

Ethical Research in Indigenous Contexts and the practical implementation of it: Guidelines for ethical research versus the practice of research

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Abstract

Indigenous Australians have been widely researched by non – Indigenous Australians which has resulted in the use of inappropriate research methodologies and excluded the involvement, participation and ownership over the research.

The National Health and Medical Research Council (NHMRC) has developed national guidelines for the conduct of research in Indigenous communities. These guidelines have precipitated a change in Indigenous control and involvement over Indigenous research to a large extent, which is long overdue.

This paper examines these guidelines and relates them to the practical experiences of researchers engaged in a school based research project in urban, rural and remote locations. The suitability of the guidelines will be analysed.

Introduction

Indigenous Australians have been widely researched by non – Indigenous researchers. In many instances, the research has resulted in the appropriation of Indigenous knowledge using methodologies and procedures which are considered to be culturally insensitive and inappropriate. Previous practices have excluded Indigenous participation and ownership over the research which in many cases today have resulted in Indigenous people being very wary of proposed research projects and presenting difficulties to researchers. Taylor and Ward reinforce this position by stating, “it is fair to say in the past that there has been suspicion of and even hostility expressed by Indigenous Australians towards some anthropological and archaeological research ideas and practice. Some suspicion continues today.” (p.16, 2001).

The National Health and Medical Research Council (NHMRC) have developed national guidelines for the conduct of all research involving humans, animals and the environment. In addition to these guidelines, the NHMRC, has established a set of complementary guidelines for the conduct of health related research involving Aboriginal and Torres Strait Islander people (Guidelines on Ethical matters in Aboriginal and Torres Strait Islander Health Research (1991). This document has been recently revised and updated by the NHMRC in response to feedback received from Aboriginal and Torres Strait Islander communities and is available in draft form (Values and Ethics in Aboriginal and Torres Strait Islander Health Research, 2002).

While these guidelines are strongly supported, the implementation process of such guidelines requires further discussion and clarification between the researcher and those being researched, particularly in Indigenous contexts where previous negative experiences have left many Indigenous persons feeling reticent toward and wary of research projects on Indigenous issues. Appropriate levels of consultation and ongoing consultation during the research process may help alleviate any concerns which may be raised by the Indigenous community.

This paper will analyse the NHMRC’s complementary set of guidelines for the conduct of research involving Aboriginal and Torres Strait Islander people and will briefly outline the major implementation strategies suggested in the document. It will then highlight some fieldwork experiences that support the need for further discussion and clarification of such guidelines. The paper will also briefly outline a number of ethical principals identified by the Aboriginal Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) as these too are useful for researchers and human research ethic committees.

Lastly, the paper will briefly highlight some fieldwork experiences concerning the reporting of research findings that fall outside the approved research study. Some research findings or observations made during the data collection process may present an ethical versus moral dilemma for researchers, particularly when the action or inaction is considered to be so profound that the situation warrants some degree of attention. It is not the intention of this paper to discuss this subject in great detail, but rather provoke further discussion on the matter.

Indigenous experiences and response to research

It is well documented that previous research methodologies and practices in Indigenous issues which have been carried out by non-Indigenous researchers have been inappropriate, culturally insensitive and in many instances, harmful to Indigenous individuals and communities (Manderson et al, 1998, Foley, 2000, Taylor and Ward, 2001, Cruse, 2001). Manderson and others in particular have been scathing on past practices of researchers who often treated Indigenous communities as ‘field laboratories.’ These authors purport that, “ Indigenous perceptions of Australian research practice have emphasised their subject status, in which academics have been seen to descend on a community, gain peremptory permission to conduct their work, collect their data (biological or social) and leave, with little or no feedback to the community and no lasting benefits to it” (1998, p.2).

In addition, past research practices have resulted in secret sacred materials being published, while other cultural practices have been sensationalised. A recent example of cultural insensitivity was reported in the Sydney Morning Herald on 10/05/03 regarding the release of a new book on Hindmarsh bridge affair in South Australia. The book’s author, Margaret Simons reveals that items in a sealed enveloped marked, ‘for woman’s eyes only’ were read by a man (Sydney Morning Herald, p.9, 2003). As a result of these experiences, Indigenous people have become reticent and wary of being researched and at times, have been reluctant to support or participate in proposed research activities.

The NHMRC believes that inter cultural differences must be recognised and acknowledged in order to develop strong ethical relationships between researchers and the Aboriginal and Torres Strait Islander community. “ The construction of ethical relationships on one hand and the research community on the other must take into account the principals and values of Aboriginal and Torres Strait Islander cultures” (2002, p.5).

The ethical guidelines established by the NHMRC and AIATSIS for the conduct of research involving Indigenous issues promotes research practices that are culturally sensitive, empowering and participatory for Indigenous individuals and communities. Aboriginal and Torres Strait Islander people have also become increasingly involved in research as researchers and have set up their own Aboriginal Health Research Ethics Committees to oversee the approval of research applications on Indigenous issues. While this is welcomed and strongly supported, some Aboriginal and Torres Strait Islander people and organisations still remain apprehensive and mistrust the enterprise of research itself as a result of negative experiences with researchers in the past (NHMRC, 2002,p.2). Some recent field work experiences involving Indigenous organisations and communities have reinforced this response, however, this situation has the potential to discourage both Indigenous and non – Indigenous researchers from considering or continuing research in Indigenous related issues, despite identified research benefits to the community. Some examples are presented later in the paper.

NHMRC's Values and Ethics in Aboriginal and Torres Strait Islander Health Research – Draft document, 2002

The proposed guidelines identify six values in Aboriginal and Torres Strait Islander Research and suggest ideas for researchers to engage with each value when writing research proposals. The six value areas are: Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity. The document also identifies ways in which each of these values can be incorporated in research proposals and research activities and some of these are outlined below.

Where appropriate, some fieldwork experiences will be also be presented to support the need for further discussion and clarification of such guidelines. The fieldwork experiences relate to a current research project concerning the teaching of Indigenous students with Conductive Hearing Loss (CHL) in remote and urban schools in Western Australia.

1. **Reciprocity** – two components are outlined here. Firstly, the *Benefits* the research will have in advancing the interests of Aboriginal and Torres Strait Islander communities and that are valued by them. Secondly, the *Inclusion* of Aboriginal and Torres Strait Islander people, their values and culture in the proposed research activity.

Implementation strategies/ideas include:

- Research proposals to clearly identify the benefits to Aboriginal and Torres Strait Islander Communities,
- The relationship of the proposed research activity to national priorities and strategies,
- The inclusion of Indigenous participants as research partners and participants in the monitoring of research.

Fieldwork experience – Unnecessary delays to the CHL research project have occurred when Indigenous organisation and community leaders have abrogated their responsibilities of assessing research applications preferring negotiations to take place between the researcher and non Indigenous personnel or colleagues. There could be a number of reasons for this: other important organisational/community priorities, feeling of being 'over researched' and as discussed earlier in the paper, previous negative experiences with researchers and research projects.

In another example, more than one ethical clearance has been required when researching across several organisations despite prior ethical approval at a university level and despite support at industry and local Indigenous community levels. The compatibility of ethical guidelines of organisations requires further discussion and clarity as this scenario can lead to lengthy delays in the approval process, delays in accessing data due to system

variations that may in turn render a research project untenable and/or discourage researchers in continuing in the project.

- 2. Respect** – A respectful relationship between researcher and participants induces trust and co-operation, in particular the respect afforded to the cultural and social values of Aboriginal and Torres Strait Islander cultures.

Implementation strategies/ideas include:

- agreement on the reporting and publication of research findings between researcher and participants,
- the elimination of cultural bias in the reporting of findings,
- provision of appropriate ongoing advice about the research project and research processes.

Field work experiences – The format and content required by the University’s ethics committee regarding consent forms have drawn negative comments such as, ‘wording too complex or too long’ from the Indigenous community. This is despite several revisions to simplify the form. In another case, consent forms used by the CHL project were deemed inadequate to access medical data.

Privacy laws also transfers the responsibility of sending and receiving the consent forms from the researcher to the school. Methods of sending and explaining the consent form have varied from the sending of newsletters to parents to the use of Aboriginal and Islander Education Workers (AIEW’s) or Aboriginal Teacher Assistants (ATA’s) who in the majority of cases, have been left to their own devices to interpret the contents of the form.

The responsibility of schools receiving signed consent forms initially on behalf of project team has also resulted in one set of forms being filed away and lost! Due to long distances involved in visiting research sites, data collection was able to proceed on the basis of the consent forms being ‘sighted!’

In order to ensure complete understanding of the consent form and subsequent research activity, the CHL team includes an Indigenous member who discusses all aspects of the research project with parents, interested community members, AIEW’s and ATA’s on each field trip.

- 3. Equality** – Aboriginal and Torres Strait Islander people regard equality as a right to be different and that “equality does not mean identical treatment.” Researchers should not ignore the value and wisdom of Aboriginal and Torres Strait Islander knowledge as this could lead to a misinterpretation of findings and also create mistrust. “Researchers’ misinterpretation and failure to recognise the cultural values and worldview of Indigenous people is often caused by the application of ethnocentric research models” (Mack & Gower, 2001, p.3).

Implementation strategies/ideas include:

- inclusion of Indigenous knowledge and wisdom in research questions, methodology and dissemination of research findings,
- intellectual property rights of Indigenous peoples must be protected,
- agreement on the collection, storage, use of research data,
- the distribution of benefit of the research to be fair and equal, ie not principally to researchers.

4. **Responsibility** – Research should be undertaken in consultation with relevant community members to minimise disruption to community and cultural obligations. Aboriginal and Torres Strait Islander societies have responsibilities to country, kinship bonds and spiritual world.

Implementation strategies/ideas include:

- ongoing monitoring by communities of project's compliance with ethical standards,
- consideration of impact the research may have on the social functioning of communities,
- the provision of honest feedback to any expressed concerns and expectations made by participants and communities.

5. **Survival and protection** – “Many Indigenous communities have the subject of research which has disempowered them by undermining and devaluing their decision making mechanisms and disregarding community-based social, cultural and economic priorities” (Mack & Gower, 2001, p. 3). Aboriginal and Torres Strait Islander peoples have a strong desire to protect and maintain their culture and identity. Researchers need to demonstrate that research practice will not repeat mistakes of the past.

Implementation strategies/ideas:

- whether research proposal respects the cultural distinctiveness and identity of Aboriginal and Torres Strait Islander peoples and communities,

6. **Spirit and Integrity** – This is an overarching value that binds all previous five values into a coherent whole. The guiding principal here is for researchers is integrity, in the development of the research proposal and ethical conduct of research (NHMRC, 2002, pp 11-23).

AIATSIS 11 Ethical Principles

The Australian Institute for Aboriginal and Torres Strait Islander Studies was established in 1964 to influence the way research is conducted in Indigenous communities. “An underlying aim of AIATSIS, in attempting to exert such influence, is to ensure that research about and involving Indigenous Australians is undertaken in ways that are both culturally appropriate and ethical: (Taylor & Ward, 2001, p.15).

AIATSIS has developed eleven ethical research principals of its own and many of these are embedded in the NHMRC’s research guidelines for the conduct of research involving Indigenous communities. These principals are very useful for researchers and human research ethic committees and are listed below:

1. Consultation, negotiation and free informed consent are the foundations for research with or about Indigenous peoples,
2. Consultation and negotiation is ongoing,
3. Consultation and negotiation should achieve mutual understanding about the proposed research,
4. Indigenous knowledge systems and processes must be respected,
5. Recognition of the diversity and uniqueness of peoples and individuals,
6. Intellectual and property rights of Indigenous peoples must be protected and preserved,
7. Indigenous researchers, individuals and communities should be involved in research as collaborators,
8. The use of and access to, research results should be agreed,
9. A researched community should benefit from, and not be disadvantaged by, the research project,
10. Negotiation of outcomes should include results specific to the needs of the researched community,
11. Negotiation should result in formal agreement for the conduct of a research project, based on good faith and free and informed consent. (Taylor & Ward, 2001, p.20).

Recording and reporting research findings: An ethical dilemma

Among the NHMRC’s principals of ethical conduct and associated guidelines for research involving humans is the protection of the welfare and rights of the participants in research. “The ethical and legal responsibilities which researchers have towards participants in research reflect basic ethical values of integrity, respect for persons, beneficence and justice” (2002, p. 11).

These principals include minimising the risks of harm, discomfort and identification in all aspects of the research process including the reporting of research findings. Researchers however, are often faced with a number of dilemmas when reporting research findings or other observations that may pose an ethical versus moral issue for them.

Researchers who engage in qualitative or interpretive research establish an intimate relationship with participants and are therefore more likely to 'discover' particular behaviours that may be considered untoward. Howe and Moses acknowledged this situation by stating that, " these discoveries may put research participants at risk in ways that they have not consented to and that the researcher had not anticipated" (1999, p.40).

The following questions are drawn from fieldwork experiences involving classroom settings and education administration staff.

Should principals be informed of poor teacher performance when such reporting falls outside the approved research project? How can this situation be reported without identifying or harming the person concerned?

Researchers may feel a strong moral obligation to take some form of appropriate action especially when the teacher has been observed to demonstrate poor qualities on a number of occasions and when the students are too young to know the difference.

Howe and Moses (1999, p.45) suggest that researchers need to tread carefully on this matter. "The problem cannot be eliminated by casting reports in wholly objective language. As description moves toward being more objective in this sense, it simultaneously move towards a 'thin' description."

Further discussion is required here to assist researchers who are confronted with moral dilemmas on the reporting of some research findings.

Conclusion:

The conduct of research in Aboriginal and Torres Strait Islander communities has improved significantly in recent times as a result of ethical guidelines being developed by the NHMRC, Aboriginal Health Ethic Committees and AIATSIS. Some Aboriginal and Torres Strait Islander people however, are still wary of past research practices and still mistrust the enterprise of research. Secondly, some fieldwork experiences outlined in the paper indicates the need for further discussion to identify strategies to implement some of these guidelines more successfully and to assist researchers in the reporting of findings that fall outside the approved research

Strategies to increase levels of informed consent and on going informed consent should greatly assist in this process and allay any mistrust or fears Indigenous organisations and people may have about research.

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