

Ethics and Governance Guideline

PCOC is a Clinical Quality Registry that makes important contributions to Australian Palliative Care by reporting on health service performance and patient outcomes. It plays a vital role in driving improvements in safety and quality of care.

The PCOC Program adheres to the Australian ethical and governance principles as outlined in the [Australian Framework for National Clinical Quality Registries 2024](#) produced by the Australian Commission on Safety and Quality in Health Care.

Ethical Oversight

The NSW Health Population and Health Services Research Ethics Committee (PHSREC) serves as the Lead Human Research Ethics Committee (HREC) for the PCOC Program. PHSREC specialises in scientific and ethical review of population health and/or public health research, which utilises routinely collected health statewide data. It is certified and accredited as a lead HREC for multi-centre ethical review processes under the NMA scheme.

PHSREC granted ethics approval to the PCOC project for the following:

- **Quality Improvement and Benchmarking** - The collection, analysis and reporting of re-identifiable data from palliative care providers without requiring patient consent.
- **Research** – The infrastructure for managing a research databank (Australian Palliative Care Outcomes Registry (APCOR)) according to relevant legal, ethical and privacy requirements.

A waiver of consent was granted for the use of re-identifiable information in accordance with Section 2.3 of the [National Statement on Ethical Conduct in Human Research](#). The PCOC project's ethical approval is valid until 20 December 2029. Any future modifications to the PCOC dataset or data collection processes will be submitted to PHSREC as amendments to maintain ethical compliance.

Participating Services Site Governance

The PCOC team recognises that participating palliative care services that submit data to PCOC maintain their own research governance processes and, where applicable, follow the [National Clinical Trial Governance Framework \(NCTGF\)](#). Since receiving PHSREC approval in January 2025, PCOC has been working collaboratively with sites to update their governance approvals to meet current regulatory standards.

Indigenous Data Sovereignty

The PCOC Data Dictionary includes the data variables Patient Indigenous Status and Patient Preferred Language, to support the program's aim of representing palliative care services nationwide across all communities. This data is stored both in the national reporting and benchmarking database and within the PCOC registry – APCOR.

To uphold Indigenous Data Sovereignty principles, PCOC has consulted with the following specialist Committees:

- The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Ethics Committee
- The Aboriginal Health and Medical Research Council of NSW (AH&MRC) HREC
- The Western Australian Aboriginal Health Ethics Committee (WAAHEC)



Palliative Care Outcomes Collaboration

- The Aboriginal Health Council of South Australia (AHREC)
- The University of Tasmania Human Research Ethics Committee
- The Victorian Aboriginal Community Controlled Health Organisation (VACCHO)
- The Northern Territory HREC at Menzies School of Research

The release of PCOC Registry data for research

PCOC develops and manages a curated dataset for the Australian Palliative Care Outcomes Registry (APCOR). Researchers can request data extracts via an Expression of Interest (EOI) followed by a formal application process, which is reviewed by the PCOC Data Release Committee three times per year. Data release is strictly governed by internal protocols to ensure responsible use, secure storage, and compliance with ethical standards.

All research projects requesting APCOR data must obtain their own ethical approval and waiver of consent from a National Health and Medical Research Council (NHMRC) certified public health HREC through a high-risk pathway. For projects involving Indigenous or Children/Adolescent data, researchers must seek approval from specialised HRECs with appropriate justification (Figure 1). Upon receipt of appropriate HREC approval, PCOC will provide data according to its release protocol.

Further information on accessing APCOR data is available on the [APCOR website](#).

Process for Researchers to secure PCOC Data

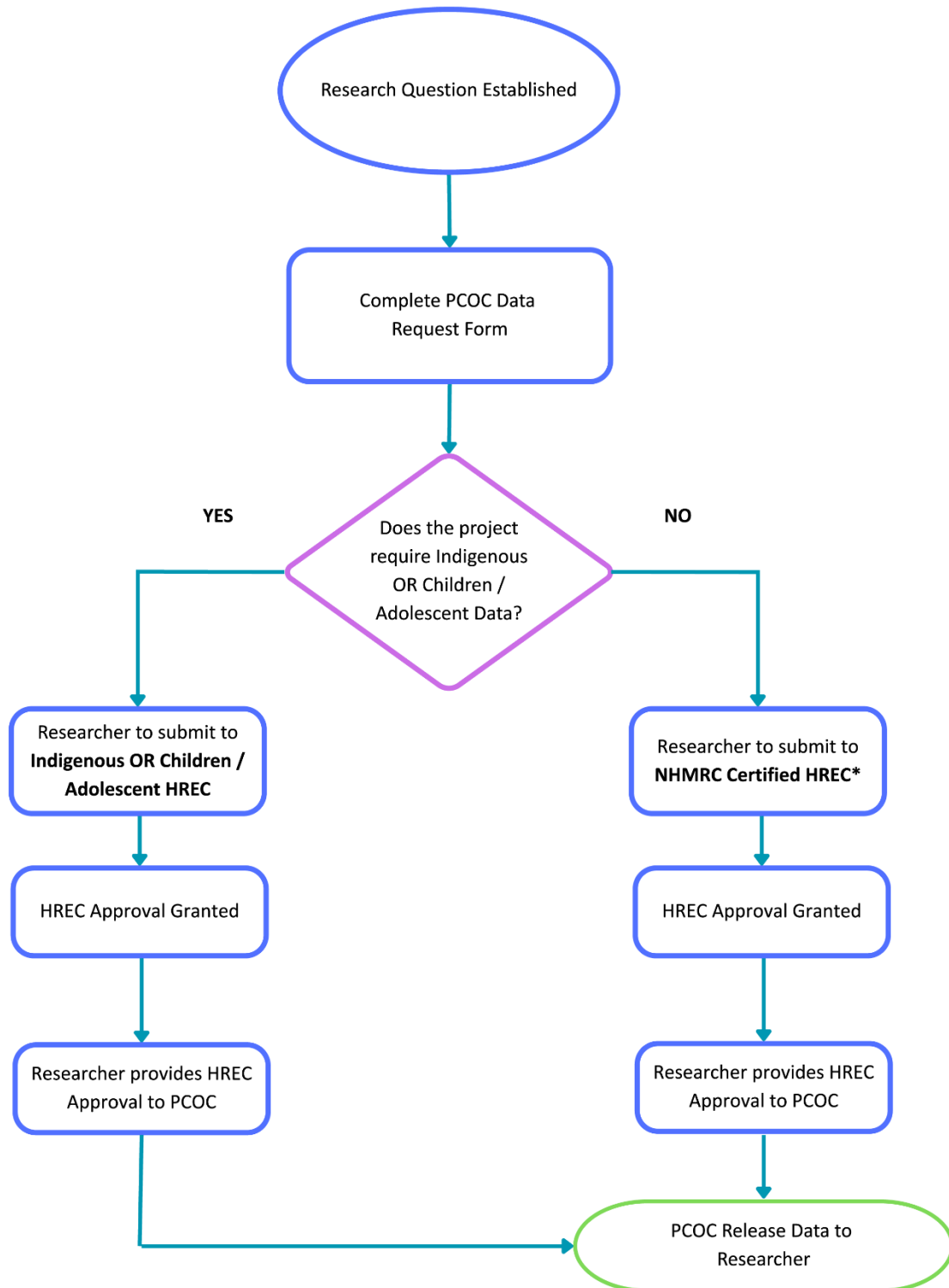


Figure 1: A guide to the ethical approval process

Note: This figure illustrates only the ethical approval component of the APCOR data request process. For details on the full application and data access procedure, please refer to the [APCOR website](#).



Palliative Care Outcomes Collaboration

PCOC remains committed to advancing high-quality, ethically sound research that improves palliative care across Australia. Through ongoing collaboration with services, researchers, and communities PCOC continues to strengthen its role as a trusted national resource. By supporting access to robust, well-governed data, PCOC fosters a research environment that drives innovation, informs policy, and enhances care for people with life-limiting illness and their families.

For all Ethics and Governance enquiries, please contact:

Nicola Howell

Ethics and Governance Manager

E: nichowell@uow.edu.au