

**REPORT OF THE NATIONAL  
WORKSHOP**

**ON**

**ETHICS OF RESEARCH IN  
ABORIGINAL HEALTH**

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# EXECUTIVE SUMMARY

## 1. Obtaining of Ethical Approval.

Appropriate consultation/negotiation with Aboriginal communities is an essential pre-requisite to ethical research practice. Researchers should, at the earliest opportunity in the development of research proposals seek the ethical approval of participating communities. Ethical approval should be obtained in the following manner:

### A. Where a local Aboriginal community controlled Health Services Exists

That the primary point of contact for Researchers shall be the local community controlled Aboriginal Health Service and the National Aboriginal and Islander Health Organisation. Where the subject matter of research has not previously received ethical approval from that community, the matter should be the subject of a community meeting or meetings.

### B. Where a local community controlled Aboriginal Health Service does not exist

That the primary point of contact for Researchers shall be the local community controlled agencies and the National Aboriginal and Islander Health Organisation. Where the subject matter of research has not previously received ethical approval from that community, the matter should be the subject of community meeting or meetings

### C. Where no local community controlled Aboriginal agency exists

Researchers must firstly seek proper Aboriginal community involvement and approval at the local level. This must be done in a manner which respects local community structures. Concurrent approval must also be sought from the National Aboriginal and Islander Health Organisation. Where the subject matter of research has not previously received ethical approval from that community, the matter should be the subject of community meeting or meetings.

## 2. The Consultation Process.

Researchers are required to demonstrate to funding agencies and/or Ethics Committees that proper consultation with Aboriginal communities has occurred. Compliance with the following requirements shall demonstrate an acceptable level of consultation:

- provision of was provided according to the level of comprehension of the community. Such documentation should come from the local community controlled agency,

- provision of evidence of meetings with the concerned Aboriginal community, including what specific efforts have been taken to inform the community i.e. translations of materials detailing the intent and methodology of the proposed research,
- provision of material that demonstrates that Researchers have considered the benefit to the community, including efforts to promote sharing of research skills,
- provision of materials that demonstrates that Researchers have addressed the question of ownership of materials,
- provision of material that demonstrates the degree to which the Researcher has addressed social and cultural imperatives within the community.

### 3. Ongoing Review of Ethical Standards.

Ethics Committee's and relevant community controlled agencies have an ongoing responsibility to ensure compliance with appropriate ethical standards. Such a responsibility shall be exercised through the management of research project funding. The following provisions shall apply:

That where Aboriginal Health Services exist, that they be responsible for the administration of funds for research initiatives,

that where no local community controlled Health Service exists, that the local community controlled agency be responsible for the administration of funds,

that where no local community controlled agency exists, that funding be administered by an agreed community controlled agency, such as the National Aboriginal and Islander Health Organisation.

### 4. Social, Gender and Cultural Issues.

The process of research in Aboriginal health presents potential areas of social and cultural conflict. Researchers must address this potential for conflict. The use, by Researchers of assumptions of moral, social or cultural correctness or appropriateness will interfere with community lifeways and denigrate research. In the development, implementation and evaluation of research proposals, researchers must seek the active participation and endorsement of communities to each stage of the process. If this Process results in revision to any stage of the research process the community should, once revisions have been incorporated consider its consent of the revised proposal to ensure protection of community lifeways.

Researchers should take great care in areas of research that deal with:

1. gender,
2. parenting, family and community structures and responsibilities,
3. personal and collective relationships,
4. invasions of the body,
5. handling of human specimens and products.

Researchers must also be aware that their social status, as determined by the community, as well as gender will be a vital consideration in determining access to sensitive areas of information or activity.

Specifically, Aboriginal women, as advised by the community must be involved when research deals with women's or children's issues. As a consequence, Aboriginal women are to monitor all research dealing with women's and children's issues.

Likewise, Researchers must not ignore the specific cultural and social needs of Aboriginal men in research programs.

The particular issue of post mortem examinations needs close attention and any research of this nature must respect the integrity of the person and relationships with the family, community and nation. For example the removal and withholding of organs presents particular difficulties.

The responsibility of Researchers to guard against violation of cultural and social imperatives beyond the primary contact with the community must also be addressed. The Researcher must obtain the approval of the community to any proposed use or publication of material or information collected during the research process.

Researchers must provide the community with an understanding of the process and intent of research. This would include an understanding of matters relating to the collection and analysis of data, the drafting and publication of reports and proposed future uses of research materials.

Researchers must be aware that any breaches of Aboriginal Lore/law may invoke community rebuff and/or punishment.

## 5. Communication and Consent.

Communities must be provided with all the relevant information and Community and must utilise appropriate Aboriginal educational process and tools.

Researchers must comply with any request for further information from relevant community controlled agencies associated with the research proposal.

The obligation of Researchers to comply with this requirement shall remain in force for the duration of any research project.

Community process of decision making will reflect varying social and cultural values. In obtaining the consent of communities to research, Researchers must respect the Aboriginal community's process of decision making.

Researchers must address this need, ensuring that they do not act in a pre-emptive or impulsive manner. For example, Researchers must allow sufficient lead time for the community to consider any proposals. Similarly, they should not seek to access cultural or community sub groups or individuals without prior permission.

Having addressed this point however, Researchers must be aware of the continuing need to obtain the consent of individual Aboriginal people that may either participate in or contribute to the execution of any research project.

## 6. Community Benefit and Employment of Local People.

Researchers seeking to work in Aboriginal communities may confront a variety of unfamiliar environments and circumstances. In many circumstances the employment of community members will aid the Researcher and improve the quality of communication and ultimately strengthen the initiative.

Researchers, where local community controlled agencies believe it necessary, must provide for the employment of local Aboriginal co-investigators.

Research should focus on, and provide knowledge about, activities and issues that will contribute to an improvement in Aboriginal health and foster community development.

Researchers must identify the areas and nature of the potential benefit and impact of research and obtain the concurrence of the local community controlled agencies that such outcomes are of value to the community at large.

## 7. Ownership and Publication of Materials.

Research material and data shall remain the property of the community. The community retains the right to censor research materials of a sensitive nature. Prior to any publication or other use of research materials or Reports, the approval of the relevant community controlled agency is required.

In preparing acknowledgement of research, the proper accreditation of participation and assistance of Aboriginal individuals, communities and their agencies should be noted.

Results of research must not be published in a form that permits identification of individual subjects and/or objects of a sensitive nature. Pictorial material should only be made with the consent of the local community and should be handled according to their wishes.

Researchers need to be aware that future utilisation and publication of materials may be jeopardised by the inclusion of pictorial materials. For example, use of pictorial materials where individuals are identified may be withdrawn from use when those identified individuals die.

## 8. Exploitation of Community Resources.

In seeking the co-operation of Aboriginal communities and local community controlled agencies, they (Researchers) must provide reimbursement of any cost incurred which relates, directly or indirectly to programs of research. Such costs could include telephones, transport, freight, gas and water, accommodation, supervision costs and wages of assistants or interpreters.

# FORWARD

In November, 1986 the National Health and Medical Research Council (N.H. & M.R.C.) and the Menzies Foundation convened, in Alice Springs a national conference on "Research Priorities in Aboriginal Health". Emerging from that conference was a series of recommendations which called on the N.H. & M.R.C. to provide resources to Aboriginal communities to convene a further national workshop which was to address the "contentious" issue of ethics, as it relates to Aboriginal health research.

The Alice Springs Conference adopted the following specific recommendations:

- that ethical guidelines for health research involving Aborigines be established,
- that these guidelines be established by a forum of Aboriginal people ... within 6 months,
- that this forum use as a basis for these guidelines a number of specific and general guidelines already in existence i.e. research guidelines of Central Australian Aboriginal Congress,
- that the close relationship between ethical guidelines and criteria for funding of research projects be recognised,
- that the Conference nominate an Aboriginal person to act as Convenor,
- that there be Aboriginal representation on the N.H. & M.R.C. Ethics Committee.

(A complete copy of the Alice Springs Conference's recommendations is attached at A.)

It is obvious that the Conference, particularly the Aboriginal participants placed considerable emphasis on the need for action in this field.

Following agreement from the Conference, a Convenor was elected whose responsibility it would be to draw together Aboriginal community representatives from around Australia in a national workshop with a view to producing a set of guidelines on the Ethical Responsibilities of research in Aboriginal Health. Mr Shane Houston, National Co-ordinator of the National Aboriginal and Islander health Organisation was subsequently elected to fulfil the role of Convenor.

That Workshop was convened in August, 1987 and was funded by the N.H. & M.R.C. Held at "Tallimba", near Camden N.S.W. it was attended by some 30 Aboriginal community representatives, representatives of the National Health and Medical Research Council and other delegates from around Australia. The Workshop met for 3 days. A list of Workshop participants is attached at Appendix B.

The Workshop was recorded and minutes have been prepared. The Report which follows is based on the preliminary minutes and Convenors notes from the Workshop.



# GOALS AND OBJECTIVES OF THE WORKSHOP

The Conference in Alice Springs provided a useful basis for the development of appropriate and achievable Goals and Objectives for the National Workshop. These were

1. develop a set of Ethical guidelines on research into Aboriginal health, and
2. identify the mechanisms necessary to establish a nexus between the guidelines and the funding of research into Aboriginal health.

These two principle aims were complimented by a number of clarifying statements which from the Alice Springs Conference. These were:

- that Aboriginal communities be given a greater say in the distribution of funds, allocation of priorities, the methodologies of research and the implementation and evaluation of research proposals;
- that Aboriginal communities be central to the development and execution of research,
- that communities receive financial support for research and development training;
- research which reflects the collective nature and needs of Aboriginal communities be given priority over that which is individualistically oriented,
- that priority be given to issues for research that are identified by Aboriginal communities.

The Workshop considered these matters and comments and adopted a set of Goals and Objectives for the Tallimba workshop. These were:-

That by the conclusion of the Workshop we shall have:

1. Prepared a draft document which outlines the ethical responsibilities relating to research in Aboriginal health,
2. Outlined a course of action to promote the positive use of the guidelines in the evaluation of proposals for research funding in Aboriginal health.
3. Identified mechanisms which recognise and respond to the pivotal role of Aboriginal communities in the design, execution and evaluation of research into Aboriginal health,

4. Identified the necessary steps and agencies to which the Guidelines are to be promulgated,
5. Identified the on-going consultation process with Aboriginal communities in respect of the above.

Having completed this task a broader workshop outline was considered and adopted. This approach fostered a sessional format in the Workshop and was based on:

- The role of research in Aboriginal health,
- The relevance of research within the Aboriginal reality,
- Principles, Standards and Rules - benefits and shortfalls,
- What are the right words - a drafting session,
- Final review - confirmation of the workshop results.

These five sessions provided the focus for further discussions and development.

# THE PROCESS OF CONSULTATION

This National Workshop heard, as the Alice Springs Conference had, of Aboriginal communities dissatisfaction with the historical approach of Researchers to the need for consultation/negotiation in respect of the subject matter and methodology of research in Aboriginal health. There was considerable discussion of the question of whether the development of "Guidelines" on this matter would be sufficient to bring about the attitudinal and behavioral change Aboriginal communities were seeking.

There was broad agreement that there was a need for some yardstick, against which, the approach and attitude of Researchers would be gauged. This yardstick would reflect what communities believed to be an acceptable level and process for consultation/negotiation. Compliance and enforcement of this minimum requirement would ensure the problems of the past were not repeated. The workshop considered that the term "Guidelines" did not convey the necessary tenor of our intent, rather it was suggested that the phrase of Principles, Standards and Rules was a clearer and more appropriate description of our intent. This phrase was adopted by the Workshop as the title of our work.

## The Process of Consultation

The Workshop agreed that research in the past, had been invasive and conducted with little or no real consultation/negotiation with Aboriginal communities. The Workshop also agreed that this was not appropriate. The lack of consultation/negotiation had contributed to conflicts within Aboriginal communities and between communities and research agents. Misconceptions about Aboriginal culture and communities, inaccuracies in research findings, reinforced Aboriginal communities suspicion of research generally as a tool of health improvement.

The Workshop endorsed the principle of Aboriginal self determination as fundamental in any consultation/negotiation process. This was taken to mean that Aboriginal communities have the right to approach any discussion on research from a point responsive to the primacy of Aboriginal interests and culture. The workshop was anxious to identify a process which clearly encompassed this principle. Participants recalled experiences where single community members had been approach for comment on particular proposals in isolation from broader discussion with the community. Similarly, there were cases cited where the cultural regimen was ignored resulting in the wrong people being asked to comment on matters which, in a cultural context, were not their prerogative to discuss. Such actions were considered inappropriate and unacceptable.

A process of consultation/negotiation had to be identified which ensured that proper discussion occurred, control of which was vested in the communities. This was necessary to ensure that communities could have trust in the process and the results of research. A number of examples were noted in which Researchers had sought advice and approval of Aboriginal individuals in Government Departments as a substitute for proper community consultations/negotiations. While this may have been the result of ignorance, the ef-

fect was to deny communities the opportunity to appropriately examine and discuss the proposals. The workshop was concerned to address these and other difficulties.

Additionally, the process identified had to accommodate the various geographic and cultural circumstances of Aboriginal communities.

That process is outlined below.

#### A. Where a local Aboriginal community controlled Health Services Exists

That the primary point of contact for Researchers shall be the local community controlled Aboriginal Health Service and the National Aboriginal and Islander Health Organisation. Where the subject matter of research has not previously received ethical approval from that community, the matter should be the subject of a community meeting or meetings.

#### B. Where a local community controlled Aboriginal Health Service does not exist

That the primary point of contact for Researchers shall be the local community controlled agencies and the National Aboriginal and Islander Health Organisation. Where the subject matter of research has not previously received ethical approval from that community, the matter should be the subject of community meeting or meetings

#### C. Where no local community controlled Aboriginal agency exists

Researchers must firstly seek proper Aboriginal community involvement and approval at the local level. This must be done in a manner which respects local community structures. Concurrent approval must also be sought from the National Aboriginal and Islander Health Organisation. Where the subject matter of research has not previously received ethical approval from that community, the matter should be the subject of community meeting or meetings.

The Workshop agreed that Researchers would be required to provide funding agencies and responsible Ethics Committees with appropriate documentation and other such evidence which demonstrated that proper community consultation had occurred.

The Workshop then addressed the question of "how does a Researcher demonstrate that she/he has consulted/negotiated properly". It was considered appropriate that the Workshop should identify a series of benchmarks, compliance with which would demonstrate acceptable consultation/negotiation.

These benchmarks are as follows:

- provision of written documentation demonstrating support and consent from communities for the particular research proposals, including evidence that shows that information was provided according to the level of comprehension of the community. Such documentation should come from the local community controlled agency,

- provision of evidence of meetings with the concerned Aboriginal community, including what specific efforts have been taken to inform the community i.e. translations of material detailing the intent and methodology of the proposed research;
- provision of material that demonstrates that they have considered the benefit to the community, including efforts to promote sharing of research skills,
- provision of material that demonstrates that they have addressed the question of ownership of materials,
- provision of material that demonstrates the degree to which the Researcher has addressed social and cultural imperatives within the community.

In formulating these benchmarks the Workshop intended that Ethics Committees should carefully assess the researchers compliance with each of the above before granting ethical approval. The Workshop was careful to identify the most important standards in order to ensure that an acceptable baseline of approach was established.

#### On Going Review and Funding of Research.

Within the process outlined above, the role of local community controlled agencies was central. This role was not seen as a once off function, the Workshop agreed that local community controlled agencies had an on-going function in monitoring the implementation of research projects. In discussing this function, the Workshop considered a number of options which were intended to maximise community scrutiny and participation in the implementation stages.

The Workshop noted that established Research Ethics Committee maintained an overview of projects for which they had granted ethical approval ( ... to maintain surveillance of projects until completion so that the committee may be satisfied that they continue to conform with approved ethical standards - N.H.&M.R.C. SUPPLEMENTARY NOTES, 1985)

Should at some time during the implementation of the project, a situation arise whereby ethical standards were contravened, mechanisms were available to compel Researchers to adjust their approach.

The Workshop accepted that a similar approach should be adopted in the case of research in Aboriginal health.

The Workshop considered that control of the funding of research was the most effective way of maintaining appropriate control over the ethical behaviour of Researchers and their initiatives. Whereas Universities and other such institutions fulfil the role of administering funds, the Workshop agreed that the local Aboriginal Health Service or local community controlled agencies should likewise administer funds for projects within their communities. The relationship between locally determined ethical standards and the administration of project funding would, in this way be a most effective monitoring mechanism.

The Workshop subsequently endorsed the following position:

- that where Aboriginal Health Services exist, that they be responsible for the administration of funds for research initiatives,
- that where no local community controlled Health Service exists, that the local community controlled agency be responsible for the administration of funds,
- that where no local community controlled agency exists, that funding be administered by an agreed community controlled agency, such as the National Aboriginal and Islander Health Organisation.

#### A National Perspective

The Workshop had so far considered projects which had a local or limited impact area. In turning to research projects of a national nature, such as a national measles or childhood immunisation research project, the Workshop again built upon community structures as the most appropriate mechanisms for determining and monitoring ethical standards.

The Workshop agreed that there should be established a National Research and Ethics Committee, auspiced by the National Aboriginal and Islander Health Organisation.

It would be the role of this committee to:

- consider ethical approval for research initiatives of a national nature, and
- input into the national process of allocation of research dollars to ensure a greater needs based allocation to Aboriginal health research.

Where this Committee grants ethical approval for an initiative the Workshop agreed that the auspice body of the Committee, the National Aboriginal and Islander Health Organisation should administer research funds. The meeting was concerned that additional funds be provided to the auspice body to meet costs of the Committee's operation.

# SOCIAL AND GENDER ISSUES

The Workshop recognised that the most difficult ethical issues related to social and cultural perspectives.

The Workshop heard of many recent and not so recent occurrences where sensitive information had been used, by non Aboriginal Researchers and institutions in a manner which caused disruption to the fabric and flow of events in Aboriginal communities. Aboriginal society is not the same as non Aboriginal society, Researchers should be conscious that social structures in Aboriginal communities are different to those they may be used too. This is particularly so when Researchers are seeking to address subjects which are of a sensitive nature within a social structure they know little about.

In discussing these issues, participants adopted an approach which recognised the cultural responsibilities and sensitivities of "women's" and "men's" business. As a consequence the Workshop divided, following a short introductory session into groups based on these cultural responsibilities and sensitivities.

This report does not go into specific detail on the nature of these discussions only in so far as is required to describe the necessary standards the Workshop thought were needed in this important area.

The following statement was carefully drafted taking into account the nature and emphasis of these discussions. All participants have agreed to the text.

The process of research in Aboriginal health presents potential areas of social and cultural conflict. Researchers must address this potential for conflict. The use by, Researchers of assumptions of moral, social or cultural correctness or appropriateness will interfere with community lifeways and denigrate research.

In the development, implementation and evaluation of research proposals, Researchers must seek the active participation and endorsement of communities to each stage of the process. If this process results in revision to any stage of the research process the community should, once revisions have been incorporated consider its consent of the revised proposal to ensure protection of community lifeways.

Researchers should take great care in areas of research that deal with:

1. gender,
2. parenting, family and community structures and responsibilities,
3. personal and collective relationships,
4. invasions of the body,
5. handling of human specimens and products.

Researcher's must also be aware that their social status, as determined by the community, as well as gender will be a vital consideration in determining access to sensitive areas of information and activity.

Specifically, Aboriginal women , as advised by the community must be involved when research deals with women's or children's issues. As a consequence Aboriginal women are to monitor all research dealing with women's and children's issues.

Likewise Researchers must not ignore the specific cultural and social needs of Aboriginal men in research programs.

The particular issue of post mortem examinations needs close attention and any research of this nature must respect the integrity of the person and relationships with the family, community and nation. For example the removal and withholding of organs presents particular difficulties.

The responsibility of Researchers to guard against violation of cultural and social imperatives beyond the primary contact with the community must also be addressed. The Researcher must obtain the approval of the community to any proposed use or publication of material or information collected during the research process.

Researchers must provide the community with an understanding of the process of research. This would include an understanding of matters relating to the collection and analysis of data, the drafting and publication of reports and proposed future uses of research materials.

Researchers must be aware that any breaches of Aboriginal Lore/law may invoke community rebuff and/or punishment.



# COMMUNICATION AND CONSENT.

Communication and consent were two issues recognised as fundamental to the development of ethical standards in the area of Aboriginal health research. It was recognised that Aboriginal health research touches on many areas which are made more sensitive because of uncertainties created by cross cultural influences.

The Workshop saw that some of these uncertainties may be based on a lack of understanding, on the part of Researchers about Aboriginal culture and community lifeways. Researchers may unwittingly impugn standards because of a lack of specific knowledge. It was also recognised however, that a small number of Researchers have used cross cultural barriers in an unscrupulous manner.

In developing standards, the Workshop sought to ensure that Researchers were guided in an approach to the provision of information, to communities that avoided misunderstandings.

Participants were conscious to ensure that Standards in this field reflected the fact that the provision of information and the obtaining of consent was not regarded as a once off or superficial exercise. Communities are concerned to know about the entire process of research from initial discussions, through implementation to publication of research reports. In order that this concern be addressed, Researchers should be prepared to provide information on and obtain the consent of communities to each stage of the research process.

The following text was accepted by the Workshop

"Communities must be provided with all the relevant information and explanations on the intent, process and methodology, evaluation and potential use of any research proposal.

This information must be provided at the level of comprehension of the community and must utilise appropriate Aboriginal educational process and tools.

Researchers must comply with any request for further information from relevant community controlled agencies associated with the research proposal.

The obligation of Researchers to comply with this requirement shall remain in force for the duration of any research project.

Community process of decision making will reflect varying social and cultural values. In obtaining the consent of communities to research, Researchers must respect the Aboriginal community's process of decision making.

Researchers must address this need, ensuring that they do not act in a pre-emptive or impulsive manner. For example, Researchers must allow sufficient lead time for the community to consider any proposals. Similarly, they should not seek to access cultural or community sub groups without prior permission.

Having addressed this process however, Researchers must be aware of continuing need to obtain the consent of individual Aboriginal people that may either participate in or contribute to the execution of any research project."

## COMMUNITY BENEFIT AND EMPLOYMENT OF LOCAL PEOPLE

Research, above all must be relevant to needs. The Workshop was clear in its support for this concept. In too many instances Researchers had embarked on a research initiative which had little or no relevance to the needs of Aboriginal communities. The Workshop considered that too often research had been used as a vehicle for aggrandisement rather than betterment of Aboriginal Peoples. It was agreed that measures were required to ensure that research in Aboriginal health contributed to a principle purpose, that of improving the health of Aboriginal Peoples.

This, in the opinion of the Workshop could be achieved in a number of direct and indirect ways. Researchers could, for example provide a direct benefit to communities where they sought to address a particular issues of concern, with a view to assisting in the development of strategies aimed at providing the community with possible scenarios to address this concern. Alternatively, benefit could accrue to communities where Researchers, in the course of their work, shared various research skills with local community members, by employing such people in the research team. The meeting considered that such a process, in the long term could equip communities to address their own research needs.

Employment of local community members, however was considered by the Workshop to be of further benefit. Such employment was recognised, together with other principles of community review detailed in this report as a prime means of avoiding the difficulties of past experience. With local people employed, research teams would benefit from local knowledge of law/lore, lifeways and other sensitive issues.

The following text was adopted by the Workshop:

"Researchers seeking to work in Aboriginal communities may confront a variety of unfamiliar environments and circumstances. In many circumstances the employment of community members will aid the Researcher and improve the quality of communication and ultimately strengthen the initiative.

Researchers, where local community controlled agencies believe it necessary must provide for the employment of local Aboriginal co- investigators.

Research should focus on, and provide knowledge about, activities and issues that will contribute to an improvement in Aboriginal health and foster community development.

Researchers must identify the areas and nature of the potential benefit and impact and obtain the concurrence of the local community controlled agencies that such outcomes are of value to the community at large."

# OWNERSHIP AND PUBLICATION OF MATERIALS

During the entire period of the Workshop, participants raised matters which in some way touched on the issues of publication and ownership of materials. Many sensitive matters, discussed within the context of social and gender issues were of such a nature that disregard for community rights on such matters of ownership, including publication could seriously impinge upon social and cultural values, thus jeopardising the basis of research.

Participants raised instances where pictures of events and/or objects which, by Aboriginal Law/lore are secret or sensitive have found their way into uncontrolled publications or into the hands on persons in which the community had little or no confidence. The nature of their sensitivity had often meant that even a single uncontrolled disclosure had damaged continuity and purpose of such events and/or objects in an Aboriginal way.

Similarly, use of names and/or pictorial material was flagged as another possible difficulty which may have an impact on the intent and manner of research. The Workshop sought to address these issues in a manner which would allow research to proceed under circumstances which were compatible with Aboriginal social and cultural values and standards.

The Workshop adopted the following text:

"Research material and data shall remain the property of the community. The community retains the right to censor research materials of a sensitive nature.

Prior to any publication or other use of research materials or Reports, the approval of the relevant Aboriginal community controlled agency is required.

In preparing acknowledgements, the proper accreditation of participation and assistance of Aboriginal communities, individuals and agencies should be noted.

Results of research must not be published in a form that permits identification of individual subjects. Pictorial material should only be made with the consent of the local community and should be handled according to their wishes.

Researchers need to be aware that future utilisation and publication, of materials may be jeopardised by the inclusion of pictorial materials. For example, the use of pictorial materials where individuals are identifiable may cause such materials to be withdrawn from use should such individuals die. Similarly, no pictorial material which identifies deceased persons should be used."

# EXPLOITATION OF COMMUNITY RESOURCES

Aboriginal community controlled organisations rarely have the financial and other resources necessary to fulfil community needs. Therefore, any additional drain on available resources detracts from the potential for achievement of community goals. Researchers must understand that local community controlled agencies are not resourced to accommodate the additional cost burden that research projects may involve.

Researchers must therefore address the question of costs to the community associated with a community's auspice, participation or support role in a particular research initiative. In preparing research budgets, Researchers should provide for direct or indirect costs associated with any proposed program to be reimbursed to relevant Aboriginal community controlled agencies.

The following text was adopted by the Workshop:

"In seeking the co-operation of Aboriginal communities and local community controlled agencies they, (Researchers) must provide reimbursement of any cost incurred which relate directly or indirectly to programs of research. Such costs could include telephones, transport, freight, gas and water, accommodation, supervision costs and wages of assistants or interpreters."

RECOMMENDATIONS ARISING FROM  
THE WORKSHOP ON PRIORITIES TO IMPROVE ABORIGINAL HEALTH

Alice Springs 26-28 November 1986

**Ethical Aspects of Research in Aboriginal Health**

1. That ethical guidelines for health research involving Aborigines be established.
2. That these ethical guidelines be established by a forum of Aboriginal people, representative of Aboriginal communities and community controlled organisation throughout Australia within 6 months.
3. That this independent forum of Aboriginal people receive the necessary funding to meet several times so as to effectively establish the guidelines.
4. That this forum use as a basis for these ethical guidelines the following:
  - Central Australian Aboriginal Congress guidelines;
  - Aboriginal Health Organisations (SA) guidelines;
  - Relevant section of the NHMRC ethical guidelines;
  - RADGAC guidelines;
  - Other relevant guidelines, eg Australian Society for Linguists: NAIHO Evaluation papers.
5. That the close relationship between ethical guidelines and criteria for funding research projects be recognised and that the health research involving Aborigines be very heavily weighted towards problems as perceived by Aboriginal communities.
6. That this workshop nominate an appropriate Aboriginal person to convene the forum. (Mr Shane Houston was nominated.)
7. That there be Aboriginal representation on the NHMRC Ethics Committee. The following have indicated their willingness to accept nomination: Dulcie Flowers, Shane Houston, Michael Mace, Grace Smallwood.

**Principles for the funding and organisation of research**

8. The highest funding priority must be given to health and mental health problems which Aborigines identify as most deserving.
9. Money for research, development and training for public health should be given for improving Aboriginal health.
10. Money should also be ear-marked for Aboriginal women's health.
11. All money for research and develop training in Aboriginal health should be subject to approval by a representative Aboriginal forum, possibly to be a role of NAIHO.
12. The Aboriginal Health Research and development and teaching forum be an assessor for all grant proposals.
13. For the interim Public Health Research and Development Fund, applications should be assessed on their significance to Aboriginal people and Public Health.
14. In assessing the scientific merit of proposals, the fund should recognise:
  - (a) the methods used in applied and social research, especially those relating to health programs and health care;
  - (b) a range of perspectives and methods for research, especially the growth in stakeholder or community-controlled research.
15. The proposed Aboriginal Forum needs to have resources. It could be granted a proportion of the Public Health Research and Development Fund.
  - (a) National Aboriginal data;
  - (b) Data available to Aboriginal/Torres Strait Island Communities to enable priorities.
16. That there should be Aboriginal involvement in Aboriginal research;
  - (a) setting priorities;
  - (b) methods;
  - (c) ethical issues; and
  - (d) implementation
17. That there should be an Aboriginal/Torres Strait Island Health Research and Development Fund with contributions from NHMRC, RADGAC, DAA and the Australian people.
18. NHMRC and other agencies consider ways of greater funding of Aboriginal women's health care and MCH research and supply information on how to apply successfully.
19. Research must be organised in such a way that:
  - (a) local communities are involved in every step of research design and execution;
  - (b) members of local communities become competent to perform such studies on their own in the future, such as the example demonstrated by the group in Brisbane report by Bill Lowah.
20. That all information about grants for research, development and community-based education, especially from Better Health Commission, the new Public Health Research and Development Fund, and NHMRC be distributed to Aboriginal organisations, and that the Commonwealth Health Department provide assistance to groups preparing submissions for funds.
21. Every research proposal involving the study of an Australian community should contain a list of skills and knowledge that shall be transmitted to community members as a process of that research. The merit of this listing of skills shall be considered integral to the overall evaluation of the quality of the proposal.
22. Research being undertaken in Aboriginal communities be given priority over individual research.
23. Aborigines be given access and support for gaining research skills to enable the various levels of necessary research to be undertaken.
24. Large scale treatment or prevention programs, eg hepatitis B, be evaluated in pilot projects before general implementation.
25. Researching to improve the health of Aboriginal people continues to be recognised as needing continuing support.

26. Future workshops of this nature involved Aboriginal people, firstly in consultation, organisation and implementation. Each AMS should have at least one delegate and information should be distributed for community discussion.
27. Funding for such delegates be readily provided.
28. Priority will be given to research in fields that are seen by Aboriginal communities themselves as being of practical importance, special emphasis placed on evaluation or application of knowledge derived from earlier research.
29. Research workers known to have confidence of Aboriginal communities be asked to assist in developing a research program by which NHMRC and other research funding agencies be guided.
30. The necessity for longitudinal studies, community based.
31. The essential role of control groups in studies was stressed, eg age and time matched.

#### Health statistics, surveillance and evaluation of services

32. The Commonwealth Government in consultation with State/Territory governments and Aboriginal communities should develop long term strategies consistent with real and lasting commitment to the development of national Aboriginal health statistics. The Commonwealth should allocate adequate resources and support for long term development projects undertaken by the States/Territories and by Aboriginal communities.
33. The development of national Aboriginal health statistics should be extended from the present priority areas of vital statistics, and the hospital morbidity and maternal/perinatal collections to include the provision for Aboriginal identification in the collections of appropriate notifiable and other diseases.
34. The resources and support for the development of national Aboriginal health statistics shall include provision for research funds to enable the evaluation of the adequacy of Aboriginal identification in the developing statistical collections.
35. Research funds should also be provided for:
  - (a) health surveys of specific diseases, disabilities and risk factors;
  - (b) longitudinal studies of specific health problems.
36. Support of Aboriginal health services and programs should include, as a routine, funds for the monitoring and surveillance of health problems within the community covered by service or program.
37. The Australian Bureau of Statistics and the Department of Aboriginal Affairs should provide reliable annual estimates of the Aboriginal population, at least by state or territory for sex and five-year group.
38. The various agencies involved in the compilation and analysis of the various health and population statistics should ensure the timely publication and dissemination of these statistics.
39. Attempts should be made to develop a standardised pro-forma for the collection of both cross-sectional and longitudinal data so that communities can be compare and so that changes can be measured within a community.
40. Ongoing evaluation of the effectiveness of health and mental health services for Aborigines be an integral part of program funding. Furthermore, the definition of effectiveness must be based on criteria appropriate to Aboriginal culture and involve the active participation of Aboriginal communities.

#### Living conditions and health

41. The meeting recognised the importance for health of poor living conditions, poor housing, overcrowding, under-nutrition, unsatisfactory hygiene practices, poor sanitation, and of inadequate knowledge about health nutrition and the causes of disease. Priority topics for research include:
  - studies of appropriate and acceptable housing styles;
  - improved land management and design (environmental control) and community education identification of best methods to address problems such as overcrowding, social disruption, dogs, rubbish, alcohol and vandalism;
  - a careful study of Aborigines, their dogs and diseases they promote;
  - studies of other vector-borne diseases (eg flies, insects, parasites);
  - the potentially catastrophic effects of blood-borne disease, including AIDS;
  - the way other infections are spread and how they can be controlled, eg gastroenteritis, streptococcal skin infections and trachoma;
  - and
  - the development of more effective methods of community education about health, hygiene and nutrition.

#### Aboriginal women's health

42. The central Australian Aboriginal Congress Birthrights Research and Congress Alukura is an initiative taken by Aboriginal women to develop services appropriate for Aboriginal women. Congress Alukura should be funded and implemented so that Aboriginal women can receive educational services, health and training, and make decisions for controlling their own health.
43. For Aboriginal women, it is essential that money for development, service and consultative projects continue to be available.

#### Alcohol and substance abuse

44. There is a need for practical, useful research which can be used by Aborigines and others to reduce substance abuse (alcohol, petrol, tobacco, analgesics, kava). Research needs to be informed by an understanding of Aboriginal perceptions of these substances. Findings must be fed back to Aboriginal communities.
45. Such is the degree of the Aboriginal substance abuse problem, 'upstream' prevention research should be the priority area.
46. We need to ensure that funds currently used for prevention, education, intervention and treatment programs are being efficiently used, by provision of adequate statistics, monitoring, follow-up and evaluation, as an ongoing program taken to the community with the consent of the community.
47. Noting the development of ethics in Aboriginal research this forum deplores the inaction of federal and state agencies in addressing the alcohol and substance abuse issue. We call upon them to adopt a more community-based responsibility to this dilemma.
48. All those undertaking research into substance abuse should be encouraged to publish and to make freely available their findings in order to assist Aboriginal organisations and other researchers.
49. The Drug and Alcohol Foundation of Australia has a directory of ongoing research into alcohol and drug use, to which researchers are urged to contribute; DAFA, GPO Box 477, Canberra ACT 2601.

### **Sexually transmitted diseases/AIDS**

50. Studies be developed to improve the early detection and prevention of STD/AIDS.
51. Emphasis be placed upon operational research where there is a clear method of intervention to improve STD/AIDS control programs and which has benefit both for the individuals concerned and the community as a whole.
52. Research be developed to investigate methods of improving community awareness programs and community initiatives for the prevention of STD/AIDS. Effective education programs need to be developed for specific age groups.
53. The prevalence and distribution of STDs in Aboriginal communities be determined and risk factors identified. Priority should be given to gonorrhoea.
54. Appropriate methods of diagnosis and treatment be developed for rural Aboriginal communities. Priority should be given to chlamydial infections.
55. A national conference on STD/AIDS be held for Aboriginal people and staff of health services providing care to Aboriginal communities.

### **Hepatitis B**

56. What are the harmful effects of hepatitis B infection in Aborigines? Studies are needed to assess the incidence of liver disease and hepatocellular carcinoma in hepatitis B carriers.
57. Is the hepatitis B vaccine effective in preventing infection in the Aboriginal population? There is a need to follow-up a group of Aboriginal infants to assess the antibody response and resistance to infection following vaccination.

### **Gastro-intestinal infections**

58. Priority topics include:
  - health education/hygiene;
  - education for facilities use (eg blocked toilets);
  - prevention;
  - treatment strategies;
  - maternal health/nutrition.
59. Specific medical problem areas identified needing research included:
  - vaccines/immunisation;
  - standardisation of definitions (eg what is diarrhoea to a community?);
  - human rota-virus;
  - dogs (campylobacter, cryptosporidia);
  - role of parasites (not known);
  - role of adults in re-infection/infective pool;
  - maternal health and nutrition;
  - what is normal and what is infection?
  - role of known pathogens (viral, bacterial, protozoal helminths);
  - new pathogens;
  - susceptibility vs severity, role of nutrition;
  - lactose intolerance;
  - host immunity;
  - small bowel overgrowth;
  - non gastro-intestinal causes of diarrhoea (eg urinary tract infection);
  - diarrhoea community studies;
  - research on interventions;
  - baseline statistics/background information/knowledge;
  - more sensitive (field?) laboratory tests (eg gene probe, giardia antigens);
  - epidemiology;
  - oral rehydration therapy (eg the most efficient use);
  - collaboration — research groups, pool information/resources/communication;
  - nutrition and growth;
  - seasonal variations eg difference;
  - new therapeutic agents, drug resistance.

### **Nutrition and related problems**

60. Expand database on the nutrient composition of bushfoods.
61. Increase the descriptive information paper on the range of foods eaten traditionally by Aborigines in different parts of Australia over a full year; seasonal variation in type and quantity of foods available; quantitative estimated of food consumption.
62. Nutritional status of Aboriginal groups continuing to rely at least partly on bushfoods (eg some Outstation Homeland groups).
63. Is there a relationship between maternal nutritional status and low birth-weight infants?
64. What are the health outcomes of low birth-weight infants and underweight children?
65. Accurate assessment of dietary intake in Aboriginal communities; development of appropriate methodology.
66. Assessment of nutritional status in adults and children; which parameters (anthropological, biochemical?) should be measured?
67. Aetiology of iron-deficiency anaemia in young Aboriginal children (diet? infection?).
68. Assessment of susceptibility to infection?
69. Relationship of susceptibility to infection and nutritional status; which comes first — malnutrition or repeated infections?
70. Stores in isolated Aboriginal communities: high cost of fresh foods; impact of stores on health outcome in Aboriginal communities.
71. Epidemiological studies on disease patterns over time. Analysis of existing available longitudinal data relating to Aboriginal health.



72. Community-based, community-controlled intervention strategies to overcome the preventable health problems in Aboriginal communities.

#### **Diabetes mellitus**

73. Establishment of diabetes registers in centres with large Aboriginal populations.
74. Determination of the patterns of microvascular disease in diabetic Aborigines relative to non-diabetic Aborigines.
75. Collection of accurate mortality data in Aboriginal diabetics.
76. Longitudinal studies of diabetes in a range of Aboriginal communities using standardised-protocols.
77. Comparison of metabolic responses in full descent/part Aborigines and Caucasians to gain insight into the genetic components of the apparent risk factors for diabetes.
78. Diabetes in pregnancy: development of standard criteria for diagnosis; health outcome of infant.
79. Increased risk of infections associated with diabetes in Aborigines.
80. Critical evaluation of treatment protocols for Aborigines with type 2 diabetes; appropriateness of oral agents and insulin.
81. Studies of physical activity and its relationship to the treatment and prevention of diabetes.
82. Development of community-based programs aimed at treating diabetes by diet and exercise.
83. Community-based programs to prevent diabetes (dietary change, regular exercise).

#### **Cardiovascular disease**

84. Epidemiological (cross-sectional and longitudinal) studies of risk factors for cardiovascular disease and for incidence and frequency of different types of cardiovascular disease using standardised protocols.
85. Systematic collection of accurate mortality (post mortem) and morbidity data on cardiovascular diseases in Aborigines.
86. Community-based intervention programs aimed at prevention (health education: diet, exercise, weight control. Appropriate methodology needs to be developed.

#### **Renal disease and hypertension**

87. Priority topics include:  
Longitudinal surveillance of blood pressure patterns;  
the relationship of hypertension with obesity;  
the relationship of renal disease with (a) obesity and (b) diabetes;  
the aetiology of renal disease and its pathogenesis;  
the prevalence of renal calculus disease and its pathogenicity;  
follow up of acute glomerulonephritis;  
the nature and cause of haematuria in infants;  
the relationship of salt - dietary intake and blood pressure;  
relevant immunological problems in renal transplantation.

## Attachment B .

### Attendance List

Mr L Collins Co-Ordinator, WuChopperan Health Service, Cairns  
Ms T Hall Administrator, Brisbane Aboriginal and Islander Community Health Service,  
Ms I Arahua N.H.& M.R.C. Public Health Awardee  
Ms J Seden Administrator, Mackay Aboriginal and Islander Community Health Service  
Mr S Nangala Regional Director, Kimberley Aboriginal Medical Services Council  
Mr T Wilks Director, Perth Aboriginal Medical Service  
Ms M Culbong Akministrator, Geraldton Aboriginal Medical Service  
Mr R Wilks West Australian Department of Health  
Ms H Winder Aboriginal Health Worker, Aboriginal Health Service, Carnarvon  
Mr J Tragenza Far West Aboriginal Progress Association, Ceduna  
Ms C Brown South Australian Aboriginal Health Organisation  
Ms I Butler South Australian Aboriginal Health Organisation  
Mr P Ah Kit Senior Aboriginal Health Worker, Central Australian Aboriginal  
Congress, Alice Springs  
Ms C George Administrator, Angingyinyi Congress, Tenant Creek  
Dr R Moodie Senior Physician, Central Australian Aboriginal Congress, Alice Springs  
Mr B McGuinness Dean of Studies, Koorie Kollij, Melbourne  
Ms A Thorpe Director, Victorian Aboriginal Health Service, Fitzroy  
Dr B Roberts Finance Co-Ordinator, National Aboriginal and Islander Health Organisation  
Mr G Austin Administrator, Victorian Aboriginal Health Service  
Dr T Cutter Medical Director, Victorian Aboriginal Health Service  
Mr P Dalton Central Gippsland Aboriginal Co-Operative  
Ms M Moran Administrator, Tharawal Aboriginal Corp. , Campbelltown  
Ms S Bailey Administrator, Cumeragunja Co-Operative  
Mr J Santos Secretary, Coomealla Aboriginal Co-Operative, Dareton  
Prof R Kaluchy National Health and Medical Research Council  
Mr P Griffen Secretary, National Health and Medical Research Council  
Prof R Lovell National Health and Medical Research Council  
Mr B Johnston Health Branch, Department of Aboriginal Affairs, Canberra  
Mr S Houston Workshop Convenor, National Co-Ordinator, National Aboriginal and  
Islander Health Organisation, Campbelltown

A number of Observers also attended the Workshop:

Cumberland College of Health Sciences  
Tharawal Aboriginal Co-Operative  
National Aboriginal and Islander Health Organisation  
Mr D Smith, Melbourne