

Palliative care outcomes

The Australian Palliative Care Outcomes Collaboration (PCOC) was established in 2005 to provide a framework for routine clinical assessments and point-of-care data collection with the intent of capturing clinically meaningful information at significant periods in a patient's disease progression. The program aims to drive improvement through providing feedback to individual services, identifying opportunities and providing service-to-service benchmarking.

Data using Version 1 of the PCOC data set were collected between January 2006 and January 2007. Version 2 of the data set was enacted from July 2007, and Version 3 has been progressively acted on since July 2012 (PCOC 2012). The information presented in this section refers to palliative care service data reported to PCOC for the 1 January to 31 December 2014 period. Three levels of PCOC data items are presented here: [patient level](#), [episode level](#) and [phase level](#) care data. The items included in the PCOC data set serve the purposes of:

- providing clinicians with an approach to systematically assess individual patient experiences
- defining a common clinical language to allow palliative care providers to communicate
- facilitating the routine collection of nationally consistent palliative care data for the purpose of reporting and benchmarking to drive quality improvement.

As participation in PCOC is voluntary, the data presented in this section capture a subset of all palliative care services delivered in Australia in 2014. For further information about PCOC, see www.pcoc.org.au.

Key points

- In 2014, 32,800 patients accessed palliative care services from 101 PCOC participating palliative care providers—an increase of 4.1% from 2013.
- There were 43,965 episodes of care, of which just over half (53%) were [inpatient](#) episodes.
- Four in five episodes (80%) were characterised by a cancer diagnosis.
- The average age for all patients reported to the PCOC during this period was 72, with a [median](#) age of 74.
- A high proportion (93.8%) of episodes met benchmark 1, relating to the timeliness of admission to palliative care, where 90% of patients had their episode start on the day of, or the day after, the date they required palliative care.

This section was last updated in February 2016.

Reference

PCOC 2012. PCOC Version 3.0 Dataset: data dictionary and technical guidelines. Wollongong: University of Wollongong. Viewed 20 July 2015, <<https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow126175.pdf>>.

Inpatient and community care

In 2014, 32,800 patients accessed palliative care services from 101 PCOC participating palliative care providers, an increase of 4.1% from 2013 (31,512). In 2014, there were 43,965 episodes of care reported to the PCOC, of which just over half (53%; 23,420) were inpatient episodes. There was an average of 1.3 episodes per patient.

The information provided on total number of days for [episodes of care](#) is categorised by two broad types of care—inpatient and community care. It should be noted that the number of patients reported to the PCOC refers to patients who may receive services both within the inpatient and community settings. Hence, the same patient can have an inpatient episode and then subsequent community episodes and may be counted for both service settings.

Patient characteristics

Age , sex and Indigenous status

People aged 65 to 84 accounted for just over half of all episodes (53%); those aged 45 to 64 accounted for almost 1 in 4 episodes (23%) and those aged 85 and over, 1 in 5 (20%). People aged 25 to 44 accounted for fewer than 1 in 20 episodes (3.5%), while those aged 24 or under made up fewer than 1 in 100 (0.6%).

The average age for all patients reported to the PCOC during this period was 72, with a median age of 74. Of the 43,965 palliative care episodes in 2014, males accounted for 53% (23,409) and females accounted for 47% (20,554) of episodes.

In 2014, 1% (344) of PCOC palliative care patients were Indigenous.

Language spoken and country of birth

Information on 'preferred language' gives information on the diversity of the palliative care patient population. This information may also help to provide a better understanding of the cultural needs of a service, such as interpreter access. In 2014, English was reported as the main language spoken at home in 91% of PCOC episodes of palliative care. This was followed by Italian (2.0%), Greek (1.4%) and Chinese (0.8%).

The main country of birth was Australia for 64% of PCOC episodes of palliative care. This was followed by England (7.5%), Italy (3.9%) and Greece (2.0%).

Diagnosis

In 2014, 4 in 5 episodes (80%) involved a cancer diagnosis, while about 1 in 5 (20%) had a non-cancer diagnosis. The 3 most frequently recorded diagnoses were lung cancer (18%), colorectal cancer (9.4%) and other gastro-intestinal cancers (7.8%), a result similar to 2013.

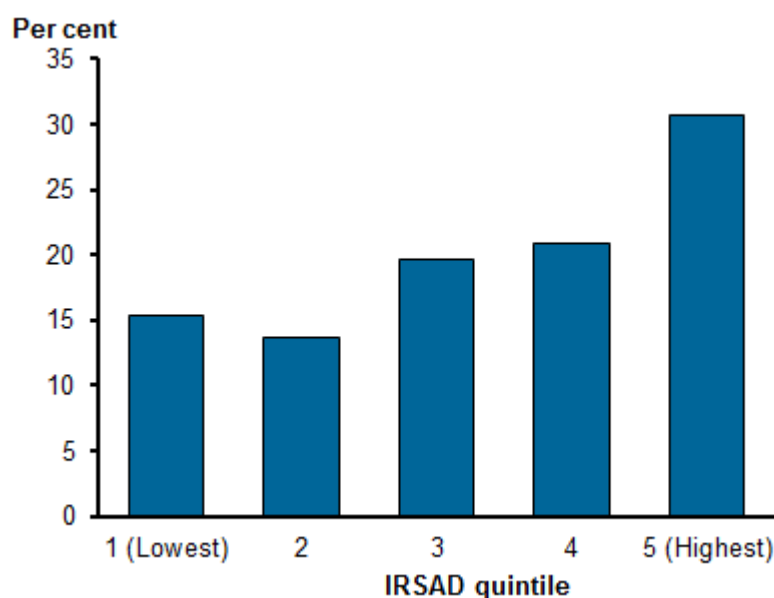
Socioeconomic status

This section presents information on PCOC episodes based on the socioeconomic status of the usual residence of the patient. Socioeconomic status is generally associated with access to material resources, educational opportunities and health status (AIHW 2010).

Socioeconomic status is expressed here using the Australian Bureau of Statistics Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD), one of a series of similar measures that allow for socioeconomic differences by geographic areas to be described (ABS 2011).

In 2014, people living in areas classified as having the lowest socioeconomic status (group '1') accounted for around 1 in 7 PCOC episodes (15%) (Figure PCOC.1). The highest proportion of episodes, almost one-third (31%), was seen for those patients living in the highest socioeconomic status area (group '5'), with this group proportionally over-represented in both the inpatient and community settings. Overall, there was little difference in proportions between inpatient and community settings.

Figure PCOC.1: PCOC palliative care episodes by socioeconomic status (IRSAD quintile), 2014



Source: PCOC analysis of 2014 data (unpublished); ABS 2011.

Source data palliative care outcomes Table PCOC.5

Reference

ABS 2011. Socio-Economic Indexes for Areas (SEIFA)—Census. Canberra: ABS. Viewed 5 July 2015, <<http://www.abs.gov.au/websitedbs/censushome.nsf/home/seifa>>.

AIHW 2010. Australia's health 2010. Australia's health series no. 12. Cat. no. AUS 122. Canberra: AIHW.

Episode length

The following information refers to closed episodes within the inpatient and community care setting reported to PCOC for 2014. Closed episodes are those that end because either the:

- setting of palliative care changes
- principal clinical intent of the care changes and the patient is no longer receiving palliative care
- patient is formally separated from the service for palliative care

- patient dies.

The length of an episode ([elapsed days](#)) for each episode of care in the inpatient setting was 11 days, with a median of 6 days during 2014. The difference between the average and the median number is noteworthy, reflecting a 'skewed' distribution for inpatient palliative care episodes because of episodes with long duration. This distribution was also reflected in the community setting.

There were 41,882 closed episodes reported to the PCOC for 2014 compared with 34,562 for 2011 (an annual average increase of 6.6%). In 2014, nearly three-quarters (72%) of inpatient episodes lasted between 1 and 14 days, with 20% lasting 1–2 days and 21% lasting 8–14 days. This pattern differed for the community setting, where the number of episodes generally increased as the days spent in care increased; 62% of community episodes were 15 days or longer.

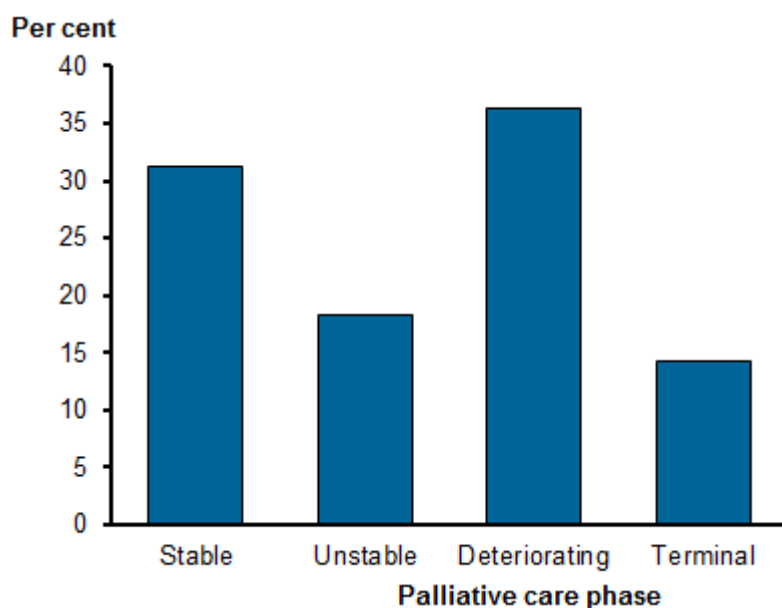
Palliative care phases

The palliative care phase describes the stage of the patient's illness within an episode of care and provides a clinical indication of the level of care required. There are 4 palliative care phases. It should be noted that palliative care phases are not necessarily sequential: the patient may transition back and forth between phases during an episode; there may also be more than one phase of care within an episode.

There was a total of 102,047 palliative care phases reported in 2014, with more than half (53%) occurring in inpatient palliative care. Of these, about one-third (31%) were in a deteriorating phase followed by stable (26%) and unstable (24%) phases. Of the 47,625 phases reported in the community care setting, 42% were in a deteriorating phase, followed by stable (37%) and unstable (12%) phases (Figure PCOC.2).

For both the inpatient and community care settings, the average phase length (elapsed days) was highest for the stable phase (at 7 days and 20 days respectively), followed by the deteriorating phase (6 days and 13 days respectively) and the unstable phase (2 days and 5 days respectively).

Figure PCOC.2: PCOC, phase counts by palliative care phase, 2014



Source: PCOC analysis of 2014 data (unpublished).

Source data palliative care outcomes Table PCOC.9

Palliative care outcome measures and benchmarks

In 2009, PCOC, in collaboration with participating palliative care services, developed a set of national palliative care outcome benchmarks. The purpose of benchmarking is to drive palliative care service innovation and provide participating services with the opportunity to compare their service nationally. In this section, 3 of PCOC's outcome measures are presented, with the national performance against each benchmark summarised.

These [outcome measures](#) cover:

1. time from date ready for care to episode start
2. time patient spent in an unstable phase
3. change in pain.

The PCOC palliative care outcomes benchmark results for 2014 were as follows:

- A high proportion of episodes (93.8%) met the benchmark relating to timeliness of care (benchmark 1), and 80.2% of unstable phases met the benchmark of lasting 3 days or less (benchmark 2).
- Of the pain benchmarks, around 4 in 5 (87.6%) phases met the benchmark relating to absent/mild pain at phase beginning and end as rated by the clinician (3.1), and 85.4% met the criteria for remaining in absent/mild distress from pain from at the beginning and end of the phase as rated by the patient (3.3).
- About half of phases met the benchmarks related to reduction in moderate/severe pain and distress from pain, with 54.4% of phases with moderate/severe pain at the beginning of the phase reducing to absent/mild pain at the end of the phase as rated by the clinician and 50.0% of phases with moderate/severe distress from pain at the beginning of the phase reducing to absent/mild distress from pain at the end of the phase as rated by the patient (Table PCOC.12).

Key Concepts

Palliative care outcomes

| Key Concept | Description |
|------------------|---|
| Community care | Community care episodes are those where the patient received palliative care either in their home or a residential aged care facility. |
| Elapsed days | The elapsed days represent the number of days between the start and end of an episode and do not take into account leave days. Within the community setting, the elapsed days do not reflect the number of times the palliative care team visited the patient. |
| Episode level | Episode level data items provide information on the following: the reasons why and how a palliative care episode starts/ends; and (where applicable) the setting in which the patient died. |
| Episode of care | An episode of care is a period of contact between a patient and a service where palliative care is provided in one setting. An episode starts the date a comprehensive palliative care assessment is undertaken and documented using the five PCOC assessment tools. An episode ends when the patient's setting of care changes (for example, inpatient to community) or when a patient dies. |
| Inpatient | Inpatient episodes of care are those for which the intent of the admission was for the patient to be in hospital overnight. This includes those patients who were admitted and died on the day of their admission. |
| Median | Median is the midpoint of a list of observations that have been ranked from the smallest to the largest. |
| Outcome measures | <p><i>Outcome measure 1: Time from date ready for care to episode start</i></p> <p>'Time from date ready for care to episode start' relates to the responsiveness of palliative care services to patient needs. This measure is the time (in days) between the date the patient is ready for care and the date of the episode start and is measured for all episodes of care and across all settings of care.</p> <p>This measure replaced 'Time from referral to first contact for the episode'. However, following feedback and consultation with PCOC participants, this measure was superseded in July 2013.</p> <p><i>Outcome measure 2: Time in unstable phase</i></p> <p>This outcome measure relates to the number of patients in the 'unstable phase' and the number of days they remain in an unstable phase during their episode of care. The unstable phase, by nature of its definition, alerts clinical staff to the need for urgent or emergency intervention. This phase shows the effectiveness of the intervention(s) implemented for a specific new problem or the worsening of an existing problem. Those patients assessed to be in the unstable phase should have their problem(s) managed and under control within this period of time, regardless of the setting of care.</p> |

This measure was originally associated with three benchmarks. However, following consultation at the 2012 PCOC benchmarking workshops, these were replaced with one consolidated benchmark.

Outcome measure 3: Change in pain

Pain management is acknowledged as a 'core business' of palliative care services; hence, measuring patient distress from pain is considered an important outcome for palliative care services. Two of the five assessment tools used in PCOC are used to measure pain: the Symptom Assessment Scale (SAS) (a patient-rated tool) and the Palliative Care Problem Severity Score (PCPSS) (a clinician-rated tool).

Palliative care patients are assessed at two levels of outcomes for pain. These are:

1. Patients with absent/mild pain at phase start
2. Patients with moderate/severe pain at phase start.

Ideally, those patients with absent/mild pain at the beginning of the phase should be maintained with absent/mild pain at the end of the phase. Similarly, patients in moderate/severe pain at the start of a phase should be able to achieve mild/absent pain at the end of the phase.

Any change in pain is measured by the difference in pain score from the beginning of a phase to the end of a phase and is calculated using both PCPSS (severity of) and SAS (distress from) pain measures.

Patient level

Patient level data relate to patient demographics.

Phase level

Phase level data items describe a palliative care patient's stage of illness, functional impairment and their levels of pain and symptom distress. Five assessment tools are used to describe the clinical condition of a patient, which, in turn, contribute to a patient's care plan. These assessment tools are phase of care, SAS, PCPSS, Australia-modified-Karnofsky Performance Status (AKPS), and Resource Utilisation Groups—Activities of Daily Living (RUG—ADL) which provide measures of quality and outcomes of care.

The PCOC analyses each service's data and compares these with the national average. The items at the phase level are used to quantify patient outcomes and are the focus of the PCOC benchmarks. The 4 palliative care phases are:

1. Stable phase

Stable Phase Start: Patient problems and symptoms are adequately controlled by an established plan of care; further interventions to maintain symptom control and quality of life have been planned and the family/carer(s) situation is relatively stable and no new issues are apparent.

Stable Phase End: The needs of the patient and or family/carer(s) increase, requiring changes to the existing plan of care.

2. Unstable phase

Unstable Phase Start: An urgent change in the plan of care or emergency treatment is required as the patient experiences a new problem that was not anticipated in the existing plan of care; and/or the patient experiences a rapid increase in the severity of a current problem; and/or the circumstances of the patient's family/carer(s) change suddenly, impacting on patient care.

Unstable Phase End: The new plan of care is in place; it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom crisis has fully resolved but there is a clear diagnosis and plan of care (that is, the patient is stable or deteriorating) and/or death is likely within days (that is, the patient is now terminal).

3. Deteriorating phase

Deteriorating Phase Start: The care plan is addressing anticipated needs but requires periodic review because the patient's overall functional status is declining; the patient has a gradual worsening of existing problem and/or a new but anticipated problem; and/or the carer(s)/family undergo(es) gradually worsening distress that impacts on the patient's care.

Deteriorating Phase End: The patient condition plateaus (that is, the patient is now stable); or there is an urgent change in the care plan or emergency treatment; and/or the family/carer(s) have a sudden change in their situation that impacts on patient care, and urgent intervention is required (that is, the patient is now unstable); or death is likely within days (that is, the patient is now terminal).

4. Terminal phase

Terminal Phase Start: Death is likely within days.

Terminal Phase End: The patient dies or the patient condition changes and death is no longer likely within days (that is, the patient is now stable or deteriorating).