there is a question about the appropriateness of parental or guardian consent, or persons in institutional care or control;

planned concealment of or deception about the researcher's identity or purpose from subjects;

controlled experiment;

issues on which the researchers themselves wish to obtain ethical advice.

Rather than giving responsibility for all ethical clearance to a small number of central HREC committees, whose expertise across a wide range of disciplines is likely to be uneven, we suggest that the AHEC review provide for the option of universities' establishing a series of ethical advisory committees, at faculty or disciplinary level, drawn from experienced researchers. These advisory committees would offer non-binding advice to colleagues and students on ethical issues in humanities and social science research, fostering a clear sense of ethical conduct to guide researchers through unexpected issues.

4.4 Recognition of ethical conduct
We suggest that the AHEC review recommend a range of ways of promoting ethical conduct in research. These might include:

the establishment of an essay prize for undergraduates and graduates in recognition of research that is both innovative and ethical;

the conducting of public lectures on best practices in research ethics, to be delivered by recognised leaders in ethical research;

the establishment of an appropriately constituted sub-committee to monitor the impact of revised HREC review processes on research in the humanities and social sciences.

5. Summary of key recommendations

Explicit recognition in the *Statement* for a model of research collaboration appropriate to research in the humanities and social sciences;

after appropriate consultation, the establishment of a formal *Code of Good Conduct in Humanities and Social Science Research*;

except in relation to clearly defined vulnerable groups or exceptional circumstances as identified above, the option of transfer of responsibility for ethics clearance of research projects from HRECs to appropriately constituted committees at the faculty or disciplinary level;

the option for the establishment of a series of ethical advisory committees, at faculty or disciplinary level, drawn from experienced researchers.

6. References

Australian Anthropological Society 2003 *Code of Ethics*.

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