

Palliative Care Outcomes Collaboration Dataset 2023: Data Quality Statement

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| <p>Data quality statement summary:</p> | <p>Description</p> <p>The Palliative Care Outcomes Collaboration (PCOC) provides 6-monthly national and state-level data from standardised clinical assessment tools which measure and benchmark patient outcomes for palliative care, including pain and symptom control. PCOC aims to improve the quality and outcomes of palliative care in Australia.</p> <p>The PCOC 2023 dataset corresponds to data reported in the 35th and 36th bi-annual reports conducted under the National Palliative Care Strategy. The 35th and 36th reports consist of phases of care completed between 1 January 2023 and 30 June 2023, and between 1 July 2023 and 31 December 2023 respectively. Annual PCOC data is incorporated in the AIHW Palliative Care Services in Australia report and the AIHW National Palliative Care Measures report.</p> <p>PCOC is a national palliative care program funded by the Australian Government Department of Health and Aged Care (Australian Government). The Australian Government has funded the PCOC program since 2005. Program funding is typically administered in three-year funding cycles. PCOC is a collaboration of three Universities with the database held at the University of Wollongong. PCOC data is reported to member organisations, states and territories, and nationally.</p> <p>Summary</p> <ul style="list-style-type: none"> • The PCOC 2023 dataset includes data from palliative care services in all states and territories except for ACT, and from both inpatient and community settings of care. There are varying care delivery models, and data collection protocols. Therefore, this variation must be considered when interpreting and comparing results. • The PCOC 2023 dataset architecture consists of three levels of linked information, patient, episode, and phase. The clinical assessment and outcome data included in PCOC data are not readily available from other sources in Australia. • Jurisdictions, and some organisations, use different information systems to collect data which result in variances in data collection between services and over time. Each 6 months, the quality of data submitted is assessed for inclusion in the dataset. As a result, some organisation or services are removed from national and state reports and only receive a service-level report labelled as ‘transitional’. This supports data quality improvement for inclusion in subsequent data cycles. Services included in the PCOC 2023 dataset and in national and state reports, are listed in the National List of Services Jul - Dec 2023 and National List of Services Jan - Jun 2023. The list of services also indicates the list of services provided with transitional reports. |

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| | <ul style="list-style-type: none"> • Data collected in the PCOC 2023 dataset for patient item Indigenous status should be interpreted with caution due to the varying quality of identification processes of First National people within services. • Although item completion is generally high (85.6% to 100% in the PCOC 2023 dataset), some phase level items vary by setting of palliative care and by specific assessment item. Individual item completion rates are tabulated for episode and phase level data items by setting of care and published in the national outcomes report. • The phase-level data include patient and clinician reported data. The Symptom Assessment Scale (SAS) can be patient-reported or clinician-reported. Due to variation in data collection processes at a service level data should be interpreted with caution. In Version 3.0 of the PCOC data dictionary, there is no requirement for services to report whether SAS is patient or clinician rated, however some services collect this information. This limitation is described in the PCOC Palliative Care Clinical Manual and the PCOC Assessment and Response Protocol. The incidence of clinician and proxy is not known nationally, however was estimated in a subset of services in Clapham et al (2021). This item is proposed as a mandatory item in Version 4.0 of the PCOC Data Dictionary. |
| <p>Institutional environment:</p> | <p>PCOC</p> <p>PCOC operates out of the Australasian Health Outcomes Consortium (AHOC), which is situated within the Faculty of Science, Medicine and Health at the University of Wollongong (UOW). AHOC is a research consortium which aims to improve services and outcomes for patients through benchmarking of care and treatment and supporting service improvement. AHOC generates robust evidence through its provision of clinical quality registries in rehabilitation, pain and palliative care. The registries provide evidence to guide treatment and care for individual patients, measure outcomes and deliver benchmarking for the relevant health sector. AHOC Centres, including PCOC, identify and promote best practice in clinical care, drive quality improvement and conduct research.</p> <p>PCOC is a national voluntary program that is improving the quality and outcomes of palliative care patients in Australia. All services registered with the PCOC program participate in the program voluntarily. A registration form is completed by each service before any data is submitted to PCOC. This registration form outlines services' responsibilities under the privacy legislation within their jurisdiction.</p> <p>The governance structure of PCOC includes a Chief Investigator's Group, a Clinical Director (State-level palliative care specialist), and internal committees and decision-making structures (clinical, quality, and data) within the PCOC team. Any errors or issue identified in published statistics are resolved as quickly as possible, with review at internal PCOC team and Chief Investigator level. Updated versions of national and state reports are published on the PCOC website with a corresponding footnote on the relevant table, but no other additional processes are in</p> |

place to notify of any revisions in national or state reports. Any issues identified at service level are corrected and communicated to the individual service.

PCOC is a collaboration of three Universities, the University of Wollongong (UOW) (lead), the University of Western Australia (UWA), and the Queensland University of Technology (QUT).

UOW

UOW was established in 1951. The duties and functions of UOW are mandated as per the [University of Wollongong Act \(1989\)](#). UOW's purpose is to inspire a better future through education, research, and partnership.

Encompassing committees, policies and processes, and legislative compliance, UOW's governance and ethical environment is grounded within a framework that fosters accountable, consistent, and transparent decision making. UOW's legal privacy obligations include the [Government Information \(Public Access\) Act 2009](#), the [Health Records and Information Privacy Act 2002](#), the [Privacy and Personal Information Protection Act 1998](#) and [The Privacy Act](#).

Compliance with confidentiality requirements in the Privacy Principles in the Privacy Act 1988, the Health Records and Information Privacy Act 2002, and the Privacy and Personal Information Protection Act 1998 ensures that PCOC releases information weighing the benefits to the public against protecting the identity of individuals and services.

For further information see the UOW website (<https://www.uow.edu.au/>) which includes information about UOW governance (<https://www.uow.edu.au/about/governance/>), and vision & strategy (<https://www.uow.edu.au/about/our-vision-strategy/>).

UWA

Established as the State's first university in 1911 and founded with a mission to 'advance the prosperity and welfare of our communities', the University opened in 1913 to just 184 students. UWA is governed by the [University of Western Australia Act 1911](#). The Senate is the University's governing body, empowered with the authority to make statutes, regulations and by-laws.

For further information see the UWA website (<https://www.uwa.edu.au/>) which includes information about UWA's leadership and governance (<https://www.uwa.edu.au/about-us/leadership-and-governance/>), and values, vision & strategy (<https://www.uwa.edu.au/about-us/values-vision-strategy/>).

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| | <p>QUT</p> <p>Queensland University of Technology (QUT) is a major Australian university with a truly global outlook. The Queensland University of Technology Act was passed in 1988, following approval of university status for the Queensland Institute of Technology. Queensland University of Technology (QUT) began operating in January 1989.</p> <p>For further information see the QUT website (https://www.qut.edu.au/) which includes information about QUT’s governance and policy (https://www.qut.edu.au/about/governance-and-policy), research vision (https://www.qut.edu.au/research/why-qut/research-and-innovation) and strategy (https://www.qut.edu.au/connections).</p> |
| Timeliness: | <p>Data provision</p> <p>Data is submitted by services through the Secured Online Submission (SOS) portal. There are twice yearly data submissions with corresponding six-month data quality and outcome reports. A data submission is due in the 3rd week in July (for January to June data), and the 3rd week of January (for July to December data). The data submission period planned close date is the last week of January and July.</p> <p>Publication</p> <p>A full suite of reports is produced including outcome reports according to a planned schedule of the 2nd week in September (for January to June data) and the 2nd week in March (for July to December data).</p> <p>Data is provided to AIHW for the Palliative care services in Australia report in June each year (https://www.aihw.gov.au/reports-data/health-welfare-services/palliative-care-services/overview), consisting of annual data on palliative care outcomes measures (see https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-outcomes) _</p> <p>Reference period</p> <p>The reference period is determined at phase level and includes all phases that ended within the reporting period. The associated episodes and patients are then determined. For 2023 data, the reporting period is 1 January 2023 to 31 December 2023. Outcomes data are available from July 2000.</p> |
| Accessibility: | <p>National and state reports and dashboards</p> <p>PCOC produces National and state outcomes reports, National and state Outcome Dashboards – Inpatient setting, and National and state Outcome Dashboards- Community setting, for each six-month period. National and State reports are publicly available on the PCOC website in pdf and Word format. The reports contain information pertaining to the reporting period and overtime results encompassing the last three years for benchmarked results and five years for some patient and episode level information</p> |

[\(https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/reports/\)](https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/reports/).

Service reports

Service-level PCOC reports are available through the PCOC Online Portal (POP), which is a secure website developed to allow services to access their PCOC reports. An individual username and password are required to access reports, and PCOC staff designate which individuals have access to reports for each service according to the membership agreement.

Aggregate and unit record data

Aggregate or unit record data may be requested and must go through a process which includes the completion of a [Data Access Request form](#) and approval from the PCOC Chief Investigator Group. Approved applicants must sign a PCOC Data User Agreement controlling the purpose, use and storage of aggregate or unit record data prior to release. The application process is described on the PCOC website (<https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/research-data/>). The scope of data available, principles for sharing and use, and process for requesting data are described in the further detail in the [PCOC Data Policy](#).

AIHW national reports

Data published in the AIHW Palliative Care Services in Australia report are available on the AIHW website (<https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/data>). Important information about data and data quality is provided, including PCOC assessment tools, definitions of PCOC outcome measures, dates for previous versions the PCOC dataset, lists of contributing services, changes in benchmark measures. This information is updated annually. The most recent published version corresponds to the 2022 data (<https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-outcomes#Datasources>).

Metadata

Data collected as part of PCOC's outcomes collection, and all associated rules and restrictions, are outlined in the [PCOC v3.0 Data Dictionary and Technical Guidelines](#).

State-specific reports

State specific reports are produced for NSW, VIC, SA, QLD, and WA. Whilst there are services that participate in PCOC that are in the other state and territories, the Australian Capital Territory, Northern Territory and Tasmania do not have as sufficient volume of data to receive a PCOC report.

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| <p>Interpretability:</p> | <p>Data is captured at three levels: the patient-level, episode-level, and phase-level. Patient-level information describes demographics such as Indigenous status, sex, preferred language, and country of birth. Episode-level information describes the setting of palliative care service provision. It also includes information relating to the facility or organisation that has referred the patient, how an episode starts and ends, and the setting in which the patient died. Phase-level information describes the clinical condition of the patient during the episode. This information is derived from five clinical tools. These tools include measures that examine palliative care phase, the patient’s functional status and performance status, pain and other common symptoms, the patient’s psychological/spiritual problems and family/carer issues.</p> <p>Information on interpreting PCOC data is available on AIHW’s website (https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-outcomes#Datasources). This website provides descriptive information and supporting publications for the PCOC assessment tools, lists contributing services, and defines each outcome measure and corresponding benchmark. A guide to PCOC National Outcome Measures and Benchmarks provides further information on how benchmarks are established and dates of revisions and provides advice to services on information on calculation and interpretation.</p> <p>Data published six-monthly in the PCOC National Outcomes reports on the PCOC website (https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/reports/) provides information on how to interpret data tables. Information is provided on data item completeness for each report for patient, episode, and phase level items in Appendix B Data Item Completion. A visual representation of the scoping method is presented in Appendix D Data Scoping Method. Information on interpreting profile graphs is contained in Appendix E Interpreting benchmark profile graphs.</p> |
| <p>Relevance:</p> | <p>Number of services, patients, episodes, and phases</p> <p>The number of services in the PCOC 2023 dataset and in previous years is shown in Table 1. In relation to the coverage of palliative care services, the absolute number of palliative care services included in national reports increased from 148 in 2019 to 200 in 2023 (35.1%). The number of services registered with the program (who may be provided transitional reports until data completeness requirements are met) increased from 135 in 2012 to 215 in 2022 services (+59.3%) (Daverson et al., 2023).</p> |

Table 1 – Number of services in PCOC dataset, 2019-2023

| | 2019 | 2020 | 2021 | 2022 | 2023 |
|-------------------------------|------|------|------|------|------|
| Participating services | 148 | 170 | 177 | 180 | 200 |

The number of patients, episodes and phases in the PCOC 2023 dataset and in previous years is shown in **Table 2**.

Table 2 – Number of patients, episodes, and phases in PCOC dataset, 2019-2023

| | 2019 | 2020 | 2021 | 2022 | 2023 |
|--------------------------------|----------------|----------------|----------------|----------------|----------------|
| Patients | 47,214 | 53,256 | 58,710 | 61,056 | 70,067 |
| Episodes of care | | | | | |
| Inpatient | 32,972 | 35,084 | 39,364 | 40,728 | 47,083 |
| Community | 31,325 | 37,330 | 38,167 | 38,772 | 43,680 |
| Total | 64,297 | 72,414 | 77,531 | 79,500 | 90,769 |
| Closed episodes of care | | | | | |
| Inpatient | 32,695 | 34,838 | 38,939 | 40,482 | 46,405 |
| Community | 29,007 | 34,145 | 34,484 | 35,449 | 38,945 |
| Total | 61,702 | 68,983 | 73,423 | 75,931 | 85,350 |
| Phases | | | | | |
| Inpatient | 74,182 | 78,339 | 84,696 | 85,264 | 101,251 |
| Community | 78,926 | 92,381 | 90,470 | 91,015 | 102,302 |
| Total | 153,108 | 170,720 | 175,166 | 176,279 | 203,553 |

Coverage

PCOC include data from all Australian states and territories and across all five remoteness areas (major cities to very remote). The postcode of usual residence of the patient is used to derive remoteness area based on the Australian Statistical Geography Standard 2021.

The most recent available information on coverage was published by PCOC in 2023 (Daveson et al., 2023). The excerpts below describe the methods and estimates of coverage from this publication.

“Coverage was assessed using two measures. Change was calculated for the period 2012–2022 regarding the volume of services registered with the programme and in relation to a range of service characteristics. This was to be presented as the total number of services divided by care setting (inpatient and community), service size, and location. The size of the service was derived by examining episodes of care in each service, with an episode of care defined as a continuous period of care for a patient in one setting.

The second measure involved the use of a well-established method of estimating the need for palliative care, developed by Murtagh et al.

(2014). This measure was used to provide an indication of the extent of coverage of the intervention over time in relation to the estimated need within the total population. This methodology was selected for use due to its expanded inclusion of ICD-10 codes and its more comprehensive consideration of underlying and contributory causes of death and inpatient admission patterns prior to death as compared to other methodologies (Gómez-Batiste et al., 2012 and Rosenwax et al., 2005).

For the analysis, the deaths recorded in the PCOC programme were calculated as a proportion of people who could potentially benefit from palliative care and analysis of this with the Australian Bureau of Statistics Cause of Death Data from 2012 to 2021. The estimate included using the number of people with a selected underlying cause of death plus a contributing cause of death for selected conditions (to estimate co-morbidities). The conditions included were all-cancer deaths (C00-C97—malignant neoplasms only included) and selected non-cancer deaths (*ICD-10*: I00-I52, I60-I69, N17, N18, N28, K70-K77, J06-J18, J20-J22, J40-J47 and J96, G10, G20, G35, G122, G903, G231, F01, F03, G30, R54, B20-B24) (Murtagh et al., 2014). The most recent and complete 10-year period was included in the analysis, that is, from January 2012 to December 2021. As 2022 data were not available at the time of our analysis, we derived an estimate based on data from previous years.”

“Our study also showed that the number of deaths reported in PCOC increased each year both in absolute terms and as a percentage of patients who might potentially benefit from palliative care (14.8% to 25.1%). In 2012, the national initiative reported 16,358 deaths, which increased to 32,421 deaths in 2022 (+98.2%). Whilst this coverage represents a major achievement by the national voluntary initiative, it is important to emphasize that the methodology we used to estimate the need for palliative care relies on the assumption that people who are missing out on accessing palliative care have unmet needs (Murtagh et al., 2014, Gómez-Batiste et al., 2012, Rosa et al., 2022). Whilst this methodology has been useful, the assumption underpinning the model has limitations (Currow et al., 2008). The limitations include how it fails to account for the effectiveness of other providers of care (e.g., primary palliative care) and patient preference. The range of methodologies that were available for us to estimate the need for palliative care for our study all failed to address these underlying assumptions. Higginson et al.'s disease-specific methodology includes a range of cancer diagnoses and six non-cancer diagnoses, with the consideration of symptom prevalence (Murtagh et al., 2014). Rosenwax et al.'s method relies on routine mortality statistics to estimate the need for palliative care for cancerous and non-cancerous populations, using all deaths from 10 specific disease groups (Rosenwax et al., 2004). Gómez-Batiste et al.'s methodology is informed by the estimated proportion of deaths from chronic progressive diseases and its prevalence (Gómez-Batiste et al., 2012). Whilst we selected Murtagh et al.'s method because of its expanded inclusion of ICD-10 codes and its more comprehensive consideration of underlying and contributory causes

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| | of death and inpatient admission patterns prior to death, it is important to discuss these assumptions.” |
| Accuracy: | <p>Well-established business rules are in place and a suite of data management and statistical processes have been automated in the PCOC data management system. This allows for standardised data assurance quality procedures to be completed in an objective and systematic manner. Continuous improvements have been undertaken in the data management and statistical processes since 2005 (when the PCOC was established). This means the data quality checks deployed within the program have been consistently and iteratively enhanced during a period of more than 18 years.</p> <p>IT systems and data requirements</p> <p>Palliative care information is obtained directly from the participating palliative care services via a range of different IT systems. The PCOC V3.0 Data Dictionary and Technical Guidelines provide advice to developers on how to collect PCOC data items required for data to be accepted into the registry. An IT system incorporating the PCOC Version 3.0 dataset is required at a minimum, to allow users to:</p> <ul style="list-style-type: none"> • Create linked Patient, Episode and Phase records • Enter the PCOC data items, restricting user input to the domains specified by PCOC • Extract data from the system in the format required by PCOC • Search for records in order to complete, update or correct entered data • Manage service and team level identifiers and related information <p>The IT system specifications encompass the business rules outlined by PCOC, to ensure that data entry errors are minimised. For each data item, the PCOC V3.0 Data Dictionary and Technical Guidelines provide a specification defining whether an item is:</p> <ul style="list-style-type: none"> • Mandatory – the item field cannot be left blank • Rule Check - this flag highlights that there are consistency rules associated with the data item. The rules may be one of the following: <ul style="list-style-type: none"> ○ Code Set Rule: the permissible code set for this item depends on values entered for previous data items. ○ Warning Error: it is unlikely (based on clinical practice) that an entry is possible. The user can proceed by checking the error source and confirming that it is correct. Example: Birth Date places the age of the patient at 15 years or less. ○ Critical Error: an entry cannot be made in this way. The user can proceed only by rectifying the error. Example: Date of Birth is in the future. • Dependencies - this flag highlights that the value entered for this data item will have an impact on subsequent data items. Types of impacts include data items: <ul style="list-style-type: none"> ○ Having different permissible code sets ○ No longer being applicable ○ Having values auto-filled |

Each item includes a definition, conditions, the data type, data domain and length, usage, and source (where applicable). This detailed specification provides transparency and consistency and is used to inform validation and quality checks.

Data validation

PCOC provide data quality reports to submitting services as an indication of the data removed from analysis (i.e., invalid data). Items that are removed or reviewed are:

Record error/ removal:

- The Start Date for a Phase doesn't match End Date for the previous Phase
- Phase type the same as phase type for previous phase
- Phase start date doesn't match Episode start date for the first phase of the episode
- Duplicated episode record: two episodes for the same patient begin on the sameday
- Episode start date must be on or after episode end date of the previous episode
- Duplicate patient records

Variable error/removal:

- Only the final episode for a patient can have an episode "End Mode" of death
- Phase end reason must be either death or discharge for final phase of episode
- Phase End Reason is Discharge, but Episode end mode is not Discharge
- Place of Death is required when Episode end mode is "Death"

Variable warning:

- Review: this community episode ends with a patient dying in hospital
- Patient's Date of Birth makes them younger than 10
- Review: episode end date is not provided

Services review their data and correct errors before resubmitting. Remaining errors will either result in the data item being not stated/inadequately described, or the whole record being excluded from the final PCOC report.

Completion rates

The PCOC reports include information on completion rates for each item. In 2023, patient and episode level completion rates were very high, ranging from 85.6% to 100% at the national level ([PCOC July-December 2023 National Report Appendix B](#)).

Completion rates for some assessments were lower at a national level:

- Discharge assessments in the community setting (range from 51% to 45.5% complete). The reason for the lower completion may be due to palliative care team being unable to assess the patient on the same day as the patient was admitted to hospital.
- Family / Carer problem severity score at phase start (range from 89.8% to 90.1%). The reason for the lower completion may be due to the absence of a family member or caregiver.
- There are a small number of services that do not use the Symptom Assessment Scale (SAS). The reason for not using the tool may relate to the Information System or preference. In 2023, five services (2.5%) did not submit SAS data. Item completion at phase start range from 85.6% to 93.5% complete at a national level.

Completion rates for state-level reports are assessed, and if the rate is below a threshold the benchmark measure will be published with a footnote to ensure the measure is used with caution.

First Nations status

The PCOC data dictionary includes Indigenous status as a measure of whether a person identifies as being of Aboriginal or Torres Strait Islander origin. This data item is based on the Australian Bureau of Statistics (ABS) standard for indigenous status. Data from PCOC on First Nations status may under- represent due to varying quality of identification across and within services. Each participating service receive data reporting on the completion of Indigenous status with a national comparison. In 2023, Indigenous status was suppressed from national and state outcome reports.

Diagnosis

The principal life limiting illness responsible for this patient requiring palliative care is coded according to a codeset developed by PCOC in 2006 (PCOC data dictionary version1). The reason for not using a standard classification is because there are no suitable existing classification for palliative care. The principal illness may not be the same as the reason for the current episode of care. This may result in the selection of ‘diagnosis not further defined’. Nationally, 2.3% of all diagnosis is reported as ‘not further defined’.

Clinician-reported and patient-reported measures

Assessment of palliative care patients is carried out by clinical staff (except for the PCOC SAS which is patient-rated wherever possible). The clinician assesses the patients’ symptom severity, functional dependence, and performance status to their best knowledge. Clinicians are trained in the use of the PCOC assessment tools. Although services can identify the proportion of patient-rated versus proxy rated scores. SAS - completed by, is not currently included in the PCOC data dictionary. In 2023, the

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| | <p>proportion of patient-rated scores were not reported. Version 4.0 of PCOC will include a mandatory item to indicated how the SAS was completed (patient, family or carer, or clinician).</p> <p>Episodes and phases of care</p> <p>It is necessary to allow Episode and Phase records to be incomplete due to the nature of PCOC data recording at the clinical level and data scoping for outcome reporting. In cases where a Phase or Episode is not completed (that is phase end and episode end information is not complete) the record is flagged as incomplete. This flag may then be used in auditing to check if a phase or episode should be closed. In addition, incomplete (open) Episodes and Phases are extracted and submitted to PCOC, to ensure that the most up-to-date information is available for benchmarking as shown in PCOC July-December 2023 National Report Appendix D.</p> |
| <p>Coherence:</p> | <p>This Data Quality Statement relates to 2023. Coherence issues important for historical data are outlined below.</p> <p>Dataset versions</p> <p>Data using Version 1 of PCOC dataset were collected from January 2006. Version 2 of the dataset was collected from July 2007, and Version 3 collected starting from January 2013.</p> <p>Reported data items</p> <p>The main changes since 2007 (between V2.0 and V3.0) were:</p> <ul style="list-style-type: none"> • additional codes of ‘not assessed’ for SAS, PCPSS, AKPS (Karnofsky) and RUG-ADL clinical assessments, • a new codeset for Phase End Reason • a new codeset and completion rules for Place of Death. <p>Changes in dataset items between Version 2 to Version 3 including added and deleted items are described in p10-12 of the PCOC v3.0 Data Dictionary and Technical Guidelines.</p> <p>Benchmarks</p> <p>PCOC benchmarks have remained the same since 2012 with additional benchmarks created in 2014.</p> <p>Services reporting data</p> <p>The list of services which contribute data are published alongside the national outcomes reports. For example the National List of Contributing Services Jul-Dec 2023. These lists are available for each 6-month period back to January 2009.</p> |

Data quality

PCOC includes data from palliative care services in all states and territories and from both inpatient and community settings of care. There are varying care delivery models, and data collection protocols. Therefore, this variation must be considered when interpreting and comparing results. Data item completeness is reported for each data item in each report to allow appropriate caveats to be considered for individual data items and time periods.

Longitudinal data

PCOC maintains a national longitudinal database of palliative care outcomes across settings of care and types of providers. The PCOC database comprises data describing more than 250,000 patients or residents, and one million phases of palliative care provided both within hospitals, patients' homes and in residential aged care facilities. This longitudinal database provides a valuable resource for both PCOC and the wider health and scientific community to conduct research into palliative care. Services participating in PCOC are the original custodians of the data they supply to PCOC and retain ownership of the intellectual property relating to those data.

PCOC releases time series data for benchmarked results

<https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/reports/>

Comparisons with other collections

The clinical, assessment and outcome data included in the PCOC dataset is not readily available from other sources in Australia.

The AIHW report on hospitalisations and the characteristics of people admitted for palliative care including the number of public acute hospitals who reported having a specialist palliative care inpatient unit nationally according to the National Public Hospital Establishments Database (NPHED) (<https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/admitted-patient-palliative-care>).

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