Aboriginal and Torres Strait Islander health research leadership

Candice McKenzie¹, Lilon G Bandler²

When will we see Indigenous Australians move from being the examined to being the examiners?



his issue of the *MJA* includes the report by Burchill and colleagues¹ of their investigation of the use of National Health and Medical Research Council (NHMRC) Indigenous research guidelines in Australia. The authors were particularly interested in the level of participation and involvement of Indigenous people in the governance of Indigenous health research. People active in Indigenous health research

were invited to complete a survey, distributed via general and Indigenous health research networks and direct invitation. The authors concede that their investigation had significant limitations; for example, "surveys are more likely to be completed by people interested". Nevertheless, the survey completion rate (247 of 329, 75%) and the fact that half of the respondents were involved in Indigenous health-related research for "at least half their time" make the study an excellent starting point for a discussion.

And the authors' conclusions are sobering: "Indigenous health research in Australia is largely informed by non-Indigenous world views, led by non-Indigenous people, and undertaken in non-Indigenous organisations."

There is a long history here. The federal *Australian Institute of Aboriginal and Torres Strait Islander Studies Act 1989* declared that the Institute was "to provide leadership in ... Aboriginal and Torres Strait Islander research; and ... to lead and promote collaborations and partnerships among the academic, research, non-government, business and government sectors and Aboriginal and Torres Strait Islander peoples in support of the other functions of the Institute." The Institute has long provided guidance to researchers in accordance with that instruction. It first published ethics guidelines in 1999, followed in 2002 by the first edition of their *Guidelines for ethical research in Australian Indigenous studies* (updated 2010 and 2012). In 2020 the Institute published a code of ethics calling for a new approach that "repositioned Indigenous peoples from subjects of research to partners in research."

Chapter 4.7 of the NHMRC National Statement on ethical conduct in human research (2007, updated 2018) urges researchers to recognise "six core values identified as being important to Aboriginal and Torres Strait Islander Peoples": reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity.⁵ In 2018, the NHMRC published Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: guidelines for researchers and stakeholders⁶ and the accompanying Keeping research on track II.⁷



All these documents urge researchers to transform their thinking, and to ensure that the application of "core values, and ... additional cultural and local-language protocols ... [is] determined by the Aboriginal and Torres Strait Islander communities or groups involved in the research." Indigenous people and communities are asked to "work in partnership with researchers to make sure the research has positive outcomes and meets Aboriginal and Torres Strait Islander peoples' and communities' needs and expectations."

Why then are Aboriginal and Torres Strait Islander Australians still objects of research, rather than researchers? Part of the answer may be provided in the study by Burchill and colleagues. As only 38% of respondents had received any formal education in the history of health research involving Indigenous people, more than 60% may not have properly understood the historical background underpinning the need for and value of the guidelines. Few respondents (13%) had received formal education in Indigenous data governance and sovereignty.

The NHMRC has expressed its commitment "to strengthen[ing] capacity amongst Aboriginal and Torres Strait Islander health researchers". There is more to be done. We support the development of a required course on the "legacy of health research exploiting Indigenous Peoples" that examines the eight domains of the Consolidated criteria for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement: 9

- research governance;
- research prioritisation;
- research relationships;
- research methodologies and methods;
- research participation;
- research capacity;

Editorials

- research analysis and interpretation; and
- research dissemination.

To transform Indigenous health research requires a substantial shift. Every researcher in the field, Indigenous and non-Indigenous, should undertake such a course, and no-one should be exempt from re-visiting these principles before undertaking future research. A fundamental change in emphasis, from "participation" to "leadership", assisted by critical skills on the part of each researcher, will mean that Aboriginal and Torres Strait Islander Australians, and other Indigenous people, will finally see movement: from being the examined to being the examiners.

Competing interests: No relevant disclosures.

Provenance: Commissioned; not externally peer reviewed.

© 2022 AMPCo Pty Ltd.

- 1 Burchill LJ, Kotevski A, Duke D, et al. Ethics guidelines use and Indigenous governance and participation in Aboriginal and Torres Strait Islander health research: a national survey. Med J Aust 2023; 218: 89-93.
- 2 Commonwealth of Australia. Australian Institute of Aboriginal and Torres Strait Islander Studies Act 1989. http://www7.austlii.edu.au/cgi-bin/viewdb/ au/legis/cth/consol_act/aioaatsisa1989702 (viewed Nov 2022).

- 3 Australian Institute of Aboriginal and Torres Strait Islander Studies. Guidelines for ethical research in Australian Indigenous studies. Revised 2nd edition. 2012. https://aiatsis.gov.au/sites/default/files/2020-09/gerais.pdf (viewed Nov 2022).
- 4 Australian Institute of Aboriginal and Torres Strait Islander Studies. AIATSIS code of ethics for Aboriginal and Torres Strait Islander research. 2020. https://aiatsis.gov.au/sites/default/files/2020-10/aiatsis-code-ethics.pdf (viewed Nov 2022).
- 5 National Health and Medical Research Council. National statement on ethical conduct in human research (2007). Updated 2018. https://www.nhmrc.gov. au/about-us/publications/national-statement-ethical-conduct-human-resea rch-2007-updated-2018 (viewed Nov 2022).
- 6 National Health and Medical Research Council. Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: guidelines for researchers and stakeholders. 2018. https://www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-research-aboriginal-and-torres-strait-islan der-peoples (viewed Nov 2022).
- 7 National Health and Medical Research Council. Keeping research on track II. A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: guidelines for researchers and stakeholders. 2018. https://www.nhmrc.gov.au/about-us/resources/keeping-research-track-ii (viewed Nov 2022).
- 8 National Health and Medical Research Council. Building and strengthening capacity of Indigenous health researchers. 2020. https://www.nhmrc.gov.au/health-advice/aboriginal-and-torres-strait-islander-health/building-and-strengthening-capacity-indigenous-health-researchers (viewed Dec 2022).
- 9 Huria T, Palmer SC, Pitama S, et al. Consolidated criteria for strengthening reporting of health research involving indigenous peoples: the CONSIDER statement. *BMC Med Res Methodol* 2019; 19: 173. ■