



Annual Report

2025

February 2026

Palliative Care Outcomes Collaboration Annual report 2025

Requests and enquiries concerning reproduction and rights should be addressed to:
Director, Palliative Care Outcomes Collaboration (PCOC)

Australasian Health Outcomes Consortium (AHOC) Building 232, Level 2, Mike Codd, Innovation Campus,
Innovation Way, NORTH WOLLONGONG NSW 2500

E: pcoc@uow.edu.au

The complete list of PCOC publications is available from: www.pcoc.org.au



Message from the Director

2025 marked a significant milestone — 20 years of the Australian Palliative Care Outcomes Collaboration (PCOC). It was a year for reflection, and a moment to look forward with renewed purpose.

From an initial eight pilot services, PCOC has grown into a truly national collaboration involving more than 230 services across Australia. Together, we have built something of enduring value: a shared system and common language for quality improvement in palliative care that makes a tangible difference to patients, families, clinicians, and the health system.

In 2025, we extended that impact into general practice through the development of a PCOC-like system designed specifically for primary care. Delivered in partnership with Primary Health Networks and shaped by expert input, including people with lived experience, this initiative supports earlier identification of need and strengthens the role of general practice in palliative care.

PCOC was also formally registered as the Australian Palliative Care Outcomes Registry on the national register of clinical registries. This recognition affirms PCOC's standing as a uniquely Australian national asset and reinforces the importance of outcomes-based data in driving improvement and research.

PCOC released a new accessible report providing a high-level summary of outcomes and access trends intended for a broader audience. This report is to inform decision-making, support policy review and refinement based on emerging evidence, and encourage broader and earlier access to palliative care.

The depth of PCOC data now provide an unparalleled window into palliative care in Australia, offering insights into approximately one in five deaths nationally and one-third of deaths from predictable causes. This contribution is made possible by the commitment of thousands of clinicians and the lived experiences of hundreds of thousands of patients and families. We recognise the privilege of holding this information and the responsibility it carries — not simply to measure care, but to learn and honour those whose experiences shape better care for others.

Looking ahead, our priorities are clear: expanding the reach and relevance of outcome measurement, enabling earlier identification of palliative care needs, strengthening equity of access, and embedding outcomes at the centre of care delivery. In a health system under increasing pressure, the ability to understand and improve the experiences of people living with serious illness has never been more important.



Sabina Clapham
PCOC Director

Investing in excellence

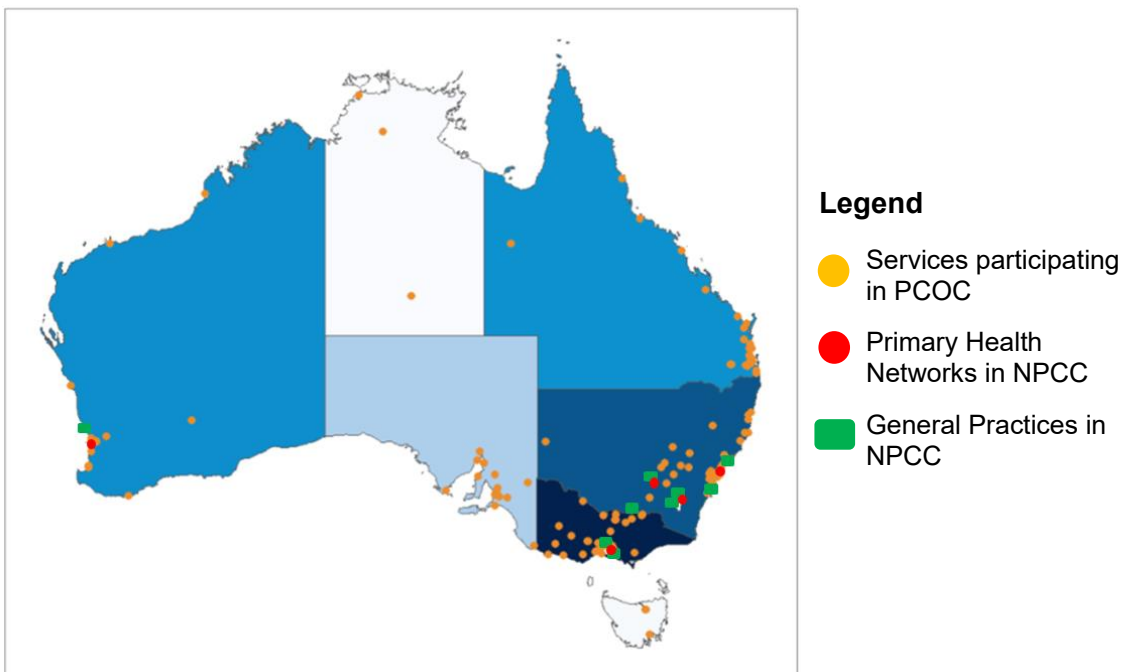
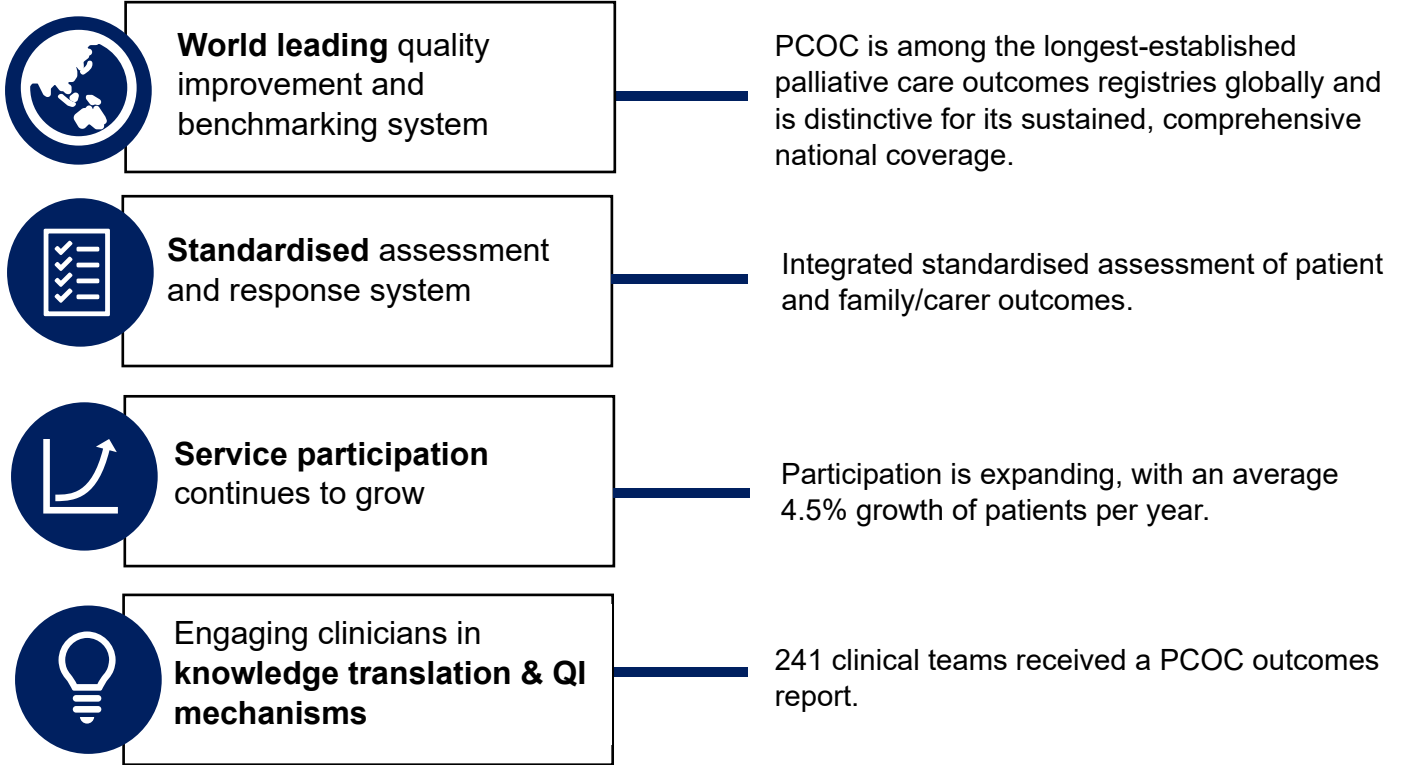


Figure 1: Map of Australia with orange dots representing PCOC participating services and varying shades of blue showing captured patient volumes by state

Referral patterns

Referral patterns remain stable, with hospitals being the main source of palliative care referrals. However, the number of referrals has more than doubled over the past decade, highlighting rising demand for palliative care.

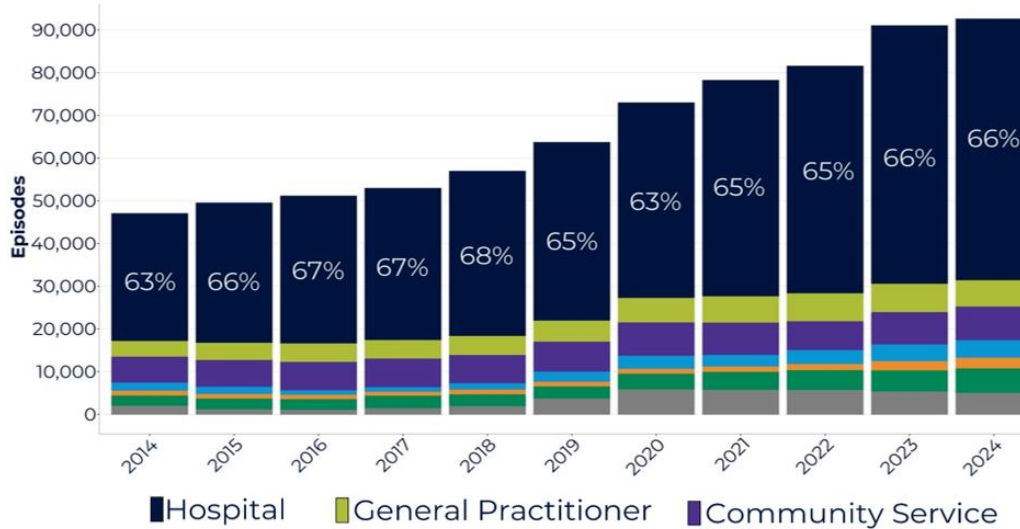


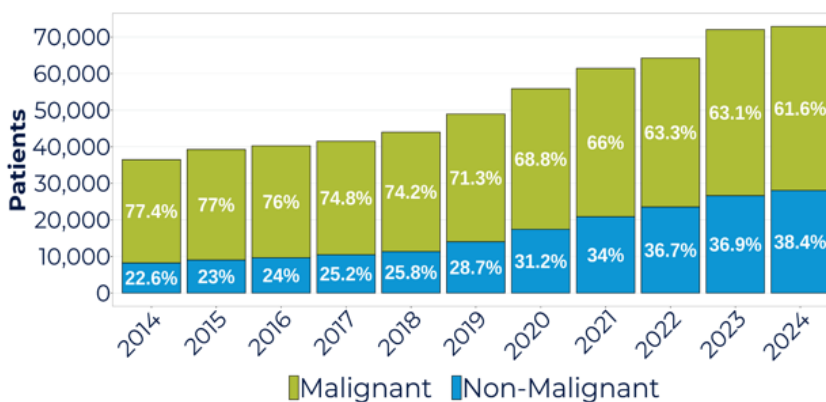
Figure 2: Number and sources of referral over time (2014-2024)

Patient profiles are also changing

While lung cancer remains the most common diagnosis, access for people with non-malignant conditions nearly doubled in the last 10 years from 22% to 38%.

The number of patients with dementia as a primary diagnosis has also increased from 1.9% in 2014 to 6.3%. This is reflective of dementia being the leading cause of death in Australia, in 2024.

Patients are commencing palliative care with lower functional status, suggesting later referral and greater complexity of needs. The average duration of palliative care from referral has remained at 35 days during the last decade.



Dementia
 2nd and fastest growing cause of death in Australia
 Represented in PCOC (1.9% in 2014, and 6.3% in 2024).

Figure 3: Number and % of patient primary diagnosis over time (2014-2024)

Performance against national benchmarks remains strong

Most patients begin palliative care within one day of being ready. Urgent clinical issues are typically stabilised within three days, and symptom outcomes continue to improve, especially for pain and breathing problems. Together, these outcomes demonstrate a responsive system, while reinforcing the need for earlier access (see [PCOC National Overview](#) for more details).

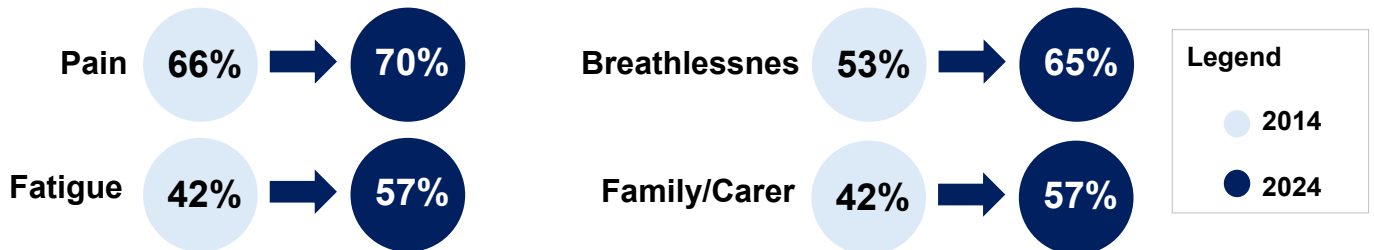


Figure 4: Percentage with moderate/severe symptoms that improved (2014-2024)

PCOC Version 4: a new version of assessments and data collection

PCOC version 4 represents a major shift toward a simplified architecture, reducing the burden on clinicians. It also introduces enhancements to meet the modern needs of the sector. The changes are outlined in the PCOC [Version 4: Clinical Manual](#) and include:

- The inclusion of emotional outcomes: the Edmonton Symptom Assessment System (ESAS-PCOC) is replacing the SAS to provide a more holistic view of symptoms.
- New clinical insights are being captured through delirium screening, delirium distress ratings and carer availability status.
- Telehealth integration through the inclusion of 'mode of assessment' to distinguish between in-person, video conference, and telephone visits.
- Improved referral tracking to better understand how patients access palliative care.

PCOC empowers services to strengthen care delivery through comprehensive education and quality improvement support. New clinical forms have been developed and education sessions commenced to support the Version 4 roll-out.

A comprehensive [Data Dictionary and Technical Guidelines](#) document will assist IT vendors when integrating the dataset into their electronic medical records. PCOC is also providing specialised support to services, acknowledging that each system is unique in its workflows and user interface. This work will continue into 2026.

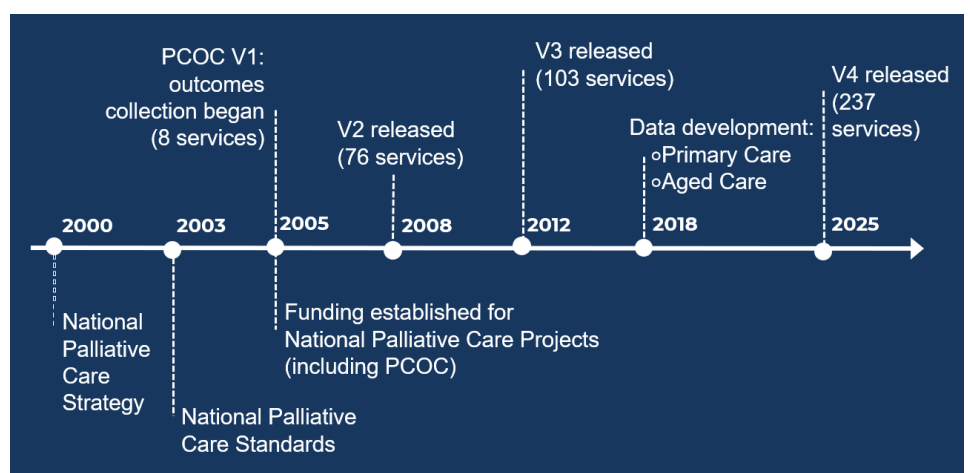


Figure 5: History of PCOC development and datasets versions

Snapshot of States and Territories

WA

- 35 services currently reporting
- PCOC V4 build underway in the state-based IT system, ePalCIS
- Onboarding continues for remaining services in the state

NT

- 3 services currently reporting
- PCOC V4 build underway in the state-based IT system, *Acacia*

SA

- 25 services currently reporting
- State-wide IT transition to *Sunrise*, enabling PCOC implementation and reporting

QLD

- 45 services currently reporting
- The PCOC Public Health Act application granted by QLD Dept of Health
- State-wide IT transition to *ieMR*, allowed 5 services for PCOC reporting, for more in progress.
- V4 build within *ieMR* is underway

VIC

- 58 services currently reporting
- Contributes to 32% of national data
- Onboarding continues from regional and metropolitan services
- First consortium report delivered

NSW

- 73 Services currently reporting
- Increased participation from community-based services
- PCOC V4 build complete in the new state-wide IT

TAS

- 2 services currently reporting
- State-wide PalCentre installation, enabling PCOC participation
- Increasing participation from community-based services

ACT

- Collaboration continues to enable PCOC reporting

Education

In 2025, PCOC continued to deliver comprehensive, free education for participating services to support accurate, consistent use of the PCOC assessment and response framework and benchmarking program. It includes the PCOC Essentials online short course, virtual webinars/workshops, and practical resources. A one-off implementation workshop is also offered to services during their implementation phase of PCOC.

1,187 Participants in Live Training



1,683 Completions in Online Learning

Essentials Modules via two platforms:

- PCOC Moodle hosted by University of Wollongong
- My Health Learning (MHL) hosted by NSW Health

Communities of practice

Community of practices (CoP) are groups of clinical leaders united by their shared goal of enhancing palliative care outcomes. Services are invited to join a PCOC CoP aligned to their organisation (such as metropolitan inpatient setting, or rural community setting). Each CoP meets three times a year to exchange knowledge and leveraging the collective expertise of the group. The meetings are virtual and led by the PCOC Improvement Facilitators. The CoPs are designed to support clinical leaders to understand their outcome and benchmark reports and identify opportunities for education and quality improvement.

CoP groups continued in 2025 (6)		New CoP groups launched in 2025 (3)
Hospice	Inpatient Level 5 / 6	New Services Group
Inpatient level 3 / 4	Community Level 5 / 6 (Standalone & shared governance)	Implementation Group
Community Level 3 / 4 regional	Community Level 3 / 4 rural	Additional inpatient CoP (for Level 3 and 4 dedicated palliative care units)

Consumer engagement

PCOC is committed to involving palliative care consumers in governance, program planning, service improvement and research to enhance outcomes across Australia. In 2025, we partnered closely with consumers to strengthen our governance structures and embed consumer engagement across the program. Key achievements include:

- Co-design of the PCOC [Consumer Engagement Framework](#) and Consumer Orientation Manual.
- Development of plain-language English versions of the PCOC-ESAS form and information sheet.
- Establishment of a formal Consumer Advisory Panel to ensure patient, family and carer perspectives remain central to strategic planning and operations.
- Development of an internal Consumer Engagement Policy with standardised processes, including involving consumers in the design, development and review of all consumer-facing PCOC resources.

The inaugural meeting of the Consumer Advisory Panel is scheduled for February 2026, and the Consumer Engagement Framework will be officially launched in March 2026.

During 2025, PCOC initiated two major projects to ensure the PCOC-ESAS meets the needs of multicultural communities and Aboriginal and/or Torres Strait Islander peoples. PCOC is collaborating with the NSW Multicultural Health Communication Service, multicultural consumers and bilingual health workers to translate ESAS resources into 19 community languages. The bilingual format, placing English and translated text side by side, will support shared understanding, inclusive care, improved symptom reporting and better clinical decision-making.

PCOC has also commenced foundational work with UOW Indigenous Strategy Unit. In 2026 we will continue this work to identify barriers and enablers to palliative care symptom assessment in Aboriginal and/or Torres Strait Islander Communities.

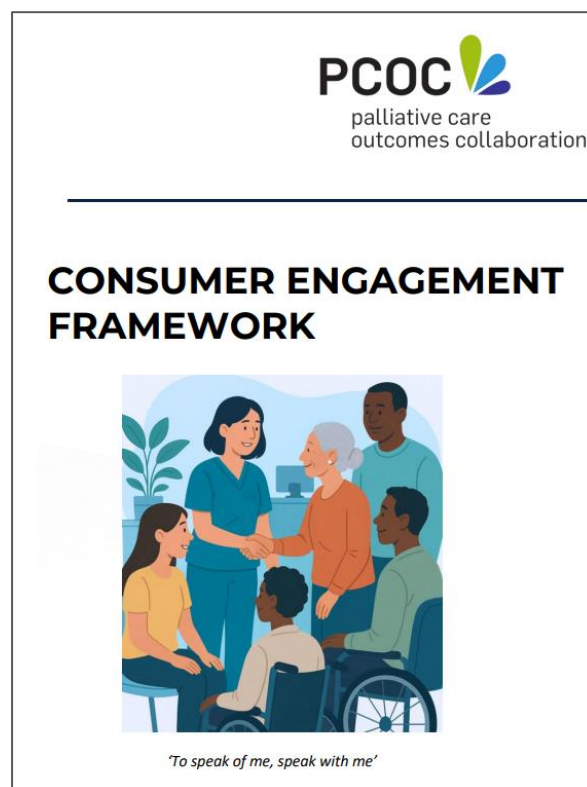


Image 1: Cover page of PCOC Consumer Engagement Framework

Governance and compliance

One Specialist data HREC approval

200+ services

Streamlined ethics, strengthened governance

During 2025, PCOC transformed its governance infrastructure to meet the rigorous standards set out in the Australian Framework for Clinical Quality Registries. This was a prerequisite for the registration of PCOC as the Australian Palliative Care Outcomes Registry. Central to this transformation was elevating PCOC's ethics pathway to the NSW Population and Health Services Research Ethics Committee (PHSREC) review under the National Mutual Acceptance Scheme, enabling all contributing services to confidently accept a single HREC approval.

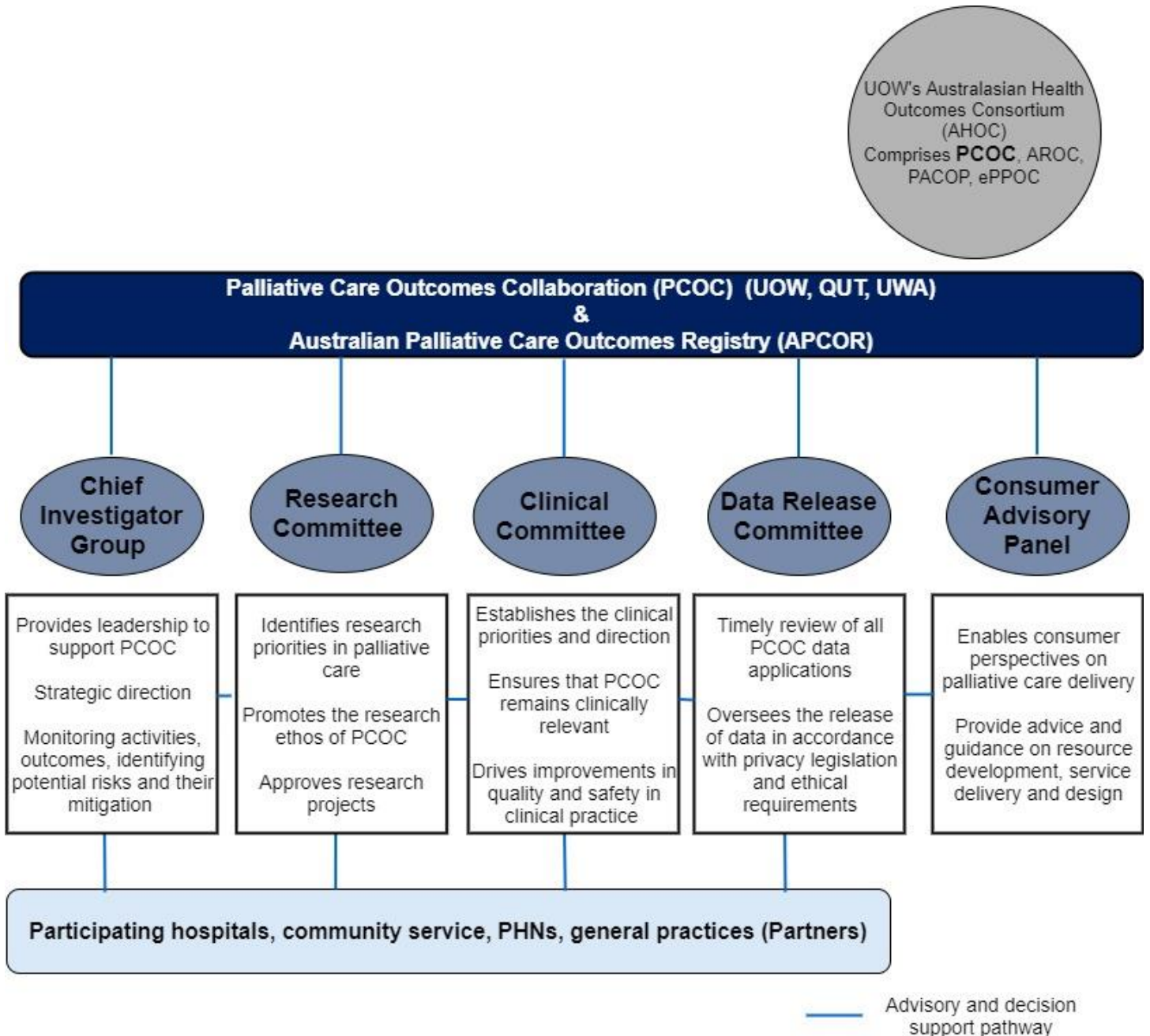
A key milestone was the development and implementation of PCOC's Data Sharing and Services Agreement (DSSA), created to provide a fit-for-purpose agreement template for a clinical quality registry with both quality improvement and research functions. This represents a significant shift towards robust, legally-sound data sharing frameworks that meet contemporary registry standards and clearly articulate the rights, responsibilities, and protections for all participating organisations. The DSSA underwent extensive stakeholder consultation and legal review to ensure alignment with privacy legislation, data sovereignty principles, and contemporary registry standards.

PCOC embedded Indigenous data sovereignty principles throughout its governance framework, engaging with national and state-based Aboriginal Health Research Ethics Committees to ensure cultural safety and appropriate data protections. These committees acknowledged PCOC's arrangements, largely deferring to the PHSREC specialist data HREC approval.

PCOC will continue to focus on working collaboratively with participating services to secure governance approvals, implementing the new DSSA framework, and strengthening relationships with HRECs and governance offices nationwide. To support this work, PCOC has developed a governance tracking systems using Power BI, enabling transparent monitoring of site-level approvals, data sharing agreements, and compliance.

Governance structure

PCOC's governance framework includes specialised committees that provide oversight, strategic direction, and ensure diverse stakeholder perspectives inform all aspects of the program.



UOW – University of Wollongong

QUT – Queensland University of Technology

UWA – University of Western Australia

PHN – Primary Health Network

AROC – Australasian Rehabilitation Outcomes Centre

PACOP – Palliative Aged Care Outcomes Program

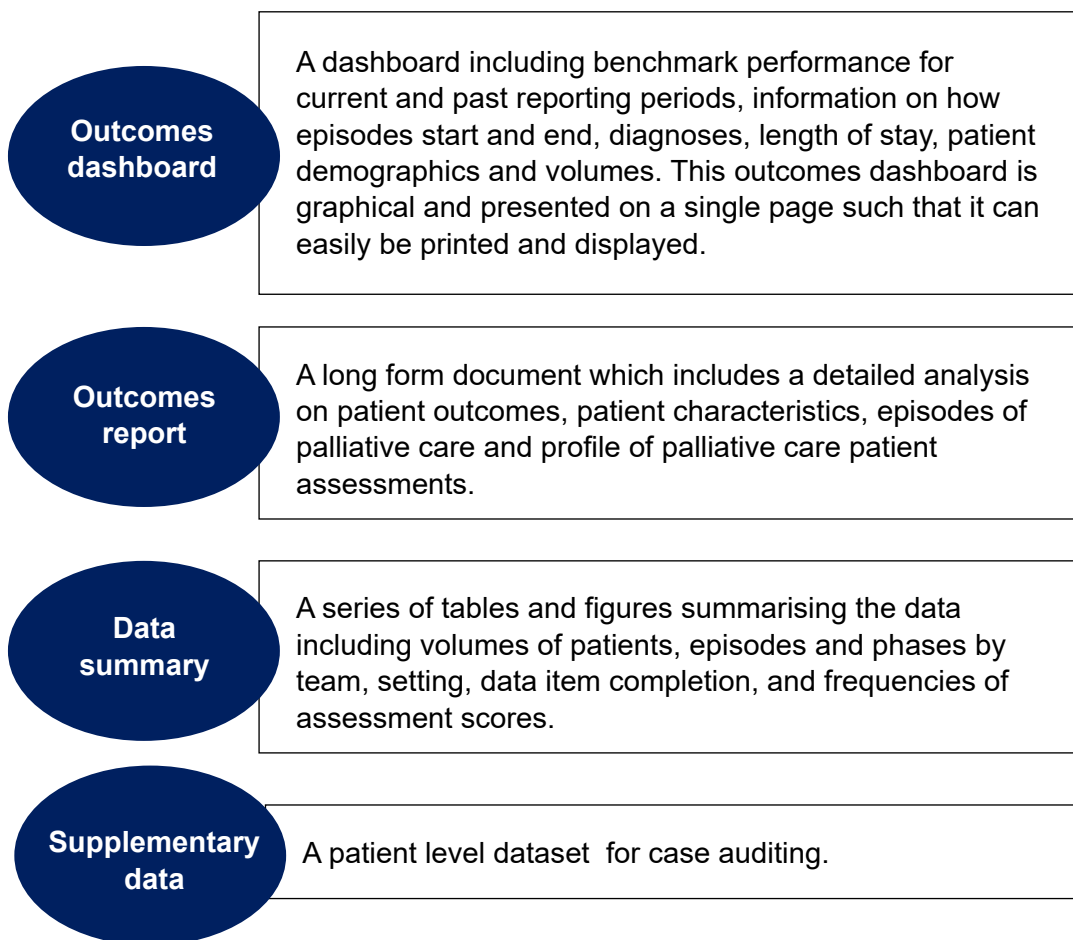
ePPOC – electronic Persistent Pain Outcomes Collaboration

Data and reporting

In 2025, a major overhaul of the PCOC reporting suite provided a more modern, user-friendly experience alongside new insights designed to support clinical decision making. The report aims to highlight key trends in access and patient outcomes to inform decision-making and encourage early access to palliative care.

This marked the completion of the first phase of a broader program to modernise the technology, from submission through to reporting.

Historically, the bi-annual static reports delivered by PCOC to participating services included the:



With the PCOC reports historically being solely static (PDF and Excel spreadsheets), the second phase of the modernisation program is to build an interactive dashboard. These tools let users explore, question, and act on their data in real time. Work commenced in mid-2025, with prototypes shared with stakeholders to support feedback and engagement. The dashboard will be officially launched in April 2026.

Research and registry impact

In April 2025, PCOC released its Strategic Research Plan, with the primary objective of enhancing the quality and effectiveness of palliative care in Australia through evidence-based practices. This roadmap focuses on two priority areas:

1. Enhancing measures and improving palliative care outcomes and
2. Advance equity, specialty care and innovation in palliative care.

Priority Area 1: Enhancing Measures and Improving Palliative Care Outcomes

Patient and Carer Experiences

Symptom Burden, Management, and Prognostication

Evaluate and Enhance PCOC Measures

Priority Area 2: Advance Equity, Specialty Care and Innovation in Palliative Care

Equity in Palliative Care

Priority Populations

Technology and Artificial Intelligence

Innovative Service Delivery Models

PCOC's research agenda is instrumental in driving evidence-informed improvements in palliative care across clinical, academic, and policymaking spheres throughout Australia and beyond. During 2025, the PCOC Research Team supported four student projects and initiated two major projects, that are supported by external grants.

The Australian Palliative Care Outcomes Registry (APCOR)

In 2025, the Australian Palliative Care Outcomes Registry (APCOR) was officially launched with the aim of governing and curating the clinical data collected through PCOC. APCOR was listed on the Australian Commission on Safety and Quality in Health Care's Register of Clinical Quality Registries (CQR). CQR registration marks APCOR's transition from a quality improvement program to a national registry that sets the benchmark for palliative care data collection and use. APCOR received 18 expressions of interest to use APCOR data for research and quality improvement projects, of which 14 were approved.

Expansion in primary care

PCOC is extending its quality improvement framework into Primary Care through a strategic initiative that enables earlier identification of palliative care needs in general practice.

This work supports GPs with practice-ready needs assessment tools and strengthens coordination between general practice, Primary Health Networks (PHNs), and specialist palliative care services.

General practice is critical for supporting people with chronic and life-limiting illness in community settings. Yet many who could benefit from a palliative approach are identified late, particularly among people with non-cancer conditions, multimorbidity, or inequitable access to specialist services. The National Primary Care Coordination (NPCC) project has completed formative research which has identified specialist palliative care referral criteria and system gaps. This evidence has informed the development of GenPal, a structured needs assessment and decision-support process designed specifically for general practice. GenPal supports general practice teams to review patient-reported outcome measures, facilitating earlier identification of changing needs. Designed to integrate within routine workflows, GenPal strengthens coordination with specialist services. Implementation is currently ongoing, with continued evaluation informing future scalability and integration of structured palliative care needs assessment across Australian general practice.

Improving palliative care screening in NSW hospitals

In 2025, PCOC secured funding from the NSW Government for the Improving Palliative Care Screening in NSW Hospitals (IMPACS-NSW) project. IMPACS-NSW focuses on developing and embedding a framework for routine palliative care screening in acute hospital wards to help identify patients needing care earlier.

IMPACS-NSW is a collaborative research project, involving three local health districts – Illawarra Shoalhaven, South Eastern Sydney and St Vincent's Health.

Research and quality improvement publications and presentations

PCOC published two peer reviewed articles in 2025, with another six submitted for publication. PCOC supported four HDR students.

In 2025, four quality improvement initiatives were showcased at the Oceanic Palliative Care Conference by PCOC participating services, demonstrating how PCOC's translates evidence into practice-based improvements.

Goulburn Valley Hospice

"Achieving 20 PCOC benchmarks in community palliative care"

Illawarra Shoalhaven Local Health District

"Integrating PCOC into routine practice for Allied Health"

St Vincent's Hospital Sydney

"Symptom Assessment Scale (SAS) Quality Improvement Project"

Western Australia Country Health Service

"Integrating Telepalliative care: creating expanded specialist palliative care access in rural WA"

PCOC publications, presentations and reports

Ayalew, A. A., Clapham, S., Clark, K., Hodiamont, F., Redwood, L., & Currow, D. (2025). Psychometric properties of palliative care outcome measures: a multi-centre study. *J Patient Rep Outcomes*, 9(1), 120. <https://doi.org/10.1186/s41687-025-00954-6>

Clapham S, Clark K, Draper K, Mastroianni F, Rand J, Redwood L, Currow D. A National Quality Initiative to Improve Palliative Care Outcomes: Identifying Enabling Factors that Drive Quality Improvement. *Palliative Medicine Reports*. 2025 May 1;6(1):241-50. <https://doi.org/10.1089/pmr.2024.0092>

Clapham S, Daveson B, Ayalew AA, Draper K, Hartati A, Reed K, Redwood L, William L, Currow D. Defining palliative care service capability: a scoping review to support quality improvement and benchmarking. *Quality of Life Research*. 2026;35(2):38. <https://doi.org/10.1007/s11136-025-04123-6>

Accepted for publication or under review

Johnson K, Poudel A, Ayalew AA, Thepsourinthone, J, Heer S, Morgan D, Mullan J, Bonney A, Clapham S. Screening Protocols for Identifying Palliative Care Needs in Primary Care: a scoping review. *Journal of Pain and Symptom Management*. (accepted for publication).

Clapham S, Ayalew, A, Yates P, Redwood, Auret K, Clark K, Currow D. Comparing severe symptom distress of inpatients and people cared for in the community in their last week of life: a national, consecutive cohort study. *Journal of Palliative Medicine*. (accepted for publication)

Poudel A, Ayalew AA, Johnson K, Thepsourinthone, J, Heer S, Burns P, Clapham S. Supporting general practices in early identification of care needs among people living with chronic illnesses. *Australian Journal of General Practice*. (under review).

Clapham, S, Burns, P, Howell, N, Draper, K, Ayalew, AA, Poudel A, Yates P, Redwood, Auret K, Clark K. The Australian Palliative Care Outcomes Collaboration (PCOC) – 20 years of measuring palliative care quality and outcomes. *International Journal for Quality in Health Care* (under review).

Ayalew, A. A., Poudel, A., Johnson, K., Thepsourinthone, J., Heer, S., Redwood, L., Mullan, J., Bonney, A., Morgan, D., Yates, P., Clark, K., Auret, K., & Clapham, S. (n.d.). Understanding palliative care referrals from general practitioners: A multicentre retrospective cohort study. (under review).

Non-peer reviewed publications

Clapham S, Burns P, Poudel A, Alebel Ayalew A, Draper K. Palliative care patient outcomes in Australia have improved in the last 10 years. *Australian Nursing & Midwifery Journal* 2025.

Conference presentations

Innovation in palliative care outcomes – a collaborative forum Sabina Clapham, Kylie Draper, Anita Hartati and Jesse Rand.

The palliative aged care program intersection – supporting aged care organisations to meet the new strengthened Aged Care Standards Claire Johnson, Distinguished Prof Patsy Yates, Prof Jennifer Tieman, Sabina Clapham, Charlotte Coulson, Annie Dullow.

Looking back, looking forward: 20 years of tracking palliative care outcomes in Australia
Distinguished Professor Patsy Yates.

Ayalew, A. A., Poudel, A., Johnson, K., Thepsourinthone, J., Heer, S., Redwood, L., Mullan, J., Bonney, A., Morgan, D., Yates, P., Clark, K., Auret, K., & Clapham, S. (n.d.). Understanding palliative care referrals from general practitioners: A multicentre retrospective cohort study. Early career researcher conference at UOW.

Poudel A, Clapham S. National Palliative Care Coordination (NPCC) Project & Program Logic presented at the 2025 GSM & ISLHD Medical Research Showcase Day. 21 October 2025.

Redwood L and Clapham S. Improving palliative care screening in hospital settings (IMPACS) presented at the 2025 GSM & ISLHD Medical Research Showcase Day. 21 October 2025.

Research grants awarded

2025 MRFF Dementia Ageing and Aged Care Mission. Shrestha S, Nissen L, Caze A, Atee M, Lovell M, Lau E, Poudel A, KC B, Saleem A, Tesfaye W, Guzman K, Cheong M. 'Implementation and evaluation of a deprescribing decision aid tool for people living with dementia and palliative needs in aged care' (Application ID: 2053053).

2025 End of Life and Palliative Care Research Grant Program, NSW Health. Clapham S, Redwood L, Johnson C, McErlean G, Blackburn P, Cerni J, Sheahan L, Seah D, Mastroianni F. 'IMPACS-NSW: Improving Palliative Care Screening in New South Wales (NSW) Hospitals.

ACKNOWLEDGEMENTS

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The work we have conducted during 2024-2025 has been supported by The Commonwealth of Australia represented by Department of Health, Disability and Ageing, ID: 4-INMGHBA

We sincerely thank our services, consumers and the palliative care sector community for their valuable interactions, insights and contributions during this reporting period.

PCOC acknowledges the Traditional Owners of the lands and waters on which we walk, live and rely. We pay our respects to Elders past and present.



Palliative Care Outcomes Collaboration (PCOC)

University of Wollongong

Faculty of Science, Medicine and Health

Innovation Campus

Building 232, Mike Codd Level 2, Innovation Way

North Wollongong NSW 2500

T 02 4239 4393

E pcoc-admin@uow.edu.au

W [PCOC](http://www.pcoc.org.au)