



Supporting Information

Supplementary results

**This appendix was part of the submitted manuscript and has been peer reviewed.
It is posted as supplied by the authors.**

Appendix to: 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* 2022; doi: 10.5694/mja2.51757.

National survey of Australian health researchers exploring guidelines, governance and consent for research involving Aboriginal and Torres Strait Islander communities

National Survey of Australian Health Researchers Exploring Guidelines, Governance and Consent for Research involving Aboriginal and Torres Strait Islander communities

THANK YOU for taking the time to complete this survey. It is open to BOTH Indigenous and non-Indigenous Australian researchers undertaking Aboriginal and Torres Strait Islander health and medical research. All responses will be kept private and confidential.

Background

Prior research has focused on the content and meaning of the National Health and Medical Research (NHMRC) Guidelines. In contrast, this Indigenous-led survey seeks to understand how the guidelines are being applied by Indigenous and non-Indigenous people engaged in Indigenous health research in Australia. Additionally, it will also explore the organisational context and governance arrangements in place for Indigenous health research.

This survey will take approximately 10-15 minutes to complete.

By proceeding with this survey, you are providing consent to participate.
Do you consent?

- Yes
 No

Section 1. Researcher and Organisation Profiles

Your answers help us understand the profile of researchers undertaking Aboriginal and Torres Strait Islander research in Australia.

- 1.1 How did you hear about this survey?
- Through my professional or social network listings
 Personal email invitation from research team
 Shared by a friend or colleague
-
- 1.2 Which of the following themes does your Aboriginal and Torres Strait Islander research explore?
 (Choose all that apply)
- Culture and heritage
 Governance and Public policy
 Health and wellbeing
 Land and water
 Languages and cultural expression
 Native Title and traditional ownership
 Other
 (Themes as outlined by the Australian Institute of Aboriginal and Torres Strait Islander Studies)
-
- 1.2.1 Research theme other

-
- 1.3 Which academic focus best describes your field of research?
 (Choose all that apply)
- Lab based experimental research
 Clinical research including case series, cohort studies, clinical trials and outcomes
 Public health and health services research
 Other
-
- 1.3.1 Research field other

-
- 1.4 In what state or territory of Australia is your primary research organisation based?
- NSW
 VIC
 TAS
 QLD
 NT
 WA
 SA
 ACT
-
- 1.5 Which age range applies to you?
- < 25 years old
 25-45 years old
 46-66 years old
 >67 years old
 Rather not say
-
- 1.6 Which of the following best describes your gender identity?
- Male
 Female
 Gender diverse/Non-binary
 Intersex
 Other
 Rather not say
-
- 1.7 Do you identify as:
- Aboriginal
 Torres Strait Islander
 Aboriginal and Torres Strait Islander
 Indigenous (but not Aboriginal or Torres Strait Islander)
 Non-Indigenous

-
- 1.8 What best describes your career stage?
- Undergraduate student
 - Graduate student (Masters or PhD)
 - Early career within 5 years of contributing to Indigenous health research
 - Mid-career >5 but < 10 years
 - Senior career >10 years
 - Indigenous Community Leader
 - Other
-
- 1.8.1 Career stage other
-
- 1.9 What amount of time do you spend conducting research of any kind?
- Some of the time
 - Half of the time
 - Most of the time
 - All of the time
-
- 1.10 What amount of time do you spend conducting Aboriginal and Torres Strait Islander research?
- Some of the time
 - Half of the time
 - Most of the time
 - All of the time
-
- 1.11 What amount of your research time is conducted on country with Aboriginal and Torres Strait Islander communities who are the research focus? This applies equally to urban, regional and remote communities who are the focus the research being conducted.
- Some of the time
 - Half of the time
 - Most of the time
 - All of the time
 - None of the time
-
- 1.12 Do you primarily undertake your Aboriginal and Torres Strait Islander research at an Indigenous organisation?
- Yes
 - No
 - Don't know
-
- 1.13 In which organisation do you undertake the majority of your Aboriginal and Torres Strait Islander research? Choose all that apply
- University
 - Hospital
 - Research Institute
 - Government Agency
 - Aboriginal community-based organisation (i.e. health service, land council)
 - Mainstream primary care setting
 - Non-government organisation (NGO)
 - Advanced health and research translation centre
 - Other (please specify)
-
- 1.13.0 Organisation other - please specify
-
- 1.14 Have you previously been listed as an author on research published relating to Aboriginal or Torres Strait Islander health in Australia. This may include manuscripts, abstracts, posters and conference presentations
- Yes
 - No

Section 2. Ethical Guidelines for Aboriginal and Torres Strait Islander Research.

We would like to understand how the NHMRC guidelines are applied by those undertaking Aboriginal and Torres Strait Islander research.

- 2.1 Do you use the NHMRC's Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders when undertaking research with Aboriginal and Torres Strait Islander people?
- All of the time
 Some of the time
 None of the time
-
- 2.2 Aside from the NHMRC Guidelines, do you use any other ethical guidelines when undertaking Aboriginal and Torres Strait Islander research?
- Yes - please specify
 No
-
- 2.2.1 Other guidelines
-
- 2.3 Does your primary organisation's ethics committee refer to the NHMRC Guidelines when reviewing Aboriginal and Torres Strait Islander ethics applications?
- Yes
 No
 My primary organisation doesn't have an ethics committee
 I don't know
-
- 2.4 Thinking about your most recent research project involving Aboriginal and Torres Strait Islander people, at what stage/s of research did you refer to the NHMRC's Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders? Choose all that apply
- Building relationships with community
 Developing the research idea
 Developing the research project methods
 Designing governance mechanisms and seeking agreement
 Data collection
 Analyzing the data and making sense of the findings
 Report writing
 Vetoing publications
 Sharing and translating the results in action
-
- 2.5 At what stage/s of research do you consider the NHMRC's Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders to be MOST IMPORTANT? Choose all that apply
- Building relationships with community
 Developing the research idea
 Developing the project and seeking agreement
 Data collection
 Analyzing the data and making sense of the findings
 Report writing
 Sharing and translating the results in action
 I don't use NHMRC guidelines
-
- 2.6 Prior to commencing any research, do you formally meet and discuss NHMRC Guidelines with the Indigenous community that is the focus of your research?
- Yes
 No
 Sometimes
 Not sure
 I don't use NHMRC guidelines
-
- 2.7 How important are NHMRC's Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders and Keeping research on track II for your Aboriginal and Torres Strait Islander health research practice?
- Very important
 Sometimes important
 Not important
 Not sure
 I don't use NHMRC guidelines

-
- 2.8 Have you received any formal training in how to apply NHMRC's Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders or Keeping research on track II to your research practice?
- Yes - please provide name of training program
 No
-

2.8.1 Training_Organisation_Other

- 2.9 How satisfied are you that NHMRC's Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders safeguard Aboriginal and Torres Strait Islander people from the risks of research?
- Satisfied
 Not satisfied
 Not sure
 I don't use the NHMRC guidelines
-

- 2.10 In your opinion, who is MOST responsible for ensuring Aboriginal and Torres Strait Islander research is conducted ethically?
Choose all that apply
- Governments and their agencies (i.e. NHMRC) funding Aboriginal and Torres Strait Islander Research
 Organisations that undertake Aboriginal and Torres Strait Islander Research
 Human research ethics committees approving Aboriginal and Torres Strait Islander Research
 Researchers undertaking Aboriginal and Torres Strait Islander Research
 Aboriginal and Torres Strait Islander researchers undertaking Indigenous research
 Aboriginal and Torres Strait Islander people leading Aboriginal and Torres Strait Islander research
 Aboriginal and Torres Strait Islander research participants
 Aboriginal Community Controlled Health Organisations
 Other
-

2.10. Responsible for ethics - other

Section 3. Governance

We would like to understand governance arrangements in your primary organisation* and how this influences your ability to effectively undertake Aboriginal and Torres Strait Islander research. Governance is the way your organisation is managed, directed and held accountable for achieving its goals. Governance arrangements include the structures, systems and process that control how your organisation operates. This can include your board, constitution, sub-committees and policies.

***Primary organisation refers to the main organisation you conduct your Aboriginal and Torres Strait Islander research in.**

- | | |
|---|---|
| 3.1 Does your primary organisation have Aboriginal and Torres Strait Islander representatives at its highest level (Executive/Board/Senate)? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know |
| 3.2 Does your primary organisation have an Aboriginal and/or Torres Strait Islander advisory board or advisory council that is involved in your Aboriginal and Torres Strait Islander research? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know |
| 3.3 Does your primary organisation have delegated seats for Aboriginal and Torres Strait Islander people on its ethics committee? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know
<input type="radio"/> My primary organisation doesn't have an ethics committee |
| 3.4 Does your primary organisation have its own Aboriginal and/or Torres Strait Islander research ethics committee? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know |
| 3.5 Does your primary organisation have its own policy or framework to guide researchers undertaking Aboriginal and/or Torres Strait Islander research? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know |
| 3.6 Do you currently have Aboriginal and/or Torres Strait Islander people on your research team? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know
<input type="radio"/> I am not currently undertaking an Indigenous project |
| 3.7 Has your primary organisation provided you with any formal education in the history of health and medical research with Aboriginal and Torres Strait Islander people? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know |
| 3.8 Has your primary organisation provided you with any formal cultural safety and awareness training? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know |
| 3.9 Does your primary organisation provide formal education in the National Statement on Ethical Conduct in Human Research (2007) and other applicable guidelines/statements to your research? | <input type="radio"/> Yes
<input type="radio"/> No
<input type="radio"/> Don't know |

-
- 3.10 Has your primary organisation provided you with any formal education or training in Indigenous data governance and/or sovereignty?
- Yes
 No
 Don't know
-
- 3.11 In your opinion, how important is it that Aboriginal and/or Torres Strait Islander researchers play a leading role in the governance of Aboriginal and/or Torres Strait Islander research?
- Very important
 Somewhat important
 Not important
 Don't know
-
- 3.12 Thinking about your Indigenous research project/s, to what extent has there been meaningful participation by Aboriginal and/or Torres Strait islander people in establishing governance arrangements?
- All of the time
 Some of the time
 None of the time
 I don't know
-
- 3.13 Thinking about your Indigenous research project/s, to what extent has there been meaningful participation by Aboriginal and/or Torres Strait islander people in developing the research idea?
- All of the time
 Some of the time
 None of the time
 I don't know
-
- 3.14 Thinking about your Indigenous research project/s, to what extent has there been meaningful participation by Aboriginal and/or Torres Strait islander people in designing research methods?
- All of the time
 Some of the time
 None of the time
 I don't know
-
- 3.15 Thinking about your Indigenous research project/s, to what extent has there been meaningful participation by Aboriginal and/or Torres Strait islander people in data collection?
- All the time
 Some of the time
 None of the time
 I don't know
-
- 3.16 Thinking about your Indigenous research project/s, to what extent has there been meaningful participation by Aboriginal and/or Torres Strait islander people in data analysis?
- All of the time
 Some of the time
 None of the time
 I don't know
-
- 3.17 Thinking about your Indigenous research project/s, to what extent has there been meaningful participation by Aboriginal and/or Torres Strait islander people in reporting and publication?
- All of the time
 Some of the time
 None of the time
 I have not yet been at the reporting and publication stage of an Indigenous research project
 I don't know
-
- 3.18 Thinking about your Indigenous research project/s, to what extent has there been meaningful participation by Aboriginal and/or Torres Strait islander people in disseminating the results of your research?
- A lot of the time
 Some of the time
 None of the time
 I have not yet been at the disseminating of results stage in an Indigenous research project
 I don't know

Section 4. Consent in Aboriginal and Torres Strait Islander Research

The NHMRC's Ethical conduct in research with Aboriginal And Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders, stipulates that all people have the right to free, prior and informed consent in all aspects of the research process and that no one party has more power or strength than any other; that Indigenous groups or community decision-making processes should be allowed to operate, and that Indigenous peoples' right to choose how they want to live is respected.

- 4.1 How satisfied are you that your current approach to consent minimises the likelihood of power imbalances between researcher and participant?
- Satisfied
 Somewhat satisfied
 Not satisfied
 Don't know
-
- 4.2 How satisfied are you that your current approach to consent respects Indigenous groups rights and community decision-making processes?
- Satisfied
 Somewhat satisfied
 Not satisfied
 Don't know
-
- 4.3 How satisfied are you that your current approach to consent respects Indigenous peoples' right to choose how they want to interact with researchers?
- Satisfied
 Somewhat satisfied
 Not satisfied
 Don't know
-
- 4.5 Have you found that arriving at appropriate consent arrangements for your projects involving Aboriginal and Torres Strait Islander people is more complicated than in your other research projects?
- Yes
 No
 Sometimes
-
- 4.4 When deciding on consent processes for your research projects, has there been meaningful participation of Aboriginal and/or Torres Strait Islander people in the design of those processes (the manner in which consent is explained to and given by Aboriginal and Torres Strait Islander people)?
- Yes
 No
 Sometimes
-
- 4.6 To what extent have you modified standard consent arrangements in your Aboriginal and Torres Strait Islander research?
- Significantly modified
 Somewhat modified
 Almost no modification
 No modification
-
- 4.7 If you have modified consent arrangements for your Aboriginal and Torres Strait Islander research, how often have you done this?
- All research projects
 Some research projects
 I have never modified consent arrangements

Thank you for your time responding to this survey. Is there anything else you might like to tell us?

Table. Meaningful Indigenous participation in Indigenous health research, by research phase, as reflected in survey responses by 247 participants (survey questions 3.13 to 3.18)

Designing the research question	
<i>All of the time</i>	149 (60%)
<i>Some of the time</i>	80 (32%)
<i>None of the time</i>	13 (5%)
<i>I don't know</i>	5 (2%)
Developing research methods	
<i>All of the time</i>	129 (52%)
<i>Some of the time</i>	93 (38%)
<i>None of the time</i>	14 (6%)
<i>I don't know</i>	11 (4%)
Data collection	
<i>All the time</i>	143 (58%)
<i>Some of the time</i>	86 (35%)
<i>None of the time</i>	15 (6%)
<i>I don't know</i>	3 (1%)
Data analysis	
<i>All of the time</i>	94 (38%)
<i>Some of the time</i>	104 (42%)
<i>None of the time</i>	39 (16%)
<i>I don't know</i>	10 (4%)
Reporting and publication	
<i>All of the time</i>	140 (57%)
<i>Some of the time</i>	75 (30%)
<i>None of the time</i>	16 (6%)
<i>I have not yet been at the reporting and publication stage of an Indigenous research project</i>	13 (5%)
<i>I don't know</i>	3 (1%)
Disseminating research	
<i>A lot of the time</i>	130 (53%)
<i>Some of the time</i>	77 (31%)
<i>None of the time</i>	12 (5%)
<i>I have not yet been at the disseminating of results stage in an Indigenous research project</i>	24 (10%)
<i>I don't know</i>	4 (2%)