

Why an Aboriginal Ethical Perspective is Necessary for Research into Aboriginal Health¹

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The history of Aboriginal health is a sad legacy of the control over Aboriginal people by a dominant culture following the conquest of their land and its subsequent colonisation. The upheaval of stable and orderly societies providing security and health to their peoples were soon to be replaced by an ever widening cordon that herded communities into concentrated enclaves oblivious of the varying cultural and societal mores, differing languages, taboos and traditions. The devastating effects that such a catastrophe had upon the forced amalgamation of divergent groups of fiercely independent peoples into sedentary holding camps is beyond adequate description. Proud and independent people were made totally subservient upon their captors for even the most basic of needs for survival. This horrendous infliction ravaged the healthy population with untold misery and disease until eventually, through further forced migration and the violation of the very sanctity of family structure itself, Aboriginal people were shell shocked into forced fringe sub-existence.

This is the context in which Aboriginal people had to grapple with the resultant momentous health and psychological illnesses. Yet, even the very discipline of studying the legacy of the ill health of Aboriginal people became an art form in the exclusion of Aboriginal people from the very process itself, relegating them to that of being the observed rather than active participants in the road to recovery.

Whilst most would assume that such a description is a matter of the dim past the need for an ethical dimension in Aboriginal health research was not addressed until a national conference in Alice Springs in 1986, entitled *Research Priorities in Aboriginal Health*. A further national meeting was arranged in Camden, NSW, in 1987 to address the "contentious" issue of ethics as it relates to Aboriginal health. The NAIHO Report from that conference developed a set of *Guidelines* on the ethical responsibilities of research in Aboriginal health.²

The National Aboriginal & Islander Health Organisation (NAIHO) Report on the National Workshop on Ethics of Research in Aboriginal Health (1987) stresses the importance of Community involvement at each stage of research and related data collection process for Aboriginal health.

In a previous AH&MRC summary of this Report the importance of the document is emphasized, in particular its recommendation that the initial stages of research and data collection into Aboriginal health have to conform to stringent guidelines that meet Aboriginal community approval. Obtaining ethical approval from the Community controlled sector is spelt out with clear expectations for what constitutes proper consultation.³ The process of "consultation/negotiation" has to be clearly identified and

¹ This paper was presented at 'From the Ground Up – A Conference on Aboriginal Health in the 63rd Millennium', at Penrith, NSW on the 3rd May, 2001, hosted by the Aboriginal Health & Medical Research Council (AH&MRC). Used by permission from the AH&MRC.

² National Aboriginal & Islander Health Organisation (NAIHO), Report on the National Workshop on Ethics of Research in Aboriginal Health (1987)

³ *National Aboriginal & Islander Health Organisation (NAIHO), Report on the National Workshop on Ethics of Research in Aboriginal Health (1987), Part 1 & Part 2. p.3.*

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ensure that proper discussion occurs and that control of these processes is vested in the Communities. Provision must be made to also ensure that appropriate cultural protocols and procedures are in place. It is clearly stated that approval by Aboriginal people in government departments is no substitute for proper community consultation/negotiations.⁴

Communication and Consent

With regards to consent the following advice was developed at the workshop which developed the *NAIHO Report*.

“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.

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

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.”⁵

Another pertinent ethical matter related to the collection of data and research into Aboriginal health is that the relevant Community and Aboriginal Ethics Committee should be provided sufficient time to enable adequate examination of all proposals.

Ownership and Publication of Materials

The *Report* also covers publication and ownership of material and the on-going role in monitoring the implementation of research, all of which are considered of vital importance to local Aboriginal communities. It was appropriate that this document was attached to the *NH&MRC Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*.⁶ Some of the recommendations in the *NAIHO Report* within this area are as follows:

“Research material and data shall remain the property of the Community. The Community retains the right to censor research of a sensitive nature. Prior to publication or other use of research materials or Reports, the approval of the relevant 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.”⁷

Other recommendations cover assurances for privacy and the non-identification of participants in research, both of which are equally binding in any collection of data on Aboriginal health or for any epidemiological study.

Exploitation of Community Resources

The *NAIHO Report* states that there should be no imposition upon the Aboriginal community controlled health sector to be involved in processes that are not adequately funded or resourced.

⁴ *ibid.*

⁵ *ibid*, Part 5, pages 5 and 6.

⁶ *Guidelines on Ethical Matters in Aboriginal and Torres Strait Island Health Research, NH&MRC, 1991*

⁷ *National Aboriginal & Islander Health Organisation (NAIHO), Report on the National Workshop on Ethics of Research in Aboriginal Health (1987), Part 7, page 6.*

Associated costs incurred by Aboriginal communities and Aboriginal community controlled organisations should be fully reimbursed. The role of the department in this respect would be considered the body responsible for meeting these costs.

“In seeking the co-operation of Aboriginal communities and local community controlled agencies, [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 and interpreters.”⁸

Employment of Aboriginal People in Research Projects

The recommendation for the employment of Aboriginal people in research projects is also within an ethical context.

“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.”⁹

Ongoing Review of Ethical Standards

The *NAIHO Report* realistically appraises ethical standards in Aboriginal health and recommends

“Ethics Committees and the relevant community controlled agencies have an ongoing responsibility to ensure compliance with appropriate ethical standards.”¹⁰

Consequently, the National Aboriginal Community Controlled Health Organisation (NACCHO) and the AH&MRC, in separate documents, have concluded that the Community itself is considered the determining body in matters relating to Aboriginal health information rather than any national, state or territory Ethics Committee solely determining matters concerning Aboriginal health. The ethics committees of State and Territory affiliate bodies of NACCHO perform invaluable representative roles but the underlying principle upon which they operate is the inviolate status of the Aboriginal communities themselves, for they alone can ultimately consider the propriety of given research into Aboriginal health.

The Emergence of the AH&MRC Ethics Committee

One major concern of the Aboriginal community controlled health sector in NSW was the absence of an Aboriginal health ethics committee. The non-existence of such a body enabled mediocrity in scholarship; duplication of unnecessary research; circumvention of Aboriginal community consent; the violation of Aboriginal personal and Community confidentiality, disregard for privacy and the distortion of the factual situation actually confronting Aboriginal communities.

It is reassuring that several state affiliate bodies of NACCHO now have introduced ethics committees but there must be continuing vigilance to ensure that these bodies are economically viable yet independent and separate from any funding body associated with the resourcing of Aboriginal health services. The delicate balance for funding bodies to possibly resource ethics committees yet remain apart from the ethical determination process must be maintained at all costs. It is for this reason that to date the AH&MRC Ethics Committee has yet to be separately funded from any source with a burdensome impact upon the Council’s budget and staffing requirements. The unfettered independence of an Aboriginal ethics committee ensures that there is no question of

⁸ *ibid*, Part 8, page 7.

⁹ *ibid*, Part 6, page 6.

¹⁰ *ibid*, Part 3, page 4.

conflict of interest or any implied inducement affecting its objectivity. It is for this reason that the AH&MRC Ethics Committee has found it necessary to refrain from identifying its members apart from its Chairperson. There have been instances where Aboriginal ethics committee members have reported that they have been singled out and offered attractive inducements for their respective medical service, contingent upon their endorsement of a particular project or line of product.

The initial ethical scrutiny of applications for research was initially undertaken by the Aboriginal Medical Service situated in Redfern but, as the workload became too onerous, the Council formed its own AH&MRC Ethics Committee which has carried out this vital task since 1996.

The underlying principle which guides the Committee is the centrality of each Aboriginal community and, in all assessments and evaluation of research proposals, close and continual liaison with Aboriginal communities is maintained. Consistent with the operating ethos of the Aboriginal community controlled health sector with regards to matters referred to it by Aboriginal Medical Services (AMS)¹¹, the Ethics Committee only provides an ethical opinion on given projects and academic studies. There is no enforcement role and it is left to each Aboriginal community controlled health service to appropriate provided advice as it sees fit. Where a monitoring responsibility is granted to the Committee by an AMS routine reporting to and evaluation of given projects are undertaken by the Committee

The AH&MRC Ethics Committee provided a comprehensive submission to the relevant NHMRC national committee in the drafting of the *National Statement on Ethical Conduct in Research Involving Humans*, which, in the words of its Chairperson, was an invaluable tool in the Committee's deliberations.

Of much concern is the persistent tendency for some scholars and academics to deliberately seek to circumvent the scrutiny of the AH&MRC Ethics Committee. Members of the Committee have actually witnessed scholars boasting how the AH&MRC Ethics Committee has been circumvented, some indicating that that this has been achieved by making research topics relate to national projects rather than state projects. However, on the whole, the recommendations within the *NSW Aboriginal Health Information Guidelines*, written jointly by the NSW Health Department and the AH&MRC through its Partnership, are increasingly being followed, namely:

“ In addition to consideration by local or Institutional Ethics Committees, it is strongly recommended that proponents submit projects to the [AH&MRC Ethics Committee], in association with the local community concerned, for consideration if one or more of the following apply:

- Aboriginality is a determinant;
- Data collection is explicitly directed at Aboriginal peoples;
- Aboriginal peoples, as a group, are to be examined in the results;
- The information has an impact on one or more Aboriginal communities; and
- Aboriginal health funds are a source of funding.¹²

The Committee has received positive feed back from students and academics who have availed themselves of this essential process. In addition, university faculties have commented that even the academic component of research proposals associated with their

¹¹ AMS is the acronym for an Aboriginal Medical Service, which in practice is synonymous with an Aboriginal Community Controlled Health Service (ACCHS). Medical care is but one component within Primary Health Care.

¹² *NSW Aboriginal Health Information Guidelines*, A NSW Aboriginal Health Partnership publication within the Aboriginal Health Information Strategy, August, 1998. p 6.

institutions have been strengthened directly as a result of evaluation from an Aboriginal community perspective. On the other hand there has been some disquiet from a minority of applicants who feel that this specific Community scrutiny intrudes and infringes upon their otherwise unquestioned right for research into Aboriginal health.

The Ethics Committee is committed to professional projects in essential epidemiological and medical research that increase scientific knowledge, demonstrate benefit to our communities and provide transfer of skills to our medical workforce.

Included in the criteria used by the Committee to evaluate applications for proposed research and publications of statistical data on Aboriginal health are the following principles which are contained within the AH&MRC publication *Guidelines for Research into Aboriginal Health*.¹³

- i. that in accordance with the priorities set out in the *National Aboriginal Health Strategy* and the *Report of the National Workshop on Ethics of Research in Aboriginal Health*, research proposals must advance scientific knowledge so as to result in demonstrated additional benefit to Aboriginal communities.
- ii. that there be Aboriginal community control over all aspects of the proposed research including research design, ownership of data, data interpretation and publication of research findings.
- iii. that the research to be conducted in a manner sensitive to the cultural principles of Aboriginal society.
- iv. that Aboriginal communities and organisations be reimbursed for all costs arising from their participation in the research process.
- v. that Aboriginal communities and organisations should be able to benefit from the transfer of skills and knowledge arising from the research project.

Ethics and Aboriginal Health Data

Closely associated with the ethical assessment of research into Aboriginal health is the vast and ever increasing area of data. It is clear that better planning leads to better health outcomes and in this regard the need for better health data is essential.

The National Aboriginal Health Strategy, 1989 (NAHS) contains an entire chapter on the specific issues of data systems and the evaluation and monitoring of the prevailing condition of Aboriginal health.

Throughout the whole document the place of the Aboriginal community is central in working through both its own health services and in co-operation with Commonwealth and State mainstream health programs and the role that the Community has in data cannot be underestimated.

The *NAHS* stated that monitoring and evaluation by the community "serve a useful purpose in promoting greater participation in the provision of Primary Health Care."¹⁴ Yet the *Strategy* cautioned against the dangers within data reporting which can make "unrealistic demands" upon an organisation yet provide "little information useful in improving services delivered".

It also alluded to past practices which gave rise to Communities having:

¹³ *AHRC Ethics Committee of the Aboriginal Health & Medical Research Council of NSW*, 1998. This document is currently being revised to accommodate the recent amendments in the *National Statement on Ethical Conduct* and will be published as Vol. 1. No. 2. in the *AH&MRC Monograph Series*.

¹⁴ *NAHS*, 12.1.2

“good reason to see the process of monitoring and evaluation as a means by which government might gather information about a community without that community’s consent and/or the means by which government might coerce a community into adopting standards it might otherwise wish to reject.”¹⁵

The *Strategy* recognised the role for:

“National, State and Territory agencies’ involvement in the collection of data information on Aboriginal health and their need for a more adequate monitoring of mainstream services and improvement in the provision and quality of data collection information systems.”¹⁶

The *Strategy* recognises the Aboriginal community’s involvement in monitoring and evaluating Primary Health Care and stresses the need to have data collections and analyses at the service delivery level. It also states that sufficient resources should be provided to Aboriginal Community Health Services to develop and operate the detailed monitoring and evaluation identified in the *Strategy*. In particular the *Strategy* relates data “to the evaluation and monitoring of the policy function and to primary, secondary and tertiary levels of care.”¹⁷

Essential attributes to the process are considered by the *Strategy* to be:

“Relevance, adequacy, progress, efficiency, effectiveness quality and impact.”¹⁸

The *Framework Agreements*¹⁹ entered into by the Commonwealth and State/Territory Ministers for Health with peak State and Territory Aboriginal community controlled bodies affiliated with NACCHO, sought to give practical application to the *NAHS* recommendations and, accordingly, have provisions for the establishment of:

“culturally sensitive and ethically sound, privacy and confidentiality protocols for the routine collection of standardised data on Aboriginal and Torres Strait Islander health. **These protocols are to recognise Aboriginal and Torres Strait Islander ownership of the data including clarity about the collection and use of data. Any change in the use of the data will require agreement from the owners of the data.**”²⁰ [italics inserted]

The first stage of these protocols, developed by the AH&MRC as consultants to NACCHO, recognised the ownership of data by Aboriginal and Torres Strait Islander peoples and enunciated clear guidelines on the collection and use of data from Aboriginal communities. There are also provisions requiring the necessity to obtain each Aboriginal community’s consent before any use or change in use of data.

It is with some degree of concern that there are attempts by parties within the current national data initiative to circumvent this definitive statement by the Aboriginal community controlled health sector and to complete the application of these principles for State and Commonwealth data collections without any previously agreed input and involvement from the Aboriginal community. This is compounded by attempts by non-Aboriginal administrators to substitute the mandated Aboriginal community voice in health matters whenever the Community is at variance with accepted and preferred departmental or governmental priorities. The whole area of data, including any intrigue

¹⁵ *ibid*, 12.1.2

¹⁶ *ibid*, (12.1.4)

¹⁷ *ibid*, 12.1.2

¹⁸ *ibid*, 12.1.3

¹⁹ *NSW Aboriginal Health Framework Agreement*,

²⁰ *ibid*. 3.12 Note: There are also provisions to “improve the quality of relevant data available on the provision of mainstream health services to, and utilisation, of mainstream health services by, Aboriginal and Torres Strait Islander peoples; 3.13.

to neutralise or substitute the voice of the Aboriginal community, has an ethical dimension that requires close examination by Aboriginal ethics committees.

In the collection of Aboriginal health data all the expected standards which are usually associated with data collection and their use are to be included in a written Agreement with provisions to ensure:

- Aboriginal community control;
- Aboriginal community ownership;
- individual and Community confidentiality and anonymity;
- terms for data security, storage and archiving;
- reporting back procedures;
- prior approval of questionnaires;
- terms for destruction and return of data;
- terms addressing the publication of materials;
- the employment of Aboriginal people where possible in data related projects;
- adequate repayment for expenses;
- due recognition for services rendered;
- publication procedures;
- free and informed written consent;
- provision for withdrawal of consent;
- terms for specified use, objectives and research purposes of data;
- provisions for modification to research;
- adequate time frames;
- complaint mechanisms; and
- access to data and security

A more definitive and detailed statement concerning these provisions can be noted in the Council's and NACCHO's publications.

In the spirit of the recommendations that relate to the collection and use of data within the *National Aboriginal Health Strategy*; the *Royal Commission into Aboriginal Deaths in Custody* and the *Framework Agreements*²¹, the NACCHO model, developed by the AH&MRC as consultants, was endorsed by NACCHO in 1997 as the national policy for the use and collection of all health data on Aboriginal people. This model will expedite data collection while at the same time ensure that Community ownership, control and participation takes place at each level of the process.²² This procedure encourages widest participation in the collection of data while at the same time allowing culturally sensitive matters to be honoured by the Community concerned. At each stage of the process reciprocal sharing of information will take place at the regional, state and national levels with mainstream services.

Regrettably, despite numerous assurances, since the Aboriginal community controlled health sector assumed this epidemiological responsibility no funding has been forthcoming to enable the Community itself to collect this vital health data. In spite of this discouraging situation it needs to be said that the Aboriginal community controlled health sector has to be ever vigilant in ensuring that the information gathering process is

²² For a summary of the NACCHO Data Protocols see appendices attached to an article by Pat Swan and J.D.B. Williams, "The Aboriginal Community Controlled Health Perspective on the Collection and Use of Aboriginal Health Data and its Relevance for People with a Disability in Aboriginal Communities" in the AIHW publication *Indigenous Disability Data, Current Status and Future Prospects, April, 1998*, pp. 94-114.

controlled by the Aboriginal community. It is a sad comment to state that this is an ever pressing necessity and funding and resources appear elusive as long as the Community seeks to ensure its indispensable and central role as recommended by the *Royal Commission into Aboriginal Deaths in Custody*

Recommendation 270

*"That: ... Aboriginal people be involved in each stage of development of Aboriginal health statistics; ..."*²³

Additional Reasons why Aboriginal Ethics Committees are Essential

Several speakers and delegates asking questions at this conference have made reference to racism within health institutions and with individual researchers into Aboriginal health. There have been many improvements over the past decade in people's attitudes and this persistent phenomenon reflects the current attitudes of society in general. Nonetheless, this lingering malaise intrudes upon the health initiatives of Aboriginal people. Even where this has been eradicated or minimised paternalism is quite evident or, where there is genuine intent, there can be gross ignorance of Aboriginal culture, protocol and experience.

It is seldom assumed by non-Aboriginal people that contemporary Aboriginal society throughout urban, rural and remote parts of this State is strongly indebted to, governed by and inextricably linked to its traditions and culture. It is not the purpose of this paper to discuss the varying extent of residual traditional knowledge throughout Aboriginal communities in this State, nor should it be. However, it simply needs to be stated that it is an ever present reality with which non-Aboriginal academia must acknowledge, respect and come to terms. Nor is it incumbent upon Aboriginal Ethics Committees to have to justify sceptical academics making application to research into Aboriginal health, what constitutes appropriate and acceptable research. There have been many occasions in the experiences of the AH&MRC Ethics Committees where gross ignorance of Aboriginal culture have resulted in trauma for participants in research projects, with violations of deeply held spiritual values, procedures and practice.

As a case in point, at a recent similar conference on Aboriginal health an overhead was shown at a plenary session by a researcher in mental health summarising every alleged Aboriginal death by suicide in NSW over the past four years. The classification was by age, alleged cause of death, date of death and the town within NSW. Anyone with a modicum of knowledge of Aboriginal society in NSW would know that such information would immediately identify many of the persons referred to, especially in smaller identified communities. The responsible ABS policy not to classify data below a certain minimal aggregation was not heeded and the inevitable occurred. The aunt of a deceased youth became traumatised following her identifying her nephew in this public display. From her knowledge he had died an accidental death. When the scholar was confronted with the seriousness of the matter, although contrite, he blamed another scholar from whose work he had copied the chart. Neither the presented paper, nor the primary source document quoted, had been endorsed by an Aboriginal Ethics Committee, contrary to the *NSW Aboriginal Health Information Guidelines*.

There have also been occasions where the ethics committee has had to provide both support for the bereaved and criticism of perpetrators of unacceptable conduct related to the deceptive practices of mortuary and research staff. Unnecessary grief and pain have been experienced due to disrespect for Aboriginal people's traditions and customs for the burial of their deceased loved ones. Here again there has been a circumvention of ethical scrutiny.

²³ *Recommendations of the Royal Commission into Aboriginal Deaths in Custody, Recommendation 270.*

Most non-Aboriginal people are oblivious of the very onerous requirements upon families for funerary arrangements and practice and have little or no comprehension of the widely differing roles of the sexes in societal matters in general, including health. It is ironic that similar practices of other religious groups in society are considered sacrosanct whilst the religious or spiritual dimension in Aboriginal communities and Aboriginal community organisations is not even recognised. It is not the obligation of the Committee to expound on these and other culturally sensitive matters nor is it appropriate to satisfy the curiosity of well meaning applicants of the residual levels of traditional belief and practice with regards to these matters.

Additionally, there are certain assumptions about group screening programs that simply are unaware of divergent traditions even amongst neighbouring communities and the mere inclusion of an Aboriginal person on a mainstream program is no guarantee of culturally appropriate procedures. This person may come from a totally different community or even another nation, and the inclination to have black representation on committees to expedite a given departmental line or generic document is inappropriate and presumptuous. There are so many variables which make an ostensibly successful health check program in one Aboriginal community inappropriate without amendment in another.

There is even the opinionated assumption that Aboriginal health is public property and the presumption that such an area is for 'experts' only. Anthropologists, sociologists, medical practitioners, health researchers and departmental employees sometimes assume that because they have worked in an Aboriginal community for some time, and may have even been given a skin colour, that they have a correct interpretation of sociological, familial and cultural matters of a particular Aboriginal community. It is more likely the case that they have only been told as much as they needed to know and, even then, only from one perspective.

What then is the answer to researchers facing the dilemma of seeking to do legitimate research into Aboriginal health? Well, the answer is very simple and it is very easy - from the outset work through an Aboriginal Ethics Committee to determine what the community itself wants. This does not mean a selective discussion with a group of Aboriginal people one happens to support or a group of people one first encounters upon arriving at an Aboriginal community. Nor does it mean the mere discussion with an individual Aboriginal employee within an Aboriginal organisation or even an AMS. The community needs time itself to consider all the issues; seek advice from its own Ethics Committee and then, through careful consideration, have an appropriate Consent Agreement signed by all parties so that no circumvention of agreed procedures occur. In **Aboriginal health matters** the appropriate process to ascertain Aboriginal community consent is that of utilising the community representative structure of the AMS. The AH&MRC has specifically developed appropriate Individual and Community Consent Forms for health and health related research and epidemiological studies in Aboriginal health that meet all the ethical requirements outlined in the NAIHO, NACCHO and AH&MRC documentation.

It is hoped that this brief analysis may be of some assistance to researchers into Aboriginal health.