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 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 2015 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 following purposes:

- providing clinicians with an approach to systematically assess individual patient experiences
- defining a common clinical language to allow palliative care providers to communicate with each other
- 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 2015. For further information about PCOC, see www.pcoc.org.au.

Key points

- In 2015, 36,338 patients accessed palliative care services from 104 PCOC participating palliative care providers—an increase of 10.8% from 2014.
- There were 48,267 episodes of care, of which just over half (52.3%) were inpatient episodes. There was an average of 1.3 episodes per patient.
- About 4 in 5 episodes (79.4%) were characterised by a cancer diagnosis.
- The median age for all patients reported to the PCOC during this period was 74.
- A high proportion (94.0%) 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 October 2016.

Reference

Inpatient and community care

In 2015, about 36,300 patients accessed palliative care services from 104 PCOC participating palliative care providers, an increase of 10.8% from 2014. In 2015, there were about 48,300 episodes of care reported to the PCOC, of which just over half (52.3%) 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** 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

The age profile of patients experiencing PCOC episodes is shown in Figure PCOC 1. People aged 65–84 accounted for over half of all PCOC episodes (52.4%).

![Figure PCOC.1: PCOC palliative care episodes by age group, 2015](image)

The average age for all patients reported to the PCOC during this period was 72.1, with a median age of 74. Males accounted for 53.0% (25,569) of episodes.

In 2015, 1.3% (455) of PCOC palliative care patients were Indigenous, compared with an estimated 3.0% of the general population (ABS 2013a) (Table PCOC.12).
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 2015, English was reported as the main language spoken at home in 90.9% of PCOC episodes of palliative care. This was followed by Italian (1.9%), Greek (1.3%) and Chinese (1.0%) (Table PCOC.1). A different distribution to these findings was seen 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 was Australia for 64.0% of PCOC episodes of palliative care. This was followed by England (7.1%), Italy (3.9%) and Greece (2.0%) (Table PCOC.2). A slightly different distribution was seen for the general population, 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 2015, 4 in 5 episodes (79.4%) involved a cancer diagnosis—the 3 most frequently recorded diagnoses were lung cancer (17.9%), colorectal cancer (9.0%) and other gastro-intestinal cancers (7.3%)—a result similar to 2014 (Table PCOC.4 and PCOC.5).

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 2014).

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 2013c).

In 2015, people living in areas classified as having the lowest socioeconomic status (group ‘1’) accounted for about 1 in 6 PCOC episodes (16.1%) (Figure PCOC.2). The highest proportion of episodes, just over one-quarter (27.3%), 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.2: PCOC palliative care episodes by socioeconomic status (IRSAD quintile), 2015

![Graph showing distribution of PCOC episodes by IRSAD quintile]
Reference

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


Episode length

The following information refers to closed episodes within the inpatient and community care setting reported to PCOC for 2015. 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 average length of an episode (elapsed days) for each episode of care in the inpatient setting was 10.6 days, with a median of 6 days during 2015. 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.

There were over 46,000 closed episodes reported to the PCOC for 2015, compared with about 34,500 for 2011 (an annual average increase of 7.5%) (Table PCOC.7). Inpatient episodes were generally shorter in duration than community episodes. In 2015, just over 7 in 10 (71.3%) of inpatient episodes lasted between 1 and 14 days, whereas 63.1% of community episodes were 15 days or longer (Figure PCOC.3).
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—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 115,000 palliative care phases reported in 2015, with more than half (52.1%) occurring in inpatient palliative care. Of these, about one–third (31.1%) were in a deteriorating phase followed by stable (25.6%) and unstable (23.3%) phases. Of the 55,000 phases reported in the community care setting, 40.8% were in a deteriorating phase, followed by stable (37.5%) and unstable (13.5%) phases (Figure PCOC.4).

For both the inpatient and community care settings, the average phase length (elapsed days) was highest for the stable phase (at 7.3 days and 20.9 days respectively), followed by the deteriorating phase (5.2 days and 12.9 days respectively) and the unstable phase (2.2 days and 4.1 days respectively) (Table PCOC.10).
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 this 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 2015 were as follows:

- A high proportion of episodes (94.0%) met the benchmark relating to timeliness of care (benchmark 1), and 82.8% of unstable phases met the benchmark of lasting 3 days or less (benchmark 2).

- Of the pain benchmarks, around 4 in 5 (88.1%) phases met the benchmark relating to absent/mild pain at phase beginning and end as rated by the clinician (3.1), and 85.5% 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 56.5% 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 51.0% 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.13).

Key Concepts

Palliative care outcomes

<table>
<thead>
<tr>
<th>Key Concept</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community care</td>
<td>Community care episodes are those where the patient received palliative care either in their home or a residential aged care facility.</td>
</tr>
<tr>
<td>Elapsed days</td>
<td>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.</td>
</tr>
<tr>
<td>Episode level</td>
<td>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.</td>
</tr>
<tr>
<td>Episode of care</td>
<td>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 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>
</tr>
<tr>
<td>Inpatient</td>
<td>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.</td>
</tr>
<tr>
<td>Median</td>
<td>Median is 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’. 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 this period of time, regardless of the setting of care.

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’s condition changes and death is no longer likely within days (that is, the patient is now stable or deteriorating).