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**A profile of patients receiving palliative care in Australia for July –
December 2019**

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A profile of patients receiving palliative care in Australia for July – December 2019

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 26,586 patients who received palliative care during July to December 2019 and had their pain, symptom, family / carer and psychological / spiritual issues assessed as part of routine clinical care.

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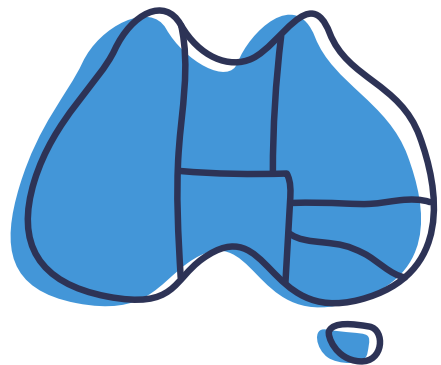
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palliative care
outcomes collaboration



A profile of patients receiving palliative care

National Report | 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 26,586 patients who received palliative care 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 Australia, July – December 2019*.

Patient characteristics

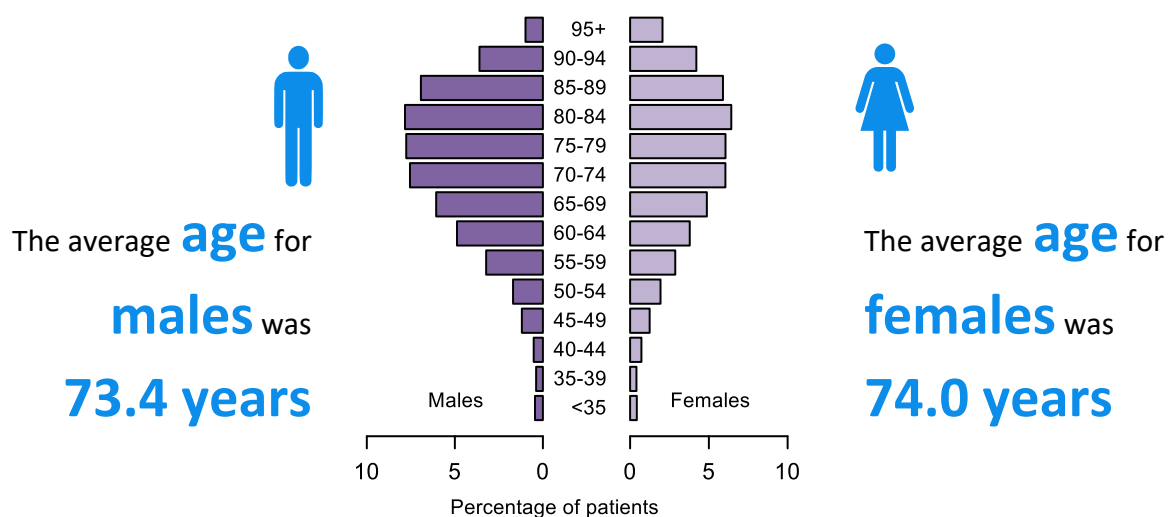
Table 1 describes the demographics of patients receiving palliative care.

Table 1 Patient demographic summary

Patient demographics		N	%
Sex	Male	13,862	52.1
	Female	12,717	47.8
Indigenous status	Aboriginal and/or Torres Strait Islander origin	410	1.5
	Not Aboriginal and/or Torres Strait Islander origin	25,239	94.9
Country of Birth	Born in Australia	16,584	62.4
	Born outside Australia	9,286	34.9
Preferred language	English	23,427	88.1
	Other than English	2,761	10.4
Primary diagnosis	Malignant	18,362	69.1
	Non-malignant	7,976	30.0
Age at beginning of episode	Average age	73.7	
	Median age	75.0	

*Age has been calculated from the beginning of the episode.

Figure 1 Patients by sex and age group



Primary 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

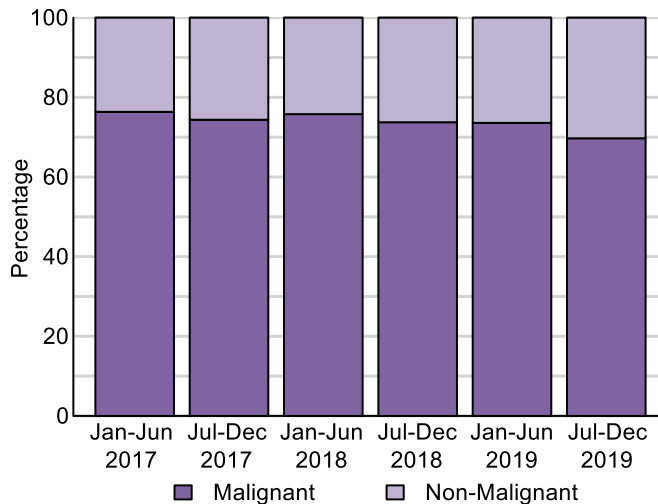
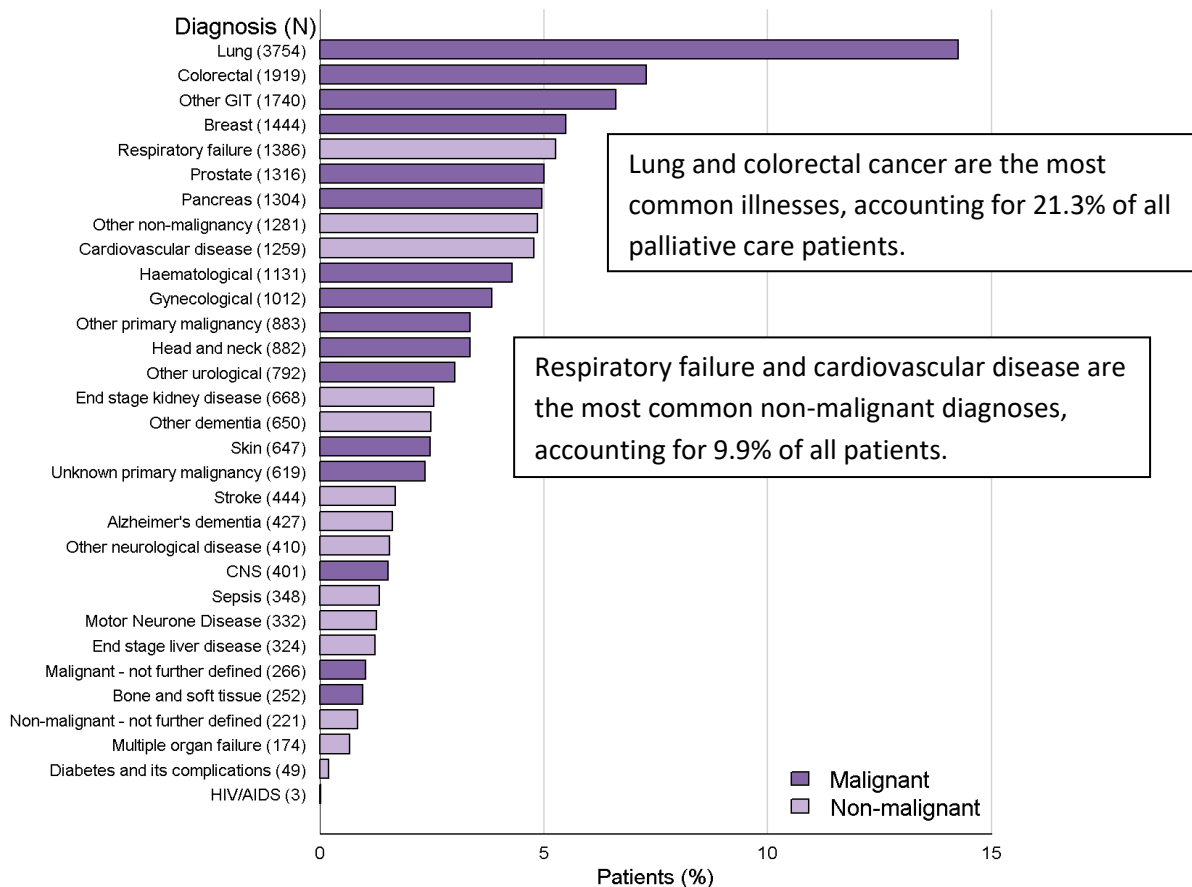


Figure 3 Diagnosis



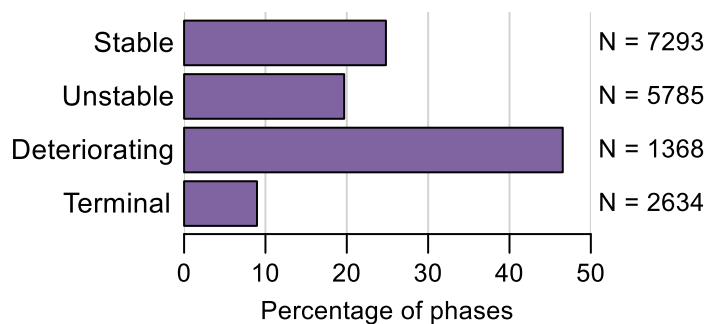
Referrals to palliative care

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=22,866	N=23,645	N=24,667	N=25,072	N=26,834	N=29,395
Public hospital	57.8	56.5	57.5	58.3	58.3	54.6
Private hospital	10.3	10.8	10.8	10.2	9.8	9.3
Outpatient clinic	0.5	0.6	0.8	0.6	0.7	0.8
General practitioner	8.1	8.0	7.5	7.8	7.5	7.2
Specialist medical practitioner	4.8	4.8	4.7	4.1	3.8	4.3
Community palliative care service	12.4	12.2	11.6	11.3	10.7	11.2
Community generalist service	0.6	0.6	0.6	0.6	0.5	0.5
Residential aged care facility	2.0	2.3	2.5	3.0	3.6	3.9
Self, carer(s), family, friends	1.5	1.7	1.9	1.7	1.6	1.6
Other	1.8	2.2	1.6	1.7	1.7	4.9
Not stated/inadequately described	0.3	0.4	0.5	0.7	1.8	1.6
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

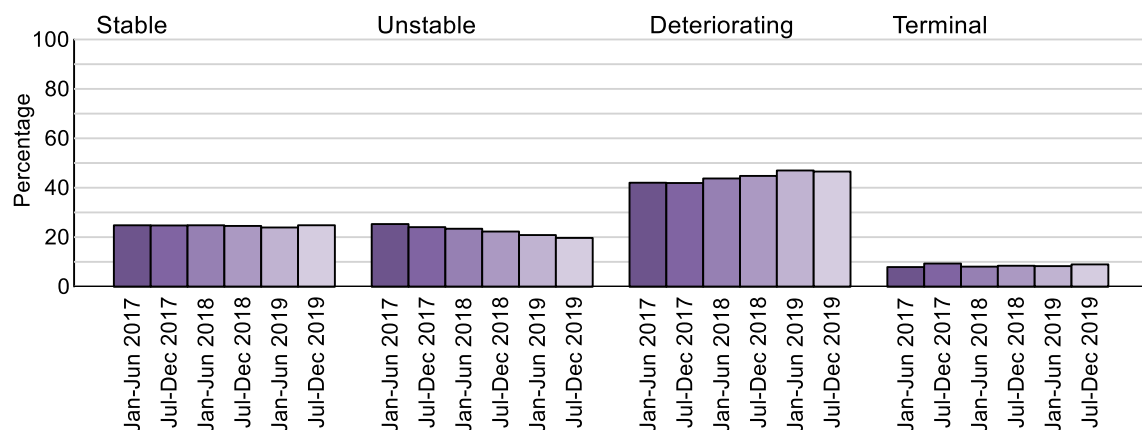


The most common first phase is

deteriorating

with an average duration of 8.5 days.

Figure 5 Phase at beginning of episode - over time



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 (4.7%). The symptom causing the least distress is nausea, rated by patients as 'absent' (76.9%) of the time.

Figure 6 Symptoms and problems at episode start

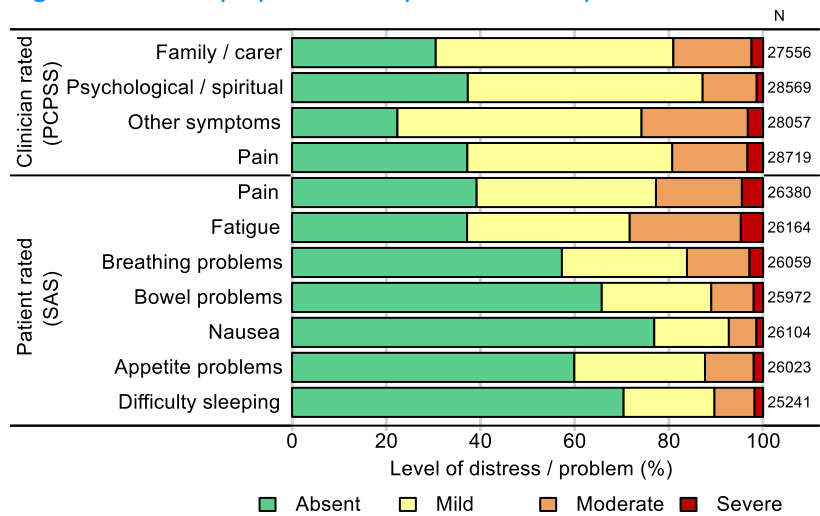


Figure 7 Moderate and severe problems at episode start over time (PCPSS)

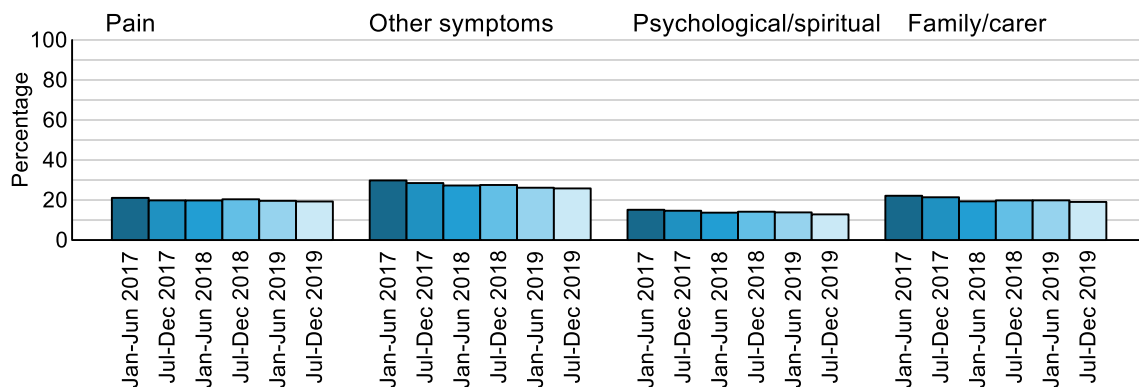
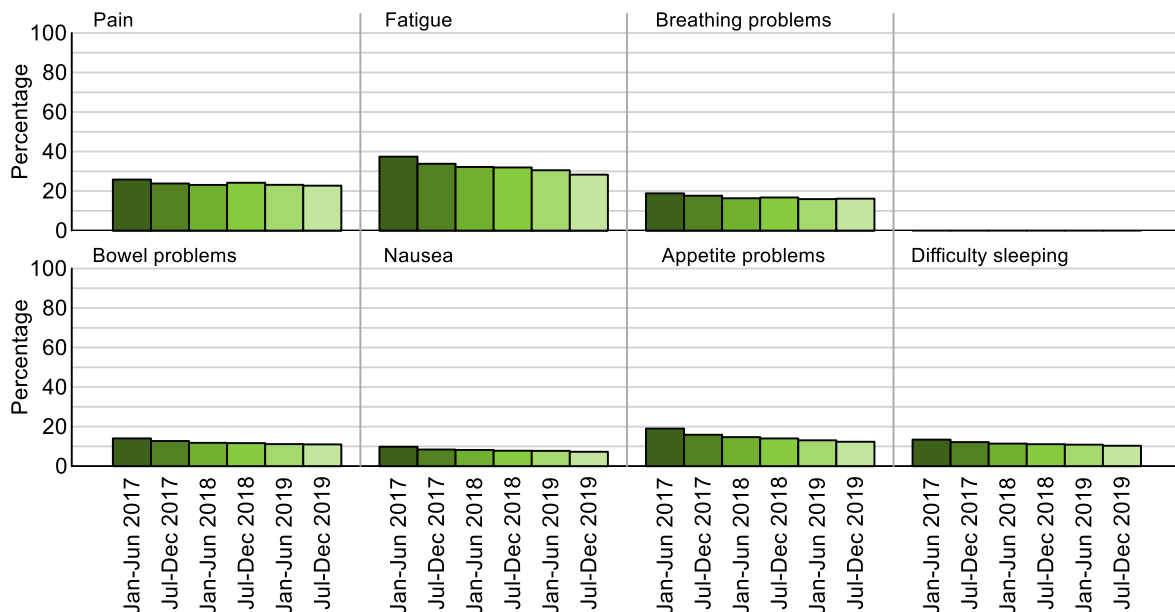


Figure 8 Moderate and severe symptoms distress at episode start over time (SAS)



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 3 describes the number of phases and phase length.

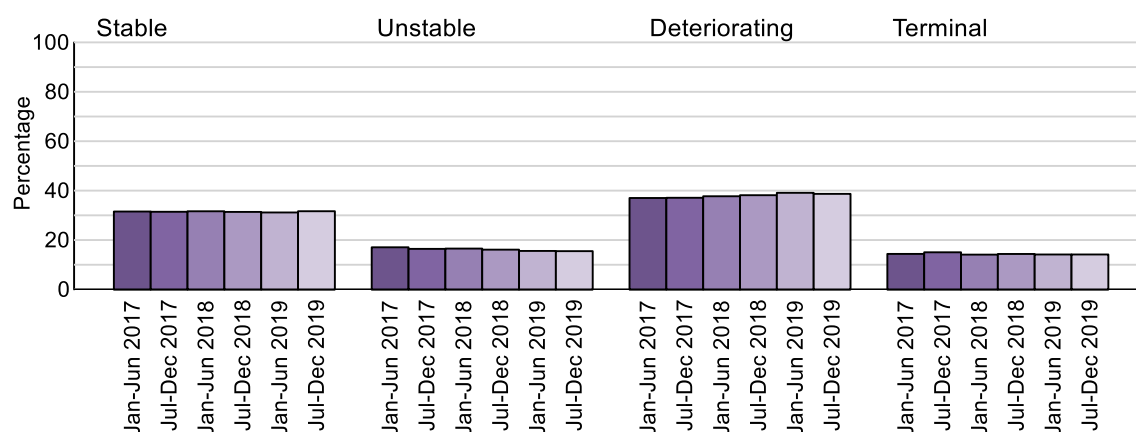
Table 3 Profile of palliative care phase

Phase type	N	%	Average phase length (days)
Stable	25,307	31.7	14.2
Unstable	12,391	15.5	2.2
Deteriorating	30,924	38.7	8.7
Terminal	11,312	14.2	2.3
All phases	79,934	100.0	8.4

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 8.7 days.

Figure 9 Phase profile overtime



Place of death

For July to December 2019, 12,569 patients died in the care of a specialist palliative care service. Of these deaths, 20.2% occurred at the persons home, 8.9% in a residential aged care facility and 70.3% in hospital.

Data included

Table 4 Data item completion

Patient level items		%
Date of birth		100.0
Sex		100.0
Indigenous status		96.5
Country of birth		97.3
Preferred language		98.6
Primary diagnosis		99.1
Episode level items		%
Date of first contact		99.6
Referral date		99.9
Referral source		98.5
Date ready for care		96.9
Mode of episode start		98.4
Accommodation at episode start		98.9
Episode end date		96.4
Mode of episode end		98.6
Accommodation at episode end		99.0
Place of death		97.8
Phase level items		%
Phase end reason		99.7
Clinical assessments (completion at phase start / discharge)		%
RUG-ADL Bed mobility		95.1 / 61.4
RUG-ADL Toileting		95.1 / 61.4
RUG-ADL Transfers		95.0 / 61.4
RUG-ADL Eating		94.6 / 61.2
PCPSS Pain		96.4 / 63.1
PCPSS Other symptoms		94.3 / 62.3
PCPSS Psychological / spiritual		95.8 / 62.8
PCPSS Family / carer		93.2 / 60.3
SAS Difficulty sleeping		87.6 / 54.5
SAS Appetite problems		89.7 / 55.8
SAS Nausea		90.5 / 56.5
SAS Bowel problems		89.8 / 55.8
SAS Breathing problems		90.2 / 56.4
SAS fatigue		90.7 / 56.7
SAS Pain		92.2 / 58.0
AKPS		95.9 / 62.3

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	21,055	21,801	22,454	23,337	24,564	26,586
Episodes	26,798	27,866	29,090	29,931	31,826	34,460
Phases	63,329	64,786	68,264	70,135	73,209	79,934
Average number of phases per episode*	2.3	2.3	2.3	2.3	2.2	2.2

*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).