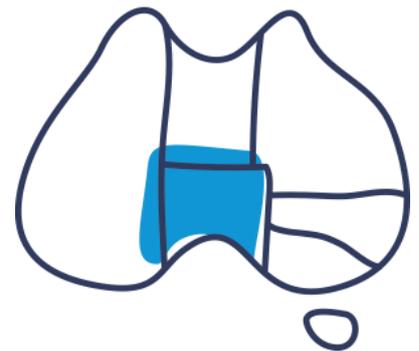




palliative care  
outcomes collaboration



# A profile of patients receiving palliative care

South Australia | 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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For additional information please contact:

The Palliative Care Outcomes Collaboration  
Building 234 (iC Enterprise 1), Innovation Campus  
University of Wollongong, NSW 2522  
Tel: +61 2 4221 5092  
email: [pcoc@uow.edu.au](mailto:pcoc@uow.edu.au)  
website: [www.pcoc.org.au](http://www.pcoc.org.au)

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 2,204 patients who received palliative care in South Australia during July to December 2019 and had their pain, symptom, family / carer and psychological / spiritual issues assessed as part of routine clinical care.

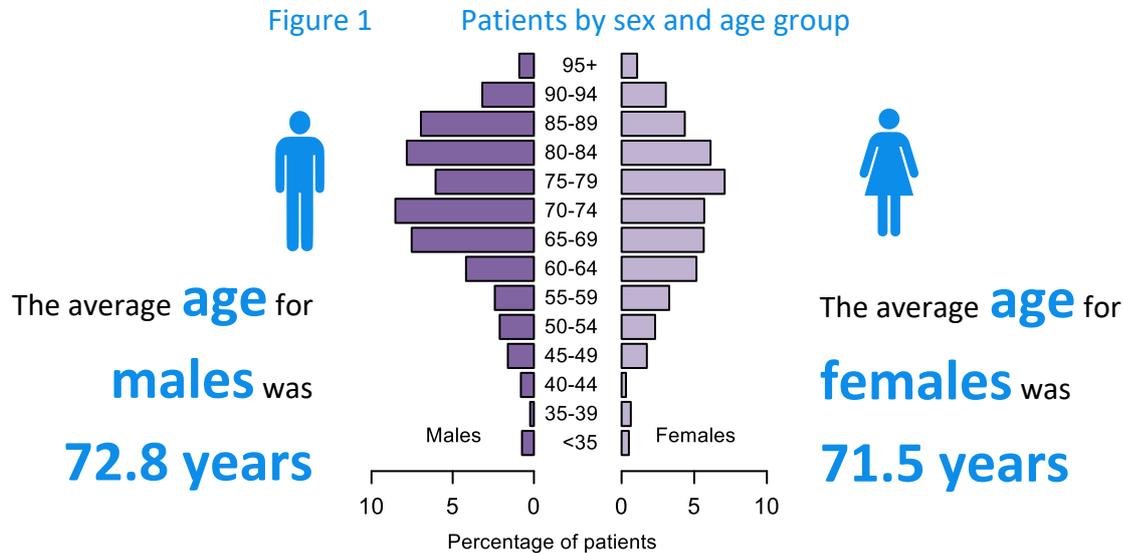
For more detailed information, including a summary of the national achievement against PCOC's 20 benchmarked patient outcome measures, please see the companion report *Patient outcomes in palliative care in South Australia, July - December 2019*.

## Patient characteristics

Table 1 describes the demographics of patients receiving palliative care.

Table 1 Patient demographic summary

Patient demographics		N	%
Sex	Male	1,181	53.6
	Female	1,023	46.4
Indigenous status	Aboriginal and/or Torres Strait Islander origin	33	1.5
	Not Aboriginal and/or Torres Strait Islander origin	2,035	92.3
Country of Birth	Born in Australia	1,372	62.3
	Born outside Australia	749	34.0
Preferred language	English	2,026	91.9
	Other than English	100	4.5
Primary diagnosis	Malignant	1,769	80.3
	Non-malignant	427	19.4
Age at beginning of episode	Average age	72.2	
	Median age	73.0	



## 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

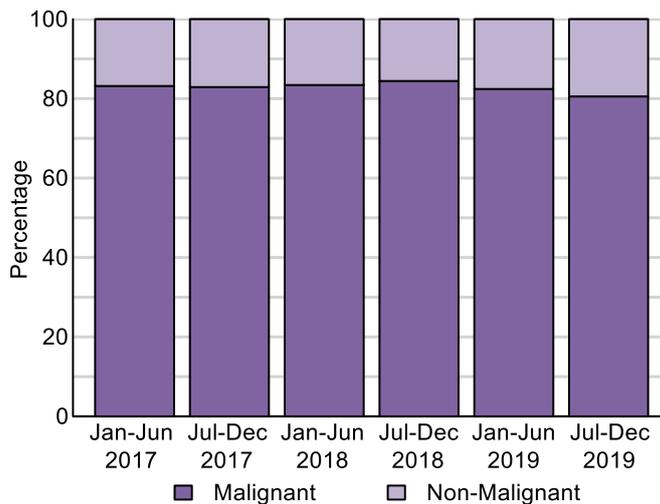
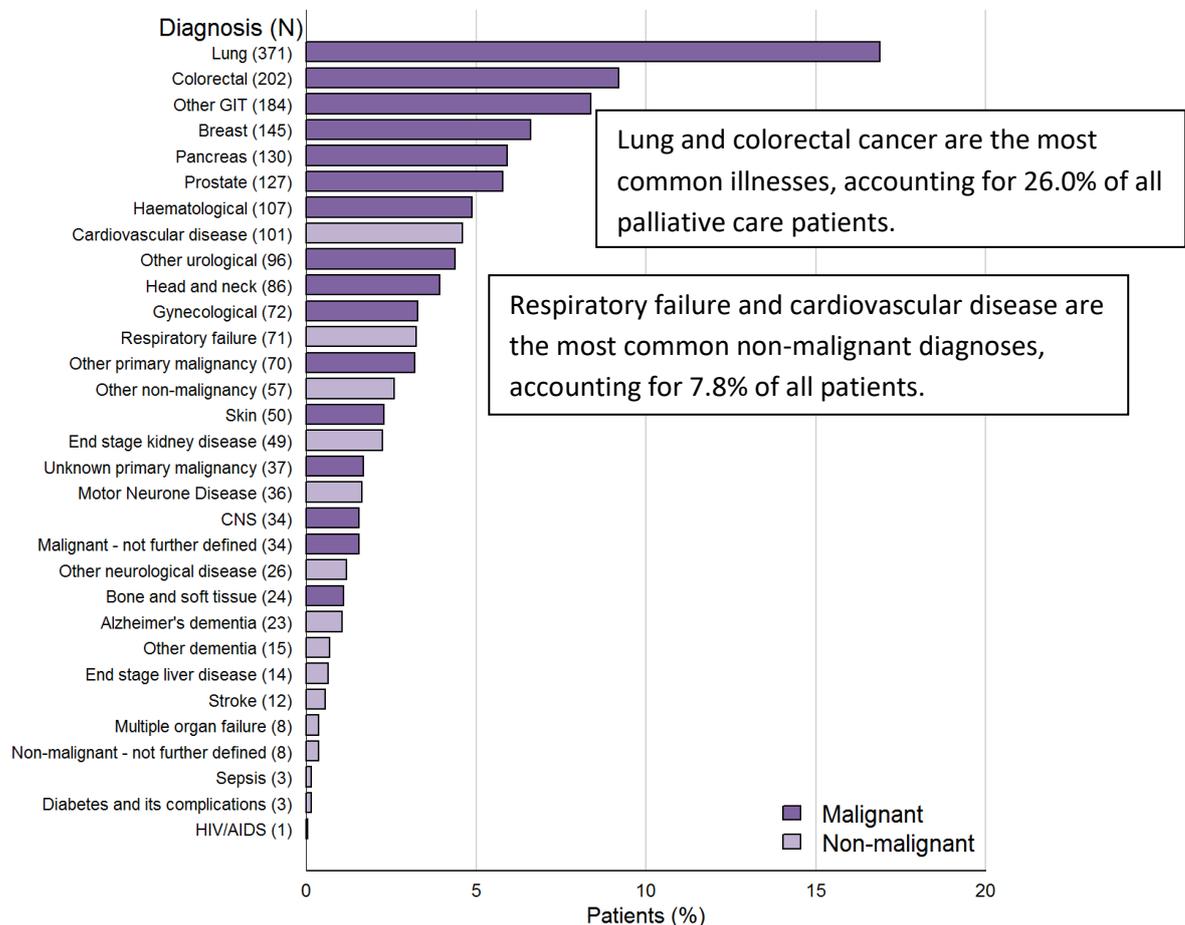


Figure 3 Diagnosis



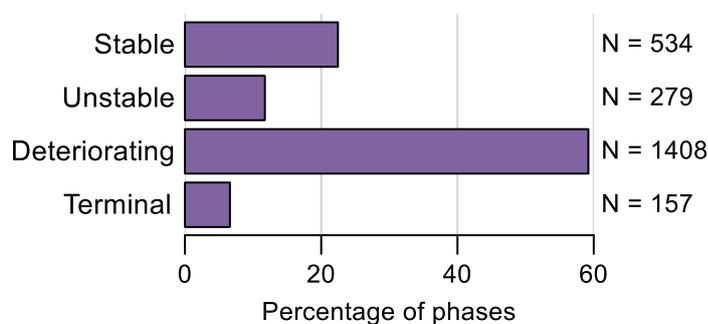
## Referrals to palliative care

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=1,647	N=1,737	N=1,896	N=1,946	N=1,939	N=2,378
Public hospital	53.7	55.5	54.4	55.6	56.1	51.1
Private hospital	9.8	10.2	11.4	9.6	10.3	9.4
Outpatient clinic	0.2	0.4	0.2	0.4	0.4	0.4
General practitioner	10.5	10.5	8.5	9.6	10.0	8.5
Specialist medical practitioner	1.5	1.6	1.5	1.6	1.8	1.8
Community palliative care service	16.7	14.3	14.5	15.4	14.9	23.0
Community generalist service	1.7	1.2	1.5	1.4	1.1	1.8
Residential aged care facility	1.0	0.6	0.9	0.8	1.3	0.7
Self, carer(s), family, friends	3.6	4.1	5.6	3.7	3.1	2.6
Other	0.9	0.9	0.8	0.7	0.3	0.4
Not stated/inadequately described	0.4	0.6	0.6	1.2	0.7	0.4
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>

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

Figure 4 Phase at beginning of episode

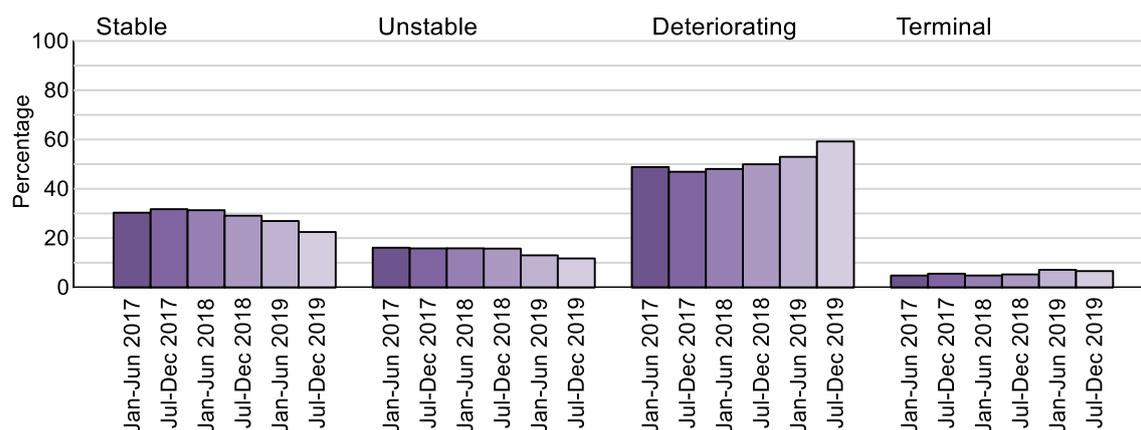


The most common first phase is

**deteriorating**

with an average duration of  
12.9 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 (6.6%). The symptom causing the least distress is nausea, rated by patients as 'absent' (72.5%) of the time.

Figure 6 Symptoms and problems at episode start

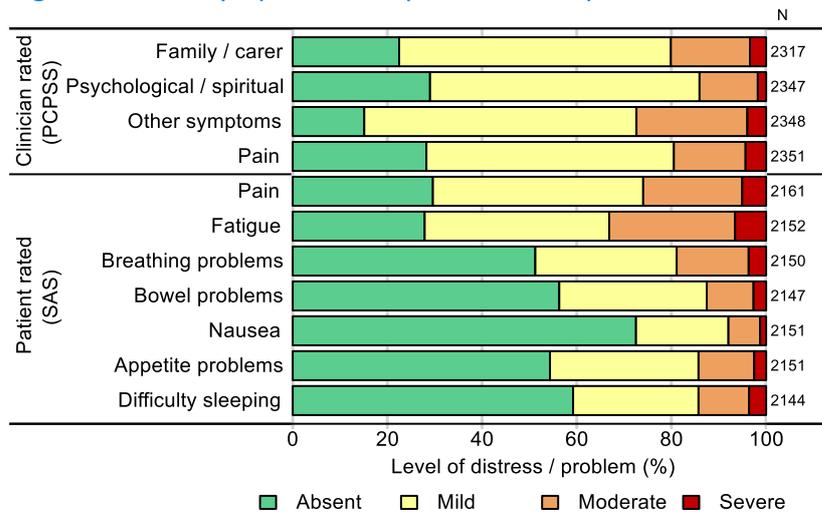


Figure 7 Moderate and severe problems at episode start over time (PCPSS)

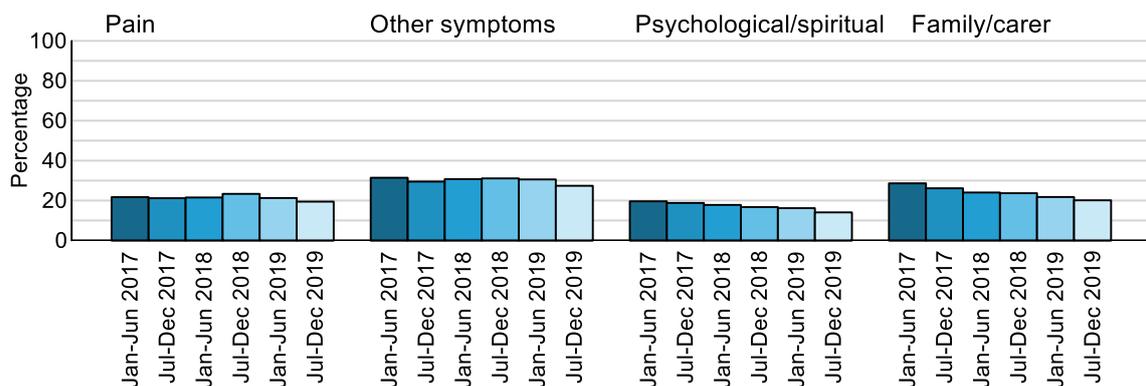
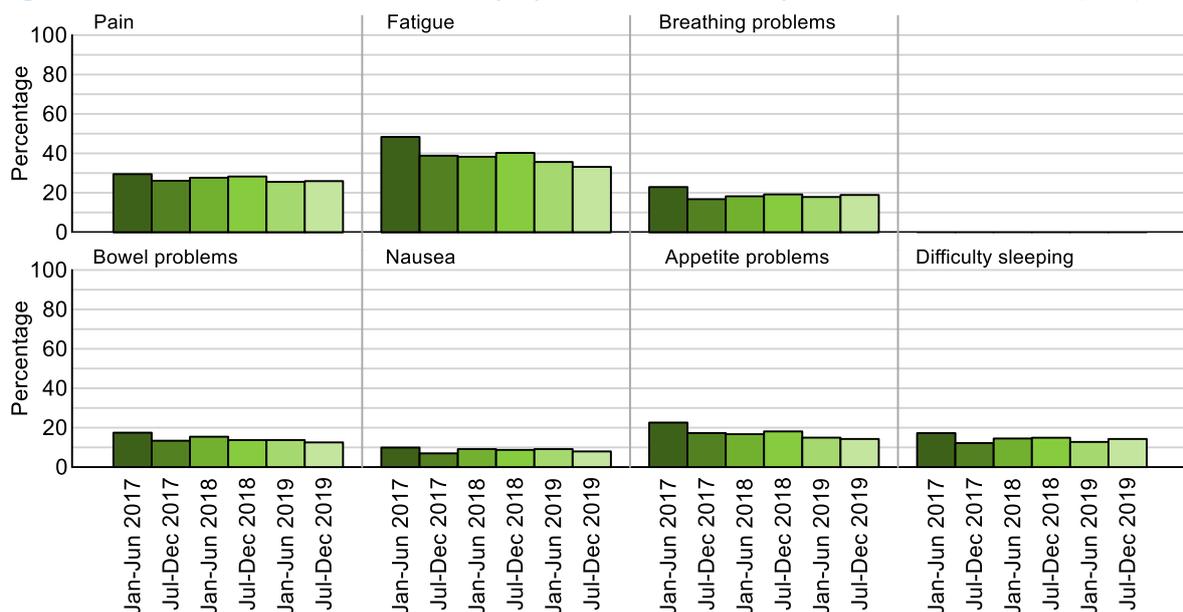


Figure 8 Moderate and severe symptoms distress at episode start over time (SAS)



## 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.

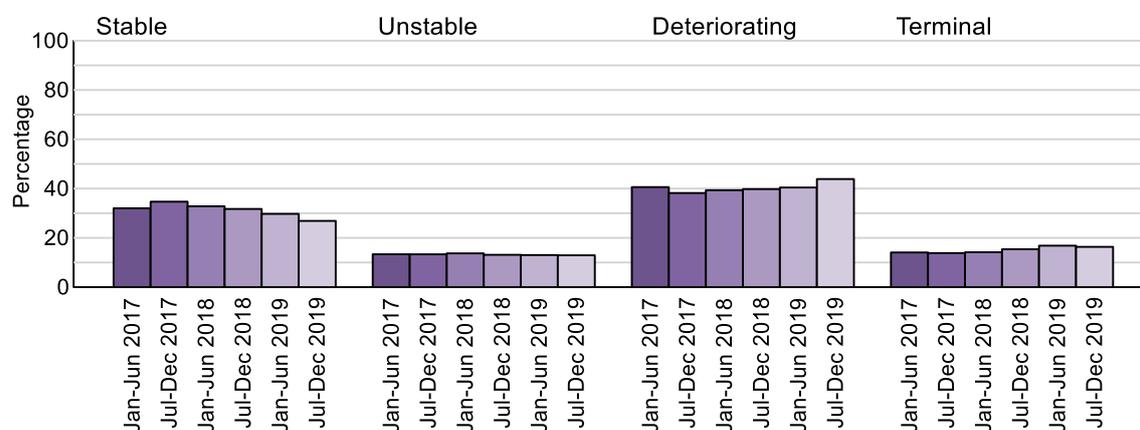
Table 3 Profile of palliative care phase

Phase type	N	%	Average phase length (days)
Stable	1,513	26.9	19.0
Unstable	727	12.9	2.5
Deteriorating	2,469	43.9	13.5
Terminal	920	16.3	2.4
All phases	5,629	100.0	11.3

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 13.5 days.

Figure 9 Phase profile overtime



## Place of death

For July to December 2019, 1,101 patients died in the care of a specialist palliative care service. Of these deaths, 38.1% occurred at the persons home, 5.6% in a residential aged care facility and 55.9% in hospital.

## Data included

Table 4 Data item completion

<b>Patient level items</b>		<b>%</b>
Date of birth		100.0
Sex		100.0
Indigenous status		93.8
Country of birth		96.2
Preferred language		97.3
Primary diagnosis		99.6
<b>Episode level items</b>		<b>%</b>
Date of first contact		100.0
Referral date		100.0
Referral source		99.5
Date ready for care		100.0
Mode of episode start		97.8
Accommodation at episode start		98.2
Episode end date		94.2
Mode of episode end		99.6
Accommodation at episode end		98.5
Place of death		99.4
<b>Phase level items</b>		<b>%</b>
Phase end reason		97.1
<b>Clinical assessments (completion at phase start / discharge)</b>		<b>%</b>
RUG-ADL Bed mobility		99.4 / 45.6
RUG-ADL Toileting		99.3 / 45.6
RUG-ADL Transfers		99.2 / 45.6
RUG-ADL Eating		98.1 / 45.5
PCPSS Pain		98.8 / 44.0
PCPSS Other symptoms		98.8 / 43.8
PCPSS Psychological / spiritual		98.7 / 44.0
PCPSS Family / carer		97.2 / 43.3
SAS Difficulty sleeping		90.5 / 41.7
SAS Appetite problems		90.6 / 41.7
SAS Nausea		90.7 / 41.8
SAS Bowel problems		90.6 / 41.7
SAS Breathing problems		90.7 / 42.0
SAS fatigue		90.8 / 42.0
SAS Pain		91.3 / 42.1
AKPS		99.1 / 44.4

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	1,541	1,753	1,770	1,903	1,845	2,204
Episodes	2,042	2,354	2,438	2,600	2,475	2,989
Phases	3,695	4,092	4,648	5,062	4,831	5,629
Average number of phases per episode*	1.9	1.8	2.0	2.0	2.0	1.9

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

## Glossary

<b>AKPS</b>	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.
<b>Episode</b>	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.
<b>Patient</b>	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.
<b>PCPSS</b>	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.
<b>Phase</b>	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.
<b>RUG-ADL</b>	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.
<b>SAS</b>	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).