

Palliative care outcomes

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In 2021, 58,700 patients received palliative care from the 177 palliative care services voluntarily participating in the Australian Palliative Care Outcomes Collaboration (PCOC) program. This section provides information on the characteristics and outcomes for patients receiving palliative care from the palliative care services participating in PCOC over the period 2017 to 2021.

Note, as participation in PCOC is voluntary, not all services participate in PCOC. The data presented in this section therefore describe a subset of all palliative care delivered in Australia. Further information about PCOC is described below and in the [Data Sources](#) section.

The information in this section was last updated in **October 2022**.

Data on this page

The Australian Palliative Care Outcomes Collaboration (PCOC), established in 2005, is a national palliative care outcomes quality improvement program. The program uses standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care, including pain and symptom control, and timely access to services when they are needed to drive quality improvements (see the [Data Sources](#) section for further details).

For the palliative care outcomes collection, data are 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, symptom burden as assessed by examining symptom severity and distress, including pain and other common symptoms, the patient's psychological/spiritual problems, and family/carer issues.

Information provided in this section is categorised into 2 broad settings of care –

- inpatient – admissions to hospital or hospice
- community – occurring in the patient's 'home'. For example, this may be in their private residence or aged care.

Participation in PCOC is voluntary and contribution to the collection is sought from all palliative care service providers in public and private health sectors, across all regions, and across inpatient and community settings. However, not all services participate in PCOC. The data presented in this section therefore describes a subset of all palliative care delivered in Australia.

The PCOC data are provided by each participating palliative care service, using a standardised data submission process (a [Data Dictionary and Technical Guideline](#) is made to assist with this process). This process also involves standardised data quality checks and assurance procedures, which are completed by clinical, quality improvement and data experts. Further, a data quality statement, as informed by the Australian Bureau of Statistics Data Quality Framework, is also available. For further information about PCOC, refer to the [Australian Health Services Research Institute's PCOC information page](#).

The information presented in this section refers to palliative care data reported to PCOC for the 1 January 2021 to 31 December 2021 period.

Key points

In 2021, among patients who received palliative care reported to PCOC:

- 2 in 3 (66%) patients had a diagnosis of cancer.
- 3 in 4 (77%) palliative care closed episodes ended within 30 days, with most ending within 2 weeks (62%).
- Almost 9 in 10 (88%) unstable phases (urgent needs) were resolved within 3 days or less.
- 9 in 10 palliative care phases that started with absent/mild patient pain remained absent/mild at the end of the palliative care phase (89% for pain severity and 88% for distress from pain).
- 3 in 5 palliative care phases that began with moderate/severe patient pain reduced to absent/mild by the end of the palliative care phase (62% for pain severity and 59% for distress from pain).

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Overview of patients, episodes of care and phases

In 2021, 58,700 [patients](#) received palliative care from the 177 palliative care services participating in PCOC. There were slightly more men (52%) than women (48%) and 2 in 3 patients had a diagnosis of cancer (66% of all palliative care patients). For further details on the characteristics of these patients, see Tables PCOC.2–4.

Defining palliative care episodes

A palliative care episode is a period of contact between a patient and a service provider where palliative care is provided in a single setting (inpatient or community setting). A palliative care episode starts on the date a comprehensive palliative care assessment is undertaken and documented. An episode ends or is closed when the following occurs:

- setting of palliative care changes (for example community to inpatient)
- principal clinical intent of the care changes and the patient is no longer receiving palliative care
- the patient is formally separated from the service
- the patient dies.

A patient may have multiple palliative care episodes over the reference period if a patient's care needs change, they no longer require palliative care, or they change settings. For example, if a patient receives care at home and then transitions to care in a hospital, this would be reflected as 2 separate episodes.

In 2021, there were 77,500 [palliative care episodes](#) reported to PCOC, equating to an average of 1.3 palliative care episodes per patient. Among these palliative care episodes:

- There were similar number of episodes in community and inpatient settings (38,200 and 39,400, respectively; Table PCOC.1).
- Median age at the start of the episode of care was 76 years (Table PCOC.2).
- Almost 3 in 5 (57%) referrals were from public hospitals and 10% from community palliative care services (Table PCOC.5).

There were 73,400 episodes that ended ([closed episodes](#)) in 2021. Among these closed episodes:

- 3 in 4 (77%) ended within 30 days, with most ending within 2 weeks (62%).
- Inpatient episodes were generally shorter in duration than community episodes – with a median duration ([elapsed days](#)) of 5 days compared with 20 days in the community setting:

- **Inpatient episodes** were 3 times as likely to end within 2 days (34% vs 11%) and twice as likely to end within 14 days (84% vs 38%) compared with **community episodes**.
- Community-based episodes were 4 times as likely to end 15 days or after (63% vs 16%) and 9 times as likely to end 31 days or after (44% vs 4.7%) compared with inpatient episodes (Table PCOC.6).

Palliative care phases

A palliative care phase in PCOC identifies a clinically meaningful period in a patient's condition, their functional ability, symptoms (including physical and psychological) and family/carer distress, using five brief clinical assessment tools. It is determined by a holistic clinical assessment which considers the needs of the patients, and their family and carers.

There are four types of palliative care phases included in PCOC:

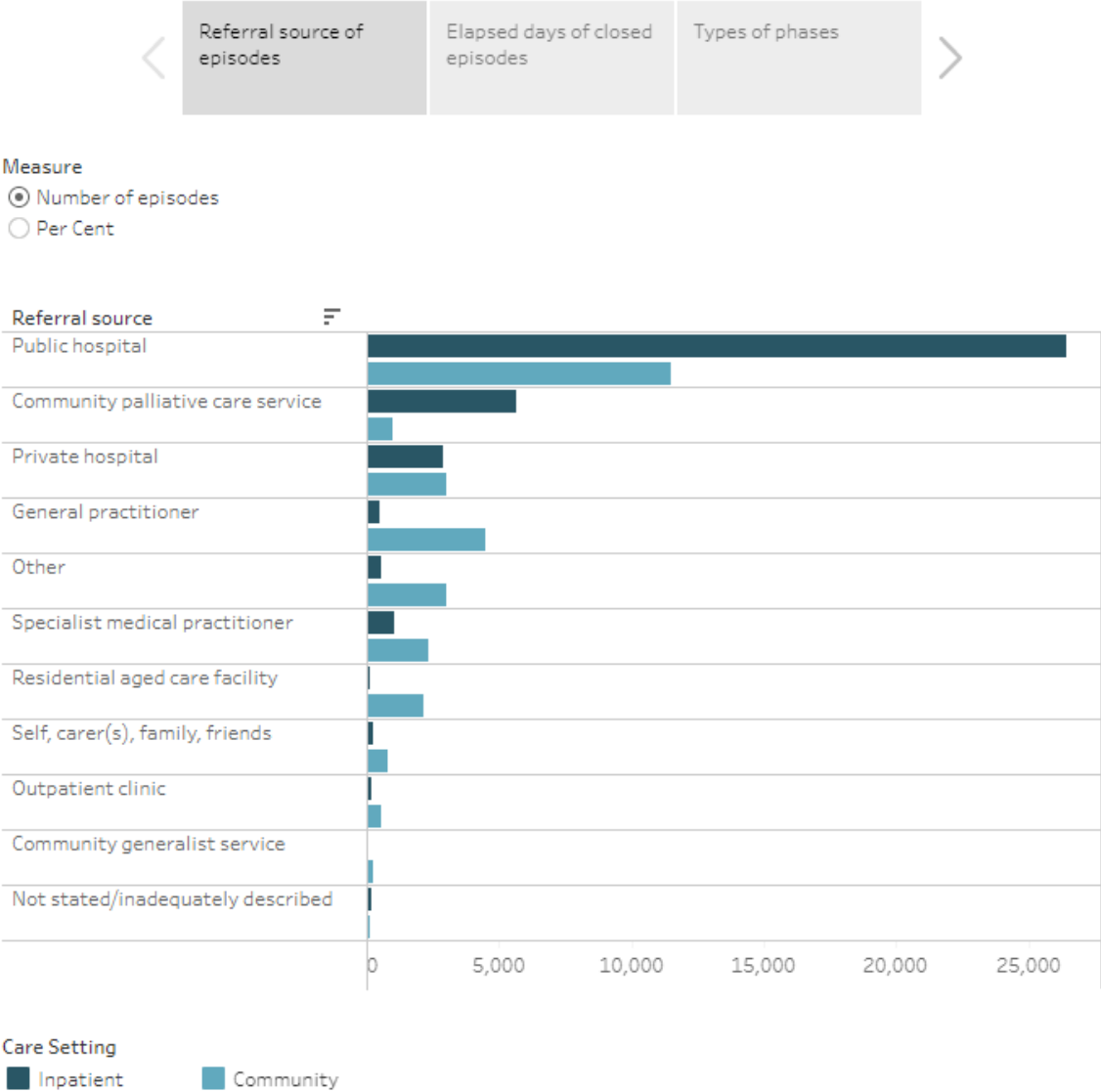
- **Stable:** patient problems and symptoms are adequately controlled by an established plan of care, and
 - further interventions to maintain symptom control and quality of life have been planned, and
 - family/carer situation is relatively stable and no new issues are apparent.
- **Unstable:** an urgent change in the plan of care or emergency treatment is required because:
 - patient experiences a new problem that was not anticipated in the existing plan of care, and/or
 - patient experiences a rapid increase in severity of a current problem, and/or
 - family/carers circumstances change suddenly impacting on patient care.
- **Deteriorating:** the care plan is addressing anticipated needs but requires periodic review because the:
 - patients overall functional status is declining, and/or
 - patient experiences a gradual worsening of existing problem, and/or
 - patient experiences a new but anticipated problem, and/or
 - family/carers experience gradual worsening distress that impacts on the patient care.
- **Terminal:** death is likely within days (Masso et al. 2015; PCOC 2021a).

It should be noted that palliative care phases are not necessarily sequential. A patient may transition back and forth between phases; therefore, it is likely that a patient will have more than one phase within an episode.

In 2021, there were 175,200 [palliative care phases](#) recorded in PCOC, with just over half (52%) occurring in community settings (90,500 compared with 84,700 in inpatient settings). On average, patients had 2.4 phases per closed episode (2.2 in inpatient settings compared to 2.6 in community settings) and 3.0 phases per patient (Table PCOC.1). Among these palliative care phases:

- 2 in 5 (41%) were deteriorating phases and 1 in 3 (31%) were stable phases, with terminal (16%) and unstable (13%) phases about half as common as stable phases (Table PCOC.7).
- Deteriorating and stable phases were more common for those in community settings (45% and 35%, respectively) than in inpatient settings (37% and 25%, respectively), while terminal and unstable phases were more common for those in inpatient settings (23% and 16% compared with 9% and 11% in community settings, respectively; Figure PCOC.1).
- The average length of each phase was longer for those in community than inpatient settings, particularly for those in stable and deteriorating phases where duration of the phase was 3.7 and 2.9 times as long for those in community settings than in inpatient settings (21.4 days vs 5.8 days for stable phase and 13.4 days vs 4.6 days for deteriorating phase, respectively; Table PCOC.7).

Figure PCOC.1: Overview of episodes of care and phases reported to PCOC, 2021



Source: AIHW. Table PCOC.5
<http://www.aihw.gov.au/pcsia>

Palliative care patient outcome measures

Key measures of quality care are the outcomes that patients, their families and carers achieve. PCOC is a national program that aims to systematically improve patient and carer outcomes, using standardised validated clinical assessment tools to benchmark and measure outcomes.

Palliative care outcome measures and benchmarks

In 2009, PCOC and its participating services developed and implemented a set of national outcome measures and associated benchmarks. The PCOC benchmarks are aspirational and reflect good practice (e.g., as achieved by the top 20% of services). The purpose of benchmarking is to drive palliative care service innovation and provide participating services with the opportunity to compare their service to other services from across the country.

The PCOC outcome measures cover:

1. Time from date ready for care to episode start – it is intended to assess whether patients received timely palliative care in response to their need. It is calculated in days between the date the patient is ready to receive palliative care to the date that the palliative care episode starts.
2. Time in the unstable phase – it is intended to assess whether there was a timely resolution of unstable palliative care phase. It is calculated as the difference between the unstable phase start date and end date.
3. Change in symptoms/problems – it is intended to provide information about the responsiveness and appropriateness of the care plan in place and therefore the care provided. It is calculated by the difference in assessment from the beginning of a phase to the end of phase, and is calculated using the measures from both the Palliative Care Problem Severity Score (PCPSS) and PCOC Symptom Assessment Scale (PCOC SAS).

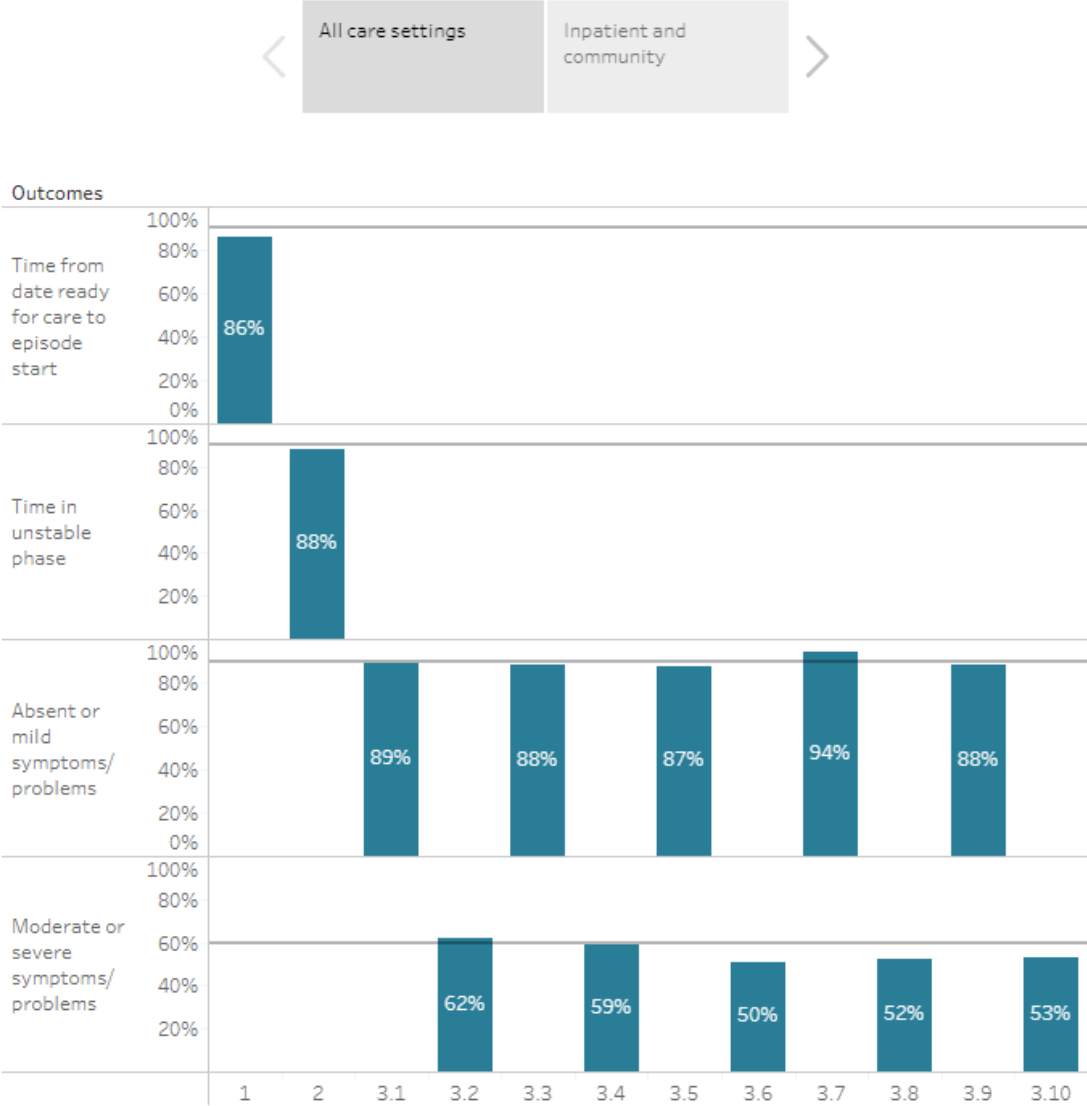
A full description of each of the PCOC outcome measures and benchmarks reported here is included in the [Data Sources](#) section. Table PCOC.8 also presents each benchmark, along with the proportion of palliative care episodes/phases meeting the outcome for each benchmark by care setting; also see Figures PCOC.2 and 4.

PCOC also reports on 8 [case mix-adjusted outcome measures](#) that are not reported here (see PCOC 2021a and PCOC 2021b for further details).

In 2021, among the 77,500 [palliative care episodes](#) and 175,200 [palliative care phases](#) recorded in PCOC:

- Over 4 in 5 (86%) episodes commenced on the day the patient was ready for palliative care, or the day after – 98% of episodes in inpatient settings and 84% in community settings.
- Almost 9 in 10 (88%) unstable phases were resolved within 3 days or less – 89% in inpatient settings and 86% in community settings.
- Almost 9 in 10 palliative care phases that started with absent/mild patient pain remained absent/mild at the end of the palliative care phase – pain severity (89%), distress related to pain (88%), distress related to fatigue (87%), and family/carer problems (88%). For distress related to breathing problems a higher proportion remained in the absent/mild phase (94%).
- The proportion of phases resolved in the absent/mild symptom outcome range was less likely when the patient had moderate/severe symptoms to begin with, especially for those with distress related to fatigue and breathing problems:
 - 3 in 5 palliative care phases that began with moderate or severe pain for patient pain or distress was reduced to absent/mild by the end of the palliative care phase (pain severity 62%, distress from pain 59%).
 - 1 in 2 palliative care phases starting with moderate or severe distress from fatigue or breathing problems was reduced to absent/mild at the end of the palliative care phase (fatigue 50%, breathing problems 52%; Figure PCOC.2.)

Figure PCOC.2: Palliative care patient outcome results for each benchmark, 2021



Note: Horizontal line refers to benchmark for each outcome measure.
 Source: AIHW, Table PCOC.8
<http://www.aihw.gov.au/pcsia>

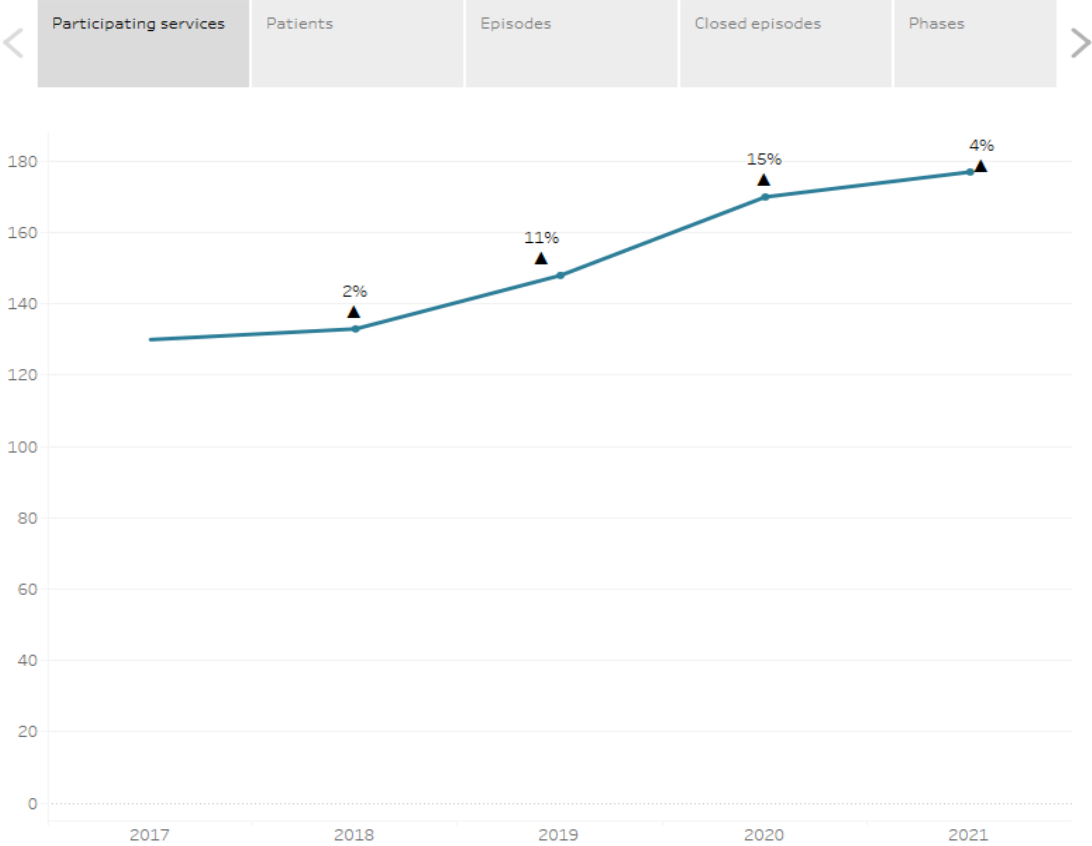
Trends in palliative care patient outcomes, including during the COVID-19 pandemic

Between 2017 and 2021, the number of services participating in PCOC increased each year, from 130 to 177 services or a 36% increase over this period. The rate of increase was steepest between 2018 and 2020 (11% increase from 2018 to 2019 and 15% increase from 2019 to 2020), and then slowed considerably between 2020 and 2021 (4% increase in services; Figure PCOC.3).

This pattern was also observed for palliative care episodes over the same period – episodes increased by 12–13% between 2018 and 2020 and slowed to a 7.1% increase in the following 12 months to 2021. However, this trend differed somewhat by care setting. For inpatient palliative care episodes, the increase was moderate from 2019 to 2020 (6.4%), but then increased more sharply (12%) in the following 12 months to 2021, which was similar to the increase from 2018 to 2019 (14%). In contrast, for community-based episodes, the increase was steepest (19%) between 2019 and 2020 and then considerably flat (2.2%) in the following 12 months to 2021. Interestingly, the number of patients steadily increased over this period – 12–13% increase between 2018 and 2020, slowing slightly to 10% increase between 2020 and 2021 (Figure PCOC.3).

These patterns of moderate increases of services and episodes reported to PCOC between 2020 and 2021 and the steeper increase in community than inpatient episodes during 2019 and 2020 may reflect the stricter public health restrictions and lockdowns in certain regions at these times to contain the spread of COVID-19.

Figure PCOC.3: Trends in services, patients, episodes of care and phases reported to PCOC, 2017 to 2021



Source: AIHW, Table PCOC.1
<http://www.aihw.gov.au/pcsia>

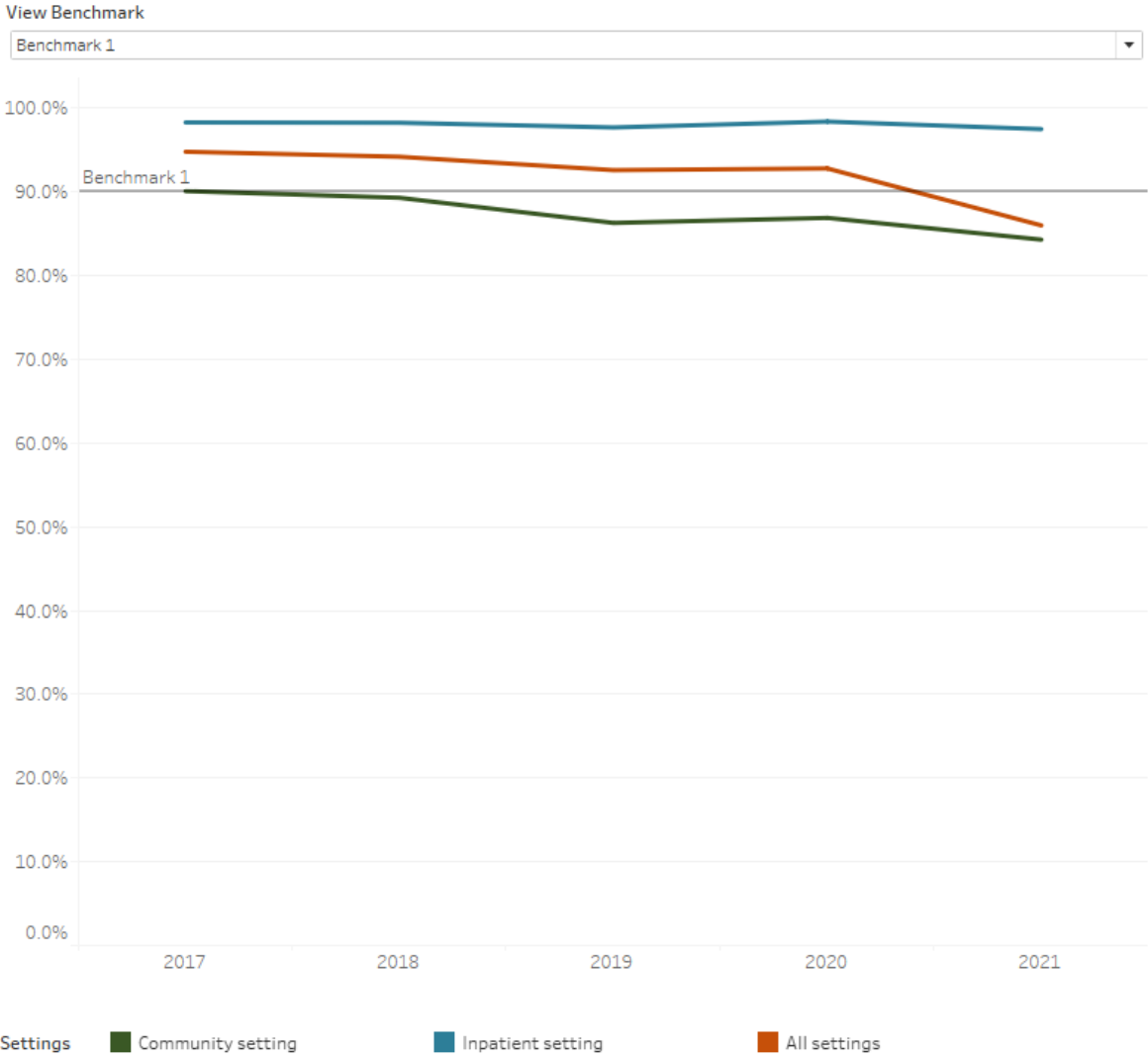
Of particular interest is whether there have been changes in recent years in the proportion of patients achieving a positive outcome, particularly given the disruptions to service delivery due to the pandemic. Since 2019, most outcome measures have remained relatively similar or improved (Figure PCOC.4). However, there have been some measures where more notable movements have been observed between 2019 and 2021:

- steady decline (by 6.6 percentage points) in those assessed as ready for care and receiving it within 2 days – from 93% to 86% between 2019 and 2021
- increase in those moving from moderate/severe to absent/mild at the end of the phase for distress from fatigue (from 45% to 50%) and from breathing problems (48% to 52%) between 2019 and 2021.

The restrictions and subsequent pressures on the health care system due to COVID-19 may have impacted on how people were accessing and receiving palliative care services, and their outcomes during this period. However, more data over a longer time, including

patients experiencing COVID-19 who received palliative care, are needed to provide insights on the effects of the COVID-19 pandemic on palliative care service activity and outcomes.

Figure PCOC.4: Trends in palliative care patient outcome results for each benchmark, 2017–2021



Source: AIHW. Table PCOC.8
<http://www.aihw.gov.au/pcsia>

References

Masso M, Allingham SF, Banfield M, Johnson CE, Pidgeon T, Yates P et al (2015) [Palliative Care Phase: inter-rater reliability and acceptability in a national study](#), *Palliative Medicine* 29(1): 22–30.

PCOC (Palliative Care Outcomes Collaboration) (2021a) [Palliative Care Outcomes Collaboration Clinical Manual](#), Wollongong: University of Wollongong, accessed 24 July 2021.

PCOC (2021b) [PCOC Research and Data](#), Wollongong: University of Wollongong, accessed 9 July 2021.

Data sources

Palliative Care Outcomes Collaboration (PCOC) Palliative care outcomes collection

The [Palliative Care Outcomes Collaboration \(PCOC\)](#) is a national program using standardised validated clinical assessment tools to measure and benchmark patient outcomes in palliative care.

Participation in the PCOC is voluntary and open to all palliative care service providers across Australia. Representation is sought from public and private health sectors, rural and metropolitan areas, and inpatient and community settings. PCOC aims to assist services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. The PCOC model is embedded into routine clinical practice. As such, the standardised clinical assessment tools are used as part of routine practice with each consecutively admitted patient.

The PCOC palliative care outcomes collection dataset (PCOC 2021) includes data on patient demographics, clinical setting information, and patient outcomes from the following [clinical assessment tools](#) (Daveson et al. 2021; PCOC 2012):

- Palliative Care Phase
- Palliative Care Problem Severity Score (PCPSS)
- PCOC Symptom Assessment Scale (PCOC SAS)
- Australia-modified Karnofsky Performance Status (AKPS)
- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

Data using Version 1 of the PCOC dataset were collected between January 2006 and January 2007. Version 2 of the dataset was enacted from July 2007, and Version 3 was implemented in July 2012 (PCOC 2012). More information about this dataset can be found in the [PCOC Version 3.0 Data Dictionary and Technical Guidelines 1.2.0](#).

The national figures used in this report reflect all palliative care services that submitted data for the January–December 2021 period. A full list of the services that contributed data to this report can be found on the [Palliative Care Outcomes Collaboration website](#).

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. The most recent update was released in 2015, which included the addition of 6 measures to Benchmark 3 relating to

fatigue, breathing problems and family/carer problems. More information can be found on the [PCOC Research and data webpage](#) (PCOC 2021).

Further detail on the definition and measurement of each outcome measure and associated benchmark are provided in the following.

Outcome measure 1: Time from date ready for care to episode start

Measures the time (in days) between the date the patient is ready to receive care and the actual start date of the episode of palliative care by the service. This is measured for all episodes of care and across all settings of care.

To meet Benchmark 1, 90% of episodes of care must commence on the day of, or the day following, the date ready for 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

Measures the number of days the patient spent in an unstable phase. An unstable phase alerts clinical staff to the need for urgent or emergency intervention requiring an associated change in the existing care plan. Once assigned, and with the new care plan in place, the clinical team monitor for improvements in the patient and/or family/carer condition. Improvement can be demonstrated through observation and clinical assessments (reducing symptom distress and problem severity scores). With signs of improvement, 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.

For services to meet Benchmark 2, 90% of unstable phases must last for 3 days or less.

Outcome measure 3: Change in symptoms/problems

Symptoms and problems for Benchmark 3 include the items of pain severity, distress related to pain, distress caused by fatigue, distress caused by breathing problems, and family/carer problems.

Symptoms and problems are measured at the start and end of a phase, and although symptoms and problems can be measured throughout the phase, an outcome is defined as the change from the beginning and at the end of the phase. It follows that phase records must have valid start and end scores to be included.

Two of the five PCOC clinical assessment tools are used to measure these patient and family symptoms and problems: the patient-rated PCOC Symptom Assessment Scale (PCOC SAS) and the clinician-rated Palliative Care Problem Severity Score (PCPSS).

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 2 benchmarks for each symptom/problem. The first benchmark is that at least 90% of phases that start with patients experiencing absent/mild symptoms (or problems) remain absent/mild at the end of the phase. This is reflective of anticipatory care. The second benchmark is that at least 60% of phases that start with patients experiencing moderate/severe symptoms (or problems) reduce to an absent/mild level by the end of the phase. This is reflective of responsive care.

Outcome measures 3.1–3.4: Pain

Pain management is acknowledged as ‘core business’ of palliative care services; hence, measuring patient pain is considered to be a vitally important outcome for palliative care services. The PCPSS measures pain severity rated by the clinician, used in Benchmarks 3.1 and 3.2, and the PCOC SAS measures patient-rated distress from pain, used in Benchmarks 3.3 and 3.4.

Outcome measure 3.5–3.6: Fatigue

Fatigue is the most common symptom in palliative care patients who have advanced cancer or other serious and/or life-threatening illnesses. The PCOC SAS is used for Benchmarks 3.5 and 3.6.

Outcome measure 3.7–3.8: Breathing problems

Breathing problems is a common symptom reported by patients receiving palliative care. The PCOC SAS is used to measure patient distress related to this symptom. This is used for Benchmarks 3.7 and 3.8.

Outcome measure 3.9–3.10: Family/carer problems

The PCPSS family/carer domain measures problems associated with a patient’s condition or palliative care needs. The clinician reports on the severity of the problems of their family/carer. This is used for Benchmarks 3.9 and 3.10.

References

Daveson BA, Allingham SF, Clapham S, Johnson CE, Currow DC, Yates P, et al (2021) [The PCOC Symptom Assessment Scale \(SAS\): A valid measure for daily use at point of care and in palliative care programs](#), *PLoS ONE* 16(3): e0247250.

Palliative Care Outcomes Collaboration (PCOC) (2012) [PCOC Version 3.0 Dataset, Data Dictionary and Technical Guidelines. Document version 1.2.0](#), Wollongong: University of Wollongong, accessed 1 July 2021.

PCOC (2021) [PCOC Research and Data](#), Wollongong: University of Wollongong, accessed 9 July 2021.

Key Concepts

Palliative care outcomes

Key Concept	Description
Anticipatory care	Anticipatory care is care that anticipates the needs of the patient and carer in order to avoid an increase in the problem or need. The PCOC anticipatory care benchmarks relate to patients who have absent or mild symptoms/problems at the start of a phase of palliative care. To meet this benchmark, 90% of these phases must end with absent or mild symptom/problem scores.
Benchmark	A predefined level of achievement. In PCOC, the outcomes of groups of palliative care patients (e.g., within a service/state /nationally) are aggregated and compared to this level. The PCOC benchmarks are aspirational and reflect good practice (top 20%). The PCOC benchmarks are the same regardless of sector (public/private), location or role.
Case-mix adjusted outcome measure	<p>This measures the mean change in symptoms, after adjusting for both phase and the symptom score at the start of each phase. This measure allows comparison of change in symptom and problem scores for 'like' patients. A positive score indicates that a service is achieving above the baseline national average and a negative score indicates that it is below the baseline national average.</p> <p>PCOC currently reports on 8 case-mix adjusted outcomes: Distress regarding pain, bowel problems, nausea, and breathing problems; and symptom severity regarding pain, other symptoms, psychological/spiritual problems, and family/carer problems.</p>
Closed palliative care episode	<p>A closed palliative care episode is one that includes an episode end date within the specified reporting period.</p> <p>An episode ends or is closed when the following occurs: setting of palliative care changes (for example community to inpatient); principal clinical intent of the care changes and the patient is no longer receiving palliative care; the patient is formally separated from the service; or the patient dies.</p>
Community episode	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 correctional facility.
Elapsed days	The number of days between the start and end of an episode. This does not include leave days. Within the community setting, elapsed days do not reflect the number of times the palliative care team visited the patient.
Inpatient episode	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 measure	<p>In PCOC, an outcome measure is both a measure used to assess change in response to an intervention (e.g., palliative care), and is also used to refer to a standardised assessment tool or methodology designed to measure clinical concepts.</p> <p>The PCOC outcome measures cover: time from the date the patient is ready for palliative care to palliative care episode start date (timeliness of palliative care); time that the patient spent in an unstable phase (responsiveness to urgent needs); change in patient symptoms and problems (responsiveness and appropriateness of the care plan in place).</p>
Palliative care episode	<p>A palliative care episode is a period of contact between a patient and a service where palliative care is provided in a single setting (for example, inpatient setting). A palliative care episode starts on the date a comprehensive palliative care assessment is undertaken and documented.</p> <p>An episode ends when one of the following occurs: setting of palliative care changes (for example community to inpatient); principal clinical intent of the care changes and the patient is no longer receiving palliative care; patient is formally separated from the service; or the patient dies.</p> <p>Palliative care episodes, as used in this report, include both open episodes (those without an episode end date in the reporting period), and closed episodes (see 'closed episodes').</p>
Palliative care patient	A person for whom a palliative care service accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record. Family and carers are included in this

definition if interventions relating to them are recorded in the patient medical record.
