

Introduction

This quick guide provides advice for health professionals and researchers undertaking research in NSW Health facilities with a focus on Aboriginal¹ people, including where Aboriginal people are considered as part of a broader study population. The purpose of the guide is to increase awareness of the appropriate principles, approaches and processes required to ensure that research projects are ethical and beneficial for Aboriginal people and communities. This includes supporting researchers to consider when and how to seek ethical approval for research conducted with Aboriginal people or communities.

Ethical conduct of Aboriginal health research respects the shared values of Aboriginal people and communities as well as their diversity, priorities, needs and aspirations; research must be of benefit to Aboriginal peoples and communities as well as researchers and other Australians. There are a number of key recommendations researchers should follow to ensure their research is ethical, culturally sensitive and beneficial for Aboriginal people in NSW.

Key recommendations

- Actively engage Aboriginal stakeholders in the conception of the research.
- Collaborate in a way that ensures Aboriginal organisations and/or community direction and benefit from the research effort.
- Complete an Aboriginal Health Impact Statement.
- Use research designs and methods that are ethical and culturally appropriate.
- Reimburse Aboriginal people, communities and organisations for their contributions.
- Involve Aboriginal researchers and community members in the team.
- Seek out and utilise opportunities to build the capacity of all involved in the research including cultural competence of the research team, and of Aboriginal people involved in research.
- Ensure the research is applied and delivers a net benefit to Aboriginal people and communities.

¹ This document uses the term 'Aboriginal' in recognition that Aboriginal people are the original inhabitants of NSW.

All research with Aboriginal people must be subject to ethical review by a qualified Human Research Ethics Committee (HREC).² In NSW the Aboriginal Health and Medical Research Council of NSW (AH&MRC) operates as a fully constituted HREC that considers applications relating to research that may affect the health and well-being of Aboriginal people and communities.

Researchers must submit research projects for ethical approval to the AH&MRC HREC if one or more of the following apply:

- the experience of Aboriginal people is an explicit focus of all or part of the research
- 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
- Aboriginal health funds are a source of funding.

Additionally, the AHM&RC HREC advises that an application should be made if a project meets any of the below criteria:

- the Aboriginal experience of the medical condition being studied is known, or is likely, to be different from the overall population
- there are Aboriginal people who use the services being studied in distinctive ways, or who have distinctive barriers that limit their access to the services
- Aboriginal people are known, or likely, to be significantly over-represented in the group being studied (compared to the 3.4% of total NSW population) and/or it is proposed to separately identify data relating to Aboriginal people at any stage in the project.

The Aboriginal Health Impact Statement can assist researchers with understanding whether any of these criteria apply. Aboriginal Health Units in local health districts and specialty networks, and the Centre for Aboriginal Health, NSW Ministry of Health, can also assist. Research that uses existing collections of data or records that contain only non-identifiable data may not require ethical approval by a HREC yet researchers are encouraged to contact the AH&MRC to determine whether their analysis or research requires ethical approval. The decision may depend on whether and how the research will be published.



² NH&MRC, 2007, National Statement on Ethical Conduct in Human Research.

The AH&MRC HREC will generally accept the same HREC application, research protocol and supporting documents submitted to other HRECs. However, applications to the AH&MRC HREC must also address all of the below principles in a separate document. The AH&MRC HREC will consider whether the research is being conducted in an ethical manner and whether the project will be undertaken with Aboriginal people in a culturally appropriate manner.

Table 1. Key Principles to be addressed in ethics applications to the AH&MRC

Principle	In Practice
Net benefits for Aboriginal people and communities	The research will advance scientific knowledge and result in a demonstrated net benefit for the health of Aboriginal people and communities.
Aboriginal community control of research	There is Aboriginal community control over all aspects of the proposed research including research design, ownership of data, data interpretation and publication of research findings. (Note: the term 'control' essentially means that at all stages of the research, Aboriginal people and communities participating in, or directly affected by the research will be fully informed about, and agree with, the purposes and conduct of the project).
Cultural sensitivity	The research will be conducted in a culturally safe manner and will recognise the historical aspects and impact of colonisation on Aboriginal people.
Reimbursement of costs	Aboriginal communities and organisations will be reimbursed for all costs arising from their participation in the research process.
Enhanced Aboriginal skills and knowledge	The project will seek and utilise opportunities to enhance the skills and knowledge of Aboriginal people, communities and organisations that are participating in the project.

Further information on these Principles can be found in the <u>AH&MRC</u> Guidelines for Research into Aboriginal Health, 2016

Aboriginal Health Units (located within each <u>local health district</u>) and the <u>Centre for Aboriginal Health</u> in the Ministry of Health can assist with navigating the concepts and approaches outlined in this document. Additionally, a variety of resources are available that provide additional information on conducting ethical and culturally appropriate research with Aboriginal and Torres Strait Islander people or communities, including:

- NSW Health, 2019, Conducting Translational Research with Aboriginal Communities or People
- NH&MRC, 2018, Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders
- NH&MRC, 2018, Keeping research on track II
- Laycock, A. with Walker, D., Harrison, N. & Brands, J. 2011, Researching Indigenous Health: A Practical Guide for Researchers, The Lowitja Institute, Melbourne
- NSW Health Guideline GL2007_020: Human Research Ethics Committees
 Quality Improvement & Ethical Review: A Practice Guide for NSW
- Department of Aboriginal Affairs, 2018, On our terms: obtaining Aboriginal community consent for social research; a literature review and case study
- Australian Institute of Aboriginal and Torres Strait Islander Studies, 2019, Code of Ethics for Aboriginal and Torres Strait Islander Research.

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SHPN (OHMR) 200094

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April 2020



