THE ETHICS OF ABORIGINAL HEALTH RESEARCH:

AN ANNOTATED BIBLIOGRAPHY

Daniel McAullay
Robert Griew
Ian Anderson

VICHEALTH KOORI HEALTH RESEARCH AND COMMUNITY DEVELOPMENT UNIT

Discussion Paper Series

The VicHealth Koori Health Research and Community Development Unit (VKHRCDU) was launched in June 1999 and has been developed in partnership with the Victorian Community Controlled Health Organisation, the Victorian Health Promotion Foundation (which funds the Unit) and the University of Melbourne through the Centre for the Study of Health and Society where the Unit is located.

At the core of the Unit's work is a commitment to undertaking, collaborating in and supporting research that directly benefits the Koori community. The work of the Unit spans academic and applied research, community development, and medical education. The combination of these activities is a central and innovative aspect of the Unit's function, as is the identification and use of mechanisms to link research with the improvement of health care practices and policy reform. Overall, these tasks are guided by both an Advisory Committee and a Research Advisory Group.

In relation to the research program, five key areas govern the inquiry undertaken within the Unit. These comprise: historical research into Koori health policy and practice; historical and contemporary research into health research practice, ethics and capacity building; applied research on the social and cultural experience of Koori health, well-being and health care delivery; health economics research on the factors and processes that impact on the provision and use of Koori health care; and the evaluation of Koori primary health care and related health promotion programs.

The Discussion Paper Series (DPS) is directly linked to this diverse program of research and provides a forum for the Unit's work. The DPS also includes papers by researchers working outside the Unit or in collaboration with VKHRCDU staff. Individual papers aim to summarise current work and debate on key issues in Indigenous health, discuss aspects of Indigenous health research practice and process, or review interim findings of larger research projects. It is assumed that the readership for the series is a broad one, and each paper is closely edited for clarity and accessibility. Additionally, draft papers are 'refereed' so as to ensure a high standard of content.

More information on the series, on the preparation of draft papers, and on the work of the Unit can be obtained by directly contacting the VKHRCDU.

Discussion Paper Series

Discussion Paper No. 1: Ian Anderson, Harriet Young, Milica Markovic and Lenore Manderson 'Aboriginal Primary Health Care in Victoria: Issues for Policy and Regional Planning' (December 2000)
Discussion Paper No. 2: Kim Humphery 'Indigenous Health and 'Western Research' (December 2000)
Discussion Paper No. 3: David Thomas 'The Beginnings of Aboriginal Health Research in Australia' (September 2001)
Discussion Paper No.4: Michael Otim, 'Indigenous Health Economics and Policy Research' (November 2001)
Discussion Paper No. 5: Daniel McAullay, Robert Griew and Ian Anderson 'The Ethics of Aboriginal Health Research: An Annotated Bibliography' (January 2002)

Forthcoming

Ian Anderson 'Critical Issues in National Aboriginal and Torres Strait Islander Health Policy and Strategy'

THE ETHICS OF ABORIGINAL HEALTH RESEARCH:AN ANNOTATED BIBLIOGRAPHY

Daniel McAullay,
Kulunga Research Network, TVW Telethon Institute for Child Health Research.

Robert Griew and Ian Anderson
VicHealth Koori Health Research and Community Development Unit.

Summary

In 1991 the National Health and Medical Research Council (NH&MRC) officially adopted the Interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research. During the 2000–2003 triennium, the Australian Health Ethics Committee, one of the NH&MRC's four principal committees, has placed the revision of the 1991 Interim Guidelines on its work program. Included in the revision was the production of this document, which comprises both an annotated bibliography and a summary of the ethical issues relating to research in Indigenous populations. This was a joint process funded from the Office of the National Health and Medical Research Council, with contributions by the VicHealth Koori Health Research and Community Development Unit at the University of Melbourne and the Kulunga Research Network at the TVW Telethon Institute for Child Health Research.

In our extensive literature review, we used a combination of various search methods to find most of what has been written in Australia over the past few decades on the issues of Indigenous health research ethics, as well as a good proportion of the international literature, at least from North America.

This document is a summary of these published works, which we have categorised into ten areas according to content. These categories are:

- articles that outline the history of ethical issues in health research which gave rise to the Interim Guidelines;
- other examples of Indigenous research guidelines and overall guiding principles needed for health research in Aboriginal and Torres Strait Islander communities;
- articles that refer to the principle of relevance, that research needs to be relevant to identified health needs of Aboriginal and Torres Strait Islander communities, and/or the usefulness of proposed interventions being tested;
- articles that refer to consultation with Aboriginal and Torres Strait Islander communities and the provision of effective consent;

- articles that refer, in particular, to Aboriginal and Torres Strait Islander people's involvement in research;

- articles that refer, in particular, to dissemination of research findings;

- articles on compliance and monitoring of research once approved, including the resourcing needs of Aboriginal and Torres Strait Islander health research ethics committees;

- examples of new collaborative research models that might provide a better ethical basis for health research in Aboriginal and Torres Strait Islander communities;

- specific issues that relate to research with a particular focus, including genetic research and pharmacological trials; and

- the extent of research-type activities that guidelines ought to cover and issues of funding for Indigenous Human Research Ethics Committees.

- We found that a majority of the literature reinforced the concerns reflected in the Interim Guidelines. Issues included the importance of consultation, community involvement, consent, and appropriate dissemination of research findings. However, a number of issues raised in the literature could be considered in the redevelopment of the Interim Guidelines. These include:

- Uncertainty about the scope of the existing guidelines and the extent to which they were intended to cover some forms of epidemiological research (such as analysis of existing administrative datasets or program evaluations).

- Whether consideration should be given to principles that advocate the right of inclusion of Aboriginal and Torres Strait Islander people in mainstream research (as is advocated in the National Institute of Health Guidelines).

- How the principles of benefit (which incorporates concepts such as the relevance of the research subject, the need for new knowledge and the usefulness of any intervention) can be incorporated in guidelines given the apparent complexity of application.

- How key principles that are well supported can be applied given some of the difficulties inherent in deciding how a community is defined and who represents that particular community.

- What processes and models provide the best examples for dealing with issues surrounding decision making about publication of results.

- Several issues not included in the Interim Guidelines that should be considered for inclusion, for example, compliance and monitoring after ethical approval has been given.

- The Interim Guidelines not anticipating in its recommendations the increasingly important role of Aboriginal and Torres Strait Islander researchers, and of the development of collaborative research models.

In addition to consider issues about the context of the guidelines – it is also important that consideration be given to the strategies need to maximise the uptake and compliance with revised guidelines. For instance, it may be that research funding processes need to be reformed in order to promote and support adherence to new guidelines. It also may be the case that specific training or skills development is required.

INTRODUCTION

In 1991 the National Health and Medical Research Council (NH&MRC) officially adopted the Interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research. These guidelines (hereafter referred to as the Interim Guidelines) were developed through a public conference in 1986 on 'Research Priorities in Aboriginal Health' and a 'National Workshop on Ethics of Research in Aboriginal Health' in 1987. The National Workshop was convened with the specific purpose of developing principles for the ethical regulation of research involving Aboriginal and Torres Strait Islander people. Subsequent to these meetings, the NH&MRC and Aboriginal representatives pursued a lengthy process of negotiation over the wording of the guidelines that were eventually released.

The Australian Health Ethics Committee (AHEC) is one of the four principal committees of the NH&MRC. It is responsible for the provision of advice and the development of guidelines on ethical matters in research involving human subjects. During the 2000–2003 triennium, AHEC has placed the revision of the 1991 Interim Guidelines on its work program. As part of this revision it is useful to look at the literature on ethical questions relating to research in Indigenous populations, especially from Australia and similar settler colonial societies, to get a 'snapshot' of the issues.

To contribute to this process and respond to increased interest in the issues, the VicHealth Koori Health Research and Community Development Unit (VKHR&CDU) at the University of Melbourne and the Kulunga Research Network at the TVW Telethon Institute for Child Health Research have undertaken a literature review, the result of which is this annotated bibliography. Funding from the Office of the National Health and Medical Research Council has supported this project.

METHOD

The bulk of the literature was obtained from a collection of articles and resources compiled by VKHR&CDU staff. This material was obtained by searching the Australian Public Affairs Information Service (APAIS) database (from 1981 to 2000), the health database Austhealth (involving various start dates from 1900 to 2000), and Medline (with a start date of 1966). In addition, a manual search of bibliographic information contained within all of the material obtained through the electronic search yielded a further body of previously unidentified literature. A number of search keywords were used in locating material, including 'Aboriginal', 'Torres Strait Islander', 'research', 'ethics', 'indigenous', and 'cross-cultural'. Using this combination of methods we found most of what has been written in Australia on issues of Indigenous health research ethics over the past few decades and a good proportion of the international literature, at least from North America.

These articles were then read and categorised according to content. There was no attempt to evaluate views or perspectives but only to categorise the written commentary. The first section of this document is a brief summary of the issues identified in the literature, and is designed as a guide to the annotated bibliography that follows.

OVERVIEW OF THE LITERATURE

Broadly, ten categories of literature were found. These are:

- articles that outline the history of ethical issues in health research, which gave rise to the Interim Guidelines;

- other examples of Indigenous research guidelines and overall guiding principles needed for health research in Aboriginal and Torres Strait Islander communities;

- articles that refer to the principle of relevance, that research needs to be relevant to identified health needs of Aboriginal and Torres Strait Islander communities, and/or the usefulness of proposed interventions being tested;

- articles that refer to consultation with Aboriginal and Torres Strait Islander communities and the provision of effective consent;

- articles that refer, in particular, to Aboriginal and Torres Strait Islander people's involvement in research;

- articles that refer, in particular, to dissemination of research findings;

- articles on compliance and monitoring of research once approved, including the resourcing needs of Aboriginal and Torres Strait Islander health research ethics committees;

- examples of new collaborative research models that might provide a better ethical basis for health research in Aboriginal and Torres Strait Islander communities;

- specific issues that relate to research with a particular focus, including genetic research and pharmacological trials; and

- the extent of research-type activities that guidelines ought to cover and issues of funding for Indigenous Human Research Ethics Committees.

Predictably, many of the articles cited are included in more than one category as their themes often cross over.

1. History of issues in health research which gave rise to the Interim Guidelines

At the conference held in 1986 the then Medical Research Ethics Committee (MREC) indicated the need for special ethical considerations in Indigenous health research. A number of reasons were cited. These included the poor status of Indigenous health, the lack of useful research, the cultural insensitivity of some researchers conducting Indigenous research, and the lack of ethical appreciation of specific issues relevant to Indigenous research.14 Consequently, the Interim

Guidelines adopted in 1991 cover the areas of consultation (aimed at producing relevant research), community involvement, and ownership and publication of data.

Several articles recount examples of poor research conducted with little or no consultation, co-operation or involvement with those being researched, or with inadequate sensitivity to cross-cultural awareness or communication.[84, 58, 46, 13, 16, 87, 20, 39, 34, 4, 23, 11, 51, 9, 28] The Interim Guidelines, and other guidelines, in part arose because of indigenous responses to such examples.

Many of these articles also propose protocols, models and guidelines of research that have been developed in response to this history. An example of this are the Australian Institute for Aboriginal and Torres Strait Islander Studies guidelines, which were formed in response to the lack of control and involvement in past research.[11] Another example was the process developed by the Bibbulung Gnarneep research project. The aim of these was to involve all parties thereby ensuring ethical research.

An article by Perkins, et al. illustrates the development of research methods/tools to ensure consultation with communities and more useful research less dominated by descriptive epidemiology. A paper by Flick outlines the need for increased Indigenous involvement in research.[84, 46, 34] The themes of partnership and participation are seen to be a positive step towards improved Indigenous research both within Australia and in other countries with Indigenous populations.[16, 87] Several articles identify the differing values between researchers and those being researched, including the application of a 'Western model' of thinking, as a key factor that, in the past, had underpinned poor research.[11, 20]

Funding guidelines issued by the National Institute of Health (NIH) in the USA address questions of who are American Indians and Alaskan Natives, what are the communities' roles in research, and how to stimulate individual and community participation research that includes women and ethnic minority groups in clinical research.[55] These guidelines represent a fundamentally different approach to what is the key ethical challenge in Indigenous health research. While all other guidelines, including the Australian Interim Guidelines, are protective in nature (of Indigenous communities from research), the NIH demands that all research proposals include minorities, women and children or explain why they do not. The focus of these latter guidelines is on the ethics of participation.

It may be that the approach taken in developing ethical guidelines will ultimately reflect a consensus view about what the most significant potential harm is with respect to research in Indigenous contexts. On the one hand, protective guidelines provide a framework for protecting Indigenous people from exploitation. Whilst the NIH approach seems to suggest the most significant ethical danger is the on-going exclusion of Indigenous peoples from research that may ultimately benefit their communities. Indigenous peoples in North America and Australia have similar histories with respect to research. So it is interesting, therefore, that such a significant divergence exists in the approach take to research ethics. The difference between protective and participatory emphases in ethical guidelines is an issue for further consideration in the process of reviewing the Interim Guidelines in Australia.

2. Guidelines and guiding principles

This collection of articles identifies many examples of guidelines that have been developed in Australia, New Zealand and North America.[95, 18, 48, 55, 5, 56, 27, 11, 42, 41, 85, 68, 29, 30, 40, 44, 37, 38, 19, 12] Internationally, guidelines tend to cover similar areas, including consultation, community involvement, cultural appropriateness, and data and information ownership. These are, of course, the core issues covered in the Australian guidelines, including both the Interim Guidelines and other complementary examples. One interesting example was of written research agreements based on guidelines and ethical checklists.[82, 44]

Within Australia, one article compares and contrasts the Interim Guidelines to other Indigenous research guidelines in South Australia, Western Australia and the Northern Territory.[27] Areas of difference include the role of Indigenous ethics committees, the use of written contracts, the need for consent to publish, and consent for media comment. Areas of agreement include the requirement to report research findings back to individuals and communities, the need for research to be of benefit to the researched community and the importance of participation.

One key topic is the type of research that guidelines should cover, for example, epidemiological studies of existing administrative data sets. There are, of course, ethical guidelines specifically written for the conduct of epidemiological studies, including cross-sectional, case control and cohort studies. These guidelines, from the Council for International Organizations of Medical Sciences, cover much the same area as other research guidelines, including the ethical principles of respect for persons, beneficence, non-maleficence, and justice. The issue here is that different types of epidemiological work attract different approaches to ethical scrutiny. Outbreak investigations, for example, are not currently given detailed scrutiny – and it unlikely given the time constraints of outbreak investigations that existing processes of ethical scrutiny would be feasible[19]. Program evaluations, initiated by government agencies as a part of ongoing program review processes are not necessarily scrutinised by ethical processes developed within the AHEC framework. On the other hand program evaluations or the analysis of existing epidemiological data sets, when this is funded through the NH&MRC, would necessarily involve, as a condition of grant, ethical scrutiny within the agreed AHEC process. The scope of research and evaluation activity that is covered by guidelines needs to be clarified as a part of the current review process.

Various academic, health and government agencies have developed their own documents of guiding principles for research among Aboriginal and Torres Strait Islander peoples. These principles cover, in essence, the same areas within the Interim Guidelines, and include consultation, collaboration, consent, involvement, and feedback.[87, 91, 52, 76, 39, 47, 75, 3, 41, 22, 36]

There are two articles in the literature worthy of note. The first is an editorial that, while examining the issues involved in research into Indigenous Canadians, also suggests that it is a community's responsibility during research consultation to ensure it is truly aware of what is being discussed.[36] This article proposes that communities be given a checklist to support them in discharging this responsibility. The second paper

examines issues surrounding data collection and ownership and recommends protocols be developed for its appropriate use.[75]

While most articles in the literature cover essentially the same list of principles a number focus on one or two areas. These are itemised in the following four sections.

3. Relevance of the subject matter, need for new knowledge, and usefulness of any intervention

These three principles focus on ensuring that the subject matter of research is relevant to the Indigenous community involved, that the research being conducted is aimed at producing new knowledge and that the research is of potential benefit to Indigenous health.[63, 2, 78, 26, 59, 22]

The Interim Guidelines cover this cluster of principles in the section on consultation. They state that the 'research proposed will be potentially useful to the community in particular or Aboriginal and Torres Strait Islanders in general'.[14] However, the Interim Guidelines do not provide criteria against which this can be assessed. In assessment criteria used in the 2000 and 2001 National Health and Medical Research Council funding cycles, researchers were asked to articulate how their proposed research would lead to sustainable, transferable solutions and how the research process would enable community participation.

Chronologically most of these papers were published in the 1990s with the exception of two in the early and late 1970s, which outlined the importance of research relevance, and another interesting paper published in 1976.[7, 2, 5]

The idea that unites these three principles is the notion of 'benefit'. Most of the literature takes the concept of benefit as self-evident and, therefore, not only has a repetitious and slightly pious feel to it but does not elaborate on how this should be assessed or put into practice. Only three articles provide a more detailed discussion of the concept of benefit, suggesting that the concept is neither straightforward in application nor as straightforward as it is sometimes taken. Anderson spells out a number of dimensions of benefit, noting that there are short-term, medium and long-term benefits (and risks) in research that need to be considered. Further, he argues that there are resourcing, political and community capacity development issues as well as the overt content of research. He notes that it is important to consider each dimension of benefit because each can be separately contested.[51]

Torzillo, in a Medical Journal of Australia (MJA) editorial, questions some of the commonly articulated propositions relating to Aboriginal health research. He suggests that the concept of benefit is sometimes narrowly applied to 'action based research' or qualitative research.[65] While Torzillo supports the principle of benefit, he argues that it is sometimes given a timeframe that requires an immediate benefit. He points out that longer term benefits need to be enabled, and that these will result from the advance of knowledge not just immediate material gain. He cautions against the ethical guidelines privileging particular disciplines or research methods regardless of the topic of the research.

Kothera, on the other hand, proposes a 'Right to Research Benefit' concept as a complement to the concept of Intellectual Property Rights, one that is less likely to be a legal minefield but one which still needs to be addressed up front. While there are presumably a few legal complexities in applying the concept of 'Right to Research Benefit', this would also need to be assessed up front (and as such still entails the uncertainties that result from our inability to foresee research outcomes).[62] More discussion of the concept of 'benefit' is a third area we would highlight for further development of the Interim Guidelines.

4. Consultation and consent

The area of consultation was a major focus in the Interim Guidelines. The guidelines give clear direction to researchers on the necessity of consulting with local community-controlled Aboriginal and Torres Strait Islander health services and State, Territory and Federal Aboriginal and Torres Strait Islander health agencies on the proposed research activity. They also state that written documentation of consent at a community level should be obtained and, where this is not possible, reasons why should be documented. Finally, any changes to the research protocol, procedure or methodology should be negotiated with and consented to by the community involved.[14]

The issue of consultation is raised in the literature many times, and the importance of consultation as a key component of Indigenous involvement in research is clear.[21, 43, 86] The literature stresses that consultation needs to produce consent at both the community and the individual level if research in Indigenous communities is to be supported. The consent of individual research subjects is one of the bedrock principles of research ethics and does not require further elucidation in this context. Community consent implies a social collectivity and, as such, the application of this principle is distinct to that of individual consent.[90, 87, 37]

A significant focus within the literature centres on problems affecting community consultation and consent strategies. Relatively limited literacy levels were also identified as being problematic in the use of model volunteer consent forms for documenting individual consent.[35] An article outlining the consultation and recruitment process of the special cohorts of the Australian Longitudinal Study on Women's Health in 1998 identified areas that could possibly impede consultation in this study, in particular, the media inappropriately identifying communities and a simplistic conceptualisation of the notion of 'community'.[77]

Other writers also stress it is important not to take 'community' for granted as a self-evident term.[13, 74, 90] Israel, et al. outline the importance of recognising the community but question who represents it and how it is defined,[74] while Weijer emphasises the need for a clear definition of community as well as identifying the importance of how we use this definition.[90] Weijer, in this article and another with Goldsand and Emanuel, also stresses the importance of involving community in the development stage of research—consultation. They identified this as an area that was not included in the Belmont Report, the North American ethical research framework document.[90, 91]

One final paper went further by providing an example of African–American groups that have developed guidelines which turn the focus from the community to the researcher, and question the suitability of researchers to conduct research within the community.[5] This is interesting in that it explicitly advocates an assessment of researcher credentials as opposed to the appropriateness of the research, a process implicit in later approaches but not elsewhere so boldly presented.

A fourth issue suggested by the literature for specific attention in the review of the Interim Guidelines is the conceptualisation of 'community' in the process of community consent requirements.

5. Indigenous research involvement

Community involvement is addressed in a number of clauses in the Interim Guidelines. The first is the involvement of Aboriginal and Torres Strait Islander people as paid research assistants wherever possible and the culturally sensitive deployment of these research workers, for example, the use of female assistants when dealing with women's or children's health issues.[14] Secondly, the Interim Guidelines stipulate that researchers should account for all costed resources used in the research and reimbursement of the community and individuals.

The literature goes further by identifying the importance of involving Indigenous people throughout all stages of the research process. The limited reference to Indigenous community members as research assistants in the Interim Guidelines may reflect the historical reality that fewer Aboriginal and Torres Strait Islander people were involved as researchers at the time when the guidelines were developed than is the case now. Since that time, there have been many articles detailing different research projects that have involved Indigenous people in various ways. The approaches documented range from the experiences of Indigenous people as research assistants, research projects that have involved explicit non-Indigenous and Indigenous collaborations, and projects that have full Indigenous ownership and control.[78, 54, 61, 20, 53, 7, 49, 6, 29]

In Australia the involvement of Aboriginal health workers in research, or Aboriginal health worker-controlled research, is specifically addressed in two articles.[61, 53] More interestingly, there is a paper from 1977 that explores the possible conflict in roles that may arise when a member of the Indigenous community involved in a research project takes on a role in the research team.[7]

The Interim Guidelines were developed in a context in which research was primarily a process driven by non-Indigenous people who only engaged Indigenous people as stakeholders or subjects. In the current context there are a growing number of Indigenous researchers, and research structures with Indigenous management processes. The implications of this transformation in research process needs to be thought through with respect to how the guidelines are framed, and in particular with the approach taken to promoting Indigenous participation in the guidelines.

6. Dissemination

The Interim Guidelines cover the area of dissemination in a section on ownership and publication of data. This section suggests the negotiation of clear agreements well before research begins, especially wherever problems are anticipated, the necessity of community consent for publication of research findings to the public and/or media and the proper acknowledgment of community members involved.[14] Other areas covered include consent for the further use of blood or tissue samples, areas surrounding storage and destruction of identifiable data, and acquiring consent prior to the use of pictorial material.

The poor dissemination of research findings in the past has seen Indigenous people become extremely wary of future research involvement. Community feedback, publication of research findings (including academic publication), and information ownership are contentious issues and ones that have been mentioned in all of the guidelines in the literature. Issues relating to dissemination have led to the development of specific guidelines or protocols.[5, 24, 13, 25, 15, 45, 20, 62, 69]

There are many articles describing the importance of feedback as a fundamental research component that should be considered at the beginning of a research project, not the end, and be appropriate in style and language to ensure future research participation.[24, 25, 15, 20, 5] Hunter, in particular, outlines a method of feedback used for a specific community-based research project.[24] He suggests that it is important to provide successful feedback using several different strategies, including local media, one-to-one, face-to-face feedback, individual written reports, and community reports.

An interesting article cited earlier proposes the use of Rights to the Benefits of Research (RBR) in non-commercial research, and as a complement to Intellectual Property Rights (IPR).[62] RBR is a strategy to enable Indigenous peoples to have access to monetary and non-monetary benefits from research, access and control of the findings, acknowledgment as being the rightful owners of the knowledge, and the opportunity to participate in the research process.[62] It may provide a pragmatic focus for discussion about future publication rights by addressing for the community the question, 'What are we going to get out of this?'. RBR complements rather than replaces IPR but can provide a focus for discussion that is more tangible and may lead more easily to meaningful agreements.

Publication remains a 'hot issue' in Aboriginal health research ethics. The literature suggest that these issues can be ethically managed with the development of agreements between researchers and Indigenous stakeholders that specify the expected ranged of publications, processes for Indigenous stakeholder input and the timeframes for such processes. It also points to at least one new way of thinking about the issue, that is, not just looking at intellectual property rights but a right to benefit. This could provide a different path to agreement-making and would be worth further discussion in the context of reviewing the Interim Guidelines in Australia.

7. Compliance and monitoring

Compliance and monitoring of research projects as priority issues, which was not an area covered in the Interim Guidelines, is also identified in the literature. One article from within the Aboriginal community-controlled health sector also suggests that the issue of the guidelines being overdue for revision is less important than the level of adherence by researchers to existing guidelines.[81]

A process is needed to ensure that compliance with the guidelines is checked by those responsible for publishing research.[81] Examples of published research not complying with the guidelines were identified in an editorial.[88] In a submission by the National Aboriginal Community Controlled Health Organisation to the Australian Health Ethics Committee, it was identified that the only threat to researchers who fail to adhere to the guidelines was the withdrawal of NH&MRC funding, which is unlikely to ensure effective compliance because it is unlikely to happen.[69]

8. New collaborative research models

Along with various examples of other guidelines, the literature also provided descriptions of recently development models for collaborative research. To some extent these are a response to the need for community engagement but there is also another common thread. This is that a lack of research is less of a problem than the application of existing research and scientific knowledge in service delivery. These models provide for institutional structures that build collaborative working relationships between Indigenous communities and research structures, and the development of relationships that enable stronger Indigenous input in priority setting and more effective processes for the feedback of research findings.[65, 78]

The Bibbulung Gnarneep project developed a strong collaborative protocol with the Aboriginal community as a key member of the research team.[84] Similarly, the Menzies School of Health Research developed an interdisciplinary and cross-cultural collaborative research model between the Aboriginal community, the researchers and the wider community in the Northern Territory. This model was designed to foster trust and communication between these parties.[78, 99]

Internationally, the literature identifies three examples of collaborative models all within Canada. The first describes a collaborative model between an academic institution and Indigenous community related to establishing primary health care research. The author identifies the strengths and weaknesses of university and community rules for collaboration, including guidelines for the university researcher and the community physician, and classic problems in 'collaboration'. These problems include a lack of knowledge, respect and understanding, and different research goals. The chapter concludes with recommendations for successful collaboration and goals for the future.[32]

The second outlines a research agreement model used in participatory research. It describes the participatory research process and its use in Northern Canada, and outlines the important aspects and steps of the study design. These include describing the research process with a focus on informing the community, defining the issues, approaching the goals and objectives, ensuring the partnerships are sustained, and analysing and presenting the findings.[44]

The final example examines the issues of risk associated with such models, including the distribution of risk and benefit and workload, and the interesting issue of confidential information or data being subpoenaed. This background paper was prepared for a workshop to promote discussion of the issues surrounding the negotiation of research within the Northern Canadian regions. The discussion covered three sections: the implications of approaching research as a negotiated relationship, the framework and subject matter of such negotiations and the process for entering negotiations. It also looked at who sets the agenda and who conducts the research, underlying principles and problems that are likely to arise.[37]

9. Specific issues

There are two current hot topics in the literature—genetic research and research using clinical pharmacological trials in third world countries. In genetic research, the impact of the Human Genome Project (HGP) and the Human Genome Diversity Project (HGDP) on Indigenous people are particular issues that were raised in the more recent literature.[34, 11, 96, 94, 83] The completed HGP aims to map and sequence the human genome, while the HGDP, a separately funded longer term project, aims to characterise the genetic diversity of humans.[83] While both projects raise many ethical questions, the HGDP is one that has been the most controversial for Indigenous peoples. Given the history of exploitative research practices, it is perhaps not surprising that Indigenous sensitivities are greatest with respect to investigations into some of the fundamental aspects of life.[11] This raises several questions on who will make decisions regarding medical research, who will plan and control this research, who benefits, and the possibility of group consent and control.[83] However, the use of gene mapping and gene therapy may be potentially useful to determine different disease incidences, which could lead to better treatment.[83]

The ethics of clinical drug trials generated some comment in the literature; especially with respect to the various randomise trials of HIV medications in sub-Saharan Africa and South America. [57, 73, 66, 89] The most significant ethical concerns include the expense of the medications being used and inability of patients to sustain their use beyond the life of the research project. It has been argued that such research is unethical in contexts where host countries do not have the capacity to sustain the use of medications in the post-trail period.

Although not directly relevant to the existing guidelines these issues may need to be considered in any future guidelines development. The Human Genome Project and its spin-offs are certainly perceived as a threat within the Aboriginal community and need to be debated. There may be risks from non-participation in terms of missing out on the advance of knowledge at one of medical science's frontiers, however, there are also clear risks in a science that makes unsustainable generalisations about racial characteristics.

10. Extent of research and funding issues

Two other issues raised in the literature need to be considered in the development of future guidelines: the extent of research covered by guidelines and issues surrounding funding.

Several articles look specifically at certain types of research and question their need to be covered by guidelines. This thinking distinguishes investigator-initiated research projects from government program evaluation and public health epidemiological studies that analyse existing health administrative data. To a certain extent, these distinctions emphasise the range of social contexts in which information is extracted and analytical activity occurs.[50, 60, 64] The question that remains for consideration is how to define the range of activities that research guidelines should cover.

A particular article in the literature summarises a meeting dealing with substance misuse that describes research principles similar to many other documents in the literature. It also raises issues surrounding the funding process, including the inadequate funding of the research consultation phase, the perceived bias towards funding only pure science research and the perception that program evaluation is a threat to program funding.[22] An article from researchers at the Menzies School in Darwin also raises the issues of Aboriginal control of research financing, and funding for Aboriginal ethics committees.[33] The issue that needs further consideration is how to align research policy and funding allocation processes with the desired intent of ethics guidelines. Further, how do we ensure there is sufficient capacity to enable the development of ethics monitoring structures that will guarantee effective Aboriginal participation in these processes.

Conclusion

• A majority of the literature reinforces the concerns reflected in the Interim Guidelines. Issues raised include the importance of consultation, involvement, consent, and appropriate dissemination. There are also a number of issues in the literature, summarised here, that could be considered in the redevelopment of the Interim Guidelines. These include:

• Uncertainty about the scope of the existing guidelines and the extent to which they were intended to cover some forms of epidemiological research (such as analysis of existing administrative datasets or program evaluations).

• Whether consideration should be given to principles that advocate the right of inclusion of Aboriginal and Torres Strait Islander people in mainstream research (as is advocated in the NIH Guidelines).

• How the principles of benefit (which incorporates concepts such as the relevance of the research subject, the need for new knowledge and the usefulness of any intervention) can be incorporated in guidelines given the apparent complexity of application.

• How key principles that are well supported can be applied given some of the difficulties inherent in deciding how a community is defined and who represents that particular community.

• What processes and models provide the best examples for dealing with issues surrounding decision making about publication of results.

- Several issues not included in the Interim Guidelines that should be considered for inclusion, for example, compliance and monitoring after ethical approval has been given.

- The Interim Guidelines not anticipating in its recommendations the increasingly important role of Aboriginal and Torres Strait Islander researchers, and of the development of collaborative research models.

Finally, it is also important to consider how to support the implementation of revised guidelines for Aboriginal and Torres Strait Islander health research. What capacity is needed? Is it important to develop the capacity of AHEC sponsored ethics committees to give proper consideration of these issues? How does is the funding of research through the NHMRC best aligned in order to support the uptake of these guidelines? Finally, consideration needs to be given to other mechanisms to support the compliance with any revised guidelines.

ACKNOWLEDGEMENTS

ABBREVIATIONS

AHEC	Australian Health Ethics Committee (Principal Committee, NHMRC)
NH&MRC	National health and Medical Research Council
HGP	Human Genome Project
HGDP	Human Genome Diversity Project
RPB	Rights to the benefits of reserach
IPR	Intellectual property rights

APPENDIX A

GUIDELINES ON ETHICAL MATTERS IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

Approved by the 11th Session
of the National and Medical Council,
Brisbane, June 1991

NATIONAL HEALTH
AND MEDICAL RESEARCH COUNCIL

NEW DEVELOPMENTS

In several states, Institutional Ethics Committees (IEC) have been established within Aboriginal and Torres Strait Islander controlled organisations. These committees can decide on ethical approval of research proposals initiated by workers within the Aboriginal and Torres Strait Islander controlled organisations or on proposals from institutions that do not have an IEC. These committees can also be invited to advise on, and facilitate deliberations on ethical matters for research proposals on Aboriginal and Torres Strait Islander communities and groups which have been initiated by workers from other institutions.

FORMAT

The guidelines are presented under the following headings:

- Consultation

- Community Involvement

- Ownership and Publication of Data

GUIDELINES CONCERNING ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

In assessing a research proposal involving study of Aboriginal and Torres Strait Islander individuals or communities, an Institutional Ethics Committee (ICE), in addition to assessing whether the proposal conforms to the NH&MRC statement of Human Experimentation and Supplementary Notes, shall satisfy itself that:

CONSULTATION

1. In the preparation of the research proposal, the researcher has sought advice not only from state, Territory and Federal Aboriginal and Torres Strait Islander Health agencies, but also from local community health services and agencies.

2. The Aboriginal and Torres Strait Islander community, or appropriate community controlled agency able to represent the Aboriginal and Torres Strait Islander group which is the focus or context of research, has indicated that the research being proposed will be potentially useful to the community in particular or Aboriginal and Torres Strait Islanders in general, and will be conducted in a way that is sensitive to the cultural and political situation of that community.

3. The researcher has obtained written documentation of consent from the communities in which it is proposed to conduct research and where this has not been possible, the reasons should be documented.

In such circumstances, informed consent should be shown to have involved:

(a) of information in a form accessible to community members and able to be readily understood by them. This information should have included details of the collection and analysis of data, and the drafting and publication of reports. It should also list any potential costs to the community as well as potential costs to the community as well as potential benefits;

(b) face-to-face discussions with community groups and individuals concerned wherever possible and where this has not been possible, the reasons should be documented;

(c) the allowance of sufficient time for the community and the individuals concerned to assimilate and respond to the information offered;

(d) demonstration of a process for obtaining free consent from individuals as well as written evidence of consent by the community-at-large;

(e) provision of information to participants that consent may be withdrawn at any time.

COMMUNITY DEVELOPMENT

4. Members of the Aboriginal and Torres Strait Islander community being studied will be offered the opportunity to assist in the research and will be paid for the assistance, and the funds to support that assistance are included in the research budget proposal. Specifically, Aboriginal and Torres Strait Islander women, as advised by the community, will be involved when research deals with women's or children's health issues; and the specific cultural and social needs of Aboriginal and Torres Strait Islander men will be similarly recognised.

5. The researcher has accounted for any resources which may be made use of in the conduct of the research, has costed these in the research proposal, and has demonstrated a process for reimbursing the community and/or individuals for any such costs.

6. The researcher recognises the right of the community to request further information about aspects of ongoing research, and accepts that changes in research protocols, procedures of methodologies will require further negotiations with the community and consent for that change by the community or an agency nominated by the community. The IEC must also be notified and be given the opportunity to approve changes to the research protocol.

7. The researchers and IECs must observe the requirements for surveillance of research set down in Supplementary Note 1 of the NH&MRC Statement on Human Experimentation and Supplementary Notes, as published from time to time.

OWNERSHIP AND PUBLICATION OF DATA

If there is any reason to expect that there may be a misunderstanding between researchers and Aboriginal and Torres Strait Islanders research subjects over the conduct of research, the ownership of raw data or the rights to publication of research findings, these matters must be discussed and negotiated and preferably agreed upon by both parties before the research begins.

8   Following completion of data collection and analysis, and before any publication or presentation of this data, a summary of the findings will be reported to the community as a whole. Details of findings relevant to their health or well-being will be confidentially conveyed to individuals who participated together with counselling as appropriate.

9   If a researcher wishes to use the information or blood or tissue samples gathered in the research for any purpose other than for which consent was obtained, further permission must be sought from the community.

10 The return of identifiable raw data, its destruction, or secure storage on completion of the research, should be negotiated with the community, or its nominated representative or agency, prior to the commencement of the research.

11 Results will not be published in a form which permits identification of individual subjects. Results which identify a particular Aboriginal or Torres Strait Islander community will not be published without permission from that community or from a community-controlled agency able to represent that community.

12 Pictorial material will be made only with the consent of the local community and will be handed in accord with their wishes.

13 Proper acknowledgment will be given to individuals and communities who took part in the research.

14 Whenever practicable, Aboriginal or Torres Strait Islander assistants who contributed to the research will be involved in the preparation of publications and will be acknowledged. Publication acknowledgment shall be in accordance with the NH&MRC Statement on Scientific Practice.

Should the media solicit comments from researchers, once their work is in the public arena, researchers should first seek the consent of the community concerned. Comments to the media should be sensitive and professional and should focus on the research issues under consideration.

ANNOTATED BIBLIOGRAPHY

1 The Tri-Council initiative to revise the guidelines for research involving humans: issues being considered. Canada: The Medical Research Council, The Canadian Social Sciences and Humanities Research Council. 1994

This is an issues document sent for comment on the revision of the Tri-Council guidelines for research involving humans. The document is arranged into three components: the context, areas of research and the issues of process. Component one covers the research context, research ethics, including autonomy, beneficence and justice, and the application of ethics on research. Component two addresses collectivities, population studies, clinical research, behavioural research, biomedical research, research involving those who cannot consent, genetic research, and industry-driven research. The third component covers accountability, research ethics boards, monitoring, the processing of private sector research, and educational issues.

2 Schapper HP. Research and evaluation. In: Schapper HP, ed. *Aboriginal advancement to integration*. Canberra: Australian National University Press, 1970:121–31.

This paper was published in 1970 and outlines what is needed for successful Aboriginal research to achieve Aboriginal integration by the year 2000. It identifies the elements of successful research to be multi-disciplinary, a training and demonstration project to guide planners and administrators, orientated towards integration and for the research to be applied and action and change orientated. The research should also have the four elements of identification of needs, standard setting, logistics, and evaluation.

3 Research: some general observations. *Research Newsletter* 1975(Issue No.1):15–18.

This commentary looks at several issues including the need for increased Aboriginal involvement in all aspects of research—from planning to the conduct, and the importance, of dissemination and feedback of research.

4 Aboriginal health research. *Research Newsletter* 1975(Issue No.2):18–20.

This article outlines the role of the Aboriginal Affairs Department and the Department of Health in Aboriginal research. The latter's role is described through looking at the work of the NH&MRC, in particular the Medical Research in Aborigine's sub-committee and the criteria it utilises to evaluate research projects.

5 Davidson GR. Feedback of psychological information to Aboriginal communities; a return visit to Bamyili, *N.T. Newsletter* 1976(New Series No. 5):31–3.

This paper outlines a researcher's experience of feeding back findings from a psychological project conducted in an Aboriginal community in the Northern Territory. It identifies the importance of feedback in the research process to ensure the continuing participation of Aboriginal communities in future research. The article cites a black US group's guidelines on the suitability of who should be admitted into a community to carry out research.

6 Rowley CD. Some guidelines for research. *Research Newsletter* 1976(3):20–36.

This paper outlines the author's personal views on Aboriginal research and the role of the Council for Aboriginal Affairs established in 1968 to advise the Aboriginal Affairs Department after the 1967 referendum. The author provides comment on the department's policy, which included the importance of action research, increasing Aboriginal employment and involvement, and community. There are also comments on the department's research program, including the issues of community-identified research projects, the use of local Aboriginal community members trained in survey techniques to survey problems highlighted by the community, and the role of the department in harnessing this effort. The author looks at various research areas covering descriptive anthropology, administration of entrapped communities, historical studies, educational research and material production, major economic studies, special urban surveys and developmental studies, and administration. The relationship the department should have with other research bodies is also examined.

7 Willmot E. Koori and Mikloo—partners in research. *Newsletter* 1977
      (Issue No.5):29–30.

This article looks at the development of partnerships between Indigenous and non-Indigenous researchers and the difficulties encountered. It identifies two practical examples of problems that an Indigenous researcher will face: determining the degree of trust and personal involvement the non-Indigenous researcher should be encouraged or permitted to use; and the conflicting roles of the Indigenous researcher. The article also evaluates the contribution of the non-Indigenous researcher to the partnership, in terms of Aboriginal affairs, and judges and understands the value and meaning of the product of research done in this way.

8 Briscoe G. What do Aboriginals want from research? *Research Newsletter*
      1978(Issue No.6):29–30.

This article is based on an intra-departmental talk, given by the author in 1978 at the Department of Aboriginal Affairs, which outlines the importance of greater involvement of Aboriginal people in research. The author states that in the past research has mainly been conducted by universities and governments on scientific issues and that there has been little dissemination and feedback of results. The author then provides examples of two research projects that had good levels of Aboriginal involvement and several examples of those that did not involve Aboriginal people. The article finishes by strongly advocating research as a tool or a service that Aboriginal people should strive to utilise.

9 Brady M. Some problems of method and theory in Aboriginal research.
      In: Cashman P, ed. *Research and the delivery of legal services*. Sydney: Law
      Foundation of New South Wales; 1981:281–5.

This chapter examines issues with methodology and theory in Aboriginal research. The author claims that communities have begun to tighten their attitudes towards research in response to issues such as lack of community feedback and benefit (including practical results) from research.

10 MacLennan R, Pope JH. Models for health research in the Northern Territory. *Transactions of the Menzies Foundation* 1982;4:93–100.

This paper describes the purpose of setting up a research institute in the Northern Territory. It looks at the health of the NT population, the history of medical research in Queensland, the work of the Queensland Institute of Medical Research, the development of the International Centres for Medical Research and Training, and the Division of Medical Research in the Territory of Papua and New Guinea.

11 Liddle J. Research guidelines. Central Australian Aboriginal Congress Inc., 1983.

Presented at the Australian Anthropologist Organisation Conference in 1982, the content of this paper includes the research guidelines from the Australian Institute for Aboriginal Studies, which cover the areas of Aboriginal involvement and control, cultural appropriateness, beneficence, and publication and dissemination. These guidelines are based on several premises: that there has been a lack of involvement in past research, inadequate non-Aboriginal solutions to Aboriginal problems, a failure to examine the political, socio-economic and cultural interface between Aboriginal and non-Aboriginal society, the alienation of Aboriginal people due to the application of Westernised thinking on Aboriginal issues, the need for Aboriginal designed and conducted research, a past history of voyeuristic research, and the amount of research conducted on issues other than Aboriginal perceived needs. The paper then describes the differences between those who have experience in Aboriginal health and cultural issues compared to those who possess purely formal credentials. It also recognises the inadequate training given to anthropologists working in Aboriginal culture.

12 *Ethical principles for the conduct of research in the North*. Ottawa, Canada: Association of Canadian Universities for Northern studies, 1988.

These are the ethical principles for the conduct of research in the Northern regions of Canada. The document provides definitions of research and community. The word 'community' is not restricted to the area of settlement but includes the surrounding areas of land that supply resources to the people inhabiting these. The document also states that the application of these principles depends on two undertakings: a continuing assessment of the principles, and the development of codes of practice to incorporate these principles.

13 Brady M. The problem with 'problematising research'. *Australian Aboriginal Studies* 1990(1):18–20.

This article outlines the problematising research method used to address the issues of increasing adolescent crime and substance abuse in Yalata. This method was used to try and get community dialogue on issues that affected communities but were not normally raised. However, the method failed due to several reasons: Yalata was not a homogenous community, there were differing views of what constituted 'problem behaviour', and people avoided any confrontation with problems that were identified.

14 NH&MRC, *Interim guidelines on ethical matters in Aboriginal and Torres Strait Islander health research*. Canberra: National Health and Medical Research Council; June 1991.

These are the national guidelines that currently cover health research in Aboriginal and Torres Strait Islander communities, and were endorsed by the NH&MRC in 1991 after three national meetings from 1987 onwards.

15 Collins L, Poulson L. Aboriginal research an Aboriginal perspective. *Aboriginal and Islander Health Worker Journal* 1991;15(2):6.

A personal perspective on Aboriginal research outlining the importance of feedback and the benefits of the research process. It also acknowledges the importance of trust building and the development of cross-cultural relationships.

16 Hunter E. Editorial. *Aboriginal and Islander Health Worker Journal* 1991;15(2):4–5.

An editorial looking at the history of research in the Aboriginal population and the development of the guidelines. It raises the issue of true participation and partnership as a way of dealing with problems arising from research, and suggests that planning is not all that is needed to answer the issues of Aboriginal research. Responsible, reflective attitudes and ethical considerations are also vital to the process.

17 Johnstone M-J. Improving the ethics and cultural suitability of Aboriginal health research. *Aboriginal and Islander Health Worker Journal* 1991;15(2):10–13.

This paper, written prior to the Interim Guidelines, outlines the need for the development of reliable guidelines designed in consultation with Aboriginal people. It recognises, however, that the reliability of guidelines depends on who writes them, whose interests they are designed to protect and what, if any, compliance mechanisms exist. The paper also examines the importance of the research ethics committee and Aboriginal involvement.

18 Ross S, Katona M, Currie B, Capon T, Mathews J. Aboriginal people, health research and ethical issues [Abstract]. *Australian Journal of Public Health* 1991;15:335.

This abstract looks at the development of a separate Aboriginal ethics sub-committee in Darwin in response to concerns that there was no time to address Aboriginal concerns adequately during the main committee meetings. This sub-committee is described as being one step closer to ensuring true Aboriginal research control. Issues raised in the paper include community consultation, proposal relevance, consent procedure, cultural aspects, and information ownership.

19 International guidelines for ethical review of epidemiology studies. Geneva: Council for International Organizations of Medical Sciences, 1991.

These international guidelines put out by the Council for International Organizations of Medical Sciences cover the general ethical principles of respect for persons, beneficence, non-maleficence and justice, and ethical principles that apply to epidemiological studies. They also cover procedures in ethical review.

20 Wax ML. The ethics of research in American Indian communities. *American Indian Quarterly* 1991;14(4):431–56.

This article outlines a study that examines the different perspectives of all parties involved in researching American Indians. The study was conducted by interviewing parties involved in a sample of research projects carried out over the previous twenty years, and asking them to evaluate the ethical quality of these research projects and to identify ethical problems. The article describes how the biomedical model of research is deficient as it does not inquire about the goals, values or interests of the research subjects, or that these subjects are social beings with other responsibilities or obligations. The author writes how it became apparent during the study that the investigators and the Indians did not share common frameworks, for example, they had different community morals, ethics, vocabulary, and language.

21. Wyatt K. The rights of Aboriginal communities: the obligations of health researchers. *Aboriginal and Islander Health Worker Journal* 1991;15(2):7–8.

This article outlines the importance of principal community involvement, control and participation in all levels of research. It also identifies practical process steps to engage communities in research.

22. How do we as researchers, most of whom are non-Aboriginal, make research into substance abuse issues among Aboriginal people more effective? Conference Discussion Papers. 19 April 1991.

Several references are included in the summary of the meeting held in 1990 entitled 'How can we as researchers, most of whom are non-Aboriginal, make our research into substance misuse amongst Aboriginal people effective?' The main topics discussed at the workshop included funding, design and conduct of research into Aboriginal alcohol issues, the impact of research on policies, programs and the quality of Aboriginal life, and the communication and dissemination of research findings. Issues around research funding covered the funding process, the perceived ethical constraints of the NH&MRC guidelines, the perception that funding bodies favoured only 'pure science' research, the inadequacy of funding during the important consultation phase of an Aboriginal project, and the perception that program evaluations are threats to program funding. Design and conduct issues looked at the need for increased Aboriginal participation in the research process; the need to determine the motivation behind research; and the identification of the roles and responsibilities of the groups involved in research including the researchers, the subjects, the Aboriginal community, and the general public. The issue of communication and dissemination included appropriate feedback mechanisms and the ownership of data.

23 Biggins DR. Ethics of health research [letter]. *Australian Journal of Public Health* 1992;16(1):107–08.

This published letter looks at the emphasis given by the new Interim Guidelines on extensive consultation and community involvement. It then draws a parallel with the Trades and Labor Council's 'Draft Trade Union Guidelines on the Assessment of Occupational Health and Safety Research', which also examines increased involvement and control over research by communities.

24 Hunter E. Feedback: towards the effective and responsible dissemination of Aboriginal health research findings. *Aboriginal Health Information Bulletin* 1992;17:17–21.

This article describes the process used to disseminate the results of a survey conducted in the Kimberley region of Western Australia during 1988, 1989 and 1991. It outlines the importance of feedback as a fundamental research component and one that should be planned for at the outset of the project. The article also looks at the different levels of feedback conducted and reinforces its importance.

25 Kimberley Aboriginal Health Workers. The importance of Aboriginal research feedback: why and how it should be given back. *Aboriginal and Islander Health Worker Journal* 1992;16(2):4–6.

This article describes an evaluation of project feedback done in 1988 and 1989, with the initial feedback carried out at community and individual levels. In 1991, a questionnaire was given to 105 workers in Aboriginal health to determine their knowledge of this research. At the same time Aboriginal health workers attempted to contact original research participants to administer a similar questionnaire. The study found that Aboriginal people felt that getting feedback was important and that it should occur as soon as possible after the research.

26 Lake P. A decade of Aboriginal health research. *Aboriginal Health Information Bulletin* 1992(17):12–16.

This is a content analysis of studies published in the Aboriginal Health Information Bulletin between 1982–92. From this limited number of studies, the author claims that the major causes of morbidity and mortality have been under-researched, that there has been limited research conducted in urban areas, that no evaluation of health promotion programs has occurred, and few intervention studies have been conducted.

27 Maddocks I. Ethics in Aboriginal research: a model for minorities or for all? *Medical Journal of Australia* 1992;157:553–5.

This paper looks at the content and recommendations of the Interim Guidelines, the South Australian guidelines published in 1988, the Menzies School of Health Research guidelines, and the 1991 Western Australian draft guidelines. It groups them into the areas of consultation, scientific merit, community involvement, and ownership of data and publication, and discusses the possibility of them inhibiting research but also being applicable to other areas of research.

28 National Health and Medical Research Council interim guidelines on ethical matters in Aboriginal and Torres Strait Islander health research. *Aboriginal Health Information Bulletin* 1993(18):17–20.

This paper describes the history, the rationale and the content of the Interim Guidelines.

29 Principles and procedures for the conduct of research. Sydney: The Koori Centre, University of Sydney, 1993.

This document—the principles and procedures for the conduct of research from the Koori Centre at the University of Sydney—covers the areas of research, employment and development, publication and ownership, and financial principles.

30 Ethics in Aboriginal research. Adelaide: Aboriginal Research Institute; May 1993.

These guidelines are intended to assist researchers in implementing ethical practice in research with Aboriginal and Torres Strait Islander people. They have general principles, and principles covering contractual, sponsored and funded research, and supervised research within academic awards.

31 Freeman WL. Research in Rural Native communities. In: Bass MJ, Dunn EV, Norton PG, Stewart M, Tudiver F, eds. *Conducting research in the practice setting.* London: Sage publications; 1993:179–96.

This chapter outlines various types of studies and current issues in research with first nation peoples in North America including the American Indians, Canadian Indians, Alaska natives, Inuit, and Native Americans. The types of studies outlined are research into epidemiological primary health care, social science research and health service research. The issues identified include dealing with differences in culture and dominance, community control of research and publication, privacy and confidentially, recruitment of research subjects, co-investigators and staff from the community, time, subpoena of data, distributive justice of benefits, risks and workload, research methods, and social realities. The chapter concludes with the suggestion that these issues are not specific to first nation peoples.

32 Macaulay AC. University/Community collaboration in primary care research. In: Bass MJ, et al., eds. *Conducting research in the practice setting.* London: Sage Publications; 1993:152–63.

This chapter discusses the collaboration between universities and communities in conducting primary care research in North America. The author identifies the strengths and weaknesses of university and community, rules for collaboration, including guidelines for the university researcher and the community physician, and 'classic' problems in collaboration. These problems include a lack of knowledge, respect and understanding, and different research goals. The chapter is concluded with recommendations for successful collaboration and goals for the future.

33 Mathews J, Currie B. Ethics in Aboriginal research. *Medical Journal of Australia* 1993;158:508.

This letter, written in response to a paper describing the Interim Guidelines and ethical issues in research involving Aboriginal people, raises two issues not discussed in the guidelines: the exclusion of Indigenous financial control of research projects within their communities, and the lack of funding for Indigenous health research ethics committees to consult communities properly on research applications.

34 Flick B. The role of the Aboriginal ethics sub-committee of the Joint Institutional ethics committee of the Royal Darwin Hospital and Menzies School of Health Research. In: Stove K, ed. *Bioethics 1971–2001*; September 1994; Adelaide: Australian Bioethics Association; 1994:94–105.

This is a paper presented at the Australian Bioethics Association Third National Conference held in Adelaide in 1994. It looks at the need for Indigenous involvement in research ethics due to a history of unethical research involving Indigenous people. Examples given include the collection and removal from the country of Indigenous body parts and the current 'Human Genome Project'—known in the Indigenous population as the 'Vampire Project'. The author describes how control in preventing further unethical research may be achieved by involving Indigenous people in the ethics process. There is then an account of the author's involvement in the Aboriginal Ethics Sub-committee in Darwin.

35 Freeman WL. Making research consent forms informative and understandable: the experience of the Indian health service. *Cambridge Quarterly of Healthcare Ethics* 1994;3:510-21.

This paper examines the use of informed consent from the Indian Health Service's (IHS) perspective, including the capacity to prohibit and regulate research and the requirement of community consent as well as individual consent. These issues have led the IHS to commit to self-determination and community involvement in research, with the goal of increased research benefit. The paper then examines the levels of literacy in the US population and looks at the model volunteer consent forms that have been developed to allow informed consent in people with limited literacy skills. It has several interesting tables which look at the levels of the researcher–community relationship, the factors that require increased literacy skills to understand the material, the characteristics of the IHS model volunteer consent form, and a table that examines the application of the three ethical principles of respect for person, beneficence and justice, and the parallel between individuals and communities.

36 Macaulay AC. Ethics of research in Native communities. *Canadian Family Physician* 1994;40:1888–90.

This editorial viewpoint explores the issues involved in researching native (refers to Indigenous inhabitants of Canada) communities. After a brief discussion of past historically bad research, the author looks at the changing attitudes towards co-operative research involving communities at all stages. This is illustrated with

examples of good research. The editorial also looks at guidelines that have been developed to improve the way research is conducted, with a focus on co-operation, consultation and involvement, and highlights the ownership and publication of data as a tricky issue in partnerships.

37 Negotiating research relationships in the north. In: *International workshop on ethical issues in health research among Circumpolar Indigenous populations* June 2–3, 1995; Inuvik, Northwest Territories, Canada.

This background paper was prepared for a workshop to promote discussion of the issues surrounding the negotiation of research within the Canadian Northern regions. The discussion covers three sections: the implications of approaching research as a negotiated relationship, the framework and subject matter of such negotiations and the process for entering negotiations. The issues of who sets the research agenda and who conducts the research are explored, as are the principles for research negotiation, which include consultation and consent. The paper also looks at possible problem areas including what form and who to negotiate with, the criteria for inclusion, community and individual rights in informed consent, confidentiality, data control and ownership, communication, and the involvement of Northern people.

38 Principles and elements on Northern scientific research. In: *International workshop on ethical issues in health research among circumpolar Indigenous populations*; June 2–3, 1995; Inuvik, Northwest Territories, Canada.

These principles and elements include the importance of Inuit involvement in research, the potential value of scientific research and information as a powerful tool, the need to acknowledge scientific opinion and Inuit knowledge and experience, the importance of codes of conduct for scientific research, and the need for financial support for Northern research and related institutions.

39 Achanfuo-Yeboah DJ. Problems of Indigenous health research: issues for Australia. *Australian Journal of Social Research* 1995;1(1):3–19.

This paper describes the poor health of the Australian Indigenous population and identifies issues in Indigenous health research. The author claims that to reduce the health disparity there needs to be adequate, valid and reliable research into Indigenous health. There are several issues surrounding this area, which can be categorised into data, methodology and funding. Data issues identified include its poor quality, inaccuracy, incompleteness, poor timeliness, the fact that most data remains unpublished and unused, and issues of Indigenous identification. Methodological issues include the inappropriate use of time series analysis, the difficulties of using birthweight as a measure of health, the inappropriateness of comparing Indigenous to non-Indigenous health, the assumption that Indigenous people are homogenous, the imbalance between urban, rural and remote research, and the overemphasis in descriptive data. In response to these issues the author suggests that there be a refocus on quantitative and qualitative methodology. Issues of confidentiality and privacy are also discussed as is the need for an increasing co-operative and consultative involvement in research by Indigenous people.

40 Asch M. A report on guidelines respecting research with collectivities made to the Tri-Council Working Group. In: *International workshop on ethical issues in health research among Circumpolar Indigenous populations*; June 2-3, 1995; Inuvik, Northwest Territories, Canada.

This paper is a report to the Tri–Council Working Group in Canada looking at research guidelines that include references to research in collectivities. These guidelines include the Royal Commission on Aboriginal Peoples' ethical guidelines for research, the Medical Research Council's ethical guidelines for research, the Social Sciences and Humanities Research Council's ethical guidelines for research with human subjects, the Social Sciences and Humanities Research Council's document on the treatment of the sexes in research, the report of the consultative group on ethics from the Canada Council, and the Council for International Organizations of Medical Sciences international ethical guidelines for biomedical research involving human subjects.

41 Bourke EA. Dilemmas of integrity and knowledge: protocol in Aboriginal research. In: Blue IA, Buckley P, Harvey DH, eds. *Serving rural and remote Australia through health information and research*. Whyalla, 1995:47–56.

This paper, presented at the First National Rural Health Research Workshop held from 13–15 July 1995, examines the development and content of protocols, principles, procedures, and guidelines. These include those from the National Aboriginal Education Committee, the Australian Anthropological Society, the University of Sydney Koori Centre, the Australian Institute for Aboriginal and Torres Strait Islander Studies, and the University of SA Aboriginal Research Institute.

42 Campbell AV. Ethics in a bicultural context. *Bioethics* 1995; 9(2):149–54.

This paper looks at the bicultural context of ethics in New Zealand. The paper identifies the Treaty of Waitangi in 1840 and the Cartwright inquiry into alleged cervical cancer research misconduct in 1987 as two formative events that have shaped research ethics in present-day New Zealand. The inquiry resulted in a change in the make-up of ethical review committees and, with a shift to biculturalism, an increased involvement by the Maori membership. The paper also looks at reproductive technologies as a current ethical issue.

43 Gilson M. Culturally appropriate strategies for evaluation. In: *Australasian evaluation society international conference*. Sydney: Injara Associates, 1995:485–9.

This is a paper presented at the Australasian Evaluation Society international conference held in Sydney, 26–29 September 1995. It describes the development of a culturally appropriate methodology used in evaluating the effectiveness of ATSIC programs in meeting the needs of Aboriginal and Torres Strait Islander women in 1994. The methodology used addresses the areas of cultural and community protocol, especially the effects of cultural protocol, community protocol and cultural barriers to communication and interaction.

44 Masuzumi B, Quirk S. A participatory research process for Dene/Me'tis communities: Exploring community-based research concerns for Aboriginal Northerners. In: *International workshop on ethical issues in health research among Circumpolar Indigenous populations*; June 2-3, 1995; Inuvik, Northwest Territories, Canada:1–16.

This paper describes the participatory research process and its use in Northern Canada. It outlines the important aspects and steps of this study design, which include describing the research process with a focus on informing the community, defining the issues, approaching the goals and objectives so as to ensure that partnerships are sustained, and analysing and presenting the findings. The paper also outlines a research agreement model to be used in this process.

45 Moisseff M. Davenport community profile 1993: a community report in fulfilment of an ethical position. *Australian Aboriginal Studies* 1995;(2).

This article, outlining a community profile, describes the research process and emphasises the importance of feedback.

46 Perkins JJ, Sanson-Fisher RW, Girgis A, Blunden S, Lunnay D. The development of a new methodology to assess perceived needs among Indigenous Australians. *Social Science and Medicine* 1995;41:267–75.

This paper outlines the development and implementation of a new methodology for assessing perceived needs among Aboriginal people. It shows the importance of the consultation process in engaging communities in developing new tools. The author also quotes Saggers and Gray, who point out that there has been enough research into morbidity and mortality of Aboriginal and Torres Strait Islander peoples—the research gap lies in the development of effective programs.

47 Savage N, Stuart J. Conducting medical research in an urban Aboriginal school. In: Robinson G, ed. *Aboriginal Health: social and cultural transitions*. Darwin: Northern Territory University Press, 1995:255–9.

Presented at the Aboriginal Health: Social and Cultural Transitions conference held in Darwin from 29–30 September 1995, this paper presents the experience of two researchers conducting clinical research in an urban Aboriginal school. The authors present the difficulties they encountered in relation to clinical research, the young age of the population, and research into the Aboriginal and Torres Strait Islander people.

48 Scott K, Receveur O. Ethics for working with communities of Indigenous peoples. *Canadian Journal of Physiology and Pharmacology* 1995;73:751–3.

This article looks at the development of Indigenous ethical guidelines in Canada due to past histories, and the imbalance between research and tangible benefits. The authors identify several professional codes of ethics and more specific guidelines to conduct research in Indigenous communities. They also identify the growing use of written agreements between researchers and communities, and the increasing need for negotiation and involvement of Aboriginal communities and committees in research.

49 Sibthorpe B, Humes G, Baas-Becking F. Public health research training among
Aboriginal health professionals—Why is it needed? In: Robinson G, ed.
Aboriginal health: Social and cultural transitions. Darwin: Northern Territory
University Press, 1995:267–70.

This paper describes the study conducted for the consultation phase of the Master of
Applied Epidemiology (Indigenous Health) course offered by the National Centre for
Epidemiology and Population Health at the Australian National University. The paper
outlines the findings of the study, which include the fact that there are very few
Aboriginal and Torres Strait Islander people with a tertiary degree working in the
health field, and even fewer being enrolled in higher postgraduate qualifications.

50 Watene-Haydon N, Keefe-Ormsby V, Reid P, Robson B. The issues of research by
Indigenous peoples. In: *Evaluation! Are you being served?*. Sydney:
Australasian Evaluation Society, 1995:490–6.

This is a paper presented at the Australasian Evaluation Society international
conference held in Sydney, 26–29 September 1995. It looks at the three frameworks
of evaluation research carried out in New Zealand—the theoretical framework, the
ethical framework and the practical framework. Within the theoretical framework the
processes of evaluation are usually set by the purchaser. Thus, there is a need to
develop appropriate cultural models of health and a danger that researchers are
perpetuating the colonialism of research. Within the ethical framework issues of trust
or voyeurism, ownership, autonomy and self-determination need to be discussed. The
practical framework includes the issues of starting points, process issues of
participating with Maori culture, and the presentation of findings. The paper also
provides a 'checklist' of issues to consider in evaluation including the purpose, the
audience, the accountability processes, and the level of community involvement.

51 Anderson I. Ethics and health research in Aboriginal communities. In: Daly J, ed.
Ethical intersections: health research, methods and researcher responsibility.
Sydney: Allen & Unwin, 1996:153–65.

This book chapter does two things. Firstly, it locates the discussion of ethical issues in
Aboriginal health research within the history of the transition of 'assimilationist
colonialism' to 'welfare colonialism'. It then expands on a number of dimensions of
the principle that ethical research should be of benefit. These include who and what is
researched; the use of research for social change; immediate benefits (e.g. in
employing Aboriginal people); directly consequent benefits (e.g. in gaining resources);
delayed benefits (e.g. in understanding a complex problem over time); and identifying
dangers and macro-structural implications. The chapter makes the point that several
of these dimensions are in fact contested, not obvious.

52 Glover A, Black-Gutman D. Reflections on cross-cultural research.
Australian Journal of Early Childhood 1996;21(3):1–5.

This is a two-part paper discussing the experiences of two researchers involved in
cross-cultural research. The first part of the paper outlines three research projects
carried out in a cross-cultural context, while the second part describes a project

conducted in Aboriginal communities by a non-Aboriginal researcher. The question of whether there is still a role for non-Aboriginal researchers in Aboriginal research is also raised. The authors believe there is if true partnerships are formed, the researchers' values do not oppose those of the community being researched, and the researchers adhere to ethical considerations during all stages of the research project, including project establishment, community involvement and choice of methodology. They should at all times be directed by the Interim Guidelines as well as local guidelines developed with the community.

53 Grootjans J, Spiers M. An approach to evaluating research developed by five Aboriginal health workers currently studying at Batchelor College. *Australian Journal of Adult and Community Education* 1996;36(3):253–8.

This article describes a workshop held in 1995 to develop a research evaluation model for use by Aboriginal health workers. The aim of the workshop was to prepare Aboriginal health workers as research cultural brokers. The structure of the workshop was based on an action research model. One of the workshop activities involved the participants developing a method for analysing research reports based on the Interim Guidelines. These guidelines provided a solid background for participants to develop their own process and to allow them to consider issues in research, such as consent and information ownership. The workshop enabled students to analyse both research methods, and enter into discussions with health professionals about these, and research reports with their own priorities, and to operate successfully within the non-Aboriginal research process.

54 McMasters A. Research from an Aboriginal health worker's perspective. *Australian and New Zealand Journal of Public Health* 1996;20:319–20.

This article is the personal account of an Aboriginal researcher's experience of working as a research assistant. It discusses the various problems identified while conducting research in an Aboriginal community, including communication barriers and the inappropriate use of Aboriginal researchers to participate meaningfully in research.

55 Norton IM, Manson SM. Research in American Indian and Alaska Native communities: navigating the cultural universe of values and process. *Journal of Consulting and Clinical Psychology* 1996;64(5):856–60.

This article looks at the National Institute of Health guidelines that require women and ethnic minority groups to be recruited into clinical research, and answers several questions for researchers unaware of some of the issues relating to researching in Indigenous populations in America. These include: who are American Indian and Alaska Native? What role do the Tribes play in research? Are there procedures for human participant protection at the local level? How can one stimulate individual and community participation? Are there cultural differences regarding confidentiality? What are the issues concerning the concept of benefit?

56 Wilson R. Conducting research in Indigenous communities. *Australian Communication Quarterly: Issues in Language, Speech and Hearing* 1996/97(Summer):19.

This is a summary of a paper given at the AASH/NZSTA conference in 1996 and outlines the draft guidelines of the Centre for Aboriginal and Torres Strait Islander Participation, Research and Development at James Cook University. These guidelines identify the process of consultation and emphasise that this exceeds the simple agreement to participate. The article also outlines the main points of the Interim Guidelines, and quotes Brady on the importance of transferring research skills and what consultation should consist of.

57 Angell M. The ethics of clinical research in the third world. *The New England Journal of Medicine* 1997;337(12):847–9.

This editorial examines the ethics of clinical research in the third world, with particular reference to a paper on the ethics of pharmaceutical trials utilising a placebo for the prevention of vertical transmission of HIV. It observes that there appears to be a retreat from the principles of the Nuremberg Code and the Declaration of Helsinki with reference to the third world. However, reasons given for this retreat include the differing local standard of care and variations in diseases and their treatments. The author alludes to the fact that research in third world countries is now becoming more attractive and better funded as they are often not regulated at the same level as elsewhere.

58 Donovan RJ, Spark R. Toward guidelines for survey research in remote Aboriginal communities. *Australian and New Zealand Journal of Public Health* 1997;21:89–94.

This article outlines the development of guidelines to facilitate communication between non-Indigenous interviewers and Indigenous interviewees, and to ensure that interviewing is done with maximum sensitivity to cultural differences and minimum discomfort to respondents. The authors assume that ethical issues in conducting research in Aboriginal communities must be adhered to. The guidelines represent their experiences in conducting research in remote Aboriginal communities.

59 Ellis R. Rural health research workshop. *Aboriginal and Islander Health Worker Journal* 1997;21(6):21–2.

This is a report on the rural health research workshop held in 1997, with particular reference to a paper given by Rose Ellis on behalf of Ian Anderson (OATSIHS). The paper outlined the need for action-oriented research, more urban research and a shift away from researcher-agenda setting. There was also a report given about a meeting held in April 1997 that identified that the Interim Guidelines should be the basis of research, research should be relevant and rigorous, research recommendations should be actioned and Aboriginal and Torres Strait Islander people should have ownership of the research.

60 Guerin B. He who pays the auditor, needs evaluation: the gap between audit, accountability and reality in Indigenous programs. In: *Australasian evaluation society international conference*. Adelaide, 1997:2–9.

This paper was presented at the Australasian Evaluation Society international conference in Adelaide, 1–3 October 1997. It is primarily a comment on the issue of how Commonwealth government programs are often not effective on the ground, with particular attention paid to the special audit of Federal Aboriginal programs.

61 Hecker R. Participatory action research as a strategy for empowering Aboriginal health workers. *Australian and New Zealand Journal of Public Health* 1997;21:784–8.

The author of this article outlines a participatory action research project conducted in the Pitjantjatjara lands in 1993. The purpose of this study was to allow Aboriginal health workers to conduct research and identify problems related with their work, to reflect on their own work ethics and to identify appropriate action on any problems encountered. The study was also carried out in such a way as to allow a process that would empower and transfer skills across to Aboriginal health workers and to allow proper consultation and ownership of Aboriginal research.

62 Kothari B. Rights to the benefits of research: compensating Indigenous peoples for their intellectual contribution. *Human Organization* 1997;56(2):127–37.

This paper proposes the idea of rights to the benefits of research (RBR) to complement the use of intellectual property rights (IPR) in research. RBR is suggested as the ethical and contractual practicable strategy for Indigenous peoples to have access to monetary and non-monetary benefits from research, access and control of the findings, acknowledgment as being the rightful owners of the knowledge, and the opportunity to participate in the research process. It is suggested that RBR is superior to the legal maze often accompanying IPR, allowing them to be used in research that is non-commercial. One of the points raised in the paper is that the RBR should not be used as an afterthought but rather built into the research process; this is reflected in several guidelines. The impact of using RBR and IPR in compensating Indigenous peoples is outlined with a case study of an ethno-botanical research project conducted in Ecuador.

63 Miller P, Rainow S. Commentary: don't forget the plumber. Research in remote Aboriginal communities. *Australian and New Zealand Journal of Public Health* 1997;21(1):96–7.

This commentary gives principles on how to proceed with research in the Anangu Pitjantjatjara lands. These include asking questions of whether the researcher will contribute to improving Aboriginal health, with an emphasis on meeting immediate needs while carrying out the research as methodology, and ensuring that the research is valid and scientific. There must also be an acknowledgment of the researcher's culture and how this will impact on the research, an understanding of concepts of time and how these vary, maintaining confidentiality and privacy, providing feedback, and never assuming the right of publication.

64 O' Donoghue L. The problems of accountability in Indigenous affairs: the need
for a view approach. In: *Australasian evaluation society international
conference*. Adelaide, 1997:1–8.

This paper was presented at the Australasian Evaluation Society international
conference held in Adelaide, 1–3 October 1997, and is a personal account by the
former head of ATSIC about the organisation's experience of government evaluation
and auditing.

65 Torzillo PJ. Correspondence. *Medical Journal of Australia* 1997;167:555–6.

This is a comment in response primarily to the media reporting of research on the
nutrition and brain size project conducted in the Northern Territory and published in
1997. The author affirms the importance of researchers considering the negative as
well as the positive consequences of publishing and on working closely with
Aboriginal ethics committees. However, he also raises several other issues for debate
suggesting that some principles become reduced to slogans that could, in fact, have
negative consequences. He questions, in particular, simplistic interpretations of the
concept of benefit, and the privilege given to qualitative over quantitative and 'action
based' research methodologies, regardless of the problem being researched and the
merits of the individual proposal. He also argues that removing barriers to
implementing programs based on existing scientific knowledge is more important
than research.

66 Varmus H, Satcher D. Ethical complexities of conducting research in developing
countries. *The New England Journal of Medicine* 1997; 337(14):1003–05.

This paper is a response to criticisms of the Center for Disease Control and
Prevention and the National Institute of Health for their involvement in research in
the third world, particularly in HIV pharmaceutical trials. The authors, who represent
both organisations, acknowledge a past history of poor ethical research, but state that
the research in these countries is conducted with participation and according to
accepted bioethical principles and guidelines.

67 *Guidelines for the provision of psychological services for and the conduct of
psychological research with Aboriginal and Torres Strait Islander people of
Australia*. Carlton, Victoria: The Australian Psychological Society Ltd; 1998.

This document is a section of the Australian Psychological Society's (APS) ethical
guidelines. This section was specifically developed because the APS recognised that
Aboriginal and Torres Strait Islander people occupy a special place in Australian
society. The guidelines are for those involved with Aboriginal people as participant
subjects in research but they also cover the provision of services, psychological testing,
other forms of assessment, provision of services in mental health, and education and
training in psychology. They do state, however, that the Interim Guidelines and other
relevant guidelines should be followed.

68 *New South Wales Aboriginal health: information guidelines.* Sydney: New South
         Wales Department of Health, The New South Wales Aboriginal Health
         Resource Cooperative Limited, August 1998. Report No.: (AHB) 980128.

The NSW Aboriginal Health: Information Guidelines have been conceived to 'ensure
consistency and good practice in the management of health and health related
information about Aboriginal people in NSW'. These guidelines, which are seen as
supplementing national and state policies, protocols and guidelines, cover the
following areas: collection, storage, security, access, release, usage, reporting of
information, confidentiality, and privacy. They use eleven guiding principles which
encourage partnership agreements, and cover information collection, health-related
information analysis, interpretation and reporting, privacy and confidentiality,
consent, diversifying information needs, value for money versus the need for research,
minimising data collection and maximising utilisation of existing data, and the regular
review of any collection.

69 The National Aboriginal Community Controlled Health Organisation, *Policy
         submission, NH&MRC strategic review*, May 1998.

These are two submission documents from the National Aboriginal Community
Controlled Health Organisation. The first, to the Health and Medical Research
Strategic Review in 1998, emphasises that Aboriginal research should be on
improving health outcomes, public health importance, interventional research,
research that identifies gaps in knowledge and will assist in evidence-based decisions,
areas of primary health care, and not allowing commercial interests to be the driving
force. The second is a submission to the Australian Health Ethics Committee
regarding the NH&MRC guidelines for the protection of privacy in the conduct of
medical research. It highlights the need for the inclusion of the unique requirements
of the Aboriginal and Torres Strait Islander population in relation to 'persistent
adverse' effects of research even in the presence of the NH&MRC guidelines. The
example given to illustrate this is the suspicions held by the Indigenous community
towards the Australian Childhood Immunisation Register. The paper argues that there
is no legislation requiring research guidelines to be adhered to, with the only penalty
NH&MRC funding withdrawal. It also describes the background to the privacy
guidelines, and provides a list for institutional ethics committees to follow to
determine if a research project requires special Aboriginal and Torres Strait Islander
considerations.

70 Atkinson W. Historical overview of Aborigines' experience. In: Ford N, ed.
         Aboriginal health: the ethical challenges. Fitzroy, Victoria: Caroline Chisholm
         Centre for Health Ethics, August 6, 1998:15–24.

This paper looks at the history of the Koori people in Victoria and the impact upon
them of government policies. The author outlines the Royal Commission into
Aboriginal Deaths in Custody Report (1992), the Gregory Report on Aboriginal
Unemployment (1994), the AIHW Report (199, the Bringing Them Home Report
(1997), the ABS Report on the Health and Welfare of Australia's Aboriginal and
Torres Strait Islander People (1997), the Indicators of Health Status for Aboriginal
People: NSW (1998), and the Council for Aboriginal Reconciliation Report (1995) as

the main documents to consider when looking at the historical effects of settlement. These illustrate the rates of imprisonment and deaths in custody, of unemployment, of health and wellbeing, and of land justice.

71 Australian National Council on AIDS and Related Diseases. *Submission to the Health and Medical Research Strategic Review*,1998.

This paper, by the Australian National Council on AIDS and related diseases submitted to the Health and Medical research strategic review in 1998, describes the organisation's research and funding structure, the key components of the HIV/AIDS research model used and the issues that need addressing. The research model components include a balance between investigator-driven and directed research, the strong link between research findings and appropriate programs, the use of multi-disciplinary teams, the recognition of social science research, community consultation and partnerships, and Indigenous Australians as a priority. Issues raised include the promotion of social science and public health research, HIV/AIDS and emerging public health issues, research funding, and research workforce issues.

72 Chalmers D, Pettit P. Towards a consensual culture in the ethical review of research. *Medical Journal of Australia* 1998;169:79–82.

This paper examines the evolution of individual researchers developing a sense of consciousness, professional bodies developing codes of behaviour for members, and independent bodies—such as governments, universities and hospitals—establishing ethical review. It argues that the strongest driving force behind our system of ethical review is the danger of controversy.

73 Gambia Government/Medical Research Council Joint Ethical Committee. Ethical issues facing medical research in developing countries. *Lancet* 1998;351:286–7.

This paper is a response from the Gambian Government Medical Research Council Joint Ethical Committee to the various opinions published in journals on the ethics of research in third world countries. The response explains the background of health in sub-Saharan Africa and the necessity of finding local, relevant and affordable solutions to localised health issues. The response also reinforces the committee's legitimacy in being able to provide ethical review to research within their country.

74 Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annual Review Public Health* 1998;19:173–202.

This review of community-based research outlines its key principles, rationale and challenges. Key principles include recognising community as a unit, building on resources within, utilising partnerships in all research phases, and addressing health issues using positive and ecological perspectives. Challenges in conducting this type of research include those related to partnerships, such as trust, power distribution and questions of who represents the community, and how a community is defined.

75 James R. Workshop on information systems and control of information. In: Ford N, editor. *Aboriginal health : the ethical challenges*. Fitzroy, Victoria: Caroline Chisholm Centre for Health Ethics, August 6, 1998:78–85.

This paper reports on the issues raised during the drafting of a national Indigenous health information plan. The first issue identified is the inadequate recording of mortality, morbidity and Indigenous status due to gaps in data. The second issue involves the limitations in the collection of quality information, such as poor levels of identification of Indigenous people in existing collections, inconsistent use of classification standards and protocols, limited efforts towards data validation and quality control, a lack of guidelines or protocols concerning ownership, usage and confidentiality, scant attention to Indigenous information needs, a dearth of information management skills, unwillingness and few mechanisms for relevant information sharing, little evidence of an information culture, and the apparent poor appreciation of the value and power of information among communities and services. Some specific issues raised from the consultation on the draft recommendations from the workshop include the need for safeguards against the potential misuse of information, the need to support the collection and use of information at the local level and the need for accurate data collection.

76 Mahoney MC, Michalek AM. Cancer control research among American Indians and Alaska Natives: a paradigm for research needs in the next millennium. *American Indian Culture and Research Journal* 1998;22(1):155-69.

This article outlines a model for approaching cancer research among American Indian and Alaskan Natives. The authors selected elements from several plans and documented them as a 'call for action', including the need for accurate surveillance systems, professional education, research, evaluation, and an increase in culturally appropriate dissemination and feedback. Research must be action orientated, involve Indigenous people, and be ethically approved and consented to by communities.

77 Manderson L, Kelaher M, Williams G, Shannon C. The politics of community: negotiation and consultation in research on women's health. *Human Organization* 1998;57(2):222–9.

This article describes the consultation and recruitment process of the special cohorts of the Australian Longitudinal Study on Women's Health (Women's Health Australia). The special cohorts identified were Aboriginal and Torres Strait Islanders and those from non-English speaking backgrounds. The paper describes the first task of determining an appropriate methodological approach to address community needs and concerns, and looks at the issues raised including access, ownership and control of the research process, consultation strategies, and community character. The ethics and politics of community research section of the paper outlines a brief historical context to Indigenous research and a background to the Interim Guidelines. The article goes on to describe the importance and complexity of defining 'community', and to establish the appropriate mechanisms for consultation. Issues include the need to clarify what is a community, who are the community's gate-keepers and at what levels do they operate, and the complex structures and processes that exist. The argument is made that the issues which have been problematic in the Aboriginal and Torres Strait

Islander are less so in the non-English speaking communities. The article also describes two problems that occurred at the beginning of the project: the first was the announcement of the study by the government without the level of consultation that the Aboriginal and Torres Strait Islander communities sought; the second was the use of the acronym ATSI. Other issues raised in the article include: funding bodies often do not consult with communities; the usefulness of reference groups; and that time delays often occur due to the extensive consultation process required.

78 Mathews JD. The Menzies School of Health Research offers a new paradigm of cooperative research. *Medical Journal of Australia* 1998;169:625–9.

This article describes the interdisciplinary and cross-cultural collaborative research model that the Menzies School of Health Research developed to improve communication and trust between researchers, Aboriginal people and the wider community. The author argues that failure to apply existing knowledge is a bigger problem than the lack of knowledge itself. He suggests, therefore, that the questions that need to be asked include: How to ensure existing knowledge is taken up and acted upon by policy and decision makers? How to ensure that Aboriginal people have access to this knowledge? How to plan research that makes a difference by finding better ways of working with cross-cultural boundaries and improving access to knowledge and resources.

79 McKendrick JH. Ethics and Aboriginal health: psychological, social and cultural considerations. In: Ford N, editor. *Aboriginal health : the ethical challenges*; Fitzroy, Victoria: Caroline Chisholm Centre for Health Ethics, August 6, 1998:55-63.

This paper describes the Resource Unit for Indigenous Mental Health Education and Research, its development and its history, and includes a discussion of its methodology for mental health research in Aboriginal communities. It discusses the Aboriginal mental health issues reported in the Royal Commission into Aboriginal Deaths in Custody and the Bringing Them Home Reports; specific mental health and wellbeing problems; the services available for Aboriginal people; future developments with a focus on partnerships; and the role of non-Aboriginal professionals.

80 O'Neil JD, Reading JR, Leader A. Changing the relations of surveillance: the development of a discourse of resistance in Aboriginal epidemiology. *Human Organization* 1998;57(2):230–7.

This article looks at the danger of using epidemiological information to describe and shape population culture. The authors achieve this by examining the epidemiological discourse that has occurred in Canadian Aboriginal health. This includes the use of surveillance as it constructs a view of a community that reinforces unequal power relationships, and the type of study that is regarded as the property of organisations and communities, with ownership of this information seen as a component of self-government. Other issues raised include the need for high quality 'trustworthy' data and the importance of nurturing researchers and research relationships. Solutions to these issues suggest that researchers develop a critical consciousness and a collaborative approach to interpreting and disseminating results, and that written contracts and steering committees are used.

81 Atkinson D. Ethics in Aboriginal health research [editorial]. *New Doctor*
      1999(Summer):2.

This editorial stresses that the key question is whether guidelines are being adhered to
rather than whether the Interim Guidelines are overdue for revision. The author
suggests that there be a process of ethical guideline compliance, which should be
checked before research is published or presented.

82 Biggins DR. Research in Aboriginal health: priorities, ethics and philosophy.
      New Doctor 1999(Summer):28–30.

This article reflects on the proposed inclusion of 'collectivities' in the draft National
Statement on Ethical Conduct in Human Experimentation, which has been argued
not to give adequate specific response to the realities of Aboriginal and Torres Strait
Islander people's history and context. The article offers some philosophical
perspectives to help make conceptual sense of the need to include social context in
moral decisions.

83 Dodson M, Williamson R. Indigenous peoples and the morality of the Human
      Genome Diversity Project. *Journal of Medical Ethics* 1999;25:204–08.

This paper outlines the aims and objectives of the Human Genome Diversity Project,
its impact on the Indigenous people of Australia in light of their culture and
interactions with colonisation, their attitudes towards it, and the issues raised with
this type of project.

84 Eades SJ, Read AW, Bibbulung Gnarneep Team. The Bibbulung Gnarneep Project:
      practical implementation of guidelines on ethics in Indigenous health
      research. *Medical Journal of Australia* 1999;170:433–6.

This article describes the process that the Bibbulung Gnarneep team underwent in
developing a protocol to ensure ethical research conduct between Aboriginal and non-
Aboriginal people involved in the project. The underpinnings of this protocol were
human rights (Declaration of Human Rights, United Nations), ethical principles
(NH&MRC Guidelines) and ethical foundations (Declaration of Helsinki) to ensure
Indigenous control of health research conducted in Indigenous communities.

85 Hawkes M. *Research Ethics*. Darwin: CINCRM—NTU, 1999.

This ethics policy for the Centre for Indigenous Natural and Cultural Resource
Management—Northern Territory University covers the areas of research ethics,
research protocols, intellectual and cultural property, recruitment and professional
development, and the recognition of Indigenous scholars.

86 Jamrozik K, Kolybaba M. Are ethics committees retarding the improvement of
      health services in Australia? *Medical Journal of Australia* 1999;170:26–8.

Using a prostate cancer management review as a case study, this article looks at the
system of Institutional Ethics Committees (IEC) and how they appear to be impeding

research through the number requiring ethical clearance and the time this takes. The article looks specifically at the issue of retrospective studies and how it is important that IECs have a member with expertise in this area.

87 Kaufert J, Commanda L, Elias B, Grey R, KueYoung T, Masuzumi B. Evolving
     participation of Aboriginal communities in health research ethics review: the
     impact of the Inuvik workshop. *International Journal of Circumpolar Health*
     1999;58:134–44.

This report on the 'ethical issues in health research among circumpolar Indigenous peoples' emanates from a workshop held in 1995, and particularly focuses on involving communities in ethical research. Areas of discussion include frameworks on protection and balance of individual and community rights, definitions of 'community', representation within communities, equal research partnerships, consent methods (individual vs community), community confidentiality, and protection from research risks. There is also a discussion on the development of more participatory research. Several themes developed through the workshop, including ethical application at individual and community levels, informed consent—individual and community, ethical reviews based on risk and benefit assessment, and community participation in the research process.

88 Paul D, Atkinson D. Learning from the past or ignoring the lessons?
     New Doctor 1999(Summer):31–3.

This paper, associated with the editorial in the same issue of New Doctor (ref. 81 in this annotated bibliography), looks at non-compliance to the NH&MRC guidelines in published articles. The authors give examples of what they perceive as 'good and bad' research projects.

89 Tan-Torres Edejer T. North-South research partnerships: the ethics of carrying out
     research in developing countries. *British Medical Journal* 1999;319:438-431.

This paper outlines the transition of past colonial research to partnership building research between the North and South Americas. However, as the paper points out, collaborative partnerships are still often biased against poorer countries as is evidenced in clinical trials and research priority setting. The paper suggests principles that research partnerships should be guided by, and recommends that the three guideposts of 'think action, think local and think long term' are used when addressing ethical issues and inequities.

90 Weijer C. Protecting communities in research: philosophical and pragmatic
     challenges. *Cambridge Quarterly of Healthcare Ethics* 1999:501–13.

This paper addresses the issue of 'how to protect communities from research risks'. It outlines the North American ethical research framework document, the Belmont Report, which highlights a respect for persons, beneficence and justice. The author criticises this document because it focuses solely upon the individual and not the community, and suggests that respect for community be included as the fourth subject in the report. The paper also looks at various research guidelines in first

nations including Canada, the US and Australia, and considers the NH&MRC guidelines to be the most comprehensive of these. There is a description of the Canadian '1996 draft code of conduct for research involving humans', which was to be used for everyone including first nations people. It goes on to describe how this was abandoned but without lessons being learnt from the process. The paper also suggests that before guidelines of this nature be implemented there be an attempt made to provide a clear definition of community and ways to use this definition.

91 Weijer C, Goldsand G, Emanuel EJ. Protecting communities in research: current guidelines and limits of extrapolation. *Nature Genetics* 1999;23:275–80.

This article further articulates issues from the Belmont Report, guidelines and limitations of current regulations. It again states that there is too much emphasis on the individual and not enough on communities or family relations. The motivation for guidelines developed for Aboriginal populations are 1. Geographical isolation that possesses histories and culture distinct from the dominant culture; 2. Evolving political consciousness for self-determination; 3. Increasing concern that research may harm persons or values. The article displays several guidelines in a table then compares and contrasts them. For example, all guidelines mention partnerships or variations on that theme, and almost all recognise the need for communities to be involved in the development of protocol.

92 Benatar SR, Singer PA. A new look at international research ethics. *British Medical Journal* 2000;321:824–6.

This paper looks at ethics in the international setting and how 'the standard of care' for clinical trial subjects is ill defined.

93 Despoja NS. The Human Genome Project: how do we protect Australians? *Medical Journal of Australia* 2000;173:596–8.

This article looks at the Human Genome Project and its ethical impact on Australians, current protection and potential ethical issues.

94 Dodson M. Human genetics: control of research and sharing of benefits. *Australian Aboriginal Studies* 2000;1&2:56–64.

This paper looks at the Human Genome Diversity Project and the issues and threats to Indigenous people from this project, in particular the threat of reducing the complex Indigenous identity to genetic text. The author identifies a lack of specific laws regarding the collection and use of human genetic material, which could allow commercialisation at the expense of the human owner, and the need for protection with legal safeguards such as contracts and protocol statements to ensure benefits and protection flow. The paper also states that Indigenous ethics committees could be useful in protecting people from exploitation.

95 Todd AL, Frommer MS, Bailey S, Daniels JL. Collecting and using Aboriginal health information in New South Wales. *Australian and New Zealand Journal of Public Health* 2000;24:378–81.

This article looks at the development, implementation and content of the guidelines for the management of Aboriginal health information in New South Wales.

96 van Holst Pellekaan S. Genetic research: what does this mean for Indigenous Australian communities? *Australian Aboriginal Studies* 2000;1&2:65–75.

This paper outlines a genetics project mapping mitochondrial DNA to analyse the genetic make-up and origin of local language groups. The paper focuses on the process of consultation used and addresses the issues arising from consultation, sample collection, community involvement, ownership and publication of data, and feedback to the community. The author identifies difficulties encountered including issues of spirituality, time, insufficient involvement of people, and unrealistic expectations.

97 Hunter E. A brief historical background to health research in Indigenous communities. *Aboriginal and Islander Health Worker Journal* 2001;25(1):6–8.

This article provides a historical background to health research in Indigenous communities, including an examination of the change from past research that had a poor reputation to the more community health controlled research of the present. The paper identifies chronologically the events that shaped this process and explores the changes by looking at research feedback.

98 Minniecon D. Thoughts at the beginning of a career in Indigenous health. *Aboriginal and Islander Health Worker Journal* 2001;25(1):16–18.

This personal reflection of the author's experience of working in Aboriginal research suggests the importance of providing opportunities for Aboriginal people to be involved in research and of mentoring them through the process. It also recommends that universities attempting to increase the number of Aboriginal people undertaking postgraduate study must acknowledge differing worldviews and employ more Aboriginal people in mentoring and student support roles. The author emphasises that Aboriginal community research should meet community protocol, educate community members on the research and ensure Aboriginal people are team members.

99 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):19–24.

This article discusses the background and development of the Cooperative Research Centre in Aboriginal and Tropical Health based in Darwin. It explains the community consultation that led to the project and the findings from this consultation. The balance of the article explores the lack of Indigenous research capacity, both in terms of resourcing for Aboriginal controlled organisations and the

educational disadvantage of Aboriginal and Torres Strait Islander people in general. This provides background for one of the centre's key programs, Indigenous Education and Health.

100 NH&MRC, *Criteria for health and medical research of Indigenous Australians.* Attachment to instructions to applicants for NH&MRC project grants. Canberra: National Health and Medical Research Council, 2001.

These are the criteria applicants had to address in the NH&MRC 2001 project grant funding round. They cover the areas of sustainability, transferability and community participation.

101 Backhouse L. Gate keeping of research in Aboriginal communities. *Aboriginal and Islander Health Worker Journal* 1999;23(5):20–5.

This paper addresses the issue of gate-keeping in Aboriginal research. It outlines the traditional role of funding bodies and researchers as gate-keepers of research in Aboriginal communities, and the responsive emergence of the Interim Guidelines and other guidelines and writings by 'enlightened researchers'. The author identifies the use of participatory research as a method that positions the gate-keeping role to the communities involved. The paper also outlines Arnstein's ladder, which describes the eight levels of community participation and what preparation the community should conduct to determine the level they wish to participate on. It goes on to identify the need to develop partnerships in research until the community has gained their own skills base to conduct research themselves. Also examined are the rights of the community, the researcher and the funding bodies in the developed partnership, and the various models of partnership that have been developed. These include the development of the University of Adelaide Aboriginal Research Centre and the proposed guidelines of community participation by Wyatt.