

Western Australia

Patient Outcomes in Palliative Care

January to June 2023

August 2023

What is PCOC?

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national palliative care outcomes and benchmarking program. PCOC's primary objective is to systematically improve patient outcomes (including pain and symptom control).

Central to the program is a <u>framework and protocol for routine clinical assessment and response</u>. This works in parallel with a routine point-of-care data collection, capturing clinically meaningful information. PCOC aims to drive improvement in patient outcomes through feedback to individual services and by facilitating service-to-service benchmarking.

The items in the PCOC data collection:

- provide clinicians with an approach to systematically assess individual patient experiences
- include routine Patient Reported Outcome Measures (PROMs) relating to symptom distress
- define a common clinical language to allow palliative care providers to communicate with each other
- facilitate the routine collection of nationally consistent palliative care data for the purpose of reporting and benchmarking to drive quality improvement at service, state, territory and national levels.

The assessment framework incorporates five validated 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).



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Introduction

The Australian palliative care sector is a world leader in using routine clinical assessment information to guide patient centred care and measure patient and family outcomes. Providers of palliative care are commended for their commitment to excellence in delivering evidence-based, patient-centred care by using the routine Palliative Care Outcomes Collaboration (PCOC) assessment framework and contributing patient data toward national outcome measurement and benchmarking. PCOC acknowledges the dedication and willingness of clinicians to improve the care of patients, their families and caregivers. The information collected is not just data - it represents the real-life outcomes of over 60,000 Australian patients each year.

While the focus of this report is on the most recent information relating to January to June 2023, results over the last three years are also presented to highlight achievements and improvement in outcomes. The most recent information corresponds to 36,772 patients, having 45,484 episodes of care and 98,152 palliative care phases from 209 services who provide palliative care in hospital or in the person's home.

The Western Australian figures in this report are based on information submitted by the services listed in Table 1 on the following page. A full list of the services included in the national figures can be found at www.pcoc.org.au.

Interpretation hint:

Please use the following key when interpreting the tables:

- The item is not applicable.
- u The item was unavailable.
- s The item was suppressed due to insufficient data.



Table 1 List of WA Services included in this report

Service name	Setting of care
Albany Community Hospice	Inpatient
Bethesda Hospital	Inpatient
Fiona Stanley Hospital Consult Service	Inpatient
Glengarry Private Hospital	Inpatient
Goldfields Regional Palliative Care Service	Inpatient and community
Great Southern Regional Palliative Care Service	Inpatient and community
Kalamunda Districts Community Hospital	Inpatient
Kimberley Regional Palliative Care Service	Inpatient and community
Metropolitan Palliative Care Consultancy Service – East Team	Community
Metropolitan Palliative Care Consultancy Service – North Team	Community
Metropolitan Palliative Care Consultancy Service – South Team	Community
Midwest Palliative Care Service combined	Community
PalCATS – Palliative Care After Hours Telehealth Service	Inpatient
Pilbara Regional Palliative Care Service	Inpatient and community
Ramsay Health Care Peel Health Campus	Inpatient
Ramsay Joondalup Health Campus – Consult	Inpatient
Ramsay Joondalup Health Campus – Inpatient	Inpatient
Rockingham General Hospital Consult Service	Inpatient
Royal Perth Hospital	Inpatient
Silver Chain Hospice Care Service – East Team	Community
Silver Chain Hospice Care Service – North Team	Community
Silver Chain Hospice Care Service – South Team	Community
South West Regional Palliative Care Service	Inpatient and community
St John of God – Bunbury Hospital	Inpatient
St John of God – Geraldton Hospital	Inpatient
St John of God – Midland	Inpatient
St John of God – Murdoch Community Hospice	Inpatient
Wheatbelt Regional Palliative Care Service	Inpatient and community



1 Benchmark summary for WA Services

Table 2 Summary of outcome measures by setting of care

			Inpa	atient	Comr	munity	Benchmark
Outcome measure		Benchmark	%	BM met?	%	BM met?	Reference No.
Timely commencement of	palliative care						
Care commencing within two days of the patient being ready		90%	95.0	Yes	95.3	Yes	1
Responsiveness in managir	ng patients with urgent needs						
Patients unstable for three	days or less	90%	92.3	Yes	83.5	No	2
Symptoms & problems in t	he absent to mild range at phase end						
	Pain (clinician reported)		92.0	Yes	86.6	No	3.1
Anticipatory care	Pain (patient reported)		91.3	Yes	87.1	No	3.3
when patient symptoms or problems are in the absent to	Fatigue (patient reported)	90%	93.6	Yes	83.8	No	3.5
mild range at phase start	Breathing problems (patient reported)		96.3	Yes	94.3	Yes	3.7
	Family/carer problems (clinician reported)		92.9	Yes*	85.0	No	3.9
	Pain (clinician reported)		68.5	Yes	67.4	Yes	3.2
Responsive care	Pain (patient reported)		61.1	Yes	64.2	Yes	3.4
when patient symptoms or problems are in the moderate to	Fatigue (patient reported)	60%	59.4	No	51.1	No	3.6
severe range at phase start	Breathing problems (patient reported)		57.1	No	55.6	No	3.8
	Family/carer problems (clinician reported)		59.2	No*	62.5	Yes	3.10
Casemix adjusted outcome	s (change scores)		Score	BM met?	Score	BM met?	
Clinician vanantad	Pain		0.15	Yes	0.03	Yes	4.1
Clinician reported problems	Other symptoms	0.0	0.28	Yes	0.08	Yes	4.2
(PCPSS)	Family/carer problems	0.0	0.23	Yes*	0.10	Yes	4.3
(. 5. 55)	Psychological/spiritual problems		0.25	Yes	0.07	Yes	4.4
Dotiont voncets	Pain		0.38	Yes	0.16	Yes	4.5
Patient reported	Nausea	0.0	0.22	Yes	0.11	Yes	4.6
symptom distress (SAS)	Breathing problems	0.0	0.35	Yes	0.21	Yes	4.7
(SAS)	Bowel problems		0.32	Yes	0.16	Yes	4.8

^{*} The item completion for this benchmark was less than 80%. This result may not be reflective of Western Australian services. See Appendix B for more details.



2 Patient outcomes in more detail

2.1 Timely commencement of palliative care

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 patient is ready for care to episode start by setting of care

		Inpa	atient			Con	nmunity	
Time (in days)	WA S	Services	All:	services	WA S	Services	Alls	services
	N	%	N	%	N	%	N	%
Same day	3,585	87.1	20,517	92.6	3,866	94.0	15,747	83.2
Following day	327	7.9	1,022	4.6	53	1.3	803	4.2
2-7	176	4.3	535	2.4	104	2.5	1,380	7.3
8-14	16	0.4	46	0.2	38	0.9	421	2.2
15 +	13	0.3	42	0.2	50	1.2	568	3.0
Average	1.2	-	1.1	-	1.6	-	2.6	-
Median	1	-	1	-	1	-	1	-

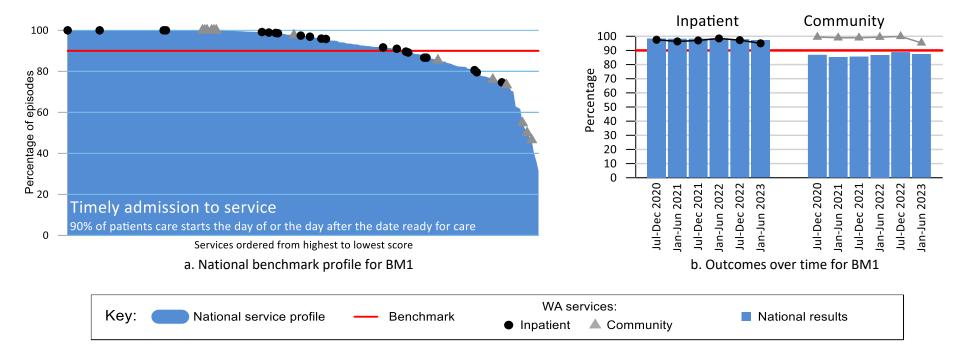
Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical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



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





2.2 Responsiveness in managing patients with urgent clinical needs

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.

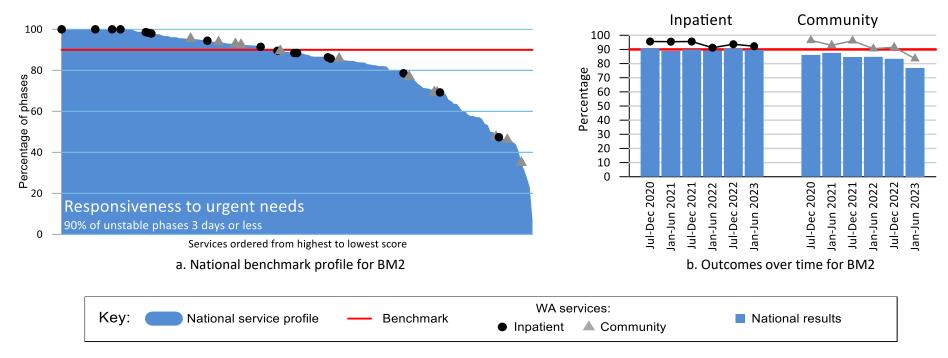
Benchmark 2: This benchmark relates to the time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for three days or less.

Table 4 Time in unstable phase by setting of care

			Cor	nmunity				
Time in unstable phase	WA S	Services	All	services	WA	Services	All	services
	N	%	N	%	N	%	N	%
Same day	111	10.2	521	8.0	185	36.4	1,641	32.9
1 day	602	55.5	3,649	55.8	166	32.7	1,429	28.6
2 days	188	17.3	1,163	17.8	51	10.0	489	9.8
3 days	99	9.1	532	8.1	22	4.3	281	5.6
4 – 5 days	48	4.4	414	6.3	37	7.3	277	5.6
6 – 7 days	20	1.8	143	2.2	16	3.1	192	3.8
8 – 14 days	10	0.9	81	1.2	16	3.1	283	5.7
15 days +	6	0.6	34	0.5	15	3.0	398	8.0
Total	1,084	100.0	6,537	100.0	508	100.0	4,990	100.0



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





2.3 Symptoms & problems in the absent to mild range at phase end

The outcome measures presented in this section focus on five symptom and problem areas:

- 1. Pain clinician reported severity
- 2. Pain patient reported distress
- 3. Fatigue patient reported distress
- 4. Breathing problems patient reported distress
- 5. Family/carer problems clinician reported severity

A positive patient outcome is achieved if the patient and family/carer assessment (using the Symptom Assessment Scale and the Palliative Care Problem Severity Score) has an absent to mild symptom/problem at the end of a palliative care phase. The type of care delivered and the corresponding benchmarks achievement depends on the patient's (or family/carer) level of symptom or problem at start of the phase; start scores in the absent to mild range trigger monitoring and review of care plans and are considered **anticipatory care**, whilst start scores in the moderate to severe range trigger interventions, actions and a change in the patient care plan to respond to needs and are considered **responsive care**.

Anticipatory care

The anticipatory care outcome measures and benchmarks relate to patients who have absent or mild symptom/problem at the start of a phase of palliative care. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild symptom/problem. Table 5 summarises the number of patient phases starting with absent to mild symptom/problem, and the percentage of those ending in the absent to mild range.

Table 5 Achieving absent to mild symptoms/problems at phase end, when absent to mild at start

		Inpatie	nt					
Symptom/problem ^a	WA S	ervices	All s	ervices	WA Se	ervices	All s	ervices
	N ^b	%						
Pain (clinician reported)	5,441	92.0	26,423	90.8	8,227	86.6	28,758	85.7
Pain (patient reported)	5,097	91.3	22,714	90.6	8,150	87.1	28,478	85.9
Fatigue (patient reported)	5,312	93.6	23,413	93.1	7,178	83.8	24,432	83.1
Breathing problems (patient reported)	5,821	96.3	25,685	95.7	8,725	94.3	29,051	93.4
Family/carer problems (clinician reported)	3,735	92.9	24,940	93.0	7,089	85.0	25,654	83.4

a. Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with absent to mild symptom/problem.



Responsive care

The responsive care outcome measure and benchmarks relate to patients, and/or family/carer, who have been assessed with moderate or severe symptoms/problems at the start of their phase of palliative care. Achieving an absent/mild symptom or problem outcome at phase end has been identified as more clinically challenging. In order to meet this benchmark, 60% of these patient phases must end with the patient experiencing absent or mild symptom/problem.

Table 6 summarises the number of patient phases assessed as starting with moderate to severe symptom/problem and of those, the percentage ending in the absent to mild range.

Table 6 Achieving absent to mild symptoms/problems at phase end, when moderate to severe at start

		Inpatier	nt			Community			
Symptom/problem ^a	WA S	ervices	All s	ervices	WA S	ervices	All s	ervices	
	N ^b	%	N ^b	%	N ^b	%	N ^b	%	
Pain (clinician reported)	1,204	68.5	6,218	65.8	1,440	67.4	5,898	59.0	
Pain (patient reported)	1,443	61.1	6,127	61.2	1,474	64.2	6,110	56.9	
Fatigue (patient reported)	1,224	59.4	5,308	57.6	2,424	51.1	8,625	47.4	
Breathing problems (patient reported)	720	57.1	3,084	58.3	886	55.6	3,635	49.0	
Family/carer problems (clinician reported)	683	59.2	3,877	58.2	1,321	62.5	6,226	49.3	

a. Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to enable outcomes to be measured.

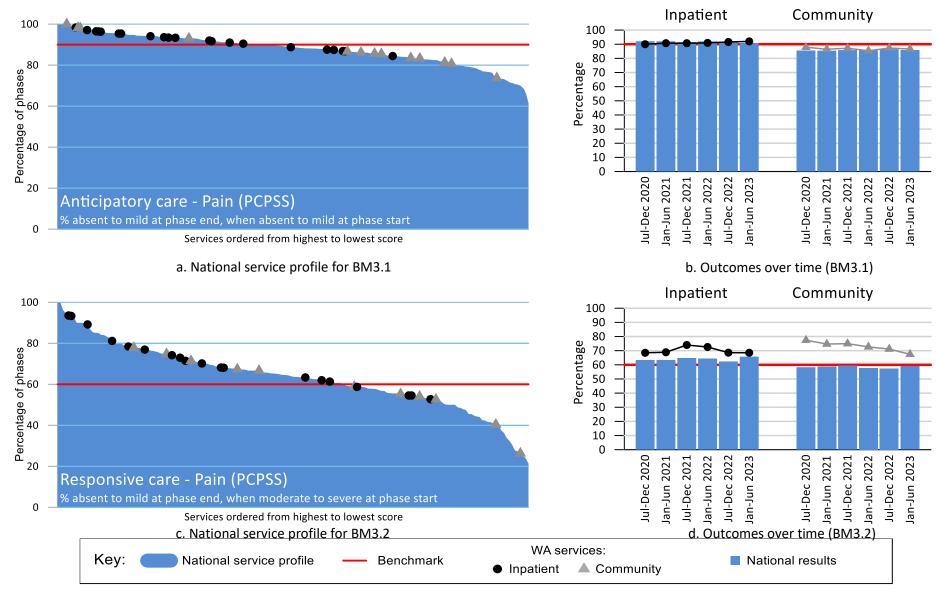
On the following pages, the results for the anticipatory and responsive care benchmarks are presented together for each of the five symptom and problem domains. The graphs included compare the outcomes achieved by Western Australian services to those of other individual services nationally, as well as showing any changes in outcomes over time.

b. N represents the total number of phases starting with the symptom or problem rated moderate to severe.



Pain (clinician reported problem severity)

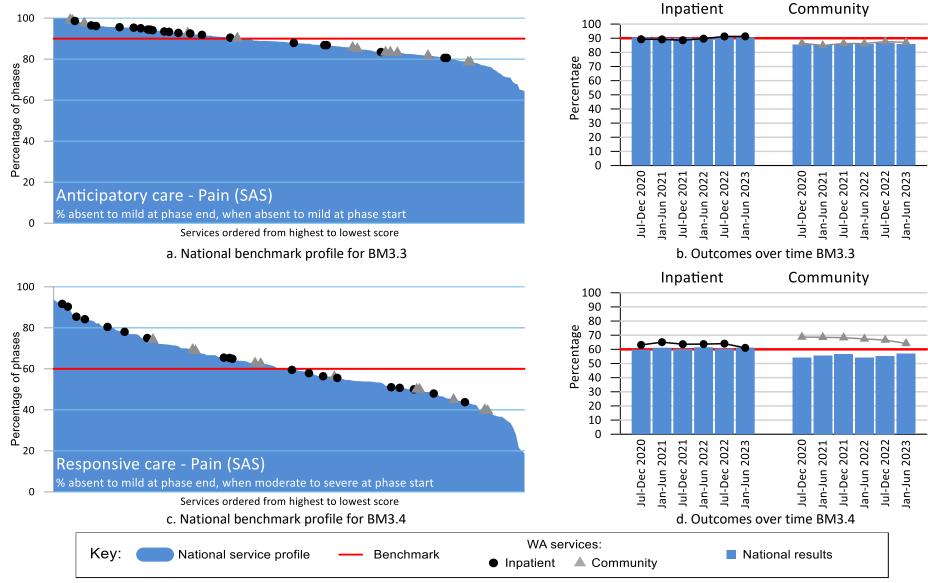
Figure 3 Pain, patients assessed with absent to mild severity at phase end





Pain (patient reported distress)

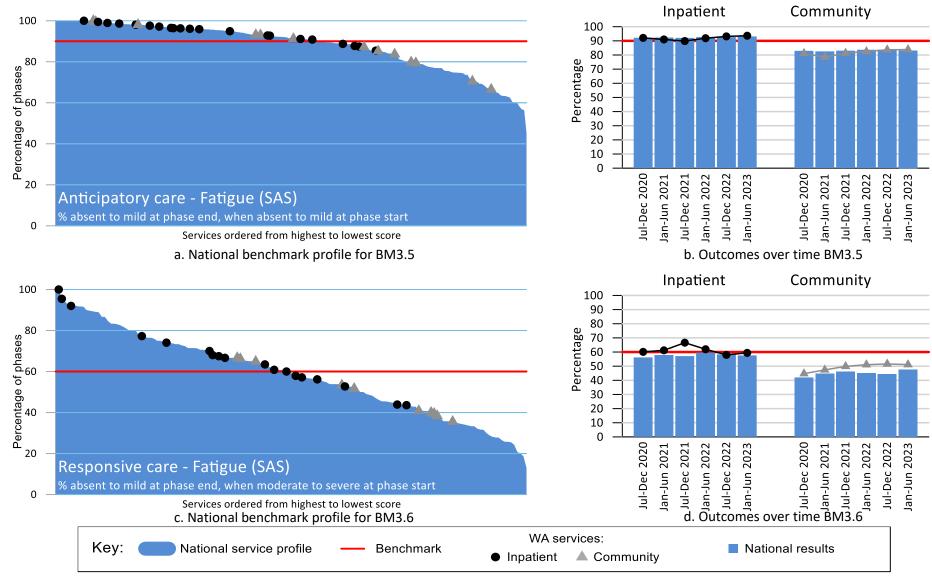
Figure 4 Pain, patients reporting absent to mild distress at phase end





Fatigue (patient reported distress)

Figure 5 Fatigue, patients reporting absent to mild distress at phase end





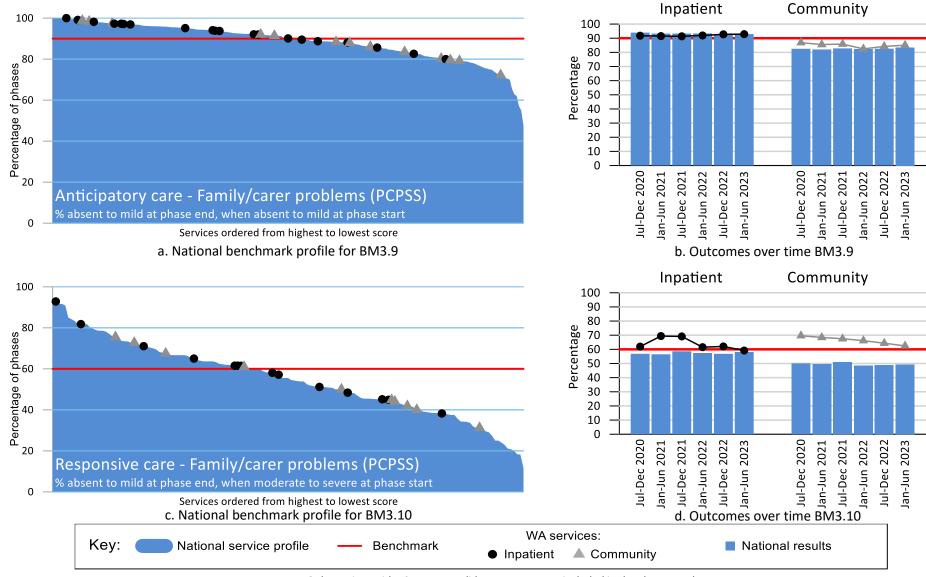
Breathing problems (patient reported distress)

Figure 6 Breathing problems, patients reporting absent to mild distress at phase end Inpatient Community 100 100 90 80 Percentage of phases Percentage 70 60 50 40 30 20 10 Jul-Dec 2020 Jul-Dec 2020 Jan-Jun 2021 Jul-Dec 2021 Jan-Jun 2022 Jul-Dec 2022 Jan-Jun 2023 Jan-Jun 2021 Jul-Dec 2021 Jan-Jun 2022 Jul-Dec 2022 Jan-Jun 2023 20 Anticipatory care - Breathing problems (SAS) % absent to mild at phase end, when absent to mild at phase start 0 Services ordered from highest to lowest score a. National benchmark profile for BM3.7 b. Outcomes over time BM3.7 Inpatient Community 100 100 90 80 Percentage of phases Percentage 70 60 50 40 30 20 10 Jul-Dec 2020 Jul-Dec 2022 lan-Jun 2021 Jul-Dec 2021 Jan-Jun 2022 Jul-Dec 2022 Jan-Jun 2023 Jan-Jun 2021 Jul-Dec 2021 lan-Jun 2022 lan-Jun 2023 20 Responsive care - Breathing problems (SAS) % absent to mild at phase end, when moderate to severe at phase start 0 Services ordered from highest to lowest score c. National benchmark profile for BM3.8 d. Outcomes over time BM3.8 WA services: Key: National service profile Benchmark National results Community Inpatient



Family/carer problems (clinician reported problem severity)

Figure 7 Family/carer problems, family/carer assessed with absent to mild problem severity at phase end





2.4 Casemix adjusted outcomes

Outcome measure 4 includes a suite of eight casemix adjusted scores used to compare the change in symptoms for similar patients. Patients in the same phase who started with the same level of symptom have their change in symptom compared to the reference period (January to June 2014).

Table 7 Casemix adjusted outcomes – inpatient setting

			WA S	ervices		All services				
Clinical tool	Symptom/problem	Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)	Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)	
PCPSS	Pain	0.15	6,645	4,449	67.0	0.09	32,641	20,160	61.8	
Clinician	Other symptoms	0.28	6,190	4,800	77.5	0.25	31,987	24,456	76.5	
reported	Family/carer	0.23	4,418	3,348	75.8	0.21	28,817	21,519	74.7	
severity	Psychological/spiritual	0.25	6,608	4,595	69.5	0.21	32,307	21,457	66.4	
SAS	Pain	0.38	6,540	4,618	70.6	0.29	28,841	19,344	67.1	
Patient	Nausea	0.22	6,543	5,912	90.4	0.19	28,730	25,307	88.1	
reported	Breathing problems	0.35	6,541	5,382	82.3	0.30	28,769	23,095	80.3	
distress	Bowel problems	0.32	6,531	5,479	83.9	0.30	28,672	23,327	81.4	

The Casemix adjusted scores are calculated relative to a baseline reference period. A Casemix adjusted score:

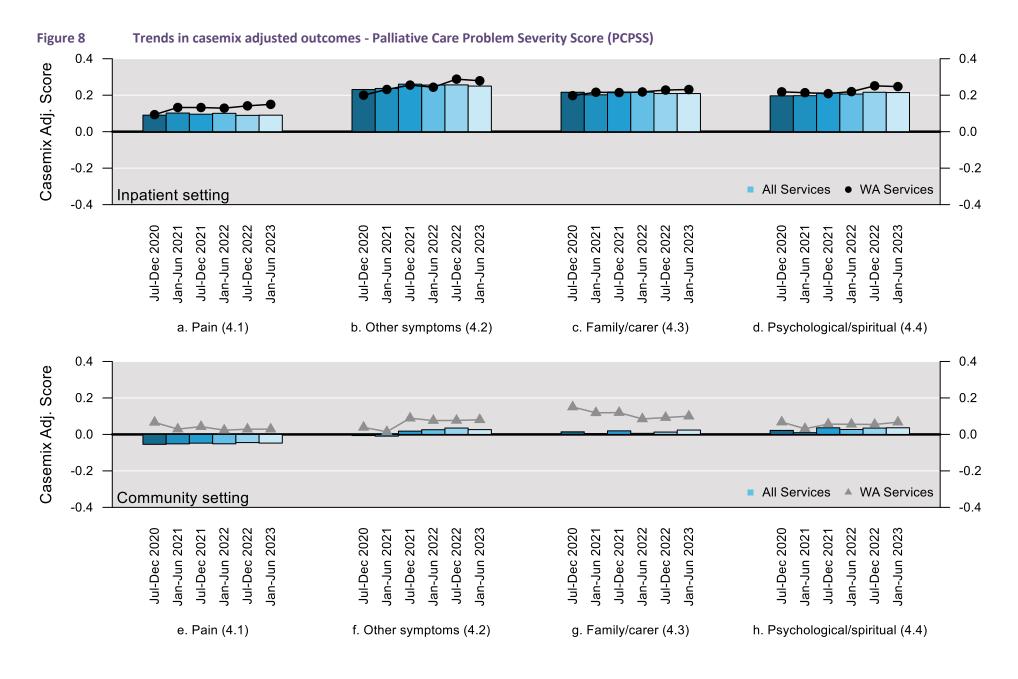
- greater than 0 means that on average WA patients' outcomes were better than similar patients in the reference period
- less than 0 means that on average, WA patients' outcomes were worse than similar patients in the reference period
- equal to 0 means that on average, WA patients' outcomes were about the same as similar patients in the reference period



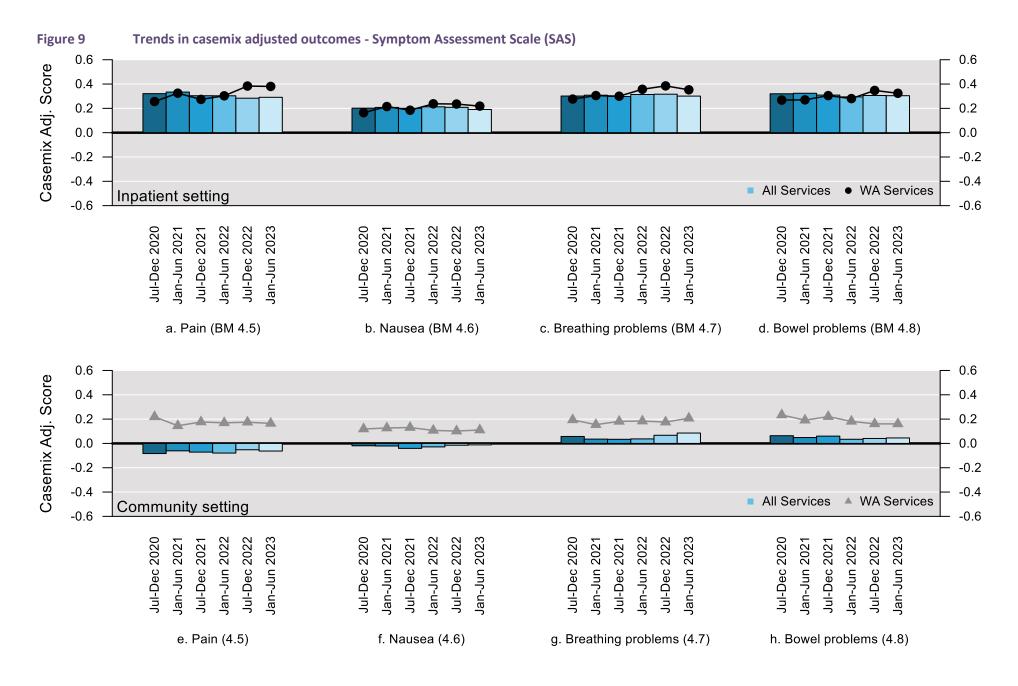
Table 8 Casemix adjusted outcomes – community setting

			WA S	ervices		All services						
	Symptom /problem	Casemix	Phases	Phases	Phases	Casemix	Phases	Phases	Phases			
Clinical tool		adjusted	included	at or above	at or above	adjusted	included	at or above	at or above			
		score	(N)	baseline (N)	baseline (%)	score	(N)	baseline (N)	baseline (%)			
PCPSS	Pain	0.03	9,667	5,755	59.5	-0.05	34,656	18,533	53.5			
Clinician	Other symptoms	0.08	9,199	6,234	67.8	0.03	33,770	22,355	66.2			
reported	Family/carer	0.10	8,410	5,805	69.0	0.02	31,880	20,961	65.7			
severity	Psychological/spiritual	0.07	9,645	5,452	56.5	0.04	33,831	18,226	53.9			
SAS	Pain	0.16	9,624	6,370	66.2	-0.06	34,588	20,276	58.6			
Patient	Nausea	0.11	9,605	8,322	86.6	-0.01	32,889	26,426	80.3			
reported	Breathing problems	0.21	9,611	7,404	77.0	0.09	32,686	23,147	70.8			
distress	Bowel problems	0.16	9,594	7,426	77.4	0.04	32,343	23,171	71.6			











3 Patient characteristics

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 9 shows the sex for the patients in Western Australian services and all participating PCOC services.

Table 9 Sex

Sau -	WA Services		All s	All services		
Sex -	N	%	N	%		
Male	3,683	51.0	18,996	51.7		
Female	3,537	49.0	17,751	48.3		
Not stated/Inadequately described/Intersex	1	0.0	25	0.1		
Total	7,221	100.0	36,772	100.0		

Table 10 shows the Indigenous status for the patients in Western Australian services and all participating PCOC services.

Table 10 Indigenous status

Indian avastatus	WA S	Services	All s	services
Indigenous status -	N	%	N	%
Aboriginal but not Torres Strait Islander origin	224	3.1	711	1.9
Torres Strait Islander but not Aboriginal origin	7	0.1	30	0.1
Both Aboriginal and Torres Strait Islander origin	9	0.1	54	0.1
Neither Aboriginal nor Torres Strait Islander origin	6,578	91.1	34,775	94.6
Not stated/inadequately described	403	5.6	1,202	3.3
Total	7,221	100.0	36,772	100.0



Table 11 Country of birth

County of hinth	V	VA Services	All	All services		
Country of birth	N	%	N	%		
Australia	4,852	67.2	23,724	64.5		
England	738	10.2	2,324	6.3		
India	59	0.8	304	0.8		
China	24	0.3	588	1.6		
New Zealand	116	1.6	643	1.7		
Philippines	11	0.2	158	0.4		
Vietnam	14	0.2	282	0.8		
South Africa	51	0.7	192	0.5		
Malaysia	48	0.7	150	0.4		
Italy	174	2.4	1,339	3.6		
Sri Lanka	5	0.1	123	0.3		
Scotland	117	1.6	443	1.2		
Nepal	0	0.0	7	0.0		
United States of America	12	0.2	85	0.2		
Germany	52	0.7	369	1.0		
All other countries	624	8.6	5,194	14.1		
Not stated	324	4.5	847	2.3		
Total	7,221	100.0	36,772	100.0		

The tables on this page 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 11 is in descending order of the most frequent country of birth according to the 2021 Census (e.g. India was the third most common country of birth in the 2021 Census). The same approach has been taken with Table 12 (e.g. Arabic was the fourth most frequently spoken language in the 2021 census). All other countries and languages have been grouped together to form the categories 'All other countries' and 'All other languages' respectively.

Table 12 Preferred language

	W	A Services	All services		
Language —	N	%	N	%	
English	6,831	94.6	32,631	88.7	
Chinese ^(a)	27	0.4	658	1.8	
Hindi ^(b)	5	0.1	118	0.3	
Arabic ^(c)	9	0.1	263	0.7	
Vietnamese ^(d)	11	0.2	222	0.6	
Filipino/Indonesian ^(e)	5	0.1	56	0.2	
Tamil/Malayalam ^(f)	S	S	17	0.0	
Spanish ^(g)	6	0.1	138	0.4	
Greek	5	0.1	467	1.3	
Italian	40	0.6	616	1.7	
Macedonian/Croatian ^(h)	23	0.3	293	0.8	
African languages	S	S	27	0.1	
Korean	S	S	55	0.1	
Samoan/Tongan ⁽ⁱ⁾	S	S	45	0.1	
Australian Indigenous languages	0	0.0	33	0.1	
All other languages	114	1.6	646	1.8	
Not stated	137	1.9	487	1.3	
Total	7,221	100.0	36,772	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) Kannada, Telugu, and Tulu
- (g) Catalan and Portuguese
- (h) Bosnian, Bulgarian, Serbian, and Slovene
- (i) Fijian, Gilbertese, Maori, Nauruan, Niue, Rotuman, Tokelauan, Tuvaluan, and Yapese



Table 13 and Table 14 present a breakdown of malignant and non-malignant diagnosis for the patients in Western Australian services and at the national level. Diagnosis is the principal life-limiting illness responsible for the patient requiring palliative care.

Diagnosis was not stated for 90 (1.2%) patients in Western Australian services and was not stated for 325 (0.9%) patients nationally.

Table 13 Principal diagnosis - malignant

		WA Services			All services		
Diagnosis	N	% of malignant diagnoses	% of all diagnoses	N	% of malignant diagnoses	% of all diagnoses	
Bone and soft tissue	48	1.3	0.7	345	1.5	1.0	
Breast	310	8.1	4.3	1,656	7.1	4.6	
CNS	99	2.6	1.4	558	2.4	1.5	
Colorectal	351	9.2	4.9	2,302	9.9	6.4	
Other GIT	403	10.5	5.7	2,359	10.1	6.5	
Haematological	277	7.2	3.9	1,628	7.0	4.5	
Head and neck	191	5.0	2.7	1,199	5.2	3.3	
Lung	766	20.0	10.7	4,592	19.7	12.7	
Pancreas	248	6.5	3.5	1,745	7.5	4.8	
Prostate	293	7.6	4.1	1,567	6.7	4.3	
Other urological	190	5.0	2.7	1,043	4.5	2.9	
Gynaecological	154	4.0	2.2	1,160	5.0	3.2	
Skin	164	4.3	2.3	868	3.7	2.4	
Unknown primary	139	3.6	1.9	668	2.9	1.8	
Other primary malignancy	129	3.4	1.8	1,110	4.8	3.1	
Malignant – Not further defined	74	1.9	1.0	463	2.0	1.3	
All malignant diagnoses	3,836	100.0	53.8	23,263	100.0	64.4	



Table 14 Principal diagnosis - non-malignant

		WA Services			All services	
Diagnosis	N	% of non- malignant diagnoses	% of all diagnoses	N	% of non- malignant diagnoses	% all diagnoses
Cardiovascular disease	462	14.0	6.5	1,794	13.9	5.0
HIV/AIDS	S	S	S	6	0.0	0.0
End stage kidney disease	186	5.6	2.6	932	7.2	2.6
Stroke	202	6.1	2.8	796	6.2	2.2
Motor neurone disease	63	1.9	0.9	366	2.8	1.0
Alzheimer's dementia	362	11.0	5.1	832	6.5	2.3
Other dementia	416	12.6	5.8	1,208	9.4	3.3
Other neurological disease	209	6.3	2.9	724	5.6	2.0
Respiratory failure	527	16.0	7.4	2,206	17.1	6.1
End stage liver disease	66	2.0	0.9	355	2.8	1.0
Diabetes & its complications	S	S	S	67	0.5	0.2
Sepsis	157	4.8	2.2	682	5.3	1.9
Multiple organ failure	64	1.9	0.9	337	2.6	0.9
Other non-malignancy	460	14.0	6.5	2,191	17.0	6.1
Non-malignant – Not further defined	101	3.1	1.4	388	3.0	1.1
All non-malignant	3,295	100.0	46.2	12,884	100.0	35.6



Figure 10 shows the proportion of patients with malignant and non-malignant diagnoses for this report compared to the previous five reports.

Figure 10 Principal diagnosis for WA Services over time

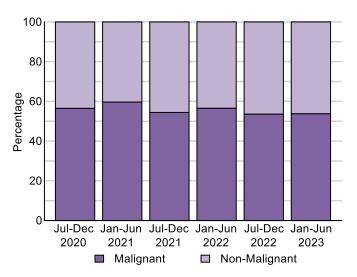


Table 15 shows the breakdown of patient deaths in Western Australian services and nationally for the reporting period. All inpatient deaths are reported in the hospital/hospice category while the community deaths are reported in the private residence and residential aged care facility categories.

Table 15 Place of death

Diago of death —	Place of death WA Services			
Place of death	N	%	N	%
Private residence	586	20.2	3,156	18.9
Residential aged care facility	359	12.4	1,756	10.5
Hospital/hospice	1,945	67.0	11,529	68.9
Not stated/inadequately described	14	0.5	285	1.7
Total	2,904	100.0	16,726	100.0



4 Episodes of palliative care

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 the comprehensive palliative care assessment is completed using the five PCOC clinical assessment tools and documented in the patient medical record.

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 16 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 episode start.

Table 16 Patient's age by sex

		W.	A Services			A	III services	
Age group		Male		Female		Male		Female
	N	%	N	%	N	%	N	%
< 15	0	0.0	0	0.0	23	0.1	10	0.0
15 - 24	S	S	0	0.0	63	0.3	26	0.1
25 - 34	S	S	13	0.3	137	0.6	173	8.0
35 - 44	41	0.9	56	1.3	369	1.6	477	2.2
45 - 54	180	3.9	151	3.5	1,162	4.9	1,184	5.4
55 - 64	352	7.6	290	6.8	2,710	11.5	2,431	11.1
65 - 74	866	18.8	597	13.9	5,129	21.8	4,164	19.0
75 - 84	1,028	22.3	881	20.5	7,005	29.7	5,753	26.3
85 +	1,024	22.2	1,274	29.7	5,391	22.9	6,233	28.5
Unknown	1,109	24.0	1,032	24.0	1,580	6.7	1,434	6.6
Total	4,616	100.0	4,294	100.0	23,569	100.0	21,885	100.0

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



Referral source refers to the facility from where the patient was referred for each episode of care. Table 17 presents referral source by setting of care.

Table 17 Source of referral

	Inpatient					Community			
Referral source	ral source WA Services All services		services	WA S	WA Services All				
	N	%	N	%	N	%	N	%	
Public hospital	3,196	79.6	16,467	74.8	1,264	34.9	6,332	39.0	
Private hospital	247	6.2	1,673	7.6	296	8.2	1,641	10.1	
Outpatient clinic	21	0.5	133	0.6	15	0.4	265	1.6	
General medical practitioner	30	0.7	190	0.9	846	23.4	2,475	15.2	
Specialist medical practitioner	88	2.2	443	2.0	68	1.9	1,373	8.5	
Community-based palliative care agency	380	9.5	2,570	11.7	75	2.1	583	3.6	
Community-based service	6	0.1	33	0.1	6	0.2	138	0.9	
Residential aged care facility	13	0.3	71	0.3	970	26.8	1,637	10.1	
Self, carer(s), family or friends	14	0.3	123	0.6	28	0.8	414	2.6	
Other	18	0.4	236	1.1	53	1.5	1,348	8.3	
Not stated/inadequately described	3	0.1	75	0.3	0	0.0	27	0.2	
Total	4,016	100.0	22,014	100.0	3,621	100.0	16,233	100.0	



Table 18 Referral source for WA Services over time

Referral source	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=5,242	N=5,148	N=6,106	N=5,780	N=6,726	N=7,637
Public hospital	42.5	53.6	51.6	55.9	56.9	58.4
Private hospital	9.3	7.6	7.7	8.2	7.7	7.1
Outpatient clinic	0.3	0.1	0.3	0.2	0.2	0.5
General practitioner	17.4	17.4	15.6	14.7	13.2	11.5
Specialist medical practitioner	4.1	4.0	3.8	3.4	2.5	2.0
Community palliative care service	5.3	5.4	5.5	5.3	4.9	6.0
Community generalist service	0.2	0.2	0.1	0.2	0.1	0.2
Residential aged care facility	18.2	10.0	13.6	10.6	13.4	12.9
Self, carer(s), family, friends	0.3	0.3	0.5	0.7	0.4	0.5
Other	1.9	1.3	1.1	0.8	0.7	0.9
Not stated/inadequately described	0.6	0.1	0.2	0.1	0.1	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0



Table 19 gives a summary of the length of episodes for patients in Western Australian services and nationally.

Table 19 Length of episode (in days) summary by setting of care

Longth of opicada	Inpatie	patient Community				
Length of episode	WA Services	All services	WA Services	All services		
Average length of episode	8.2	8.3	32.1	39.1		
Median length of episode	4.0	4.0	23.0	28.0		

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 20 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 by setting of care

Length of		In	patient			Cor	nmunity	
episode	WA S	Services	Alls	services	WAS	Services	Alls	services
(days)	N	%	N	%	N	%	N	%
Same day	384	9.3	2,295	10.3	235	5.7	784	4.2
1-2	1,141	27.7	5,688	25.4	189	4.6	1,053	5.6
3-4	668	16.2	3,565	15.9	170	4.1	965	5.1
5-7	708	17.2	3,582	16.0	353	8.6	1,429	7.6
8-14	589	14.3	3,678	16.4	526	12.8	2,225	11.8
15-21	274	6.7	1,587	7.1	455	11.1	1,759	9.3
22-30	164	4.0	931	4.2	537	13.0	1,712	9.1
31-60	128	3.1	830	3.7	841	20.4	3,242	17.2
61-90	33	0.8	140	0.6	242	5.9	1,644	8.7
91+	23	0.6	77	0.3	569	13.8	4,069	21.5
Total	4,112	100.0	22,373	100.0	4,117	100.0	18,882	100.0



Table 21 How inpatient episodes start

Faireds shout words a	WA S	Services	All services	
Episode start mode	N	%	N	%
Admitted from community ¹	2,869	71.4	14,616	66.4
Admitted from another hospital	840	20.9	3,186	14.5
Admitted from acute care in another ward	178	4.4	3,045	13.8
Change from acute care to palliative care – same ward	106	2.6	737	3.3
Other ²	20	0.5	236	1.1
Not stated/inadequately described	3	0.1	194	0.9
Total	4,016	100.0	22,014	100.0

Table 22 How inpatient episodes end

Fuirede and made	WA S	Services	All services	
Episode end mode ⁻	N	%	N	%
Discharged to community ¹	1,419	34.5	6,857	30.6
Discharged to another hospital	333	8.1	1,638	7.3
Death	1,945	47.3	11,529	51.5
Change from palliative care to acute care ²	45	1.1	207	0.9
Change in sub-acute care type	6	0.1	155	0.7
End of consultative episode – inpatient episode ongoing	321	7.8	1,351	6.0
Other	41	1.0	256	1.1
Not stated/inadequately described	2	0.0	394	1.8
Total	4,112	100.0	22,387	100.0

¹ includes: admitted from usual accommodation, admitted from other than usual accommodation.

² includes: change of sub-acute/non-acute care type and other categories.

 $^{^{\}rm 1}$ includes: discharged to usual accommodation, discharged to other than usual accommodation.

² includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.



Table 23 How inpatient episodes start for WA Services over time

Episode start mode (%)	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=2,044	N=2,520	N=2,866	N=2,920	N=3,356	N=4,016
Admitted from community ¹	70.9	68.6	69.9	71.2	71.9	71.4
Admitted from another hospital	24.8	27.8	25.6	21.5	21.6	20.9
Admitted from acute care on another ward	2.6	2.2	3.2	4.1	3.5	4.4
Change from acute care to palliative care – same ward	1.2	0.8	1.0	2.4	2.5	2.6
Other ²	0.3	0.4	0.2	0.7	0.4	0.5
Not stated/inadequately descried	0.2	0.2	0.0	0.1	0.1	0.1
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 24 How inpatient episodes end for WA Services over time

Episode end mode (%)	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=2,099	N=2,598	N=2,927	N=3,003	N=3,452	N=4,112
Discharged to community ¹	39.4	40.9	39.6	36.1	35.7	34.5
Discharged to another hospital	8.3	8.3	7.7	7.6	7.2	8.1
Death	46.8	44.0	44.9	46.4	47.3	47.3
Change from palliative care to acute care ²	0.2	1.4	1.2	1.2	1.3	1.1
Change in sub-acute care type	0.0	0.1	0.1	0.1	0.1	0.1
End of consultative episode – inpatient episode ongoing	2.6	3.0	5.0	7.2	7.1	7.8
Other	2.2	1.6	1.3	1.2	1.3	1.0
Not stated/inadequately described	0.4	0.7	0.2	0.3	0.1	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0

¹ includes: admitted from usual accommodation, admitted from other than usual accommodation.

² includes: change of sub-acute/non-acute care type and other category.

¹ includes: discharged to usual accommodation, discharged to other than usual accommodation.

² includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.



Table 25 How community episodes start

Episode start mode —	WA S	Services	All s	All services		
	N	%	N	%		
Admitted from inpatient palliative care	1,238	34.2	4,835	29.8		
Other ¹	2,355	65.0	11,247	69.3		
Not stated/inadequately described	28	0.8	151	0.9		
Total	3,621	100.0	16,233	100.0		

Table 26 How community episodes end

Faired and made	WA S	Services	All s	All services		
Episode end mode ⁻	N	%	N	%		
Admitted for inpatient palliative care	390	9.5	5,565	29.4		
Admitted for inpatient acute care	1,106	26.9	4,422	23.4		
Admitted to another palliative care service	43	1.0	219	1.2		
Admitted to primary health care	972	23.6	1,523	8.1		
Discharged/case closure	234	5.7	1,354	7.2		
Death	959	23.3	5,197	27.5		
Other	41	1.0	191	1.0		
Not stated/inadequately described	372	9.0	435	2.3		
Total	4,117	100.0	18,906	100.0		

¹ includes: patient was not transferred from being an overnight patient.



Table 27 How community episodes start for WA Services over time

Episode start mode (%)	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=3,198	N=2,628	N=3,240	N=2,860	N=3,370	N=3,621
Admitted from inpatient palliative care	45.6	50.4	42.0	43.5	37.8	34.2
Other ¹	54.4	49.5	57.8	56.4	62.1	65.0
Not stated/inadequately described	0.0	0.0	0.2	0.1	0.1	0.8
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

Table 28 How community episodes end for WA Services over time

Episode end mode (%)	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=3,450	N=2,921	N=3,431	N=3,206	N=3,650	N=4,117
Admitted for inpatient palliative care	2.9	9.5	3.2	8.9	7.8	9.5
Admitted for inpatient acute care	36.1	33.4	36.5	31.3	27.6	26.9
Admitted to another palliative care service	0.7	0.5	0.7	0.6	0.5	1.0
Admitted to primary health care	22.6	18.9	23.5	20.2	22.0	23.6
Discharged/case closure	6.3	6.8	4.4	5.3	4.8	5.7
Death	31.2	30.6	30.7	30.2	23.7	23.3
Other	0.2	0.3	0.5	0.4	0.6	1.0
Not stated/inadequately described	0.1	0.1	0.5	3.2	13.0	9.0
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

¹includes: patient was not transferred from being an overnight admitted palliative care patient



5 Profile of palliative care patient assessments

The palliative care profile of patients is determined using five clinical assessment tools which in combination with each other provides a total picture of patients' trajectory at specific points in time along their journey. These five assessment tools are completed daily for inpatient services, and at each contact for community services. Assessments are reported on admission to the service, at phase change and at discharge from the service. These tools include:

- Palliative care phase an assessment used to identify a clinically meaningful period in a patient's condition. The five palliative care phases are stable, unstable, deteriorating, terminal and bereavement (PCOC does not report on bereavement phases).
- Palliative Care Problem Severity Score (PCPSS) a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains being pain, other symptoms, psychological/spiritual and family/carer. The scores are 0 absent, 1 mild, 2 moderate and 3 severe.
- Symptom Assessment Scale (SAS) a patient (or proxy) rated tool that assesses the level of distress using a numerical rating scale from 0 no distress to 10 worst possible distress for seven symptoms (insomnia, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain).
- Resource Utilisation Groups-Activities of Daily Living (RUG-ADL) four items (bed mobility, toileting, transfers and eating) to record the level of functional dependence.
- Australia-modified Karnofsky Performance Status (AKPS) a measure of overall performance status and ability to perform common tasks relating to activity, work and self care. It is a single score between 0 and 100. PCOC does not report 0 (deceased).



5.1 Phase

The palliative care phase identifies a clinically meaningful period in a patient's care. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family or carers. The five palliative care phases are stable, unstable, deteriorating, terminal and bereavement (PCOC does not report on bereavement phases). A patient may move back and forth between the phase types based on assessments and clinical care and they may occur in any sequence. See Appendix F for more information on the definition of palliative care phase.

The patients are assessed using the 5 PCOC assessment tools daily in the inpatient units, or at each visit or phone contact in the community, and are reported on admission to the service, at phase changes and at discharge from the service.

Table 29 Number of patient phases by phase type and setting of care

		Inpa	tient		Community						
Phase type	WA	Services	es All services		WA S	Services	All	services			
	N	%	N	%	N	%	N	%			
Stable	2,327	25.9	11,847	24.3	4,595	39.5	17,979	36.4			
Unstable	1,084	12.1	6,537	13.4	508	4.4	4,990	10.1			
Deteriorating	3,667	40.8	19,124	39.2	5,721	49.2	22,333	45.2			
Terminal	1,899	21.2	11,238	23.1	799	6.9	4,104	8.3			
Total	8,977	100.0	48,746	100.0	11,623	100.0	49,406	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 30 Average phase length (in days) by phase type and setting of care

Dhace tune	Inpa	tient	Comn	nunity
Phase type	WA Services	All services	WA Services	All services
Stable	5.0	5.6	17.3	23.0
Unstable	1.9	1.9	2.7	4.5
Deteriorating	4.2	4.7	11.6	14.5
Terminal	2.2	2.0	4.2	3.2

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



Figure 11 and Figure 12 show the percentage of phases over time. These graphs allow Western Australian services to identify changes in the profile of your patients' phase type by setting of care over time.

Figure 11 Patient phase profile over time – inpatient setting

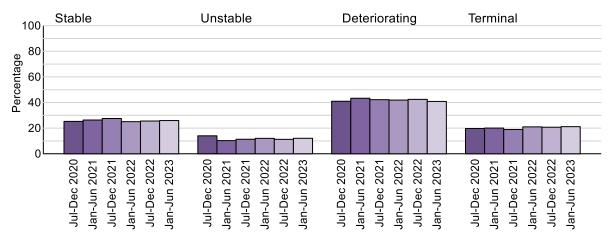


Figure 12 Patient phase profile over time – community setting

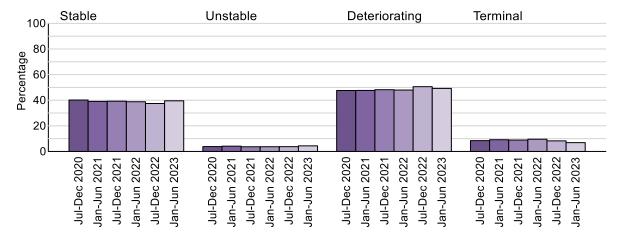




Table 31 presents the patients' first phase type for the episode, both for Western Australian services and nationally. The first phase of the episode allows you to understand the type of patient, complexity and reason patients are entering Western Australian services.

Table 31 First phase of episode by setting

		Inj	oatient		Community					
First phase	WA	WA Services		ervices	WA S	Services	All services			
	N	%	N	%	N	%	N	%		
Stable	521	12.7	3,426	15.3	1,220	29.7	7,235	37.2		
Unstable	593	14.4	4,175	18.6	82	2.0	1,061	5.5		
Deteriorating	2,323	56.4	11,436	51.0	2,609	63.5	10,263	52.8		
Terminal	680	16.5	3,384	15.1	200	4.9	881	4.5		
Total	4,117	100.0	22,421	100.0	4,111	100.0	19,440	100.0		

Note: This table only includes the first phase if the episode has started in the reporting period.



5.2 Palliative Care Problem Severity Score

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 to assess patients and their family/carer are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe.

Table 32 shows the percentage of phases that were rated absent, mild, moderate and severe at phase start for each key domain for WA inpatient setting of care compared to all participating PCOC inpatient services. Table 33 shows the same for WA community setting of care compared to all participating PCOC community services. Alternative graphical representations of PCPSS profile by phase type are shown in Appendix C.

Table 32 PCPSS at phase start by phase type – inpatient setting

Phase type	Ducklana		WA Servi	ces (%)			All service	es (%)	
	Problem —	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	61.7	34.1	4.0	0.2	51.2	41.5	6.8	0.5
	Other symptoms	47.0	46.3	6.5	0.2	41.7	50.4	7.6	0.3
	Psychological/spiritual	62.7	33.1	4.2	0.0	56.9	38.2	4.6	0.3
	Family/carer	62.0	32.1	5.2	0.6	58.9	35.5	5.0	0.6
Unstable	Pain	26.8	30.5	31.9	10.8	25.3	36.3	29.8	8.6
	Other symptoms	20.6	30.7	36.5	12.2	18.3	43.5	30.5	7.8
	Psychological/spiritual	29.9	39.2	24.1	6.9	34.8	42.2	19.1	3.9
	Family/carer	28.8	40.3	27.5	3.3	37.0	40.5	18.8	3.7
Deteriorating	Pain	40.6	40.0	18.0	1.4	37.7	42.8	17.8	1.7
	Other symptoms	26.6	48.5	23.5	1.5	25.9	50.5	21.6	1.9
	Psychological/spiritual	43.9	43.2	12.5	0.4	42.8	44.7	11.6	0.9
	Family/carer	40.4	44.1	14.0	1.5	40.5	44.7	13.3	1.5
Terminal	Pain	52.7	32.8	13.2	1.3	44.8	39.8	13.4	1.9
	Other symptoms	42.0	36.8	18.6	2.6	40.4	40.3	16.6	2.6
	Psychological/spiritual	71.2	22.1	6.2	0.4	64.1	28.7	6.4	0.8
	Family/carer	32.4	46.3	19.0	2.4	33.7	46.5	17.1	2.7



Table 33 PCPSS at phase start by phase type – community setting

Di	Bullen		WA Servi	ces (%)		Al	ll services	(%)	
Phase type	Problem —	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	51.5	44.7	3.7	0.1	45.8	49.9	4.2	0.1
	Other symptoms	26.8	65.9	7.2	0.1	25.7	66.6	7.5	0.2
	Psychological/spiritual	47.5	48.1	4.4	0.1	44.6	50.7	4.5	0.2
	Family/carer	47.4	47.2	5.3	0.1	41.6	51.8	6.3	0.3
Unstable	Pain	23.1	24.9	33.0	19.1	19.6	30.4	35.8	14.2
	Other symptoms	5.9	26.3	50.5	17.4	8.3	30.8	47.3	13.7
	Psychological/spiritual	17.6	36.9	37.9	7.6	24.0	40.8	29.4	5.9
	Family/carer	16.5	32.9	44.4	6.2	20.2	35.6	36.6	7.6
Deteriorating	Pain	34.7	44.3	19.3	1.7	29.6	50.3	19.0	1.2
	Other symptoms	13.6	49.4	35.9	1.1	11.4	55.2	32.2	1.2
	Psychological/spiritual	27.0	54.5	17.9	0.6	26.6	56.8	15.9	0.7
	Family/carer	27.0	51.5	20.7	0.8	21.5	55.2	22.1	1.2
Terminal	Pain	39.0	36.3	21.2	3.5	33.7	47.5	16.4	2.4
	Other symptoms	26.4	38.8	30.6	4.2	25.2	48.5	23.5	2.8
	Psychological/spiritual	42.7	37.8	18.1	1.4	45.5	41.0	12.7	0.8
	Family/carer	13.9	43.3	40.4	2.4	15.7	48.4	33.1	2.9

5.3 Symptom Assessment Scale

The Symptom Assessment Scale (SAS) is a patient (or proxy) rated 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 C.



Table 34 Symptom distress at phase start by phase type – inpatient setting

			WA	Services (%)					
Phase type	Symptom	Absent	Mild	Moderate	Severe	Absent	All serv Mild	Moderate	Severe
Stable	Difficulty sleeping	84.7	12.5	2.6	0.3	79.8	16.5	3.5	0.3
	Appetite problems	82.7	15.6	1.7	0.0	76.3	20.0	3.3	0.3
	Nausea	90.9	8.4	0.7	0.1	85.2	12.4	2.2	0.3
	Bowel problems	79.8	16.6	3.3	0.2	73.0	22.3	4.3	0.4
	Breathing problems	74.6	20.9	4.3	0.3	73.4	21.3	4.9	0.4
	Fatigue	57.4	34.2	7.6	0.7	51.9	36.8	10.5	0.8
	Pain	60.3	32.6	6.7	0.4	51.2	39.1	9.1	0.7
Unstable	Difficulty sleeping	57.9	20.0	17.0	5.0	60.0	24.4	12.9	2.7
	Appetite problems	62.5	24.0	11.0	2.5	57.6	29.5	11.3	1.6
	Nausea	75.8	13.4	8.0	2.8	69.0	18.9	9.9	2.2
	Bowel problems	65.4	19.9	11.5	3.1	59.6	26.1	11.8	2.5
	Breathing problems	56.4	23.3	14.2	6.2	57.7	24.3	14.1	3.9
	Fatigue	36.0	34.2	25.4	4.4	32.2	39.6	24.3	4.0
	Pain	28.1	28.2	29.4	14.3	25.9	34.7	29.7	9.7
Deteriorating	Difficulty sleeping	75.4	17.5	6.4	0.7	75.6	18.0	5.7	0.7
	Appetite problems	73.0	20.0	6.6	0.4	69.5	23.6	6.3	0.7
	Nausea	82.5	12.3	4.9	0.3	79.6	14.4	5.4	0.6
	Bowel problems	72.3	20.0	7.1	0.6	69.8	22.4	7.0	0.8
	Breathing problems	64.5	22.3	12.0	1.2	64.1	23.7	10.8	1.4
	Fatigue	42.5	35.2	21.0	1.2	41.8	38.2	18.1	1.9
	Pain	39.2	35.5	23.6	1.6	37.8	40.1	20.1	2.1
Terminal	Difficulty sleeping	92.2	5.2	2.4	0.1	91.1	6.7	2.0	0.2
	Appetite problems	93.9	4.5	1.4	0.2	92.3	5.8	1.4	0.4
	Nausea	93.8	4.6	1.4	0.2	93.0	5.3	1.5	0.2
	Bowel problems	91.6	6.1	2.0	0.2	89.4	8.4	2.0	0.3
	Breathing problems	67.9	20.2	10.7	1.3	67.0	22.0	9.3	1.7
	Fatigue	81.9	10.9	6.6	0.6	76.7	15.3	6.8	1.2
	Pain	54.3	31.4	13.2	1.1	48.6	35.2	14.7	1.5



Table 35 Symptom distress at phase start by phase type – community setting

Division I	- Comment		WA Se	rvices (%)		Α	ll services	(%)	
Phase type	Symptom	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Difficulty sleeping	80.6	16.7	2.5	0.1	72.3	23.3	4.2	0.3
	Appetite problems	75.3	22.4	2.2	0.1	62.7	33.9	3.3	0.2
	Nausea	90.8	8.6	0.6	0.0	84.2	14.6	1.1	0.1
	Bowel problems	78.9	19.4	1.6	0.0	72.1	24.9	2.8	0.2
	Breathing problems	69.8	24.8	5.4	0.1	62.0	32.0	5.7	0.3
	Fatigue	41.1	41.6	16.9	0.4	30.3	54.1	14.8	0.7
	Pain	57.8	37.4	4.7	0.1	46.5	47.7	5.5	0.3
Unstable	Difficulty sleeping	61.0	24.0	13.4	1.6	49.3	27.6	20.3	2.8
	Appetite problems	57.4	27.6	13.2	1.8	42.1	38.0	17.6	2.3
	Nausea	64.9	18.2	14.8	2.2	60.6	20.0	16.0	3.5
	Bowel problems	61.5	23.8	12.4	2.4	52.5	26.7	17.2	3.6
	Breathing problems	54.9	26.8	11.7	6.6	50.0	28.0	17.7	4.4
	Fatigue	28.6	30.4	35.2	5.8	20.6	37.0	36.2	6.3
	Pain	26.5	25.1	29.7	18.6	18.3	33.7	34.4	13.5
Deteriorating	Difficulty sleeping	72.4	20.8	6.4	0.4	63.6	26.6	9.2	0.5
	Appetite problems	62.6	30.1	7.1	0.2	48.7	41.7	9.1	0.6
	Nausea	81.7	13.6	4.5	0.2	74.2	20.1	5.3	0.4
	Bowel problems	66.9	25.3	7.4	0.4	61.0	29.8	8.6	0.5
	Breathing problems	61.0	27.2	11.3	0.6	53.1	33.2	12.6	1.0
	Fatigue	31.7	37.6	29.5	1.2	21.9	46.6	29.6	2.0
	Pain	40.1	38.8	19.4	1.8	30.7	49.1	18.6	1.6
Terminal	Difficulty sleeping	83.4	8.3	7.7	0.5	79.0	15.4	5.1	0.5
	Appetite problems	92.2	4.6	2.9	0.4	83.5	11.5	4.3	0.6
	Nausea	85.7	7.2	7.0	0.1	84.9	10.9	3.8	0.3
	Bowel problems	81.4	12.8	5.8	0.0	76.1	19.0	4.7	0.2
	Breathing problems	73.1	16.1	9.5	1.4	63.2	25.7	9.8	1.4
	Fatigue	76.0	7.8	14.4	1.8	64.6	17.3	15.4	2.6
	Pain	48.5	26.8	22.1	2.5	37.3	41.7	19.2	1.8



5.4 Resource Utilisation Groups – Activities of Daily Living

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) tool consists of four items to assess the patient's level of functional dependence and give an overall picture of the level of assistance required for patient care. These four items are bed mobility, toileting, transfers and eating. The RUG-ADL items are assessed daily for inpatients, or at each visit or phone contact for patients in the community. The items are reported at admission to the service, when the phase changes and at discharge.

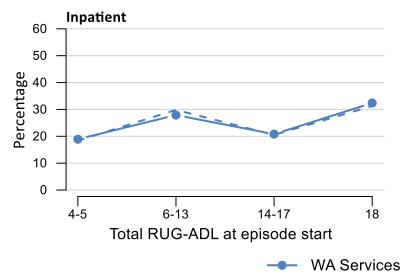
Table 36 summarises the RUG-ADL items at phase start for inpatient and community patients.

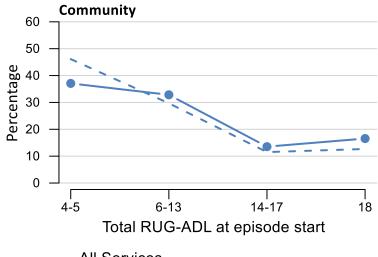
Table 36 The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) at phase start by setting of care

			Inpat	tient		(Communi	ty	
Item	RUG-ADL assessment at phase start _	WA S	ervices	Alls	services	WA S	ervices	Alls	services
		N	%	N	%	N	%	N	%
Bed mobility	Independent or supervision only (1)	2,968	33.3	12,849	27.2	7,324	63.1	26,820	58.9
	Limited physical assistance (3)	1,003	11.3	6,910	14.6	1,454	12.5	6,152	13.5
	Other than two person physical assist (4)	949	10.7	5,345	11.3	765	6.6	3,805	8.4
	Two or more person physical assist (5)	3,988	44.8	22,173	46.9	2,063	17.8	8,777	19.3
Toileting	Independent or supervision only (1)	1,825	20.5	8,456	17.9	5,373	46.3	21,684	47.6
	Limited physical assistance (3)	1,401	15.7	8,491	18.0	2,665	23.0	8,913	19.6
	Other than two person physical assist (4)	1,313	14.7	6,708	14.2	1,215	10.5	5,381	11.8
	Two or more person physical assist (5)	4,367	49.0	23,564	49.9	2,350	20.3	9,573	21.0
Transfers	Independent or supervision only (1)	1,801	20.2	8,432	17.9	5,119	44.2	21,230	46.6
	Limited physical assistance (3)	1,388	15.6	8,205	17.4	2,786	24.0	9,227	20.3
	Other than two person physical assist (4)	1,263	14.2	6,440	13.6	1,195	10.3	5,232	11.5
	Two or more person physical assist (5)	4,449	50.0	24,106	51.1	2,488	21.5	9,834	21.6
Eating	Independent or supervision only (1)	4,091	46.4	19,112	40.7	7,270	63.3	28,777	63.7
	Limited physical assistance (2)	1,472	16.7	9,411	20.0	2,240	19.5	8,230	18.2
	Extensive assistance/total dependence/tube fed (3)	3,262	37.0	18,454	39.3	1,976	17.2	8,154	18.1



Figure 13 Distribution of patients RUG-ADL Total at episode start







5.5 Australia-modified Karnofsky Performance Status

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 (deceased) and 100 (normal performance, no evidence of disease). For PCOC, patients are assessed from 10 (comatose or barely rousable) to 100. The AKPS is assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. It is recorded as part of the five PCOC assessment tools.

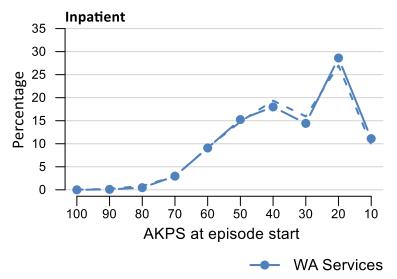
Table 37 shows the performance status of patients using the AKPS at phase start.

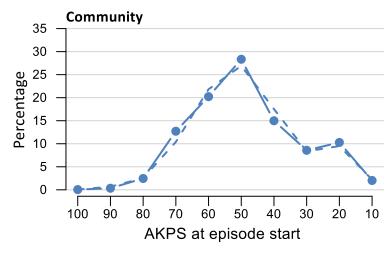
Table 37 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting of care

		Inpat	ient			Commun	ity	
AKPS assessment at phase start _	WA	Services	All	services	WA	Services	All	services
	N	%	N	%	N	%	N	%
Comatose or barely rousable (10)	1,115	12.4	6,075	12.5	229	2.0	1,598	3.2
Totally bedfast and requiring extensive nursing care (20)	2,502	27.9	13,361	27.4	1,245	10.7	5,547	11.2
Almost completely bedfast (30)	1,263	14.1	7,053	14.5	908	7.8	4,379	8.9
In bed more than 50% of the time (40)	1,559	17.4	8,765	18.0	1,585	13.6	8,384	17.0
Requires considerable assistance (50)	1,377	15.3	6,271	12.9	2,947	25.4	12,112	24.5
Requires occasional assistance (60)	841	9.4	3,791	7.8	2,876	24.7	10,115	20.5
Cares for self (70)	205	2.3	1,010	2.1	1,597	13.7	4,287	8.7
Normal activity with effort (80)	26	0.3	260	0.5	203	1.7	805	1.6
Able to carry on normal activity; minor signs or symptoms (90)	S	S	66	0.1	S	S	171	0.3
Normal; no complaints; no evidence of disease (100)	S	S	15	0.0	S	S	13	0.0
Not stated/inadequately described	80	0.9	2,079	4.3	7	0.1	1,995	4.0
Total	8,977	100.0	48,746	100.0	11,623	100.0	49,406	100.0



Figure 14 Distribution of AKPS for patients at episode start





- - All Services



Appendices

A Summary of data included in this report

During the reporting period, data were provided for a total of 36,772 patients who between them had 45,484 episodes of care and 98,152 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 D contains a more detailed explanation of this process). Table 38 shows the number of patients, episodes and phases included in this report – both for Western Australian services and all participating PCOC services nationally.

Table 38 Summary of patients, episodes and phases by setting

	Inpatier	nt	Commun	ity	Total	
	WA Services	All services	WA Services	All services	WA Services	All services
Patients (N)	3,593	19,406	3,860	18,863	7,221	36,772
Episodes (N)	4,203	22,945	4,708	22,539	8,911	45,484
Phases ¹ (N)	8,977	48,746	11,623	49,406	20,600	98,152
Patients (%)	49.8	52.8	53.5	51.3	100.0	100.0
Episodes (%)	47.2	50.4	52.8	49.6	100.0	100.0
Phases ¹ (%)	43.6	49.7	56.4	50.3	100.0	100.0
Average number of phases per episode ²	2.1	2.1	2.2	2.1	2.1	2.1

¹ Bereavement phases are excluded from this count.

² 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 39 shows the number of completed episodes and phases by setting of care for each month in the current reporting period for Western Australian services. This table allows Western Australian services to identify any significant change in the number of episodes and phases during the reporting period.

Table 39 Number of completed episodes and phases by month and setting

Setting		Jan	Feb	Mar	Apr	May	Jun
Inpatient	Completed episodes (N)	645	612	685	617	803	750
	Completed phases (N)	1,449	1,385	1,566	1,344	1,680	1,553
Community	Completed episodes (N)	670	673	696	625	730	723
Community	Completed phases (N)	1,983	1,884	2,088	1,791	1,991	1,886

Table 40 shows the number of patients, episodes and phases for Western Australian services over time and is reported by setting of care. It allows you to identify any significant changes in volume over a three-year period and may assist in understanding changes in service delivery or model of care.

Table 40 Number of patients, episodes and phases by setting and reporting period

	Inpatient								Comm	unity		
	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
Patients ¹	1,828	2,289	2,527	2,599	3,000	3,593	3,054	2,601	3,120	2,894	3,307	3,860
Episodes	2,123	2,633	2,973	3,051	3,503	4,203	3,858	3,268	3,876	3,584	4,098	4,708
Phases ²	4,860	5,607	6,588	6,611	7,707	8,977	10,927	9,638	10,561	9,996	10,424	11,623
Phases per episode ³	2.3	2.1	2.2	2.2	2.2	2.1	2.5	2.7	2.4	2.5	2.1	2.2

¹ Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.

² Bereavement phases are excluded from this count.

³ Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.



B Data item completion

Table 41, Table 42, Table 43 and Table 44 report the rate of data completion. In reviewing the tables the percentage represents the number of valid records as a proportion of the number of records where the data item was relevant. For example, place of death is only required for episodes that end in death – episodes that end in discharge will not have a place of death.

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 41 Item completion (%) - patient level

Data item	WA Services	All services
Date of birth	76.7	92.4
Sex	100.0	100.0
Indigenous status	94.4	96.7
Country of birth	95.5	97.7
Preferred language	99.7	99.1
Diagnosis	98.8	98.3

Table 42 Item completion (%) - episode level, by setting of care

Data itawa	Inpat	tient	Comm	nunity	Total		
Data item	WA Services	All services	WA Services	All services	WA Services	All services	
Date of first contact	100.0	99.9	100.0	99.4	100.0	99.7	
Referral date	100.0	100.0	100.0	99.8	100.0	99.9	
Referral source	99.9	99.7	100.0	99.8	100.0	99.7	
Date ready for care	100.0	98.8	100.0	97.4	100.0	98.1	
Mode of episode start	99.9	99.1	99.3	99.1	99.6	99.1	
Accommodation at episode start	99.8	99.5	99.9	96.5	99.9	97.7	
Episode end date ¹	99.2	98.8	89.5	86.2	94.1	92.6	
Mode of episode end	99.9	98.2	91.0	97.7	95.4	98.0	
Accommodation at episode end	99.5	98.6	100.0	97.7	99.7	98.3	
Place of death	-	-	98.6	94.6	98.6	94.6	

¹ Episode end date item completion may be affected by open episodes.



Table 43 Item completion (%) - phase level, by setting of care

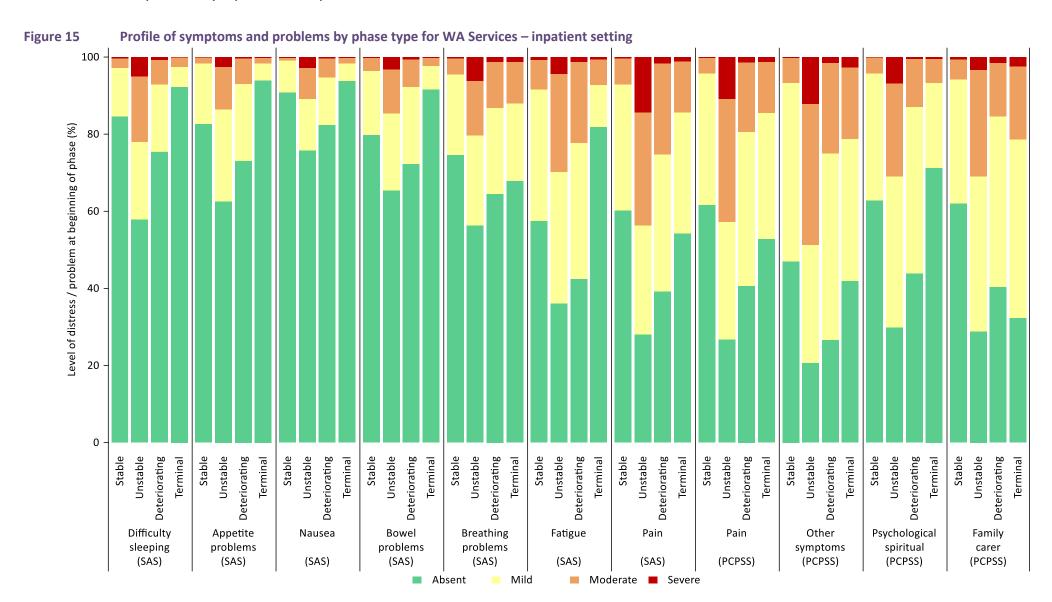
Data itam	Sub-Category	Inpatie	nt	At phase Commu		Total		Inpatie	nt	At discha Commu		Total	
Data item	(where applicable)	WA Services	All services	WA Services	All services	WA Services	All services	WA Services	All services	WA Services	All services	WA Services	All services
	Bed mobility	99.2	97.0	99.9	92.2	99.6	94.6	88.2	70.9	72.7	51.3	79.2	60.1
DUC ADI	Toileting	99.2	96.9	99.8	92.2	99.6	94.5	88.2	70.9	72.8	51.3	79.2	60.1
RUG-ADL	Transfers	99.2	96.8	99.7	92.1	99.5	94.5	88.2	70.9	72.7	51.3	79.2	60.1
	Eating	98.3	96.4	98.8	91.4	98.6	93.9	87.9	70.7	72.2	50.9	78.7	59.8
	Pain	98.9	96.9	99.8	95.3	99.4	96.1	87.9	73.1	72.6	52.0	78.9	61.4
PCPSS	Other symptoms	92.4	95.4	94.7	93.4	93.7	94.4	85.7	72.5	62.3	49.4	72.0	59.7
	Psychological/spiritual	98.5	96.3	99.6	93.9	99.1	95.1	87.4	72.3	72.3	51.1	78.6	60.6
	Family/carer	76.0	89.2	88.2	89.4	82.9	89.3	61.8	62.3	52.7	46.8	56.5	53.7
	Difficulty sleeping	97.9	85.3	99.3	90.0	98.7	87.6	87.4	59.0	72.4	49.3	78.6	53.7
	Appetite problems	97.9	85.3	99.3	90.4	98.7	87.9	87.3	58.9	72.5	49.5	78.7	53.7
CAC	Nausea	98.0	85.4	99.4	91.4	98.8	88.4	87.3	59.1	72.5	50.2	78.7	54.2
SAS	Bowel problems	97.9	85.3	99.4	90.5	98.7	87.9	87.3	59.0	72.4	49.4	78.6	53.7
	Breathing problems	98.0	85.5	99.4	91.0	98.8	88.3	87.3	59.2	72.6	50.1	78.7	54.1
	Fatigue	97.9	85.4	99.4	91.6	98.7	88.6	87.3	59.0	72.5	50.5	78.7	54.3
	Pain	98.0	85.7	99.5	93.9	98.8	89.8	87.3	59.2	72.6	52.0	78.7	55.2
AKPS	-	99.1	95.7	99.9	96.0	99.6	95.8	88.1	70.4	72.9	53.1	79.2	60.9

Table 44 Item completion (%) - phase end, by setting of care

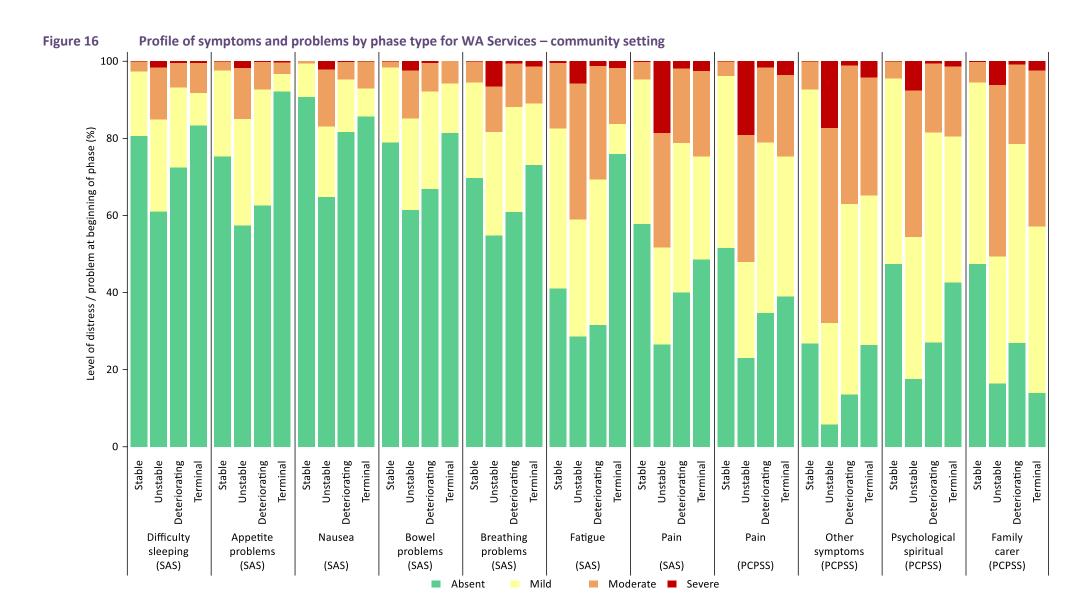
Data itawa	Inpati	ent	Commı	ınity	Total		
Data item	WA Services	All services	WA Services	All services	WA Services	All services	
Phase End Reason	100.0	99.6	99.8	98.9	99.8	99.3	



C Profile of patient symptoms and problems





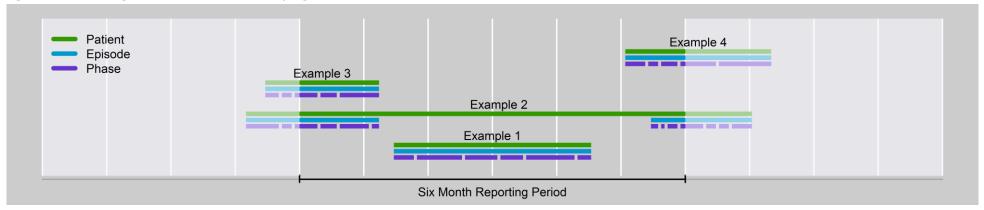




D Data scoping method

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 17 below displays four examples to help visualize this process.

Figure 17 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.

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.

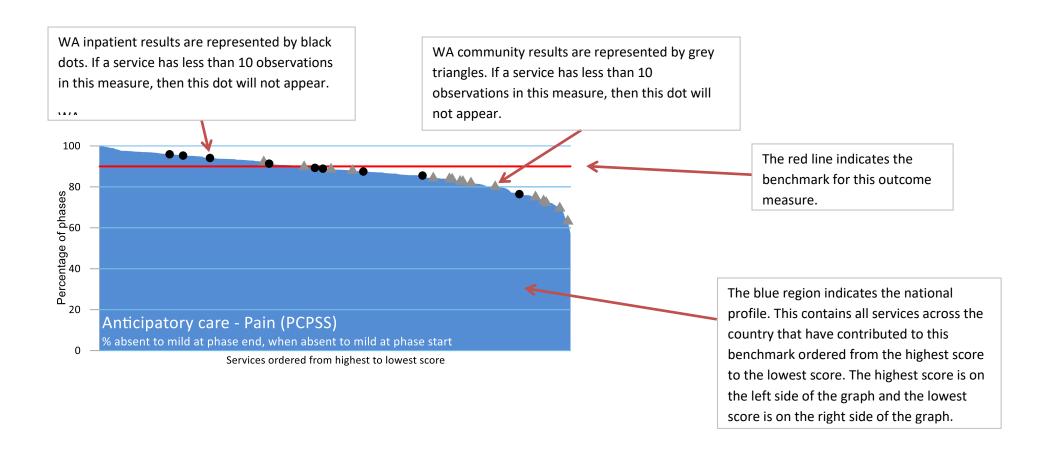
In <u>Example 4</u>, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.



Interpreting benchmark profile graphs

Ε

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. WA inpatient services are highlighted as a black dots on the graph. WA community services are highlighted as grey triangles on the graph.





Palliative Care Phase definitions

Phase type	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	An urgent change in the plan of care or emergency treatment is required because Patient experiences a new problem that was not anticipated in the existing plan of care, and/or Patient experiences a rapid increase in the severity of a current problem; and/or Family/carers circumstances change suddenly impacting on patient care.	 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 Death is likely within days (i.e. patient is now terminal).
Deteriorating	The care plan is addressing anticipated needs but requires periodic review because Patients overall functional status is declining and/or Patient experiences a gradual worsening of existing problem and/or Patient experiences a new but anticipated problem and/or Family/carers experience gradual worsening distress that impacts on the patient care.	 Patient condition plateaus (i.e. patient is now stable) or An urgent change in the care plan or emergency treatment and/or 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 Death is likely within days (i.e. patient is now terminal).
Terminal	Death is likely within days.	 Patient dies or Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).



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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.

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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