Palliative care outcomes

The Australian Palliative Care Outcomes Collaboration (PCOC) was established in 2005. It is a framework for routine clinical assessments and point-of-care data collection to capture clinically meaningful information at significant periods in a patient’s disease progression. The PCOC aims to drive improvement through providing feedback to individual services and providing service-to-service benchmarking.

The information presented in this section refers to palliative care service data reported to PCOC for the 1 January to 31 December 2016 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:

- provide clinicians with an approach to systematically assess individual patient experiences
- define a common clinical language to allow palliative care providers to communicate with each other
- facilitate 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 2016. For further information about PCOC, see www.pcoc.org.au.

Key points

- In 2016, 36,586 patients accessed palliative care services from 124 PCOC participating palliative care providers—an increase of 0.7% from 2015.
- There were 48,901 episodes of care, of which just over half (54.8%) were inpatient episodes. There was an average of 1.3 episodes per patient.
- Almost 4 in 5 episodes (78.2%) were characterised by a cancer diagnosis.
- The median age for all patients reported to the PCOC during this period was 74.
- A high proportion (95.0%) of episodes met the benchmark relating to the timeliness of admission to palliative care, where at least 90% of patients had their episode start on the day of, or the day after, the date they required palliative care (Benchmark 1).
- Almost 4 in 10 (38.4%) phases met Benchmark 3.6, where at least 60% of patients with moderate/severe distress from fatigue at phase start are reduced to absent/mild distress from fatigue at phase end.

This section was last updated in October 2017.

Reference

Inpatient and community care

In 2016, about 36,600 patients accessed palliative care from 124 palliative care services, an increase of 0.7% from 2015. In 2016, there were about 48,900 episodes of care reported to the PCOC, of which just over half (54.8%) 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 2 broad types of care—

- inpatient
- community

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 therefore may be counted for both service settings.

Patient characteristics

Age, sex and Indigenous status

The age profile of patients receiving palliative care is shown in Figure PCOC 1. People aged 65–84 accounted for over half of all episodes (52.7%). The age profile of patients in inpatient and community care settings did not differ significantly, though patients under 65 comprised a slightly higher proportion of patients in community (27.1%) than inpatient (25.8%) care.

**Figure PCOC.1: PCOC palliative care episodes by age group, 2016**

The average age for all patients reported to the PCOC during this period was 72.3, with a median age of 74.

Males accounted for 53.4% (26,093) of episodes.

In 2016, 1.4% (508) of PCOC palliative care patients were Indigenous, compared with an estimated 3.0% of the general population (ABS 2013a).
Language spoken and country of birth

In 2016, English was reported as the main language spoken at home by 90.5% of PCOC patients. This was followed by Italian (2.2%), Greek (1.4%) and Chinese (1.0%). A different distribution to these findings was observed in the 2011 Census (ABS 2013b), where 76.8% of the Australian population were recorded as speaking English, followed by Mandarin (1.6%), Italian (1.4%) and Arabic (1.3%).

The main country of birth of PCOC patients was Australia (62.6%). This was followed by England (7.2%), Italy (4.3%) and Greece (2.2%). A slightly different distribution was observed for the general population in the 2011 Census, with Australia and England being the top two countries of birth (69.8% and 4.2%, respectively) followed by New Zealand (2.2%) and China (1.5%) (ABS 2013b).

Diagnosis

In 2016, almost 4 in 5 episodes (78.2%) involved a cancer diagnosis—the 3 most frequently recorded diagnoses were lung cancer (16.4%), colorectal cancer (8.8%) and other gastro-intestinal cancers (7.3%)—a result similar to that observed in 2015.

Socioeconomic status

In 2016, people living in areas classified as having the lowest socioeconomic status accounted for about 1 in 7 PCOC episodes (14.7%) (Figure PCOC.2). The highest proportion of episodes, more than one-quarter (28.6%), was seen for those patients living in the highest socioeconomic status area, with this group proportionally over-represented in both the inpatient setting and, particularly, the community setting.

Socioeconomic status based on the socioeconomic status of the usual residence of the patient is described here using the Australian Bureau of Statistics Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) (AIHW 2016, ABS 2013c).

Figure PCOC.2: PCOC palliative care episodes by socioeconomic status (IRSAD quintile), inpatient and community care settings, 2016

Source: PCOC analysis of 2016 data (unpublished)
Source data: Palliative care outcomes Table PCOC.6
References

ABS 2013a. Estimates of Aboriginal and Torres Strait Islander Australians, June 2011. ABS cat. no. 3238.0.55.001. Canberra: ABS.


AIHW 2016. Australia’s health 2016. Australia’s health series no. 15. Cat. no. AUS 199. Canberra: AIHW.

Episode length

The following information refers to closed episodes within the inpatient and community care setting reported to PCOC for 2016. Closed episodes are those that end because 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
- patient dies.

There were about 47,300 closed episodes reported to the PCOC for 2016, compared with about 37,600 in 2012 (an annual average increase of 5.9%). Inpatient episodes were generally shorter in duration than community episodes. In 2016, just over 7 in 10 (71.4%) of inpatient episodes lasted between 1 and 14 days, whereas 62.6% of community episodes were 15 days or longer (Figure PCOC.3).

In 2016, the average length of an episode (elapsed days) for each episode of care in the inpatient setting was 10.5 days, with a median of 6 days. The difference between the average and the median number is noteworthy, reflecting a skewed distribution for inpatient palliative care episodes because of a relatively small set of very long episodes. This distribution was also reflected in the community setting.
Palliative care episodes over time

Between 2012 and 2016 the number of PCOC closed episodes increased for both inpatient (from 21,603 to 26,592) and community palliative care patients (from 15,979 to 20,726). This is a 23.1% increase for inpatient closed episodes and a 29.7% increase for community based closed episodes over the period. The number of service providers reporting to the PCOC increased by 14.8% over the same period. The proportion of closed episodes taking place in the community setting gradually increased from 2012 to 2015 and dropped slightly in 2016 (Figure PCOC.4).

Figure PCOC.4: PCOC, percentage of closed episodes by palliative care setting, 2012 to 2016

Palliative care phases

A palliative care phase in PCOC 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 PCOC palliative care phases—stable, unstable, deteriorating and terminal. It should be noted that palliative care phases are not necessarily sequential: as the patient may transition back and forth between phases during an episode; and there may also be more than one phase of care within an episode.

There were about 117,000 palliative care phases reported to PCOC in 2016, with more than half (54.7%) occurring in inpatient palliative care. Of these, almost one-third (32.2%) were in a deteriorating phase followed by stable (25.6%) and unstable (21.3%) phases. Of the almost 53,000 phases reported in the community care setting, 43.2% were in a deteriorating phase, followed by stable (36.8%) and unstable (12.1%) phases (Figure PCOC.5).

For both the inpatient and community care settings, the average phase length (elapsed days) was highest for the stable phase (at 7.2 days and 20.4 days respectively), followed by the deteriorating phase (5.1 days and 12.6 days respectively) and the unstable phase (2.0 days and 3.2 days respectively).

Figure PCOC.5: PCOC, phase counts by palliative care phase, inpatient and community care settings, 2016

![Bar chart showing phase counts by palliative care phase](image)


Palliative care outcome measures and benchmarks

In 2009, PCOC, in collaboration with participating palliative care services, implemented a set of national palliative care outcome measures (benchmarks) to drive palliative care service innovation and allow participating services to compare their service nationally. These outcome measures cover:

1. time from date ready for care to episode start (Benchmark 1)
2. time patient spent in an unstable phase (Benchmark 2)
3. change in symptoms and problems (Benchmark 3).
In 2015, six additional measures relating to fatigue, breathing problems and family/carer problems were introduced, expanding the existing measures which were related to pain. A full description of each of the PCOC benchmarks reported here is shown in Table PCOC.13.

A high proportion of episodes (95.0%) met the benchmark relating to timeliness of care (benchmark 1) while 93.3% of phases met the benchmark relating to the management of absent to mild breathing problems (benchmark 3.7).

The benchmark relating to improving moderate to severe distress from fatigue (benchmark 3.6) was the least likely to be met, with 38.4% of phases meeting this benchmark. The benchmark relating to improving moderate to severe distress from breathing problems (benchmark 3.8) was met by 43.5% of phases. Episodes or phases in community based settings were less likely than those in inpatient settings to meet PCOC benchmarks 1 to 3 (Figure PCOC.6).

**Figure PCOC.6: PCOC palliative care outcome benchmark results (episodes/phases), inpatient and community care settings, 2016**


Source data: Palliative care outcomes Table PCOC.13
### Key Concepts

#### Palliative care outcomes

<table>
<thead>
<tr>
<th>Key Concept</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Community care</strong></td>
<td>Episodes where the patient received palliative care either in their home or a residential aged care facility.</td>
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<tr>
<td><strong>Elapsed days</strong></td>
<td>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.</td>
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<tr>
<td><strong>Episode level</strong></td>
<td><strong>Episode level</strong> 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.</td>
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<tr>
<td><strong>Episode of care</strong></td>
<td>A period of contact between a patient and a service where palliative care is provided in one setting. An episode starts on 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.</td>
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<tr>
<td><strong>Inpatient</strong></td>
<td><strong>Inpatient</strong> 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.</td>
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<tr>
<td><strong>Median</strong></td>
<td>The midpoint of a list of observations that have been ranked from the smallest to the largest.</td>
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| **Outcome measures**| **Outcome measure 1:** ‘Time from date ready for care to episode start’  
‘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.  
This measure replaced ‘Time from referral to first contact for the episode’ in July 2013. However, following feedback and consultation with PCOC participants, this measure was superseded in July 2013.  
**Outcome measure 2:** Time in unstable phase  
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 three days, regardless of the setting of care. |
**Outcome measure 3: Change in symptoms and problems**

3.1–3.4. 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).

Ideally, those patients with absent/mild pain at the beginning of a 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.

3.5–3.6 Change in distress from fatigue. Fatigue is the most common symptom reported to PCOC via the SAS tool. In 2015, PCOC introduced this outcome measure to routine reporting. The change in distress from fatigue is measured from the start of a phase to the end of the same phase. There are two benchmarks associated with this outcome measure: one relating to patients with an absent or mild score, and the other relating to patients with a moderate or severe score. Phase records must have valid start and end scores for it to be included in the benchmarks.

3.7–3.8 Change in distress from breathing problems. Breathing problems is a common symptom reported by patients receiving palliative care. In 2015, PCOC introduced this outcome measure to routine reporting. The change in distress from breathing problems is measured from the start of a phase to the end of the same phase. There are two benchmarks associated with this outcome measure: one relating to patients with an absent or mild score, and the other relating to patients with a moderate or severe score. Phase records must have valid start and end scores for it to be included in the benchmarks.

3.9–3.10 Change in family/carer problems. Palliative care is a holistic discipline which considers the needs of the patients and their family and carers. The PCPSS family / carer domain measures problems associated with a patient’s condition or palliative care needs. In 2015, PCOC introduced this outcome measure to routine reporting. The change in family/carer problems is measured from the start of a phase to the end of the same phase. There are two benchmarks associated with this outcome measure: one relating to patients with an absent or mild score, and the other relating to patients with a moderate or severe score. Phase records must have valid start and end scores for it to be included in the benchmarks.

<table>
<thead>
<tr>
<th><strong>Patient level</strong></th>
<th>Data relate to patient demographics.</th>
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<td><strong>Phase level</strong></td>
<td><strong>Phase level</strong> 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</td>
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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 four 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’s condition changes and death is no longer likely within days (that is, the patient is now stable or deteriorating).