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A profile of patients receiving palliative care in NSW and ACT for July – December 2019

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A profile of patients receiving palliative care in NSW and ACT 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 6,150 patients who received palliative care in NSW and ACT 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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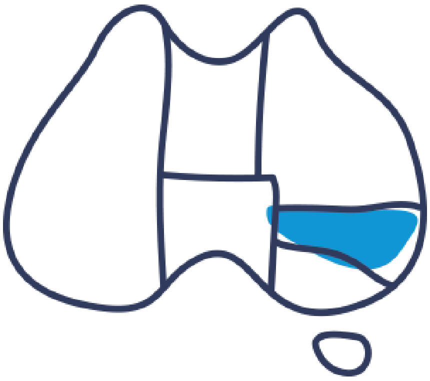
PCOC
palliative care
outcomes collaboration



A profile of patients receiving palliative care

NSW and ACT | July to December 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 6,150 patients who received palliative care in NSW and ACT 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 NSW and ACT, July to December 2019.*

Patient characteristics

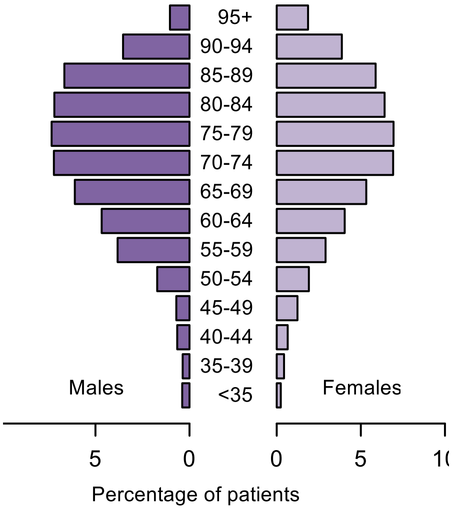
Table 1 describes the demographics of patients receiving palliative care.

Table 1 Patient demographic summary

Patient demographics		N	%
Sex	Male	3,157	51.3
	Female	2,993	48.7
Indigenous status	Aboriginal and/or Torres Strait Islander origin	127	2.1
	Not Aboriginal and/or Torres Strait Islander origin	5,862	95.3
Country of Birth	Born in Australia	3,785	61.5
	Born outside Australia	2,223	36.1
Preferred language	English	5,164	84.0
	Other than English	919	14.9
Primary diagnosis	Malignant	4,549	74.0
	Non-malignant	1,562	25.4
Age at beginning of episode	Average age	73.5	
	Median age	75.0	

Figure 1 Patients by sex and age group

The average **age** for **males** was **73.4 years**



The average **age** for **females** was **73.5 years**

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

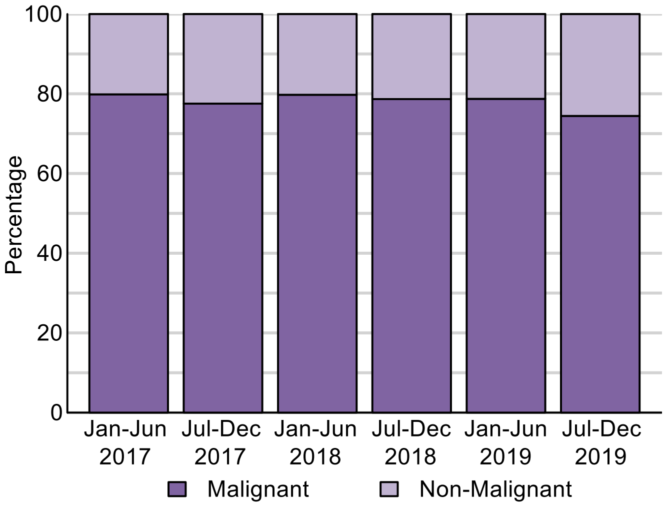
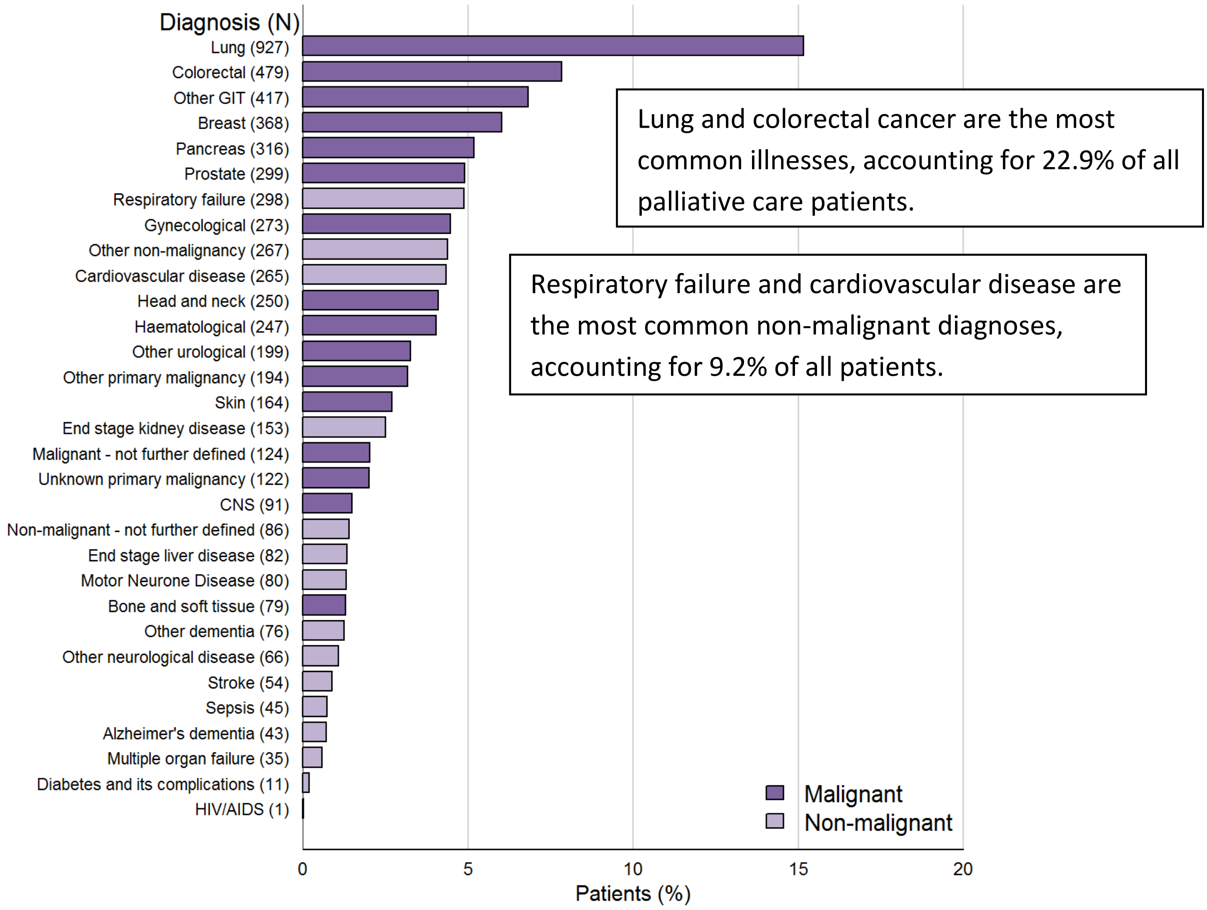


Figure 3 Diagnosis



Lung and colorectal cancer are the most common illnesses, accounting for 22.9% of all palliative care patients.

Respiratory failure and cardiovascular disease are the most common non-malignant diagnoses, accounting for 9.2% of all patients.

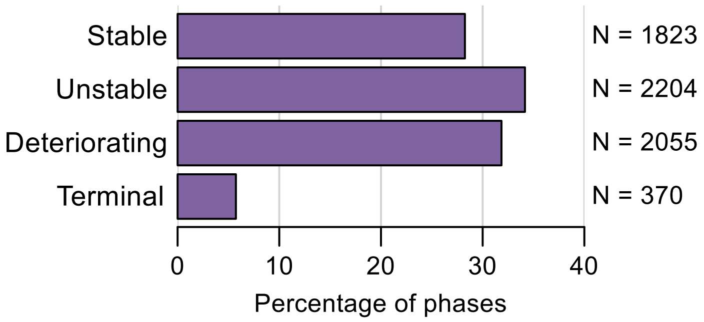
Referrals to palliative care

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=5,116	N=5,296	N=5,930	N=5,890	N=6,140	N=6,452
Public hospital	55.1	54.8	57.8	61.1	59.6	59.8
Private hospital	4.8	5.1	5.2	4.4	6.1	6.2
Outpatient clinic	0.6	0.4	0.9	0.5	0.5	0.4
General practitioner	7.3	7.0	7.1	7.0	6.6	7.2
Specialist medical practitioner	9.6	9.5	9.1	6.3	6.7	7.1
Community palliative care service	18.6	19.3	16.0	15.8	15.7	14.6
Community generalist service	0.9	0.8	0.9	1.0	0.9	0.9
Residential aged care facility	1.1	0.9	0.7	0.7	0.5	0.8
Self, carer(s), family, friends	1.2	1.1	1.0	1.1	1.3	1.2
Other	0.7	0.9	0.9	0.9	0.7	0.7
Not stated/inadequately described	0.1	0.3	0.3	1.1	1.3	1.0
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

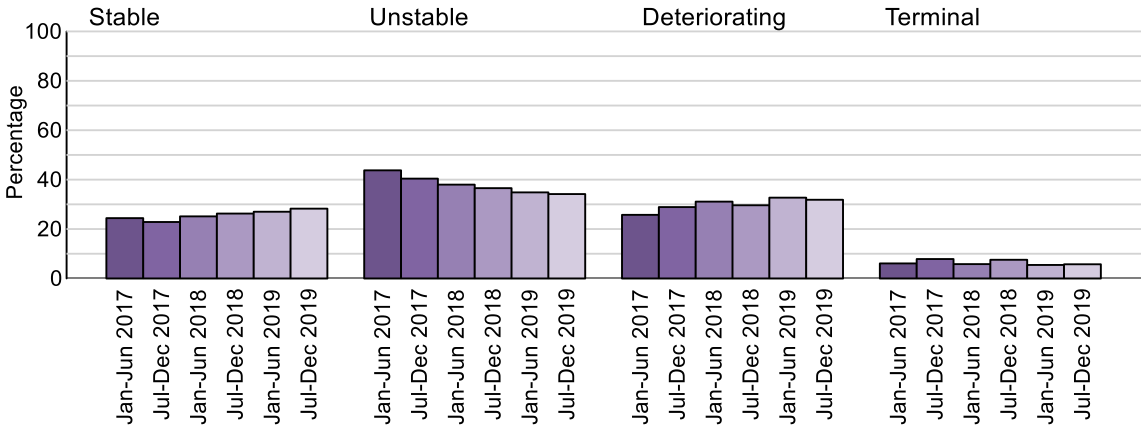


The most common first phase is

unstable

with an average duration of 2.2 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 (5.9%). The symptom causing the least distress is nausea, rated by patients as 'absent' (74.8%) of the time.

Figure 6 Symptoms and problems at episode start

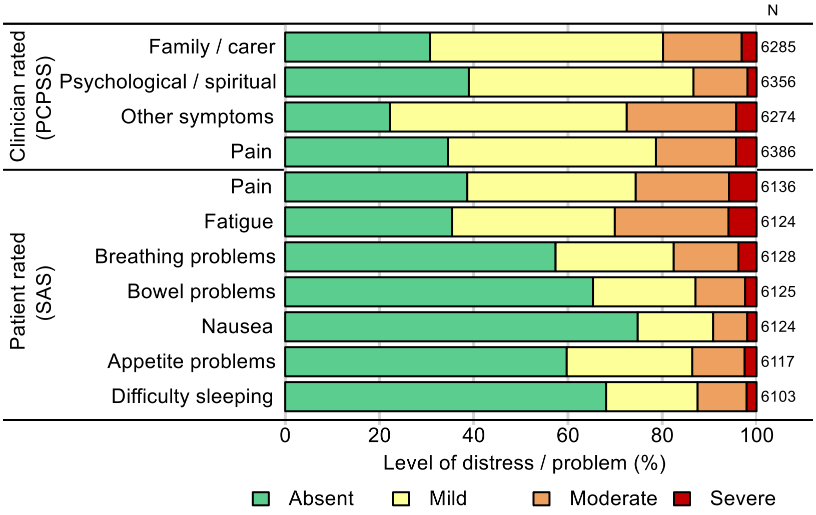


Figure 7 Moderate and severe problems at episode start over time (PCPSS)

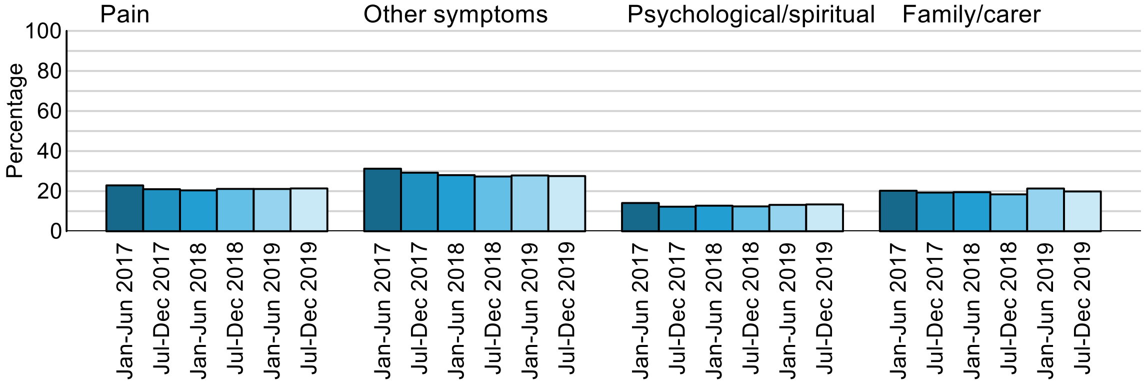
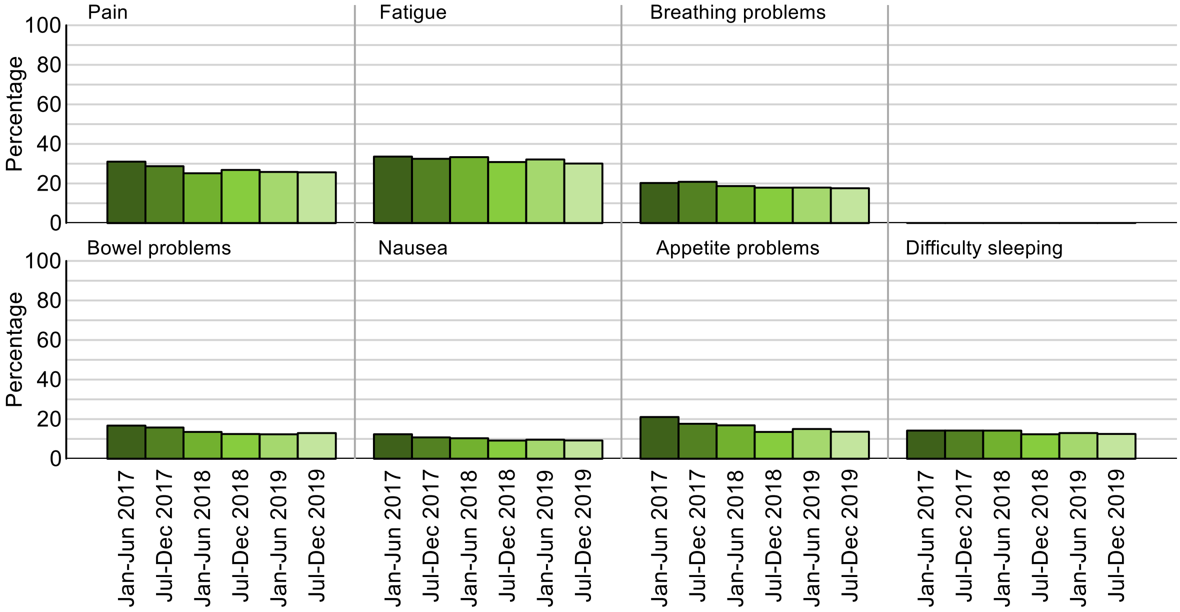


Figure 8 Moderate and severe symptoms distress at episode start over time (SAS)



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.

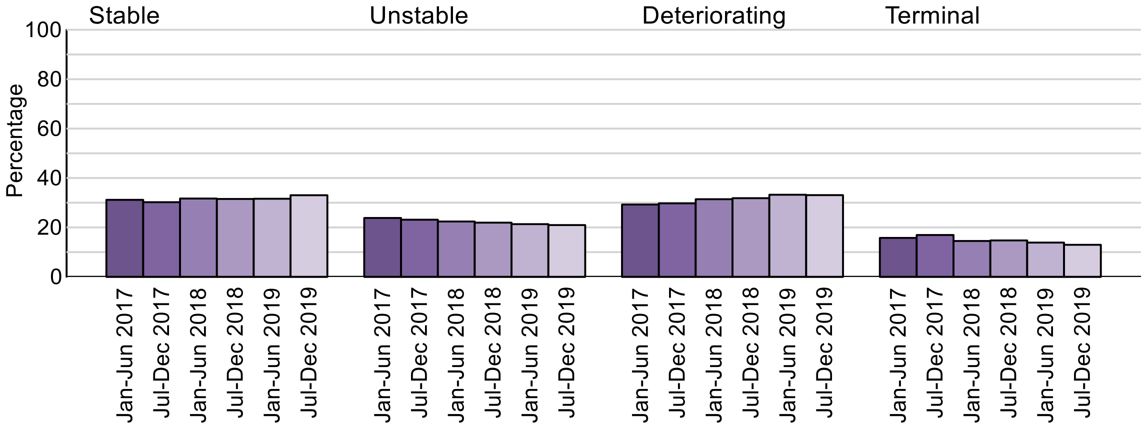
Table 3 Profile of palliative care phase

Phase type	N	%	Average phase length (days)
Stable	7,049	33.0	14.1
Unstable	4,471	20.9	2.4
Deteriorating	7,058	33.1	7.3
Terminal	2,765	13.0	2.1
All phases	21,343	100.0	7.7

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 7.3 days.

Figure 9 Phase profile overtime



Place of death

For July - December 2019, 6,478 patients died in the care of a specialist palliative care service. Of these deaths, 14.7% occurred at the persons home, 3.1% in a residential aged care facility and 80.9% in hospital.

Data included

Table 4 Data item completion

Patient level items	%
Date of birth	100.0
Sex	100.0
Indigenous status	97.4
Country of birth	97.7
Preferred language	99.0
Primary diagnosis	99.4
Episode level items	**%**
Date of first contact	98.5
Referral date	99.8
Referral source	99.0
Date ready for care	90.6
Mode of episode start	99.8
Accommodation at episode start	99.7
Episode end date	96.1
Mode of episode end	99.7
Accommodation at episode end	97.9
Place of death	93.6
Phase level items	**%**
Phase end reason	100.0
Clinical assessments (completion at phase start / discharge)	**%**
RUG-ADL Bed mobility	99.0 / 72.6
RUG-ADL Toileting	99.0 / 72.6
RUG-ADL Transfers	98.9 / 72.6
RUG-ADL Eating	98.5 / 72.3
PCPSS Pain	98.7 / 72.4
PCPSS Other symptoms	97.1 / 71.5
PCPSS Psychological / spiritual	98.3 / 71.9
PCPSS Family / carer	97.1 / 71.1
SAS Difficulty sleeping	94.2 / 67.7
SAS Appetite problems	94.2 / 67.7
SAS Nausea	94.5 / 67.8
SAS Bowel problems	94.4 / 67.9
SAS Breathing problems	94.5 / 68.1
SAS fatigue	94.4 / 67.9
SAS Pain	94.7 / 68.4
AKPS	99.0 / 75.4

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	4,783	5,019	5,404	5,588	5,873	6,150
Episodes	5,925	6,149	6,863	6,967	7,383	7,738
Phases	15,620	15,990	18,142	19,001	20,204	21,343
Average number of phases per episode*	2.7	2.6	2.7	2.7	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).