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NHMRC

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INVESTING IN AUSTRALIA'S HEALTH

Values and Ethics:
Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research

Values and Ethics:
Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research

Endorsed by Council at its 148th Session on 5 June 2003

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1. BACKGROUND

1.1 INTRODUCTION

Over the course of the previous two triennia (1994–6 and 1997–9), the previous Australian Health Ethics Committee (AHEC) reviewed and revised the *NHMRC Statement on Human Experimentation and Supplementary Notes* (1992). These were the guidelines on the ethics of health research for the whole community, to provide protection to all Australians, including Aboriginal and Torres Strait Islander Peoples. That review led to the issuing in 1999 of the *National Statement on Ethical Conduct in Research Involving Humans* (the *National Statement*).

When revising the *National Statement*, AHEC was informed, both in submissions and in personal representations at public forums, that Aboriginal and Torres Strait Islander communities, researchers and health organisations still saw a clear need for a separate, complementary set of guidelines covering research in Aboriginal and Torres Strait Islander health. They also heard that the 1991 *Interim Guidelines on Ethical Matters in Aboriginal and Torres Straight Islander Health Research* (the *Interim Guidelines*) were in need of review and updating. In response to that feedback AHEC undertook to follow up the new *National Statement* by reviewing the 1991 *Interim Guidelines* over the course of AHEC's three-year term, which finished in mid-2003.

It is noteworthy that the *Interim Guidelines* took a number of years to develop. Three major meetings facilitated by the National Aboriginal and Islander Health Organisation and/or the National Health and Medical Research Council (NHMRC) were held over the last years of the 1980s. These meetings involved a wide range of stakeholders and led eventually to the current 1991 *Interim Guidelines*, which have had a high degree of community ownership.

Much has changed since the development of the *Interim Guidelines*. New collaborative partnerships involving research institutes and the community, including the Aboriginal community controlled health sector, have emerged. There are now more Aboriginal and Torres Strait Islander people involved in research as researchers. The level of interest in research as a way to contribute to the health of Aboriginal and Torres Strait Islander Peoples has grown and with it the level of NHMRC funding. However, some Aboriginal and Torres Strait Islander Peoples and organisations remain mistrustful of the enterprise of research itself.

1.2 CONTEXT

How people see the world is generally informed by their own experiences, values, norms and learning. From the earliest periods of colonisation, ill-formed perceptions and assumptions about the values and ways of Aboriginal and Torres Strait Islander cultures and social organisation have emerged from the comparison of the Aboriginal and Torres Strait Islander world to the spiritual, social, political and economic perspectives of European colonisers. Colonists judged the civility and worthiness of

Aboriginal and Torres Strait Islander cultures and societies by the degree to which they perceived it conforming to European customs and norms. Not surprisingly the early observers knew nothing about Aboriginal and Torres Strait Islander Peoples and cultures. The substantial errors of judgement that followed have had a significant impact on Aboriginal and Torres Strait Islander Peoples ever since.

Non-Aboriginal society has, however, increasingly improved its knowledge of the ways and life of Aboriginal and Torres Strait Islander cultures. Gradually, decision-makers started to recognise that Aboriginal people held cultural values and principles that provided the basis for orderly Aboriginal and Torres Strait Islander societies. Clearly, however, much remains to be done to ensure the genuine recognition of the fundamental values and principles of Aboriginal and Torres Strait Islander cultures within Australian society and its institutions.

Aboriginal and Torres Strait Islander societies have sustained enormous impacts over the past two centuries, to which their cultures have responded. For long periods both an official and popular view was that this change essentially involved the disconnection of contemporary Aboriginal existence from the values and integrity of traditional or historic society. However, on the contrary, contemporary Aboriginal and Torres Strait Islander societies draw their strength and existence from the body of knowledge, values and wisdom that has emerged from the interaction of tradition and history.

When making judgements about Aboriginal and Torres Strait Islander Peoples, Australia and its public institutions must acknowledge the history, and bridge the difference in cultural outlooks to find a fair, respectful and ethical way forward. These Guidelines are designed to help fulfil these obligations.

This document does not use the term *Indigenous*. While this term has been used recently, most Aboriginal and Torres Strait Islander Peoples prefer terms that better reflect their cultural identity such as Nyoongar, Koori, Murri, Ngaanyatjarra, Nunga and Palawa. This is about more than just language. It is a reflection of real cultural diversity. The use of *Aboriginal and Torres Strait Islander Peoples* in these guidelines is intended to encapsulate this diversity.

A key concept is the notion of community. In these Guidelines community is recognised as a complex notion that can be invoked in relation to cultural groups, geographic groups or communities of interest.

1.3 THE APPROACH TO WRITING THESE GUIDELINES

1.3.1 Ethical relationships

The construction of ethical relationships between Aboriginal and Torres Strait Islander Peoples on the one hand and the research community on the other must take into account the principles and values of Aboriginal and Torres Strait Islander cultures.

In resorting to the past to determine the future course of action in new situations one must look for the principles involved.[1]

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[1] E T Durie, *Ethics and Values*, Te Oru Ranahau Maori Research and Development Conference, 1998

Values underpin what we perceive, believe, value and do. In the research context, to ignore the reality of inter-cultural difference is to live with outdated notions of scientific investigation. It is also likely to hamper the conduct of research, and limit the capacity of research to improve human development and wellbeing. Contemporary writing about science recognises this.

> To '*mis*recognise or fail to recognise (cultural difference) can inflict harm, can be a form of oppression, imprisoning someone [or a group] in a false, distorted and reduced model of being'… Research cannot be 'difference-blind'.[2]
>
> Research relationships are also influenced by what is not said. 'Problems [emerge] if we do not recognise that values operate in the everyday world from *undeclared* evaluations and judgements about other people, their behaviours and practices.'[3]

Within the research process, failing to understand difference in values and culture may be a reckless act that jeopardises both the ethics and quality of research. However, to do better is not always straightforward. Working with difference in a research context takes time, care, patience and the building of robust relationships.

Research involves groupings of people in a collaborative exercise. The soundness of trust among its stakeholders is essential to a successful and ethical outcome. Trust has to function at all levels of the research enterprise — between participant and researcher, between research partners and sponsors, between researchers, institutions and the scientific community and lastly, and perhaps most importantly, with the wider community. Where trust persists, research can be sustained.

Unethical behaviour need not always be a glaring act or infraction. It often includes subtle or only sub-consciously intended encroachments on values and principles. Yet these can significantly erode trust. Similarly, it is often through many small personal interactions that trust is built. Researchers need to consider, as an integral part of the research enterprise, that trust and ethical behaviour are not just about rules but also about discretion and judgement — both complex and challenging matters.

Eliminating 'difference-blindness' in relationships is made more complex by the trivialisation of values and principles in contemporary society. Advocates who talk about values and cultural difference are often told they are being too political or are adopting an 'ideologically correct' view. Token gestures worsen this situation by exposing the debate to dismissive labelling.

'Difference blindness' in research can occur not only in research focused specifically on Aboriginal and Torres Strait Islander Peoples but also in the way researchers consider Aboriginal and Torres Strait Islander Peoples within more generalised research questions, policy and institutions. The outcome of generalised research may be of general or specific benefit or harm to Aboriginal and Torres Strait Islander Peoples. It is important that researchers are prompted to ask whether their general research could contribute to the health of Aboriginal and Torres Strait Islander Peoples.

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2 Taylor C, *Multiculturalism and 'the politics of recognition'*, Princeton University Press, Princeton, 1992.

3 Cameron H, *Values Education for a Pluralist Society*, Australian Association for Professional and Applied Ethics, 8th Annual Conference, Adelaide, 2001.

Researchers should consider the application of their general research for the benefit of Aboriginal and Torres Strait Islander Peoples and the implications of cultural difference for its conduct.

1.3.2 Integrating written guidelines with the development of ethical relationships

The responsibility for maintaining trust and ethical standards cannot depend solely on rules or guidelines. Trustworthiness of both research and researchers is a product of engagement between people. It involves transparent and honest dealing with values and principles, the elimination of 'difference blindness' and a subtlety of judgement required to eliminate prejudice and maintain respect and human dignity.[4]

These guidelines are based on the importance of trust, recognition and values. The guidelines move away from a sole reliance on the quasi-legal consideration of compliance with rules. They promote a more flexible approach that encourages research to reposition itself to incorporate alternative perspectives, and exercise nuanced judgement as to its ethical implications.

Ethical research requires not only the limiting of inappropriate behaviour, but also that researchers develop an awareness of the settings that may lead unintentionally to imprudent or untrustworthy behaviours.[5]

The review of the literature undertaken in the development of these guidelines reiterates continuing concerns from Aboriginal and Torres Strait Islander Peoples about poor consultation, lack of communication and infringement of deeply held values arising from cross-cultural insensitivity — despite researchers' compliance with the legal requirements of ethical guidelines.

It is possible for researchers to 'meet' rule-based requirements without engaging fully with the implications of difference and values relevant to their research. The approach advanced in these guidelines is more demanding of researchers as it seeks to move from compliance to trust.

The challenge of balancing rules and ethical behaviour is not new. The 1986 National Conference on Research Priorities in Aboriginal Health exhibited all of the hallmarks of lack of trust and difference-blindness. Yet participants courageously moved the debate forward by recommending the creation of a set of ethical standards for research in Aboriginal health. The subsequent national workshop (Tallimba workshop 1987) produced a set of proposals that implicitly reflected a desire to protect Aboriginal and Torres Strait Islander Peoples' cultures and value base, and not surprisingly sought to do so in a prescriptive process.

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[4] For example in *Lovelace v Ontario*, in giving expression to the right to equality under section 15(1) of the Canadian Constitution, the Canadian Supreme Court focused on the fundamental value of human dignity.

[5] Whitbeck C, 'Truth and Trustworthiness in Research', originally in *Science and Engineering Ethics*, October 1995, 1(4):403–416.

Explicitly, the 1987 workshop proposals indicated a lack of trust both of researchers and of self-regulation of ethical behaviour. Importantly, however, Aboriginal and Torres Strait Islander Peoples left open the opportunity for researchers and research institutions to demonstrate trustworthiness by example. It is clear that some researchers have been able to satisfy communities as to their trustworthiness. Some, however, have not.

The evolution of the relationship between Aboriginal and Torres Strait Islander communities and the research community has taken a number of twists and turns since 1986, 'oscillating between taking concrete steps towards actually changing research practice and placing too great a reliance on written guidelines and positive rhetoric'.[6] However, concerns persist in many Aboriginal and Torres Strait Islander communities about the ethical qualities of the research enterprise.[7] Adding emphasis is yet other work[8] reinforcing the importance of trust, integrity and recognition in building partnerships that 'can withstand some difficulties'.

Is it possible to reconcile the interests of research and researchers with the values, expectations and cultures of Aboriginal and Torres Strait Islander communities? The evidence suggests that it is. Several different models have been used successfully to build trust and recognition of cultural values and principles while advancing the objectives of the research enterprise. Some models have placed greater reliance on participatory processes.[9] Some have established innovative institutional arrangements with the ongoing involvement of communities ensuring integrity in the research enterprise.[10] Yet others have resorted to legal agreements that codify substance and definition as a means of ensuing ethical behaviour.[11] Other models promote Aboriginal community control over the research process, with Aboriginal people leading and implementing the research activity.[12]

A common feature across these models is the explicit recognition and commitment to respect for Aboriginal and Torres Strait Islander cultural values and principles. The models also promote local relationships to ensure that the nuances of judgement and practice necessary to promote trustworthiness and trust are created and maintained. They also illustrate important aspects of accountability and transparency in standards, processes and structures.

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[6] Humphery K, Dirty Questions: Indigenous health and 'Western research', *Australian and New Zealand Journal of Public Health*, 2001, 25(3), pp.197-202.

[7] McAullay D, Griew R, Anderson I, 2002.

[8] See for example Henderson R et al., 'Development of guidelines for non Indigenous Peoples undertaking research among the Indigenous population of north east Victoria', *MJA* 2002; 176 (10):pp.482-485

[9] For example see Henderson R et al. 2002.

[10] For example see Tsey K, 'Making research more relevant to the needs and aspirations of Indigenous Australians: the importance of research capacity development', *Aboriginal and Islander Health Worker Journal* 2001, 25(1), pp. 19-24; and Eades S, Read A, Bibbulung Gnarneep Team, 'The Bibbulung Gnarneep Project: practical implementation of guidelines on ethics in indigenous Health research', *MJA* 1999, 170, pp. 433-6. See also the work of the Co-Operative Research Centre for Aboriginal and Tropical Health Research in Darwin.

[11] For example see Tiwi Health Board and Menzies School of Health Research, *Legal Agreement between Tiwi Health Board and the Menzies School of Health Research*, Northern Territory, 1998.

[12] For example, NACCHO, 'The NACCHO Ear Trial: A Partnership Research Model, Not Just Participatory', WONCA International Conference, Melbourne, May 2002.

2. THE GUIDELINES

2.1 COVERAGE

The *National Statement on Ethical Conduct in Research Involving Humans* is the authoritative statement on research involving humans. These guidelines are, in addition to the *National Statement*, the authoritative statement on health research involving Aboriginal and Torres Strait Islander Peoples. They have the same status and authority as the *National Statement*. That status and authority derive from the requirement of the *National Health & Medical Research Council Act 1992* that Council issue ethical guidelines for the conduct of medical research involving humans as developed by the Australian Health Ethics Committee (AHEC). This means that for health research involving Aboriginal and Torres Strait Islander Peoples both the *National Statement* and these Aboriginal and Torres Strait Islander specific guidelines apply.

The *National Statement* sets out basic principles (paragraphs 1.1–1.21) and guidance specific to types of participants and types of research. Types of participants considered are children and young people (paragraphs 4.1–4.4), people with mental or intellectual disabilities (paragraphs 5.1–5.4), people highly dependent on medical care (paragraphs 6.1–6.10), people in dependent or unequal relationships (paragraphs 7.1–7.3) and collectivities (paragraphs 8.1–8.2). Types of research considered are use of ionising radiation (paragraph 10), assisted reproductive technology (paragraph 11), clinical trials (paragraphs 12.1–12.13), innovative therapy (paragraph 13), epidemiological research (paragraphs 14.1–14.13), use of human tissue (paragraphs 15.1–15.9), genetic research (paragraphs 16.1–16.16) and research involving deception (paragraphs 17.1–17.2).

A proposal involving, for example, research with Aboriginal children must consider both the protection afforded children under the *National Statement* and these Aboriginal and Torres Strait Islander guidelines. Likewise, a proposal for epidemiological research must consider both the relevant section in the *National Statement* and these Aboriginal and Torres Strait Islander guidelines.

To help identify the connections between the *National Statement* and these Aboriginal and Torres Strait Islander guidelines, related *National Statement* basic principles are listed under the heading for each of the values identified in the guidelines.

The NHMRC requires all institutions or organisations that receive NHMRC funding for research to establish a Human Research Ethics Committee (HREC) and to subject all research involving humans to ethical review.

Research involving human participation is subject to a variety of legal regulation at federal, state and territory levels. Researchers need to conform to relevant legal requirements, and HRECs need to be satisfied that the conduct of research that they approve is lawful. In the event that both the legal requirement and an ethical guideline apply, the legal requirement will prevail, although they will normally be consistent. Where the guidelines prescribe a standard that exceeds that required by law researchers should apply this higher standard.

2.2 VALUES AND ETHICS IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

These guidelines provide guidance to researchers in the conception, design, and conduct of research, as well as to HRECs, including Aboriginal specific HRECs or sub-committees. Researchers, communities, other stakeholders and HRECs should consider proposals for research in the light of the proposal's attention to the values and requirements detailed below.

These guidelines are not intended to reduce the capacity of health departments to meet their statutory responsibilities for public health protection, including disease surveillance and investigation of outbreaks of infectious disease. However, the values expressed in these guidelines should inform those activities. Health departments should consider seeking HREC review of reports based on these activities that are intended for publication. When health departments are conducting research related to public health programs and strategies that include Aboriginal and Torres Strait Islander communities, it is intended that these guidelines be used.

These guidelines are likewise not intended to limit inappropriately the capacity of government departments, statutory bodies and health service organisations to collect and analyse data from routine collections such as birth, morbidity and mortality records. However, the values expressed in these guidelines should inform those activities. Where others seek access to these data for the purpose of research, then it is intended that these guidelines be used.

The guidelines articulate the meaning to Aboriginal and Torres Strait Islander Peoples of each of the six values identified and agreed upon at a workshop held in Ballarat in June 2002 to direct the drafting of these guidelines.[13] The guidelines then drew out the implications of each value for research, and how researchers and research proposals might demonstrate engagement and consistency with each value. The participants in the Ballarat workshop saw this as an appropriate way to ensure that Aboriginal and Torres Strait Islander values are at the heart of ethical assessment.

The six values that lie at the heart of these guidelines are:

- Spirit and Integrity
- Reciprocity
- Respect
- Equality
- Survival and Protection
- Responsibility

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[13] The process followed in developing these guidelines is described in Appendix 1.

They can be represented in diagrammatic form:

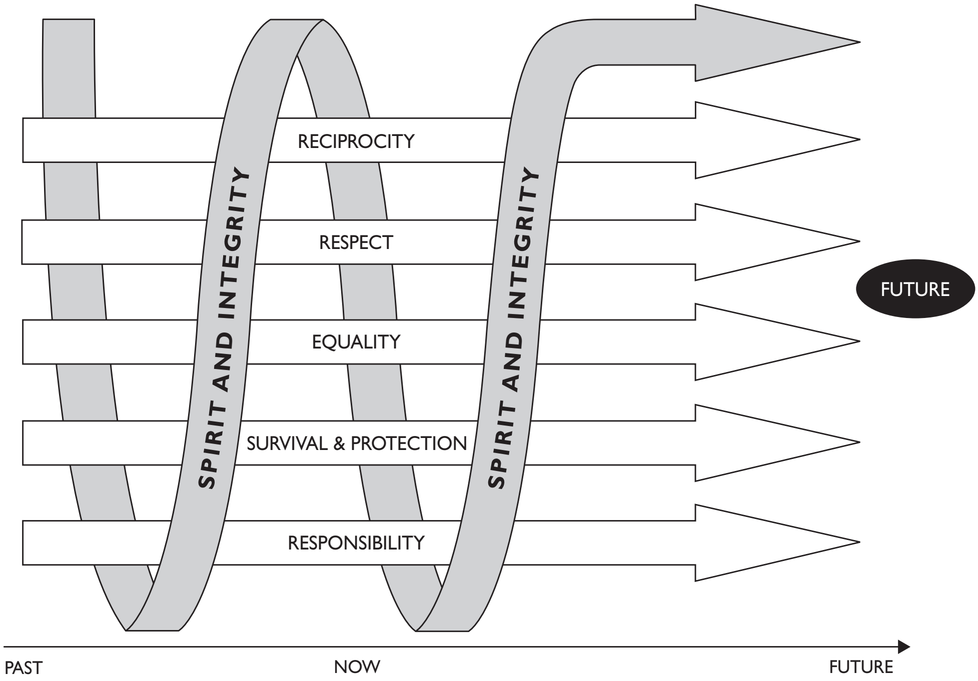

Diagram 1: Aboriginal and Torres Strait Islander Peoples values relevant to health research ethics

Discussions during the development of these guidelines emphasised the relationship of these values over time and their importance to Aboriginal identity. Of particular importance to Aboriginal participants was the nature of Spirit and Integrity as outlined in the diagram, working over time to bind together the other five values to each other.

The understanding that the present and the future are absolutely bound up in the past, and that these cannot be separated from each other when discussing issues where key values are at stake, is shown in the diagram by indicating that these values are present through time — past, present and future.

The sections which follow detail the meaning which may be accorded to each value in the context of research. Each section includes a series of questions. These are not intended as a compliance checklist but rather as a series of concrete ways in which researchers and research proposals can demonstrate their level of engagement with the values at the heart of these guidelines.

Given that values are complex concepts, it is not surprising that there is an overlap between them in both description and interpretation.

2.2.1 Reciprocity

A mutual obligation exists among members of Aboriginal and Torres Strait Islander families and communities to achieve an equitable distribution of resources, responsibility and capacity and to achieve cohesion and survival of the social order. This mutual obligation extends to the land, animals and other natural elements and features. In contemporary settings the value of reciprocity continues in various forms, and may vary between locations. Examples include the redistribution of income, benefits from the air, land and sea, and the sharing of other resources such as housing.

In the research context, reciprocity implies inclusion and means recognising partners' contributions, and ensuring that research outcomes include equitable benefits of value to Aboriginal and Torres Strait Islander communities or individuals. (Recognition of contribution is discussed below under Respect.) Reciprocity requires the researcher to demonstrate a return (or benefit) to the community that is valued by the community and which contributes to cohesion and survival. It is important to remember that Aboriginal and Torres Strait Islander Peoples may place greater or lesser value on the various returns than researchers. Reciprocity involves exchange although in the context of research this often involves unequal power relationships. In negotiating the conduct of research, Aboriginal and Torres Strait Islander communities have the right to define the benefits according to their own values and priorities.

Benefits may not take only one form or be immediate. Some benefits may be available to participating Aboriginal and Torres Strait Islander communities, to Aboriginal and Torres Strait Islander Peoples more generally or to the wider community as well. They must, however, be valued by the participating community. It is also important that unethical inducements in the provision of service are not linked to agreements about research.

The implications of reciprocity extend to all those involved in the potential research enterprise. HRECs can contribute by promoting real rather than superficial engagement between partners to the endeavour. Examples have been cited where an HREC was able to mediate an outcome where mistrust had emerged because of superficial engagement between communities and researchers. The engagement of other stakeholders such as service providers may also help build real engagement focussed on outcomes of benefit to Aboriginal and Torres Strait Islander communities.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers and HRECs need to consider how the research proposal demonstrates the value of reciprocity, taking into account the following components:

- *Inclusion*

  Inclusion, the basis for mutual obligation, describes the degree of equitable and respectful engagement with Aboriginal and Torres Strait Islander Peoples, their values and cultures in the proposed research.

- *Benefit*

  Benefit in this context describes the establishment or enhancement of capacities, opportunities or outcomes that advance the interests of Aboriginal and Torres Strait Islander Peoples and that are valued by them.

Demonstrating reciprocity

Participating communities, researchers and HRECs should consider:

- How the proposed research demonstrates intent to contribute to the advancement of the health and wellbeing of participants and communities.
- Whether the proposal links clearly to community, regional, jurisdictional or international Indigenous health priorities and/or responds to existing or emerging needs articulated by Aboriginal and Torres Strait Islander Peoples.
- The nature of benefits for participants or other Aboriginal and Torres Strait Islander communities, and whether there is evidence of clear and truthful discussions about the potential benefit of the research proposal prior to approval.
- Whether the researcher has demonstrated willingness to modify research in accordance with participating community values and aspirations.
- Whether the proposed research will enhance the capacity of communities to draw benefit beyond the project, eg through the development of skills and knowledge or through broader social, economic or political strategies at local, jurisdictional, national or even international level.

Allied National Statement requirements[14]

NS 1.14 All research proposals must be so designed as to ensure that any risks of discomfort or harm to participants are balanced by the likely benefit to be gained.

NS 1.4 Each research protocol must be designed to ensure that respect for the dignity and well being of the participants takes precedence over the expected benefits to knowledge.

2.2.2 Respect

Respect for human dignity and worth as a characteristic of relationships between people, and in the way individuals behave, is fundamental to a functioning and moral society. Within Aboriginal and Torres Strait Islander cultures respect is reinforced by and in turn strengthens dignity. A respectful relationship induces trust and co-operation. Strong culture is a personal and collective framework built on respect and trust that promotes dignity and recognition.

Respectful research relationships acknowledge and affirm the right of people to have different values, norms and aspirations. Those involved in research processes should not be blind to difference.

Also essential to a respectful research relationship is the recognition of the contribution of others and the consequences of research. Contributions to the research enterprise come in a variety of connected forms and all should be respected. The trust, openness

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[14] The relevant sections in the *National Statement* are reproduced in full under these headings. The paragraph numbers are preceded by the initials 'NS'.

and engagement of participating communities and individuals is as important as the scientific rigour of the investigation. A respectful relationship is fundamental to a sustainable research relationship. Such a relationship will require ongoing attention to cumulative decisions of participating communities and to the engagement of individuals.

The structures and processes for negotiating community involvement vary. Researchers should inform themselves about local structures and seek to engage with these in a spirit of respect and integrity. Where Aboriginal and Torres Strait Islander institutional structures exist, these should be used as the best means of community and institutional engagement by researchers, both in dealing with communities and in seeking HREC approval.

It is critical that respect underlies all aspects of the research process, especially sensitive negotiations such as those related to publication of research findings. Here, sensitivity may arise from tensions between on the one hand, the independence and integrity of research and, on the other, the risk of vilification and exploitation of Aboriginal and Torres Strait Islander Peoples. In addition researchers should not make the publication of research findings a greater priority than feedback of findings to the community in an appropriate and understandable way.

Respectful relationships require that agreements are made at the outset of any research project which make clear when, how and who will engage in the research process. In this way the value positions of all parties can be equally respected.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers and HRECs need to consider how the research proposal demonstrates the value of respect, taking into account the following components:

- *Respect of people and their contribution*

  Respect acknowledges the individual and collective contribution, interests and aspirations of Aboriginal and Torres Strait Islander Peoples, researchers and other partners in the research process.

- *Minimising difference blindness*

  Respectful research relationships acknowledge and affirm the right of people to have different values, norms and aspirations. Those involved in research should recognise and minimise the effect of difference blindness through all stages of the research process.

- *Consequences of research*

  Researchers need to understand that research has consequences for themselves and others, the importance of which may not be immediately apparent. This should be taken into account through all stages of the research process.

Demonstrating respect

Participating communities, researchers and HRECs should consider:

- Whether the proposal responds to the diversity of Aboriginal and Torres Strait Islander Peoples and communities, including the way decisions are made.

- How the proposal acknowledges the individual and collective contribution of Aboriginal and Torres Strait Islander Peoples.
- How the researchers propose to minimise the effects of difference blindness on and in the research process.
- How the research proposal engages with Aboriginal and Torres Strait Islander Peoples' knowledge and experience.
- Whether appropriate agreements have been negotiated about ownership and rights of access to Aboriginal and Torres Strait Islander Peoples' intellectual and cultural property.
- Whether the processes of reaching agreement demonstrate engagement with the values and processes of participating communities.
- Whether the participating communities have expressed satisfaction with the research agreement and decision making processes.
- Whether in reaching agreement with participating communities all relevant issues including management of data, publication arrangements and the protection of individual and community identity have been adequately addressed.

Allied National Statement requirements

NS 1.2 When conducting research involving humans, the guiding ethical principle for researchers is respect for persons which is expressed as regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research.

NS 1.7 Before research is undertaken, whether involving individuals or collectivities, the consent of the participants must be obtained, except in specific circumstances elsewhere in this Statement [see paragraphs 1.11, 6.9, 14.4, 15.8, 16.13].

The ethical and legal requirements of consent have two aspects: the provision of information and the capacity to make a voluntary choice. To conform with ethical and legal requirements, obtaining consent should involve:

(a) provision to participants, at their level of comprehension, information about the purpose, methods, demands, risks, inconveniences, discomforts and possible outcomes of the research (including the likelihood and form of publication of research results); and

(b) the exercise of voluntary choice to participate.

Where a participant lacks competence to consent, a person with lawful authority to decide for that participant must be provided with that information and exercise that choice.

NS 1.8 A person may refuse to participate in a research project and need give no reasons nor justification for that decision.

NS 1.9 Where consent to participate is required, research must be so designed that each participant's consent is clearly established, whether by a signed form, return of a survey, recorded agreement for interview or other sufficient means.

In some circumstances and some communities, consent is not only a matter of individual agreement, but involves other properly interested parties, such as formally constituted bodies of various kinds, collectivities or community elders. In such cases the researcher needs to obtain the consent of all properly interested parties before beginning the research.

NS 1.10 The consent of a person to participate in research must not be subject to any coercion or to any inducement or influence which could impair its voluntary character.

NS 1.12 A participant must be free at any time to withdraw consent to further involvement in the research. If any consequences may arise from such withdrawal, advice must be given to participants about these before consent to involvement in the research is obtained.

2.2.3 Equality

One of the values expressed by Aboriginal and Torres Strait Islander Peoples and cultures is the equal value of people. One of the ways this is reflected is a commitment to distributive fairness and justice. Equality affirms Aboriginal and Torres Strait Islander Peoples' right to be different.

Equality as a value may sometimes be taken to mean sameness. However, Aboriginal and Torres Strait Islander Peoples hold strong beliefs that sameness is not equality. Aboriginal and Torres Strait Islander Peoples have sought the elimination of 'difference blindness' so that Aboriginal and Torres Strait Islander cultures can be appreciated and respected.

Crude or unsubstantiated assumptions of the value or vitality of Aboriginal and Torres Strait Islander cultures and societies have led Australian history in many instances to discriminate against Aboriginal and Torres Strait Islander Peoples. Such assumptions have created significant and longstanding difficulties that have at times been reflected in research practices. The marginalisation of Aboriginal and Torres Strait Islander cultures by the dominant society has created myriad inequalities that "pursue them from sphere to sphere in the form of stereotyping, discrimination and disregard."[15]

International and domestic studies have increasingly revealed a correlation between social and economic inequality and poor health. Research should seek to advance the elimination of inequalities. Equality is also a feature of the fundamental dignity of humanity. To treat people less favourably is not only unethical, but discriminatory.

Historically, Aboriginal and Torres Strait Islander Peoples have perceived the benefit as flowing principally to researchers and institutions.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers and HRECs need to consider how the research proposal demonstrates the value of equality, taking into account the following components:

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[15] Miller D and Walzer M, Pluralism Justice and Equality, Oxford University Press, 1995

- *Valuing knowledge and wisdom*

  Aboriginal and Torres Strait Islander Peoples value their collective memory and shared experience as a resource and inheritance. Researchers who fail to appreciate or ignore Aboriginal and Torres Strait Islander Peoples' knowledge and wisdom may misinterpret data or meaning, may create mistrust, otherwise limit quality or may overlook a potentially important benefit of research.

- *Equality of partners*

  Ethical research processes treat all partners as equal notwithstanding that they may be different. In the absence of equal treatment, trust among research funders, researchers, host institutions, Aboriginal and Torres Strait Islander communities and other stakeholders is not possible. Without such trust ethical research is undermined.

- *The distribution of benefit*

  The distribution of benefit stands as a fundamental test of equality. If the research process delivers benefit in greater proportion to one partner in the initiative than other partners, the distribution of benefit may be seen as unequal.

Demonstrating equality

Participating communities, researchers and HRECs should consider:

- Whether the ways that participating communities are included in the research processes demonstrate equality.
- Whether the research agreements have the strength necessary to sustain equality.
- Whether participating communities have understood and expressed satisfaction with the proposed research, its potential benefits and their distribution. Researchers therefore have a responsibility to ensure that the information that they provide is understood and usable in decision making by participating communities.

Allied National Statement requirements

NS 1.5 The ethical value of justice requires that, within a population, there is a fair distribution of the benefits and burdens of participation in research and, for any research participant, a balance of burdens and benefits. Accordingly, a researcher must:

(a) avoid imposing on particular groups, who are likely to be subject to over researching, an unfair burden of participation in research;

(b) design research so that the selection, recruitment, exclusion and inclusion of research participants is fair; and

(c) not discriminate in the selection and recruitment of actual and future participants by including or excluding them on the grounds of race, age, sex, disability or religious or spiritual beliefs except where the exclusion of inclusion of particular groups is essential to the purpose of the research.

NS 1.6 The proportion of burdens to benefits for any research participant will vary. In clinical research, where patient care is combined with an intent to contribute to knowledge, the risks of participation must be balanced by the possibility of intended benefits for the participants. In other research involving humans that is undertaken solely to contribute to knowledge, the absence of intended benefits to a participant should justly be balanced by the absence of all but minimal risk.

2.2.4 Responsibility

Central to Aboriginal and Torres Strait Islander societies and cultures is the recognition of core responsibilities. These responsibilities include those to country, kinship bonds, caring for others and the maintenance of harmony and balance within and between the physical and spiritual realms. A key responsibility within this framework is to do no harm, including avoiding having an adverse impact on others' abilities to comply with their responsibilities. As well, one person's responsibilities may be shared with others so that they will also be held accountable.

The assignment or inheritance of responsibilities within communities functions to ensure the order and survival of individuals, families and whole communities. Survival includes maintaining the bonds and relationships between people and between them and their environment. It also encompasses responsibilities in respect of spiritual domains. A transparent accountability regime ensures the timely and appropriate discharge of responsibilities.

When engaging Aboriginal and Torres Strait Islanders Peoples in the research enterprise, researchers carry responsibilities in addition to the science of their inquiry. The nexus between their research and community life brings responsibilities for which they or those of the community with whom they work may be held accountable. Ethical research occurs when harmony between the sets of responsibilities is established, participants are protected, trust is maintained and accountability is clear.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers and HRECs need to consider how the research proposal demonstrates the value of responsibility, taking into account the following components:

- *Doing no harm*

  There is a clear responsibility for researchers to do no harm to Aboriginal and Torres Strait Islander individuals or communities and also to those things that they value.

- *Accountability*

  Researchers and participating communities need to establish processes to ensure researchers' accountability to individuals, families and communities, particularly in relation to the cultural and social dimensions of Aboriginal and Torres Strait Islander life.

Demonstrating responsibility

Participating communities, researchers and HRECs should consider:

- What measures are identified to demonstrate transparency in the exchange of ideas and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of research.
- How provision is made for appropriate ongoing advice and review from the participating community, including mechanisms to monitor ethics standards and to minimise the likelihood of any unintended consequences arising from or after the research project.
- What does the proposal say about timely feedback obligations to communities and whether that feedback is relevant to the expressed concerns, values and expectations of research participants and communities.
- How the proposal demonstrates agreed arrangements regarding publication of the research results, including clear provisions relating to joint sign off for publication and the protection of individual and community identity if appropriate.
- Whether there is clarity about the demand on partners created by the proposed research and the potential implications for partners arising from it.

Allied National Statement requirements

NS 1.1 The guiding value for researchers is integrity, which is expressed in a commitment to the search for knowledge, recognised principles of research conduct and in the honest and ethical conduct of research and dissemination and communication of results

NS 1.3 In research involving humans, the ethical principle of beneficence is expressed in researchers' responsibility to minimise risks of harm and discomfort to participants in research projects.

NS 1.13 Every research proposal must demonstrate that the research is justifiable in terms of its potential contribution to knowledge, and is based on a thorough study of current literature as well as prior observation, approved previous studies, and where relevant, laboratory and animal studies.

NS 1.18 The results of research (whether publicly or privately funded) and the methods used should normally be published in ways which permit scrutiny and contribute to public knowledge. Normally, research results should be made available to research participants.

NS 1.19 Where personal information about research participants or a collectivity is collected, stored, accessed, used, or disposed of, a researcher must strive to ensure that the privacy, confidentiality and cultural sensitivities of the participants and/or collectivity are respected. Any specific agreements made with the participants or the collectivity are to be fulfilled.

2.2.5 Survival and Protection

Aboriginal and Torres Strait Islander Peoples continue to act to protect their cultures and identity from erosion by colonisation and marginalisation. A particular feature of Aboriginal and Torres Strait Islander cultures and these efforts has been the importance of a collective identity. This collective bond reflects and draws strength from the values base of Aboriginal and Torres Strait Islander Peoples and cultures.

Aboriginal and Torres Strait Islander Peoples do not intend to forego the distinctiveness of their cultures. Barriers between research and Aboriginal and Torres Strait Islander Peoples have been created for example where some researchers or institutions have ignored or sought to undermine this distinctiveness. The repeated marginalisation in research of Aboriginal and Torres Strait Islander values has reinforced these barriers over time creating a ‘collective memory’ that is an obstacle to research today. Researchers will need to make particular effort to deal with the perception of research held by many Aboriginal and Torres Strait Islander communities as an exploitative exercise. They will need to demonstrate through ethical negotiation, conduct and dissemination of research that they are trustworthy and will not repeat the mistakes of the past.

As noted throughout, the distinctive cultures and community life of Aboriginal and Torres Strait Islander Peoples rests at the heart of these guidelines. It is, therefore, essential that researchers engage with Aboriginal and Torres Strait Islander communities collectively, not just with individuals.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers should describe and HRECs should consider issues of survival and protection including the following components:

- *Importance of values based solidarity to Aboriginal and Torres Strait Islander Peoples*

    Aboriginal and Torres Strait Islander Peoples vigorously oppose the assimilation, integration or subjugation of their values and will defend them against perceived or actual encroachment. Researchers must be aware of the history and the continuing potential for research to encroach on these values.

- *Respect for social cohesion*

    The importance of the personal and collective bond within Aboriginal and Torres Strait Islander communities and its critical function in their social lives.

- *Commitment to cultural distinctiveness.*

    The cultural distinctiveness of Aboriginal and Torres Strait Islander Peoples is highly valued by them. Within the scope of these guidelines, researchers must find ways of working that do not diminish the right to the assertion or enjoyment of that distinctiveness.

Demonstrating survival and protection

Participating communities, researchers and HRECs should consider:

- Whether the research project contributes to or erodes the social and cultural bonds among and between Aboriginal and Torres Strait Islander families and communities.
- What safeguards are in place against the research project contributing to discrimination or derision of Aboriginal and Torres Strait Islander individuals or cultures.
- Whether the proposal respects the intrinsic values based expectations and identity of Aboriginal and Torres Strait Islander Peoples and communities including the balance between collective and individual identity.
- How the proposal contributes to the opportunity for Aboriginal and Torres Strait Islander Peoples to better advocate for or enjoy their cultural distinctiveness.
- What strategies have been identified to eliminate any threats to Aboriginal and Torres Strait Peoples' ability to enjoy their cultural distinctiveness.

2.2.6 Spirit and Integrity

This is an overarching value that binds all others into a coherent whole. It has two components. The first is about the continuity between past, current and future generations. The second is about behaviour, which maintains the coherence of Aboriginal and Torres Strait Islander values and cultures. Any behaviour that diminishes any of the previous five values could not be described as having integrity.

Aboriginal and Torres Strait Islander communities have demonstrated a continuity of values and bonds that has sustained and been sustained by the overarching value of spirit and integrity. This continuity has remained evident in individuals and communities despite changes in physical environment and behaviours. These bonds and values have often been the touchstone for personal or community level action to renew or protect identity, culture and life.

Aboriginal and Torres Strait Islander communities are not homogeneous. However, there are core values and principles that remain common across the cultural spectrum and Aboriginal and Torres Strait Islander Peoples will assert the dignity and worthiness of their particular efforts to protect and uplift their own.

Researchers are perceived as owing an obligation to the spirit and integrity of communities not just to individuals. It is clear that Aboriginal and Torres Strait Islander communities will look to see if what is proposed is consistent with their values. However, the responsibility to demonstrate consistency falls to those proposing research.

Community decision making based on shared values is an implicit part of spirit and integrity.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers should describe and HRECs should consider issues of spirit and integrity including the following:

- *Motivation and action*

  This means that researchers must approach the conduct of research in Aboriginal and Torres Strait Islander communities with respect for the richness and integrity of the cultural inheritance of past, current and future generations, and of the links which bind the generations together.

- *Intent and process*

  Negotiations with Aboriginal and Torres Strait Islander communities will need to exhibit credibility in intent and process. In many circumstances this will depend not only on being able to demonstrate that the proposal is in keeping with these guidelines, but also on the behaviour and perceived integrity of the proponents of research.

Demonstrating spirit and integrity

Participating communities, researchers and HRECs should consider:

- How the proposed research demonstrates an understanding of and agreement about the relationship between the proposed research and the community's cultural, spiritual and social cohesion, including workable timeframes.
- Whether the proposal recognises in the conduct and reporting of research the diversity of Australian Aboriginal and Torres Strait Islander People's cultures, including the mechanisms through which communities may make decisions.
- Whether the proponents of the proposal are able clearly to demonstrate personal integrity, specifically in the development of their proposal.
- Does the proposal demonstrate a commitment to working within the spirit and integrity of Aboriginal and Torres Strait Islander Peoples?

Allied National Statement requirements

NS 1.1 The guiding value for researchers is integrity, which is expressed in a commitment to the search for knowledge, to recognised principles of research conduct and in the honest and ethical conduct of research and dissemination and communication of results.

NS 1.2 When conducting research involving humans, the guiding ethical principle for researchers is respect for persons which is expressed as regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research.

APPENDIX 1: THE DEVELOPMENT OF THE GUIDELINES

In order to revise the *Interim Guidelines*, AHEC adopted a number of strategies. The first saw Mr Daniel McAullay, an Aboriginal researcher and community research partnership coordinator, and Mr Robert Griew, AHEC member, travel widely and talk to a range of stakeholders in Aboriginal and Torres Strait Islander health research. In a report prepared for AHEC, they described a continuing level of support for and ownership of the *Interim Guidelines*, a sense that more was needed to move beyond a kind of superficial compliance mentality and that, in some cases, tension had grown up around the structures to support the guidelines.[16] They also found that researchers in Aboriginal and Torres Strait Islander health, and Aboriginal and Torres Strait Islander Peoples themselves, while widely aware of the *Interim Guidelines*, were not as aware of the application of the *National Statement* to Aboriginal and Torres Strait Islander Peoples.

Secondly, in collaboration with Associate Professor Ian Anderson, head of the VicHealth Koori Health Research and Community Development Unit at the University of Melbourne, an annotated bibliography of the international literature on the ethics of Aboriginal health research was prepared and published.[17]

Thirdly, AHEC brought together a group of people from a wide range of stakeholder interests in Melbourne in May 2001 for further discussions. Following this meeting, a Working Party of researchers, Aboriginal community controlled health sector representatives, Human Research Ethics Committee representatives and policy makers was formed. This group then organised a two-day workshop in Ballarat, Victoria in June 2002. That workshop attended by representatives from the National Aboriginal Community Controlled Health Organisation and its State/Territory affiliates, researchers, HRECs, government and other Aboriginal participants considered all of the material brought together by the processes to date.

It was recognised by the Working Party and the Ballarat meeting that there were issues that needed to be discussed that did not all fall within the guidelines themselves but included, for example:

- The resourcing, accountabilities and support for Human Research Ethics Committees;
- The relationship of public health surveillance activity within State and Territory Health Departments to their HRECs and to the guidelines;
- Monitoring, follow up and accountability of research projects after the ethics clearance process;

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[16] Griew R, McAullay D, 'Review of the Interim *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*', background paper for the meeting to review the interim *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research* for the Australian Health Ethics Committee, Melbourne, 25 May 2001.

[17] McAullay D, Griew R, Anderson I, *Ethics of Aboriginal Health Research: An Annotated Bibliography*, Koori Health Research and Community Development Unit, University of Melbourne, Melbourne, 2002.

- Education and promotion of the guidelines among researchers, communities and organisations;
- Resources for the development of Aboriginal and Torres Strait Islander health research more generally, support for community consultation and for the development of research priorities with Aboriginal and Torres Strait Islander Peoples.
- Following from the last point, strong support for the NHMRC Research Agenda Working Group's (RAWG's) 2002 Aboriginal health research 'Roadmap' exercise.
- Developing the capacity of Aboriginal community controlled health services to undertake their own research and participate directly in research (including the conduct of national studies through their peak body NACCHO), using the significant amount of vital information that they hold and which could contribute to health strategies and better understanding of the role of the Sector in health generally.
- Expansion of efforts to communicate AHEC's current work on ethical issues to Aboriginal and Torres Strait Islander Peoples and others involved in Indigenous health research. This includes work on new privacy legislation, genetic research and the handling of organs and samples taken at autopsy or other health surveys.

As well as deciding to refer these issues separately back to the NHMRC, the Ballarat workshop provided a framework for the draft of these guidelines themselves that were then prepared by the Working Group.

Public consultation on the draft of these guidelines ran until the beginning of January 2003. In response 56 submissions were received from a cross section of interests. The Working Party then reviewed the draft in the light of the submissions received, and has revised it as needed.

APPENDIX 2: SUGGESTED APPLICATION OF THE GUIDELINES

SUPPORTING THE GUIDELINES

AHEC recognises that HRECs need to examine research proposals comprehensively in order to determine whether they comply with the values set out in these guidelines. Consequently, there will be an addition to the *Human Research Ethics Handbook* to provide further practical measures to inform the application of the values outlined in these guidelines, thereby assisting researchers and HRECs in their use.

An implementation strategy that provides for the orderly, informed and coherent application of these guidelines is also an integral part of the process. The inclusion of relevant stakeholder interests in the preparation and conduct of the implementation strategy will provide additional opportunity to build ownership of the revised guidelines.

THE RESEARCH PROCESS

Researchers need to put forward a proposal in which each of the following phases of the research process, where relevant, is ethically defensible on the grounds of each of the values of these guidelines:

- Conceptualisation
- Development and approval
- Data collection and management
- Analysis
- Report writing
- Dissemination

Consultation and other strategies that facilitate Aboriginal participation are critical in all phases of this research process.

COMMUNITY ENGAGEMENT AND PARTICIPATION

Aboriginal and Torres Strait Islander health research may be conducted at a local, regional or national level. The structures and processes for negotiating community engagement and participation will therefore vary. Researchers should therefore inform themselves about appropriate structures and processes and seek to engage with these in a spirit of respect and integrity.

In some jurisdictions, review or approval procedures may have been given regulatory status by government legislation or published policy. These will vary between jurisdictions, however these procedures need to be followed.

Even within local communities, structures and processes may vary. In some communities there is an Aboriginal community controlled health service, which would normally be assumed to speak for the community in terms of its community interests about health research. In some communities these health services conduct their own research and/or lead research collaborations and partnerships. In some communities there is not a community controlled health service. In other communities there are elected Community Councils and/or other clear lines of authority about who would speak on a subject like health research and the community. In other communities some or all of those structures are not present. There are also national and state based associations of Aboriginal community controlled health services.

Where Aboriginal and Torres Strait Islander institutional structures and processes exist these should be used as the best means of community and institutional engagement by researchers, both in dealing with communities and in seeking HREC approval.

The variety of existing models indicate that national efforts to improve ethical behaviours in Aboriginal and Torres Strait Islander health research should allow for different circumstances in different communities, while affirming the importance of Aboriginal and Torres Strait Islander cultural values, community controlled organisations and these guidelines in all cases.

THE ROLE OF HUMAN RESEARCH ETHICS COMMITTEES

The role of HRECs is well established. Their primary function is to 'protect the welfare and the rights of participants in research'.[18] The complexity of human involvement in research demands of HRECs the resolution of complex and often competing considerations. The composition of HRECs is intended to establish a broad scope of contribution that enables decision making inclusive of legal, spiritual, professional and lay considerations. Historically, most HRECs had few if any Aboriginal or Torres Strait Islander members and this unfortunately led to instances where clearance or monitoring of research failed to consider Aboriginal and Torres Strait Islander perspectives.

The historic inability of HRECs to fulfil their function in a way that Aboriginal and Torres Strait Islander Peoples valued led Aboriginal and Torres Strait Islanders to seek initially greater representation on existing HRECs and more recently for separate Aboriginal HRECs.

A number of Aboriginal HRECs have been established with majority Aboriginal membership and with the specific brief of reviewing the ethical quality of research proposals in Aboriginal health. The Aboriginal HRECs proceed uniquely from an Aboriginal and Torres Strait Islander value base and perspective. However, there are not yet sufficient committees with this composition to review all health research involving Aboriginal and Torres Strait Islander Peoples. This means attention needs to be given by non-Aboriginal HRECs to the question of how they will equip themselves to implement these guidelines when they encounter research involving Aboriginal and Torres Strait Islander communities.

Strategies that non-Aboriginal HRECs should consider include:

- referring relevant research proposals to a properly constituted and appropriate Aboriginal HREC for consideration;
- creating an Aboriginal and Torres Strait Islander sub-committee or advisory group;
- expanding membership of their committees to include an appropriate number of members from the Aboriginal and Torres Strait Islander communities; or
- such other processes as will contribute to achievement of the goals of the guidelines.

The implementation phase needs to consider the range of structural and relationship issues necessary to ensure the optimal implementation of these guidelines.

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[18] *Human Research Ethics Handbook*, Commentary on the National Statement, NHMRC, 2001, p.C20.