



AIDA

The Australian Indigenous Doctors' Association
ABN: 84 131 668 936

Ethics and Governance
National Health and Medical Research Council
16 Marcus Clarke Street
Canberra ACT 2601

To whom it may concern

Re: Review of Aboriginal and Torres Strait Islander research ethics guidelines

Introduction

The Australian Indigenous Doctors' Association (AIDA) is a not-for-profit professional association contributing to equitable health and life outcomes, and the cultural wellbeing of Aboriginal and Torres Strait Islander Peoples. AIDA's ultimate goal is to reach population parity in the medical profession of Indigenous doctors, and to inform and support a culturally safe health care system. AIDA has a research agenda to support the work with our members and uses the National Health and Medical Research Council (NHMRC) *Values and Ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research 2003* for research alongside the *Guidelines for Ethical Research in Australian Indigenous Studies* from the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS).

AIDA has reviewed the revised NHMRC Aboriginal and Torres Strait Islander research ethic guidelines as outlined in *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* (the Guidelines). Overall, AIDA is satisfied the Guidelines meet the requirements to include the broader range of research areas beyond health. AIDA advocates for Aboriginal and Torres Strait Islander-led research and we suggest that this is an area which is lacking within the proposed changes. Furthermore, AIDA agrees that case studies are required to support the topic of intellectual property in the revised guidelines, specifically in the *Keeping Research on Track II* (companion document).

Overview

The Guidelines and companion document are predominantly concerned with research with Aboriginal and Torres Strait Islander Peoples. While this is currently still the most dominant form of research regarding Aboriginal and Torres Strait Islander issues, such a focus would be strengthened by the important and emerging area of research led by Aboriginal and Torres Strait Islander Peoples.

Indigenous-led research needs to be prioritised to support Aboriginal and Torres Strait Islander Peoples to self-determine the agendas, topics and methodologies of research. As noted in the 2012 *AIATSIS Guidelines for Ethical Research in Australian Indigenous Studies*:

It should also be recognised that there is no sharp distinction between researchers and Indigenous people. Indigenous people are also researchers, and all participants must be regarded as equal participants in research engagement (AIATSIS p 3).

This acknowledgement should also extend to recognition of the validity of Indigenous ways of knowing and being. The research methodologies and principles at the heart of the current guidelines remain based on an

approach that has its origins in and is determined by western scientific models; as such both the research methods and the ways of measuring impact and results are still inherently culturally biased. AIDA suggests that an approach to Aboriginal and Torres Strait Islander-led research would consider research based on Indigenous ways of knowing and being, as equally valid to the western models of empirical and scientific research. Aboriginal and Torres Strait Islander Peoples and health researchers are uniquely placed to not only determine research needs, but also utilise their cultural competency and socio-cultural skills to lead research that is self-determined, culturally appropriate, transformational in nature and thus leads to improved health outcomes for Aboriginal and Torres Strait Islander Peoples.

Case studies

AIDA advocates for the inclusion of case studies that consider the topic of intellectual property, namely in the companion document. Intellectual property in Aboriginal and Torres Strait Islander research reaches beyond one particular element in the research continuum. As such, AIDA suggests including multiple shorter case studies to help contextualise this issue for participants, communities and researchers. The two areas in the document that are most relevant for intellectual property case studies are:

- Point 3 (NHMRC p 14), developing the project and seeking agreement: jointly develop the ethics application for approval. Do not start the project without ethics approval; and
- Point 7 (NHMRC p 15), sharing and translating the results into action: present findings to organisations and community.

Although AIDA itself does not have any specific suggestions for the case study for point 3, we consider it an imperative to focus on what informed consent looks like in the ethics approval process and in particular for Aboriginal and Torres Strait Islander communities for whom English is an additional language. AIDA proposes that the *2016 AIDA Member Survey on bullying, racism and lateral violence in the workplace* could serve as a suitable case study for point 7 as presented below:

The Australian Indigenous Doctors' Association (AIDA) is a professional body that represents Indigenous doctors and medical students. AIDA is governed by a board of nine directors, all of whom are elected by the membership body through annual general meetings. The board considers all publications, policy papers and memorandums before dissemination to the public.

As part of its work, AIDA conducts research to ascertain issues of importance to, and the impact of unique characteristics of the workplace for, Aboriginal and Torres Strait Islander doctors. These include issues of race and racism, lateral violence, and mentoring. In 2016 AIDA facilitated a survey that was distributed to its members to identify the prevalence of racism and lateral violence in the workplace; and the support mechanisms that are available for instances of these types of social violence.

In 2017, the findings from this research was presented in a detailed policy paper that was published with free and open access for AIDA members including the research participants and the general public. The policy paper identified specific actions which would allow key stakeholders such as health care service providers to start to address the issues identified by Aboriginal and Torres Strait Islander doctors.

The process that AIDA goes through to present research results to community and organisations is transparent. The aim is that the information is relevant for the people that AIDA works with in the research cycle, and that it reaches beyond the current position of the issues in the field of medicine. AIDA allows for an accessible feedback mechanism about any of its publications, either through the board or via contact with the secretariat.

Summary

AIDA recognises the importance of Indigenous-led, ethical, and beneficial research. In doing so AIDA welcomes the review of the Aboriginal and Torres Strait Islander research ethics guidelines and the design of guidelines applicable to research across various disciplines, including health. While generally supportive of the revised documents, it is the view of AIDA that the Guidelines do not adequately promote research undertaken by Aboriginal and Torres Strait Islander researchers. It is the view of AIDA that the material would benefit from the inclusion of case studies in the companion document as suggested in the consultation. Relevant and clear case studies on intellectual property would be beneficial, particularly those which illustrate the project development and ethics approval process, and the sharing of results to inform actions.

I would like to extend my thanks for considering AIDA's comments in this review process. I can be contacted on (02) 6273 5013 or at Craig.Dukes@aida.org.au if you would like any further discussion around any of the issues raised in our submission.

Yours sincerely

A handwritten signature in black ink that reads "Craig Dukes". The signature is written in a cursive, flowing style.

Craig Dukes
Chief Executive Officer

06 July 2017