

NATIONAL ABORIGINAL AND ISLANDER HEALTH ORGANISATION

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FAX COVER SHEET

TO: Bill, W. K., Bruce, Alan.....

FR: Shane.....

SUBJECT: 2nd installment
on Ethics paper.....

Comments pls.....

DATE: 29 April 88.....

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 to:

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. prepare a draft document which outlines the ethical responsibilities relating to research in Aboriginal health,

2. Outline 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 behavioural 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 approached 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 effect 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 has 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.