Palliative care outcomes

The Australian Palliative Care Outcomes Collaboration (PCOC), established in 2005, is a national palliative care outcomes and benchmarking program. PCOCs primary objective is to systematically improve patient outcomes (including pain and symptom control).

The information presented in this section refers to specialist palliative care service data reported to PCOC for the 1 January to 31 December 2017 period. Three levels of PCOC data items are presented here: patient level, episode level and phase level care data. The items in the PCOC data collection:

- **provide clinicians with an approach to systematically assess individual patient experiences**
- **include routine Patient Reported Outcomes Measures (PROMs) relating to symptom distress**
- **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 describe a subset of all specialist palliative care services delivered in Australia in 2017. An estimated 85% of palliative care services voluntarily participate in PCOC. For further information about PCOC, refer to their website (www.pcoc.org.au).

Data downloads:

Palliative care outcomes tables 2017

Palliative care outcomes section 2017

This section was last updated in October 2018.

Key points

- **39,800 patients accessed specialist palliative care services from 130 PCOC participating palliative care providers in 2017.**
- **53,200 episodes of care were provided, of which just over half were inpatient episodes.**
- **77.6% of episodes were characterised by a cancer diagnosis.**
- **74 was the median age for all patients reported to PCOC during 2017.**
- **94.8% of patients had their care commence on the day of, or the day after, the date they were ready for palliative care (Benchmark 1).**
- **86.9% of patients had urgent needs (i.e. unstable phase) managed in 3 days or less.**

Inpatient and community care

In 2017, 39,805 patients accessed palliative care from 130 specialist palliative care services participating in PCOC, an increase of 8.8% from 2016. There were 53,232 episodes of care reported to PCOC, of which just over half (53.4%) were inpatient episodes. This equates to an average of 1.3 episodes of palliative care per patient.

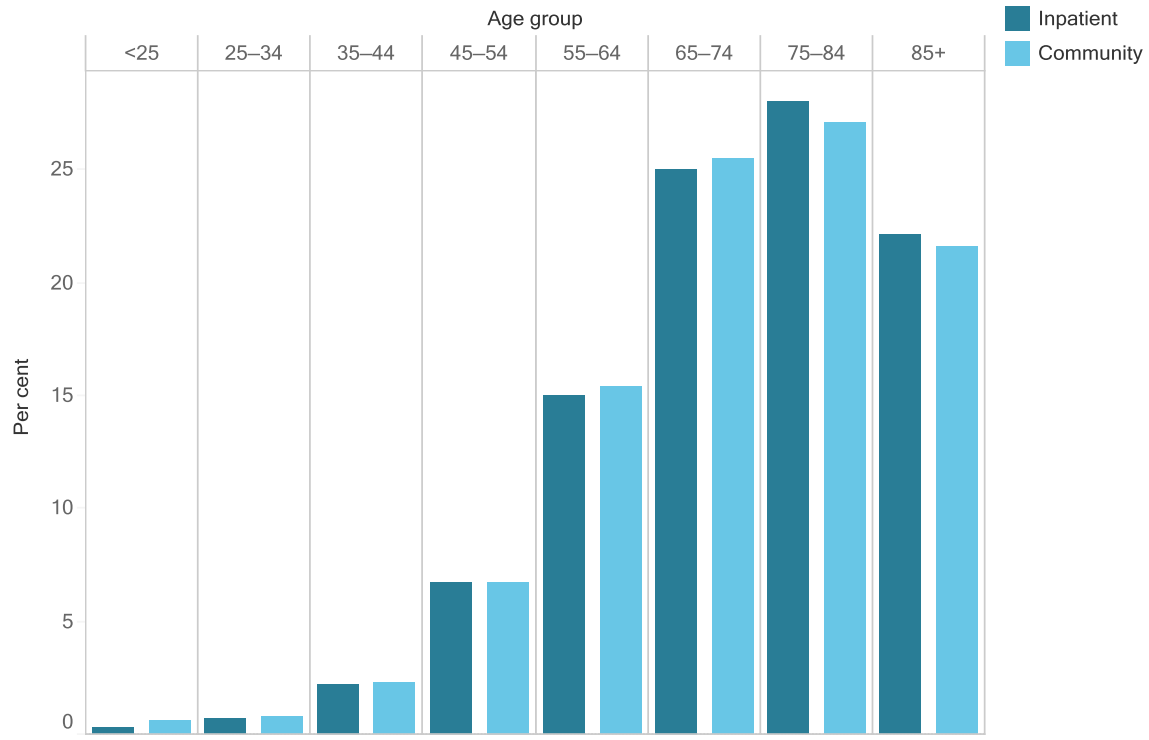
The information provided on total number of days for episodes of care is categorised by two broad types of care—inpatient and community. It should be noted that the number of patients reported to PCOC refers to patients who may receive services both within the inpatient and community settings. Hence, 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 (52.8%). The age profile of patients in inpatient and community care settings did not differ significantly.

Figure PCOC.1: PCOC palliative care episodes by age group, 2017



Source: Table PCOC.11

Alt text: Vertical bar chart showing the per cent of PCOC palliative care episodes by age group and setting. Inpatient and community settings respectively <25 0.3, 0.6; 25—34 0.7, 0.8; 35—44 2.2, 2.3; 45—54 6.7, 6.7; 55—64 15.0, 15.4; 65—74 25.0, 25.5; 75—84 28.0, 27.1; 85+ 22.1, 21.6. Refer to Table PCOC.11.

The average age for all patients reported to PCOC during this period was 72.8, with a median age of 74.0. Males accounted for 53.2% (28,336) of episodes.

In 2017, 1.8% (606) of PCOC palliative care patients were Indigenous, compared with an estimated 3.0% of the general population (ABS 2013a).

Preferred language and country of birth

In 2017, English was reported as the preferred language by 89.9% of PCOC patients. This was followed by Italian (2.1%), Greek (1.6%) and Chinese (1.2%). A different distribution to these findings was observed in the 2016 Census (ABS 2017a) for the Australian population, where 72.7% of people were recorded as speaking English only, followed by Mandarin (2.5%), Arabic (1.4%), Cantonese (1.2%) and Vietnamese (1.2%).

The main country of birth of PCOC patients was Australia (61.7%), followed by England (7.2%), Italy (4.4%) and Greece (2.4%). A slightly different distribution was observed for the Australian population in the 2016 Census, with Australia and England being the top two

countries of birth (71.5% and 4.1%, respectively) followed by New Zealand (2.5%) and China (2.2%) (ABS 2017b).

Diagnosis

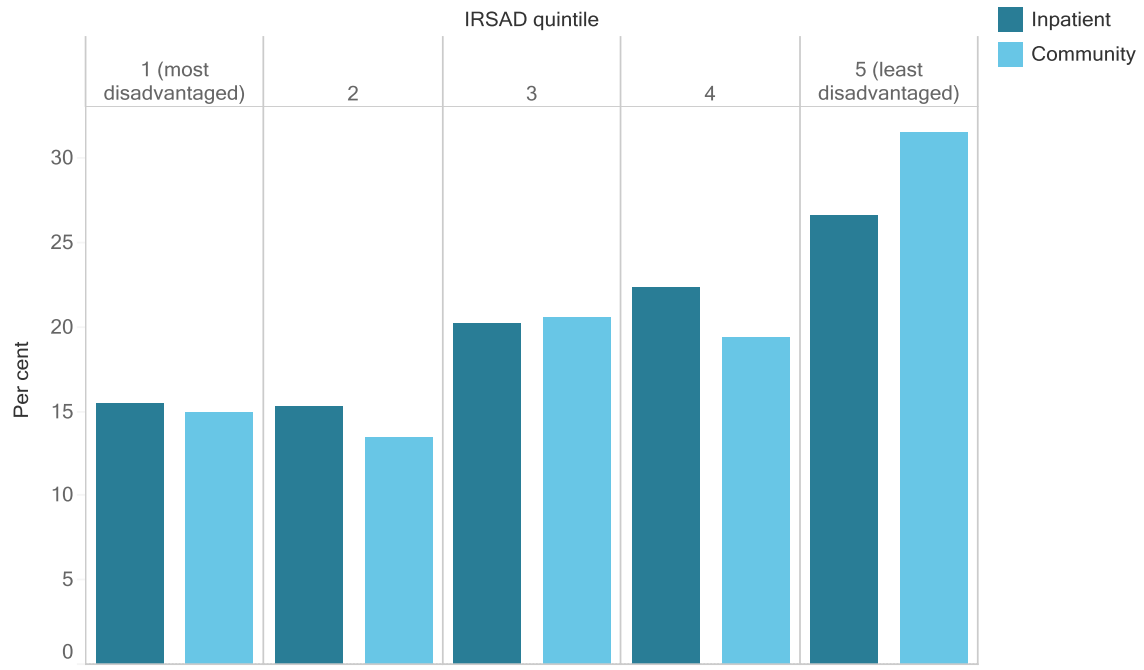
In 2017, almost 4 in 5 episodes (77.6%) involved a cancer diagnosis—the 3 most frequently recorded diagnoses were lung cancer (16.3%), colorectal (bowel) cancer (8.7%) and other gastro-intestinal cancers (7.2%)—a result similar to that observed in 2016.

Socioeconomic status

Compared to the distribution of the Australian population across socioeconomic status groups (i.e. 20% of the population per socioeconomic quintile or level), PCOC episodes were slightly over-represented, proportionally, towards those living in the least disadvantaged socioeconomic status areas. In 2017, people living in areas classified as having most socioeconomic disadvantage accounted for about 1 in 7 PCOC episodes (15.3%) (Figure PCOC.2). The highest proportion of episodes, more than one-quarter (28.9%), was seen for those patients living in the least disadvantaged socioeconomic status area, with this group proportionally over-represented in both the inpatient setting and, particularly, the community setting.

Socioeconomic status is described here using the Australian Bureau of Statistics Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) (AIHW 2016, ABS 2013b).

Figure PCOC.2: PCOC palliative care episodes by socioeconomic status (IRSAD quintile), inpatient and community care settings, 2017



Source: Table PCOC.6

Alt text: Vertical bar chart showing the per cent of PCOC palliative care episodes by socioeconomic status (IRSAD quintile), for inpatient and community care settings. Quintile 1 15.5 (inpatient), 15.0 (community); quintile 2 15.3, 13.4; quintile 3 20.2, 20.6; quintile 4 22.3, 19.4; quintile 5 26.6, 31.5. Refer to Table PCOC.6.

Episode length

The following information refers to closed episodes within the inpatient and community care setting reported to PCOC for 2017. An episode may be closed because the:

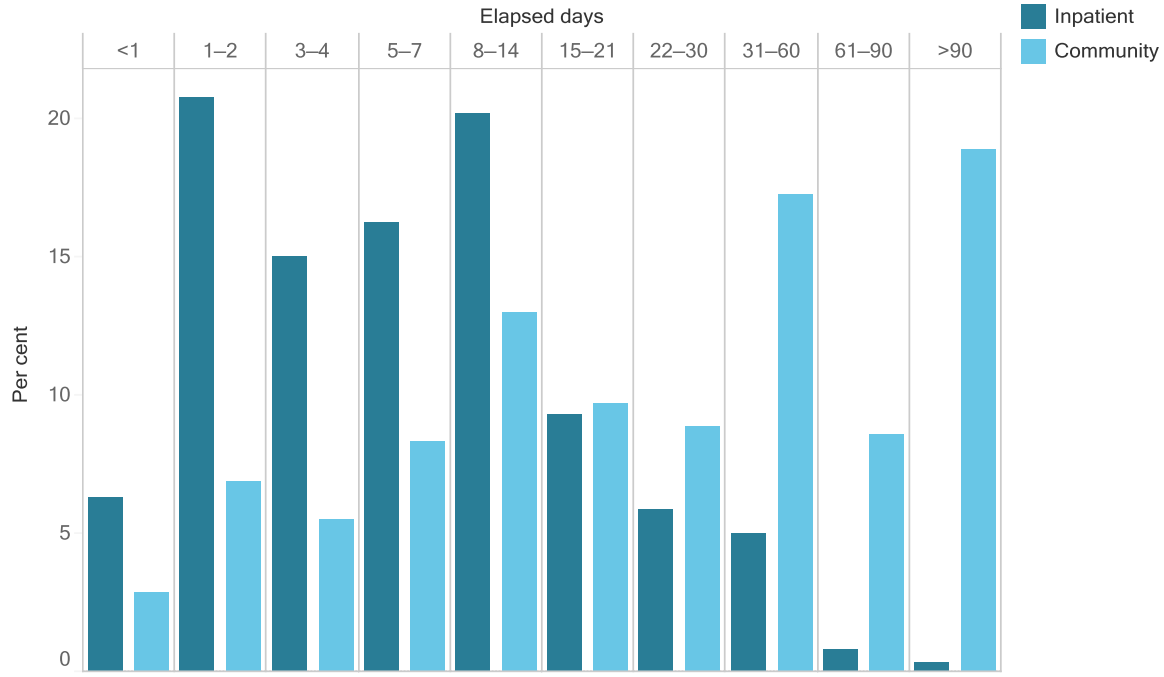
- **setting of palliative care changes**
- **principal clinical intent of the care changes and the patient is no longer receiving palliative care**
- **patient is formally separated from the service**
- **patient dies.**

There were 51,090 PCOC episodes which ended in 2017, compared with 40,248 in 2013 (an annual average increase of 6.1%). Inpatient episodes were generally shorter in duration than community episodes. In 2017, over 7 in 10 (72.3%) inpatient episodes lasted between

1 and 14 days, whereas about 3 in 5 (63.4%) community episodes were 15 days or longer (Figure PCOC.3).

In 2017, the average length of all episodes (elapsed days) in the inpatient setting was 10.1 days, with a median of 6.0 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 type of distribution was also reflected in the community setting.

Figure PCOC.3: PCOC closed episodes, number of elapsed days, inpatient and community care settings, 2017



Source: Table PCOC.8

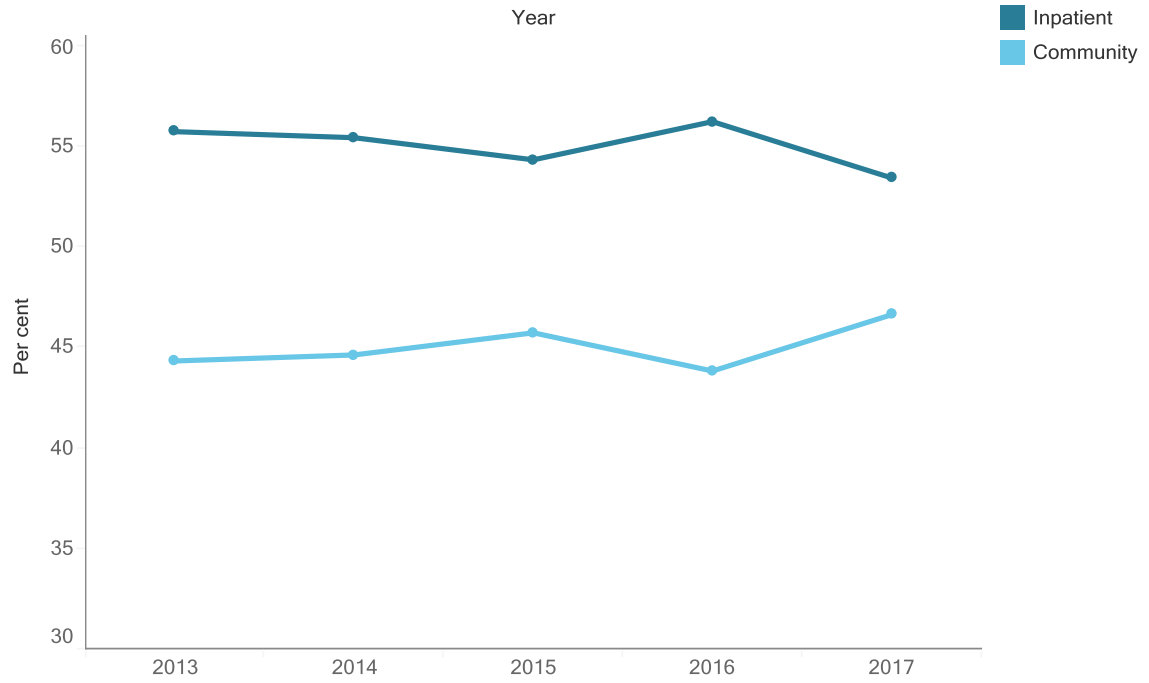
Alt text: Vertical bar chart showing the per cent of PCOC closed episodes by number of elapsed days, for inpatient and community care settings. Same-day 6.3 (inpatient), 2.9 (community); 1–2 days 20.8, 6.9; 3–4 15.0, 5.5; 5–7 16.3, 8.3; 8–14 20.2, 13.0; 15–21 9.3, 9.7; 22–30 5.9, 8.9; 31–60 5.0, 17.3; 61–90 0.8, 8.6; >90 0.3, 18.9. Refer to Table PCOC.8.

Palliative care episodes over time

Between 2013 and 2017 the number of PCOC closed episodes increased for both inpatient (from 22,428 to 28,137) and community palliative care patients (from 17,820 to 22,953). This is a 25.5% increase for inpatient closed episodes and a 28.8% increase for community

based closed episodes over the period (Figure PCOC.4). The number of service providers reporting to PCOC increased by 22.6% over the same period.

Figure PCOC.4: PCOC, per cent of closed episodes by palliative care settings, 2013 to 2017



Source: Table PCOC.7

Alt text: Horizontal line chart showing the per cent of closed episodes by palliative care setting from 2013 to 2017. 2013 55.7% (inpatient), 44.3% (community); 2014 55.4, 44.6; 2015 54.3, 45.7; 2016 56.2, 43.8; 2017 55.1, 44.9. Refer to Table PCOC.7.

Palliative care phases

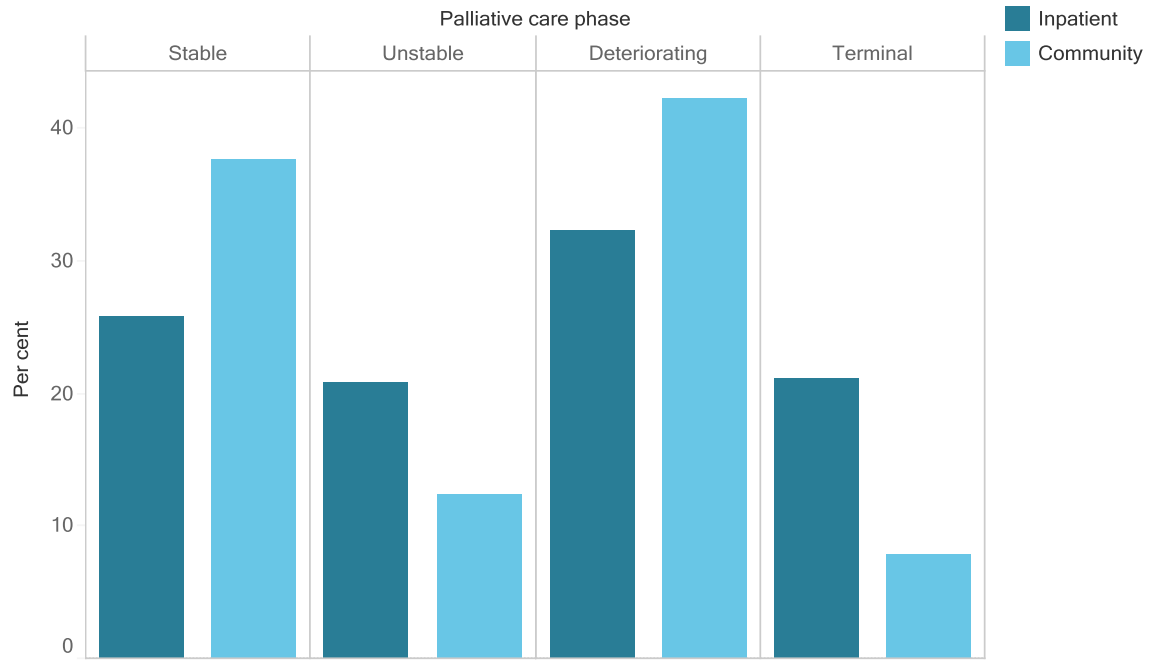
In PCOC, a palliative care phase describes a stage of the patient's illness within an episode of care and provides a clinical indication of the level of care required. There are 4 palliative care phases used in PCOC—stable, unstable, deteriorating and terminal. When assigned, the first three phases reflect the effectiveness of the plan of care and the urgency of response to patient and family care needs. The terminal phase is assigned when the patient is likely to die within days. It should be noted that palliative care phases are not necessarily sequential: the patient may transition back and forth between phases during an episode and there is also likely to be more than one phase of care within an episode.

There were 128,115 palliative care phases reported to PCOC in 2017, with more than half (52.0%) occurring in inpatient palliative care. Of these, almost one-third (32.3%) were in a deteriorating phase followed by stable (25.8%) and unstable (20.8%) phases. Of the almost

61,500 phases reported in the community care setting, 42.2% were in a deteriorating phase, followed by stable (37.6%) and unstable (12.4%) 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 6.9 days and 20.5 days respectively), followed by the deteriorating phase (4.9 days and 11.8 days respectively) and the terminal phase (2.1 days and 3.1 days respectively).

Figure PCOC.5: PCOC, phase counts by palliative care phase, inpatient and community care settings, 2017



Source: Table PCOC.9

Alt text: Vertical bar chart showing the per cent of phase counts by palliative care phase by inpatient and community setting. Stable 25.8% (inpatient), 37.6% (community); unstable 20.8, 12.4; deteriorating 32.3, 42.2; terminal 21.1, 7.8. Refer to Table PCOC.9.

Palliative care outcome measures and benchmarks

In 2009, PCOC and participating services, developed and implemented a set of national outcome measures and associated benchmarks to drive 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).

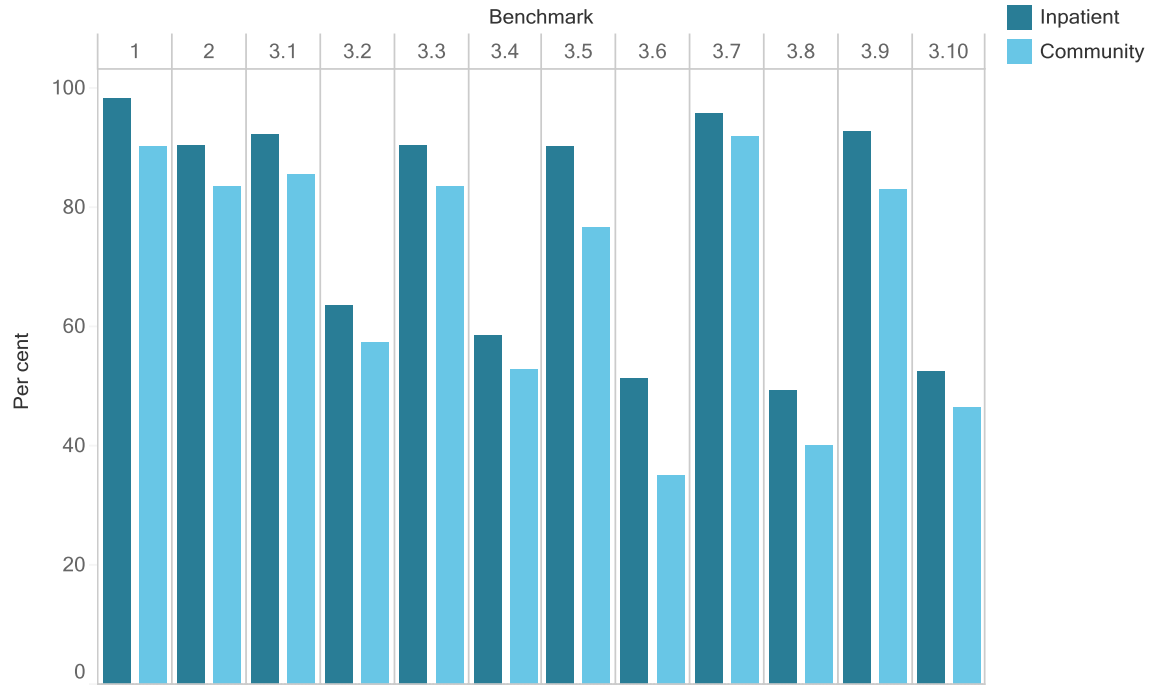
In 2015, six additional measures relating to fatigue, breathing problems and family/carer problems were introduced. A full description of each of the PCOC benchmarks reported here is shown in Table PCOC.13. PCOC also reports on 8 casemix adjusted outcomes measures, not reported here.

Based on PCOC palliative care outcome benchmark results, in general, patients receiving inpatient (hospital/hospice) care are more likely to achieve better outcomes than patients receiving care at home (Figure PCOC.6)

A high proportion of all patient episodes (94.8%) had care start within two days of the patient being ready (benchmark 1) whilst 86.9% of patients spent three days or less in the unstable phase. Positive outcomes were achieved for 93.7% of patients beginning a phase management of absent to mild breathing problems (benchmark 3.7).

The majority of patients experience no more than absent or mild symptoms or problems. For those patients who did experience moderate to severe distress from fatigue, 42.2% had this reduced to absent or mild (benchmark 3.6). Similarly, moderate to severe distress from breathing problems (benchmark 3.8) was reduced to absent or mild for 44.9%. Over half (56.0%) of patients who began experiencing moderate to severe distress from pain had this improved to absent/mild (benchmark 3.4). Achieving an absent/mild symptom (or problem) outcome is less likely when the patient has moderate or severe symptoms (or problems) to begin with as is reflected in the outcome results.

Figure PCOC.6: PCOC palliative care outcome benchmark results (episodes/phases), inpatient and community care settings, 2017



Source: Table PCOC.13

Alt text: Vertical bar chart showing PCOC palliative care outcome benchmark results, by inpatient and community care settings. Benchmark 1 98.3 (inpatient), 90.1 (community); Benchmark 2 90.4, 83.4; Benchmark 3.1 92.1, 85.4; Benchmark 3.2 63.6, 57.4; Benchmark 3.3 90.6, 83.5; Benchmark 3.4 58.7, 52.7; Benchmark 3.5 90.2, 76.6; Benchmark 3.6 51.4, 35.1; Benchmark 3.7 95.6, 91.8; Benchmark 3.8 49.3, 39.9; Benchmark 3.9 92.8, 82.9; Benchmark 3.10 52.4, 46.5. Refer to Table PCOC.13.

Key concepts

Palliative care outcomes

Key Concept	Description
Benchmark	A predefined level of achievement. In PCOC, the outcomes of groups of palliative care patients (e.g. witihin a service / state / nationally) are aggregated and compared to this level. The PCOC benchmarks are aspirational and based on what high performing services are able to achieve.
Community care	Episodes where the patient received specialist palliative care in a community setting, often deemed as the patient's 'home'. This may be in their private residence, an aged care, mental health or disability residential facility or in a correctiional facility.
Elapsed days	The number of days between the start and end of an episode does not take into account leave days. Within the community setting, 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 specialist palliative care episode started and ended; and (where applicable) the setting in which the patient died.
Episode of care	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.
Inpatient	Inpatient episodes of care are those for which the intent of the admission was for the patient to be in a hospital or hospice overnight. This includes those patients who were admitted and died on the same day.
Median	The midpoint of a list of observations that have been ranked from the smallest to the largest.
Outcome measures	*Outcome measure 1:* Time from date ready for care to episode start This measure is the time (in days) between the date the patient is ready to receive care to the date that the episode of care actually

starts by the service. This 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 in consultation with participating services.

Outcome measure 2: **Time in unstable phase**

This outcome measure relates to the number of days the patient spends in an unstable phase. To meet this benchmark, 90% of patients must have an unstable phase last for three days or less.

The unstable phase alerts clinical staff to the need for urgent or emergency intervention requiring an associated change in the exisiting plan of care. Once assigned, and with the new plan of care in place, the clinical team monitor for improvements in the patient and or family/carer condition. Improvement can be demonstrated via other clinical assessments (reducing symptom distress and problem severity scores). With improvement reported and observed, the new care plan demonstrates its effectiveness and thus, the patient/family/carer can be moved out of the unstable phase into another relevant phase. However, at any time a patient is identified as dying within days (clinical indicators), the phase is immediately changed to terminal phase.

Outcome measure 3: **Change in symptoms and problems**

These measures include the items of distress caused by pain, fatigue, breathing problems and family/carer problems.

Two of the five PCOC clinical assessment tools used by clinicians are used to measure these patient and family symptoms and problems: the Symptom Assessment Scale (SAS) and the Palliative Care Problem Severity Score (PCPSS). The SAS supports patient rating of symptom related distress and the PCPSS supports the clinician rating of the severity of a problem.

A positive outcome for a patient is to have the symptom / problem in the absent to mild range at the end of a phase (i.e. when the type of phase changes or the person is discharged from the service).

There are two benchmarks for each symptom/ problem. The benchmark is 90% for patients experiencing absent / mild symptoms (problems) to begin with and 60% for patients experiencing moderate / severe symptoms (problems) to begin with.

	Phase records must have valid start and end scores to be included in the benchmarks. **3.1–3.4. Pain** **Pain management is acknowledged as 'core business' of palliative care services; hence, measuring patient distress from pain is considered to be a vitally important outcome for palliative care services. Two of the five PCOC assessment tools are used to measure pain: the Symptom Assessment Scale (SAS) (a patient-rated distress tool) and the Palliative Care Problem Severity Score (PCPSS) (a clinician-rated tool).** **3.5–3.6 Fatigue** **Fatigue is the most common symptom reported to PCOC. 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 via SAS.** **3.7–3.8 Breathing problems** **Breathing problems is a common symptom reported by patients receiving palliative care. In 2015, PCOC introduced this outcome measure to routine reporting.** **3.9–3.10 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.**

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