

# Patient outcomes in Palliative Care:

Results for Western Australia

January – June 2016

**Detailed report** 

September 2016

PCOC is a national palliative care project funded by the Australian Government Department of Health

www.pcoc.org.au

#### **About the Palliative Care Outcomes Collaboration**

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice. This is achieved via the PCOC patient outcome improvement framework which is designed to:

- provide clinicians with the tools to systematically assess individual patient experiences using validated clinical assessment tools,
- define a common clinical language to streamline communication between palliative care providers,
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking,
- provide service-to-service benchmarking reports and opportunities to discuss sector results at benchmarking workshops, and
- support research using the PCOC longitudinal database (2006-2016).

The PCOC dataset includes the clinical assessment tools: Palliative Care Phase, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status (AKPS) scale and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

PCOC has divided Australia into four zones for the purpose of engaging with palliative care service providers. Each zone is represented by a chief investigator from one of the collaborative centres. The four PCOC zones and their respective chief investigators are:



Each zone is also represented by one or more quality improvement facilitators, whose role includes supporting services to participate in PCOC and facilitating ongoing service development and quality improvement. The national team, located within the Australian Health Services Research Institute at the University of Wollongong, coordinates the patient outcomes reporting, education program, and quality activities across the four zones.

If you would like more information or have any queries about this report please contact your local quality improvement facilitator or contact the national office at <a href="mailto:pcoc@uow.edu.au">pcoc@uow.edu.au</a> or phone (02) 4221 4411.



# **Table of Contents**

Introduct	tion	1
Section 1	Benchmark summary for WA Services	3
Section 2	Benchmark summary for WA Services	4
2.1	Outcome measure 1 – Time from date ready for care to episode start	
2.2	Outcome measure 2 – Time in unstable phase	6
2.3	Outcome measure 3 – Change in pain	8
2.4	Outcome measure 3 – Change in distress from fatigue	11
2.5	Outcome measure 3 – Change in distress from breathing problems	13
2.6	Outcome measure 3 – Change in family / carer problems	15
	Outcome measure 4 – Change in symptoms relative to the baseline national average (X-CAS)	
Section 3	Descriptive analysis	21
3.1	Profile of palliative care patients	22
3.2	Profile of palliative care episodes	27
3.3	Profile of palliative care phases	33
Appendix	α A Summary of data included in this report	45
A1 Dat	a summary	45
A2 Dat	ra item completion	47
Appendix	R Additional information on profile of SAS and PCPSS	49
	C Data scoping method	
Appendix	CD How to interpret benchmark profile graphs	52
Appendix	¢ E Palliative Care Phase definitions	53
Acknowle	edgements	54



# **List of Tables**

Table 1 List of Western Australian Services included in this report	2
Table 2 Summary of outcome measures by setting	3
Table 3 Time from date ready for care to episode start by setting	4
Table 4 Time in unstable phase by setting	6
Table 5 Summary of outcome measure 3 – change in pain	8
Table 6 Summary of outcome measure 3 – distress from fatigue	11
Table 7 Summary of outcome measure 3 – distress from breathing problems	13
Table 8 Summary of outcome measure 3 – family / carer problems	15
Table 9 Summary of outcome measure 4 – inpatient setting	17
Table 10 Summary of outcome measure 4 – community setting	18
Table 11 Indigenous status	22
Table 12 Place of death	22
Table 13 Country of birth	23
Table 14 Preferred language	24
Table 15 Primary diagnosis - malignant	25
Table 16 Primary diagnosis - non-malignant	26
Table 17 Age group by sex	27
Table 18 Referral source by setting	28
Table 19 Referral to first contact by setting	29
Table 20 Length of episode (in days) summary by setting	30
Table 21 Length of episode (in days) by setting	30
Table 22 How episodes start – inpatient setting	31
Table 23 How episodes end – inpatient setting	31
Table 24 How episodes start – community setting	32
Table 25 How episodes end – community setting	32
Table 26 Number of phases by phase type and setting	33
Table 27 Average phase length (in days) by phase type and setting	33
Table 28 How stable phases end – by setting	34
Table 29 How unstable phases end – by setting	35
Table 30 How deteriorating phases end – by setting	36
Table 31 How terminal phases end – by setting	37



Table 32	Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)	.38
Table 33	Profile of PCPSS at beginning of phase by phase type –community setting (percentages)	.39
Table 34	Profile of SAS scores at beginning of phase by phase type – inpatient setting (percentages)	.40
Table 35	Profile of SAS scores at beginning of phase by phase type –community setting (percentages)	41
Table 36	Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting	42
Table 37	Number and percentage of patients, episodes and phases by setting	45
Table 38	Number of completed episodes and phases by month and setting	46
Table 39	Number of patients, episodes and phases by setting and reporting period	46
Table 40	Item completion (per cent complete) - patient level	.47
Table 41	Item completion by setting (per cent complete) - episode level	47
Table 42	Item completion by setting (per cent complete) - phase level	48



# **List of Figures**

Figure 1 Time from date ready for care to episode start, Western Australian services compared to all services (BM1)	5
Figure 2 Time in unstable phase, Western Australian services compared to all services (BM2)	7
Figure 3 Clinician rated change in pain, Western Australian services compared to all services (PCPSS, BM3.1 and 3.2)	9
Figure 4 Patient rated change in pain, Western Australian services compared to all services (SAS, BM3.3 and 3.4)	10
Figure 5 Patient rated change in fatigue, Western Australian services compared to all services (SAS, BM3.5 and 3.6)	12
Figure 6 Patient rated change in breathing problems, Western Australian services compared to all services (SAS, BM3.7 and 3.8)	14
Figure 7 Clinician rated change in family / carer problems, Western Australian services compared to all services (SAS, BM3.9 and 3.10)	16
Figure 8 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – inpatient setting	19
Figure 9 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – community setting	19
Figure 10 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – inpatient setting	20
Figure 11 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – community setting	
Figure 12 Stable phase progression	35
Figure 14 Deteriorating phase progression	36
Figure 14 Deteriorating phase progression	37
Figure 16 Total RUG-ADL at beginning of phase by phase type – inpatient setting	43
Figure 17 Total RUG-ADL at beginning of phase by phase type – community setting	
Figure 18 Profile of SAS and PCPSS by phase type for WA Services – inpatient setting	
Figure 19 Profile of SAS and PCPSS by phase type for WA Services – community setting	50
Figure 20 Diagram of the PCOC data scoping method	51



#### Introduction

The Palliative Care Outcomes Collaboration (PCOC) assists services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this patient outcome report, data submitted for the January to June 2016 period are summarised and patient outcomes benchmarked. The purpose of benchmarking is to drive palliative care service innovation and provide participating services with the opportunity to compare their service nationally.

Patient outcomes are reported for a total of 19,117 patients, with 24,696 episodes of care and 56,976 palliative care phases. The information included in this report is determined by a data scoping method. See Appendix A for more information on the data included in this report.

Throughout this report, patient information for Western Australian services is presented alongside the national figures for comparative purposes. The national figures are based on information submitted by 95 services, of which:

- 59 are inpatient services. Inpatient services include patients who have been seen in designated palliative care beds as well as non-designated bed consultations.
- 23 are community services. These services include primarily patients seen in the community as well as some patients with ambulatory/clinic episodes.
- 13 are services with both inpatient and community settings.

The Western Australian figures in this report are based on information submitted by 9 Services. A list of these Services is presented in Table 1 on the following page. A full list of the Services included in the national figures can be found at <a href="https://www.pcoc.org.au">www.pcoc.org.au</a>.

#### **Interpretation hint:**

Some tables throughout this report may be incomplete. This is because some items may not be applicable to Western Australian services or it may be due to data quality issues.

Please use the following key when interpreting the tables:

- na The item is not applicable.
- u The item was unavailable.
- s The item was suppressed due to insufficient data as there was less than 10 observations.



Table 1 List of Western Australian Services included in this report

Service name	Setting of care
Bethesda Hospital	Inpatient
Metropolitan Palliative Care Consultancy Service	Community
Northam Palliative Care	Inpatient and community
Royal Perth Hospital	Inpatient
Royal Perth Hospital - Nurse Practitioner	Inpatient
Silver Chain Hospice Care Service	Community
St John of God - Murdoch Community Hospice	Inpatient
St John of God Bunbury Hospital	Inpatient
St John of God Geraldton Hospital	Inpatient



# **Section 1 Benchmark summary for WA Services**

Table 2 Summary of outcome measures by setting

Description		Benchmark	In <sub>l</sub> %	patient BM Met?	C %	ommunity BM Met?
Outcome measure 1 – time	ely admission to service		/0	DINI INIEL!	/0	DINI INIGE!
	Patients episode commences on the day of, or the day after date ready for care (BM1)	90%	97.7	Yes	99.8	Yes
Outcome measure 2 – res	ponsiveness to urgent needs					
	Patients in the unstable phase for 3 days or less (BM2)	90%	95.7	Yes	95.7	Yes
Outcome measure 3 – cha	nge in symptoms and problems					
Pain	Absent or mild pain, remaining absent or mild (PCPSS, BM3.1)	90%	92.7	Yes	87.9	No
(clinician rated)	Moderate or severe pain, becoming absent or mild pain (PCPSS, BM3.2)	60%	56.5	No	71.7	Yes
Pain	Absent or mild distress from pain, remaining absent or mild (SAS, BM3.3)	90%	90.6	Yes	85.1	No
(patient rated)	Moderate or severe distress from pain, becoming absent or mild (SAS, BM3.4)	60%	61.1	Yes	64.6	Yes
Fatigue	Absent or mild distress from fatigue, remaining absent or mild (SAS, BM3.5)	90%	90.2	Yes	65.7	No
(patient rated)	Moderate or severe distress from fatigue, becoming absent or mild (SAS, BM3.6)	60%	55.0	No	32.2	No
Breathing problems	Absent or mild distress from breathing problems, remaining absent or mild (SAS, BM3.7)	90%	95.8	Yes	91.9	Yes
(patient rated)	Moderate or severe distress from breathing problems, becoming absent or mild (SAS, BM3.8)	60%	59.6	No	45.0	No
Family / carer problems	Absent or mild family / carer problems, remaining absent or mild (PCPSS, BM3.9)	90%	90.5	Yes	86.2	No
(clinician rated)	Moderate or severe family / carer problems, becoming absent or mild (PCPSS, BM3.10)	60%	43.3	No	62.3	Yes
Outcome measure 4 – cas	e-mix adjusted outcomes (X-CAS)					
Clinician rated	Pain (BM4.1)	0.0	0.14	Yes	0.02	Yes
(PCPSS)	Other symptoms (BM4.2)	0.0	0.27	Yes*	0.03	Yes
	Family / carer (BM4.3)	0.0	0.15	Yes	0.10	Yes
	Psychological / spiritual (BM4.4)	0.0	0.16	Yes	0.00	Yes
Patient rated	Pain (BM4.5)	0.0	0.48	Yes	0.11	Yes
(SAS)	Nausea (BM4.6)	0.0	0.28	Yes	0.08	Yes
	Breathing problems (BM4.7)	0.0	0.46	Yes	0.07	Yes
	Bowel problems (BM4.8)	0.0	0.30	Yes	0.18	Yes

<sup>\*</sup>The item completion for this benchmark was less than 80%. This result may not be reflective of your service. See Appendix A for more details.



#### Section 2 Outcome measures in detail

#### 2.1 Outcome measure 1 – Time from date ready for care to episode start

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This benchmark was set following feedback and subsequent consultation with PCOC participants. Service providers acknowledge that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday to Friday) are not distinguished from services operating seven days a week (all services are being benchmarked together).

#### Benchmark 1:

This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following date ready for care.

Table 3 Time from date ready for care to episode start by setting

		Inpa	tient		Community					
Time (in days)	WA Se	ervices	All Se	rvices	WA Se	rvices	All Services			
	N	%	N	%	N	%	N	%		
Same day	1024	90.8	11,172	92.9	2495	99.8	8,035	82.4		
Following day	78	6.9	519	4.3	1	0.0	484	5.0		
2-7 days	23	2.0	279	2.3	2	0.1	903	9.3		
8-14 days	3	0.3	41	0.3	1	0.0	189	1.9		
Greater than 14 days	0	0	12	0.1	2	0.1	138	1.4		
Average	1.1	na	1.1	na	1.1	na	1.9	na		
Median	1	na	1	na	1	na	1	na		

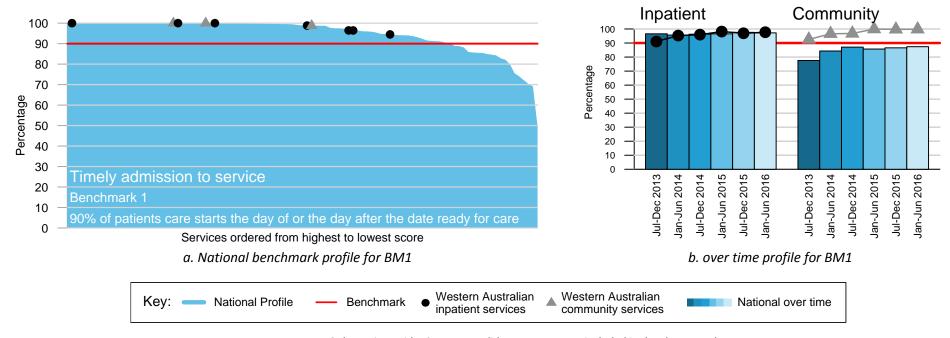
Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

#### Interpretation hint:

Outcome measure 1 only includes episodes that have commenced in the reporting period. As a result, the number of episodes included in the calculation of this benchmark may not match the number of episodes in Appendix A. For more information on data scoping methods, see Appendix C.



Figure 1 Time from date ready for care to episode start, Western Australian services compared to all services (BM1)





#### 2.2 Outcome measure 2 – Time in unstable phase

The unstable phase type, by nature of its definition, alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Those patients assessed to be in the unstable phase require intense review for a short period of time.

An unstable phase is triggered if:

- a patient experiences a new, unanticipated problem, and / or
- a patient experiences a rapid increase in the severity of an existing problem, and / or
- a patient's family / carers experience a sudden change in circumstances that adversely impacts the patient's care.

The patient moves out of the unstable phase in one of two ways:

- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom / crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the patient will move to either the stable or deteriorating phase.
- The patient is likely to die within a matter of days. In this situation, the patient will be moved into the terminal phase.

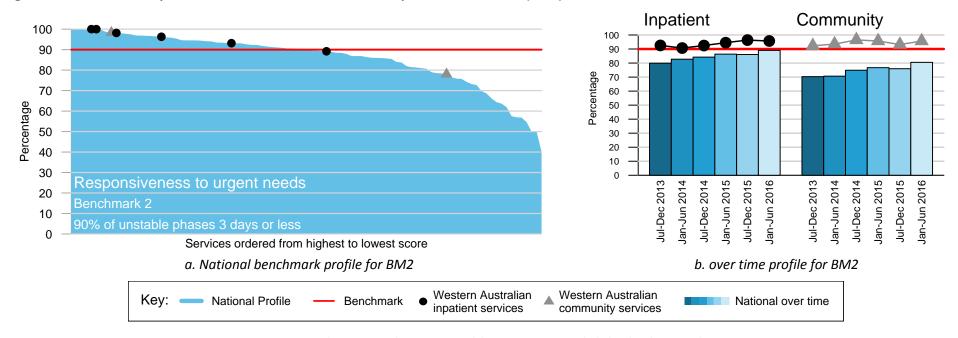
Benchmark 2: This benchmark relates to the time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for 3 days or less.

Table 4 Time in unstable phase by setting

		Inpa	tient		Community					
Time in unstable phase	WA Services		All Services		WA Se	ervices	All Services			
	N	%	N	%	N	%	N	%		
Same day	32	10.6	293	4.6	235	37.5	881	26.8		
1 day	175	57.8	3,282	51.5	303	48.3	1,185	36.1		
2 days	67	22.1	1,471	23.1	44	7.0	398	12.1		
3 days	16	5.3	634	9.9	18	2.9	178	5.4		
4-5 days	8	2.6	446	7.0	14	2.2	193	5.9		
6-7 days	2	0.7	150	2.4	6	1.0	154	4.7		
8-14 days	2	0.7	79	1.2	4	0.6	148	4.5		
Greater than 14 days	1	0.3	24	0.4	3	0.5	145	4.4		
Total	303	100.0	6,379	100.0	627	100.0	3,282	100.0		



Figure 2 Time in unstable phase, Western Australian services compared to all services (BM2)





#### 2.3 Outcome measure 3 – Change in pain

The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS) provide two different perspectives of pain. The PCPSS is clinician rated and measures the severity of pain as a clinical problem while the SAS is patient rated and measures distress caused by pain. There are two benchmarks related to each tool: one relating to patients with an absent or mild score, and the other relating to patients with a moderate or severe score. Phase records must have valid start and end scores for the PCPSS and / or SAS clinical assessment tools to be included in the benchmarks.

Scores for PCPSS

0 absent

1 mild

2 moderate

3 severe

Scores for SAS

0 = absent distress

1-3 = mild distress

4-7 = moderate distress

8-10 = severe distress

#### Interpretation hint:

This outcome measure should be viewed in conjunction with Table 32 to Table 35 and Appendix B.

Benchmark 3.1: This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool.

To most this benchmark 20% of these phases must end with the patient still experiencing only absent or mild pain.

To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild pain.

Benchmark 3.2: This benchmark relates to patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the PCPSS clinical

tool. To meet this benchmark, 60% of these phases must end with the patient's pain reduced to being absent or mild.

Benchmark 3.3: This benchmark relates to patients who have absent or mild distress from pain at the start of their phase of palliative care, as rated via the SAS

clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild distress from pain.

Benchmark 3.4: This benchmark relates to patients who have moderate or severe distress from pain at the start of their phase of palliative care, as rated via the

SAS clinical tool. To meet this benchmark, 60% of these phases must end with the patient's distress from pain reduced to absent or mild.

Table 5 Summary of outcome measure 3 – change in pain

		Inpa	tient		Community				
Benchmarks: change in pain	WA Services		All Services		WA Services		All Services		
	N*	%	N*	%	N*	%	N*	%	
Benchmark 3.1: PCPSS (severity)	1,547	92.7	17,595	91.5	7,434	87.9	15,826	85.7	
Benchmark 3.2: PCPSS (severity)	444	56.5	5,015	59.9	1,133	71.7	3,549	54.9	
Benchmark 3.3: SAS (distress)	1,447	90.6	15,241	89.5	7,056	85.1	14,978	82.5	
Benchmark 3.4: SAS (distress)	542	61.1	6,257	55.4	1,489	64.6	4,676	49.3	

<sup>\*</sup>Total number of phases included in this benchmark.



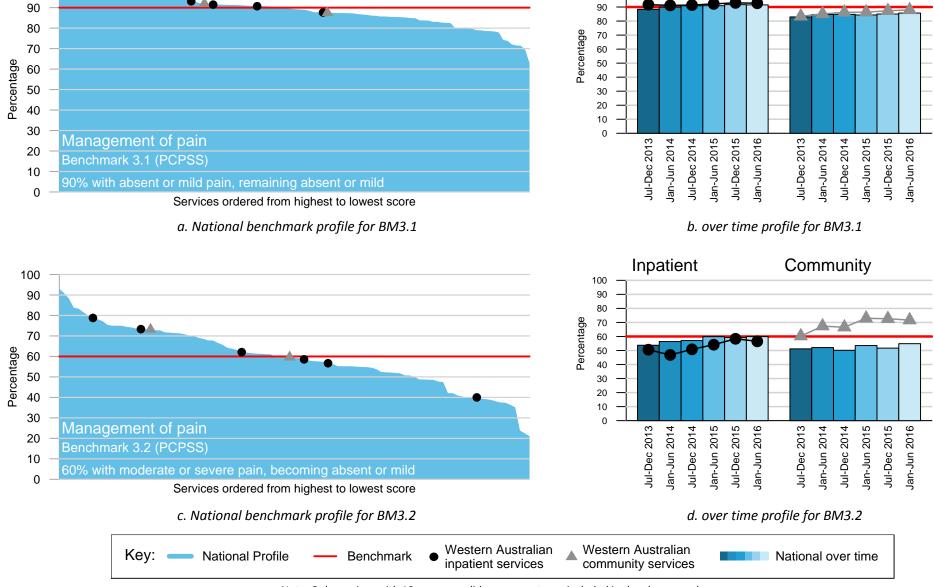
Community

Inpatient

100

Figure 3 Clinician rated change in pain, Western Australian services compared to all services (PCPSS, BM3.1 and 3.2)

100





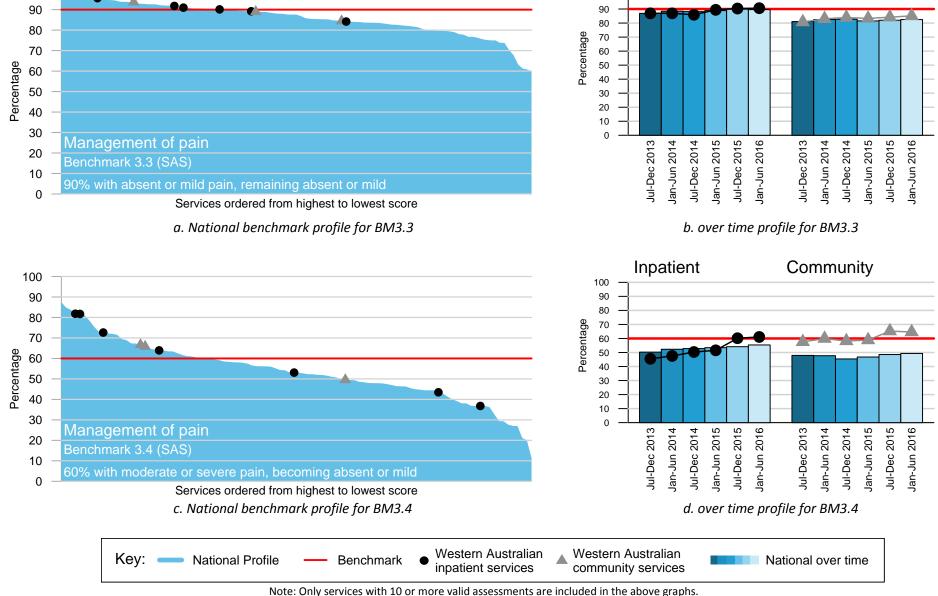
Community

Inpatient

100

Figure 4 Patient rated change in pain, Western Australian services compared to all services (SAS, BM3.3 and 3.4)

100





#### 2.4 Outcome measure 3 – Change in distress from fatigue

Fatigue is the most common symptom reported to PCOC via the SAS tool. In 2015, PCOC introduced this outcome measure to routine reporting. The change in distress from fatigue is measured from the start of a phase to the end of the same phase. There are two benchmarks associated with this outcome measure: one relating to patients with an absent or mild score, and the other relating to patients with a moderate or severe score. Phase records must have valid start and end scores for it to be included in the benchmarks.

Benchmark 3.5: This benchmark relates to patients who have absent or mild distress from fatigue at the start of their phase of palliative care. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild distress from fatigue.

Benchmark 3.6: This benchmark relates to patients who have moderate or severe distress from fatigue at the start of their phase of palliative care. To meet this benchmark, 60% of these phases must end with the patient's distress from fatigue reduced to absent or mild.

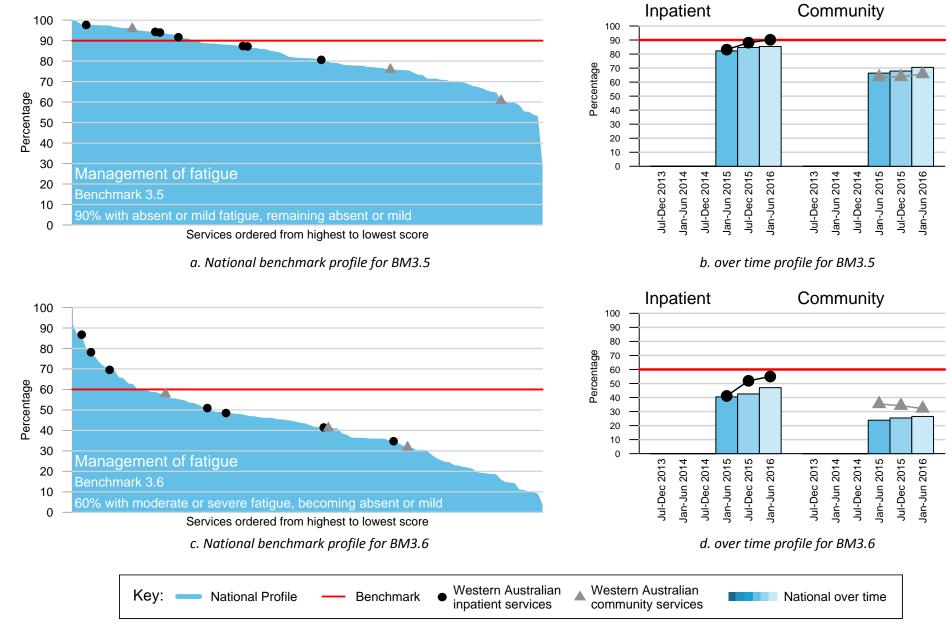
Table 6 Summary of outcome measure 3 – distress from fatigue

			Inpa	tient		Community				
	Benchmark: change in distress from fatigue	WA Services		All Services		WA Services		All Services		
	mange in distress from fatigue	N*	%	N*	%	N*	%	N*	%	
	absent or mild fatigue, remaining absent or mild (BM3.5)	1,243	90.2	12,403	85.4	3,890	65.7	8,801	70.5	
	moderate or severe fatigue, becoming absent or mild (BM3.6)	731	55.0	9,106	47.0	4,630	32.2	10,229	26.5	

<sup>\*</sup>Total number of phases included in this benchmark.



Figure 5 Patient rated change in fatigue, Western Australian services compared to all services (SAS, BM3.5 and 3.6)





#### 2.5 Outcome measure 3 – Change in distress from breathing problems

Breathing problems is a common symptom reported by patients in palliative care. In 2015, PCOC introduced this outcome measure to routine reporting. The change in distress from breathing problems is measured from the start of a phase to the end of the same phase. There are two benchmarks associated with this outcome measure: one relating to patients with an absent or mild score, and the other relating to patients with a moderate or severe score. Phase records must have valid start and end scores for it to be included in the benchmarks.

- Benchmark 3.7: This benchmark relates to patients who have absent or mild distress from breathing problems at the start of their phase of palliative care. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild distress from breathing problems.
- Benchmark 3.8: This benchmark relates to patients who have moderate or severe distress from breathing problems at the start of their phase of palliative care.

  To meet this benchmark, 60% of these phases must end with the patient's distress from breathing problems reduced to absent or mild.

Table 7 Summary of outcome measure 3 – distress from breathing problems

Benchmark:		Inpa	tient		Community			
change in distress from breathing	WA Services		All Services		WA Services		All Services	
problems	N*	%	N*	%	N*	%	N*	%
absent or mild breathing problems, remaining absent or mild (BM3.7)	1,651	95.8	17,493	94.8	7,307	91.9	15,631	91.5
moderate or severe breathing problems, becoming absent or mild (BM3.8)	339	59.6	4,024	46.6	1,219	45.0	3,158	35.8

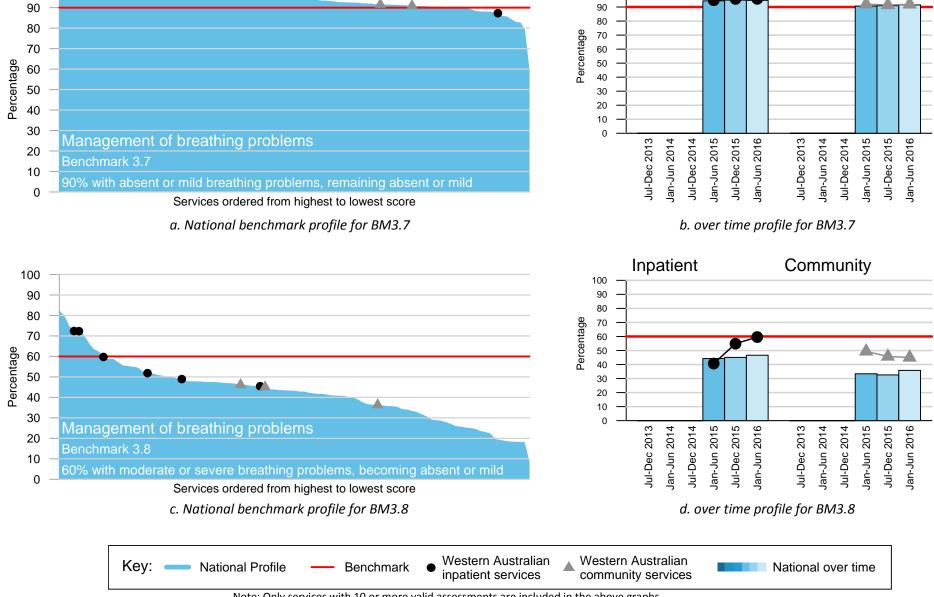
<sup>\*</sup>Total number of phases included in this benchmark.



Community

Figure 6 Patient rated change in breathing problems, Western Australian services compared to all services (SAS, BM3.7 and 3.8)

100



Inpatient

100



#### 2.6 Outcome measure 3 – Change in family / carer problems

Palliative care is a holistic discipline which considers the needs of the patients and their family and carers. The PCPSS family / carer domain measures problems associated with a patient's condition or palliative care needs. In 2015, PCOC introduced this outcome measure to routine reporting. The change in family / carer problems is measured from the start of a phase to the end of the same phase. There are two benchmarks associated with this outcome measure: one relating to patients with an absent or mild score, and the other relating to patients with a moderate or severe score. Phase records must have valid start and end scores for it to be included in the benchmarks.

Benchmark 3.9: This benchmark relates to patients who have absent or mild family / carer problems at the start of their phase of palliative care. To meet this

benchmark, 90% of these phases must end with the patient still experiencing only absent or mild family / carer problems.

Benchmark 3.10: This benchmark relates to patients who have moderate or severe family / carer problems at the start of their phase of palliative care. To meet

this benchmark, 60% of these phases must end with the patient's family / carer problems reduced to absent or mild.

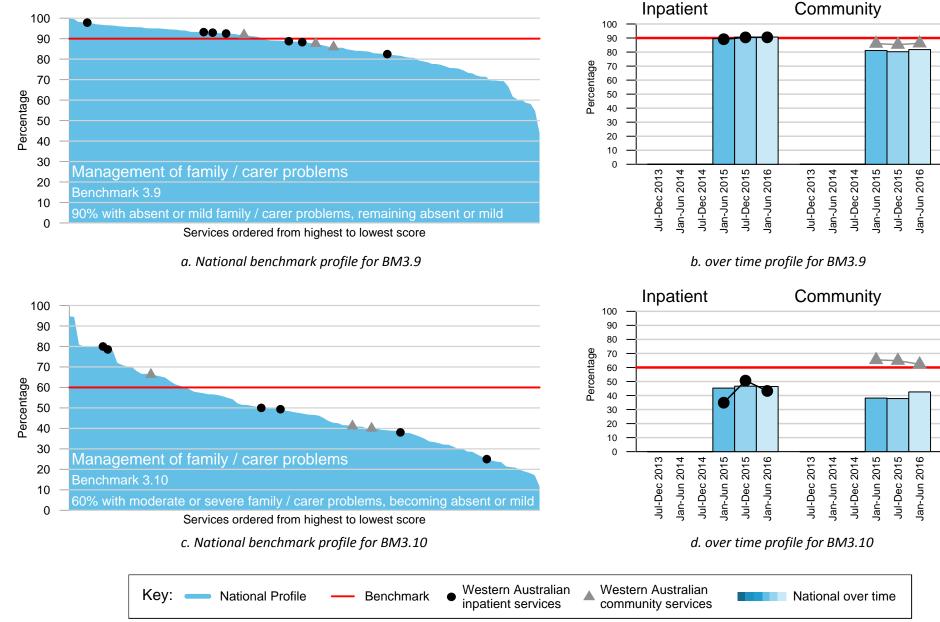
Table 8 Summary of outcome measure 3 – family / carer problems

		Inpa	tient		Community				
Benchmark: change in family / carer problems	WA Services		All Services		WA Services		All Services		
Change in family / Carer problems	N*	%	N*	%	N*	%	N*	%	
absent or mild family / carer problems, remaining absent or mild (BM3.9)	1,220	90.5	17,697	90.7	7,269	86.2	14,318	81.8	
moderate or severe family / carer problems, becoming absent or mild (BM3.10)	393	43.3	4,281	46.4	1,299	62.3	4,502	42.6	

<sup>\*</sup>Total number of phases included in this benchmark.



Figure 7 Clinician rated change in family / carer problems, Western Australian services compared to all services (SAS, BM3.9 and 3.10)





### 2.7 Outcome measure 4 – Change in symptoms relative to the baseline national average (X-CAS)

Outcome measure 4 includes a suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included in this report and the baseline reference period is January to June 2014. The suite of benchmarks included in outcome measure 4 are generally referred to as <u>X-CAS</u> – *CAS* standing for *Case-mix Adjusted Score*, and the *X* to represent that multiple symptoms are included. As X-CAS looks at change in symptom, they are only able to be calculated on phases which ended in phase change or discharge (as the phase end scores are required to determine the change).

Table 9 Summary of outcome measure 4 – inpatient setting

			WA Se	ervices		All Services			
Clinical Tool	Benchmark: Symptom	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline
PCPSS	4.1: Pain	0.14	1,991	1,321	66.3	0.10	22,610	14,373	63.6
(severity)	4.2: Other symptoms	0.27	1,615	1,210	74.9	0.21	22,221	16,370	73.7
	4.3: Family / carer	0.15	1,613	1,131	70.1	0.13	21,978	14,823	67.4
	4.4: Psychological / spiritual	0.16	1,988	1,302	65.5	0.16	22,614	13,799	61.0
SAS	4.5: Pain	0.48	1,989	1,422	71.5	0.32	21,498	14,631	68.1
(distress)	4.6: Nausea	0.28	1,980	1,793	90.6	0.21	21,456	18,909	88.1
	4.7: Breathing problems	0.46	1,990	1,625	81.7	0.29	21,517	17,021	79.1
	4.8: Bowel problems	0.30	1,968	1,562	79.4	0.23	21,471	16,699	77.8

#### **Interpretation hint:**

The X-CAS measures are calculated relative to a baseline reference period (currently January to June 2014). As a result:

If X-CAS is greater than 0 then on average, patients' change in symptom was better than similar patients in the baseline reference period.

If X-CAS is <u>equal to 0</u> then on average, patients' change in symptom was <u>about the same as similar patients</u> in the baseline reference period.

If X-CAS is <u>less than 0</u> then on average, patients' change in symptom was <u>worse than similar patients</u> in the baseline reference period.



Table 10 Summary of outcome measure 4 – community setting

			WA Se	ervices		All Services			
Clinical Tool	Benchmark: Symptom	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline
PCPSS	4.1: Pain	0.02	8,567	4,916	57.4	-0.07	19,375	10,096	52.1
(severity)	4.2: Other symptoms	0.03	8,568	5,725	66.8	-0.05	18,639	11,572	62.1
	4.3: Family / carer	0.10	8,568	5,974	69.7	-0.03	18,820	11,668	62.0
	4.4: Psychological / spiritual	0.00	8,568	4,383	51.2	-0.05	19,126	9,022	47.2
SAS	4.5: Pain	0.11	8,545	5,554	65.0	-0.23	19,654	11,201	57.0
(distress)	4.6: Nausea	0.08	8,534	7,364	86.3	-0.11	19,077	15,043	78.9
	4.7: Breathing problems	0.07	8,526	6,064	71.1	-0.07	18,789	12,376	65.9
	4.8: Bowel problems	0.18	8,501	6,834	80.4	-0.01	18,638	13,363	71.7





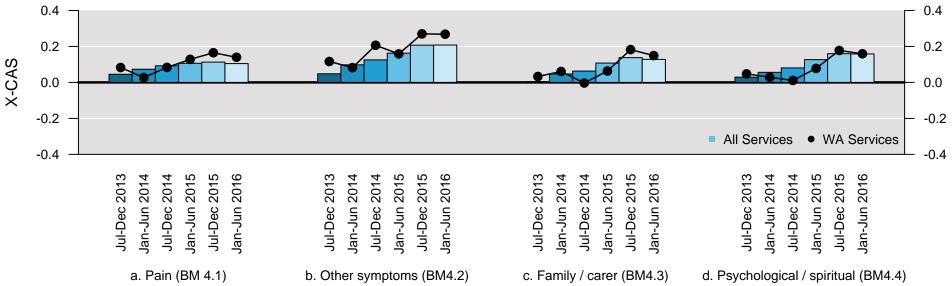
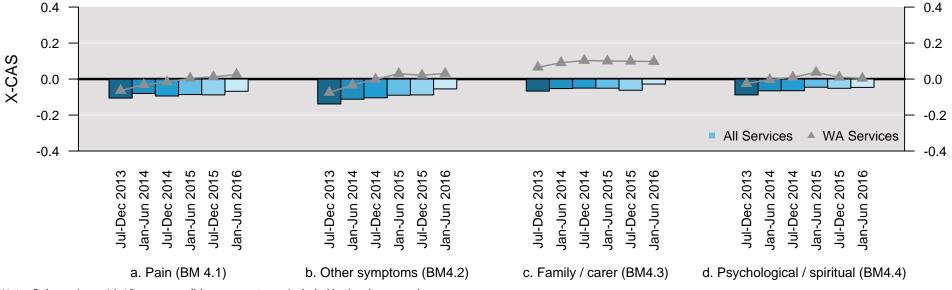


Figure 9 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – community setting







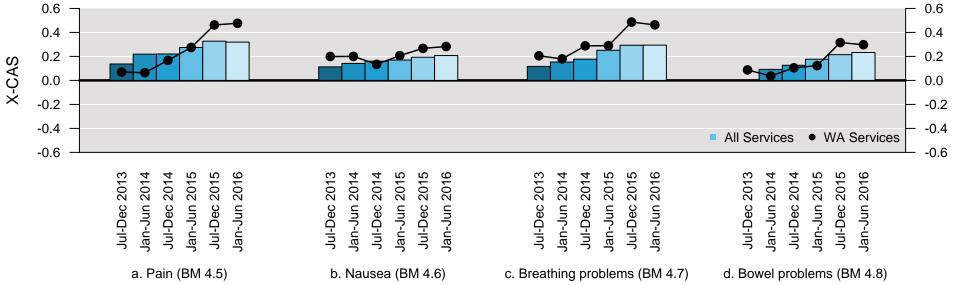
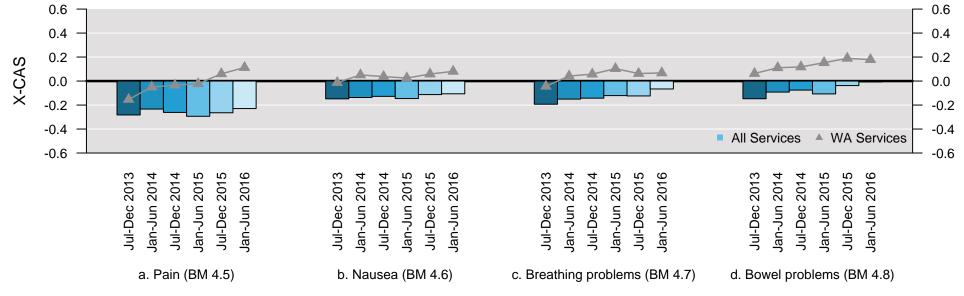


Figure 11 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – community setting





## **Section 3** Descriptive analysis

This section provides descriptive information of the data submitted by Western Australian services at each of the three levels – patient, episode and phase.

Patient level information describes demographics such as Indigenous status, sex, preferred language and country of birth. This information about the patient provides a context to the episode and phase level information and enhances the meaningfulness of patient outcomes.

Episode level information describes the setting of palliative care service provision. It also includes information relating to the facility or organisation that has referred the patient, how an episode starts and ends, and the setting in which the patient died.

Phase level information describes the clinical condition of the patient during the episode, using five clinical assessment tools. These are phase of illness, the patient's functional status and performance, pain and other common symptoms, the patient's psychological / spiritual and family / carer domain.

Summaries of the national data are included for comparative purposes.



#### 3.1 Profile of palliative care patients

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 and carers are included in this definition if interventions relating to them are recorded in the patient medical record.

Table 11 shows the Indigenous status for the patients in Western Australian services and nationally.

Table 11 Indigenous status

Indianana atatus	WA Se	rvices	All Services		
Indigenous status	N	%	N	%	
Aboriginal but not Torres Strait Islander origin	43	1.3	219	1.1	
Torres Strait Islander but not Aboriginal origin	3	0.1	22	0.1	
Both Aboriginal and Torres Strait Islander origin	7	0.2	21	0.1	
Neither Aboriginal nor Torres Strait Islander origin	3,093	96.2	18,421	96.4	
Not stated / inadequately described	69	2.1	434	2.3	
Total	3,215	100.0	19,117	100.0	

Table 12 shows the breakdown of deaths for the patients in Western Australian services and nationally for the reporting period. All inpatient deaths are reported in the hospital category while the community deaths are reported in the private residence and residential aged care facility categories.

Table 12 Place of death

Diagonal death	WA Se	ervices	All Services		
Place of death	N	%	N	%	
Private residence	649	45.9	1,880	19.8	
Residential aged care facility	203	14.4	640	6.7	
Hospital	560	39.6	6,857	72.2	
Not stated / inadequately described	2	0.1	122	1.3	
Total	1,414	100.0	9,499	100.0	



The following two tables show the country of birth and the preferred language respectively for the patients in Western Australian services and nationally. To allow for comparison with the broader Australian community the list of country of birth in Table 13 is in descending order of the most frequent country of birth according to the 2011 Census (e.g. India was the fifth most common country of birth in the 2011 Census). The same approach has been taken with Table 14 (e.g. Italian was the fifth most frequently spoken language in the 2011 census). All other countries and languages have been grouped together to form the categories 'All other countries' and 'All other languages' respectively.

Table 13 Country of birth

Country of high	WA Se	ervices	All Se	rvices
Country of birth	N	%	N	%
Australia	1,778	55.3	11,922	62.4
England	501	15.6	1,409	7.4
New Zealand	75	2.3	300	1.6
China (excludes SARs and Taiwan)	15	0.5	198	1.0
India	38	1.2	127	0.7
Italy	133	4.1	813	4.3
Vietnam	23	0.7	149	0.8
Philippines	7	0.2	90	0.5
South Africa	43	1.3	109	0.6
Scotland	72	2.2	266	1.4
Malaysia	24	0.7	60	0.3
Germany	40	1.2	255	1.3
Greece	21	0.7	397	2.1
Sri Lanka	4	0.1	56	0.3
United States of America	12	0.4	46	0.2
All other countries	376	11.7	2,584	13.5
Not stated / inadequately described	53	1.6	336	1.8
Total	3,215	100.0	19,117	100.0



Table 14 Preferred language

Duefound lawrence	WA Se	rvices	All Se	rvices
Preferred language	N	%	N	%
English	2,964	92.2	17,070	89.3
Chinese <sup>(a)</sup>	23	0.7	177	0.9
Hindi <sup>(b)</sup>	3	0.1	20	0.1
Arabic <sup>(c)</sup>	4	0.1	100	0.5
Italian	67	2.1	424	2.2
Vietnamese <sup>(d)</sup>	16	0.5	79	0.4
Greek	10	0.3	278	1.5
Filipino / Indonesian <sup>(e)</sup>	3	0.1	18	0.1
Macedonian / Croatian <sup>(f)</sup>	18	0.6	127	0.7
Spanish <sup>(g)</sup>	6	0.2	49	0.3
Tamil / Malayalam <sup>(h)</sup>	2	0.1	6	0.0
German <sup>(i)</sup>	10	0.3	25	0.1
Korean	0	0.0	18	0.1
Samoan / Tongan <sup>(j)</sup>	0	0.0	7	0.0
African languages <sup>(k)</sup>	5	0.2	11	0.1
All other languages	55	1.7	396	2.1
Not stated / inadequately described	29	0.9	312	1.6
Total	3,215	100.0	19,117	100.0

- Also includes (a) Cantonese, Hakka, Mandarin, Wu and Min Nan
  - (b) Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, and Fijian Hindustani
  - (c) Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, and Mandaean (Mandaic)
  - (d) Khmer and Mon
  - (e) Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo, Javanese, and Pampangan
  - (f) Bosnian, Bulgarian, Serbian, and Slovene
  - (g) Catalan and Portuguese
  - (h) Kannada, Telugu, and Tulu
  - (i) Letzeburgish and Yiddish
  - (j) Fijian, Gilbertese, Maori, Nauruan, Niue, Rotuman, Tokelauan, Tuvaluan, and Yapese
  - (k) Acholi, Akan, Mauritian Creole, Oromo, Shona, Somali, Swahili, Yoruba, Zulu, Amharic, Bemba, Dinka, Ewe, Ga, Harari, Hausa, Igbo, Kikuyu, Krio, Luganda, Luo, Ndebele, Nuer, Nyanja (Chichewa), Shilluk, Tigré, Tigrinya, Tswana, Xhosa, Seychelles Creole, Anuak, Bari, Bassa, Dan (Gio-Dan), Fulfulde, Kinyarwanda (Rwanda), Kirundi (Rundi), Kpelle, Krahn, Liberian (Liberian English), Loma (Lorma), Lumun (Kuku Lumun), Madi, Mandinka, Mann, Moro (Nuba Moro) and Themne



Table 15 and Table 16 present a breakdown of malignant and non-malignant diagnosis for the patients in Western Australian services and at the national level. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 48 (1.5%) patients in Western Australian services and was not stated for 110 (0.6%) patients nationally.

Table 15 Primary diagnosis - malignant

		WA Services			All Services	
Primary diagnosis	N	% malignant diagnosis	% all diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	25	1.1	0.8	234	1.6	1.2
Breast	166	7.4	5.2	1,100	7.5	5.8
CNS	57	2.5	1.8	311	2.1	1.6
Colorectal	225	10.0	7.0	1,628	11.2	8.5
Other GIT	265	11.8	8.2	1,418	9.7	7.4
Haematological	166	7.4	5.2	981	6.7	5.1
Head and neck	67	3.0	2.1	706	4.8	3.7
Lung	502	22.3	15.6	3,130	21.5	16.4
Pancreas	137	6.1	4.3	1,049	7.2	5.5
Prostate	162	7.2	5.0	1,011	6.9	5.3
Other urological	91	4.0	2.8	630	4.3	3.3
Gynaecological	123	5.5	3.8	762	5.2	4.0
Skin	94	4.2	2.9	499	3.4	2.6
Unknown primary	83	3.7	2.6	405	2.8	2.1
Other primary malignancy	69	3.1	2.1	523	3.6	2.7
Malignant – not further defined	19	0.8	0.6	190	1.3	1.0
All malignant	2,251	100.0	70.0	14,577	100.0	76.3



Table 16 Primary diagnosis - non-malignant

		WA Services			All Services	
Primary diagnosis	N	% non-malignant diagnosis	% all diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	116	12.7	3.6	736	16.6	3.8
HIV / AIDS	0	0.0	0.0	4	0.1	0.0
End stage kidney disease	74	8.1	2.3	444	10.0	2.3
Stroke	61	6.7	1.9	312	7.0	1.6
Motor neurone disease	36	3.9	1.1	213	4.8	1.1
Alzheimer's dementia	65	7.1	2.0	181	4.1	0.9
Other dementia	74	8.1	2.3	274	6.2	1.4
Other neurological disease	35	3.8	1.1	246	5.6	1.3
Respiratory failure	145	15.8	4.5	769	17.4	4.0
End stage liver disease	38	4.1	1.2	195	4.4	1.0
Diabetes and its complications	1	0.1	0.0	15	0.3	0.1
Sepsis	30	3.3	0.9	151	3.4	0.8
Multiple organ failure	18	2.0	0.6	108	2.4	0.6
Other non-malignancy	213	23.3	6.6	639	14.4	3.3
Non-malignant – not further defined	10	1.1	0.3	143	3.2	0.7
All non-malignant	916	100.0	28.5	4,430	100.0	23.2



#### 3.2 Profile of palliative care episodes

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 – for the purposes of this report, either as an inpatient or community patient.

An episode of palliative care starts on the date when the comprehensive palliative care assessment is undertaken and documented using the five clinical assessment tools.

An episode of palliative care ends when:

- the patient is formally separated from the current setting of care (e.g. from community to inpatient) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 17 below presents the number and percentage of episodes by age group and sex for the patients seen by Western Australian services and at the national level. Age has been calculated as at the beginning of each episode.

Table 17 Age group by sex

		WA Se	rvices		All Services				
Age group	M	ale	Fen	Female		ale	Female		
	N	%	N	%	N	%	N	%	
< 15	14	0.6	4	0.2	47	0.4	19	0.2	
15 - 24	9	0.4	6	0.3	38	0.3	48	0.4	
25 - 34	15	0.7	13	0.7	106	0.8	101	0.9	
35 - 44	37	1.7	60	3.1	239	1.8	330	2.9	
45 - 54	143	6.5	131	6.8	875	6.6	961	8.5	
55 - 64	309	14.1	259	13.4	1,997	15.0	1,721	15.2	
65 - 74	596	27.2	395	20.5	3,503	26.3	2,591	22.8	
75 - 84	617	28.2	528	27.4	3,982	29.9	3,002	26.4	
85+	451	20.6	531	27.6	2,536	19.0	2,577	22.7	
Not stated / inadequately described	0	0.0	0	0.0	9	0.0	9	0.0	
Total	2,191	100.0	1,927	100.0	13,332	100.0	11,359	100.0	

Note: Records where sex was not stated or inadequately described are excluded from the table.



Referral source refers to the facility or organisation from which the patient was referred for each episode of care. Table 18 presents referral source by setting.

Table 18 Referral source by setting

		Inpa	tient		Community			
Referral source	WA Se	ervices	All Se	rvices	WA Services		All Services	
	N	%	N	%	N	%	N	%
Public hospital	660	57.4	7,657	60.2	1,302	43.9	6,365	53.2
Private hospital	27	2.3	946	7.4	375	12.6	1,467	12.3
Outpatient clinic	2	0.2	91	0.7	0	0.0	129	1.1
General medical practitioner	44	3.8	350	2.8	958	32.3	1,987	16.6
Specialist medical practitioner	99	8.6	494	3.9	2	0.1	712	5.9
Community-based palliative care agency	297	25.8	2,797	22.0	1	0.0	101	0.8
Community-based service	2	0.2	47	0.4	4	0.1	117	1.0
Residential aged care facility	6	0.5	61	0.5	282	9.5	479	4.0
Self, carer(s), family or friends	8	0.7	167	1.3	0	0.0	341	2.8
Other	2	0.2	96	0.8	45	1.5	247	2.1
Not stated / inadequately described	2	0.2	16	0.1	0	0.0	29	0.2
Total	1,149	100.0	12,722	100.0	2,969	100.0	11,974	100.0



Table 19 provides a summary of the time between referral to first contact by setting of care. The time from referral to first contact is calculated as the time from the date of referral received to either the date of first contact (if provided) or the episode start date.

Table 19 Referral to first contact by setting

		Inpa	tient		Community				
Time (in days)	WA Services		All Services		WA Se	ervices	All Services		
	N	%	N	%	N	%	N	%	
Same day or following day	1,122	97.7	11,975	94.2	1,689	56.9	6,045	50.6	
2-7 days	23	2.0	613	4.8	1,128	38.0	4,023	33.7	
8-14 days	3	0.3	75	0.6	110	3.7	1,024	8.6	
Greater than 14 days	1	0.1	54	0.4	42	1.4	863	7.2	
Average	1.1	na	1.2	na	2.3	na	2.9	na	
Median	1	na	1	na	1	na	1	na	

Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.



Table 20 gives a summary of the length of episode for patients in Western Australian services and nationally. Table 21 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 20 Length of episode (in days) summary by setting

Laurette of outloads	Inpat	tient	Community			
Length of episode	WA Services	All Services	WA Services	All Services		
Average length of episode	9.1	10.7	34.6	36.4		
Median length of episode	5.5	6.0	22.0	25.0		

Note: Records where length of episode was greater than 180 days were considered to be atypical and are excluded from the average calculations. Only episodes ending during the reporting period are included.

Table 21 Length of episode (in days) by setting

Length of episode	Inpatient				Community			
	WA Services		All Services		WA Services		All Services	
	N	%	N	%	N	%	N	%
Same day	60	5.3	842	6.7	43	1.7	512	4.7
1-2 days	267	23.8	2,468	19.7	187	7.3	723	6.7
3-4 days	169	15.0	1,774	14.2	165	6.4	586	5.4
5-7 days	188	16.7	2,023	16.2	227	8.8	859	7.9
8-14 days	221	19.7	2,559	20.4	367	14.3	1,412	13.0
15-21 days	99	8.8	1,161	9.3	264	10.3	957	8.8
22-30 days	67	6.0	821	6.6	266	10.4	993	9.2
31-60 days	44	3.9	695	5.6	466	18.2	1,826	16.9
61-90 days	7	0.6	122	1.0	248	9.7	984	9.1
Greater than 90 days	2	0.2	55	0.4	333	13.0	1,969	18.2
Total	1,124	100.0	12,520	100.0	2,566	100.0	10,821	100.0

Note: Only episodes ending during the reporting period are included.



Table 22 How episodes start – inpatient setting

Full and a start mode	WA Se	ervices	All Services		
Episode start mode	N	%	N	%	
Admitted from community*	755	65.7	7,222	56.8	
Admitted from another hospital	332	28.9	3,030	23.8	
Admitted from acute care in another ward	51	4.4	2,185	17.2	
Change from acute care to palliative care – same ward	1	0.1	190	1.5	
Other**	10	0.9	84	0.7	
Not stated / inadequately described	0	0.0	11	0.1	
Total	1,149	100.0	12,722	100.0	

<sup>\*</sup> includes: admitted from usual accommodation, admitted from other than usual accommodation.

Table 23 How episodes end – inpatient setting

Enjands and made	WA Se	ervices	All Se	rvices
Episode end mode	N	%	N	%
Discharged to community*	411	36.6	4,247	33.9
Discharged to another hospital	60	5.3	747	6.0
Death	560	49.8	6,857	54.8
Change from palliative care to acute care**	2	0.2	66	0.5
Change in sub-acute care type	0	0.0	51	0.4
End of consultative episode – inpatient episode ongoing	16	1.4	407	3.3
Other	73	6.5	137	1.1
Not stated / inadequately described	2	0.2	8	0.1
Total	1,124	100.0	12,520	100.0

Note: Only episodes ending during the reporting period are included.

<sup>\*\*</sup> includes: change of sub-acute/non-acute care type and other categories.

<sup>\*</sup> includes: discharged to usual accommodation, discharged to other than usual accommodation.

<sup>\*\*</sup> includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.



Table 24 How episodes start – community setting

Enicodo etart modo	WA Se	rvices	All Services		
Episode start mode	N	%	N	%	
Admitted from inpatient palliative care	1,950	65.7	4,519	37.7	
Other*	1,019	34.3	7,436	62.1	
Not stated / inadequately described	0	0.0	19	0.2	
Total	2,969	100.0	11,974	100.0	

<sup>\*</sup>includes: patient was not transferred from being an overnight patient.

Table 25 How episodes end – community setting

Fuicada and wada	WA Se	ervices	All Se	rvices
Episode end mode	N	%	N	%
Admitted for inpatient palliative care	85	3.3	3,166	29.2
Admitted for inpatient acute care	1,215	47.3	3,213	29.6
Admitted to another palliative care service	13	0.5	54	0.5
Admitted to primary health care	93	3.6	236	2.2
Discharged / case closure	306	11.9	1,262	11.6
Death	854	33.3	2,642	24.4
Other	0	0.0	149	1.4
Not stated / inadequately described	0	0.0	116	1.1
Total	2,566	100.0	10,838	100.0

Note: Only episodes ending during the reporting period are included.



#### 3.3 Profile of palliative care phases

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. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence. See Appendix E for more information on the definition of palliative care phase.

The clinical assessments are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge.

Table 26 Number of phases by phase type and setting

		Inpa	tient		Community					
Phase type	WA S	ervices	All Services		WA Se	ervices	All Services			
	N	%	N	%	N	%	N	%		
Stable	676	26.2	7,760	25.6	3,823	37.7	9,904	37.1		
Unstable	303	11.7	6,379	21.1	627	6.2	3,282	12.3		
Deteriorating	1,063	41.2	9,930	32.8	4,839	47.7	11,415	42.7		
Terminal	539	20.9	6,186	20.4	846	8.3	2,120	7.9		
Total	2,581	100.0	30,255	100.0	10,135	100.0	26,721	100.0		

Note: Bereavement phases have been excluded due to inconsistent data collection and bereavement practices. Bereavement phases are not included in the total phases count.

Table 27 Average phase length (in days) by phase type and setting

Dhace type	Inpa	tient	Community			
Phase type	WA Services	All Services	WA Services	All Services		
Stable	5.5	7.2	14.6	20.5		
Unstable	1.6	2.0	1.4	3.3		
Deteriorating	5.0	5.3	8.6	12.9		
Terminal	2.2	2.0	3.0	2.9		

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



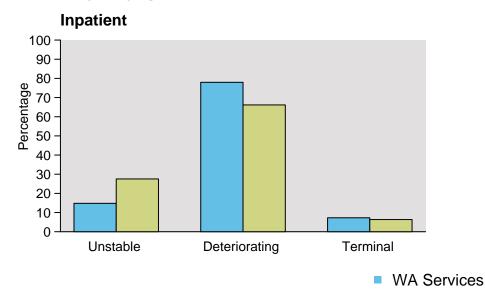
Table 28 presents information relating to the manner in which stable phases ended, both for Western Australian services and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 12 summarises the movement of patients out of the stable phase for the inpatient and community settings. This movement from one phase to another is referred to as phase progression and is derived by PCOC.

Similar information is presented for the unstable (Table 29, Figure 13), deteriorating (Table 30, Figure 14) and terminal (Table 31, Figure 15) phases on the following pages.

Table 28 How stable phases end - by setting

		Inpa	tient		Community				
How stable phases end	WA Services		All Services		WA Se	ervices	All Services		
	N	%	N	%	N	%	N	%	
Patient moved into another phase	331	49.0	4,011	51.7	3,077	80.5	6,327	63.9	
Discharge / case closure	339	50.1	3,649	47.0	679	17.8	3,293	33.2	
Died	5	0.7	91	1.2	67	1.8	252	2.5	
Not stated / inadequately described	1	0.1	9	0.1	0	0.0	32	0.3	
Total	676	100.0	7,760	100.0	3,823	100.0	9,904	100.0	

Figure 12 Stable phase progression



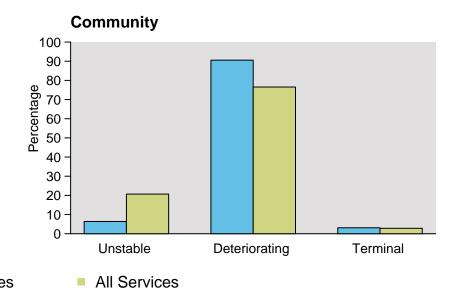




Table 29 How <u>unstable</u> phases end – by setting

		Inpa	tient		Community				
How unstable phases end	WA Services		All Services		WA Se	ervices	All Services		
	N	%	N	%	N	%	N	%	
Patient moved into another phase	282	93.1	5,991	93.9	444	70.8	2,075	63.2	
Discharge / case closure	17	5.6	270	4.2	172	27.4	1,164	35.5	
Died	4	1.3	116	1.8	11	1.8	41	1.2	
Not stated / inadequately described	0	0.0	2	0.0	0	0.0	2	0.1	
Total	303	100.0	6,379	100.0	627	100.0	3,282	100.0	

Figure 13 Unstable phase progression

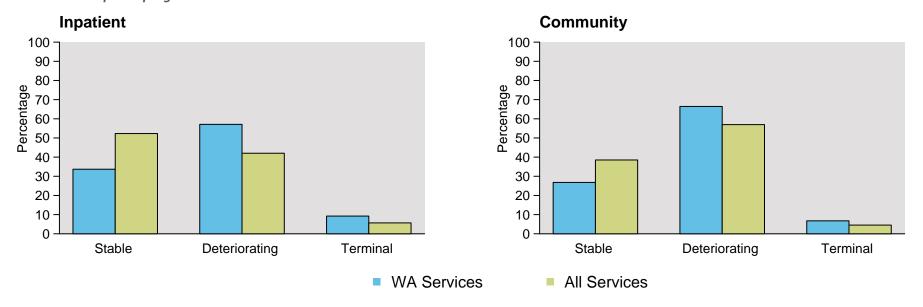




Table 30 How <u>deteriorating</u> phases end – by setting

		Inpa	tient		Community				
How deteriorating phases end	WA Services		All Services		WA Services		All Services		
	N	%	N	%	N	%	N	%	
Patient moved into another phase	822	77.3	7,484	75.4	3,841	79.4	7,170	62.8	
Discharge / case closure	167	15.7	1,583	15.9	817	16.9	3,483	30.5	
Died	73	6.9	861	8.7	181	3.7	729	6.4	
Not stated / inadequately described	1	0.1	2	0.0	0	0.0	33	0.3	
Total	1,063	100.0	9,930	100.0	4,839	100.0	11,415	100.0	

Figure 14 Deteriorating phase progression

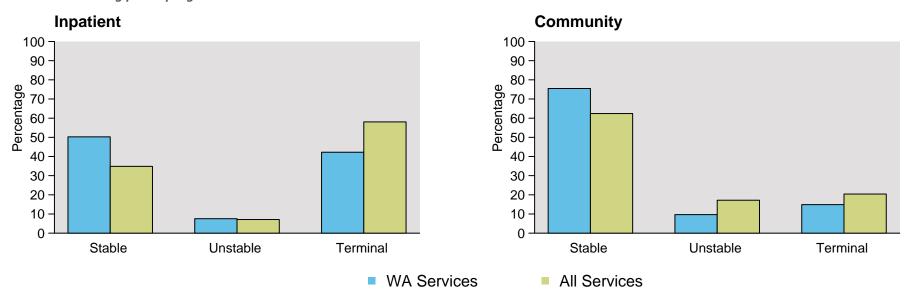
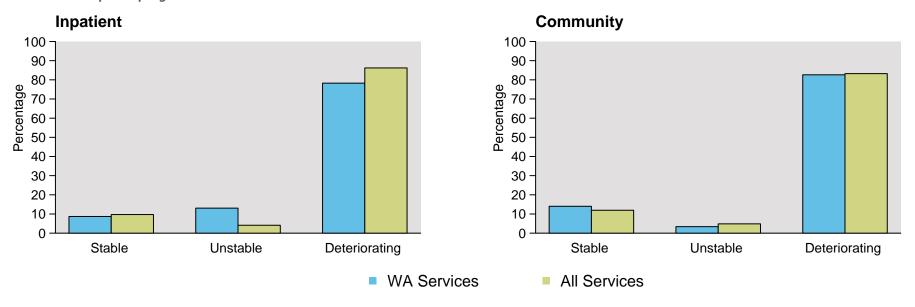




Table 31 How <u>terminal</u> phases end – by setting

		Inpa	tient		Community				
How terminal phases end	WA Services		All Se	All Services		ervices	All Services		
	N	%	N	%	N	%	N	%	
Patient moved into another phase	23	4.3	268	4.3	207	24.5	310	14.6	
Discharge / case closure	38	7.1	145	2.3	44	5.2	181	8.5	
Died	477	88.5	5,772	93.3	595	70.3	1,628	76.8	
Not stated / inadequately described	1	0.2	1	0.0	0	0.0	1	0.0	
Total	539	100.0	6,186	100.0	846	100.0	2,120	100.0	

Figure 15 Terminal phase progression





The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains (pain, other symptoms, psychological / spiritual and family / carer). The ratings are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe.

Table 32 and Table 33 show the percentage scores for the inpatient and community settings, respectively, for both Western Australian services and nationally. Alternative graphical representations of PCPSS profile by phase type can be found in Appendix B.

Table 32 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)

Dhana tura			WA Se	ervices			All Services			
Phase type	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe	
	Pain	56.6	34.8	7.9	0.7	49.6	38.7	9.9	1.8	
Stable	Other symptoms	39.9	48.9	10.4	0.7	32.8	51.0	13.9	2.3	
Stable	Psychological / spiritual	43.4	44.4	10.8	1.3	43.9	45.9	8.6	1.6	
	Family / carer	42.5	42.3	13.9	1.4	47.6	41.1	9.2	2.1	
	Pain	21.5	27.4	33.0	18.2	30.9	33.7	25.1	10.3	
Unatable	Other symptoms	14.7	26.1	43.3	15.9	17.8	39.4	31.6	11.1	
Unstable	Psychological / spiritual	19.1	42.6	30.0	8.3	28.7	47.7	18.8	4.8	
	Family / carer	21.5	40.1	29.6	8.8	31.0	45.2	18.2	5.7	
	Pain	40.8	35.7	18.8	4.6	39.1	39.1	17.1	4.7	
Deterieration	Other symptoms	33.3	34.6	27.3	4.8	22.8	44.8	26.5	5.9	
Deteriorating	Psychological / spiritual	43.6	35.0	18.6	2.8	36.0	46.5	14.6	3.0	
	Family / carer	36.5	37.1	22.9	3.5	33.3	43.7	17.9	5.1	
	Pain	58.0	30.9	8.9	2.2	49.1	34.1	13.3	3.6	
Torminal	Other symptoms	57.5	22.4	15.3	4.8	40.3	35.7	17.5	6.5	
Terminal	Psychological / spiritual	69.0	21.9	7.4	1.7	57.0	31.3	8.7	3.0	
	Family / carer	35.5	38.8	21.3	4.4	28.2	39.6	23.5	8.7	



Table 33 Profile of PCPSS at beginning of phase by phase type –community setting (percentages)

Dhace type			WA Se	ervices		All Services			
Phase type	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
	Pain	48.2	48.8	2.9	0.1	41.5	52.7	5.4	0.3
Stable	Other symptoms	18.8	72.3	8.6	0.2	16.7	69.9	12.8	0.6
Stable	Psychological / spiritual	34.0	60.6	5.0	0.4	29.1	61.9	8.3	0.7
	Family / carer	44.4	49.0	5.8	0.8	31.6	56.2	11.1	1.0
	Pain	25.7	27.4	28.1	18.8	17.6	31.8	35.7	14.9
Unstable	Other symptoms	5.4	26.3	51.7	16.6	3.9	30.7	50.7	14.8
Unstable	Psychological / spiritual	10.4	42.4	38.4	8.8	11.1	48.1	34.8	6.0
	Family / carer	16.3	38.0	39.6	6.2	10.8	38.8	41.9	8.5
	Pain	32.4	49.6	16.7	1.3	28.0	52.3	18.0	1.7
Deteriorating	Other symptoms	8.2	53.3	37.5	1.0	6.9	54.2	36.2	2.7
Deteriorating	Psychological / spiritual	17.5	62.3	19.5	0.7	16.1	62.7	19.9	1.4
	Family / carer	26.3	54.0	18.7	1.0	17.4	55.1	24.9	2.6
	Pain	45.0	39.1	14.7	1.2	35.2	48.0	15.0	1.7
Terminal	Other symptoms	31.1	40.7	24.8	3.4	24.0	44.6	26.6	4.7
Terminal	Psychological / spiritual	48.0	37.0	13.9	1.1	43.1	42.1	13.4	1.4
	Family / carer	16.0	48.3	32.2	3.5	11.1	46.5	36.1	6.3

The Symptom Assessment Scale (SAS) is a patient rated (or proxy) assessment tool and reports a level of distress using a numerical rating scale from 0 - no distress to 10 - worst possible distress. The SAS reports on distress from seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient's perspective. The SAS scores are grouped in Table 34 and Table 35 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Alternative graphical representations of the SAS profile by phase type can be found in Appendix B.



Table 34 Profile of SAS scores at beginning of phase by phase type – inpatient setting (percentages)

	e of SAS scores at beginning			ervices			All So	ervices	
Phase type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
	Difficulty sleeping	76.5	15.8	6.4	1.3	75.2	13.4	9.8	1.7
	Appetite problems	68.6	20.7	9.7	1.0	64.8	20.3	12.6	2.2
	Nausea	88.4	8.9	2.2	0.4	82.8	10.9	5.3	0.9
Stable	Bowel problems	71.3	20.6	6.7	1.5	67.7	19.4	10.6	2.3
	Breathing problems	70.9	21.4	7.4	0.3	69.6	17.2	10.6	2.6
	Fatigue	41.8	33.3	21.8	3.1	39.3	28.0	28.3	4.4
	Pain	53.6	34.2	10.8	1.3	48.8	31.4	17.4	2.4
	Difficulty sleeping	47.3	19.0	25.3	8.3	62.1	17.0	15.5	5.4
	Appetite problems	51.2	17.6	24.6	6.6	48.2	22.3	22.7	6.7
	Nausea	72.2	14.2	10.6	3.0	70.5	13.8	11.1	4.6
Unstable	Bowel problems	55.3	20.9	16.9	7.0	56.0	21.4	16.8	5.8
	Breathing problems	53.1	16.8	21.8	8.3	58.2	18.8	16.3	6.7
	Fatigue	25.9	22.9	37.2	14.0	26.4	23.5	36.5	13.6
	Pain	22.4	26.4	32.3	18.8	31.9	27.4	28.5	12.2
	Difficulty sleeping	67.6	15.7	13.4	3.4	74.6	12.8	10.2	2.3
	Appetite problems	54.2	21.7	20.3	3.7	58.5	20.1	16.9	4.5
	Nausea	76.5	12.5	9.1	1.8	78.0	11.8	8.1	2.1
Deteriorating	Bowel problems	60.1	23.6	13.0	3.4	64.7	19.1	13.1	3.1
	Breathing problems	58.8	22.0	15.1	4.1	61.1	17.8	15.9	5.2
	Fatigue	35.7	23.5	33.7	7.2	34.5	19.7	35.2	10.6
	Pain	37.3	32.2	24.5	6.0	40.0	30.8	23.5	5.7
	Difficulty sleeping	94.6	2.4	2.8	0.2	93.1	3.7	2.5	0.7
	Appetite problems	96.3	1.7	1.5	0.6	91.7	3.8	2.7	1.8
	Nausea	95.3	3.4	1.1	0.2	94.3	3.3	1.8	0.6
Terminal	Bowel problems	94.4	3.5	1.3	0.7	88.2	6.7	3.8	1.4
	Breathing problems	77.0	12.8	8.0	2.2	73.7	12.1	10.5	3.7
	Fatigue	89.4	2.2	5.4	3.0	79.2	6.8	8.9	5.0
	Pain	69.1	20.7	9.5	0.7	60.2	24.1	13.5	2.2



Table 35 Profile of SAS scores at beginning of phase by phase type –community setting (percentages)

Dhaga tuus		3 - 3		ervices	, (p	All Services				
Phase type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	
	Difficulty sleeping	79.8	15.9	4.1	0.2	67.7	24.2	7.5	0.6	
	Appetite problems	66.3	26.0	7.4	0.3	51.4	34.7	12.7	1.1	
	Nausea	90.9	8.2	0.9	0.0	82.3	15.0	2.5	0.2	
Stable	Bowel problems	81.2	15.7	2.9	0.1	68.8	24.6	6.0	0.5	
	Breathing problems	66.8	23.8	9.3	0.1	56.0	31.5	11.5	1.0	
	Fatigue	21.5	35.0	42.3	1.2	17.2	40.1	39.8	3.0	
	Pain	57.5	36.2	5.8	0.5	46.3	42.8	9.9	1.0	
	Difficulty sleeping	55.2	19.0	21.9	3.9	46.7	26.4	22.0	4.9	
	Appetite problems	49.4	16.5	28.8	5.3	34.9	28.2	30.1	6.9	
	Nausea	67.1	11.4	17.2	4.3	59.8	17.7	17.4	5.2	
Unstable	Bowel problems	69.9	13.8	12.8	3.6	55.6	24.1	15.2	5.0	
	Breathing problems	56.3	18.3	19.8	5.6	47.3	27.4	20.3	5.0	
	Fatigue	17.1	12.9	54.8	15.2	11.9	22.4	51.6	14.1	
	Pain	27.3	22.8	30.1	19.8	18.2	25.4	39.7	16.6	
	Difficulty sleeping	67.7	19.8	12.0	0.5	59.0	27.5	12.5	0.9	
	Appetite problems	56.0	25.3	17.2	1.6	42.0	34.1	20.7	3.2	
	Nausea	79.9	13.8	6.0	0.4	72.3	19.9	7.0	0.8	
Deteriorating	Bowel problems	71.1	19.2	9.4	0.3	60.9	27.4	10.7	1.0	
	Breathing problems	55.3	27.1	16.9	0.7	47.5	33.6	16.9	1.9	
	Fatigue	14.6	23.1	58.5	3.9	12.5	28.3	51.7	7.5	
	Pain	42.1	35.0	20.9	2.1	33.0	42.2	22.1	2.7	
	Difficulty sleeping	79.5	8.4	11.1	1.0	78.6	11.7	8.5	1.1	
	Appetite problems	92.6	3.2	3.5	0.7	84.1	7.2	5.1	3.6	
	Nausea	89.3	6.9	3.8	0.0	86.4	9.2	3.9	0.4	
Terminal	Bowel problems	87.5	6.8	5.2	0.5	77.7	15.8	5.8	0.8	
	Breathing problems	63.9	18.1	15.3	2.7	58.6	23.9	14.3	3.2	
	Fatigue	75.7	2.3	16.6	5.5	65.2	7.1	16.0	11.6	
	Pain	55.0	25.8	17.7	1.5	42.1	38.0	17.9	2.0	



The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 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. Table 36 shows the data for the AKPS at phase start.

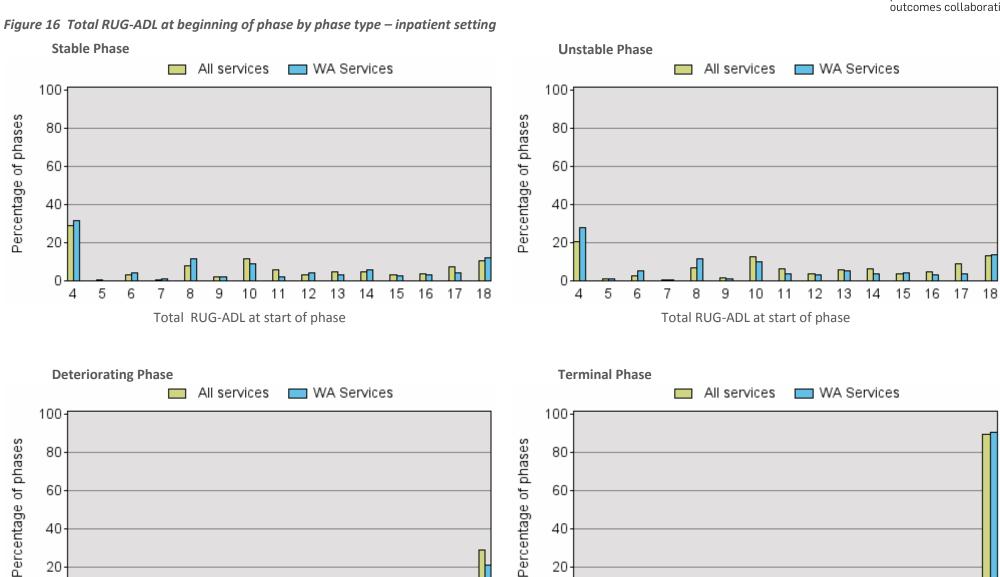
Table 36 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting

		Inpa	tient		Community				
AKPS assessment at phase start	WA Services		All Se	ervices	WA Services		All Services		
	N	%	N	%	N	%	N	%	
10 - Comatose or barely rousable	305	11.8	3,197	10.6	348	3.4	852	3.2	
20 - Totally bedfast and requiring extensive nursing care	583	22.6	7,200	23.8	1,041	10.3	2,504	9.4	
30 - Almost completely bedfast	341	13.2	4,128	13.6	667	6.6	1,941	7.3	
40 - In bed more than 50% of the time	440	17.0	5,417	17.9	1,051	10.4	3,401	12.7	
50 - Requires considerable assistance	458	17.7	4,828	16.0	2,340	23.1	6,859	25.7	
60 - Requires occasional assistance	340	13.2	2,998	9.9	2,619	25.8	6,450	24.1	
70 - Cares for self	91	3.5	674	2.2	1,765	17.4	3,301	12.4	
80 - Normal activity with effort	11	0.4	203	0.7	261	2.6	624	2.3	
90 - Able to carry on normal activity; minor signs or symptoms	4	0.2	84	0.3	42	0.4	97	0.4	
100 - Normal; no complaints; no evidence of disease	2	0.1	10	0.0	0	0.0	4	0.0	
Not stated/inadequately described	6	0.2	1,516	5.0	1	0.0	688	2.6	
Total	2,581	100.0	30,255	100.0	10,135	100.0	26,721	100.0	

The 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. The RUG-ADL are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. Figure 16 and Figure 17 on the following two pages summarise the total RUG-ADL at the beginning of each phase for inpatients and community patients. The total score on the RUG-ADL ranges from a minimum of 4 (lowest level of functional dependency) to a maximum of 18 (highest level of functional dependency).

AKPS & RUG-ADL can be used together to provide a profile of both patient dependency, equipment requirements, need for allied health referrals and carer burden/respite requirements.



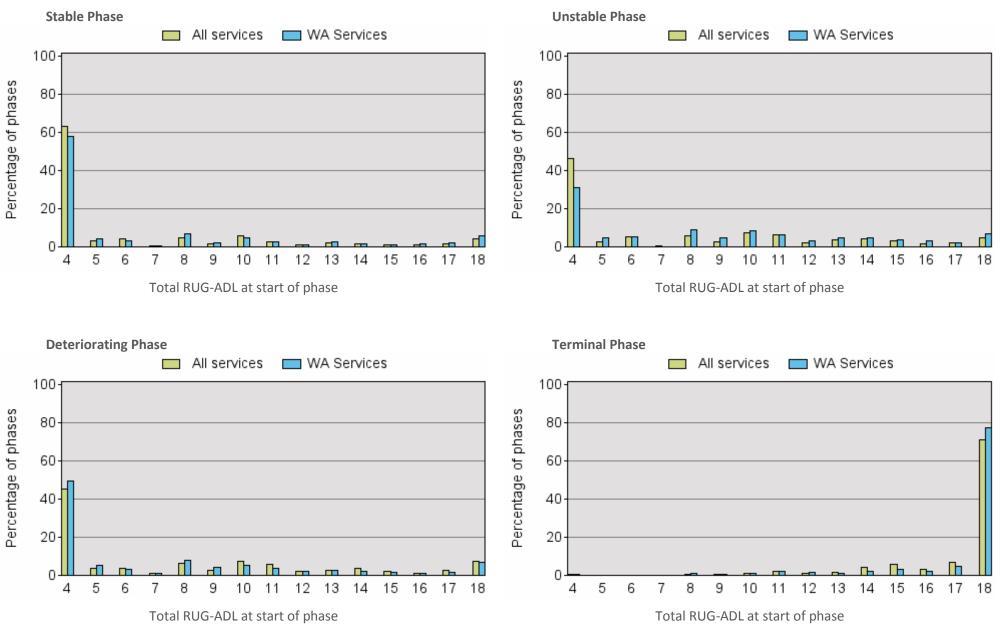


Total RUG-ADL at start of phase

Total RUG-ADL at start of phase









# **Appendix A** Summary of data included in this report

#### A1 Data summary

During the reporting period, data were provided for a total of 19,117 patients who between them had 24,696 episodes of care and 56,976 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Appendix C contains a more detailed explanation of this process). Table 37 shows the number of patients, episodes and phases included in this report – both for Western Australian services and nationally.

Table 37 Number and percentage of patients, episodes and phases by setting

	Inpa	tient	Comn	nunity	Total		
	WA Services	All Services	WA Services	All Services	WA Services	All Services	
Number of patients*	999	10,810	2,229	9,219	3,215	19,117	
Number of episodes	1,149	12,722	2,969	11,974	4,118	24,696	
Number of phases**	2,581	30,255	10,135	26,721	12,716	56,976	
Percentage of patients*	31.1	56.5	69.3	48.2	100	100	
Percentage of episodes	27.9	51.5	72.1	48.5	100	100	
Percentage of phases	20.3	53.1	79.7	46.9	100	100	
Average number of phases per episode***	2.2	2.4	3.2	2.1	2.9	2.3	

<sup>\*</sup> Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.

<sup>\*\*</sup> Bereavement phases are excluded from this count.

<sup>\*\*\*</sup> Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.



Table 38 shows the number of completed episodes and phases by setting for each month in the current reporting period for Western Australian services. This table allows a service to identify any change in patient numbers during the reporting period.

Table 38 Number of completed episodes and phases by month and setting

Setting		Jan	Feb	Mar	Apr	May	Jun
Innations	No. of completed episodes	187	183	185	194	168	207
Inpatient	No. of completed phases	405	443	408	444	428	453
Community	No. of completed episodes	446	415	445	432	411	417
Community	No. of completed phases	1,634	1,624	1,803	1,737	1,702	1,635

Table 39 shows the number of patients, episodes and phases for Western Australian services over time and is reported by setting of care. This table allows a service to identify any changes in volume over a three-year period.

Table 39 Number of patients, episodes and phases by setting and reporting period

		Inpatient							Community					
	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2014	Jan-Jun 2015	Jul-Dec 2015	Jan-Jun 2016	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2014	Jan-Jun 2015	Jul-Dec 2015	Jan-Jun 2016		
Number of patients*	1,368	943	1,272	1,097	1,103	999	1,921	1,855	2,044	1,952	2,240	2,229		
Number of episodes	1,612	1,153	1,463	1,233	1,275	1,149	2,489	2,412	2,602	2,434	2,854	2,969		
Number of phases**	3,203	2,289	2,980	2,615	2,729	2,581	8,941	9,095	9,466	8,966	9,854	10,135		
Average number of phases per episode***	2.0	2.0	2.0	2.1	2.1	2.2	3.2	3.6	3.3	3.4	3.1	3.2		

<sup>\*</sup> Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.

<sup>\*\*</sup> Bereavement phases are excluded from this count.

<sup>\*\*\*</sup> Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.



#### A2 Data item completion

As shown in Table 40, Table 41 and Table 42 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

PCOC strongly encourages services to complete and submit the whole data set on every patient as non-completion may result in services being excluded from relevant benchmarking activities or erroneous conclusions being drawn. Low completion of data items may also distort percentages and graphs in some sections.

Table 40 Item completion (per cent complete) - patient level

Data item	WA Services	All Services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	97.9	97.7
Country of birth	98.4	98.2
Preferred language	99.1	98.8
Primary diagnosis	98.5	99.4

Note: This table is not split by setting to be consistent with the patient level analysis throughout this report.

Table 41 Item completion by setting (per cent complete) - episode level

	Inpa	tient	Comn	nunity	То	tal
Data item	WA	All	WA	All	WA	All
	Services	Services	Services	Services	Services	Services
Date of first contact	100.0	98.7	100.0	99.8	100.0	99.3
Referral date	100.0	100.0	100.0	99.8	100.0	99.9
Referral source	99.8	99.9	100.0	99.8	100.0	99.8
Date ready for care	100.0	97.7	100.0	92.6	100.0	95.2
Mode of episode start	100.0	99.9	100.0	99.8	100.0	99.9
Accommodation at episode start	99.3	99.8	100.0	95.0	99.9	96.8
Episode end date*	99.9	99.8	91.0	94.3	93.5	97.1
Mode of episode end	99.8	99.9	100.0	99.0	99.9	99.5
Accommodation at episode end	99.8	99.0	100.0	91.0	99.9	96.8
Place of death	na	na	99.8	95.5	99.8	95.5

Episode end date item completion may be affected by open episodes.



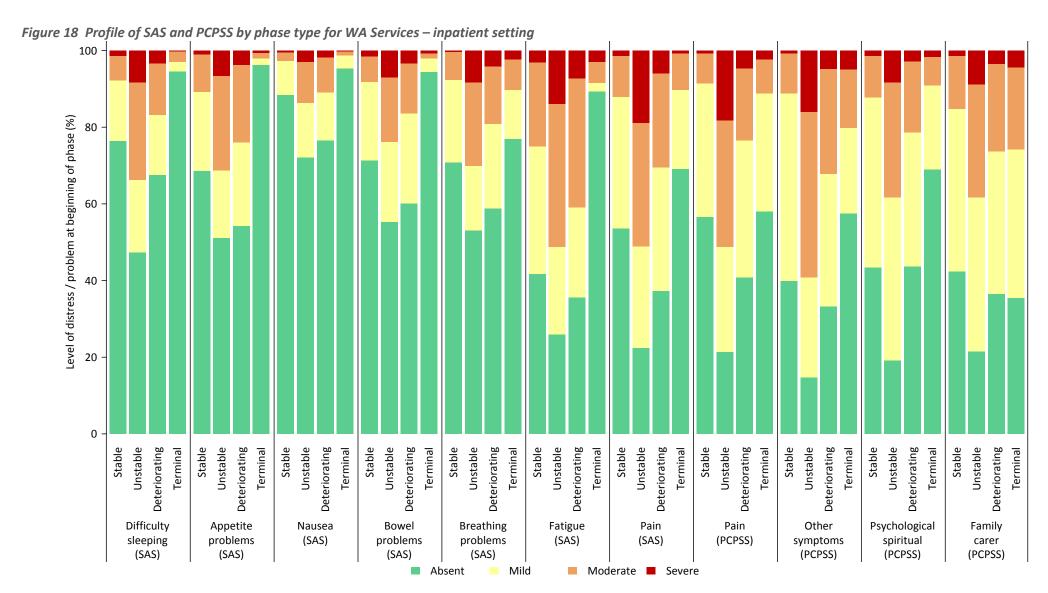
Table 42 Item completion by setting (per cent complete) - phase level

	Cula Catamani	At phase start							At discharge					
<b>D</b> 4 4	Sub-Category	Inpatient		Comn	nunity	Total		Inpatient		Community		То	tal	
Data item	(where emplicable)	WA	All	WA	All	WA	All	WA	All	WA	All	WA	All	
	(where applicable)	Services	Services	Services	Services	Services	Services	Services	Services	Services	Services	Services	Services	
	Bed mobility	100.0	99.6	99.7	97.2	99.8	98.5	97.1	92.7	58.2	54.4	67.8	70.1	
RUG-ADL	Toileting	100.0	99.5	99.7	97.1	99.8	98.4	97.1	92.7	58.2	54.3	67.8	70.0	
RUG-ADL	Transfers	100.0	99.5	99.5	97.1	99.6	98.4	97.1	92.7	58.2	54.4	67.8	70.1	
	Eating	99.9	99.4	98.7	96.4	99.0	98.0	97.1	92.7	58.2	54.1	67.8	69.9	
	Pain	99.7	98.9	100.0	97.3	99.9	98.2	96.4	92.2	58.4	54.3	67.8	69.8	
PCPSS	Other symptom	79.0	97.1	100.0	94.4	95.7	95.9	85.2	91.1	58.4	52.1	65.0	68.1	
	Psychological / spiritual	99.5	98.9	100.0	96.5	99.9	97.8	97.0	92.3	58.5	53.9	68.0	69.6	
	Family / carer	86.9	97.0	100.0	95.2	97.3	96.1	76.5	88.3	58.5	53.1	62.9	67.5	
	Difficulty sleeping	98.6	91.7	99.5	89.8	99.3	90.9	95.5	81.0	58.3	47.3	67.5	61.1	
	Appetite problems	99.1	93.5	99.6	95.3	99.5	94.4	96.3	82.0	58.1	52.0	67.5	64.3	
CAC	Nausea	99.3	93.6	99.8	96.3	99.7	94.8	95.5	81.4	58.4	53.0	67.5	64.7	
SAS	Bowel problems	99.0	93.5	99.6	95.1	99.5	94.3	95.4	82.0	58.2	52.0	67.4	64.3	
	Breathing problems	99.6	93.6	99.8	95.6	99.7	94.5	96.3	82.4	58.2	52.5	67.6	64.8	
	Fatigue	99.2	93.5	99.7	96.2	99.6	94.8	95.4	82.6	58.2	52.9	67.4	65.1	
	Pain	99.6	93.6	99.9	97.8	99.8	95.6	96.1	82.3	58.3	54.1	67.6	65.7	
AKPS	-	99.8	95.0	100.0	97.4	99.9	96.1	96.6	90.5	58.4	56.0	67.8	70.2	

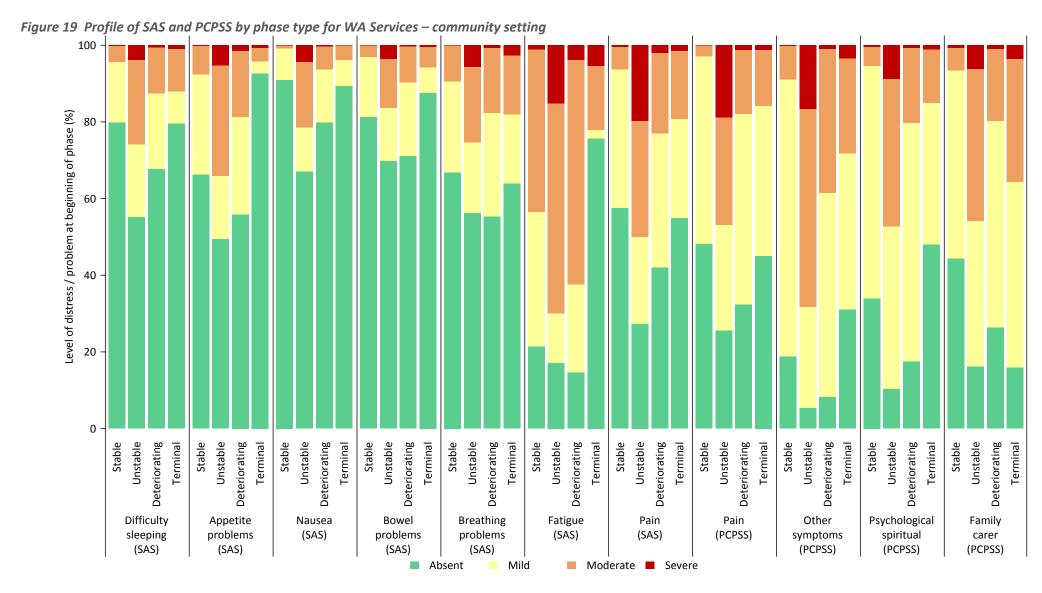
	Inpa	tient	Comn	nunity	Total	
Data item	WA	All	WA	All	WA	All
	Services	Services	Services	Services	Services	Services
Phase End Reason	99.8	99.6	100.0	99.7	99.9	99.7



### **Appendix B** Additional information on profile of SAS and PCPSS









#### Appendix C Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that <u>end</u> within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 20 below displays four examples to help visualize this process.

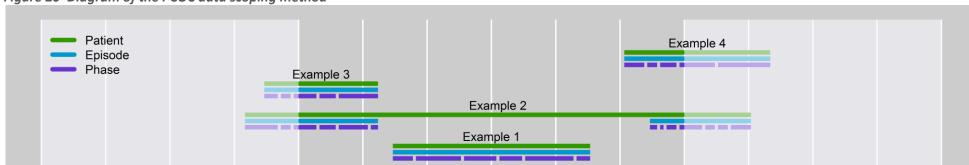


Figure 20 Diagram of the PCOC data scoping method

In <u>Example 1</u>, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

Six Month Reporting Period

In <u>Example 2</u>, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in the previous report. For the phases relating to the second episode, only the first three end within the reporting period, so only these would be included in the report. The following four phases would be included in the next report. Both of the episode records and the patient record would also be included in the report.

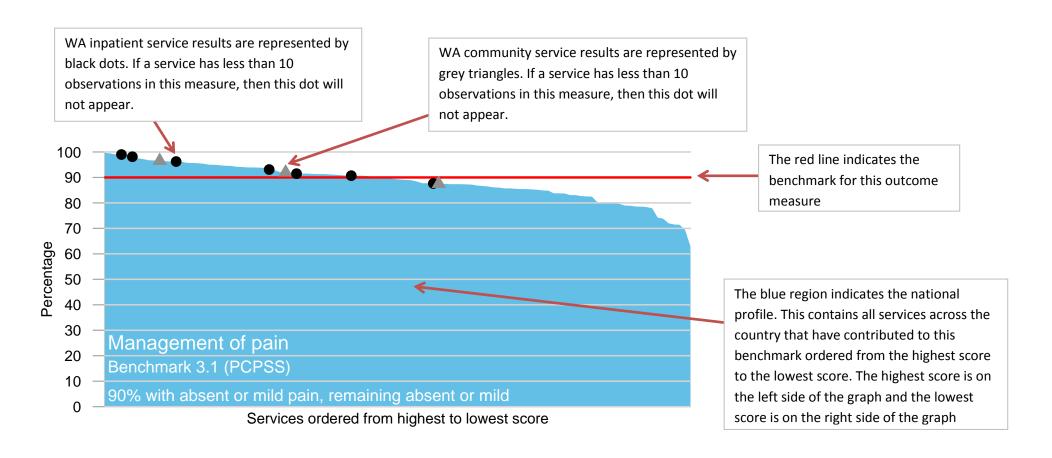
In <u>Example 3</u>, the patient has one episode and five phases. Only the last three phases will be included in the report as they are the only ones ending within the reporting period (the first two phases would have been included in the previous report). The episode and patient records would be included in the report.

In <u>Example 4</u>, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.



# **Appendix D** How to interpret benchmark profile graphs

The national profile graphs present WA services in comparison to all other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. Western Australian inpatient service are highlighted as a black dots on the graph. Western Australian community service are highlighted as grey triangles on the graph.





# **Appendix E** Palliative Care Phase definitions

START	END
Stable	
Patient problems and symptoms are adequately controlled by established plan of care and  Further interventions to maintain symptom control and quality of life have been planned and  Family / carer situation is relatively stable and no new issues are apparent.	The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care.
Unstable	
<ul> <li>An urgent change in the plan of care or emergency treatment is required because</li> <li>Patient experiences a new problem that was not anticipated in the existing plan of care, and / or</li> <li>Patient experiences a rapid increase in the severity of a current problem; and / or</li> <li>Family / carers circumstances change suddenly impacting on patient care.</li> </ul>	<ul> <li>The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom / crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and / or</li> <li>Death is likely within days (i.e. patient is now terminal).</li> </ul>
Deteriorating	
<ul> <li>The care plan is addressing anticipated needs but requires periodic review because</li> <li>Patients overall functional status is declining and</li> <li>Patient experiences a gradual worsening of existing problem and / or</li> <li>Patient experiences a new but anticipated problem and / or</li> <li>Family / carers experience gradual worsening distress that impacts on the patient care.</li> </ul>	<ul> <li>Patient condition plateaus (i.e. patient is now stable) or</li> <li>An urgent change in the care plan or emergency treatment and / or</li> <li>Family / carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) or</li> <li>Death is likely within days (i.e. patient is now terminal).</li> </ul>
Terminal	
Death is likely within days.	<ul> <li>Patient dies or</li> <li>Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).</li> </ul>
Bereavement – post death support	
<ul> <li>The patient has died</li> <li>Bereavement support provided to family / carers is documented in the deceased patient's clinical record.</li> </ul>	<ul> <li>Case closure</li> <li>Note: If counselling is provided to a family member or carer, they become a client in their own right.</li> </ul>



#### **Acknowledgements**

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Disclaimer 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 the PCOC report. We would advise readers to use their professional judgement in considering all information contained in this report.

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