

Lessons learned 2024

Justifying Exclusion of Participants

The Lessons Learned 2023 document highlighted the impacts inclusion and exclusion decisions can have on the ethical conduct of research. Exclusion of identifiable cohorts was an issue again in 2024.

The exclusion of participants in research must be justifiable in terms of their contribution to answering the research question. Groups of people should not be excluded from participation in research merely because they are difficult to engage, have diminished or compromised capacity, or are vulnerable. By excluding people during the research design phase because it is inconvenient or too much work disrespects whole cohorts from the outset.

A particular and recurring theme that is evident in funded research is the claim that groups that require more engagement because of communication issues must be excluded because there is no funding in the project budget. The HREC is right to ask why this might be the case. By not seeking funding for the inclusion of all groups that are relevant to answering the research question, research projects are ethically compromised against each of the principles of the National Statement. Where funding is not requested, it appears that, these groups are excluded during the conception of the research as just being too hard and not worthy of respect.

Excluding cohorts may invalidate research findings. People should only be excluded in research where it is ethically, legally, or methodologically necessary. Researchers should not exclude participants on the grounds of convenience, availability, or increased complexity.

When excluding identified cohorts from participation in research, researchers should consider the ethical implications inherent in the decision:

- Is it fair to exclude these groups?
- Does the exclusion of some groups place a higher research burden on other groups?
- Are groups being exploited on the basis that they are easier to access?
- Will the exclusion of these groups reduce the generalisability of outcomes?
- Will particular cohorts or individuals be disadvantaged if the benefits of the research cannot be extended to them through their exclusion from the dataset?
- Will particular groups feel disrespected?

The inclusion or exclusion of specific groups and cohorts from research has the capacity to dramatically impact on the ethical acceptability of a research proposal. Researchers have an obligation to consider recruitment practices more widely than convenience, availability, or having access to a captive audience. Where additional resources are necessary to engage with all methodologically relevant groups, researchers should include these costs in funding applications.

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Data Sovereignty and Owning the Narrative

Owning the Narrative

The HREC pays particular attention to considerations of self-determination when assessing research where any community or individual forms an identifiable cohort; not only when these groups are Indigenous. This has been a deliberate change of focus in the assessment of research applications and deserves some explanation.

1. Societal expectations of engagement in research evolve.
2. Community advocacy for empowerment of identifiable cohorts has become more effective.
3. Research practices must evolve to remain relevant to the communities that they serve.

The HREC will be looking for evidence that the applicant understands the implications of working with identifiable communities. It is the responsibility of the applicant to ensure that this evidence is both relevant and explicit.

The most obvious and organised of these cohorts is the Aboriginal and Torres Strait Islander communities, primarily through the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) in relation to human research expectations. However, the principles of the AIATSIS Code of Conduct are directly translatable to many other identifiable cohorts. The principles of natural justice and respect support the need for researchers to engage with participant communities about how they may be portrayed. If research is to respect the autonomy of participants, then, participants should guide the narrative. Where the research outcomes may portray people, communities, or cultures in particular ways (either positive or negative), communities have a vested interest in maintaining a level of control over that narrative. This is particularly important in sociological, ethnographical, and cultural research fields.

Data Sovereignty

Some data, particularly in culturally, or socially significant, research may have value beyond the research outcomes. Researchers should consult with participants in the development of the research data management plan. Communal stories may carry special weight when understanding: Indigenous ways of understanding, knowing, and being; trauma-related cohorts; and contested histories.

Data Sovereignty and controlling the research narrative are particularly important for participants in research involving Indigenous people and communities. The AIATSIS Code of Conduct highlights that it is a responsibility of the researcher to ensure that they treat Indigenous peoples with respect and to recognise their rights under the United Nations Declaration on the Rights of Indigenous Peoples.

Researchers who conduct research where Indigenous communities or individuals form an identifiable cohort are encouraged to think about the rights enshrined in the UN Declaration, in particular:

Article 11

Indigenous peoples have the right to practise and revitalize their cultural traditions and customs. This includes the right to maintain, protect and develop the past, present and future manifestations of their cultures, such as archaeological and historical sites, artefacts, designs, ceremonies, technologies and visual and performing arts and literature.

Article 12

Indigenous peoples have the right to manifest, practise, develop and teach their spiritual and religious traditions, customs and ceremonies; the right to maintain, protect, and have access in privacy to their religious and cultural sites; the right to the use and control of their ceremonial objects; and the right to the repatriation of their human remains

Article 13

Indigenous peoples have the right to revitalize, use, develop and transmit to future generations their histories, languages, oral traditions, philosophies, writing systems and literatures, and to designate and retain their own names for communities, places and persons.

Where research either explicitly target specific groups or which, by the nature of the research, is likely to highlight the circumstances within identifiable communities, the HREC will expect to see discussion that openly addresses:

- Who controls participant stories?
- How, or if, participants would like to be identified in research outputs?
- Who owns the data that is collected?
- If collected data are socially, historically, or culturally significant – do communities have ongoing access to these data and who can access it?
- Are the appropriate people telling the story?
- Are there contested histories involved?