Navigating the process of developing a research project in Aboriginal health

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ABSTRACT

- Research in Aboriginal health may be hampered by a lack of experience with the process of collaboration with Aboriginal communities, and additional ethics approval requirements.
- Awareness of resources and advice from Aboriginal mentors with in-depth knowledge of clinical and research issues can greatly assist researchers.
- A collaborative approach between researchers and Aboriginal communities is pivotal to developing a research project consistent with Indigenous cultural values and health concepts, with the potential to improve services and outcomes for Aboriginal peoples.
- Planning and broad consultation can ensure that research is feasible, ethical, culturally sensitive and beneficial.
- This article outlines lessons learned from personal experience of developing a project in Aboriginal health, which we hope may serve as a practical guide for others.

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Developing a health research project requires gathering information, planning, consultation and consideration of ethical issues. In Aboriginal health research, there is a legacy of mistrust of researchers, who have often made false assumptions and misunderstood the values and practices of Aboriginal and Torres Strait Islander cultures by approaching them through their own cultural lens.[1] There are ongoing concerns from Indigenous peoples that communication by researchers is poor, consultation is inadequate, values are violated by inadvertent cross-cultural insensitivity, and the research often fails to benefit the community.[1]

The important processes of developing a project that will benefit Aboriginal and Torres Strait Islander peoples, consulting broadly with Aboriginal communities, and comprehensively considering ethical issues must be navigated by researchers. Non-Indigenous researchers may be unsure of how to address these concerns, and may even be deterred from embarking on research in Aboriginal health. This is unfortunate, and may contribute to ongoing concerns about trust and the loss of opportunities to develop worthwhile collaborative relationships between researchers and Aboriginal and Torres Strait Islander peoples.

Here, we present a suggested broad guide for approaching project development and ethics approval in research with Aboriginal and Torres Strait Islander peoples. This is enhanced by the personal experience of one of us (AW) in developing a research project in Aboriginal mental health; an outline of some of the processes undertaken for this project is given in Box 1.

Developing the project

The research question

Aboriginal peoples have long argued that research conducted in their communities does not benefit them or lead to improvements in health.[2] The *NSW Aboriginal health information guidelines* encourage research questions that involve collection of health-related information that is “ethical, meaningful and useful to Aboriginal peoples, based on an agreed view negotiated between the relevant parties to the Partnership” (Box 1).[3] The information gathered must also be used to facilitate improved health and to better plan and deliver health services.

In a literature review, Anderson and colleagues advocated for ethical guidelines to promote transparent negotiation with Indigenous Australians about the potential benefits of proposed research, suggesting that this could occur by demonstrating that the investigators intend to contribute to improved health and wellbeing of participating communities; the proposal is linked with local Indigenous community priorities; the proposal contributes tangible and accessible outcomes for participants; and the proposal reflects needs identified in health improvement plans and strategies.[4]

Supervision and the investigating team

Selection of a supervisor for less experienced researchers should be carefully considered. It is of great value to have a supervisor or co-investigators with an Aboriginal or Torres Strait Islander background and insight into culturally appropriate conduct and protocols for community consultation. They may also be able to introduce the researcher to key stakeholders in the community and initiate the process of becoming known and trusted in the community. The *National strategic framework for Aboriginal and Torres Strait Islander peoples’ mental health and social and emotional wellbeing 2004–2009* recommends the “employment of, and/or skills transfer to, Aboriginal and Torres Strait Islander peoples in all aspects of the research process, including project management, research and research analysis”.[5]

Community consultation

There has been a paradigm shift in Indigenous health research over the past 50 years, from researchers objectifying, to consulting, and, more recently, collaborating with Indigenous peoples.[6] The focus is now on partnerships and Indigenous-directed research.[4] In practice, consultation and negotiation with Aboriginal communities are continual, and should achieve mutual understanding about the proposed research.[7] The community should be fully informed about the aims, methods, implications and potential outcomes of a research project, so that they can decide whether to accept or oppose it.[7]

Identifying who represents a particular community may be complex (Box 1).[8] In some areas, this role may not belong to an Aboriginal community-controlled health service, but to a community council or other authority.[1] For larger studies, there are also state-based and national associations of Aboriginal community-controlled health services.

There are multiple national[1,5,7,8-12] and state[3,13,14] guidelines on community consultation in Indigenous health research. The National Strategic Framework recommends an approach that emphasises partnership and collaboration, and Aboriginal and Torres Strait Islander ownership and control as key components underlying successful and ethical research.[5]

The structure and procedures guiding community engagement and participation vary. Researchers should ideally consult with people experienced in Aboriginal research on how to approach community consultation, or seek advice from a senior member of the Aboriginal community organisation. As such services are often under-resourced, it is important to succinctly inform the service directors in writing about the project and to allow sufficient time for a response.[8] Researchers should be prepared to meet with the service directors to further discuss their background and the project's aims, ethical issues, implications and potential benefits to the community. How the project fits with community priorities for research, opportunities for involvement of Aboriginal peoples in data gathering and analysis, and how results will be reported back to the community must be considered. It is not just the principles of transparency and respect inherent in such meetings that are important, but also forming partnerships with Aboriginal people, which greatly enhances the quality and validity of the research.

1 Personal experience with the processes of developing a research project in Aboriginal mental health

The following outlines the experience of one of us (A W) in developing a research project in Aboriginal mental health for the award of Master of Psychiatry.

The research question

Over a year before starting the project, A W met with health workers at the local community-controlled Aboriginal Medical Service (AMS) and hospital where the research was to take place. She presented some initial ideas from her knowledge of the literature for discussion and comment.

Observations, recommendations and identified priority areas for research made by these key Aboriginal informants were used to develop the hypotheses and methods of the project.

Community consultation

Guidelines on community consultation in Indigenous health research were applied by first identifying who represented the Aboriginal community in which the study would take place in terms of its community interests about health research.

As the study involved analysis of hospital medical records rather than direct contact with participants, three Aboriginal community-controlled health services in the area (whose clients were likely to overlap with the study sample) and Aboriginal health workers within the hospital where files were to be accessed were approached.

This lengthy process involved telephone and formal correspondence with AMS executives, group and individual meetings with health workers at the AMS and hospital, and communicating with Aboriginal hospital managers. Other key informants were often identified at these meetings and subsequently approached.

A W's supervisor, S E, an experienced Aboriginal researcher, facilitated introductions to key Aboriginal health workers, managers and community organisations.

Obtaining ethics approval

Ethics approval for the project was sought from and granted by the ethics committees of the Aboriginal Health and Medical Research Council of New South Wales (AH&MRC), Sydney South West Area Health Service, and the NSW Institute of Psychiatry.

There was an ongoing dialogue with the AH&MRC Ethics Committee, and it took several months for the project to be approved. This dialogue included thoroughly describing the proposed process of consultation with the Aboriginal community in all phases of the project and describing how the cultural expertise of Aboriginal peoples would be sought by the researchers and used to analyse the data obtained.

A W was fortunate to have an Aboriginal mentor, who had clinical expertise in mental health and had been a member of the AH&MRC Ethics Committee. She discussed the proposal with A W on a number of occasions, proofread drafts of the ethics applications and made recommendations on cultural issues to be considered.

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For projects directly involving a hospital or other general health facility, it is worthwhile meeting with the facility's Aboriginal health workers, liaison officers, cultural workers and managers to introduce the research team and the project, discuss ideas and seek feedback (Box 1). In regional and rural areas, the process of collaboration and consultation may be less clear. A useful model has been described for negotiation between an Aboriginal community and researchers, using regular meetings of a community reference group comprising members of both parties.[2]

Obtaining ethics approval

Where to apply

As well as seeking approval from the ethics committee of the academic institution or hospital where the research will take place, the National Health and Medical Research Council (NHMRC) stipulates that for Aboriginal health research, the ethics approval process must include an assessment by, or advice from, people who have connections with Aboriginal and Torres Strait Islander peoples or knowledge of research in the area, and who are familiar with the culture and practices of Indigenous participants in the study.[9] Most states and territories have their own dedicated ethics committee for Aboriginal health research proposals (Box 2). Their individual requirements vary, but most refer researchers to the NHMRC[1,9,12] or Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) ethical guidelines.[7]

In practice, the local or institutional ethics committees will generally only grant approval for the project after it has been accepted by the relevant Aboriginal ethics committee (Box 1).

Helpful resources

Researchers should be familiar with the resources listed in Box 3. Most Aboriginal ethics applications have common elements, which are captured by the NHMRC *National statement on ethical conduct in human research*:[9]

- Research merit and integrity: including demonstrating support for the project from relevant Aboriginal and Torres Strait Islander communities;
- Justice: including developing trust and a sense of equal research partnership with Aboriginal peoples, ensuring that the project reflects Aboriginal research priorities;
- Beneficence: demonstrating how Aboriginal peoples will benefit from the research; and
- Respect: active engagement with Aboriginal and Torres Strait Islander peoples, drawing on their knowledge and wisdom in the research process and recognising and valuing cultural diversity.

The AIATSIS guidelines emphasise ongoing consultation and negotiation.[7] It should be noted that the National Aboriginal Community Controlled Health Organisation, the peak representative body for Aboriginal peoples, does not endorse the most recent

NHMRC guidelines but recommends following the 1991 NHMRC guidelines[12] and those of the Aboriginal Health and Medical Research Council of New South Wales (AH&MRC).[13,16]

People are arguably the most valuable resource. Presenting a draft of the ethics application to people experienced in Aboriginal research and ethical issues for feedback before submission can streamline the process and provide the researcher with additional guidance in conducting culturally aware research (Box 1).

Special issues

Ownership and custodianship of information are important concepts. Custodianship refers to day-to-day responsibility for the protection of individual client records, including those held within data collection systems, while ownership refers to the right to control the dissemination and use of personal information. Custodians of information about Aboriginal peoples are responsible for maintaining the quality and accuracy of the information record, ensuring the information is stored securely and destroyed at the appropriate time, and determining when and where it is appropriate to disclose and use the information.[3]

Another consideration is how the consent of study participants is documented. In addition to standard participant information sheets and consent forms, an organisation (Aboriginal Medical Service [AMS] or Aboriginal community-controlled health service) consent form for research in Aboriginal communities may be required.

Researchers should also be familiar with the recommended terminology for referring to Aboriginal and Torres Strait Islander peoples.[17]

Disseminating the results

Feedback to the Aboriginal community

Given that the purpose of collecting Aboriginal health information is to benefit Aboriginal peoples, there needs to be a plan for sharing the results with the community.[4,6]

The AIATSIS guidelines recommend:

- early discussions with the community on how and when the results of research will be fed back to and discussed with the relevant community members or organisations, which should occur before publication or broader dissemination of the results;
- establishing a clear understanding of the level of community control over any research results or materials developed; and
- negotiations with the community about the disposition and storage of research data, including any agreed restrictions on use of information.[7]

2 Ethics committees that assess Aboriginal health research

New South Wales, Australian Capital Territory

Aboriginal Health and Medical Research Council

South Australia

Aboriginal Health Research Ethics Committee

Western Australia

Western Australian Aboriginal Health Information and Ethics Committee

Northern Territory

Central Australian Ethics Committee (Central Australia); Human Research Ethics Committee of the NT Department of Health and Community Services and Menzies School of Health Research (Top End)

Tasmania

University of Tasmania Ethics Committee

Victoria, Queensland

Variable, depending on the institution affiliated with the research project

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3 Key resources for preparing ethics applications

- *National statement on ethical conduct in human research*[9]
- *Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*[1]
- *Guidelines for ethical research in Indigenous studies*[7]
- Coalition for Research to Improve Aboriginal Health — tools for collaboration[10]
- *National strategic framework for Aboriginal and Torres Strait Islander peoples' mental health and social and emotional well being 2004–2009*[5]
- *Ways forward: national Aboriginal and Torres Strait Islander mental health policy national consultancy report*[15]
- *Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics*[11]
- *Ethical guidelines in Aboriginal and Torres Strait Islander research*[12]

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The results, implications and recommendations derived from the study may then be presented to local AMS or Aboriginal community-controlled health services, hospitals and community centres in the area, and then be more broadly disseminated in publications and conference presentations.

Ethical use of the data

The great disparity in health between Indigenous and non-Indigenous Australians is well documented. Research that simply highlights this inequality may further demoralise and stigmatise Aboriginal and Torres Strait Islander peoples and may not generate ideas for change and improvement in health services. Results, whether favourable or not, must be reported accurately; however, it is important that they are presented so as to emphasise strengths and avenues for action rather than deficits or negative comparisons and hopelessness.[18]

Additionally, any explanations of Indigenous health data obtained should be comprehensive and must address cultural issues and the consequences of political and historical climates, as well as socioeconomic variables. Multiple explanations may be needed, as well as flexible interpretation of the data, as Indigenous people see health in complex, interrelated ways that may not seem understandable or relevant to non-Indigenous people.[18]

Ethics committee requirements

Information must be sensitively analysed and reported to avoid unintended interpretations or consequences. As a standard condition of its ethics approval, the AH&MRC Ethics Committee stipulates that it must review a final report for compliance with ethical and cultural criteria before submission for publication or any dissemination of the report.[13] Such requirements should be considered when planning journal submissions and conference presentations.

Conclusion

Aboriginal health research can be a rewarding field, with great scope to improve services and outcomes for Aboriginal peoples. Adequate preparation and planning, broad consultation and approaching research in partnership and collaboration with Aboriginal peoples and community-controlled organisations can ensure that research is feasible, ethical, culturally sensitive and beneficial.

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Competing interests

None identified.

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