



palliative care
outcomes collaboration

Version 4

Building on 20 Years of
Continuous Improvement in Palliative Care

February 2025



Strengthening PCOC for the Future

Palliative Care Outcomes Collaboration (PCOC) is funded by the Australian Government and offers free, voluntary participation for all services providing palliative care. Since its establishment in 2005, PCOC has served as a platform for standardised clinical data collection, national benchmarking, and ongoing quality improvement.

PCOC is a collaboration between three universities: the University of Wollongong, Queensland University of Technology, and the University of Western Australia. It is led by the Australian Health Outcomes Consortium at the University of Wollongong.

PCOC provides biannual national, state and service-level reports. The data collection spans all Australian states and territories, across all five remoteness areas, offering valuable insights into palliative care across the country.

Participation has grown from eight services in 2006 to over 220 in 2024. We wish to acknowledge the pioneering services that participated in the initial PCOC pilot: Adelaide Hills Community Health Service, Calvary Health Care Sydney, Calvary Health Care Canberra, Coffs Harbour Palliative Care Service, Sacred Heart Palliative Care Service, Mater Adults Hospital Brisbane, Silverchain Hospice Care Service, and Southern Adelaide Palliative Services.

This year, PCOC marks 20 years of continuous quality improvement in palliative care outcomes, acknowledging the invaluable contributions of palliative care services. To mark this milestone, we are making significant enhancements to ensure that PCOC program remains fit for purpose while adapting to meet the evolving needs of the sector.



Sabina Clapham
Director, PCOC

PCOC History of Datasets

Key milestones in PCOC's data development are represented in Appendix 1 and can be summarised as follows:

VERSION

1
2006

- Program launch with eight pilot services
- Focused on feasibility of standardising the collection of palliative care data to support benchmarking and quality improvement
- Four selected included assessment tools were the Palliative Care Phase, the Australian Karnofsky Performance Scale (AKPS), the Resource Utilisation Groups - Activities of Daily Living, and the Palliative Care Problem Severity Score.

VERSION

2
2007

- Following the pilot phase, Version 2 introduced additional clinical benchmarks and measures such as the 'unstable phase' and 'improvement in pain'
- Assessment tools were expanded to five, with the addition of the Symptom Assessment Scale.

VERSION

3
2012

- Expanded the dataset to include additional items at the patient, episode, and phase levels
- Used for national benchmarking from 2012 to 2024. The [Version 3 data dictionary and technical guide](#) is available for download.

VERSION

4
2025

- Developed over many years through extensive consultation, Version 4 improves the data collection and reporting to meet the evolving needs of the palliative care sector, as well as to be versatile and scalable beyond specialist palliative care
- Includes refined items and new items on carer support, delirium assessment and the inclusion of non-physical assessment items through the Edmonton Symptom Assessment System, replacing the PCOC Symptom Assessment Scale.

Version 4 Development

Guiding Principles and Rationale

The development of Version 4 began in response to stakeholder feedback, sector growth and increasing maturity, as guided by the following principles and rationales



minimise the burden of data collection



improve data relevance at point of care



maximise use of data for multiple purposes (quality improvement & research)



integrate new clinical and holistic insights, such as carer involvement, delirium, and non-physical symptoms

Consultation Process

A comprehensive consultation process that engaged a wide range of stakeholders were conducted to ensure a responsive, evidence-based approach (focus groups, interviews, consensus-based methods).

2017

Public consultations and submissions

A public portal was launched to gather broad feedback on PCOC Version 3 for consideration in development of Version 4. The proposed changes included the addition of delirium screening, increased emphasis on non-physical symptoms, modifications to referral item, and a change in the architecture toward assessment level data (e.g., capture and reporting on daily assessments). The first draft of Version 4 of PCOC was developed and evaluated through PCOC's governance structures.

2021

Expert Reference Group (ERG)

This group was established to review and advise on proposed changes and develop the item responses.

2022

First round of field testing

A cross section of services participated in field testing, revealing practical challenges with collection of the draft Version 4 items. Modifications to response options were required to further inform these developments.

2024

Second round of field testing

The field testing (based on seven PCOC registered services) resulted in refinements to the sequence of assessments, modified item responses, and identified missing variables.

Key Changes in Version 4

Version 4 introduces several significant enhancements to the data quality and usability, represented in Appendix 2. The Version 4.0 dataset architecture offers significant benefits to clinicians and the PCOC program, enhancing flexibility, efficiency, and data accuracy.



Streamlined and Flexible

Version 4 provides a simplified approach for documenting palliative care encounters, now enabling assessments during the terminal phase to be reported, as well as triage assessments, and one-off consultations.

Assessments can now be identified as standalone events or linked to subsequent admissions, enhancing adaptability to various clinical scenarios and models of care.



Improved Data Architecture

The previous three-tier structure (patient, episode, and phase) is now streamlined into a two-tier format; patient and assessment.

The Profile collection (previously standalone) has been integrated into the patient and assessment structure to enable the capture of single assessments, such as one-off consultation assessments and triage assessments (see Appendix 2).

This will simplify data entry for clinicians and IT systems, as episodes will no longer need to be created.



New Data Items

Version 4 includes additional elements such as carer status, the screening for and intensity rating of delirium, and expanded symptom tracking utilising and the Edmonton Symptom Assessment System (ESAS).

This enables a more comprehensive view of patient care needs and outcomes.



Versatile Application

The dataset is designed to support application to diverse service and care models beyond the specialist palliative care context, and includes expanded options for holistic assessments.

New Items in Version 4

Assessment item	Description	Purpose	Measurement point
ESAS	The Edmonton Symptom Assessment System	Replace the PCOC Symptom Assessment Scale (SAS). Monitor a range of symptoms (physical and psychosocial), aiding in evaluation of intervention effectiveness.	At each assessment or contact
Presence of delirium	If delirium is present - yes or no The use of a delirium assessment tool is recommended	Trigger a delirium assessment. Track delirium prevalence to inform care strategies and symptom management.	At each assessment or contact
Delirium intensity	The level of intensity relating to delirium on an 11-point scale, 0-10	Monitor the impact of delirium and its intervention effectiveness.	At each assessment or contact
Carer status	Identify if the patient has a carer as defined by Australian Carer Recognition Act 2010	Aid in care and discharge planning, health service utilisation measurement, and outcome adjustment.	At the first assessment or on admission

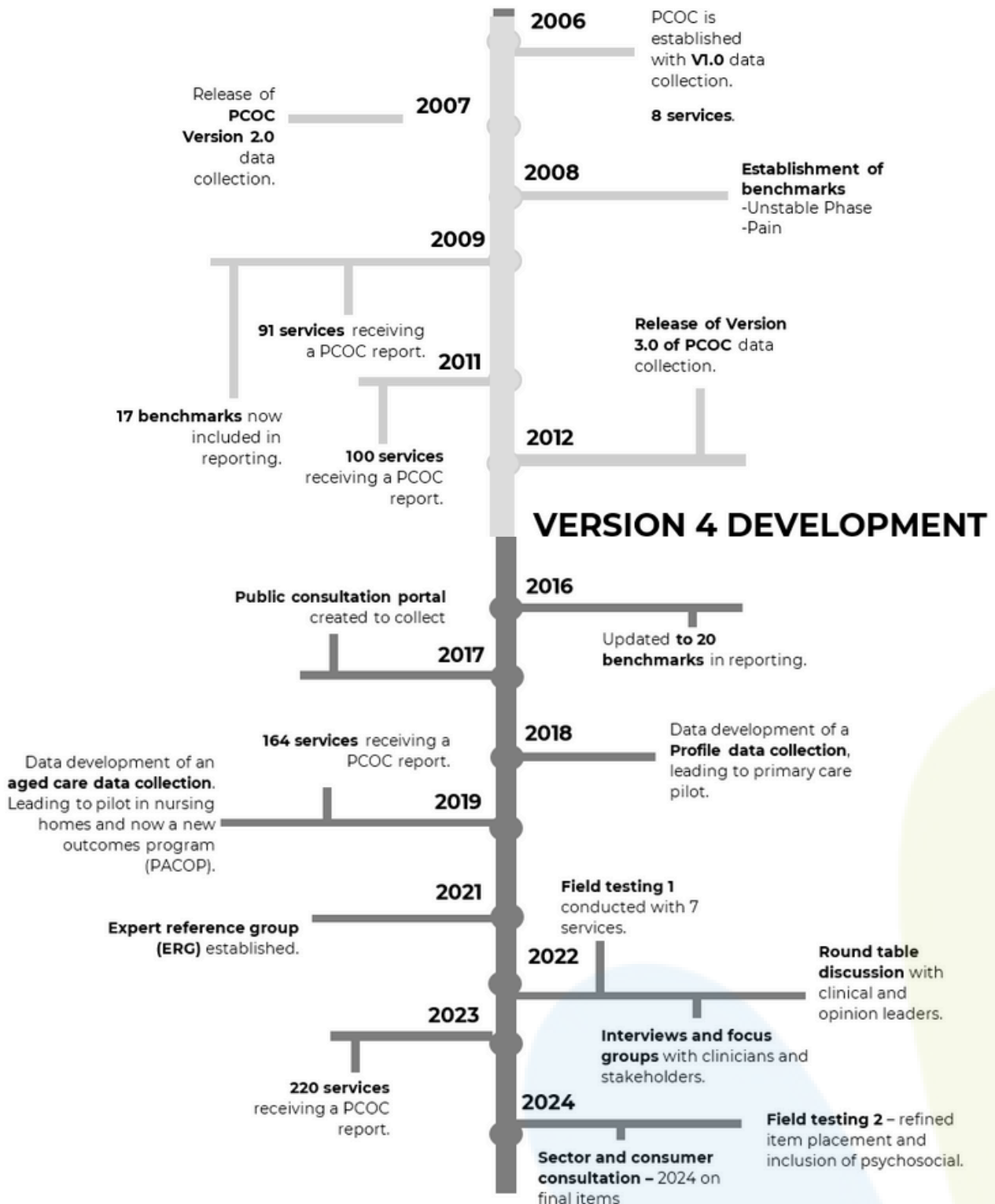
New Items in Version 4 (continued)

Assessment item	Description	Purpose	Measurement point
Referring speciality	The specialist or health care team who referred the patient for palliative care	Separated from referring provider, and with expanded list of specialties. Establish referral patterns and provide an opportunity to improve access for patients who require palliative care.	At the first assessment or on admission
Time of assessment	The time the assessment was conducted	Capture more than one assessment per day. Improve specificity in assessment sequence and measure of change.	At each assessment or contact
Mode of assessment	Identify how the assessment was conducted - in person, video conference or telephone	Capture the mode of care, distinguishing between in-person and telehealth visits, to support understanding of care delivery.	At each assessment or contact

Revised Items in Version 4

Assessment item	Description	Purpose	Measurement point
Referring provider type	<p>Identify the source from which the referral originated</p> <p>Response options are more nuanced and separated from referral specialty categories</p>	<p>Provide insight into referral pathways and assist in tracking how patients access palliative care.</p>	<p>At the first assessment or on admission</p>
Patient location prior to assessment	<p>The location of the patient prior to the start of palliative care</p> <p>Response options are refined with timeframe included</p>	<p>Offer insight if patients were admitted directly or via another hospital ward, which helps in reviewing admission processes, care continuity and access to palliative care.</p>	<p>At the first assessment or on admission</p>
Usual accommodation	<p>The place where the patient currently lives</p> <p>Response options now include prison and group home</p>	<p>Provide insight into service transitions and the referral pathways that lead to palliative care.</p>	<p>At the first assessment or on admission</p>
Patient location after separation or discharge	<p>The location of the patient after palliative care is no longer required</p> <p>Response options more nuanced</p>	<p>Help describe patient pathways and service utilisation patterns.</p>	<p>At separation or on discharge</p>

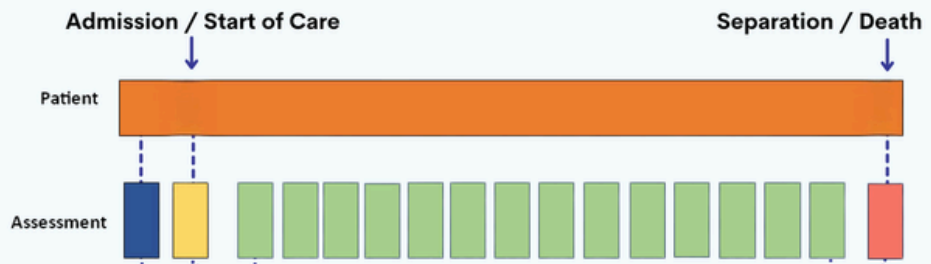
Appendix 1: PCOC History of Datasets



Appendix 2: Key Improvements Poster

Key Improvements in PCOC Version 4

1
Simplified
two-tier
data architecture



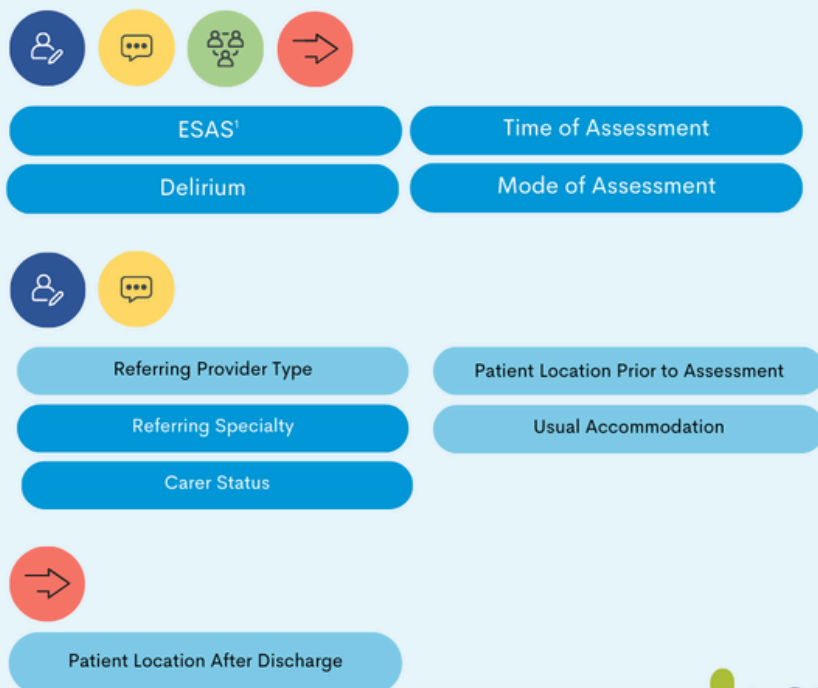
2
Streamlined
for various clinical
scenarios & models of
care, including
telehealth



*This categorisation will be derived from assessment data

3
Holistic
view of patient care
needs and outcomes

- New Items
- Modified Items



¹ The Edmonton Symptom Assessment System



Celebrating 20 years in improving palliative care outcomes

Palliative Care Outcomes Collaboration

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PCOC values the contribution of palliative care services and clinicians in shaping its development to enhance clinical care and improve outcomes for patients and their families/carers.