

2019

A profile of patients receiving palliative care in NSW and ACT for July - December 2018

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Abstract

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 5,588 patients who received palliative care in NSW and ACT during July to December 2018 and had their pain, symptom, family / carer and psychological / spiritual issues assessed as part of routine clinical care.

Keywords

profile, palliative, receiving, patients, care, act, july, -, december, nsw, 2018

Publication Details

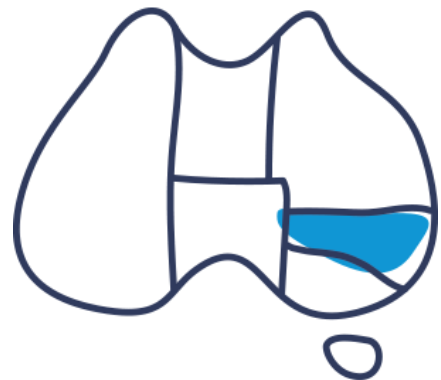
A. Connolly, S. Burns, S. Allingham, G. Bishop, L. Foskett & S. Clapham, A profile of patients receiving palliative care in NSW and ACT for July - December 2018 (Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong, 2019).

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palliative care
outcomes collaboration



A profile of patients receiving palliative care

NSW and ACT | July to December 2018

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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Suggested citation: Connolly A, Burns S, Allingham S, Bishop G, Foskett L and Clapham S (2019) *A profile of patients receiving palliative care in NSW and ACT for July – December 2018*. Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong

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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.

Published April 2019

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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 5,588 patients who received palliative care in NSW and ACT during July to December 2018 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 NSW and ACT, July – December 2018*.

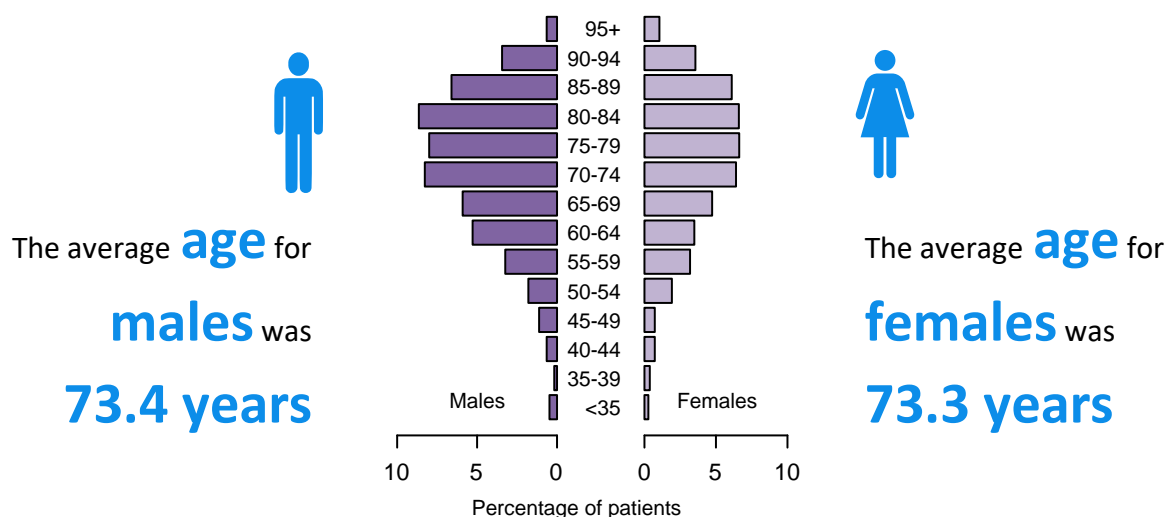
Patient characteristics

Table 1 describes the demographics of patients receiving palliative care.

Table 1 Patient demographic summary

Patient demographics		N	%
Sex	Male	3,028	54.2
	Female	2,558	45.8
Indigenous status	Aboriginal and/or Torres Strait Islander origin	93	1.7
	Not Aboriginal and/or Torres Strait Islander origin	5,356	95.8
Country of Birth	Born in Australia	3,302	59.1
	Born outside Australia	2,182	39.0
Preferred language	English	4,647	83.2
	Other than English	931	16.7
Primary diagnosis	Malignant	4,352	77.9
	Non-malignant	1,180	21.1
Age at beginning of episode	Average age	73.4	
	Median age	75.0	

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

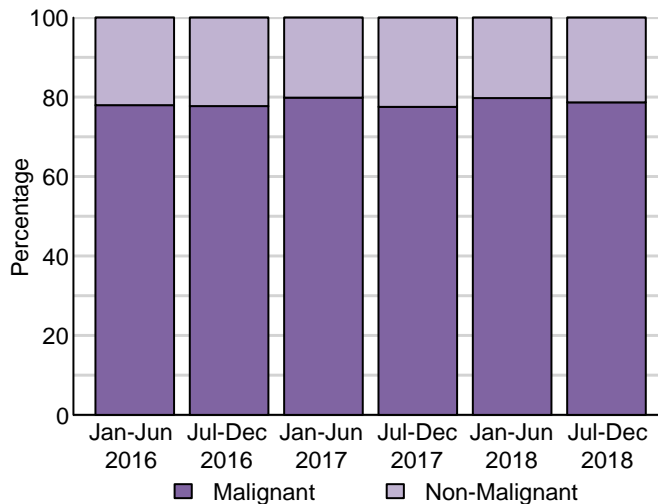
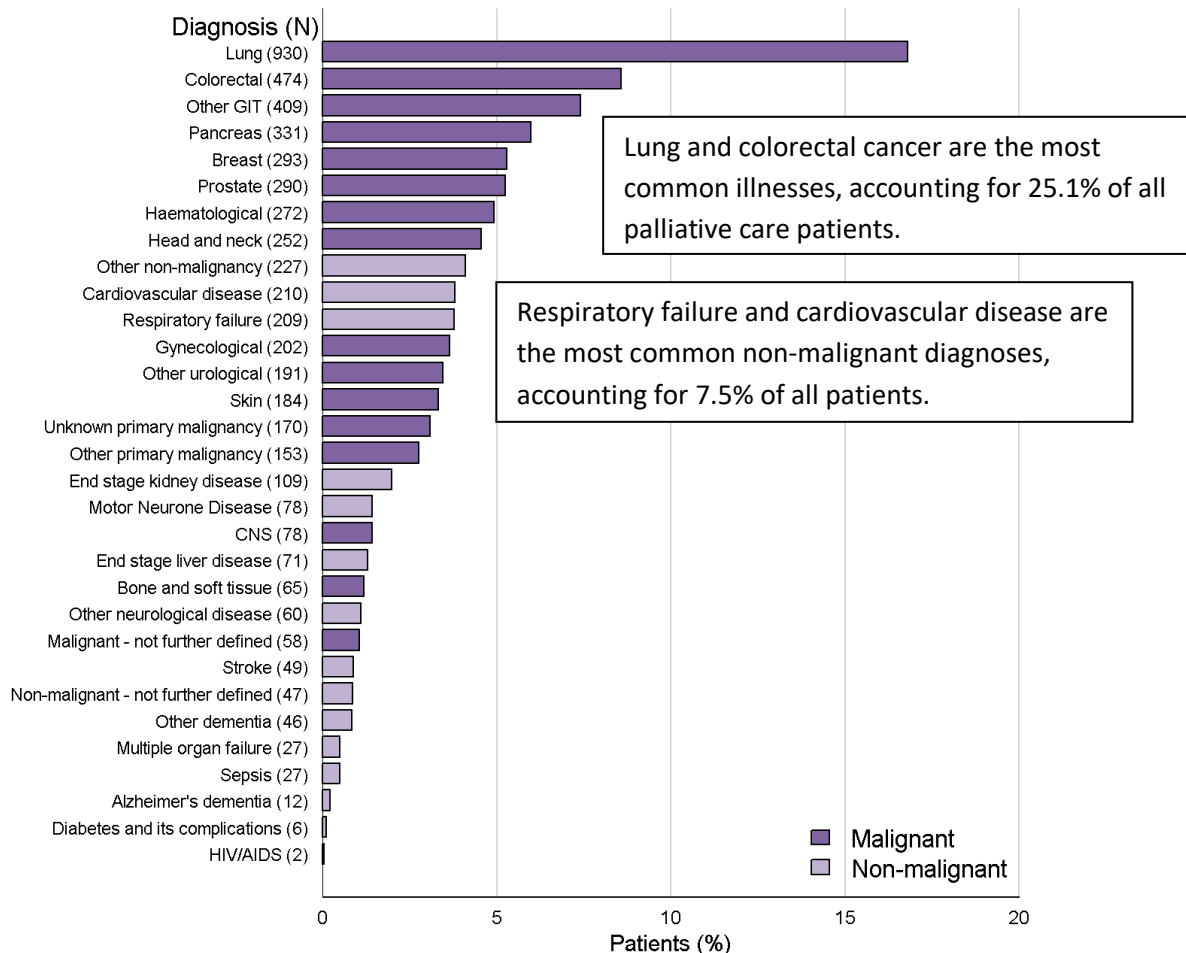


Figure 3 Diagnosis



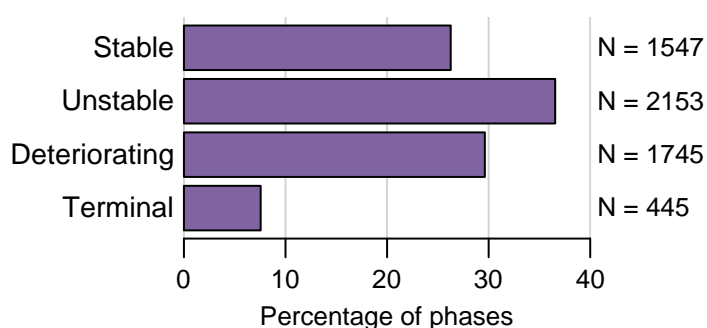
Referrals to palliative care

Table 2 Referral source over time

Referral Source	Jan-Jun 2016	Jul-Dec 2016	Jan-Jun 2017	Jul-Dec 2017	Jan-Jun 2018	Jul-Dec 2018
	N=4,291	N=4,602	N=5,116	N=5,296	N=5,930	N=5,890
Public hospital	52.3	51.1	55.1	54.8	57.8	61.1
Private hospital	3.4	3.9	4.8	5.1	5.2	4.4
Outpatient clinic	0.8	1.1	0.6	0.4	0.9	0.5
General practitioner	8.9	8.5	7.3	7.0	7.1	7.0
Specialist medical practitioner	11.4	11.6	9.6	9.5	9.1	6.3
Community palliative care service	19.0	19.9	18.6	19.3	16.0	15.8
Community generalist service	0.4	0.8	0.9	0.8	0.9	1.0
Residential aged care facility	1.4	0.7	1.1	0.9	0.7	0.7
Self, carer(s), family, friends	1.6	1.7	1.2	1.1	1.0	1.1
Other	0.7	0.7	0.7	0.9	0.9	0.9
Not stated/inadequately described	0.0	0.1	0.1	0.3	0.3	1.1
Total	100	100	100	100	100	100

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

Figure 4 Phase as beginning of episode



The most common first phase is

unstable

with an average duration of 2.1 days.

Figure 5 Phase at beginning of episode - over time

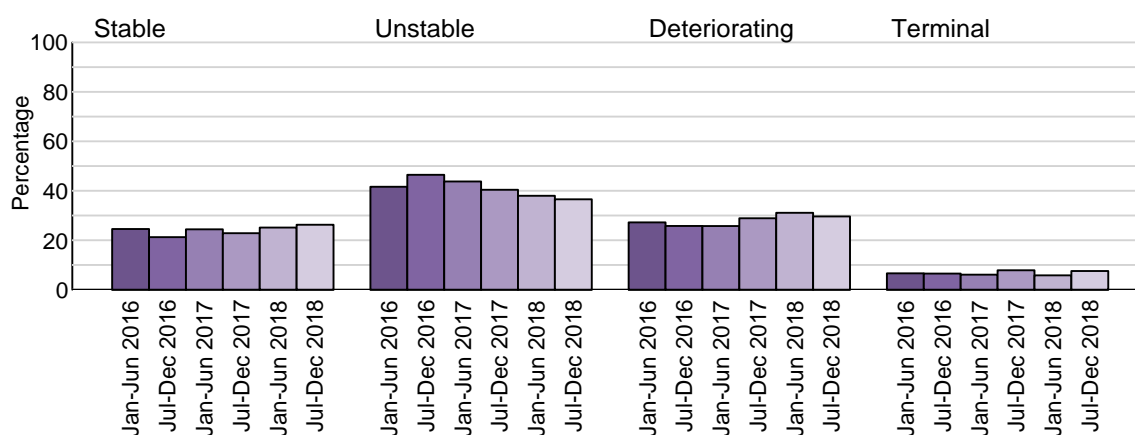


Figure 6 Symptoms and problems at episode start

Despite pain often being thought to be the most distressing symptom at the end of life, the patient rated symptom with the highest number of severe scores is fatigue (6.0%). The symptom causing the least distress is nausea, rated by patients as 'absent' 76.1% of the time.

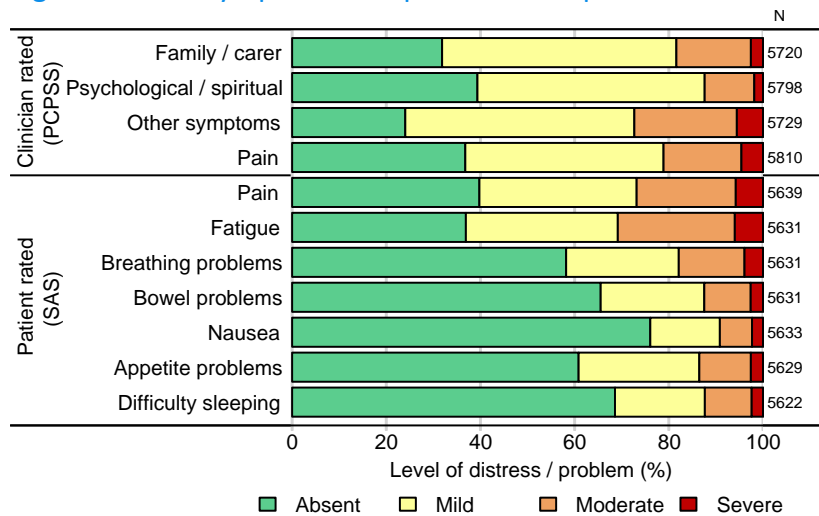


Figure 7 Moderate & severe problems at episode start (Clinician rated)

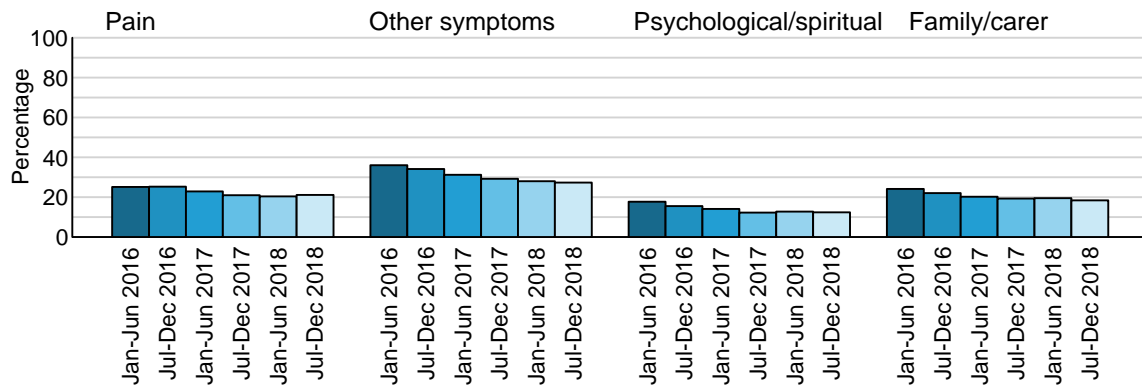
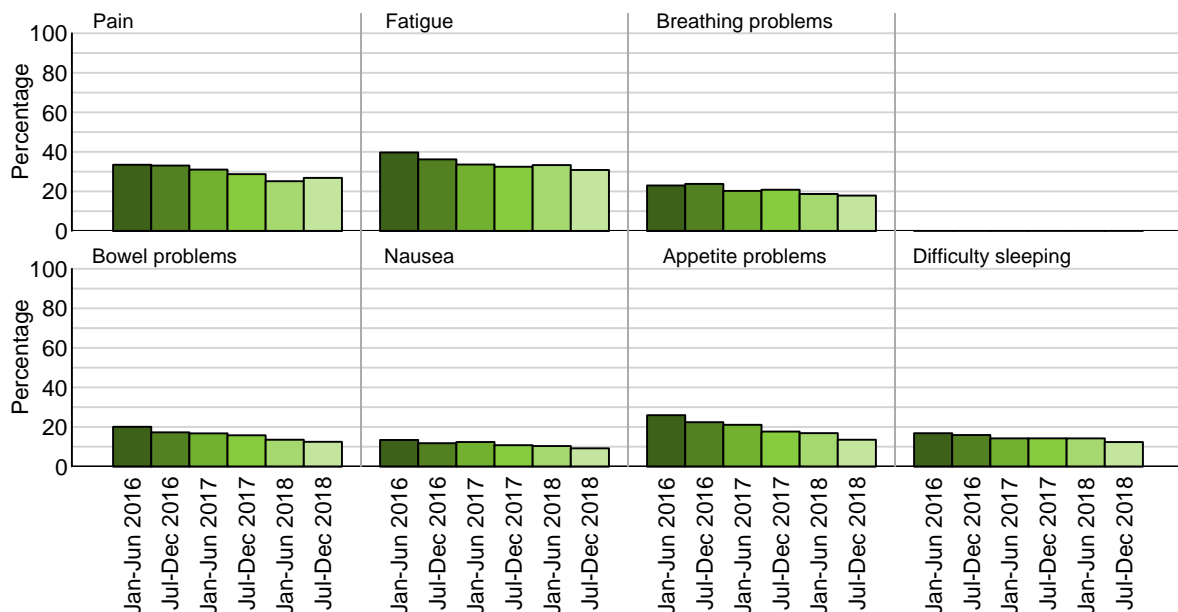


Figure 8 Moderate & severe symptom distress at episode start (Patient rated)



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 3 describes the number of phases and phase length.

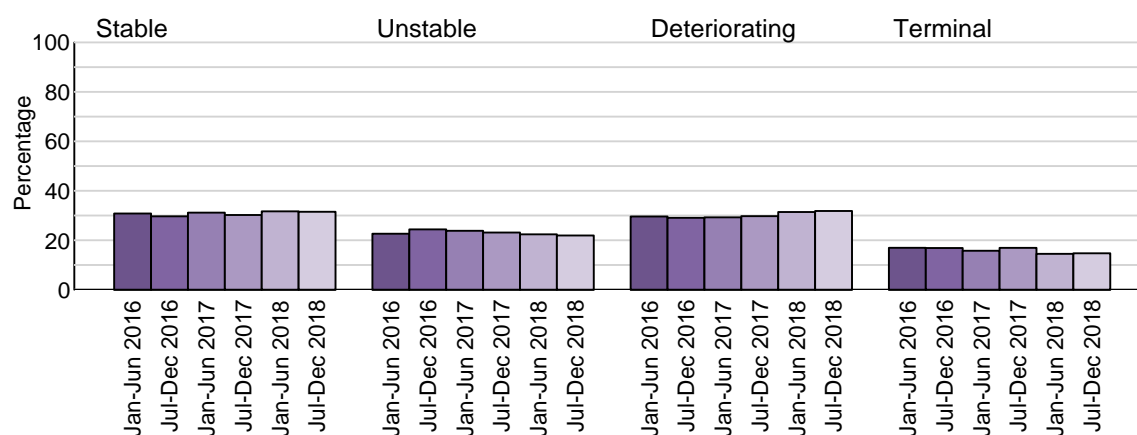
Table 3 Profile of palliative care phase

Phase type	N	%	Average phase length (days)
Stable	5,988	31.5	13.0
Unstable	4,166	21.9	2.2
Deteriorating	6,049	31.8	8.0
Terminal	2,798	14.7	2.1
All phases	19,001	100.0	7.3

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 8 days.

Figure 9 Phase profile overtime



Place of death

For July - December 2018, 3,058 patients died in the care of a specialist palliative care service. Of these deaths, 13.3% occurred at the persons home, 2.3% in a residential aged care facility and 83.9% in hospital.

Data included

Table 4 Data item completion

Patient level items		%
Date of birth		99.9
Sex		100.0
Indigenous status		97.5
Country of birth		98.1
Preferred language		99.8
Primary diagnosis		99.0
Episode level items		%
Date of first contact		98.8
Referral date		99.3
Referral source		98.9
Date ready for care		91.4
Mode of episode start		99.7
Accommodation at episode start		99.7
Episode end date		95.6
Mode of episode end		99.5
Accommodation at episode end		97.4
Place of death		97.3
Phase level items		%
Phase end reason		99.9
Clinical assessments (completion at phase start / discharge)		%
RUG-ADL Bed mobility		99.1 / 83.0
RUG-ADL Toileting		99.0 / 82.9
RUG-ADL Transfers		99.0 / 82.9
RUG-ADL Eating		98.6 / 82.3
PCPSS Pain		98.6 / 82.7
PCPSS Other symptoms		97.2 / 81.6
PCPSS Psychological / spiritual		98.3 / 82.3
PCPSS Family / carer		97.1 / 80.8
SAS Difficulty sleeping		94.6 / 79.0
SAS Appetite problems		94.6 / 79.1
SAS Nausea		94.8 / 79.4
SAS Bowel problems		94.7 / 79.4
SAS Breathing problems		94.8 / 79.9
SAS fatigue		94.7 / 79.5
SAS Pain		95.0 / 80.0
AKPS		96.5 / 83.6

Table 5 Number of patients, episodes and phases over time

	Jan-Jun 2016	Jul-Dec 2016	Jan-Jun 2017	Jul-Dec 2017	Jan-Jun 2018	Jul-Dec 2018
Patients	3,890	4,253	4,783	5,019	5,404	5,588
Episodes	4,871	5,222	5,925	6,149	6,863	6,967
Phases	12,731	14,283	15,620	15,990	18,142	19,001
Average number of phases per episode*	2.6	2.8	2.7	2.6	2.7	2.7

*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).