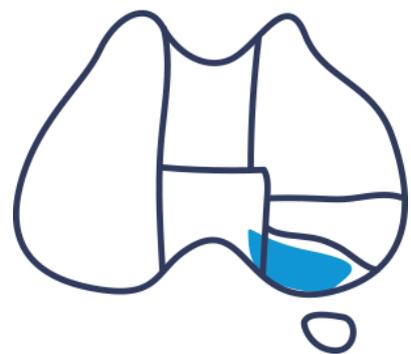




palliative care
outcomes collaboration



A profile of patients receiving palliative care

Victoria | July to December 2019

PCOC wishes to acknowledge the valuable contribution made by the many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible.

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PCOC has made every effort to ensure that the data used in this report are accurate. Data submitted to PCOC are checked for anomalies and services are asked to re-submit data prior to the production of this report. We would advise readers to use their professional judgement in considering all information contained in this report.

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Introduction

The Palliative Care Outcomes Collaboration (PCOC) is a national program that aims to improve the quality and outcomes of palliative care in Australia. This is achieved via a standardised clinical language that supports a national data collection. This report provides a high level profile of 8,032 patients who received palliative care in Victoria during July to December 2019 and had their pain, symptom, family / carer and psychological / spiritual issues assessed as part of routine clinical care.

For more detailed information, including a summary of the national achievement against PCOC's 20 benchmarked patient outcome measures, please see the companion report *Patient outcomes in palliative care in Victoria, July - December 2019*.

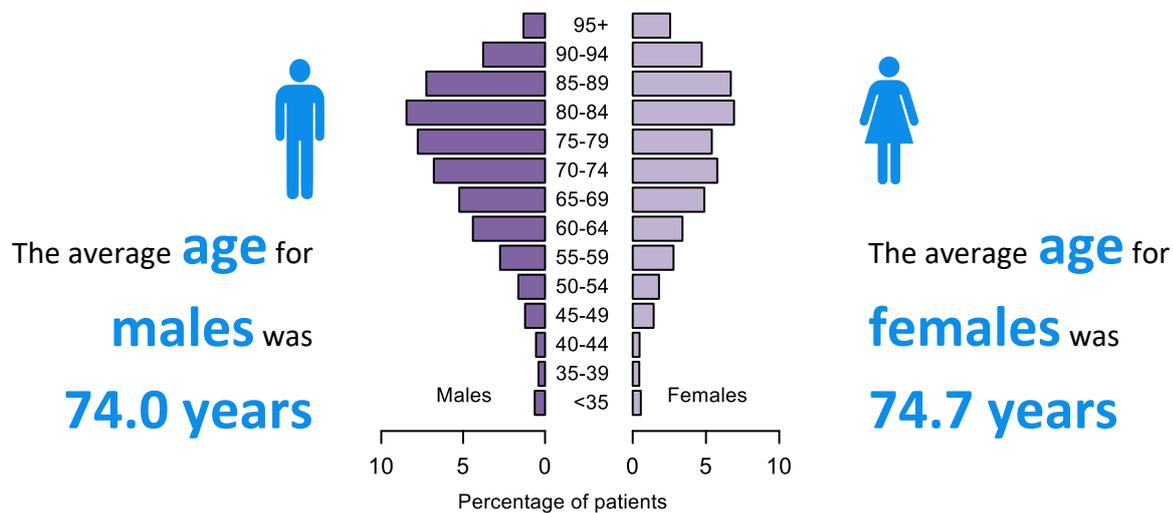
Patient characteristics

Table 1 describes the demographics of patients receiving palliative care.

Table 1 Patient demographic summary

| Patient demographics | | N | % |
|-----------------------------|---|-------|------|
| Sex | Male | 4,146 | 51.6 |
| | Female | 3,881 | 48.3 |
| Indigenous status | Aboriginal and/or Torres Strait Islander origin | 60 | 0.7 |
| | Not Aboriginal and/or Torres Strait Islander origin | 7,772 | 96.8 |
| Country of Birth | Born in Australia | 4,388 | 54.6 |
| | Born outside Australia | 3,376 | 42.0 |
| Preferred language | English | 6,552 | 81.6 |
| | Other than English | 1,319 | 16.4 |
| Primary diagnosis | Malignant | 5,283 | 65.8 |
| | Non-malignant | 2,592 | 32.3 |
| Age at beginning of episode | Average age | 74.3 | |
| | Median age | 76.0 | |

Figure 1 Patients by sex and age group



Diagnosis

Diagnosis reflects the primary illness responsible for the person requiring palliative care. These illnesses are classified as either malignant (cancer) or non-malignant (illnesses other than cancer). Figure 2 shows how the split between malignant and non-malignant has changed since 2016, whilst Figure 3 shows a more detailed breakdown of diagnoses for the current six-months.

Figure 2 Diagnosis over time

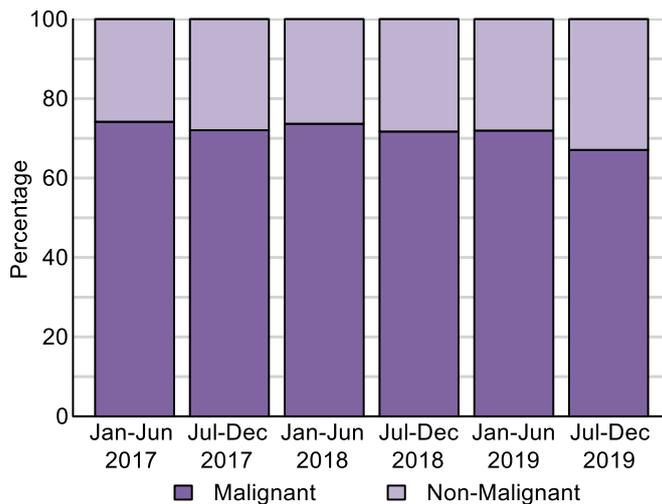
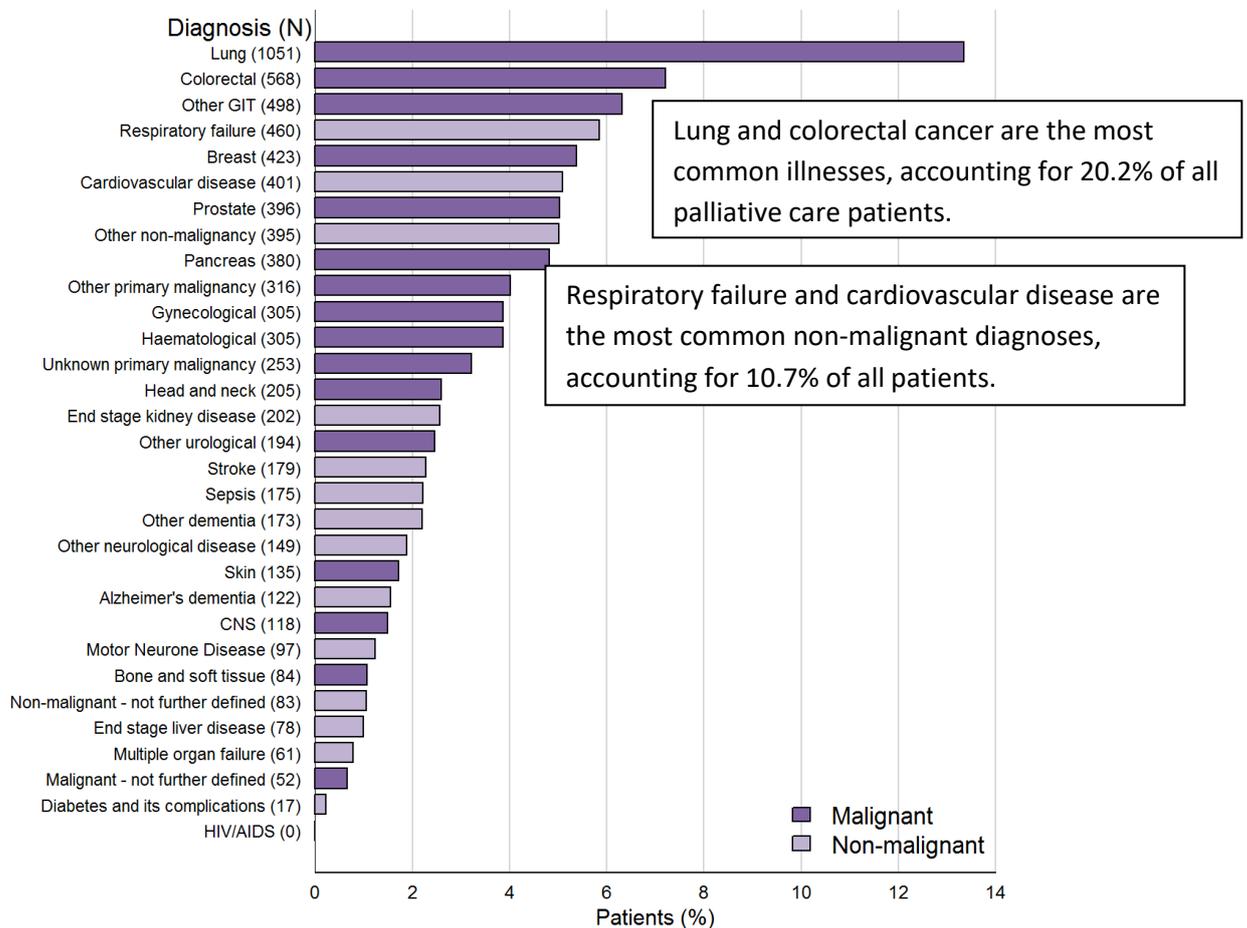


Figure 3 Diagnosis



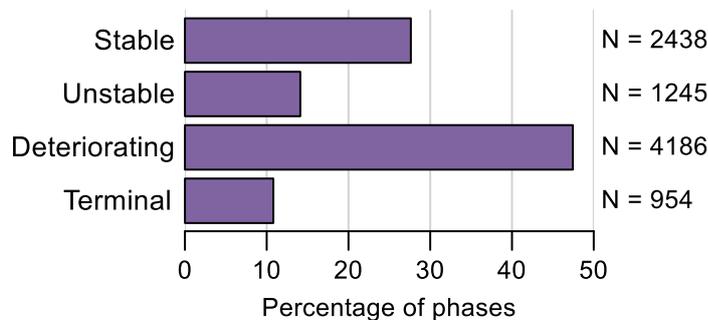
Referrals to palliative care

Table 2 Referral source over time

| Referral Source | Jan-Jun 2017 | Jul-Dec 2017 | Jan-Jun 2018 | Jul-Dec 2018 | Jan-Jun 2019 | Jul-Dec 2019 |
|-----------------------------------|--------------|--------------|--------------|--------------|--------------|--------------|
| | N=7,099 | N=7,324 | N=7,202 | N=7,656 | N=7,962 | N=8,823 |
| Public hospital | 60.6 | 58.0 | 57.7 | 58.9 | 57.1 | 48.3 |
| Private hospital | 13.5 | 15.4 | 15.6 | 14.2 | 12.8 | 11.3 |
| Outpatient clinic | 0.6 | 1.0 | 1.3 | 1.1 | 1.1 | 1.8 |
| General practitioner | 3.9 | 4.0 | 3.7 | 3.7 | 3.9 | 2.9 |
| Specialist medical practitioner | 4.5 | 4.6 | 4.6 | 4.4 | 3.5 | 4.5 |
| Community palliative care service | 10.4 | 8.7 | 9.5 | 9.4 | 8.5 | 8.4 |
| Community generalist service | 0.4 | 0.4 | 0.2 | 0.3 | 0.4 | 0.3 |
| Residential aged care facility | 1.2 | 1.5 | 1.5 | 1.9 | 2.4 | 2.2 |
| Self, carer(s), family, friends | 1.8 | 2.2 | 2.5 | 2.4 | 2.4 | 2.2 |
| Other | 3.0 | 3.8 | 2.6 | 2.9 | 3.6 | 14.3 |
| Not stated/inadequately described | 0.2 | 0.6 | 0.8 | 0.8 | 4.2 | 3.8 |
| Total | 100 | 100 | 100 | 100 | 100 | 100 |

Note: Only includes episodes that started during each six month reporting period.

Figure 4 Phase at beginning of episode

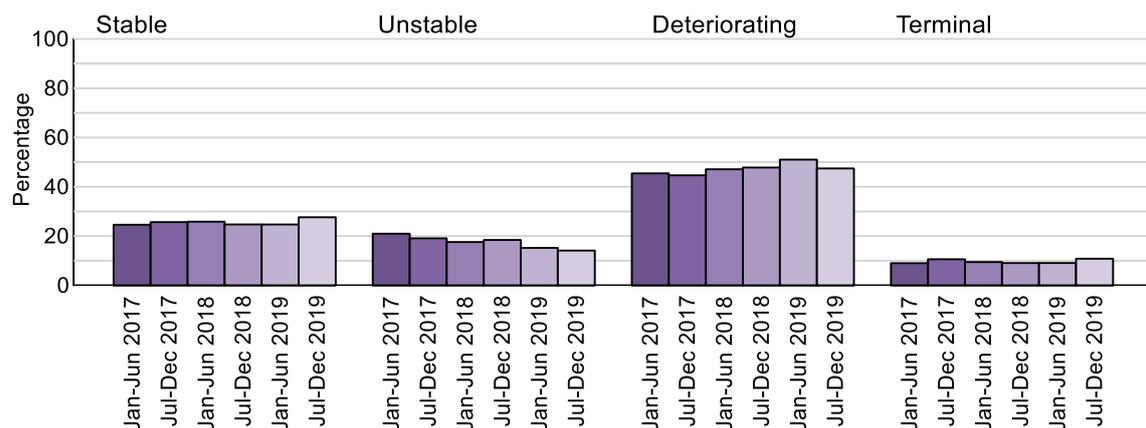


The most common first phase is

deteriorating

with an average duration of 8.7 days.

Figure 5 Phase at beginning of episode – over time



The symptom with the highest number of severe scores is distress from pain (2.8%).
The symptom causing the least distress is nausea, rated by patients as 'absent' (79.0%) of the time.

Figure 6 Symptoms and problems at episode start

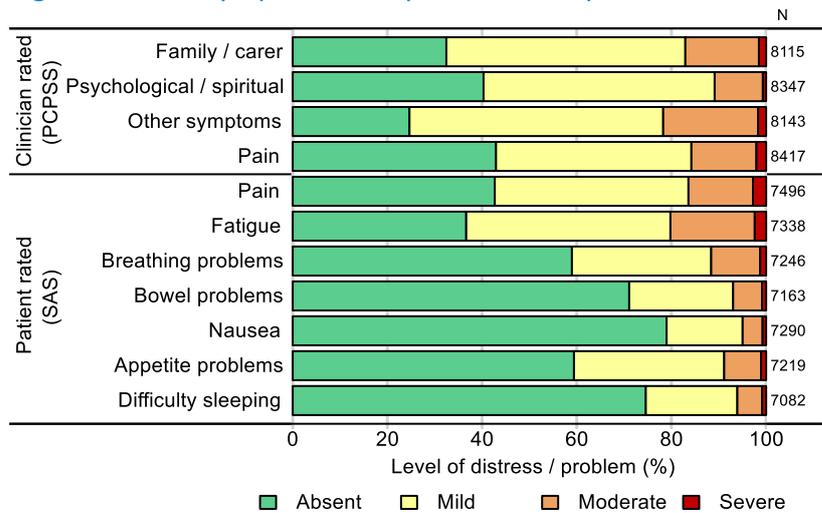


Figure 7 Moderate and severe problems at episode start over time (PCPSS)

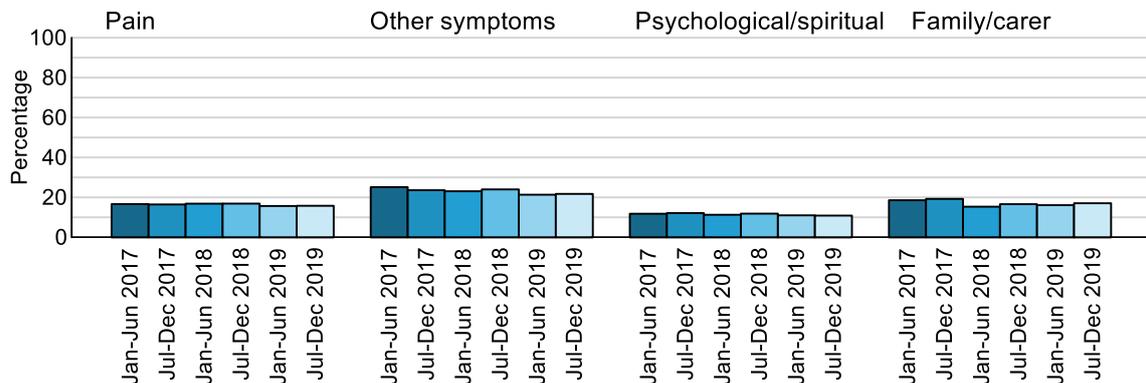
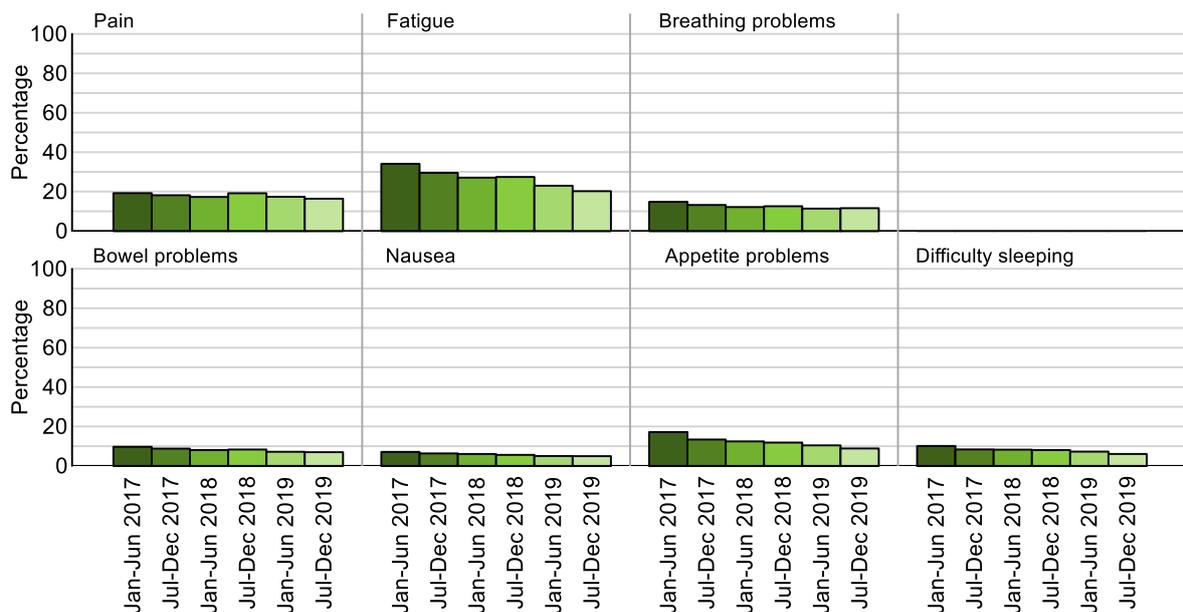


Figure 8 Moderate and severe symptoms distress at episode start over time (SAS)



Palliative care phase

The palliative care phase type describes the stage of the patient’s illness and provides a clinical indication of the level of care a patient requires. Table 2 describes the number of phases and phase length.

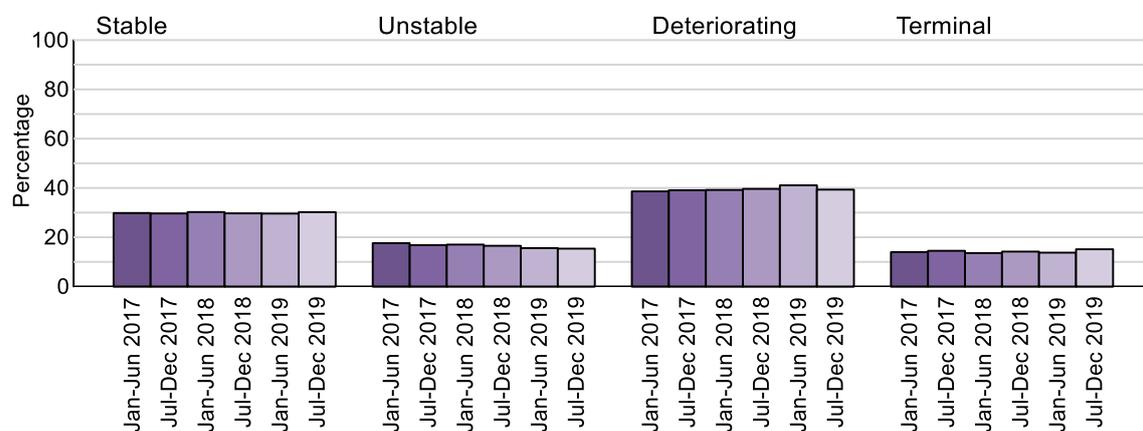
Table 3 Profile of palliative care phase

| Phase type | N | % | Average phase length (days) |
|---------------|--------|-------|-----------------------------|
| Stable | 6,899 | 30.2 | 16.9 |
| Unstable | 3,513 | 15.4 | 1.8 |
| Deteriorating | 8,983 | 39.3 | 10.3 |
| Terminal | 3,454 | 15.1 | 2.2 |
| All phases | 22,849 | 100.0 | 9.6 |

Note: Phase records where phase length was greater than 90 days were considered to be atypical and are excluded from the average calculations.

The **deteriorating phase** is the most common with an average duration of 10.3 days.

Figure 9 Phase profile overtime



Place of death

For July to December 2019, 3,460 patients died in the care of a specialist palliative care service. Of these deaths, 16.7% occurred at the persons home, 13.7% in a residential aged care facility and 69.2% in hospital.

Data included

Table 4 Data item completion

| Patient level items | | % |
|---|--|-------------|
| Date of birth | | 100.0 |
| Sex | | 100.0 |
| Indigenous status | | 97.5 |
| Country of birth | | 96.7 |
| Preferred language | | 98.0 |
| Primary diagnosis | | 98.0 |
| Episode level items | | % |
| Date of first contact | | 100.0 |
| Referral date | | 100.0 |
| Referral source | | 96.7 |
| Date ready for care | | 100.0 |
| Mode of episode start | | 95.9 |
| Accommodation at episode start | | 97.6 |
| Episode end date | | 95.5 |
| Mode of episode end | | 95.8 |
| Accommodation at episode end | | 98.9 |
| Place of death | | 98.8 |
| Phase level items | | % |
| Phase end reason | | 99.9 |
| Clinical assessments (completion at phase start / discharge) | | % |
| RUG-ADL Bed mobility | | 85.3 / 47.0 |
| RUG-ADL Toileting | | 85.3 / 47.0 |
| RUG-ADL Transfers | | 85.3 / 47.0 |
| RUG-ADL Eating | | 85.0 / 46.8 |
| PCPSS Pain | | 90.6 / 53.9 |
| PCPSS Other symptoms | | 87.8 / 53.2 |
| PCPSS Psychological / spiritual | | 89.5 / 53.3 |
| PCPSS Family / carer | | 87.8 / 53.3 |
| SAS Difficulty sleeping | | 79.2 / 40.0 |
| SAS Appetite problems | | 80.8 / 40.9 |
| SAS Nausea | | 82.8 / 42.9 |
| SAS Bowel problems | | 80.8 / 40.6 |
| SAS Breathing problems | | 82.1 / 42.3 |
| SAS fatigue | | 83.7 / 43.0 |
| SAS Pain | | 88.1 / 46.3 |
| AKPS | | 87.8 / 48.0 |

Table 5 Number of patients, episodes and phases over time

| | Jan-Jun 2017 | Jul-Dec 2017 | Jan-Jun 2018 | Jul-Dec 2018 | Jan-Jun 2019 | Jul-Dec 2019 |
|--|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Patients | 6,687 | 6,728 | 6,681 | 7,189 | 7,472 | 8,032 |
| Episodes | 8,628 | 8,837 | 8,825 | 9,371 | 9,734 | 10,489 |
| Phases | 19,374 | 19,372 | 19,549 | 21,075 | 20,921 | 22,849 |
| Average number of phases per episode* | 2.2 | 2.1 | 2.1 | 2.2 | 2.1 | 2.1 |

*Calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Glossary

| | |
|----------------|--|
| AKPS | The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient’s performance across the dimensions of activity, work and self-care at phase start. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient’s ability to perform common tasks relating to activity, work and self-care. |
| Episode | An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting. An episode of care ends when either; the patient is formally separated from the current setting of care; the patient dies; or the principal clinical intent of the care changes and the patient is no longer receiving palliative care. Under this definition, a patient receiving palliative care is likely to have more than one episode of care. |
| Patient | PCOC defines a patient as 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 / carers are included in this definition if interventions relating to them are recorded in the patient medical record. As a result, if a patient is seen in two different services with different medical record systems they will be counted twice in the total number of patients. |
| PCPSS | Palliative Care Problem Severity Score (PCPSS) is a clinical tool used for initial screening and ongoing coordination of specialist palliative care. Clinician rated, it facilitates the global assessment of four palliative care domains: pain, psychological / spiritual, other symptoms and family / carer. |
| Phase | Palliative care phase identifies a clinically meaningful period in a patient’s condition. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. The phases provide a framework for referrals, triage and care planning. |
| RUG-ADL | Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence, based on what a person actually does, rather than what they are capable of doing. |
| SAS | Symptom Assessment Scale (SAS) describes the patient’s level of distress relating to individual physical symptoms. The symptoms in the scale are the seven most commonly experienced by palliative patients; difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. The instrument is designed to be a patient rated tool but also allows for rating by proxy (e.g. family, carer or clinician). |