

Case Study – Principles for engaging ethically with Aboriginal and Torres Strait Islander Australians as part of evaluation co-design

The evaluation of the Australian Government’s investment in Aboriginal and Torres Strait Islander Primary Health Care under the Indigenous Australians’ Health Programme (PHC Systems Evaluation) has adopted a principles-based ethical approach to guide the evaluation design and implementation phase with formal ethics approval sought for the implementation phase.

This case study is provided to help inform the Productivity Commission’s development of a principles-based Evaluation Framework and the development of guidance for working in an ethical and culturally appropriate way with Aboriginal and Torres Strait Islander people and communities. It also outlines some of the practical challenges inherent in seeking ethical approval for cross-jurisdictional evaluations that the Productivity Commission may wish to consider as part of its remit.

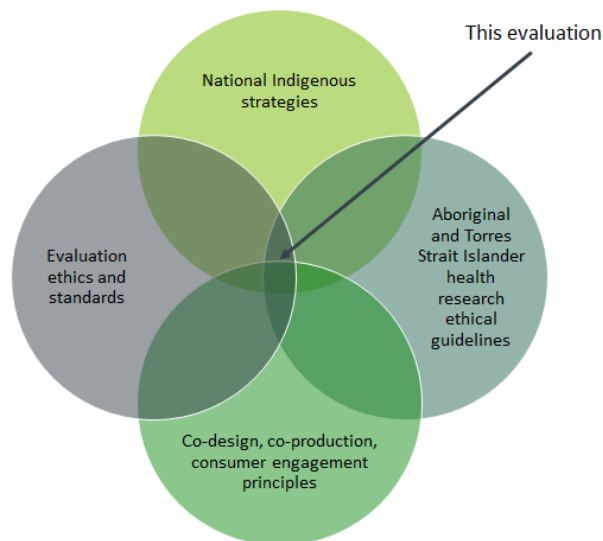
Core ethical principles

In the absence of Aboriginal and Torres Strait Islander ethical guidelines and standards for evaluation, which include considerations for co-designing an evaluation through to implementation, the evaluation has drawn on a range of applicable principles, ethics and standards which affect the conduct of the evaluation, as illustrated in the Figure 1. The co-design phase and early implementation of the evaluation has been guided to date, by five ethical principles developed specifically for the evaluation:¹

1. Including and respecting diverse voices, values and knowledge
2. Building trustworthy and trusting relationships
3. Ensuring equity of power and respecting self-determination
4. Negotiating consent, accountabilities, resources and governance
5. Ensuring benefit and adopting a strengths-based approach.

Figure 1: Range of applicable principles, ethics and standards applicable to a co-designed evaluation

¹ Appendix 1 of the *Monitoring and Evaluation Design Report* available at www.IPHCeval.com describes the rationale for selecting these principles and how they are being applied in the implementation of the evaluation.



This aims to ensure that the evaluation is:

1. Closely guided by those principles, ethics and standards which are specific to working with Aboriginal and Torres Strait Islander people and communities; and
2. Informed by additional relevant considerations from evaluation and co-design.

The principles, ethics and standards that have been considered include:

National Indigenous strategies

1. The Indigenous engagement principles from the National Indigenous Reform Agreement;
2. Cultural Respect Framework 2016-2026 for Aboriginal and Torres Strait Islander Health: A National Approach to Building a Culturally Respectful Health System²; and
3. National Aboriginal and Torres Strait Islander Health Plan 2013-2023, and its Implementation Plan.

Aboriginal and Torres Strait Islander health research

4. Guidelines for Ethical Research in Australian Indigenous Studies, Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), 2012;
5. National Health and Medical Research Council (NHMRC) ethical guidelines:
 - a. Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, 2003; and
 - b. Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics, 2005.

Evaluation ethics and standards

6. Australasian Evaluation Society's (AES) Guidelines for the Ethical Conduct of Evaluations, 2010;
7. Evaluation standards for Aotearoa New Zealand, 2015;
8. Program Evaluation Standards, The Joint Committee on Standards for Educational Evaluation (JCSEE), 2011; and

² Renewal of the 2004-2009 Framework. Prepared by the Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee.

9. Adapted SEVAL Standards for the Evaluation of the Child Health Check Initiative and Expanding Health Services Delivery Initiative, Evaluation Design Report, *Allen + Clarke, 2009.*

Co-design, co-production and consumer engagement principles

In the absence of Aboriginal and Torres Strait Islander ethical guidelines and standards for evaluation and co-design, other non-Australian/non-Indigenous evaluation specific ethics and standards will likely require consideration as part of the development of principles appropriate for the design and implementation of these types of evaluations.

The evaluation design phase is typically about stakeholder involvement to secure clarity about the purpose, objectives, key questions and use of an evaluation, identifying and developing the approaches (i.e. methodological, methods, tools and analytical design) for gathering information and data to answer and report on the key evaluation questions. Key to undertaking this phase as a co-design process are relationships.

Challenges in meeting Human Research Ethics Committee protocols and requirements

A co-design, participatory approach will be implemented throughout the implementation of the evaluation. The emergent and adaptive nature of co-design makes a detailed, pre-specified evaluation design, including to the level often required by ethics committee protocols, challenging. A multi-layered, health system evaluation, such as this PHC systems evaluation which is occurring across jurisdictional boundaries, also creates ethical approval challenges.

Suggestions for facilitating the ethics process for co-designed, participatory research and evaluation with a strong focus on continuous quality improvement include³:

- Seeing whether an ethics committee already has specified requirements for participatory methodology applications;
- Supplying information on the participatory approach to the Committee prior to the formal application, to establish any particular concerns or questions that need to be addressed in the formal application; and/or supplying information on the participatory approach as a supplementary paper;
- Explicitly addressing any methodological and ethical tensions in the application;
- Establishing co-design/partnership governance of the evaluation prior to the application. Make explicit the power-sharing measures and how this can diminish risk for participants; and
- Identifying the components that will not be amendable to change, and those that will be co-designed and/or require flexibility across different settings. Outline the process for how ethical principles and concerns will be addressed for those components that are amendable to change.

Approach taken to seeking ethical approvals

In practical terms the evaluation team has adopted a two-stepped approach to seeking ethical approval:

- The first round of applications focused on seeking ethical approval for two of the evaluation's foundational tasks: (i) engaging and establishing 20 evaluation sites, and (ii) undertaking a data feasibility assessment; and

³ Based on ideas from Goodyear-Smith, F., Jackson, C., & Greenhalgh, T. (2015). *Co-design and implementation research: challenges and solutions for ethics committees.* BMC Medical Ethics, 16:78.

- The second round of applications has sought ethical approval for the implementation activities of the evaluation, i.e. gathering, analysing and reporting quantitative and qualitative data.

A distinction between the two rounds of ethics applications is that the former focuses on setting the foundations of the evaluation to address the evaluation questions and objectives, whereas the latter focuses on ‘answering’ the evaluation questions. This means that the first round of applications will:

- For the site engagement processes, gather and use only publicly available data and information for defining the site and tailoring the evaluation processes to meet local community and evaluation needs. For example, information will be gathered about the range of services available within the site boundaries and health service utilisation patterns of the Aboriginal and Torres Strait Islander population who live within the site boundaries. Data and information will not be gathered from individuals or organisations for the purpose of answering the evaluation questions.
- For the data feasibility, use data in the form of meta-data, or if actual data are required to assess fitness-for-purpose, the data will be de-identified at source and will not be used for the purpose of answering the evaluation questions prior to completion of the ethics process.

A further distinction is that the first round of ethics applications was accompanied by Letters of Support from national organisations whereas the second round of ethics applications will need to be accompanied by Letters of Support from the sites that agree to partner with the evaluation. The benefits of this stepped approach are that it has:

- Enabled the evaluation team to ensure that its proposed engagement processes and management and use of data and information for Phase 1 are robust and ethical.
- Ensured that the proposed Phase 1 processes and practices will substantively address the National Health and Medical Research Council (NHMRC) values of spirit and integrity, reciprocity, respect, equity, responsibility, and cultural continuity.⁴
- Enabled the team to continue developing and implementing the evaluation in collaboration with the HSCG and sites. This emergent approach is key to ensuring Aboriginal and Torres Strait Islander knowledge and perspectives are central to the evaluation and that the spirit of co-design is honoured.

In addition, the first round of applications has enabled the evaluation team to ‘socialise’ the evaluation. Ethics committees have been provided with an overview of the evaluation approach ahead of the next round of applications.

The process of obtaining ethics approval was not without its own challenges. One challenge has been completing forms not designed for seeking ethical approval for engagement processes.

Managing multiple ethics applications

An additional challenge relates to the complication of gaining ethics approval for complex, cross-jurisdictional evaluations and the requirement to submit applications to multiple Human Research Ethics Committees (HRECs). Initially, the evaluation team approached the *Australian Institute of Aboriginal and Torres Strait Islander Studies* (AIATSIS), who in turn advised the team to submit an application to both itself and to Australian Capital Territory (ACT) Health with the idea that approval from both committees would be recognised by committees in other states and

⁴ 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), Commonwealth of Australia: Canberra.

territories via their prior-approval processes,⁵ similar to the *National Mutual Acceptance* system for multi-site studies.⁶ The application from this evaluation was to be a test case.

However, two factors mitigated against this process. Firstly, the need to secure agreement across all states and territories within a short timeframe, December 2018 – March 2019, and secondly, the risk to project timelines if this process was subsequently delayed. The team's prior experience with ethics committees across Australia led to the decision to proceed with multiple applications at the same time to mitigate this risk.

The result is that the project has submitted eleven ethics applications to date, with a further three anticipated. In terms of jurisdictional approval, three states/territories required multiple applications. This experience highlights that consideration could be given for the establishment of a suitable National Ethics Committee that can consider ethical requirements for cross-jurisdictional evaluations.

Ethical approval requirements

Applying for ethical approval to implement the evaluation also requires the evaluation team to explicitly address how it will enact the six core values of the National Health and Medical Research Council (NHMRC) guidelines for researchers and stakeholders - *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities* (August 2018). The six core values are:

1. Spirit and integrity
2. Cultural continuity
3. Equity
4. Reciprocity
5. Respect
6. Responsibility.

The following sections describes how these values were enacted in the development of the PHC Systems evaluation framework.

Spirit and Integrity

The evaluation team recognises the sovereignty of Aboriginal and Torres Strait Islander peoples as the indigenous people of Australia. We also recognise the centrality of culture to the health of Aboriginal and Torres Strait Islander people.

The evaluation is being co-designed with Indigenous researchers, Indigenous health sector practitioners, Indigenous members of the Health Sector Co-design Group (HSCG) and Indigenous community groups. The co-design process reflects a genuine interest in an evaluation journey that respects Indigenous knowledge, expertise and leadership, responds to multiple Indigenous perspectives and demonstrates commitment to partnership.

Features of the evaluation approach such as flexibility and ongoing co-design, a focus on strengths and quality improvement and careful, negotiated processes around data (shared governance and agreed processes to 'make meaning' of data, for example) are central to the way the evaluation framework is being developed. The evaluation approach has a focus on relationships, clarity and

⁵ A prior-approval process refers to ethics approvals from other HRECs supporting an application, and in some cases, means the application may be considered and approved out-of-session by the Chair of the Committee.

⁶ https://www.health.act.gov.au/sites/default/files/2018-10/NMA%20Brochure%20Aug%202016_0.pdf;
https://www.health.qld.gov.au/data/assets/pdf_file/0025/153178/Fact-Sheet-Feb-2018.pdf

honesty about the evaluation elements, capacity and resources, understanding local contexts and exploration of mutual interests.

Cultural Continuity

The evaluation team's approach is respectful of cultural norms and customs, and mindful of historical and contemporary experiences of evaluation and research in Indigenous communities. The evaluation design includes a process for tailoring the evaluation in each site to reflect local priorities and the diverse interests within and between Aboriginal and Torres Strait Islander communities. There will be widely varying understandings of 'health', and a range of views on factors affecting health and wellbeing. Where there is interest in participating in the evaluation, discussions will be needed to canvas issues such as rights related to Indigenous knowledge, cultural and intellectual property, data governance and ownership and other areas as necessary to respect and protect the rights of Aboriginal and Torres Strait Islanders Peoples. How evaluation findings are interpreted, translated, and disseminated are also aspects that will be discussed and negotiated.

Equity

The evaluation team recognises multiple dimensions of inequity for Aboriginal and Torres Strait Islander Peoples. A range of factors: including policy and contracting approaches; funding levels; geographical, socioeconomic and historical factors; different models of service delivery influence or contribute to this inequity in health outcomes.

The approach needs to allow for negotiation around the meaning of the evaluation questions, different emphases/interests in different sites, processes to agree the meaning of data and how the evaluation hopes to influence outcomes, and for whom. The evaluation design reinforces that responsibility for improving Aboriginal and Torres Strait Island peoples' health sits with all health sector players, across all agencies and programs, and recognises the vital role of Aboriginal and Torres Strait Island communities themselves. A key focus is to generate actionable findings and facilitate the translation of these findings into changes in policy and service delivery.

Reciprocity

Reciprocity is about recognising and enabling 'all' stakeholder contributions in ways that disperse power more equally. For the evaluation framework, this means identifying what stakeholders, at all levels of the system, think is important to focus on.

Reciprocity also ensures the benefits from research outcomes are equitable and of value for Aboriginal and Torres Strait Islander people and communities. If the evaluation focuses on too narrow a set of questions (or the wrong questions), the evaluation team will not have an evaluation of value to the Department of Health or others. Fully scoping the evaluation requires the team to engage in respectful discussion whereby different stakeholders have a say in defining the questions and benefits up front. We need to ensure the evaluation aligns with the values and aspirations of Aboriginal and Torres Strait Islander people and communities.

Respect

The evaluation co-design process endeavoured to put into practice the principles of cultural respect. It has at its heart, recognition of the rights of Aboriginal and Torres Strait Islander people, and the centrality of cultural traditions and self-determination to health and wellbeing.

The evaluation team will actively consider and enact respectful practice as the evaluation framework is developed. In the engagement process, there will be an emphasis on good information about the

evaluation 'design' and sufficient time for key stakeholders to input into 'what matters'. It will take time to establish the relationships, gain a degree of trust and comfort with different groups, and get to the point where community participants can engage in the evaluation with confidence.

Responsibility

This principle is about doing no harm. There is a risk of unintended negative or harmful consequences if we do not adhere to the other principles. To avoid potential harm, it is important that the evaluation framework is negotiated with key stakeholders.

In addition to formal ethics processes, these principles will continue to be applied during the evaluation implementation.

Application of Program Evaluation Standards

The evaluation team has also explicitly articulated how each of the 30 Program Evaluation Standards will be met covering standards in relation to utility, feasibility, propriety, accuracy and evaluation accountability.^{7 8}

Key observations

The evaluation team has endeavoured to take a principles based approach to designed and implementing the Primary Health Care System Evaluation. The team has also strived to follow best-practice approaches to ensuring ethical considerations are appropriately embedded. The Productivity Commission's proposal to develop a principles based framework and the development of guidance for working in an ethical and culturally appropriate way with Aboriginal and Torres Strait Islander people and communities would be welcome, given some of the practical challenges inherent in seeking ethical approval for cross-jurisdictional evaluations.

⁷ Yarbrough DB, Shulha LM, Hopson RK, Caruthers FA. The program evaluation standards: a guide for evaluators and evaluation users (3rd edn). California: Sage Publications, 2011.

⁸ These are documented in Appendix 1 of the *Monitoring and Evaluation Design Report* available at www.IPHCeval.com.