

***THE DEVELOPMENT OF THE NATIONAL
HEALTH AND MEDICAL RESEARCH
COUNCIL GUIDELINES ON ETHICAL
MATTERS IN ABORIGINAL AND TORRES
STRAIT ISLANDER HEALTH RESEARCH:
A BRIEF DOCUMENTARY AND
ORAL HISTORY***

Kim Humphery

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of the National Health and Medical Research Council and funded
by the Office for Aboriginal and Torres Strait Islander Health,
Australian Department of Health and Ageing***

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VicHealth Koori Health Research and Community Development Unit

Discussion Paper Series

The VicHealth Koori Health Research and Community Development Unit (VKHR&CDU) was launched in June 1999 and has been developed in partnership with the Victorian Aboriginal 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 VKHR&CDU 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 VKHR&CDU.

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Contents

THE DEVELOPMENT OF THE NATIONAL HEALTH AND
MEDICAL RESEARCH COUNCIL GUIDELINES ON
ETHICAL MATTERS IN ABORIGINAL AND TORRES
STRAIT ISLANDER HEALTH RESEARCH:

A BRIEF DOCUMENTARY AND ORAL HISTORY

One: *Introduction*

Two: *From the Documents*

Three: *From the Transcripts*

Four: *Conclusion*

Acknowledgments

References

The Development of the National Health and Medical Research Council Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research: A Brief Documentary and Oral History

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Summary

From 1986 to 1991 the National Health and Medical Research Council (NHMRC) in close consultation with Indigenous organisations and representatives embarked on a process of formulating ethical guidelines for the conduct of Aboriginal and Torres Strait Islander health research. These guidelines were drafted under the direction of the National Aboriginal and Islander Health Organisation, reviewed by a NHMRC appointed Aboriginal Working Party, and eventually published—though not formally ratified—as the interim *NHMRC Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*, 1991.

This Discussion Paper reports on this lengthy and sometimes difficult process, offering both a documentary and oral history of the events and actions that led to the release of the 1991 interim guidelines. The importance of this historical account lies not only in recording the past, but in contributing as well to a contemporary process of reviewing and of re-writing the guidelines themselves. This research was specifically commissioned by the Australian Health Ethics Committee (of the NHMRC) and funded through the Office for Aboriginal and Torres Strait Islander Health (of the Australian Department of Health and Ageing) with a view to informing this revision process.

Nevertheless, this paper stands as a broadly useful and important historical account of the manner in which the processes and politics of ‘Western’ research have been debated and confronted within the context Indigenous/non-Indigenous relations in Australia. Thus, it is of relevance to all those involved in cross-cultural research practice and to those beyond the health field.

One Introduction

In Australia, the National Health and Medical Research Council (NHMRC) has a key, statutory responsibility to oversee the ethical conduct of health and medical research. The NHMRC performs this function through one of its principal committees known as the Australian Health Ethics Committee (AHEC). AHEC is effectively the peak health ethics committee in the country in that it is charged with advising the NHMRC on ethical issues relating to health, developing guidelines for ethical conduct in the health field and monitoring the work of Human Research Ethics Committees (HRECs) nationwide.¹

Established in 1936, the NHMRC is the leading national health research and advisory body in Australia with responsibility for advising government on health and medical issues and allocating funding to health research. The council operates as a statutory authority within the Commonwealth Department of Health and Family Services and is governed by a 1992 Act of the Commonwealth parliament. Although long involved in promoting and funding health research, the NHMRC's formal attention to ethical issues is comparatively recent and reflects a more general rise, both nationally and internationally, of 'research ethics' as a field of vigorous intellectual and political debate.

By the 1960s the ethics of medical and scientific practice and research was emerging as an important area of professional and public concern, and the rising critique of medical and scientific conduct was to make itself increasingly felt within mainstream health and scientific organisations in Australia and elsewhere.² Although, on an official level, attempts to shift the 'culture' of medical research practice in Australia have been gradualist, by the mid-1960s the NHMRC had published its own *Statement on Human Experimentation*. This statement was, in succeeding years, to be developed through the addition of 'Supplementary Notes', which provided guidance on specific areas of research or categories of research participants.³ The original NHMRC *Statement on Human Experimentation* and subsequent ethical protocols were issued in response to a number of international developments, particularly the 'Declaration of Helsinki', adopted at the World Medical Assembly of 1964, and the publication in 1982 by the World Health Organization and the Council for

1 For a brief guide to the structure and function of the NHMRC see *The Inside Guide to the National Health and Medical Research Council for the 2000–2003 Triennium*, NHMRC, Canberra, 2000. AHEC was formed in 1991, through amalgamation with National Bioethics Consultative Committee, and replaced the previous NHMRC body known as the Medical Research Ethics Committee formed in 1982.

2 For a history of the field of bio-ethics and of national and international developments in relation to ethical codes and ethics committees see P. M. McNeill, *The Ethics and Politics of Human Experimentation*, Cambridge University Press, Cambridge, 1993.

3 This statement was first released in 1966 with supplementary notes added in 1982 on the advice of the Working Party on Ethics in Medical Research, convened in January 1982. For the last published version see NHMRC, *NHMRC Statement on Human Experimentation and Supplementary Notes 1992*, NHMRC, Canberra, 1992.

International Organizations of Medical Sciences of the 'Proposed International Guidelines for Biomedical Research Involving Human Subjects'.⁴ Equally, The NHMRC has been influenced in its ethical deliberations by the development of codes of conduct in countries such as Britain, Canada and the United States of America.⁵

It was not until the mid-1970s, however, that the function of the NHMRC as an 'ethical watchdog' in relation to medical research became more defined. Originally, no mention was made within the *Statement on Human Experimentation* of the need for 'peer ethical review' of research projects. Indeed, on both a national and international level the development of ethics committees lagged behind the development of ethical codes. This problem was addressed by the NHMRC in 1973 when provision was made within an amended *Statement on Human Experimentation* for peer review by committee. By 1976, this provision had become an explicit requirement through a further amendment of the statement in which the NHMRC stipulated that medical research should be subject to review by Institutional Ethics Committees (IECs). By 1982, this ethical review process was made mandatory for continuing eligibility for NHMRC research funds, and by 1985 the NHMRC was requiring that all research on human subjects—not just medical research—be dependent on ethical review.⁶

The core, unchanging clauses of the *Statement on Human Experimentation*, which remained in force until 1999, largely focused on attempting to ensure that any health research undertaken observed 'generally accepted moral and scientific principles', that the potential benefits of research outweighed the risks and that, during the conduct of research, investigators respected the 'personality, rights, wishes, beliefs, consent and freedom of the individual subject'. The statement also sought to ensure that investigators were competent to undertake the research proposed, that any harmful effects of research were properly monitored and addressed, and that 'research subjects' were both fully informed of the research to be undertaken and able to consent formally to participation (with the option to withdraw at any time).

The *Statement on Human Experimentation and Supplementary Notes* (as it became known after 1982) was to be quickly adopted as a benchmark set of 'guidelines' by existing ethics committees operating within institutional contexts such as universities, hospitals and research organisations. The statement was also an impetus, particularly during the 1980s and early 1990s, to the formation of new ethics committees given the fact that NHMRC funding was, as noted above, eventually tied to ethics committee review. Furthermore, while the principles outlined by the NHMRC related

⁴ Recent versions of both the Helsinki statement, published by the World Medical Association, and the present Council for International Organisations of Medical Sciences statement on International Ethical Guidelines for Biomedical Research Involving Humans (1993) are reprinted in Baruch A. Brody, *The Ethics of Biomedical Research: An International Perspective*, Oxford University Press, New York, 1998, Appendices. Brody also reprints the important Nuremberg Code of 1947, the first international statement on ethical scientific conduct.

⁵ See McNeill, *The Ethics and Politics of Human Experimentation*, pp. 69–76.

⁶ For a summary and review of these developments see the section 'Historical Context' in NHMRC, *National Statement on Ethical Conduct in Research Involving Humans*, Commonwealth Government Printer, Canberra, 1999. See also, Section 2 of the *Report of the Review of the Role and Functioning of Institutional Ethics Committees*, Commonwealth Department of Health & Family Services, Canberra, 1996. In addition, see McNeill, *The Ethics and Politics of Human Experimentation*, pp. 71–3.

ostensibly to experimental health and medical research, they increasingly became 'generalised' to other research areas, for example, in the social sciences.⁷

By the mid-1990s, however, there was widespread recognition of the need for an exhaustive review of the NHMRC *Statement on Human Experimentation and Supplementary Notes*, particularly in light of the recommendations of the 1996 Review of the Role and Functioning of Institutional Ethics Committees.⁸ Thus, during the late 1990s the NHMRC undertook a full review of the statement, and in 1999 it was superseded by the new *National Statement on Ethical Conduct in Research Involving Humans*.⁹ This substantial set of guidelines now governs the deliberations of more than 200 Health Research Ethics Committees presently registered with AHEC.¹⁰ The new statement, which runs to nearly forty pages of specific guidelines, is also designed to be applicable to human research across disciplinary fields, and has thus been endorsed by the Australian Vice-Chancellors Committee, the Australian Research Council and the Academies of Science, Humanities, Social Sciences, and Engineering and Technological Sciences.

There are potentially many issues to discuss in relation to the release of these 'ethical guidelines' in the 1960s, and the subsequent review and extension of them in the late 1990s. Perhaps the most important of these issues is to ask what has been the effect of the guidelines in bringing about ethical research practice, and what are the limits of this guideline-based and ethics committee approach to transforming orthodox research cultures? These kinds of issues will certainly be partially explored in the following pages. At this point, however, we must turn to another related issue as the purpose of this report is to explore the specific development of ethical research guidelines in the field of Indigenous health.

The NHMRC *Statement on Human Experimentation* was, above all, general in focus. The statement did not identify particular social groups—other than children and the mentally ill or incapacitated—as the particular targets of research. As such, it sought to comment in general terms on the relationship between the researcher and the research subject and to put in place overall rules of conduct, regardless of the social or cultural background of the researcher and the researched.

⁷ It should be noted, however, that similar concerns about the ethics of research were part of the discourse of other non-medical disciplinary areas from at least the 1970s onwards and a range of alternative guidelines were to be developed for specific disciplinary fields. Indeed, the use of the NHMRC guidelines and its IEC regulations in assessing social research has, for those working in the social sciences and humanities, been problematic and the subject of considerable criticism. See *Report of the Review of the Role and Functioning of Institutional Ethics Committees*, Commonwealth Department of Health and Family Services, Canberra, 1996. p. 18. The Australian Research Council, the principal funding body for non-medical research, endorsed a code of ethics for human research in 1996-98.

⁸ See the above *Report of the Review of the Role and Functioning of Institutional Ethics Committees*, particularly Section 10 in which the review recommends that the Statement undergo 'substantial revision and be given a more appropriate title', p. 58.

⁹ See NHMRC, *National Statement on Ethical Conduct in Research Involving Humans*.

¹⁰ See HREC *Bulletin of the Australian Health Ethics Committee*, NHMRC, Canberra, December 2000.

By the 1980s, however, the NHMRC was clearly becoming aware that within certain research contexts ethical issues, or, more broadly, issues to do with the process and politics of research practice, were particularly sensitive. Indigenous health research was perhaps the most sensitive of these areas and, as a consequence, separate guidelines were to be developed for Aboriginal and Torres Strait Islander health research.

This specific attention to Indigenous health, however, was by no means simply NHMRC initiated or lead. On the contrary, the development of specific ethical guidelines for Indigenous health research has been the result of a complex and often difficult process. It has also, necessarily, been a highly political process in which the power to address and define issues of research conduct has continually shifted between different 'players' within the Indigenous health field.

In the following pages we outline the process through which the present NHMRC guidelines on the ethics of Aboriginal and Torres Strait Islander health research were developed using both written sources and oral testimony. In outline, this process of guideline development began in the mid-1980s and culminated in the release in 1991 of the interim NHMRC *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*, hereafter referred to as the *Interim Guidelines*.¹¹

As we explore in detail in the following pages, the Interim Guidelines were developed principally through a public conference in 1986, a closed workshop in 1987 and several years of subsequent negotiation between the NHMRC and Aboriginal organisations. While some of this process of development has been partially documented, much of this 'history' lives on only in people's memories. For this reason, a substantial part of this report is based on a series of oral history interviews with a small number of key people who attended the various meetings connected with the development of the *Interim Guidelines* or who were, in some way, involved with this process.

In exploring this history it is not the intention of this report to suggest that the *Interim Guidelines* are the only, or indeed the best, example of such rules of research conduct. On the contrary, over the past decade or so a number of both Indigenous and 'mainstream' organisations have developed ethical protocols in relation to research practice within Indigenous contexts.¹² These protocols relate not only to health research, but also to research in the humanities and social sciences.

11 NHMRC, *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*, 1991 (hereafter cited as NHMRC, *Interim Guidelines*). This statement replaced the earlier NHMRC document 'Some Advisory Notes on Ethical Matters in Aboriginal Research', released in July 1988.

12 Many other sets of ethical guidelines in relation to Indigenous research were to be formulated and adopted during the late 1980s and 1990s by various organisations attached to an array of disciplinary fields including: Australian Institute of Aboriginal and Torres Strait Islander Studies; Aboriginal Health Research Ethics Committee of South Australia; Australian Anthropological Society; Australian Archaeological Association; Aboriginal Research Institute, Faculty of Aboriginal and Islander Studies, University of South Australia; Koori Centre, University of Sydney; Centre for Aboriginal and Torres Strait Islander Participation, Research and Development, James Cook University; Jumbanna Centre for Australian Indigenous Studies, Education and Research, University of Technology, Sydney; Centre for Indigenous Natural and Cultural Resource Management, Northern Territory University, and Institute of Koori Education, Deakin University. This is by no means an exhaustive list.

Arguably, however, the 1991 *Interim Guidelines* have, over the past decade, proved dominant as an aid to the deliberations of Institutional Ethics Committees across the country—and not only in relation to health research. Indeed, one of the points to be made in this report is that this dominance has, in part, been due to the professional and political influence of the NHMRC and, in part, to the fact that the 1991 *Interim Guidelines* were developed at a time when few such written protocols existed. That this is no longer the case clearly has implications for any review of these guidelines. It potentially challenges their continued dominance as a guide to the deliberations of HRECs, and it raises questions about how the various Indigenous research guidelines now available complement and/or contradict each other.

The Study: Formulation, Purpose and Methodology

In raising this issue of ‘review’ we come to the immediate purpose of undertaking this study. As part of the AHEC ‘workplan’ for the triennium 2000–2002, the committee undertook to revise the Interim Guidelines. The guidelines themselves, although extensively utilised by HRECs, have never been officially endorsed by the NHMRC. A decade after their release, and in light of the recent overhaul of the NHMRC *Statement on Human Experimentation*, it was felt that the Indigenous guidelines should undergo a separate but similar process of review with a view to ultimately producing an updated and officially adopted set of ethical protocols.

In early 2001, AHEC member Mr Robert Griew approached the VicHealth Koori Health Research and Community Development Unit (VKHR&CDU) for the purposes of involving the Unit in developing a process of consultation over the proposed review of the Interim Guidelines. From its establishment in 1999, the VKHR&CDU has been involved in historical and analytical inquiry into the content, ethics and process of Indigenous health research in Australia.¹³ Given this ongoing work, it was agreed that the Unit’s Senior Research Fellow (a historian and social researcher) should undertake a brief historical study of the development of the *Interim Guidelines* in order to collect information unavailable in written sources and to document their development in ways useful to the review process. In addition, the Unit’s Director, Associate Professor Ian Anderson, has collaborated with Mr Daniel McAullay of the Kulunga Research Network in Western Australia on a detailed literature review relating to the ethics of Indigenous health research both in Australia and overseas.¹⁴

This brief historical study of the development of the 1991 *Interim Guidelines* was undertaken between April and December 2001, and was partly funded through a consultative grant from the Office for Aboriginal and Torres Strait Islander Health within the Commonwealth Department of Health and Aged Care. The study principally involved a number of detailed oral history interviews with six key

13 For background to this study see in particular Kim Humphery, *Indigenous Health and ‘Western’ Research*, VKHR&CDU Discussion Paper No. 2, VicHealth Koori Health Research & Community Development Unit, University of Melbourne, Melbourne, 2000.

14 See Daniel McAullay, Robert Griew & Ian Anderson, *The Ethics of Aboriginal Health Research: An Annotated Bibliography*, VKHR&CDU Discussion Paper No. 5, VicHealth Koori Health Research & Community Development Unit, University of Melbourne, Melbourne, 2002.

individuals who had been closely involved in the development of the 1991 *Interim Guidelines*. In addition, another six individuals involved with the development of the guidelines were either interviewed or consulted. These purposefully selected participants were chiefly identified through a search of existing written records relating to the development of the guidelines. All interviews (except one) were conducted on a one-to-one basis and took place in person, usually at the interviewee's workplace. Each interview was audio-taped and later fully transcribed. Although semi-formal in structure, the interviews were guided by a set of 'open-ended' questions.

Clearly, given the small number of individuals consulted, the task here has been to document the process of guideline development historically by providing an 'insider view' of this process, rather than to canvass a broad array of perspectives and opinions (a task more suited to other forms of social research than to oral history). This form of 'focused', or what is often jargonistically called 'key informant', research is useful in constructing detailed historical narratives of particular events or actions.

In terms of ethical research practice, this study has been approved by the University of Melbourne Ethics Committee and governed by a set of procedures that has involved obtaining the written consent of interviewees, returning confidential interview transcripts for review to each participant prior to the use of this material in the written report, and providing each participant with a limited release draft of the report for further final comment or revision. Participants have also been free to withdraw their participation and the information they have provided at any stage in the process, prior to the final printing of this report.

Through this means, the VKHR&CDU has attempted to ensure that participants have retained a firm level of control over the information they have supplied. This has been particularly important given that, as an oral history project, participants are identified by name in various places within this report. For this reason, too, final publication of this report has been a necessarily slow process.

The Purpose of Applied History

In alluding to the applied nature of this study it is necessary, briefly, to situate this research intellectually. Applied history is a comparatively neglected field in Australia, although over the past decade, in particular, there has been a growth of interest in the broad area of public and applied historical work.¹⁵

Certainly, the use of historians to undertake specific research that can then feed into, or be 'applied to', the formulation of public policy or institutional decisions is not usual in Australia, other than within certain fields such as heritage conservation. It is

¹⁵ For a discussion of public history in Australia see Graeme Davison, *The Use and Abuse of Australian History*, Allen & Unwin, Sydney, 2000. See also his 'Paradigms of Public History,' in John Rickard & Peter Spearritt (eds), *Packaging the Past: Public Histories* (Special Issue, *Australian Historical Studies*), 1991, pp. 4–15; and Ann Curthoys & Paula Hamilton, 'What Makes History Public?', *Public History Review*, vol. 1, 1992, pp. 8–13.

more common in the USA where the field of applied history, particularly in relation to the work of commercial firms and government agencies, is now well entrenched. Potentially, as with all applied or institutionally commissioned forms of research, public historical work can be highly constrained by institutional and political agendas. At its best, however, applied history can combine a scholarly approach with a practical, exploratory and critical form of inquiry that seeks to engage directly with contemporary issues.

It is in this spirit that this report seeks to document and explore the development of the 1991 Interim Guidelines in a way that does not simply confirm the worth of that process, but also raises questions about the limits, hidden assumptions and political dynamics of the process itself. This, hopefully, will yield a historical picture that is not only of scholarly value and interest but which can also be directly used as an informative backdrop to any process of revising the guidelines in question.

The Structure of the Report

Having, within this introduction, provided a brief background to the study, the following sections of the report move on to give a narrative history of the development of the 1991 *Interim Guidelines*. Section Two offers such a history based principally on the written information available on the process of guideline development, while Section Three draws exclusively on the interviews conducted as part of this study. In the final, brief concluding section an effort is made both to summarise this historical information and to draw out some of the possible implications of this history for any future redevelopment of the ethical guidelines in Aboriginal and Torres Strait Islander health research.

Two From The Documents

The 1986 Alice Springs Conference

In November 1986, the Araluen Arts Centre in Alice Springs acted as the main venue for a three-day 'workshop' on 'Research Priorities to Improve Aboriginal Health'. This gathering—effectively a full conference—was organised jointly by the Special Purposes Committee of the NHMRC and the Menzies Foundation (under the rubric of the fledgling Menzies School of Health Research in Darwin).

The attendance list and final program indicates that it was a sizeable event, with more than 200 people registered and nearly 100 speakers, many of them (though certainly not a majority) Aboriginal.¹⁶ This list and program also indicates what a significant conference this was to be, with so many of the key people then (and still now) involved in the field of Indigenous health gathered together.

The conference proceedings were clearly designed to provide a broad survey (at least from a predominantly biomedical perspective) of the contemporary state of Indigenous health and of the research being undertaken in the area. Thus, the various sessions, held alternatively at the Araluen Arts Centre and the Alice Springs Hospital, focused on the following themes:

- the ethics of research;
- nutrition, diabetes and cardiovascular disease;
- hepatitis;
- gastro-intestinal infections;
- health problems as seen by Aborigines in remote communities;
- urban health problems;
- health problems of children;
- anthropological and social issues;
- alcohol and substance abuse;
- living conditions and health;
- health problems of women;
- obstetric and paediatric problems;
- Aboriginal health surveillance;
- sexually transmitted diseases;
- education and Aboriginal health evaluation;

16 These documents are: 'Workshop: Research Priorities to Improve Aboriginal Health 26–28 November 1986, Final Program' and 'Complete List of Registrations at 12 November 1986'. The only 'conference report' available is the newsletter of the Menzies School of Health Research, No. 1, February 1987, which reports that approximately 300 people eventually attended the conference. I am most grateful to Dr Maggie Brady for supplying me with these documents.

- trachoma and chlamydia;
- methods of health care delivery;
- ear and respiratory problems;
- renal disease and hypertension; and
- funding for research and training in Aboriginal health.

Although this was certainly an exhaustive list for a three-day conference, it was, as is discussed below, to be the source also of considerable discontent.

The conference itself was opened by the then Commonwealth Minister for Health, Neal Blewitt, with an additional address by Charles Perkins, then Secretary of the Federal Department of Aboriginal Affairs. Although the conference was to lead to the development of ethical guidelines, its focus was, in fact, somewhat mixed with most emphasis being placed on papers relating to Aboriginal health and social 'problems', rather than on research ethics. Indeed, in the run-up to the conference the coming event was talked of as a chance to 'examine the health needs of Aborigines in Australia' and identify 'priorities for the provision of health care'.¹⁷ While these were admirable aims, there was also a strong emphasis, at least within some sessions, on addressing the social and economic determinants of Aboriginal ill-health, thus pushing the conference beyond a strictly 'health issues' focus.

In terms of the conference outcomes, however, the history and process of health research clearly became the central theme as the program progressed. There was recognition by both Aboriginal and non-Aboriginal delegates at the conference of the exploitative history of research within Indigenous communities and of the distrust that many Indigenous people felt towards researchers and research establishments. This history and disposition was articulated well by Neal Blewitt in his opening address, although only indirectly in relation to Indigenous Australians. As Blewitt argued:

In many places in Papua New Guinea 'research' has become a dirty word; a 'researcher' is a despised person, a 'researcher' for many Papua New Guineans is a person who goes into a village or a community, demands hospitality, demands answers to embarrassing questions, asks people to do things they consider strange, takes photographs and special objects and who finally vanishes. They never hear from that person again. The researcher took all that was offered, and sometimes more, and in return, gave nothing, not even the results of the 'research'.¹⁸

There would be symmetry between these opening words and the final 'sessions' of the conference, sessions that were, in fact, to be suspended through the actions of a group of Aboriginal delegates.

¹⁷ See 'Seminar to Discuss Aboriginal Health', *Canberra Times*, 7 November 1986.

¹⁸ Cited in the newsletter of the Menzies School of Health Research, No. 1, February 1987.

There are few written sources available on the events that took place on the final day of the conference, although one newspaper report, perhaps with predictable sensationalism, ran the headline ‘Aboriginal Activists Take over Conference’.¹⁹ According to the report this ‘take over’, on Friday, 28 November, was led by Bill Lowah and Grace Smallwood (described as Queensland rights campaigners) who, to cite the article directly, ‘launched into a spirited and critical attack on the “insensitivity” of “white middle-class” researchers who were “only interested in the conference as a rubber stamp to improved funding for their research projects”’.

The report went on to outline how the ‘formality of the conference was swept aside’ in order to allow Aboriginal people to speak freely and in their own time, and for the drafting of recommendations and resolutions from the conference. In instituting such a ‘take over’, Aboriginal delegates also clearly wished to place the issue of land rights and political power on the agenda, arguing that, as Grace Smallwood put it, ‘There is no viable and healthy future for Aboriginals without a sound economic base, political representation, and secure tenure of land’.

Whatever the accuracy of this report—and we will come to look in detail at this ‘take-over’ in the section that follows—it was evident, as the article pointed out, that non-Aboriginal conference delegates were, for a time, silenced and made the target of sustained critique. This was a new experience for many of the non-Aboriginal delegates, a point made by a number of the people interviewed for this brief study. It also clearly caused some consternation within the institutions organising the conference. As a result, the NHMRC acted relatively quickly in addressing at least some of the requests made within the conference recommendations formulated by delegates on the Friday evening of the conference.

In other respects, however, the challenge to research practices embodied within the Aboriginal protests and the recommendations of the final day were to be grasped only slowly. For example, in its rather diplomatic report on the conference the Menzies School of Health Research’s newsletter only tentatively dealt with the volatile dynamics of the final day and failed to report at all on the ‘take-over’. The newsletter did, however, offer a comparatively brief report on the issue of research ethics, in which it attempted to offer a balanced juxtaposition of Aboriginal and non-Aboriginal views on research and to highlight the conference call for the formulation of specific ethical guidelines within Aboriginal health research.²⁰

With hindsight, this very juxtaposition between Aboriginal and non-Aboriginal views was itself questionable, since opinion on the history and process of research did not (and still does not) necessarily divide neatly along such lines. Moreover, the newsletter

¹⁹ ‘Aboriginal Activists Take Over Conference’, *Adelaide Advertiser*, 29 November 1986.

²⁰ See the section ‘Research’ in newsletter, Menzies School of Health Research, February 1987.

indicated the difficulty that mainstream health institutions clearly had at this time in coming to grips with the depth of Indigenous critique.²¹ Thus, the newsletter commented:

When the potential benefits of health research are more widely appreciated by Aboriginal people, there will be a greater incentive for Aborigines to themselves acquire the technical skills to carry out necessary research on the problems of Aboriginal health.²²

Here, the purpose and process of health research was still not effectively being brought into question, and Aboriginal objections were still being rather patronisingly framed as emanating from a lack of understanding. In light of the detailed recommendations made by the conference, and the subsequent moves made towards the development of ethical guidelines, such a reactive position would remain unsustainable.

In all, the Alice Springs conference made eighty-seven recommendations, nearly half of which related to the ethics, funding and organisation or practice of research within Aboriginal health.²³ Chief among these recommendations was the call for the development of specific ethical guidelines for health research involving Aboriginal people, and for the formation of a representative Aboriginal forum to establish these guidelines. Also embodied within the final recommendations was a strong emphasis on issues of community control and on ensuring that research activities resulted in practical outcomes and benefits for the Indigenous communities involved. The recommendations thus highlighted the need both for Indigenous people themselves to be involved in research activities—as researchers rather than research subjects—and for the pursuit of culturally appropriate research methodologies. Emphasis was also given to the necessity of researchers providing community-based skills development and ongoing information or ‘feedback’ during the progress of research. Importantly, too, the recommendations stressed the need for overall Indigenous control of research development and funding.

The Camden Workshop

While only a few of these aims were to be realised, the important call for the development of guidelines would be acted upon within little more than six months of the Alice Springs conference. In August 1987, the ‘National Workshop on Ethics of Research in Aboriginal Health’ was convened through funding from the NHMRC. This three-day workshop took place at ‘Tallimba’, a government ministerial retreat near Camden, New South Wales, and effectively fulfilled the earlier call for a ‘forum of Aboriginal people’ to establish ethical guidelines.

21 An Indigenous critique of ‘Western’ research in Australia was, by the mid-1980s, being directed towards a range of disciplinary areas, including the biomedical. For a brief overview of Indigenous commentary of research practices and traditions see Humphery, *Indigenous Health and ‘Western’ Research*.

22 See the section ‘Research’ in newsletter, Menzies School of Health Research, February 1987.

23 A copy of the recommendations is included in the NHMRC, *Interim Guidelines*.

The only detailed written source on this gathering is the extensive report by Shane Houston—then National Coordinator of the National Aboriginal and Islander Health Organisation—who had previously been nominated to convene the forum.²⁴ His report indicates that the workshop was attended by nearly thirty Aboriginal community representatives, as well as a small number of representatives of the NHMRC and a handful of ‘observers’.

In outline, the principal goals of the workshop were to ‘develop a set of ethical guidelines on research into Aboriginal health’, and to ‘identify the mechanisms necessary to establish a nexus between the guidelines and the funding of research into Aboriginal health’. An important additional goal, however, was the intention to identify ‘mechanisms which recognise and respond to the pivotal role of Aboriginal communities in the design, execution and evaluation of research into Aboriginal health’.²⁵ This latter aim related much more closely to the broader desire of many of the Indigenous representatives at the workshop to increase Indigenous communities’ control over the identification of research priorities, the methodological approach of research undertaken, the ‘selection’ of research projects, and the allocation and on-going supervision of research funds.

Over three days, the forum thus worked through a complex range of issues connected in an immediate sense to the formulation of ethical guidelines, but in a broader one to the politics of ‘cross-cultural’ research and research funding itself. Significantly, it was not assumed at the 1987 workshop that ethical guidelines were any *guarantee* to better research practice, nor that they would bring about deeper attitudinal change on the part of non-Indigenous researchers. As such, the term ‘guidelines’ was dropped in favour of the phrase ‘principles, standards and rules’, and the formulation and enforcement of these was clearly seen as one step in a broader process of transforming research.²⁶

First and foremost, the ‘principles, standards and rules’ adopted at the workshop emphasised a need for consultation and negotiation by researchers that both recognised the right of Aboriginal communities to self-determination and acknowledged the key co-ordinating role of Aboriginal community-controlled organisations. The workshop thus outlined various protocols to be followed by researchers in obtaining the authority and full involvement of Aboriginal communities in devising and undertaking research. These protocols entailed negotiating not simply with particular individuals but with Aboriginal Medical Services, local community-controlled agencies and/or the national peak body of community-controlled health services.²⁷

24 This ‘Report of the National Workshop on Ethics of Research in Aboriginal Health’ is reproduced within the NHMRC, *Interim Guidelines*.

25 As above, p. 9.

26 As above, p. 11.

27 As above, pp. 11–13.

In formulating such protocols, the Camden workshop insisted that researchers should be obliged to demonstrate actively that consultation and negotiation over proposed research projects had taken place. This was to be done through obtaining the written consent and support of communities, as well as through providing details of how the research directly benefited the community concerned, who was to 'own' the data collected, and how social and cultural 'imperatives' within the community were to be addressed. Moreover, the workshop resolved that this level of project scrutiny should be ongoing, rather than simply 'once-off', and that such scrutiny should be performed by local community-controlled agencies. Indeed, the workshop participants went even further by putting forward a key proposal in which funds for research projects were to be channelled through, and managed by, Aboriginal Medical Services or other community-controlled organisations as a way of 'maintaining appropriate control over the ethical behaviour of researchers'.²⁸

Such proposals clearly went strictly beyond the formulation of 'on paper' ethical guidelines. They began to address the history of control of research and its funding by non-Indigenous bodies, and to activate the notion of 'guidelines' as not just a set of written procedures but as potentially facilitating concrete mechanisms for the Indigenous control and possible transformation of health research. In essence, the workshop explicitly recognised the connection between the formulation of 'principles, standards and rules', and the broader task of challenging mainstream institutional control of research funds.

In addition to consultation and negotiation, the 1987 workshop advocated the need for principles of conduct in relation to specific social, cultural and gender issues, emphasising that researchers should recognise, and work respectfully with, the different belief systems and social structures present within Aboriginal communities. In particular, the workshop outlined the necessity for researchers to recognise the sensitivity of information that might be gained through research activities, and the manner in which gaining such information could be offensive, invasive or contravene Aboriginal lore/law.²⁹

Just as importantly, the workshop drew attention to the need for appropriate and ongoing mechanisms for ensuring communication about, and consent to, the research being undertaken. Workshop 'statements' on this aspect of research ethics stressed that such communication/consultation was not to be 'regarded as a once off or superficial exercise', but that communities should be informed in a clear, understandable and appropriate manner of the 'intent, process and methodology, evaluation and potential use of any research proposal'. Emphasis was also placed on the need for researchers to respect, and allow time for, decision-making processes within Aboriginal communities. While these imperatives gave central importance to the notion of 'community consent', the workshop also reiterated the continued importance of

²⁸ As above, pp. 13–14.

²⁹ As above, pp. 15–16.

gaining the individual consent of community members participating in research. The notion of gaining ‘informed consent’ was thus formulated as a dual process.³⁰

The issue of how researchers were addressing community needs and research benefits was also a source of concern. The workshop pointed out that the research undertaken on Aboriginal communities was often of little direct relevance to the needs of those communities or to the primary principle of improving the health of Aboriginal people. The workshop thus advocated for the employment and training of Aboriginal co-investigators and for an emphasis within research projects on the development of knowledge leading to improvements in Aboriginal health and community development.³¹

Finally, the 1987 workshop directly confronted the contentious issue of ownership and publication of materials. Workshop participants expressed deep concern about the publication of sensitive written or pictorial material, and the fact that this was often beyond the control of the communities concerned. The workshop thus resolved that research data should remain the property of the community being researched and that ‘the community retains the right to censor research materials of a sensitive nature’. It was also resolved that relevant Aboriginal community-controlled agencies be given the right of approval/disapproval in relation to the publication of research results.³²

The Advisory Notes

By mid-1988 the NHMRC had responded to the outcomes and resolutions of the Camden workshop through the release of a document entitled ‘Some Advisory Notes on Ethical Matters in Aboriginal Research’. Prepared by Ross Kalucy and Elizabeth Grant of the NHMRC, and incorporating extracts from Shane Houston’s report on the 1987 workshop, the notes were issued not as ‘official ethical guidelines’ but as representing ‘the views of a group of Aboriginal people’ over which further consultation was to take place.³³ Thus, couched as informal ‘source material for research workers, NHMRC committees and other bodies’, the ‘Advisory Notes’ were to be used in conjunction with the NHMRC *Statement on Human Experimentation and Supplementary Notes*. Indeed, at this time it was still intended that any set of guidelines relating to Indigenous research eventually be included as an additional ‘supplementary note’ to the broader NHMRC statement.

The ‘Advisory Notes’ are of value in illustrating both the admirable speed with which the NHMRC responded to the 1987 workshop, and the reservations held within the organisation itself about some of the workshop recommendations—since the

30 As above, pp. 17–18.

31 As above, p. 19

32 As above, p. 20. The workshop also discussed the exploitation of community resources by researchers and resolved that provision should be made within research projects for reimbursing Aboriginal communities and agencies the costs of cooperating with researchers.

33 NHMRC, ‘Some Advisory Notes on Ethical Matters in Aboriginal Research including Extracts from a Report of the National Workshop of Research in Aboriginal Health’, c. July 1988.

'Advisory Notes' are, in essence, a provisional NHMRC 'position paper' on the workshop. Within the 'Advisory Notes', workshop discussions and resolutions, as reported within Houston's conference overview, are paraphrased and partially quoted in a way 'digestible' to a NHMRC audience.

Within these notes is a genuine and constructive openness to many of the concerns raised within the 1987 workshop, particularly around issues of consultation, socio-cultural sensitivities, communication and consent, community benefit, and the exploitation of community resources. The one identified 'sticking point' is over the ownership of data, an area that the 'Advisory Notes' conceded required extensive discussion, designating it a 'very difficult issue'. The 'Advisory Notes' thus rather judiciously avoided any substantive reference to the issue of 'ownership', alerting researchers instead to a number of basic issues relating to acknowledgment, confidentiality and cultural sensitivity, and the possible clash of values between the imperative of Aboriginal control and the integrity of Western academic conventions in relation to publishing research results.

Less clearly identified within the 'Advisory Notes', however, is another such 'sticking point'; that of full community control of research and its funding. The introduction to the 'Advisory Notes' openly draws attention to its omission of issues raised within the workshop report relating to the ownership of data, the administration of research funds and the surveillance of research projects. Once again, discussion of the latter issues was avoided within the 'Advisory Notes' because of the need both for further consultation and for the broader involvement of various NHMRC committees in broaching these issues.

Yet while the attempt to identify these 'omissions' was a frank and honest one, the 'Advisory Notes' are also marked by a more subtle, and perhaps unconscious, effort to somewhat 'de-politicise' the workshop proceedings. This is done through effectively side-stepping all the workshop talk of the centrality of community-based organisations and utilising instead the more amorphous notion of 'community' consultation. Indeed, very little mention is made within the 'Advisory Notes' of community-based organisations, such as Aboriginal Medical Services or Aboriginal peak bodies, a fact that contrasts substantially with Houston's report. Thus, while Aboriginal organisations were mentioned as sources of 'advice', there was no reference to them as having any clear 'authority' in relation to research matters.

Here, then, was really the beginning of a 'bargaining process' in which the broader intent of the 1987 workshop to interpret the development of guidelines as one step in a process of wresting Aboriginal control of research from mainstream bodies was pared back. Cognisant of the challenge that some of the 1987 workshop resolutions posed to NHMRC control of health research and to Western research traditions, and of the sheer difficulty of bringing about broader institutional change, the 'Advisory Notes' thus clearly sought to draw some lines in the sand as much as to identify issues for 'further discussion'.

The Interim Guidelines

At about the same time as the release of the 'Advisory Notes', the NHMRC initiated a program of consultation to 'iron out' some of the more contentious issues involved in the development of ethical guidelines in Aboriginal health research. The NHMRC allocated \$25,000 to this process of consultation, which was reported on within the mainstream media,³⁴ and a MREC Aboriginal working party was formed to develop the guidelines further. The working party members included two Aboriginal representatives, Jim Ramsey and Marion Kickett, and one non-Indigenous social researcher, Maggie Brady.

By 1990, and as a result of the activities of the working party, the 'Advisory Notes' had been superseded by a working document entitled *Guidelines on Ethical Matters in Aboriginal Research*, on which comment was invited. This document went beyond the 'Advisory Notes' by recommending twelve possible guidelines in relation to ethical conduct in Aboriginal health research, which covered the 'process of consultation', 'cultural issues', 'communication and consent', 'community benefit and local employment', 'ownership and publication of data', 'exploitation of community resources', and two additional areas, 'mechanisms of ongoing surveillance of research' and 'sanctions'.

Many of these recommended protocols were eventually included within the 1991 *Interim Guidelines*, although none word for word. It is unclear, however, as to whether or not the 1990 document, *Guidelines on Ethical Matters in Aboriginal Research*, was widely circulated as it seems to have been quickly replaced by an alternative set of recommended guidelines, which greatly shortened and streamlined the draft code into the three principal areas of 'consultation', 'community involvement', and 'ownership and publication of data'. It was this tripartite version of the guidelines that was subsequently considered by the MREC in early 1991. Community comment was invited and it was eventually released—for the most part unchanged—as the 1991 *Interim Guidelines*.

This rather rapid shift from a document embodying twelve 'recommendations' to one that offered a draft set of fifteen guidelines (eight of which related to the issue of ownership of data) was, in part, done in the interests of providing a clear and useable set of protocols—and one 'acceptable' to mainstream research establishments. However, it was a product also of the perhaps inevitable manner in which the process of developing the guidelines narrowed down to the input of a handful of key people. Indeed, it could be said that, to a significant degree, the final 'tripartite' draft version of the guidelines was the product of one person's 'take' on the various points raised and issues discussed by the dozens of people involved in the process itself. This person was Ian Maddocks, then a member of the MREC, who in late 1990 undertook single handedly the re-draft of the issued 1990 *Guidelines on Ethical Matters in Aboriginal*

³⁴ See 'Researchers to Consult Aborigines', *Courier Mail*, 2 June 1988, p. 20.

Research, a redraft that, as noted above, was to be eventually issued almost word for word as the *Interim Guidelines*.

To draw attention to this fact does not necessarily undermine the value or use of the *Interim Guidelines* themselves. On the contrary, Ian Maddocks, in drafting the simplified, tripartite version of the guidelines, drew carefully on existing recommendations and was concerned to clarify a number of points of potential confusion. Thus, he did not somehow ‘invent’ his own guidelines but worked closely and respectfully with the existing documents, particularly the report of the Camden workshop of 1987. The Aboriginal Working Party of the MREC also vetted Ian Maddocks’s re-draft, suggesting a number of minor changes to various clauses and the addition of others.

Yet, in terms of a historical investigation of the process of developing the *Interim Guidelines*, the ‘final mechanics’ of this process is certainly of interest. It would appear that as the process of developing guidelines haltingly and slowly progressed, fewer and fewer individuals would be directly involved in the final steps of drafting the guidelines themselves. Thus, after almost five years of ‘negotiation’ and ‘consultation’ over the development of ethical guidelines, the documentary evidence suggests that this was a process that ‘ended’ somewhat problematically. Indeed, there would appear to be a disjunction between the authority and regard almost immediately given to these guidelines—by both Indigenous and non-Indigenous organisations—and the historical facts of their making. A documentary history of this making would suggest that the current guidelines, whatever their merit, are a ‘frozen moment’ of a partially ad hoc process of guideline development, rather than an end outcome of a concerted, clearly conceived program of consultation, development, drafting, and ratification.

Three From The Transcripts

A central facet of this study was the completion of a series of oral history interviews with key individuals who had been involved in the process of developing the 1991 *Interim Guidelines*. As previously noted, the purpose of undertaking such interviews was to document further the process of guideline building, and to do so in a manner that moves beyond the written record, preserves an oral testimony of the process, and provides an 'insider' account that can then be used to inform any review of the guidelines themselves.

To reiterate, this qualitative aspect of the study involved the conduct of detailed oral history interviews with six key individuals closely involved in the development of the 1991 *Interim Guidelines*. In addition, another six individuals were either interviewed or consulted. These purposefully selected participants were chiefly identified through a search of existing written records relating to the development of the guidelines. All interviews (except one) were conducted on a one-to-one basis and took place in person, usually at the interviewee's workplace. Each interview was taped and later fully transcribed. Although semi-formal in structure, the interviews were guided by a set of 'open-ended' questions.

In undertaking these interviews, we sought to explore in a focused manner three inter-related issues: the emergence of public debate around the 'ethics' of Aboriginal health research; the perceived key events and issues involved in the development of the *Interim Guidelines*; and the perceived importance and reception of the guidelines themselves. The interviews, however, were not ethnographic in approach. That is because our intention here is not to explore the perceptions or beliefs of the interviewees themselves, or evaluate their comments. Nor is it our purpose, here, to identify and analyse the actions of particular individuals involved in the process of guideline development. Rather, throughout this section we utilise people's recollections to add detail to the historical narrative of the previous section, and to explore further selected aspects of the processes surrounding the development of the 1991 *Interim Guidelines*. This is done in a manner that offers only sparse commentary, and which relies instead upon extensive quotations from the transcripts.

The Ethics Debate

It is generally acknowledged that in Australia the 1970s and 1980s were crucially significant decades in terms of the development of a vocal and vibrant Indigenous movement, a movement that built on the activism of previous decades. One central target of this activism was the field of 'research' and many of those interviewed for this

study noted that, by the early 1980s, research within Indigenous contexts had become a hot political issue. As Maggie Brady observed:

The 1970s were significant in terms of what was happening generally in terms of the rise of an Indigenous self-consciousness and Indigenous identity, which really got going then. I mean the 1970s were a final breaking away from the notion of 'Black Power' and an identification with Black Americans and *their* struggle, and the decade saw the rise of an emphasis on Indigenous rights... In the late '70s, and particularly in the early '80s, or right through the 80s, there was a huge amount of world travel by Aboriginal activists, including those in the health field... Indigenous people, particularly in the United States, were getting stropy about research and I think that influenced what was going on here.³⁵

Shane Houston also commented on the rise of an increased Indigenous activism around research by the early 1980s. Recalling his early work with the National Aboriginal and Islander Health Organisation (NAIHO) he noted that:

When I went to NAIHO in the early '80s there was always examples, regular examples, of where people had been misrepresented, misused, ripped off or otherwise prostituted to advance the careers of some academics. So in NAIHO we consistently heard the frustrations of Aboriginal people about how they were being prosecuted by researchers who were basically doing what they always did; just using the research to get a degree, trucking off to the community and never going back there again. People started really agitating from NAIHO about research around this time.³⁶

A number of those interviewed for this study mentioned various research projects and publications that illustrated for them inappropriate research practices, and that stood out as emblematic of why Indigenous Australians distrust 'research'. Less frequently, but importantly, some also identified a handful of projects that showed positive efforts to shift conventional research paradigms. In the latter case, a number of people mentioned the work of Pam Nathan and Dick Japanangka (1983) in particular.

There were, however, seen to be costs to this increasing activism in relation to research, which was recognised even by those who were supportive of it. One such 'cost' was the tendency for all Western research paradigms to be placed under a cloud of suspicion, a point clearly and frankly brought out in conversation with Maggie Brady:

I think I found it (the Indigenous critique of research) mildly irritating at times, particularly since so little credence was given to the way in which anthropologists comported themselves. I mean, unless you want to start talking about the 1920s or something... I think anthropologists were demonised by Indigenous groups... it just always used to be galling to go to meetings and have this old stuff hurled up again which

³⁵ This and subsequent comments by Maggie Brady are taken from a taped and transcribed interview conducted with her in Canberra on 21 June 2001.

³⁶ This and subsequent comments by Shane Houston are taken from a taped and transcribed interview conducted with him and Ted Wilkes in Perth on 2 July 2001.

was totally irrelevant to what was going on [by then]. Obviously there are some glaring examples of [poor recent] anthropology... but in this country an overwhelming majority of anthropologists working since the 1970s have been sympathetic to Aboriginal people... and knew that you couldn't continue to operate in an unethical way...

This comment raises important issues about the need to avoid a homogenisation of 'research' in seeking to critique it, and to recognise that the notion of a 'research community' within the Indigenous health field often disguises crucial disciplinary and political differences. It could be that for central strategic reasons the emerging Indigenous critique of research in the 1970s and 1980s needed to utilise a broad and powerful rhetoric of political opposition to 'Western' research, and to draw on the long history of the exploitation of Indigenous Australians as research subjects. More recently, this critique, although no less powerful, appears to have shifted to an exploration of collaborative/cooperative research, and of the possibilities of Indigenous people 'researching back' utilising both 'Western' and 'Indigenous' principles of investigation (see Brady 1999; Tuhiwai Smith 1999).

Having noted this 'shift', however, none of those interviewed sought to deny the basic validity of the Indigenous critique of research emerging during the 1980s. Indeed, all of the non-Aboriginal interviewees readily acknowledged that this critique had been pivotal for them in developing an awareness of the limits of their own research practices. It is, nevertheless, unclear from the interviews conducted for this study to what extent this increased Indigenous activism around research influenced the NHMRC in its decision to address more vigorously both Aboriginal health issues and the ethics of Aboriginal health research. What is clear is that by the early 1980s the NHMRC was identifying Aboriginal health as a research priority and also grappling with an emerging sense of the politics of the research enterprise. As Ross Kalucy commented:

Eventually, by the early 1980s, we got together a sort of group of areas we thought needed special attention in terms of research and subsumed them all under what we called the 'Research Priorities Committee', which I chaired. And Indigenous peoples' health was one of those priority areas. The committee was an early attempt to address, if you like, Australia's health from the point of view of what were the health priorities, rather than pursue investigator driven research. A second component of the committee's work was to help people put together a 'better' project. But in the area of Aboriginal health it was very marginally successful and what we learnt was that there didn't seem to be people out there who were working with Aboriginal people in some kind of way that was harmonious and able to generate appropriate studies. And this was the first time we learnt about quite how suspicious Aboriginal people were about research. It was probably about that time that an Aboriginal leadership was beginning to come to the fore, and they were experimenting with notions like community control, and those kinds of things.³⁷

³⁷ This and subsequent comments by Ross Kalucy are taken from a taped and transcribed interview conducted with him in Adelaide on 4 July 2001.

For the NHMRC this period, according to both Ross Kalucy and Elizabeth Grant, was very much a learning period, and it was in this spirit that some form of consultation was sought between the NHMRC and Aboriginal representatives. As Elizabeth Grant noted:

We wanted to consult, and the only way to consult was to have a meeting with the Aboriginal community. We thought at one stage, I think, and you sort of lose a sense of which came first, we thought we would get together a group of elders or of community leaders that we could talk to. It was quite clear that we had to meet with a lot of people. So that was where the idea of the Alice Springs conference came in, Alice Springs was the centre of so many communities, so we decided to go there.³⁸

Evidently, the broader NHMRC was most receptive to the idea of staging such a conference, not least because of the problems the council had experienced in funding successful Aboriginal health research projects. As Ross Kalucy noted, in recognising that the council lacked the ability to vet the 'cultural dimensions' of proposed research projects:

I suggested that we needed to have some kind of conference where Aboriginal people were present in large numbers, and to try to get a handle on what their priorities were and why we [the NHMRC] were not succeeding in what we were doing [funding successful research projects], and to my stunned amazement within a very short time, maybe even days, I was give \$30000 to run this conference.

However, as all the interviewees noted, the NHMRC and the Menzies Foundation, in initiating this conference in partnership with the Central Australian Aboriginal Congress, got considerably more than they had bargained for. And it is to this Alice Springs event that we now turn.

The 1986 Alice Spring Conference

In Section Two we provided an outline of the 1986 conference on 'Research Priorities in Aboriginal Health'. We also noted how this conference culminated in a 'watershed' event in which Aboriginal delegates took control of part of the agenda and redirected the attention of conference delegates to issues connected with the politics and process of research. While Aboriginal organisations, particularly the Central Australian Aboriginal Congress, were closely involved from the beginning in organising the Alice Springs conference, the proceedings themselves were to give rise to an increasing sense of unease and anger among some Indigenous (and non-Indigenous) participants—an unease that brought a long-standing Indigenous distrust of 'Western' research processes into stark visibility. As Shane Houston frankly observed:

Remember, Aboriginal people weren't the people who had power at this forum, you know this was convened by two of the 'right-wing' research agencies and Menzies had a

³⁸ This and subsequent comments by Elizabeth Grant are taken from a taped and transcribed interview conducted with her in Canberra on 20 June 2001.

reputation for being one of the worst... so it got to the stage where Aboriginal people were increasingly frustrated with the meeting... It wasn't a pleasant conference, people increasingly got shitty and were caucusing quite regularly about how to arrest some control back from the conservative forces, that was how we described them because that was the nature of the time.

As noted by a number of people interviewed, the division of the conference proceedings into separate areas of 'clinical interest' was a major source of contention. Maggie Brady summarised this well:

I often wonder whether this time, the 1986 conference, was the origin of that phrase 'the body parts approach'. Because, as I recall, the 'coup' on the third day took the form of a series of speeches which attacked the way in which the conference had been set up—with having those areas, those 'body parts' if you like, the different illness categories, as the basis for proceedings. It was done because the NHMRC, I assume, genuinely wanted to know what should our priorities be in each area... I felt it [the take-over] was really a rebellion against experts, because there *were* the experts there, everybody was there, I mean all the top people of the time in all those different areas... But Aboriginal delegates were saying 'yes, we need research priorities, but the first thing is research itself'...

Rob Moodie confirmed this underlying groundswell of unease as the conference progressed:

I think it was a boiling up from the day before it [the takeover] started. And, you know, it was sort of an argument about who is speaking for whom, I mean it was a sort of a classic argument about who has got control of this conference and where is it going.³⁹

Among those interviewed there was some uncertainty as to what extent the 'coup' was an organised affair. The comment from Shane Houston, above, indicates that Indigenous delegates to the conference were indeed organising a concerted opposition to the conference proceedings. For others, such as Maggie Brady, the action seemed as much 'spur of the moment' as carefully planned:

It may have just been a fairly spontaneous reaction to having sat through two days of listening to all these doctors and other people talking about Aboriginal this and Aboriginal that, and this invoked a sudden kind of rebelling against that sense of being under the microscope—which, of course, they were... There were people who decided to 'take charge' [on the day of the takeover] and talked about it among themselves, but I don't think that it was planned from day one. My hunch would be that it was a kind of growing unease about feeling that the focus was on them as subjects, or objects in fact.

³⁹ This and subsequent comments by Rob Moodie are taken from a taped and transcribed interview conducted with him in Melbourne on 29 June 2001.

Whatever the case, the conference proceedings were indeed to be seriously challenged. As Elizabeth Grant commented:

It must have been around lunchtime (on the Friday of the conference) either all the Aboriginal people were going to walk out and leave us, and we were going to get nowhere, or they were going to tell us what they wanted. Which was exactly what happened. And for about three hours we sat there while they talked at us... It was pretty fiery and there was an enormous amount of anger. I think from all of us, because at that stage, in 1986, we weren't willing to be talked at. We thought we knew the lot I guess. Things have changed. You realise now how much things have changed between Aboriginal communities and ourselves and we now are willing to listen, but back then we were the experts and thought we knew it all.

Just as interviewees differed over the extent to which they felt the 'take-over' was highly planned, those interviewed also offered different memories of the conflictual nature of the event. As is evident in the comments already cited here, many felt that the 'take-over' was a pretty 'fiery' affair. This was reconfirmed by a further comment of Shane Houston's:

There was, eventually, this argument about the resolution of the workshop and the researchers were really getting shitty that Aboriginal people were exercising their right to tell researchers to fuck off, that we were not going to be guinea pigs, we were not going to be exploited any more... and it all got really hairy... it was not an easy meeting, there was real conflict at that meeting.

Others, however, took a slightly different view, as Ross Kalucy noted:

The vast amount of the audience were Aboriginal people, but the vast amount of speakers were white and there was this highly orchestrated protest... it wasn't alarming or anything, you could see that these guys had all got together and said we are going to give them a run and tell them what we need is this and this... We all kind of listened, and a lot of things they said you could write the speeches yourself, you know, but in some ways it was probably the first time the NHMRC had been talked to like that...

Despite these varying interpretations of the event both Shane Houston and Ross Kalucy independently argued against interpreting the actions of Aboriginal delegates as a straightforward Indigenous 'attack' on white researchers. As Ross Kalucy observed:

No, it wasn't like that, it had a funny side. Morning tea would come out and we would all go outside and chat, it was quite funny. I thought it was quite impressive really.

While Shane Houston insisted that:

It wasn't an 'attack', I think it was an opportunity to very articulately set out our point of view... what was interesting about the '86 meeting as well is that it wasn't just Aboriginal

people who were pissed off, it wasn't just Aboriginal people who could see the opportunity, who had experienced the opportunity, for research to be used productively.

Nevertheless, there were clearly deep ideological differences underlying the events on the last day of the conference, as noted by Rob Moodie:

You know there were philosophical differences about approaches to research, not only in terms of exploring the cause of illnesses but of the interventions to be devised. There was a sort of philosophical divide about that and [about] whose research it was, who controlled it, who did it, who paid for it, the training of Aboriginal people and their involvement in it... You know they [Aboriginal communities] weren't seeing any benefit in terms of building their capacity or building the capacity of Aboriginal health researchers.

With hindsight, almost all of those interviewed recognised that this 'divide' fuelled both the heatedness of debate and encouraged a certain 'ritualised' or 'rehearsed' critique in which, as Ross Kalucy implies in his comment above, Indigenous delegates said things that needed to be said, but which were not necessarily 'new' to many of those present. There were, then, clearly 'costs' to this process, however assertive and positive the actions of Indigenous delegates might have been. We have already noted the blanket demonising of research and researchers. Equally, there were costs relating to the divisions being drawn between camps, divisions that were both constructive and destructive, as Rob Moodie noted:

There was quite a political divide [created]. I mean some of it, a lot of it, was obviously driven by Aboriginal people but people like myself who are non-Aboriginal were very forceful in helping create or continue that divide; sometimes it [this division] worked... but other times it probably didn't help.

Finally, there were more practical costs to revising the agenda, as Maggie Brady observed:

I remember that the people in each session [of the conference] did nut out beforehand what they thought were the crucial issues that needed more research within their topic and, in fact, [the conference] was on target to produce what the NHMRC had in mind for it. But for whatever reason it was thrown out and I can remember being terribly disappointed actually, because I remember thinking that [the conference] was going somewhere because everyone was sifting through and... workshopping what were the key issues within those topics... I think it [the takeover] was very much about 'it's our turn to tell our stories' and I can remember thinking, this is great but it's not really going to help setting the priorities for research...

It is interesting now to recognise the energy being directed over the past few years into revisiting this issue of priorities. As early as 1991, recognising the need to return to this issue, a further conference was organised on 'Aboriginal Health Research Priorities' involving delegates both from government agencies and community-based organisations. This conference, held at the Australian Institute of Aboriginal and

Torres Strait Islander Studies in Canberra, once again questioned the direction of Aboriginal health research. However, it focused specifically on the *use and usefulness* of research and the knowledge derived from it (Houston & Legge 1992). In some sense, then, the earlier 1986 ‘fight’ over research practices and the subsequent development of guidelines may have postponed, but also eventually *enabled*, constructive discussion about such ‘priorities’.

As we noted in Section Two, the 1986 Alice Springs conference ended up in the open air with delegates nutting-out a detailed and lengthy set of eighty-seven conference recommendations that were to prove both contentious and act as the basis for the subsequent Camden workshop. Elizabeth Grant recalled this process and noted, too, how challenging it was, at least for those involved in organising the conference itself:

We finished up [after the ‘take over’] when it was dark, sitting out in the garden, all sitting on the grass just talking and somebody taking notes and somebody else facilitating. You could hardly see it was dark, black as pitch. And we sat there till quite late and finally came out of it. It was a big lesson to us all and we came home thinking ‘where are we going now and what are we going to do?’ But, boy it gave us the idea that we weren’t going to write things like guidelines quickly. We weren’t going to write them ourselves, without lots of consultation and we weren’t necessarily going to get them accepted very quickly and, as you know, they never have been officially accepted. They are still interim after all these years.

The Camden Workshop

The development of the *Interim Guidelines* was, as Elizabeth Grant well observed, certainly not going to be an easy task. For Indigenous organisations such as NAIHO the concentration on devising guidelines was not seen as an end process in itself. Indeed, a number of those interviewed noted that by concentrating on establishing ‘Aboriginal authority’ over the research process, Indigenous organisations and individuals were seeing this as an avenue to broaching the issue of Aboriginal control of the broader health sphere; both research and services. As Rob Moodie commented:

[Concentrating on the ethics of research] was only part of the bigger picture. I don’t think anybody [at the Camden gathering] was fooling themselves about the hemisphere of research. But it [concentrating on research ethics] actually provided quite a tangible place for a good fight about broader issues relating to who runs what. And that’s actually why I think there was a hell of a lot of interest in it [the development of guidelines] because there was resentment about research from Aboriginal people but there was also this opportunity to discuss disputed territory, not only in terms of research but the delivery of health services. In many ways it was sort of easier to focus on this area [research] as one of those areas of disputed territory, and one that should obviously be resolved in favour of Aboriginal communities.

This perception of Camden as an important opportunity for Indigenous communities to assert authority within the Aboriginal health field, as well as to tackle the ethics of the research process, was confirmed by Ted Wilkes:

When I had the opportunity to go to Camden and talk about health ethics I thought; ‘Wow, this is great, if we can get something documented or down that us Aboriginal people start together, rather than depending on non-Aboriginal people to help us, this is what I want to do’... it was striking while the iron was hot, and whilst the NHMRC was something we could have easily turned our back on, our leadership said to us at that time, ‘If we walk away now we won’t get this done for another decade... While we had to chew on iron and we had to spit chips, we did it... and I think a lot of us thought it was a very bold step for some of us to take, cementing a partnership and saying to a very instrumental resource agency [the NHMRC] that the partnership had to be around the Aboriginal right to self determine and control.’⁴⁰

And, as Shane Houston further observed, the impetus to work with the NHMRC came, in part, from a political shift within Aboriginal community organisations:

From about 1985 it really started to emerge that the old way of doing things had worked and had delivered to this point, but the further growth of the Aboriginal health movement needed new themes and new approaches in some ways.

Part of this ‘shift’ was the emergence of a more vigorous Indigenous interest in selectively working with government agencies, such as the NHMRC, and this eventually culminated in the organisation of the Camden gathering. Ross Kalucy remembered, in good spirit, that his invitation to this workshop came somewhat ‘out of the blue’, six months after the Alice Springs conference, and that it was wholly organised by NAIHO. Of the workshop itself Kalucy noted that:

There were only two white people there, as I remember, and all these Aboriginal people, some of whom I knew, but most of whom I didn’t. Shane [Houston] was chairing it and... about once every hour and a half Dick [Lovell] and I got kicked out while they discussed something or other, and then we got brought back in and [through this process] a document was written up. It was a stormy day, but quite productive.

This ‘document’, as far as can be ascertained, eventually became the basis for Shane Houston’s report on the workshop, which, in turn, became the primary working document for the development of the *Interim Guidelines*. This document constituted progressive notes on the various issues discussed during the workshop sessions and was typed up during the workshop itself. Of the content of these notes Ross Kalucy further commented that:

What we decided to do was, wherever possible, just use the exact language delegates used, we used their language wherever we could, this was crucial to the process but also... underneath the surface of this there was a lot of tension and worry and paranoia... and we could easily see that if we changed something we could be in strife. We found [by the end] that we had in fact covered everything we wanted to cover, except we couldn’t get an

⁴⁰ This and subsequent comments by Ted Wilkes are taken from a taped and transcribed interview conducted with him and Shane Houston in Perth on 2 July 2001.

agreement on who owned the data... we got it 80% right, but we just couldn't get the last 20%... we just didn't get any agreement on that so we elected to say that this [document] is incomplete, but it does some of the things we wanted it to do.

While the ownership of data was certainly a major sticking point, so too, though perhaps to a lesser extent, was the issue of funding. As Shane Houston commented:

Control over the funding was one way of ensuring people did it right and that was one of the important issues that came up and that was always present [during the Camden negotiations]. The community-controlled sector strongly believed at that time, and still does, that if you control the purse you actually control the policy and control what happens.

Ross Kalucy, however, suggested that while funding may have been an issue it seemed less prominent as a point of discussion, not least because it was made clear that the NHMRC representatives at Camden had no authority to negotiate over this issue. As Kalucy commented:

As far as funding of research goes, at the end of the day we weren't going to change the way the NHMRC worked... We couldn't say to them that out of this [the Camden workshop] there would be more money... We had to explain how the system worked, and I don't recall that becoming a bone of contention, it may have done, but I don't recall it. But what is true is that it [the Camden workshop] helped focus people's minds on how you fund Aboriginal research...

Finalising the Interim Guidelines

In Section Two we noted that by 1988, in response to the Camden meeting, the NHMRC had allocated \$25,000 to a process of consultation regarding the drafting of the ethical guidelines. Initially it was intended to use this money to visit Aboriginal communities around Australia but, as Elizabeth Grant explained, this process was quickly truncated:

Originally we thought that once we had gotten to the stage of having a draft set of guidelines [after the Camden meeting] we would then travel around and do a tour of a number of Aboriginal communities right throughout Australia, but it just proved too expensive. We had \$25,000 and it wasn't going anywhere. And we realised that you needed a year and you would need to be very flexible... and we didn't have that sort of money or that sort of time. So then we compromised and talked more to people where we could get them around a table.

As previously noted this process of consultation, and the years between the Camden workshop and the eventual release of the *Interim Guidelines* in 1991, has proved difficult to map out, not least because the process of guideline development in this period was both somewhat ad hoc and rather 'stop-start'. This difficulty was also evident in the interview process, with few of those interviewed able to pin down the sequence of activities pursued during this time. The process itself was, however, as we

have already noted, eventually managed through an Aboriginal ‘working party’ formed under the auspices of the MREC. Drafts and redrafts of the guidelines moved back and forth between the working party and Shane Houston, as head of NAIHO, who would then consult with the membership. Ted Wilkes remembered:

Shane sending it [the draft guidelines] to me a couple of times for comment, and to the membership, and saying we need comment on these, and I sent it back. Certainly there was a period of consultation in relation to those guidelines that we went through.

This period was, no doubt for all involved, a drawn-out process. As Elizabeth Grant further observed:

Everything we wrote we sent to Shane Houston and it would come back with marks all over it and we’d have to start again. We tried hard and we tried to consult but it was not as easy as we thought it was going to be and it took us a lot longer... I remember there were times when I couldn’t see any way through and I would think ‘Oh God, we are never going to get anywhere’... But we were resourced at least well enough to be able to do it...

Others were slightly more critical, not of those involved in the process but of the form it took. As one interviewee put it:

I do think on reflection that the committee process relating to the drafting of the guidelines was pretty ad hoc. The process involved basically scrolling through the latest version of the original ‘Camden’ document. And, ultimately, the *Interim Guidelines* were sent out as, quite frankly, an unwieldy document because everyone was too nervous to do much more. I think the processes were a little bit vague.

The Reception of the Guidelines

The rise of ethical guidelines within the area of health research, as in other disciplinary contexts, has been met as much with scepticism and opposition as acceptance and celebration. This is no less the case with Indigenous health research guidelines. Indeed, the efforts of a body like the NHMRC to pursue the formulation of such guidelines was greeted with apprehension by many biomedical researchers. As Elizabeth Grant noted:

As I remember, yes, [medical] researchers weren’t happy, researchers at that stage were not really happy about guidelines when we started off. They thought they knew the lot, and I think people out there looking at Aboriginal health had the idea that they wanted to help Aboriginal communities... but they didn’t really think they should have to go and do the sorts of things [the guidelines] said they should do, or to consult... I think there was a certain amount of antagonism towards what we were doing.

Ross Kalucy confirmed these sentiments, adding that in response to the guidelines ‘both sides’ still held on to the past:

I have to say that [in responding to the guidelines] there were faults on both sides. Some of the white researchers were put out by having to go through the process... and some of them, to my eye anyway, held on to a state of mind about bringing 'good' to Aboriginal communities [through their research]. On the other side there was no forgiving and forgetting in the Aboriginal community about past insults and so on. But, for all this, there were clearly immediate examples of where the guidelines did help.

They might also have 'helped' in unpredictable ways. The guidelines themselves, as a number of interviewees noted, quickly had 'ripple effects' beyond that originally envisaged, effects that significantly challenged research bodies. As Kalucy further noted:

The guidelines had quite an important effect on the NHMRC's understanding of culture, this was not something the NHMRC was strong on before and the guidelines made them realise that traditional Western research methods were not always the best, and this left them thinking about research in other areas as well (such as HIV/AIDS) and it gave impetus to the establishment of state Aboriginal health ethics committees.

Ted Wilkes also recognised a ripple effect in that the whole process of co-operation and collaboration over the formulation of the guidelines served as a model for other collaborations between Aboriginal and non-Aboriginal people. Further, Wilkes noted the usefulness of having a set of even 'interim' ethical principles on which to draw in other contexts:

... the greatest [immediate] thing that happened as a result of the guidelines being presented is that people who were then selected to develop and deliver a National Aboriginal Health Strategy were far more equipped to do it... with these draft guidelines to refer to.

Finally, there was a sense among many of those interviewed that the guidelines themselves at least enabled some form of Aboriginal empowerment in relation to research, however limited. As Ross Kalucy noted:

[One] of the reasons why I thought the guidelines were important was that here was a community that was disempowered and here at last they found something, one little thing... that might help [in relation to research].

Shane Houston put this idea even more forcefully when he importantly observed:

This [the guideline development process] was one of the early successful examples of the community taking control of an issue and saying this is how it's going to be done, and negotiating through a partnership to deliver a result.

A Decade on

Without exception, all of those consulted for this study spoke of the *Interim Guidelines* as a document of crucial historical and practical importance. For many, the guidelines were understood as undoubtedly contributing to a significant, if somewhat incomplete, transformation of research practices within the Indigenous health sphere. In addition, many saw them as being of broader significance in terms of building a sense of the importance and possibility of collaboration between Indigenous and non-Indigenous organisations and individuals. None of the interviewees, however, were under any illusion that the *Interim Guidelines* have been able to ‘remake’ research practice fully. As Maggie Brady noted:

Well I mean that’s the other thing, really they [the guidelines] have no teeth if you are honest about it... Whilst they can sieve out people who can’t be bothered to go through all those processes... there’s still no real comeback if [researchers] do anything wrong apart from word of mouth, which is powerful in the Aboriginal field. I mean, honestly, with the guidelines what comeback does any Aboriginal group have... in a way it’s all a kind of heuristic device, which works to quite a large extent.

In a slightly different vein, some interviewees lamented how slow the ‘research establishment’ has been to engage fully with the issue of research ethics, particularly given the contemporary culture of academia. As Ted Wilkes commented:

I think what’s alarmed me more than anything [over the last decade] is the reluctance of researchers, non-Aboriginal researchers, to actually take up the fight [over research ethics] themselves, to become more ethically and morally obliged, and it’s only come about [the attention to research ethics] because of our insistence, saying to non-Aboriginal people, you’ve got to do it.

These comments—on the heuristic nature of the guidelines and on the continued reticence by some researchers to embrace more fully, and to advocate for, the formal establishment of ethical protocols—touch on key issues that have been central to the past decade of debate over the *Interim Guidelines* and, in fact, ethical guidelines more generally. In a slightly different vein, however, some of those interviewed mentioned one further contentious but important issue; the possible emergence of a culture of ‘over-regulation’ as ethics committees multiply, often without sufficient regulation of their own activities. Once again, Maggie Brady raised this issue with clarity and frankness:

One wonders now whether things have gone, you know, too far the other way so that there are now so many complex processes [to go through]. I mean there’s no controls over the number of ethics committees that a particular proposal has to go through; some people end up going through three or four different Indigenous health committees... so there’s a sort of overkill in some places... It [also] has to work both ways in my view. If there are going to be properly constituted ethics committees, which I fully support, and people are forced to go through them... then there has to be some expectation of the

responsibilities of the committees. That includes guarantees of response within a certain amount of time... and that they have to run efficiently and have to treat applications seriously...

To reiterate, however, these critical comments from Maggie Brady, Ted Wilkes and others were embedded within a highly positive assessment of the role of the guidelines overall. Indeed, there was a general consensus among all those consulted for this study that, while not bringing about a radical change in research culture, the development of the presence of the *Interim Guidelines* has been important as a 'gradualist' mechanism through which to transform research practices. As Elizabeth Grant commented:

Yes I think they [the guidelines] have been productive. I think there is much more understanding within the research community that you can't march in and do your research, and I think that Aboriginal communities are starting to see some benefits from the research that is being done. But I don't think we have got there quite yet.

This productive gradualism was also noted by Ross Kalucy:

The feeling I get, and I think it was and remains the same feeling on both sides, is that [the guidelines] were going somewhere, and if they went 50% of the way, then it was worth being involved and worth doing.

And, indeed, Ted Wilkes echoed these sentiments:

I thought the guidelines were a step in the right direction... we had moved to something better than we had in the previous five years and I thought, well that's good enough for me because in five to ten years time we could review them...

Revising the Guidelines

In bringing this section of the report to a close, it is perhaps timely to comment briefly on how those interviewed for this study conceptualised the process of revising the *Interim Guidelines*. Although this issue was not explored in detail with interviewees, a number of passing comments relating to such revision were certainly offered, with most people, at the very least, insisting that, given the previous model of co-operation, any revision should be an 'easier' and 'known' process. Two comments on the revision of the guidelines, however, stood out and provide a suitable note on which to move to a conclusion. Firstly, Elizabeth Grant insisted that:

I don't think you have got any option but to do it [revise the guidelines] in much the same way again. I think you can use the existing guidelines as a basis, but I think you have got to go out and consult. I think you have got to talk to the communities, because they have changed in twenty years and their needs are much different. I [also] think you have got to retain the emphasis on the fact that these guidelines are for health improvement, first and foremost, not just for facilitating research into something, and that there are special rules

to follow. I think these sorts of things have got to be emphasised, they haven't gone away. And I think we have still got to be careful that we don't try and impose research on communities.

Secondly, Ted Wilkes cemented this final point on the need to continue tackling entrenched understandings of the role of research:

We [Aboriginal people] realise that research is very necessary, but researchers haven't realised that Aboriginal people don't want research to happen for the sake of research, we still say that to researchers; stop research for research's sake, do it with the practical importance of a quality of life in mind.

Four Conclusion

Should we conclude this report with an affirmation of the development of the *Interim Guidelines* and their use over the past decade or, instead, point to the problems involved in this development and use? Clearly, in the interests of balance, we would want to do both. As the comments cited throughout Section Three overwhelmingly indicate, the Interim Guidelines have proven highly significant: firstly, as a means of partially transforming research practices within the Indigenous health field; secondly, as an illustration of collaboration and co-operation between Indigenous and non-Indigenous organisations; and, thirdly, as an assertion of Indigenous authority and control.

However, in a report of this nature there is limited value in simply ending on a warm and fuzzy note. If we are to ‘apply’ the history constructed here, our interest should be in exploring critically and constructively the process of guideline development; this critical perspective has framed the narrative offered within this report. In briefly concluding this narrative account, attention will thus be drawn to several problematic issues concerning the development of the *Interim Guidelines*: the apparent absence of a broad conceptualisation and discussion of the role and limits of ‘guidelines’ and a related inattention to the role and dynamics of ethics committees in interpreting them; the ad hoc nature of the guideline development process; and the concomitant ‘unfinished’, ‘unbalanced’ and ‘unratified’ nature of the interim guidelines released.

Conceptualising the Guidelines and their Interpretation

In his 1993 study of the ethics and politics of human experimentation, Paul M. McNeill noted that there is an implicit dilemma within processes of ethical review between, on the one hand, *promoting* research and, on the other, *protecting* the rights and interests of those being studied.⁴¹ Although McNeill’s discussion—and useful exploration of the balance between the interests of ‘science’ and of the ‘subject’—does not directly deal with Indigenous health issues, his point has even greater relevance in this context. Always lurking in the background of the development of the *Interim Guidelines*, and present still, is this very question; are the guidelines there to facilitate or to prevent research into Indigenous health? This question could be answered in one of two ways; the *Interim Guidelines* are either there to promote appropriate or to prevent inappropriate research. Although these are seemingly different ways of saying the same thing, they are not. Rather, these responses differ subtly in the value accorded to ‘research’ as a way of producing knowledge about a particular area, and in the role accorded to protocols designed to govern this activity.⁴²

41 McNeill, *The Ethics and Politics of Human Experimentation*, p. 5.

42 In McNeill’s terms this tension arises in part from the fact that protocols such as those of the *Interim Guidelines* differ from other such rules of research conduct in that they move beyond a benevolent ‘protectionism’ and in fact represent a process of consultation and consensus between ‘both sides’ of the research agenda, those wanting to do the research and those who are conventionally the subjects of it.

In reviewing the history of the development of the *Interim Guidelines* this tension constantly made itself evident, though often in intangible ways. It was clear in documenting this history that the first imperative for Indigenous organisations and individuals involved in the process of guideline development was to 'block' research, at least initially. Conversely, for organisations such as the NHMRC the impetus to formulate protocols was clearly underlined by a desire to increase 'successful' research into aspects of Indigenous health. This tension, informed as it is by different evaluations and historical experiences of research, is deeply ingrained within the written guidelines themselves. And it is a tension that will probably always remain present in any such guidelines, notwithstanding their revision.

In the face of this, most would probably agree that such tensions can only be dealt with effectively *in process*, in applying the letter and spirit of the *Interim Guidelines* to specific instances of research. But this is also a recognition of the *limits* of guidelines themselves; that guidelines do not work 'on paper' but only through their actual use, through making interpretations and judgments based on the protocols outlined.

One central aspect of the development of the *Interim guidelines* that came through very clearly in documenting their history was the absence of discussion, at least publicly, of these perhaps more philosophical issues about the purpose and possible effectiveness of 'guidelines' themselves. Equally, the guideline development process showed little awareness of, or concern for, the way in which the guidelines released were inevitably to be interpreted through a *committee system* that was itself a relatively new and underformulated process. Thus, notwithstanding some early qualms by Aboriginal representatives about the usefulness of guidelines in changing research practices, ultimately a certain rather static and legalistic conception of the *Interim Guidelines* seemed to inform their final release and use. To recognise this is not to criticise those involved in developing the guidelines; after all, they had few 'models' for such guideline development. It is to suggest, with hindsight, that any revision of the guidelines might usefully involve some broader discussion both of the *limits* of such written protocols and, perhaps most importantly, of the *committee systems* that will draw on them.

Improving the Process

Perhaps the most obvious, even glaring, limitation of the guideline development process evidenced within the history offered here is the highly *ad hoc* nature of that process, or at least aspects of it. While it would generally be recognised that there is always a need for great flexibility in pursuing collaborations between Indigenous and non-Indigenous organisations and agencies, the historical evidence suggests that with the development of the *Interim Guidelines* things were slightly too unplanned, particularly in the intervening years between the Camden workshop and the release of the guidelines in 1991. This fact was confirmed by a number of those interviewed. Indeed, all of those closely involved in the drafting of the guidelines had difficulty in remembering and sequencing this process.

Once again, no particular criticism is intended here, not least because as a quite ‘new’ form of collaboration those involved in developing the *Interim Guidelines* were, in no uncertain terms, exploring a rather unknown ground of co-operation. There is, however, a definite sense within the documentary and oral history offered here both of a ‘funneling effect’, in which fewer and fewer people were ultimately to have input into the drafting of the guidelines, and of an ‘exhaustion effect’, in which the guideline development process somewhat stumbled to completion. Thus, in revising the *Interim Guidelines* it might be important to attend more closely to the final steps of any process pursued, and to have clear strategies in place for bringing that process of guideline development to a transparent, more highly participatory and solid, rather than ‘just over the line’, finish.

The Wording and Authority of the Guidelines

In closing, it is worth commenting briefly on the framework of the *Interim Guidelines* themselves, as well as on what could be called their aura of legitimacy.

As we have noted in this report, and particularly in Section Three, one of the major ‘sticking points’ in negotiations between NAIHO and the NHMRC over the content of the guidelines was in relation to the issue of the ownership and publication of data. Perhaps rather oddly, the eventual manner in which this source of tension was expressed in the final *Interim Guidelines* was through an over-preponderance of clauses relating to data issues. Thus, the guidelines issued were, even on a sympathetic reading, lacking in ‘balance’ with eight of the fifteen clauses relating to ‘ownership and publication of data’, and only three relating to ‘consultation’ and four to ‘community development’. While one cannot approach such guidelines with the mentality of an accountant, it does appear that the tensions over the formulation of the guidelines could be said to have partially ‘skewed’ the protocols formulated, and led to the centering of the document around an issue of particular concern to a ‘Western’ research paradigm.

The issue here, then, is not the number of clauses on data and publication issues released within the *Interim Guidelines*, but the lack of equal treatment of other areas and the manner in which this skewed aspect of the guidelines was incidentally created through the then pattern of debate and negotiation. It would seem that in any revision of the document, attention should be given to the internal balance of the protocols adopted. Those people involved in the process should guard against the particular issues of the moment dominating a set of guidelines that will need to be utilised for years to come. In a sense, this is the basic proviso of any process of revising a set of written principles; those principles need not only to be ‘of the moment’ but also to look to possible future issues.

Finally, evident as well within this history is a perhaps more contentious issue on which to close. Historically, the ‘making’ of the *Interim Guidelines* does not wholly support the authority or legitimacy they have been given. Not only do the *Interim Guidelines* remain unratified by the NHMRC, but the process of their construction

and final wording was, as we have already noted, *ad hoc* and less than transparent. The guidelines certainly have legitimacy, but it is tenuous. Indeed, the *Interim Guidelines* are, arguably, nowhere near as comprehensive or as encompassing as a number of other Indigenous research guidelines that have been developed, often within Indigenous-controlled or directed organisations, over the past decade. Yet, it is the *Interim Guidelines* that are most regularly, even exclusively, used by ethics committees nationwide. Perhaps the lesson to be noted here for any successful revision of the guidelines is the need to: firstly, more clearly justify or substantiate any ‘authority’ that a revised set of guidelines will be given; and, secondly, to relate a revised set of guidelines much more closely to other existing sets of Indigenous research protocols.

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