

Aboriginal and Torres Strait Islander Human Research Ethics Committees (HRECs) are essential in promoting our health and wellbeing

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Key points

- There is a long legacy of unethical and inhumane research conducted on Aboriginal and Torres Strait Islander people since colonisation
- Aboriginal Human Research Ethics Committees (AHRECs) play a vital role in ensuring research is delivered for Aboriginal and Torres Strait Islander people in a way that protects and promotes their health and wellbeing
- Increased investment is needed to support Aboriginal and Torres Strait Islander HRECs, fill current gaps and ensure the wellbeing of Aboriginal and Torres Strait Islander research participants

Abstract

The history of unethical and inhumane research conducted on Aboriginal and Torres Strait Islander people since colonisation highlights the critical need for specific Human Research Ethics for research involving Aboriginal and Torres Strait Islander peoples in Australia. The development of Aboriginal Human Research Ethics Committees (AHRECs) has played a vital role in ensuring research is safe and delivered for Aboriginal and Torres Strait Islander people in a way that protects and promotes their health and wellbeing. However, there remains a lack of appropriate and critical ethical governance for such research in areas without specific Aboriginal HRECs in each jurisdiction. This perspective argues that greater investment in state-based AHRECs and consideration of a national AHREC are essential to ensure the ongoing health and wellbeing of Aboriginal and Torres Strait Islander people in the research process –the ultimate aim of any research that involves them.

Background

Standards for ethical conduct in research practice and governance of ethical review have been operationalised in medical research in Australia since the 1960s to protect the health and wellbeing of research participants.¹ Alongside these guidelines, Aboriginal and Torres Strait Islander peoples have driven the prioritisation, establishment, and governance of Aboriginal and Torres Strait Islander-specific Human Research Ethics.²⁻⁴ The critical need for this ethical regulation was driven by the legacy of unethical and inhumane research conducted on Aboriginal and Torres Strait Islander people since colonisation.⁵⁻⁷ This was, and still is, causing harm.⁸

Despite the well-documented need for and development of HRECs^{3,9-11}, we, as Aboriginal researchers (MK, SMF and MD) and co-chairs of the Aboriginal

Health and Medical Research Council of NSW (SMF and MD), know that more needs to be done in the Aboriginal and Torres Strait Islander research ethics space to ensure the wellbeing of research participants. Many researchers do not apply the Aboriginal and Torres Strait Islander guidelines appropriately.^{12,13} It is unclear if this results from a lack of education and knowledge of the guidelines, researchers' competing demands and time limitations, a lack of understanding of Aboriginal and Torres Strait Islander cultures and histories² or, at worst, blatant disregard for Aboriginal and Torres Strait Islander people's specific values and principles for research to ensure no further harm is caused due to research practice. The previous and ongoing issues gave rise to the development of Aboriginal Human Research Ethics Committees, which play a vital role in ensuring research is safe and delivered for Aboriginal and Torres Strait Islander people in a way that protects and promotes their health and wellbeing.

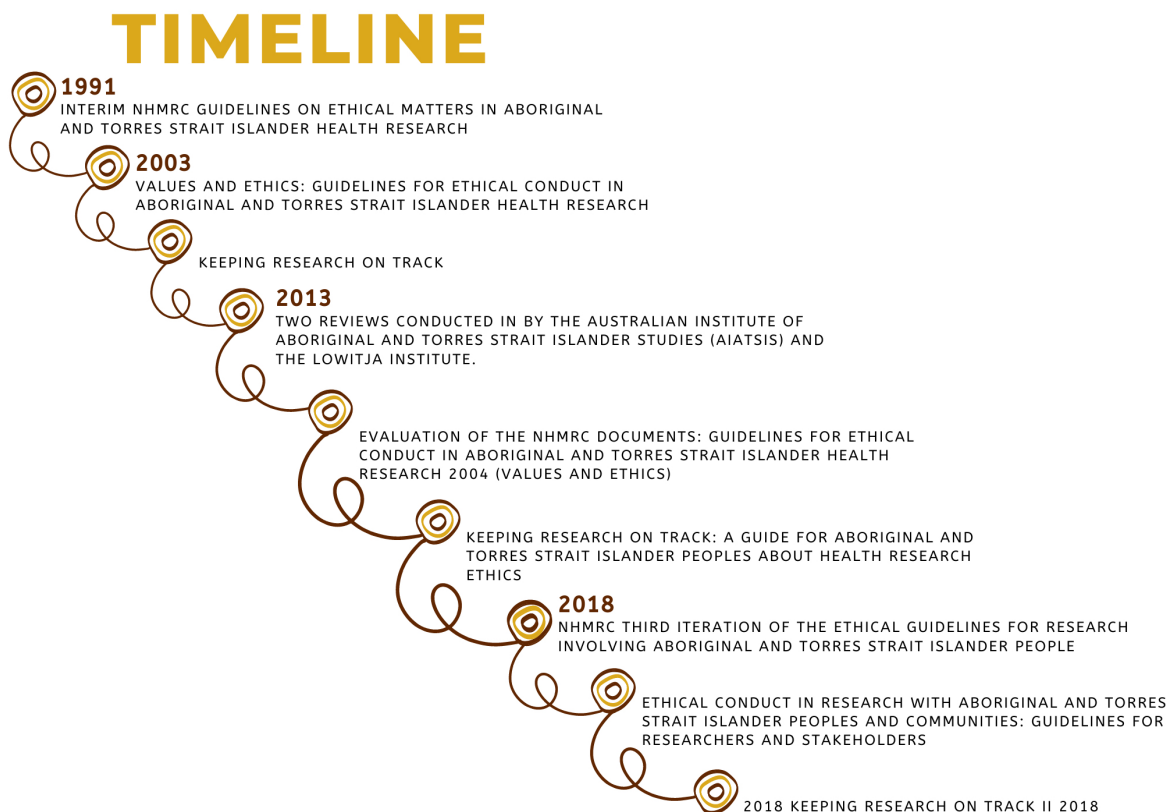
The first Aboriginal and Torres Strait Islander guidelines were published in 1991¹⁴, with the most recent version published in 2018⁸ by the National Health and Medical Research Council (NHMRC). There have also been several reviews of the guidelines to ensure they reflect today's standards (see Figure 1).

Aboriginal health research guidelines

The NHMRC, a statutory body responsible for managing investment in and the integrity of health and medical research¹⁸, has developed these guidelines with Aboriginal and Torres Strait Islander people. They are referred to in the National Statement of Ethical Conduct in Human Research (National Statement), which requires studies involving Aboriginal and Torres Strait Islander people must consult the Aboriginal and Torres Strait Islander guidelines when designing research.¹⁹

While ethical guidelines for Aboriginal and Torres Strait Islander health research have been implemented for decades, the governance of ethical review continues to have limitations and challenges for researchers and Aboriginal and Torres Strait Islander communities. There are currently two types of ethical governance: Aboriginal and Torres Strait Islander Human Research Ethics Committees (AHRECs) (see Figure 2)²⁰⁻²² under the auspices of Jurisdictional Aboriginal Community Controlled Health Organisation (ACCHOs) and one Aboriginal sub-committee in the Northern Territory under the auspices of the Menzies School of Health Research.²³ Jurisdictional ACCHOs, otherwise known as Jurisdictional Peak Bodies or National Aboriginal

Figure 1. Timeline of Aboriginal and Torres Strait Islander Human Research Ethics Guidelines in Australia^{2,9,15-17}



Community Controlled Health Organisation Jurisdictional Affiliates, are Aboriginal organisations that are member-based organisations run by and for the Aboriginal people. Their members are ACCHOs from within their jurisdiction. Their governance structure ensures Aboriginal self-determination with Boards consisting of Aboriginal people who represent their members.²⁴ Their primary function is policy, advocacy and programs to support their members' comprehensive primary health care service delivery.²⁵

The essential role of AHRECs

The AHRECs require researchers to detail how the health and wellbeing research that impacts Aboriginal and Torres Strait Islander people is conducted in a culturally safe way and is of maximum benefit to Aboriginal and Torres Strait Islander people. It is worth noting that researchers self-report the mechanisms to ensure cultural safety. The AHRECs ensure appropriate levels of community engagement throughout research projects and, wherever possible, that Aboriginal and Torres Strait Islander people are the research leads. Chaired by Aboriginal people, with a majority of Aboriginal and Torres Strait Islander people on the HREC committees²⁰⁻²², AHRECs are best placed to interpret and apply the National Statement and the relevant guidelines from an Aboriginal and Torres Strait Islander perspective. This is because, for other types of AHRECs, the implementation of the NHMRC Guidelines varies significantly.¹²

Aboriginal and Torres Strait Islander-specific ethics has a long and proud history in Australia. Aboriginal and Torres Strait Islander people have the right to participate in and lead research to improve their health and wellbeing. The appropriate governance of ethical review and research monitoring is critical to implementing respectful and ethical research practices and the health and wellbeing of Aboriginal and Torres Strait Islander people. However, where there is no Aboriginal and Torres Strait Islander HREC (Victoria, Queensland, Australian Capital Territory and Tasmania), there is a lack of appropriate and critical ethical governance. Consideration should also be given to funding an AHREC in the Northern Territory, as the current HREC sub-committee is not community controlled.

AHRECs are essential to ensure the ongoing health and wellbeing of Aboriginal and Torres Strait Islander people in the research process – the ultimate goal of research involving them.

A call for national action

We, therefore, call for increased investment in the current state-based HRECS and established Aboriginal and Torres Strait Islander-specific HRECs within the remaining community-controlled peak bodies. We firmly believe that AHRECs are best placed to ensure that research projects are positioned to be conducted in a culturally safe way that benefits Aboriginal and Torres Strait Islander people.

Figure 2. Aboriginal Human Research Ethics Committees in Australia by state²⁰⁻²²



AHREC = Aboriginal Human Research Ethics Committee; AH&MRC = Aboriginal Health and Medical Research Council NSW Ethics Committee; WAHREC = Western Australian Aboriginal Human Research Ethics Committee.

The Northern Territory Human Research Ethics Committee (HREC) sub-committee is not included in this image because it is not Aboriginal community controlled; therefore, it is not an AHREC.

Additionally, given that much research is national or multijurisdictional, there is merit in exploring the establishment of a national Aboriginal and Torres Strait Islander HREC. What this would look like, how it would engage with the jurisdictional AHRECs and who would fund it would need to be addressed. These issues are not insurmountable, given the potential benefits to AHRECs, researchers and Aboriginal and Torres Strait Islander people.

AHRECs are essential to ensure the ongoing health and wellbeing of Aboriginal and Torres Strait Islander people in the research process – which is the ultimate goal of research that involves Aboriginal and Torres Strait Islander people.

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Competing interests

None declared.

Author contributions

All authors planned the article. SMF drafted the initial version of the paper and edited the manuscript based on the reviewers feedback. MD and MK reviewed and edited the article and provided input on the revised manuscript.

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