

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

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CONTENTS

	Page
Submission	1
FOREWORD	3
HISTORICAL BACKGROUND	4
NEW DEVELOPMENTS	6
FORMAT	6
GUIDELINES CONCERNING ABORIGINAL AND TORRES STRAIT	
ISLANDER HEALTH RESEARCH	6
CONSULTATION	6
COMMUNITY INVOLVEMENT	7
OWNERSHIP AND PUBLICATION OF DATA	8

Submission

June 1991

Dr D Horvath
Chairman
National Health and Medical Research Council

Dear Dr Horvath

On behalf of the Medical Research Ethics Committee I have pleasure in submitting our Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research.

The general ethical principles in the area of research on Aboriginal and Torres Strait Islander health are not different from those that apply to any research where human experimentation is undertaken. These are covered by the NHMRC Statement on Human Experimentation and Supplementary Notes as published from time to time. This document should be used in conjunction with these guidelines.

The Medical Research Ethics Committee (MREC) believes that research programmes involving Aborigines and Torres Strait Islanders and Aboriginal and Torres Strait Islander communities require particularly sensitive attention to ethical issues.

The impetus for these guidelines can be traced to the initiatives of the Special Purposes Committee of the NHMRC and the Menzies Foundation in convening a national conference on 'Research Priorities in Aboriginal Health' in Alice Springs in December 1986. It emerged from that conference that ethics in relation to Aboriginal and Torres Strait Islander health was seen as a high priority.

In response to this acknowledged priority, the 'National Workshop of Ethics in Aboriginal Health' was held at Camden, NSW in August 1987. Some thirty Aboriginal community representatives from around Australia attended. As a result of this meeting a set of Advisory Notes were prepared by MREC as a forerunner to the publication of comprehensive guidelines.

In preparing these guidelines we gratefully acknowledge the support and assistance provided by the workshop participants and in particular, the convenor Mr Shane Houston. We are also particularly indebted to Mrs Elizabeth Grant and the members of the Aboriginal Working Party, Ms Maggie Brady, Ms Marion Kickett and Mr Jim Ramsey for their time and expertise and their thoughtful and relevant comments. We also extend our thanks to the NHMRC Secretariat for their support and assistance.

We sought comment on the guidelines from the health and medical research community and from Aboriginal and Torres Strait Islander groups and communities. The replies we received were most supportive and constructive. Wherever possible we have incorporated appropriate comments into the guidelines.

As with other documents that we have prepared, we believe these guidelines should be seen as an evolutionary document that should be reviewed from time to time to take into account changes in social and community attitudes.

Yours sincerely

Chairman
Medical Research Ethics Committee

FOREWORD

This document 'Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Research' replaces the previous document from the Medical Research Ethics Committee (MREC) of the National Health and Medical Research Council (NHMRC) - 'Some Advisory Notes on Ethical Matters in Aboriginal Research'. That document contained extracts from the 'Report on the National Workshop of Research in Aboriginal Health' held at Camden, NSW, 29 July 1989. The workshop report is now included as an appendix.

When the advisory notes were written, there were certain issues which were not able to be addressed. However, following further consultation, those issues have now been included and have resulted in this series of guidelines to assist Aboriginal and Torres Strait Island communities, ethics committees and the research community when research involving Aboriginal and Torres Strait Island people is being considered and undertaken.

HISTORICAL BACKGROUND

In December 1986, the NHMRC and the Menzies Foundation convened a national conference on 'Research Priorities in Aboriginal Health' in Alice Springs. Of the recommendations that emerged, ethics in relation to Aboriginal health was seen as a high priority.

Following agreement from the Conference, a convenor, Mr Shane Houston, was elected with responsibility to draw together Aboriginal community representatives from around Australia at a national workshop with the view to producing a set of guidelines on the ethical aspects of research in Aboriginal health.

The 'National Workshop of Ethics in Aboriginal Health' (the Ethics Workshop) was convened in August 1987, and was funded by the NHMRC. It was held over three days at "Tallimba", near Camden, New South Wales. It was attended by some thirty Aboriginal community representatives, and two NHMRC observers. The result of this meeting was a set of Advisory Notes which would lead to a final comprehensive document with recommendations and guidelines.

At the time of the Alice Springs Workshop the MREC was convinced that the Aboriginal community singles itself out for special consideration because of:

- (a) its conspicuous level of poor health stemming from social, historical and cultural factors.
- (b) the fact that past research into Aboriginal health has failed to address this poor level of health adequately, but has often concerned itself primarily with matters of interest to science or to white Australians
- (c) insensitivity among researchers to the values, needs and customs of Aboriginal and Torres Strait Islander communities*. These have included:
 - . lack of understanding concerning cultural responsibilities and sensitivities of 'women's business' and 'men's business';

* The term 'communities' is used throughout this document for ease of expression, to refer to Aboriginals and Torres Strait Islanders living in urban, rural or remote locations. Where no clearly identifiable community exists in a geographical sense, an Aboriginal or Torres Strait Islander controlled agency may be an appropriate body to negotiate with a researcher.

- . inadequate awareness of the sensitivity of medical dealings with women as opposed to men;
 - . inappropriate procedures in performing post-mortem examinations (in which the removal or withholding of organs presents particular difficulties)
 - . inappropriate requests for, and handling of, blood and other biological specimens;
 - . publication of inappropriate pictorial material (e.g. Photographs of deceased persons)
- (d) a lack of appreciation of ethical issues relevant to research involving Aboriginal and Torres Strait Islander people, which led to:
- . advice and approval of Aboriginal or Torres Strait Islander individuals in Government departments being accepted as a substitute for proper community consultations and negotiations;
 - . lesser standards for obtaining consent among disadvantaged Aboriginal and Torres Strait Islander communities;
 - . failure to appreciate that the researcher's social status as determined by a community will be a vital consideration in determining whether access to sensitive areas will be permitted;
 - . conflict between activities thought to be ethically proper for scientific research and Aboriginal and Torres Strait Islander views on moral, social and cultural correctness;
 - . Aboriginal and Torres Strait Islander groups being more vulnerable than other human groups in Australia to exploitation by persons conducting research.

The special consideration which is due to Aboriginal and Torres Strait Islander communities and groups does not justify anything less than the highest standards in the conduct of research concerning them. In particular, open publication of methods and findings is the essence of ethical, verifiable scientific research.

NEW DEVELOPMENTS

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

FORMAT

The guidelines are presented under the following headings;

- . Consultation
- . Community Involvement
- . Ownership and Publication of Data

GUIDELINES CONCERNING ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

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

CONSULTATION

1. In the preparation of the research proposal, the researcher has sought advice not only from State, Territory and Federal Aboriginal and Torres Strait Islander Health agencies, but also from local community-controlled Aboriginal and Torres Strait Islander health services and agencies.
2. The Aboriginal and Torres Strait Islander community, or appropriate community controlled agency able to represent the Aboriginal and Torres Strait Islander group which is the focus or context of research, has indicated that the research being proposed will be potentially useful to the community in particular or Aboriginal and Torres Strait Islanders in general, and will be conducted in a way that is sensitive to the cultural and political situation of that

community.

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

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

- (a) provision of information in a form accessible to community members and able to be readily understood by them. This information should have included details of the collection and analysis of data, and the drafting and publication of reports. It should also list any potential costs to the community as well as potential benefits;
- (b) face-to-face discussions with community groups and individuals concerned wherever possible and where this has not been possible, the reasons should be documented;
- (c) the allowance of sufficient time for the community and the individuals concerned to assimilate and respond to the information offered;
- (d) demonstration of a process for obtaining free consent from individuals as well as written evidence of consent by the community-at-large;
- (e) provision of information to participants that consent may be withdrawn at any time.

COMMUNITY INVOLVEMENT

4. Members of the Aboriginal and Torres Strait Islander community being studied will be offered the opportunity to assist in the research and will be paid for the assistance, and the funds to support that assistance are included in the research budget proposal. Specifically, Aboriginal and Torres Strait Islander women, as advised by the community, will be involved when research deals with women's or children's health issues; and the specific cultural and social needs of Aboriginal and Torres Strait Islander men will be similarly recognised.
5. The researcher has accounted for any resources which may be made use of in the conduct of the research, has costed these in the research proposal, and has demonstrated a process for reimbursing the community and/or individuals for any such costs.
6. The researcher recognises the right of the community to request further information about aspects of ongoing research, and accepts that changes in research protocols, procedures or methodologies will require further negotiations with the community and consent for that change by the community or an agency nominated by the community. The IEC must also be notified and be given the opportunity to approve changes to the research protocol.

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

OWNERSHIP AND PUBLICATION OF DATA

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

8. Following completion of data collection and analysis, and before any publication or presentation of this data, a summary of the findings will be reported to the community as a whole. Details of findings relevant to their health or well-being will be confidentially conveyed to individuals who participated together with counselling as appropriate.
9. If a researcher wishes to use the information or blood or tissue samples gathered in the course of research for any purpose other than that for which consent was obtained, further permission must be sought from the community.
10. The return of identifiable raw data, its destruction, or secure storage on completion of the research, should be negotiated with the community, or its nominated representative or agency, prior to the commencement of the research.
11. Results will not be published in a form which permits identification of individual subjects. Results which identify a particular Aboriginal or Torres Strait Islander community will not be published without permission from that community or from a community-controlled agency able to represent that community.
12. Pictorial material will be made only with the consent of the local community and will be handled in accord with their wishes.
13. Proper acknowledgement will be given to individuals and communities who took part in the research.
14. Wherever practicable, Aboriginal or Torres Strait Islander assistants who contributed to the research will be involved in the preparation of publications and will be acknowledged. Publication acknowledgement shall be in accordance with the NHMRC Statement on Scientific Practice.
15. Should the media solicit comments from researchers, once their work is in the public arena, researchers should first seek the consent of the community concerned. Comments to the media should be sensitive and professional and should focus on the research issues under consideration.