



The Palliative Care Outcomes Collaboration

New South Wales Outcome Report - January to June 2026

Inpatient and Non-admitted Setting

October 2026

Acknowledgements

Contributions	PCOC wishes to acknowledge the valuable contribution made by the many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible.
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What is PCOC?

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

Central to the program is a framework and protocol for routine clinical assessment and response. 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) and
- Resource Utilisation Groups - Activities of Daily Living (RUG-ADL).

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What PCOC data tells us about palliative care in Australia

Palliative care improves quality of life - but too many people access it too late or miss out altogether.

1



High-quality care is delivered nationally

People experience improvements in symptoms, distress and function once they receive palliative care.

4



Care often starts too late

For people who die while receiving palliative care, the average time from referral to death is around 8 days

2



Hospitals remain the main entry point to receive care

Most people are referred to palliative care during a hospitalisation, rather than through earlier identification in the community.

5



More people with conditions other than cancer are receiving care

Palliative care is increasingly supporting people with dementia, heart failure and chronic respiratory disease.

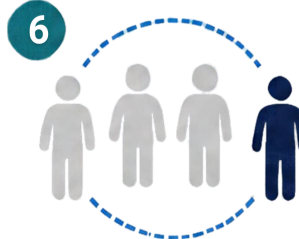
3



Inequities in access remain

Aboriginal and Torres Strait Islander peoples, people in rural and remote areas, and people with non-malignant diagnoses continue to face barriers to care.

6



Many people are missing out

More Australians could benefit from palliative care but are not being identified or referred early enough.

Source: Palliative Care Outcomes Collaboration, National Overview of Patient Outcomes in Australia for 2025, 2026, Faculty of Science, Medicine and Health, University of Wollongong

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 2026, results over the last three years are also presented to highlight achievements and improvement in outcomes. The most recent information corresponds to 42,545 patients, having 52,790 episodes of care and 108,712 Palliative Care Phases from 246 services who provide palliative care in hospital or in the persons home.

How to use this report

The outcomes achieved by your service are compared to national benchmarks. The purpose of benchmarking is to drive quality improvement and palliative care service innovation by providing participating services with the opportunity to compare with other services. PCOC has identified five key strategies for achieving improved patient outcomes. They comprise a set of predisposing, reinforcing and enabling factors that have been associated with patient outcomes. A self-assessment tool is available to help identify gaps and to focus improvement strategies. Information in this report should be considered in the context of these factors. The PCOC suite of audit tools improve consistency and reliability of the PCOC assessments. Auditing reduces variation and helps identify areas for improvement. Audit templates are available for download on the PCOC website.

Please use the following key when interpreting the tables throughout this report

- The item is not applicable
- u** The item was unavailable
- s** The item was suppressed

Table 1: List of NSW Services included in this report

Service name	Setting of care
Auburn Hospital Supportive and Palliative Care	Inpatient
Bega Valley Community Health Service Palliative Care	Community
Bellinger River District Hospital	Inpatient
Blacktown Hospital	Inpatient
Broken Hill Health Service	Community
Broken Hill Health Service	Inpatient
Broken Hill Health Service - Consult	Inpatient
Bulli District Hospital	Inpatient
Buronga Specialist Palliative Care Service	Community
Calvary Health Care Kogarah	Community
Calvary Health Care Kogarah	Inpatient
Calvary Health Care Riverina - Mary Potter PCU	Inpatient
Calvary Mater Newcastle	Inpatient
Canterbury Hospital	Inpatient
Chris O'Brien Lifehouse	Inpatient
Coffs Harbour Palliative Care Service	Community
Concord Centre for Palliative Care	Inpatient
Cooma Community Health Service Palliative Care	Community
Cowra Health Service	Inpatient
David Berry Hospital	Inpatient
Dubbo Base Hospital	Inpatient
Eurobodalla Community Health Service Palliative Care	Community
Gosford Hospital - Inpatient Unit	Inpatient
Gosford Hospital Consult	Inpatient
Goulburn Community Health Service Palliative Care	Community
HammondCare - Braeside Hospital	Inpatient
HammondCare - Greenwich Hospital	Community
HammondCare - Greenwich Hospital	Inpatient
HammondCare - Neringah Hospital	Community
HammondCare - Neringah Hospital	Inpatient

HammondCare Community Northern Beaches	Community
HammondCare Community Palliative Care Choices Program	Community
HammondCare Community Residential Aged Care Inreach	Community
Hastings Macleay Community Palliative Care Service	Community
Hawkesbury District Health Service	Community
Hornsby Hospital Palliative Care Consult Service	Inpatient
Illawarra Shoalhaven Community Service	Community
Liverpool Hospital	Inpatient
Macarthur Palliative Care Service (Camden Hospital)	Inpatient
Macksville Community Palliative Care Service	Community
Maitland Dungog Community Palliative Care Service	Community
Manly Adolescent & Young Adult Hospice	Inpatient
Manning Rural Referral Hospital	Inpatient
Mater Hospital, North Sydney	Inpatient
Mercy Care Centre - Young	Inpatient
Mercy Health Service Albury	Community
Mercy Health Service Albury	Inpatient
Mona Vale Palliative Care Unit	Inpatient
Mt Druitt Hospital Supportive and Palliative Care Service	Inpatient
Mudgee Health Service	Inpatient
Murrumbidgee LHD Palliative Care Service	Community
Murrumbidgee LHD Palliative Care Service	Inpatient
Nepean Hospital	Inpatient
Northern Beaches Hospital Palliative Care Consult	Inpatient
Northern Sydney Home Nursing Service	Community
Palliative Aged Care Supportive Service	Community
Queanbeyan Community Health Service Palliative Care	Community
Royal North Shore Hospital Palliative Care Consult Service	Inpatient
Royal Prince Alfred Hospital	Inpatient
Royal Prince Alfred Hospital - Consult	Inpatient
Ryde Hospital Palliative Care Consult Service	Inpatient
Shellharbour Hospital	Inpatient
Shoalhaven District Memorial Hospital	Inpatient

St George Hospital	Inpatient
St Vincent's Hospital, Sydney	Community
St Vincent's Hospital, Sydney	Inpatient
Sutherland Hospital	Inpatient
Sydney Virtual (Sydney District Nursing) - Canterbury	Community
Sydney Virtual (Sydney District Nursing) - Concord	Community
Sydney Virtual (Sydney District Nursing) - Croydon	Community
Sydney Virtual (Sydney District Nursing) - Marrickville	Community
Sydney Virtual (Sydney District Nursing) - Redfern	Community
Tamworth Base Hospital	Inpatient
Tamworth Nundle Community Health Service	Community
Wauchope District Memorial Hospital	Inpatient
Western Sydney Community Palliative Care	Community
Westmead Hospital	Inpatient
Wollongong Hospital - Consult	Inpatient
Wolper Jewish Hospital	Inpatient
Wyong Hospital Consult	Inpatient

1 Benchmark Summary for NSW Services

Table 2: Summary of outcome measures by setting of care

Category	Outcome Measure	Benchmark	Inpatient		Non-Admitted		Benchmark Reference Number
			%	BM Met	%	BM Met	
Timely commencement of palliative care							
Care commencing within two days of the patient being ready		90%	98.1	Yes	87.8	No	1
Responsiveness in managing patients with urgent needs							
Patients unstable for three days or less		90%	84.6	No	72.1	No	2
Symptoms & problems in the absent to mild range at phase end							
Anticipatory Care <i>when patient symptoms or problems are in the absent to mild range at phase start</i>	Pain (clinician reported)	90%	91.4	Yes	82.3	No	3.1
	Pain (patient reported)		90.7	Yes	80.2	No	3.3
	Fatigue (patient reported)		92.4	Yes	78.9	No	3.5
	Breathing problems (patient reported)		95.9	Yes	89.6	No	3.7
	Family/carer problems (clinician reported)		92.9	Yes	84.0	No	3.9
Responsive Care <i>when patient symptoms or problems are in the moderate to severe range at phase start</i>	Pain (clinician reported)	60%	71.3	Yes	66.9	Yes	3.2
	Pain (patient reported)		66.8	Yes	63.3	Yes	3.4
	Fatigue (patient reported)		70.7	Yes	62.9	Yes	3.6
	Breathing problems (patient reported)		66.8	Yes	59.4	No	3.8
	Family/carer problems (clinician reported)		67.7	Yes	61.6	Yes	3.10
Casemix adjusted outcomes (change scores)		Baseline	Score		Score		
Clinician Reported Problems (PCPSS)	Pain	0.0	0.13	Yes	-0.03	No	4.1
	Other Symptoms		0.28	Yes	0.03	Yes	4.2
	Family/Carer Problems		0.26	Yes	0.10	Yes	4.3
	Psychological/Spiritual Problems		0.27	Yes	0.13	Yes	4.4
Patient Reported System Distress (SAS)	Pain	0.0	0.34	Yes	-0.12	No	4.5
	Nausea		0.19	Yes	-0.05	No	4.6
	Breathing Problems		0.32	Yes	-0.01	No	4.7
	Bowel Problems		0.31	Yes	-0.03	No	4.8

2 Detailed Analysis on Patient Outcomes

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' care starts the day of or the day after the date ready for care.

Table 3: Time from date patient is ready for care to episode start by setting of care

Time (in days)	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Same day	7,685	95.3	21,946	91.8	2,441	83.0	14,980	79.0
Following day	227	2.8	1,170	4.9	142	4.8	999	5.3
2-7	101	1.3	686	2.9	220	7.5	1,777	9.4
8-14	12	0.1	51	0.2	66	2.2	633	3.3
15+	38	0.5	60	0.3	73	2.5	562	3.0
Average	1.4	-	1.2	-	2.6	-	2.7	-
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.

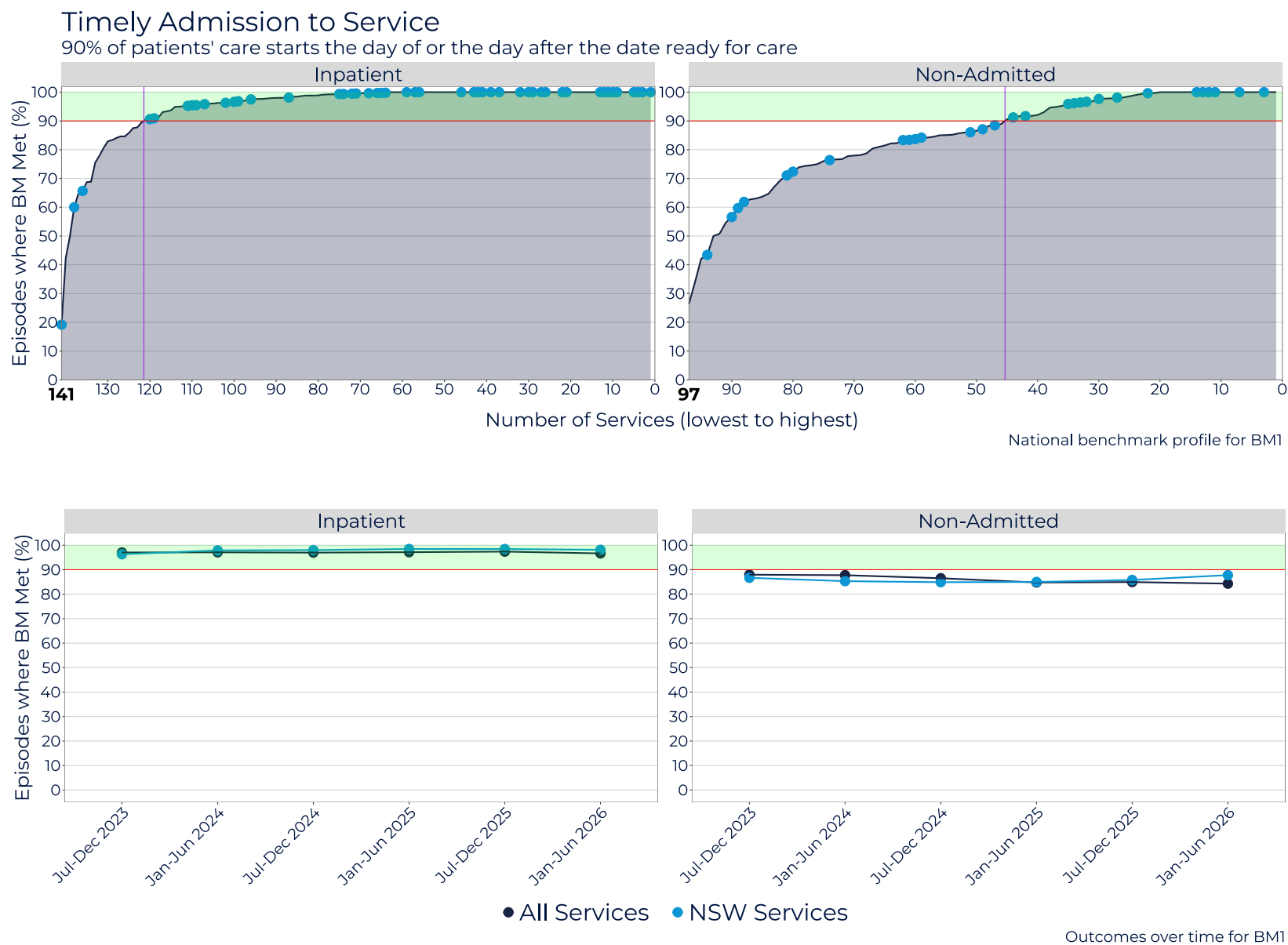


Figure 1: Time from date patient is ready for care to episode start, NSW Services compared to all services (BM1)

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

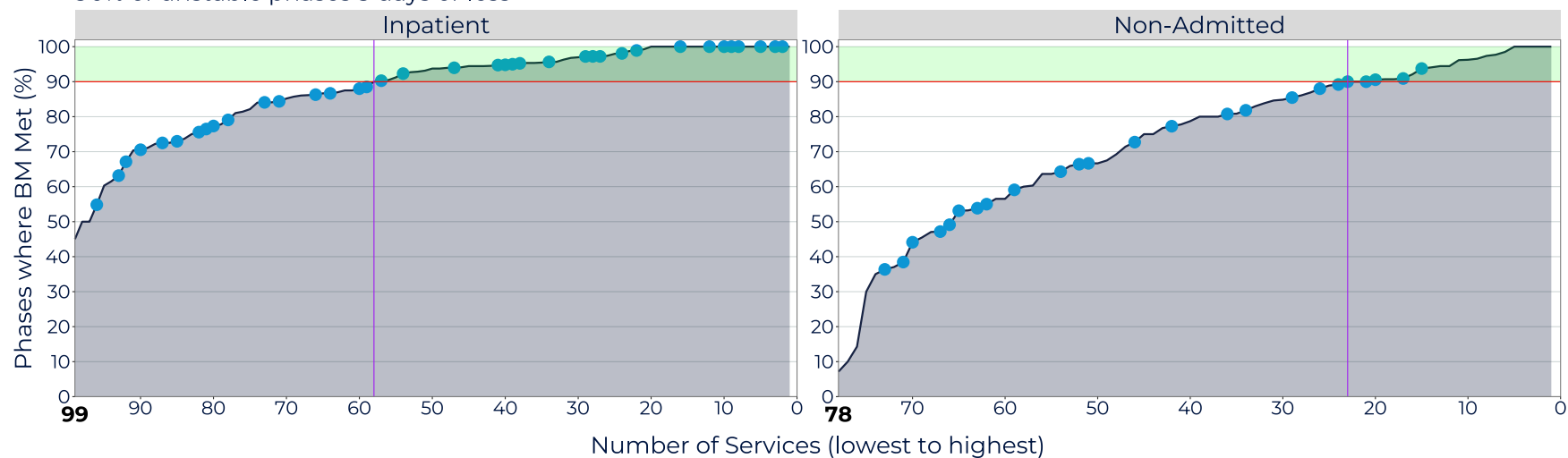
This benchmark relates to the time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for three days or less.

Table 4: Time in unstable phase by setting of care

Time in Unstable Phase	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Same day	266	7.5	597	9.1	173	17.1	1,425	33.0
1 day	1,822	51.5	3,427	52.2	351	34.6	1,359	31.4
2 days	573	16.2	1,080	16.5	126	12.4	437	10.1
3 days	330	9.3	587	8.9	80	7.9	244	5.6
4-5 days	269	7.6	453	6.9	69	6.8	231	5.3
6-7 days	136	3.8	199	3.0	69	6.8	181	4.2
8-14 days	105	3.0	165	2.5	63	6.2	195	4.5
15+ days	35	1.0	53	0.8	82	8.1	251	5.8
Total	3,536	100.0	6,561	100.0	1,013	100.0	4,323	100.0

Responsiveness to urgent needs

90% of unstable phases 3 days or less



National benchmark profile for BM2

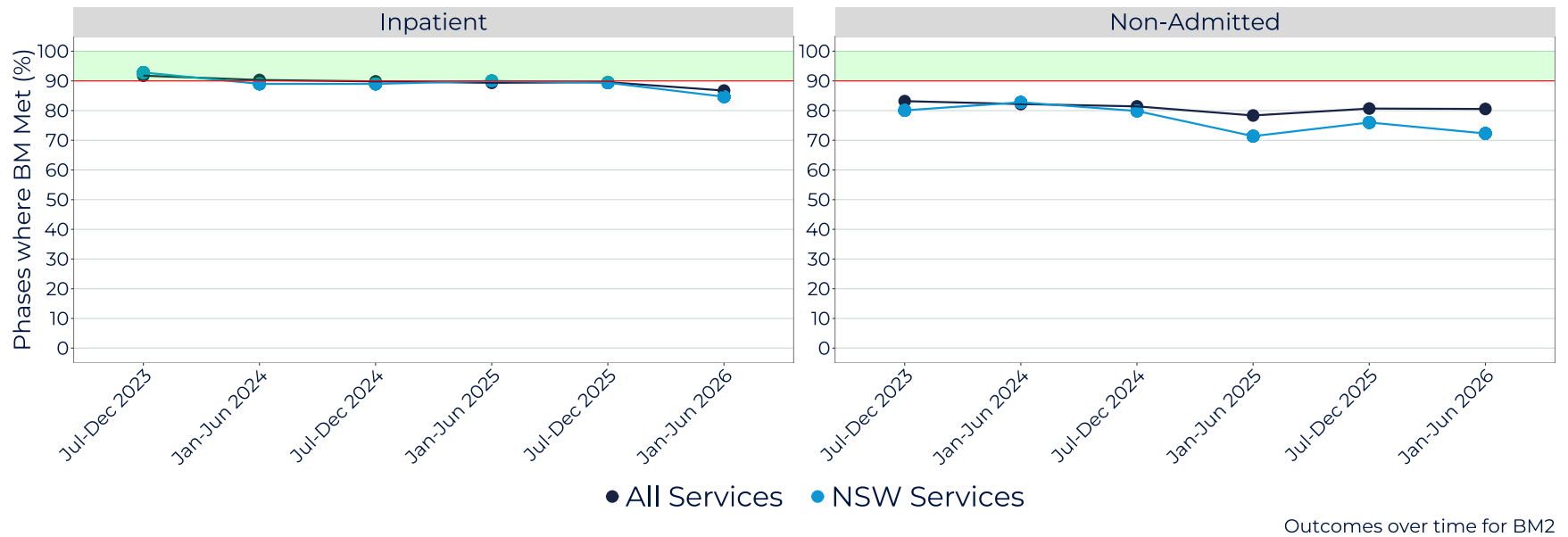


Figure 2: Time in unstable phase, NSW Services compared to all services (BM2)

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

- Pain - clinician reported severity
- Pain - patient reported distress
- Fatigue - patient reported distress
- Breathing problems - patient reported distress
- Family/carers 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 patients (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 symptoms/problems 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 symptoms/problems. Table 5 summarises the number of patient phases starting with absent to mild symptoms/problems, 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

Symptom/Problem ^a	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N ^b	%	N ^b	%	N ^b	%	N ^b	%
Pain (clinician reported)	11,609	91.4	28,199	91.3	5,899	82.3	30,873	85.8
Pain (patient reported)	10,600	90.7	24,928	90.7	5,680	80.2	30,545	84.6
Fatigue (patient reported)	11,141	92.4	26,015	93.3	5,564	78.9	27,602	83.2
Breathing problems (patient reported)	11,899	95.9	28,103	96.1	6,386	89.6	32,510	93.0
Family/carer problems (clinician reported)	12,325	92.9	28,173	93.6	6,113	84.0	28,079	84.8

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** symptoms/problems.

Responsive care

The responsive care outcome measure and benchmarks relate to patients, and/or family/carers, who have been assessed with moderate or severe symptoms/problems at the start of the 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 phases must end with absent or mild symptoms/problems.

Table 6 summarises the number of phases assessed as starting with moderate to severe symptoms/problems 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

Symptom/Problem ^a	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N ^b	%	N ^b	%	N ^b	%	N ^b	%
Pain (clinician reported)	2,304	71.3	6,168	64.2	1,455	66.9	6,829	57.8
Pain (patient reported)	2,409	66.8	6,036	62.3	1,690	63.3	7,634	54.4
Fatigue (patient reported)	1,858	70.7	4,709	62.6	1,766	62.9	9,251	46.2
Breathing problems (patient reported)	1,149	66.8	2,721	62.1	960	59.4	4,009	50.2
Family/carers problems (clinician reported)	1,533	67.7	3,516	59.2	1,155	61.6	6,246	50.7

^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.

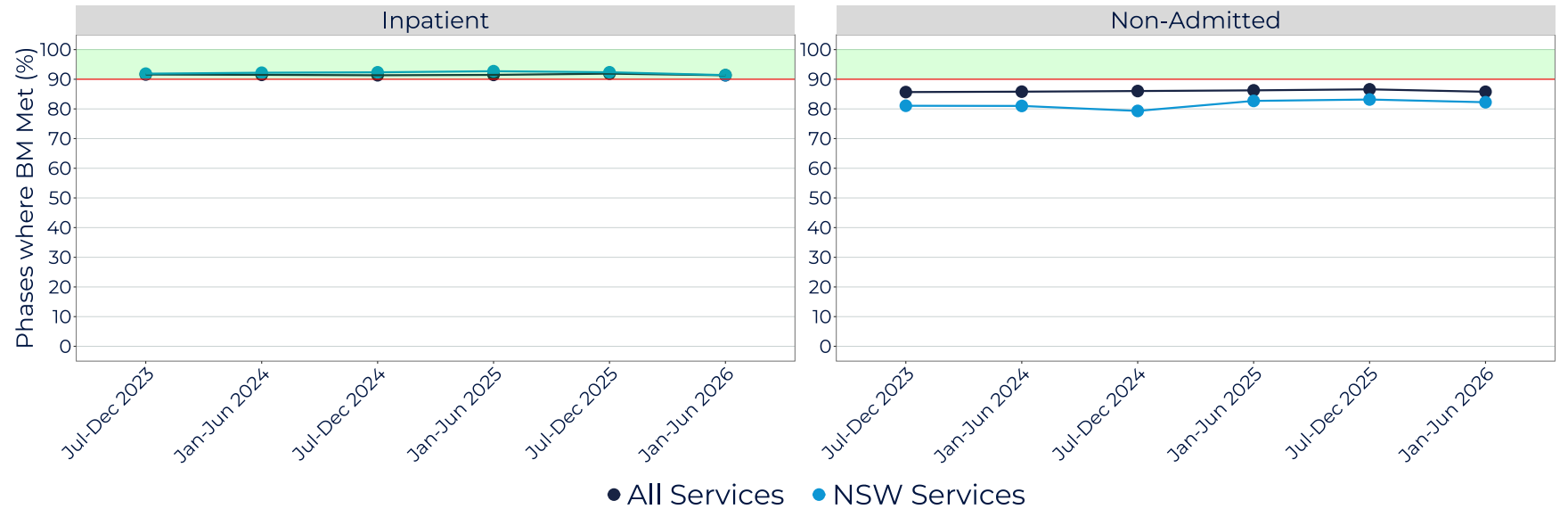
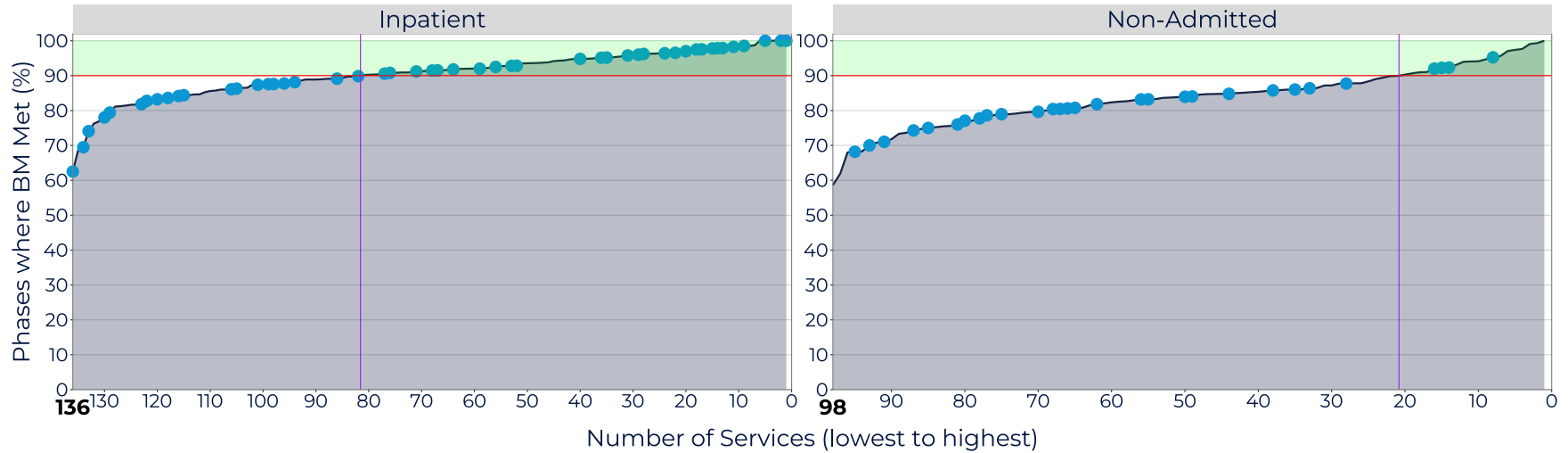
^b. N represents the total number of phases starting with the symptom or problem rated **moderate to severe**.

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 NSW Services to those of other individual services nationally, as well as showing any changes in outcomes over time.

For a guide on how to interpret these graphs, see Appendix E.

Anticipatory care - Pain (PCPSS)

% absent to mild at phase end, when absent to mild at phase start

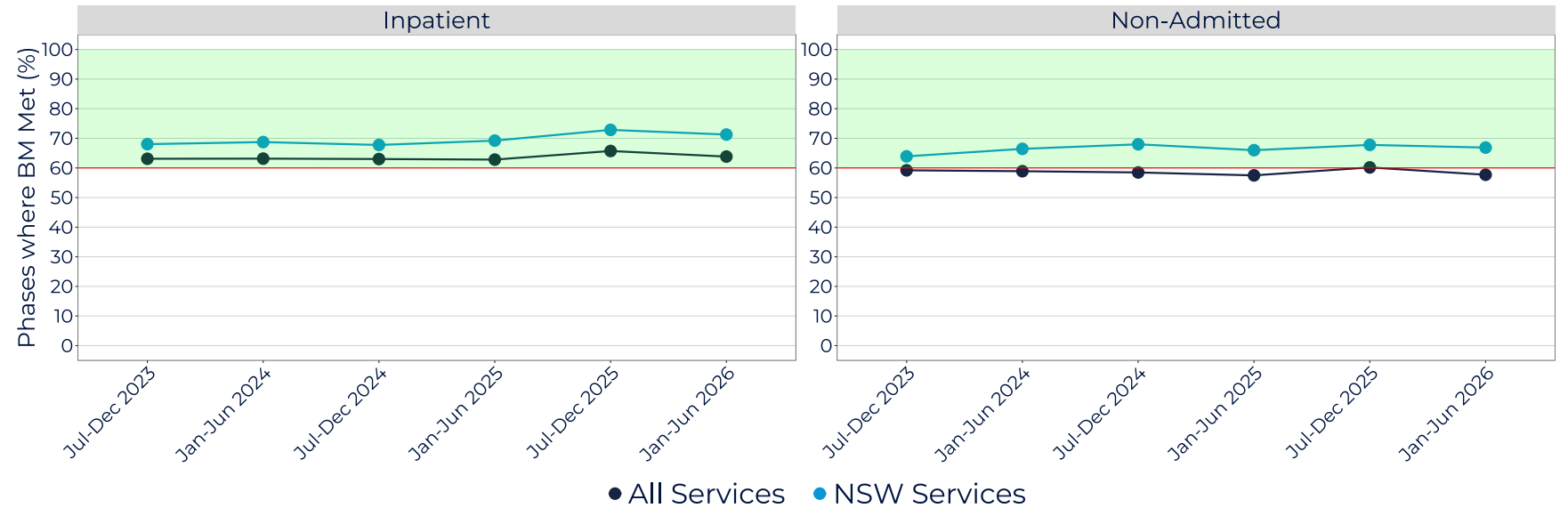
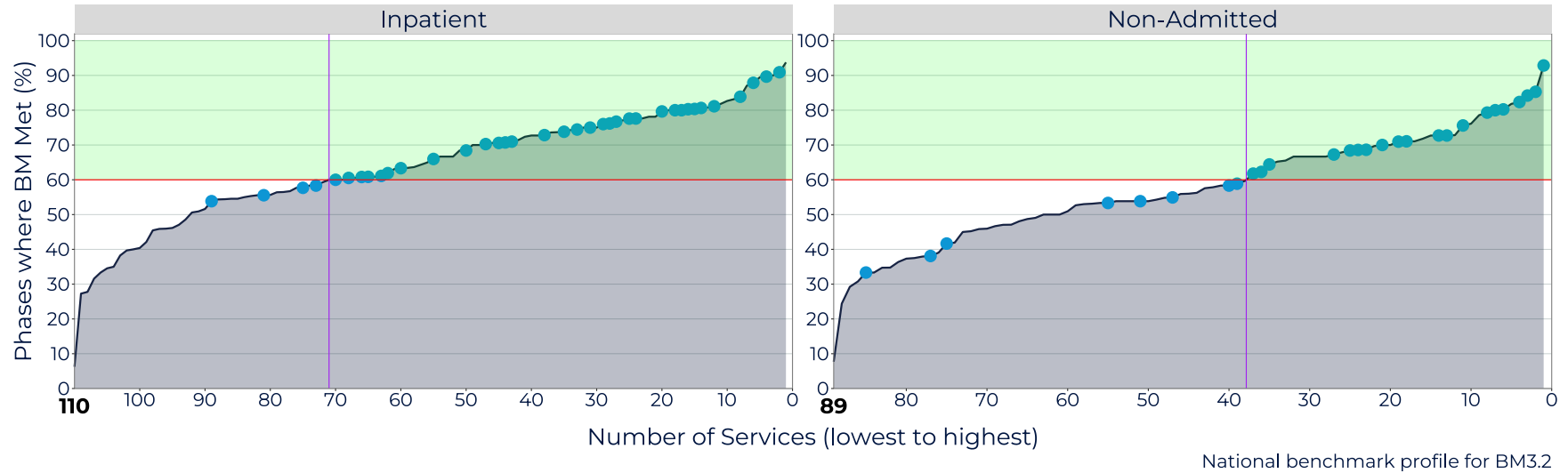


Outcomes over time for BM3.1

Figure 3: Pain, patients assessed with absent to mild severity at phase end (anticipatory)

Responsive care - Pain (PCPSS)

% absent to mild at phase end, when moderate to severe at phase start

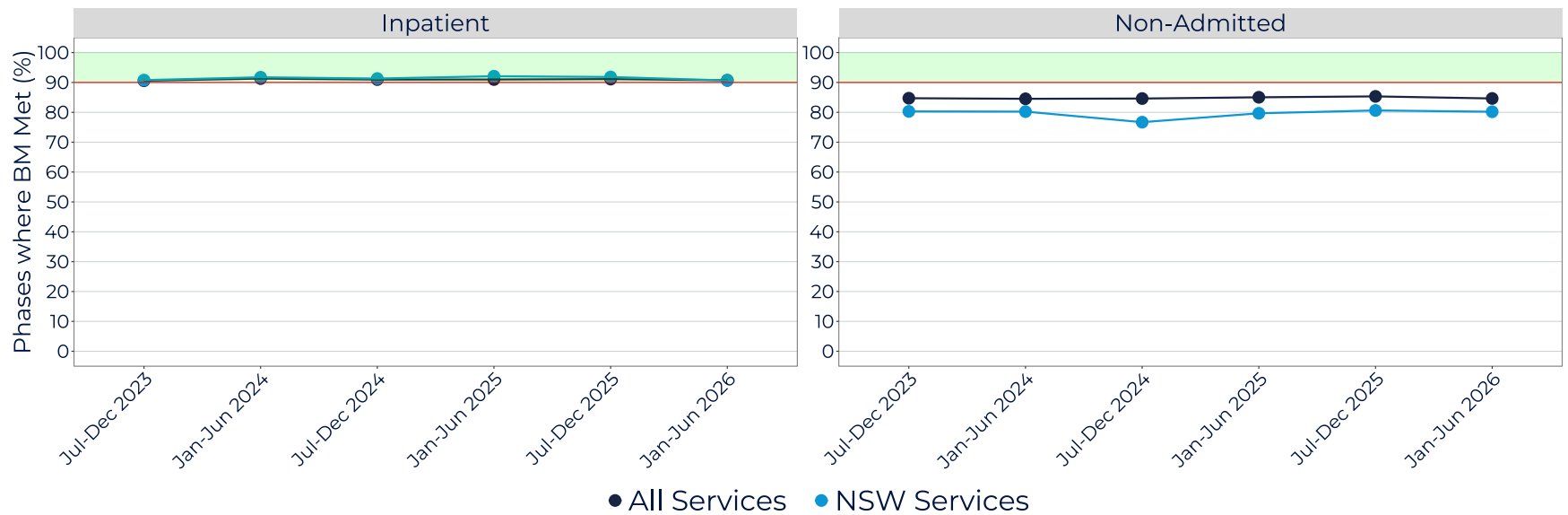
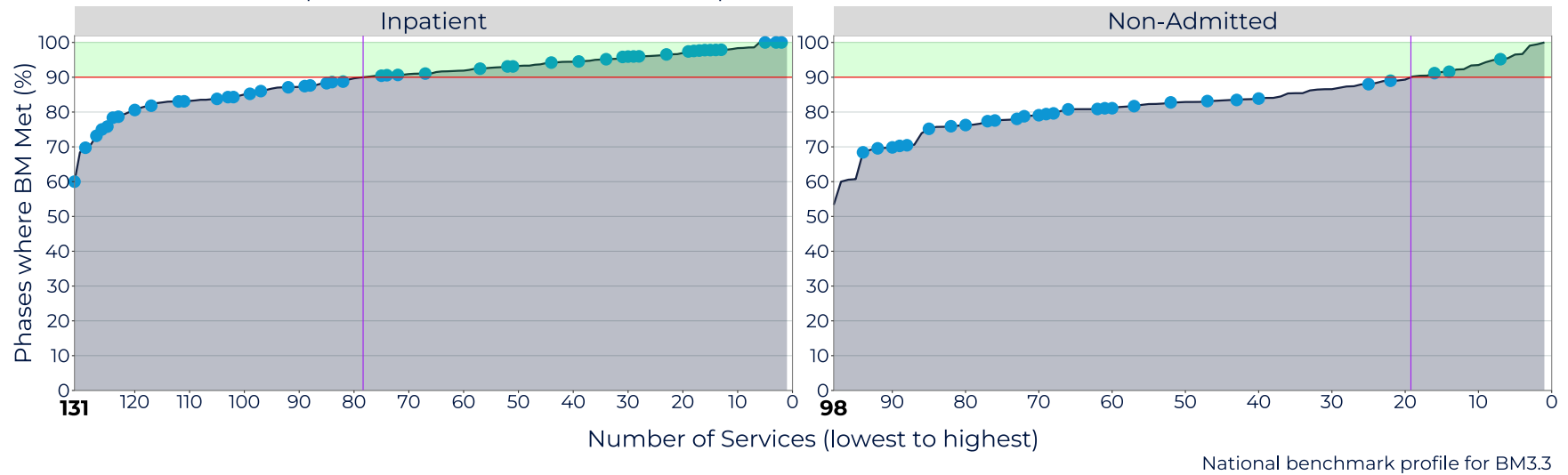


Outcomes over time for BM3.2

Figure 4: Pain, patients assessed with absent to mild severity at phase end (responsive)

Anticipatory care - Pain (SAS)

% absent to mild at phase end, when absent to mild at phase start

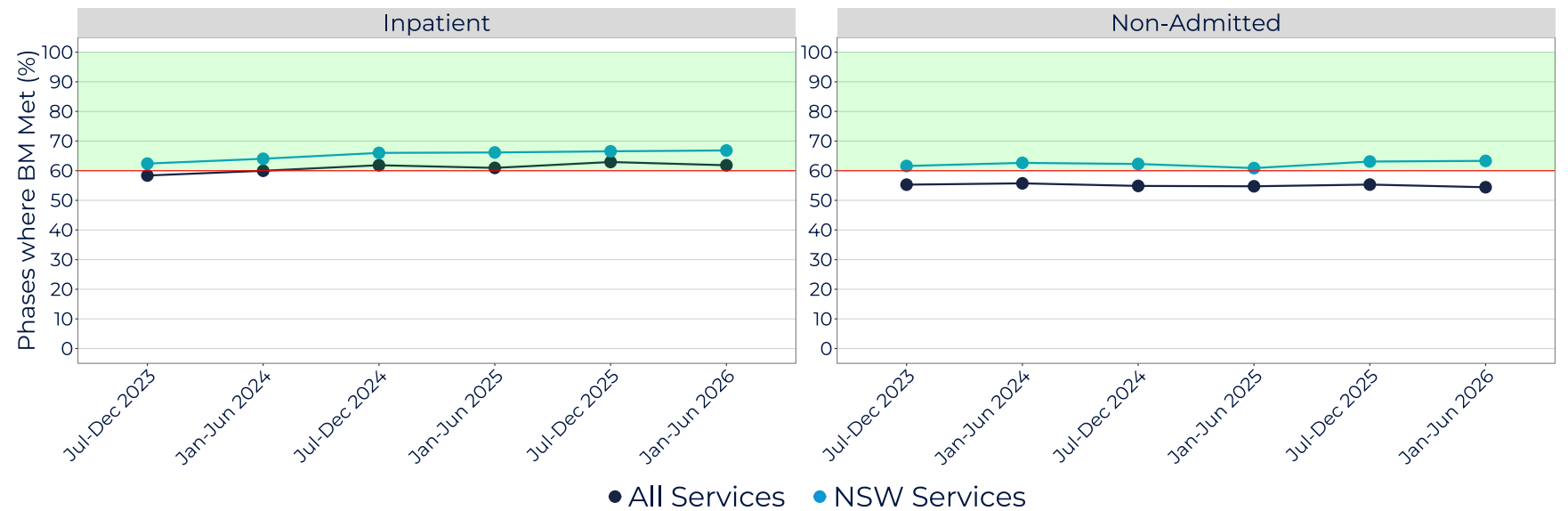
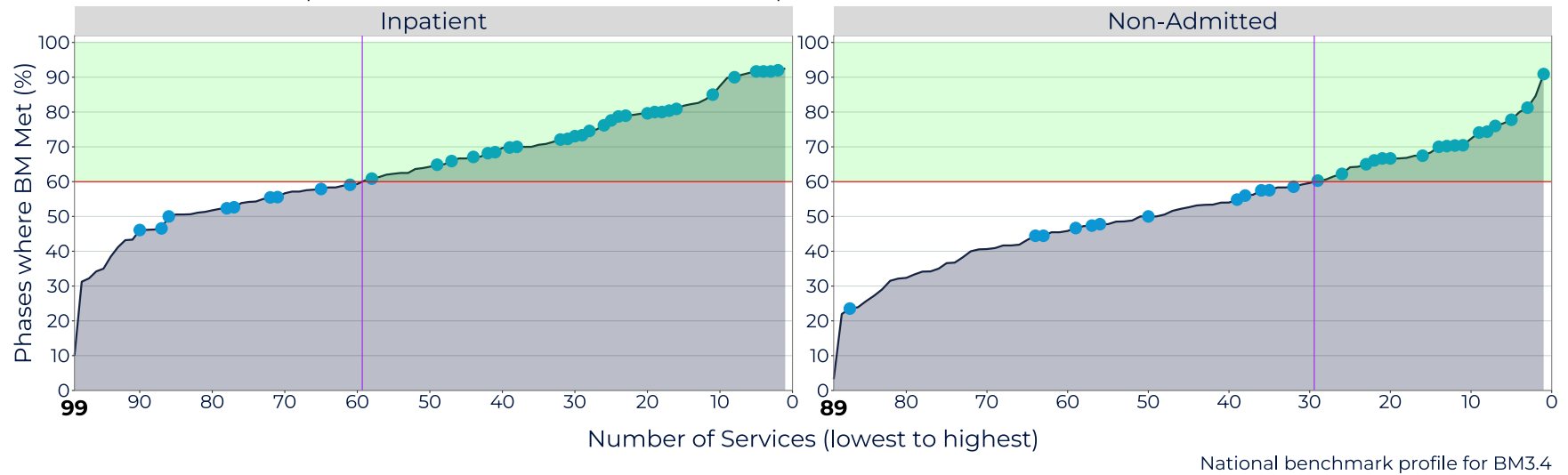


Outcomes over time for BM3.3

Figure 5: Pain, patients reporting absent to mild distress at phase end (anticipatory)

Responsive care - Pain (SAS)

% absent to mild at phase end, when moderate to severe at phase start

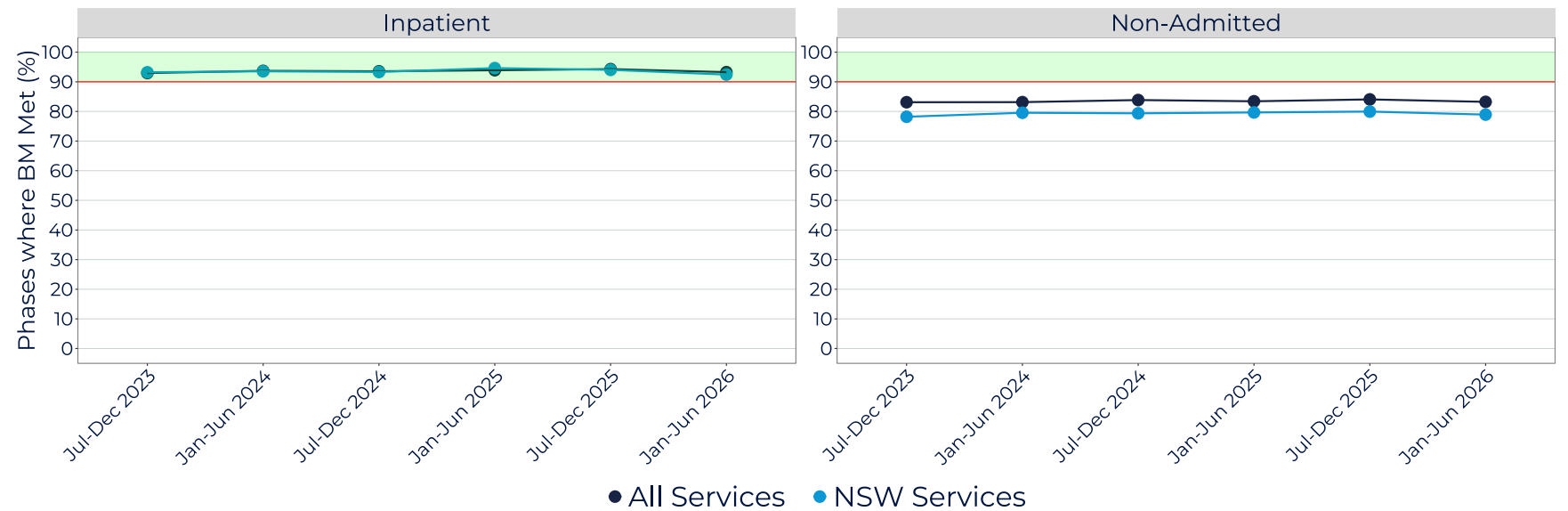
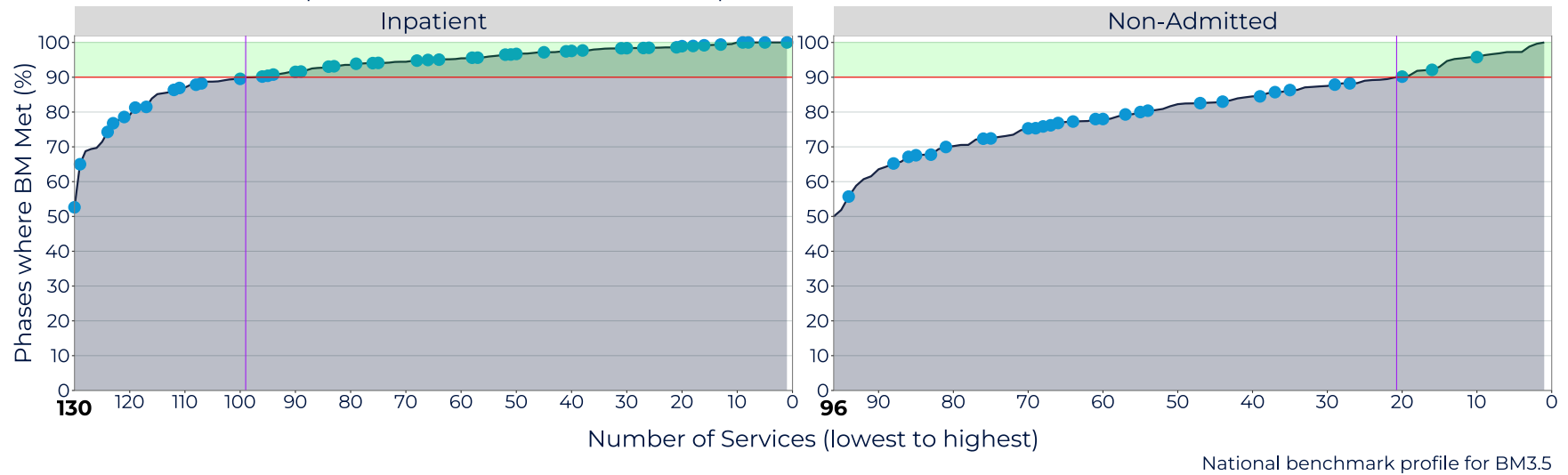


Outcomes over time for BM3.4

Figure 6: Pain, patients reporting absent to mild distress at phase end (responsive)

Anticipatory care - Fatigue (SAS)

% absent to mild at phase end, when absent to mild at phase start

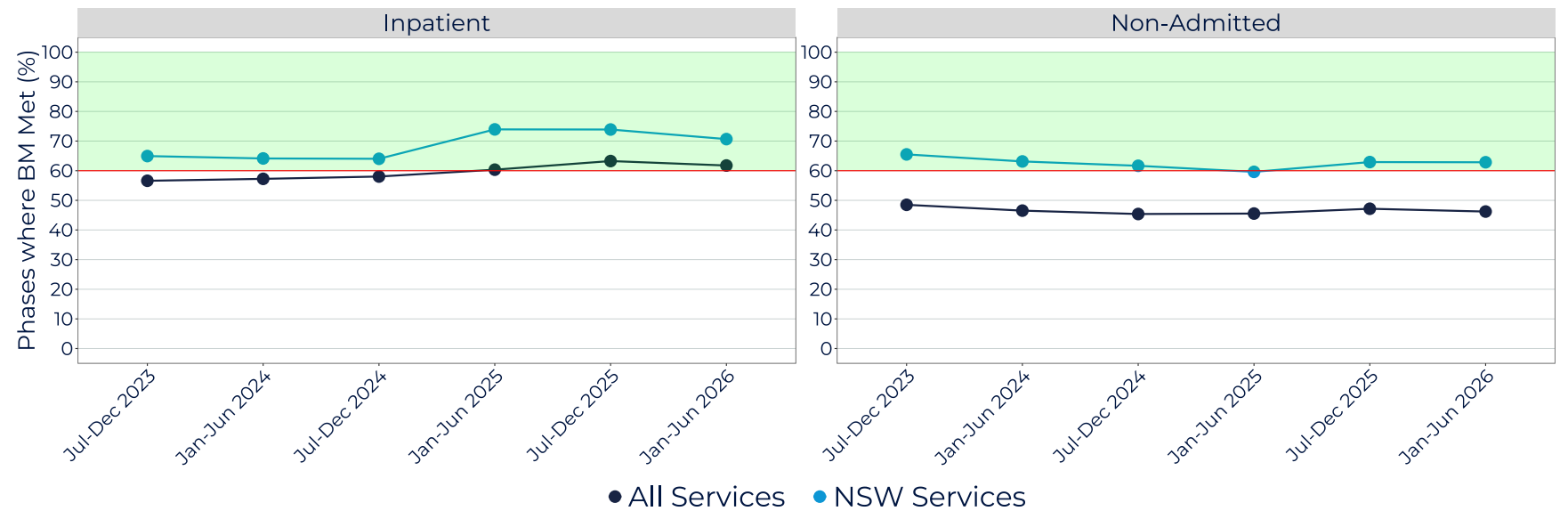
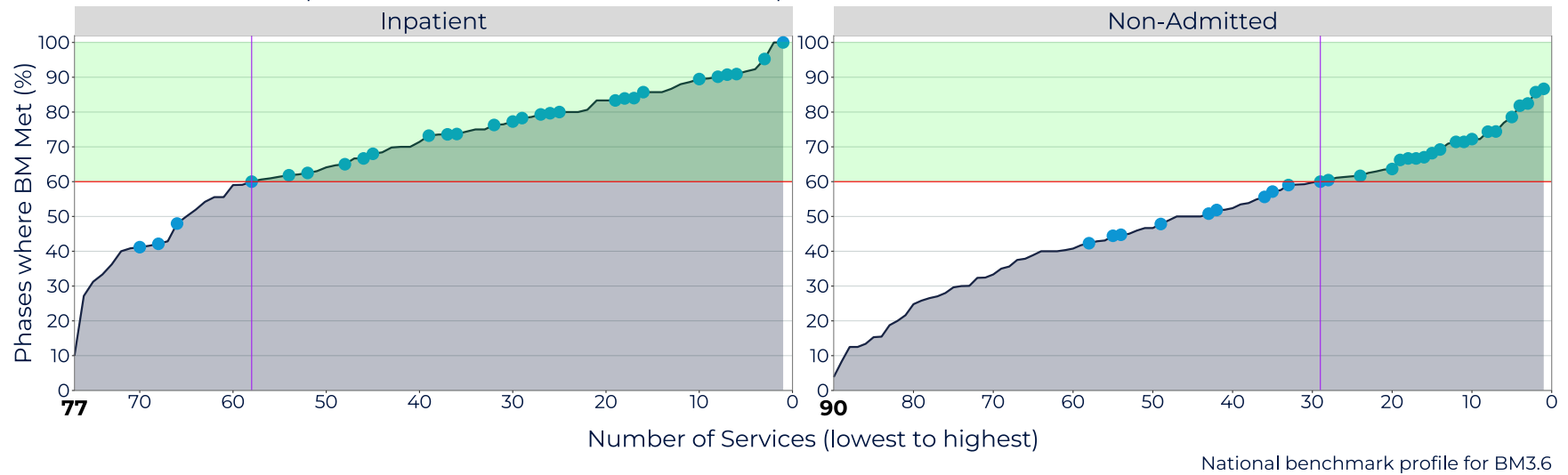


Outcomes over time for BM3.5

Figure 7: Fatigue, patients reporting absent to mild distress at phase end (anticipatory)

Responsive care - Fatigue (SAS)

% absent to mild at phase end, when moderate to severe at phase start

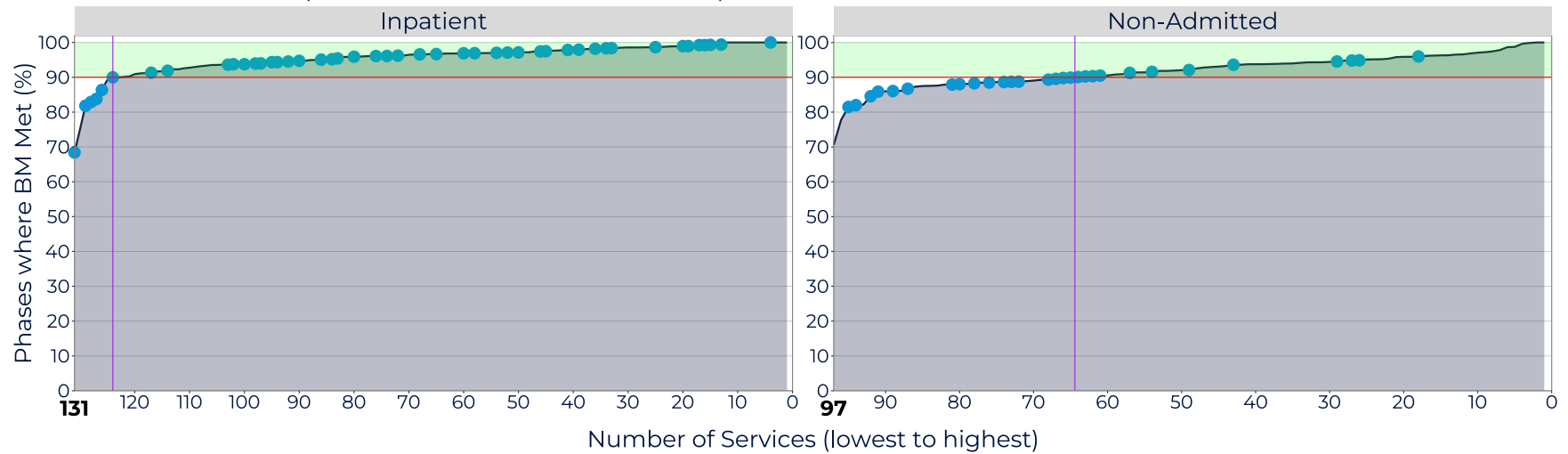


Outcomes over time for BM3.6

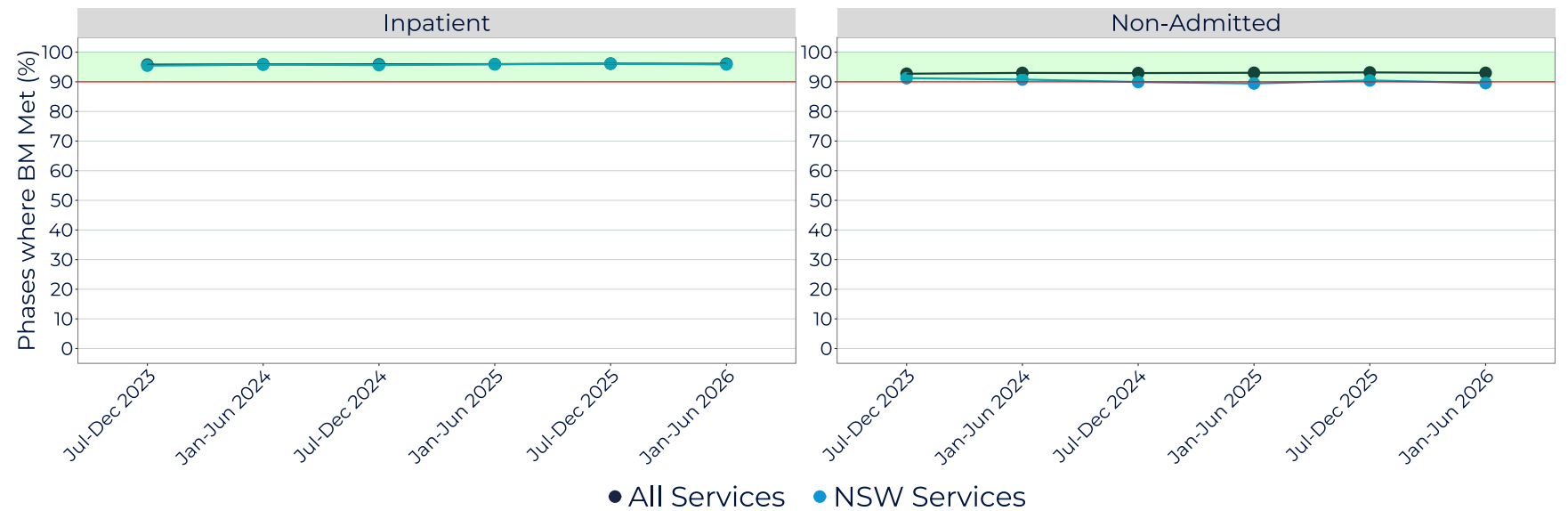
Figure 8: Fatigue, patients reporting absent to mild distress at phase end (responsive)

Anticipatory care - Breathing problems (SAS)

% absent to mild at phase end, when absent to mild at phase start



National benchmark profile for BM3.7

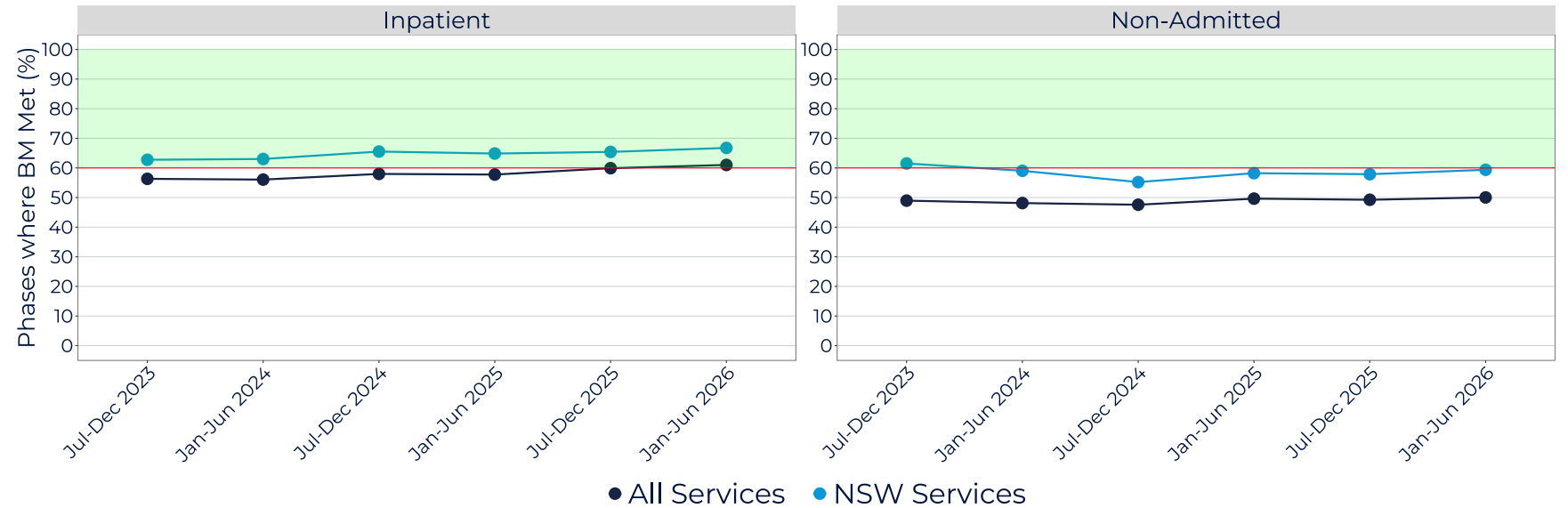
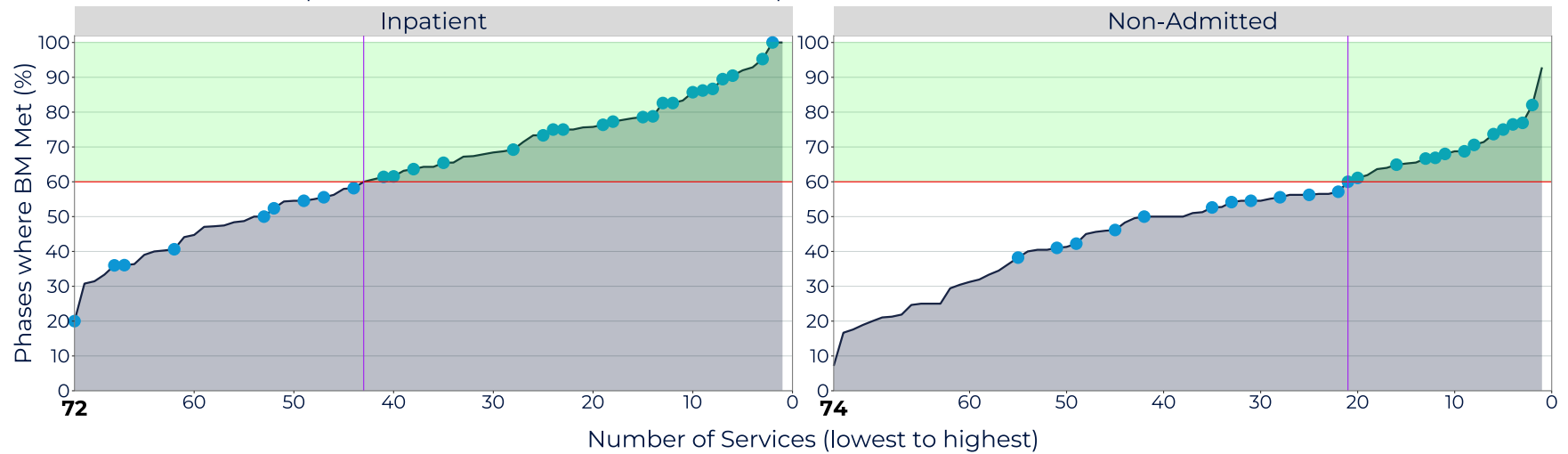


Outcomes over time for BM3.7

Figure 9: Breathing problems, patients reporting absent to mild distress at phase end (anticipatory)

Responsive care - Breathing problems (SAS)

% absent to mild at phase end, when moderate to severe at phase start

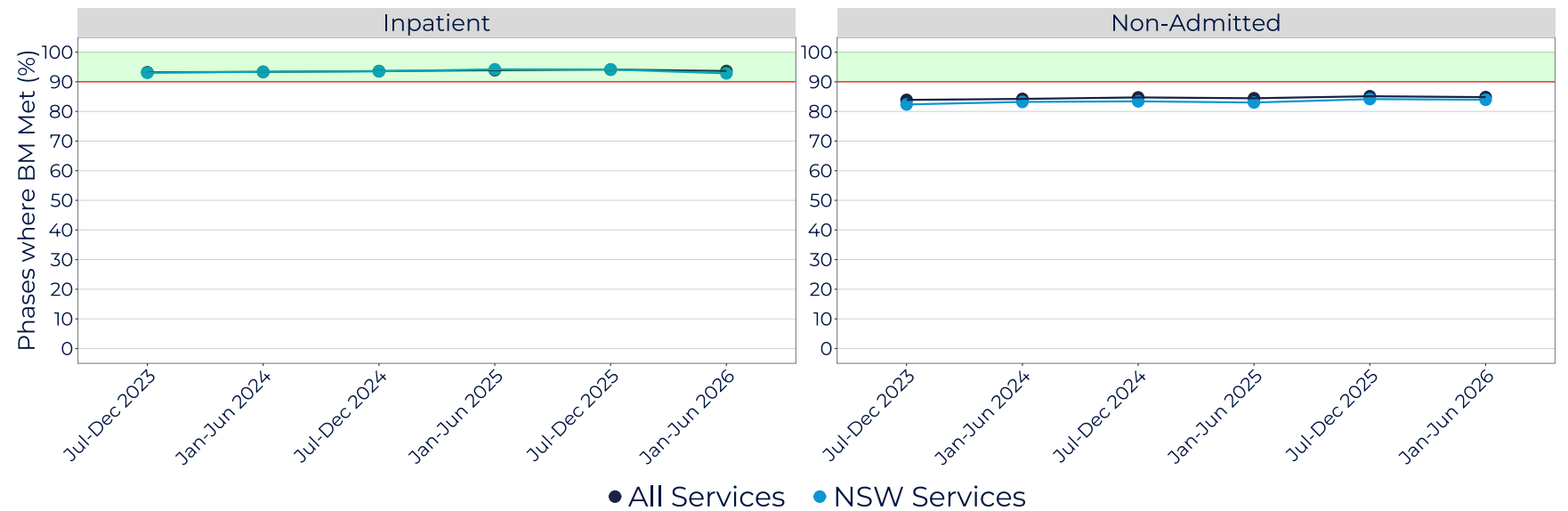
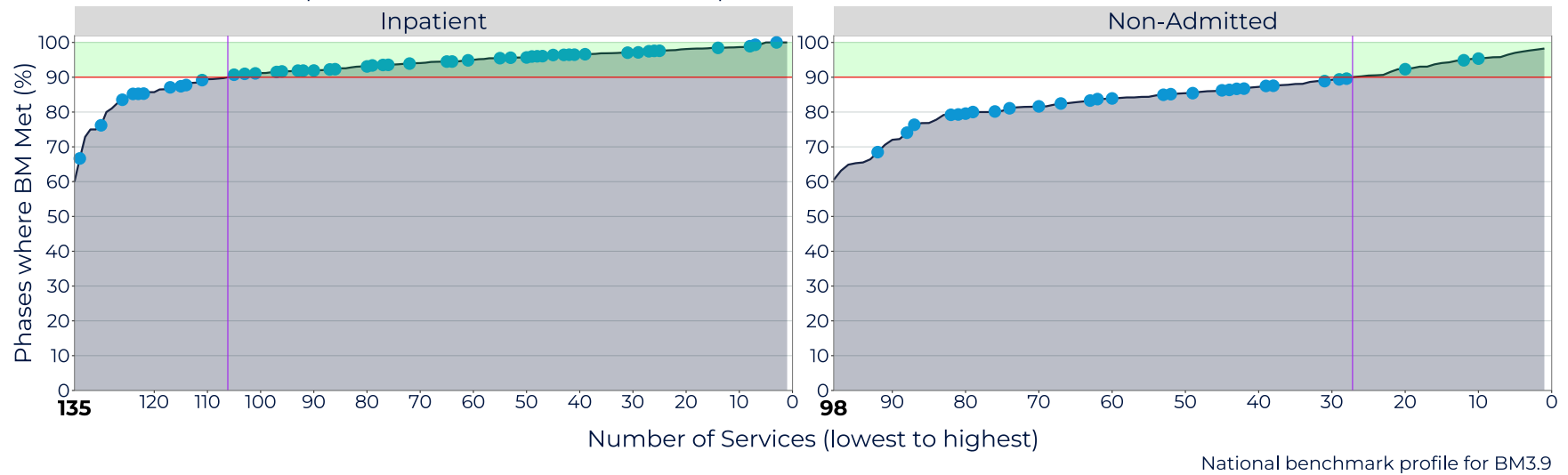


Outcomes over time for BM3.8

Figure 10: Breathing problems, patients reporting absent to mild distress at phase end (responsive)

Anticipatory care - Family/carer problems (PCPSS)

% absent to mild at phase end, when absent to mild at phase start

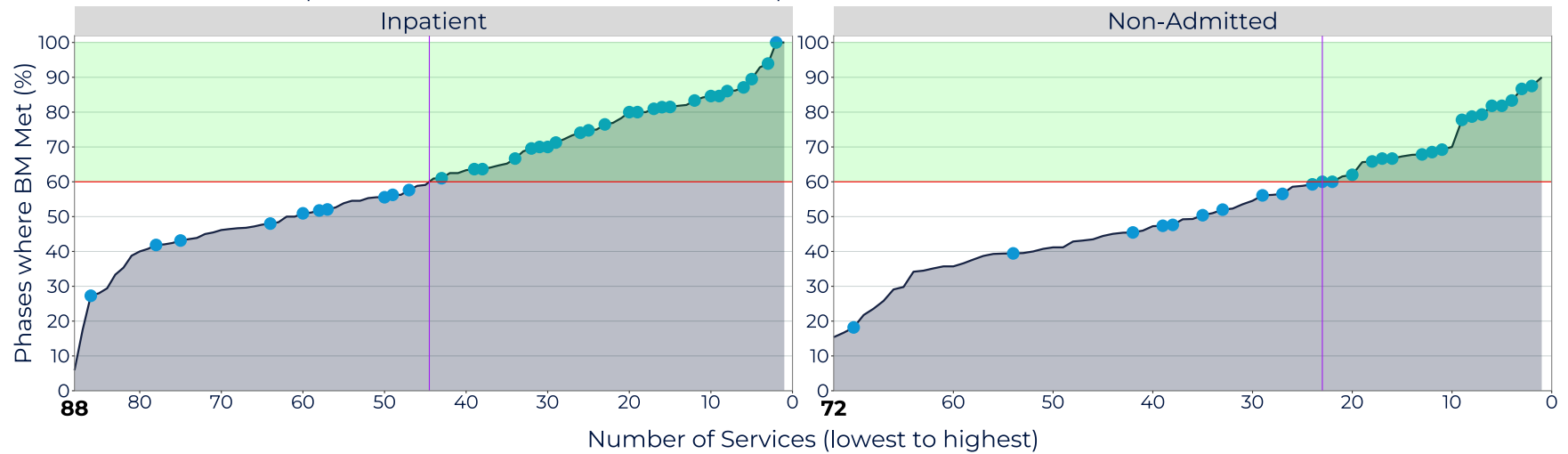


Outcomes over time for BM3.9

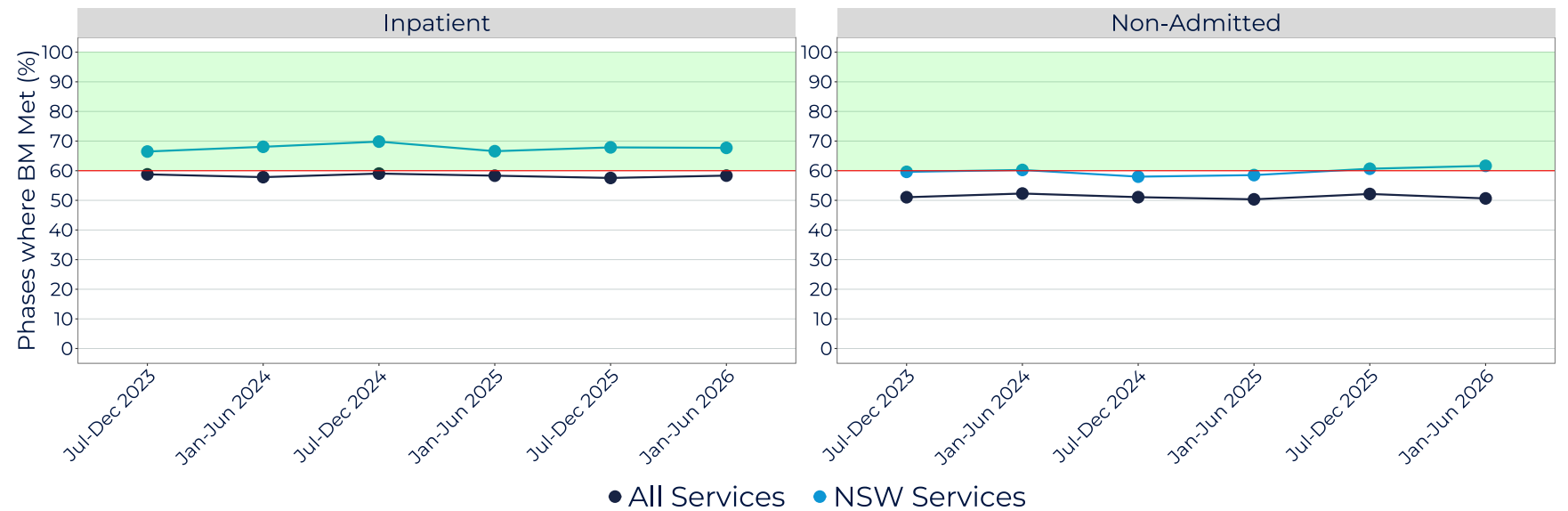
Figure 11: Family/carer problems, family/carer assessed with absent to mild problem severity at phase end (anticipatory)

Responsive care - Family/carers problems (PCPSS)

% absent to mild at phase end, when moderate to severe at phase start



National benchmark profile for BM3.10



Outcomes over time for BM3.10

Figure 12: Family/carers problems, family/carers assessed with absent to mild problem severity at phase end (responsive)

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

Clinical Tool	Symptom/Problem	NSW Services				All Inpatient Services			
		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 <i>Clinician reported severity</i>	Pain	0.13	13,913	9,014	64.8	0.10	34,367	21,352	62.1
	Other symptoms	0.28	13,916	10,319	74.2	0.27	33,356	25,330	75.9
	Family/carer	0.26	13,824	10,384	75.1	0.24	31,557	24,216	76.7
	Psychological/spiritual	0.27	13,889	10,041	72.3	0.24	34,097	23,605	69.2
SAS <i>Patient reported distress</i>	Pain	0.34	13,009	8,819	67.8	0.29	30,964	20,817	67.2
	Nausea	0.19	13,009	11,438	87.9	0.20	30,705	27,166	88.5
	Breathing problems	0.32	13,017	10,510	80.7	0.31	30,735	25,033	81.4
	Bowel problems	0.31	13,002	10,529	81.0	0.31	30,652	24,974	81.5

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

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

Table 8: Casemix adjusted outcomes - non-admitted setting

Clinical Tool	Symptom/Problem	NSW Services				All Non-Admitted Services			
		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 <i>Clinician reported severity</i>	Pain	-0.03	7,354	4,176	56.8	-0.03	37,702	20,633	54.7
	Other symptoms	0.03	7,367	4,515	61.3	0.04	36,555	23,913	65.4
	Family/carers	0.10	7,251	4,800	66.2	0.07	34,214	23,109	67.5
	Psychological/spiritual	0.13	7,324	4,568	62.4	0.08	36,757	20,991	57.1
SAS <i>Patient reported distress</i>	Pain	-0.12	7,370	4,347	59.0	-0.08	38,179	22,382	58.6
	Nausea	-0.05	7,317	5,700	77.9	-0.01	36,602	29,290	80.0
	Breathing problems	-0.01	7,333	5,034	68.6	0.07	36,429	25,768	70.7
	Bowel problems	-0.03	7,319	5,037	68.8	0.05	36,172	26,279	72.7



Figure 13: Trends in casemix adjusted outcomes - Palliative Care Problem Severity Score (PCPSS)

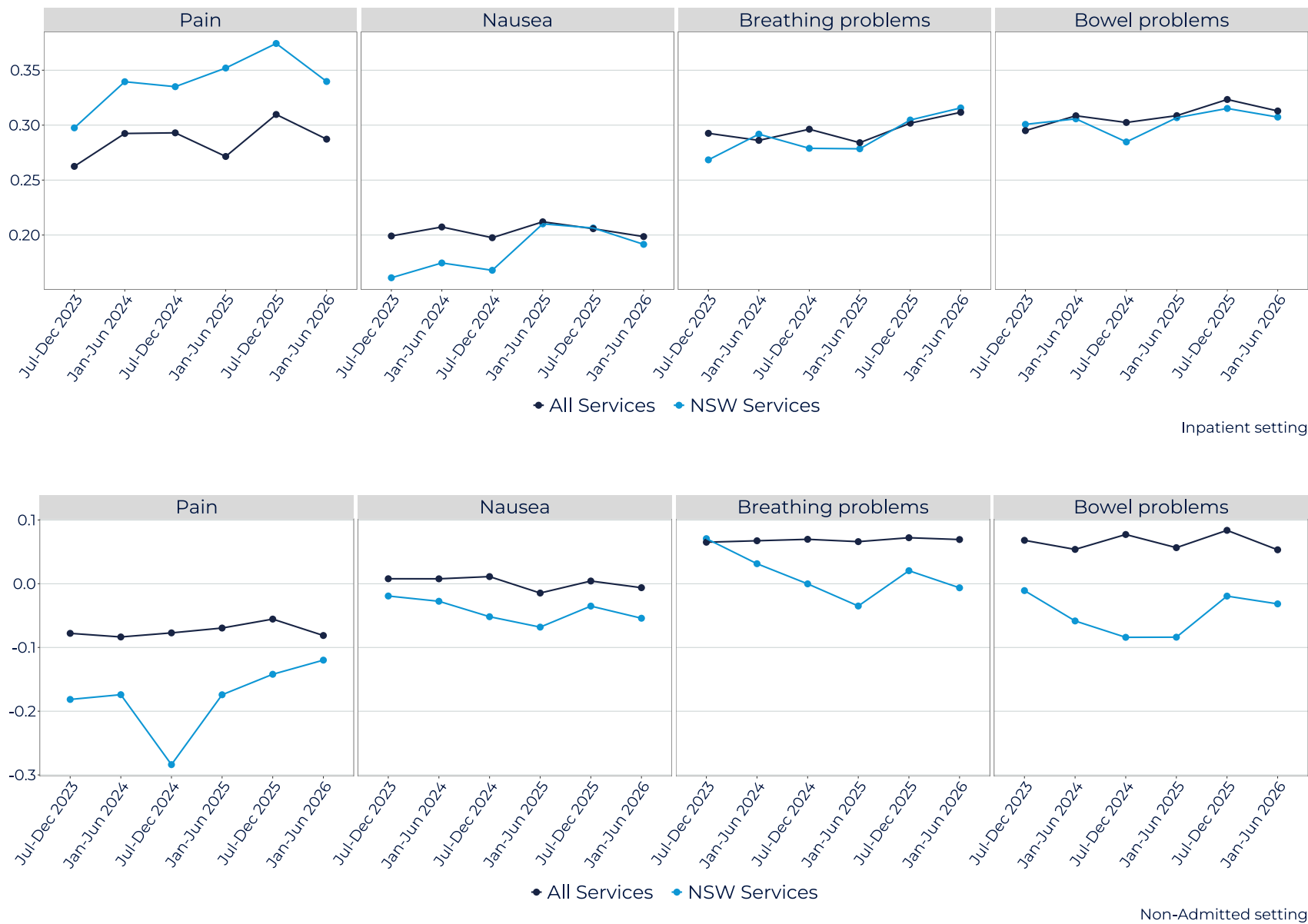


Figure 14: Trends in casemix adjusted outcomes - Symptom Assessment Scale (SAS)

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 NSW Services and all participating PCOC services.

Table 9: Sex

Sex	NSW Services		All Services	
	N	%	N	%
Male	5,941	50.9	21,571	50.7
Female	5,721	49.1	20,967	49.3
Not stated/Inadequately described/Intersex	0	0.0	7	0.0
Total	11,662	100.0	42,545	100.0

Table 10 shows the sex for the patients in NSW Services over time.

Table 10: Sex for NSW Services over time

Sex	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Male	52.1	51.8	51.1	52.0	50.7	50.9
Female	47.9	48.2	48.9	48.0	49.3	49.1
Not stated/Inadequately described/Intersex	0.0	0.0	0.0	0.0	0.0	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 11 shows the Indigenous status for the patients in NSW Services and all participating PCOC services.

Table 11: Indigenous status

Indigenous status	NSW Services		All Services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	251	2.2	925	2.2
Torres Strait Islander but not Aboriginal origin	7	0.1	51	0.1
Both Aboriginal and Torres Strait Islander origin	4	0.0	57	0.1
Neither Aboriginal nor Torres Strait Islander origin	11,241	96.4	40,271	94.7
Not stated/inadequately described	159	1.4	1,241	2.9
Total	11,662	100.0	42,545	100.0

Table 12 shows the Indigenous status for the patients in NSW Services over time.

Table 12: Indigenous status for NSW Services over time

Indigenous status	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Aboriginal but not Torres Strait Islander origin	2.0	2.0	2.2	2.2	2.6	2.2
Torres Strait Islander but not Aboriginal origin	0.0	0.1	0.1	0.1	0.1	0.1
Both Aboriginal and Torres Strait Islander origin	0.1	0.1	0.1	0.1	0.1	0.0
Neither Aboriginal nor Torres Strait Islander origin	96.5	95.7	96.2	96.7	96.5	96.4
Not stated/inadequately described/Intersex	1.4	2.1	1.5	0.9	0.8	1.4
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 13: Country of birth

Country of birth	NSW Services		All Services	
	N	%	N	%
Australia	6,863	58.8	26,903	63.2
England	620	5.3	2,677	6.3
India	111	1.0	400	0.9
China	470	4.0	763	1.8
New Zealand	232	2.0	974	2.3
Philippines	103	0.9	275	0.6
Vietnam	85	0.7	354	0.8
South Africa	58	0.5	242	0.6
Malaysia	44	0.4	171	0.4
Italy	357	3.1	1,397	3.3
Sri Lanka	34	0.3	157	0.4
Scotland	115	1.0	478	1.1
Nepal	9	0.1	17	0.0
United States of America	41	0.4	103	0.2
Germany	125	1.1	433	1.0
All other countries	2,317	19.9	6,490	15.3
Not stated	78	0.7	711	1.7
Total	11,662	100.0	42,545	100.0

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.

Table 14: Preferred language

Language	NSW Services		All Services	
	N	%	N	%
English	9,677	83.0	37,364	87.8
Chinese^a	500	4.3	860	2.0
Hindi^b	53	0.5	174	0.4
Arabic^c	251	2.2	411	1.0
Vietnamese^d	62	0.5	279	0.7
Filipino/Indonesian^e	25	0.2	77	0.2
Tamil/Malayalam^f	11	0.1	23	0.1
Spanish^g	97	0.8	198	0.5
Greek	224	1.9	591	1.4
Italian	148	1.3	576	1.4
Macedonian/Croatian^h	140	1.2	369	0.9
African languages	s	s	30	0.1
Korean	45	0.4	53	0.1
Samoan/Tonganⁱ	32	0.3	68	0.2
Australian Indigenous languages	12	0.1	63	0.1
All other languages	206	1.8	769	1.8
Not stated	175	1.5	640	1.5
Total	11,658	100.0	42,545	100.0

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.

The tables on the previous page show the country of birth and the preferred language respectively for the patients in NSW 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 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 14 (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 15 and Table 16 present a breakdown of malignant and non-malignant diagnosis for the patients in NSW 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 26 (0.2%) patients in NSW Services and was not stated for 1,276 (3.0%) patients nationally.

Table 15: Principal diagnosis - malignant

Diagnosis	NSW Services			All Services		
	N	% of malignant diagnoses	% of all diagnoses	N	% of malignant diagnoses	% of all diagnoses
Bone and soft tissue	99	1.3	0.8	350	1.4	0.8
Breast	534	6.9	4.6	1,872	7.2	4.4
CNS	149	1.9	1.3	662	2.6	1.6
Colorectal	827	10.7	7.1	2,656	10.3	6.2
Other GIT	735	9.5	6.3	2,580	10.0	6.1
Haematological	599	7.8	5.1	1,911	7.4	4.5
Head and neck	412	5.3	3.5	1,301	5.0	3.1
Lung	1,512	19.6	13.0	5,007	19.4	11.8
Pancreas	606	7.9	5.2	2,039	7.9	4.8
Prostate	417	5.4	3.6	1,605	6.2	3.8
Other urological	386	5.0	3.3	1,205	4.7	2.8
Gynaecological	449	5.8	3.9	1,322	5.1	3.1
Skin	316	4.1	2.7	959	3.7	2.3
Unknown primary	185	2.4	1.6	805	3.1	1.9
Other primary malignancy	471	6.1	4.0	1,332	5.2	3.1
Malignant Not further defined	22	0.3	0.2	245	0.9	0.6
All malignant	7,719	100.0	66.2	25,851	100.0	60.9

Table 16: Principal diagnosis - non-malignant

Diagnosis	NSW Services			All Services		
	N	% of non-malignant diagnoses	% of all diagnoses	N	% of non-malignant diagnoses	% of all diagnoses
Cardiovascular disease	500	12.8	4.3	2,046	13.3	4.8
End stage kidney disease	249	6.4	2.1	1,211	7.9	2.8
Stroke	243	6.2	2.1	810	5.3	1.9
Motor neurone disease	126	3.2	1.1	419	2.7	1.0
Alzheimers dementia	175	4.5	1.5	1,151	7.5	2.7
Other dementia	330	8.4	2.8	1,543	10.0	3.6
Other neurological disease	244	6.2	2.1	810	5.3	1.9
Respiratory failure	756	19.3	6.5	2,519	16.3	5.9
End stage liver disease	97	2.5	0.8	408	2.6	1.0
Diabetes & its complications	14	0.4	0.1	81	0.5	0.2
Sepsis	244	6.2	2.1	836	5.4	2.0
Multiple organ failure	187	4.8	1.6	471	3.1	1.1
Other non-malignancy	743	19.0	6.4	2,661	17.3	6.3
Non-malignant Not further defined	9	0.2	0.1	452	2.9	1.1
All non-malignant	3,917	100.0	33.6	15,418	100.0	36.3

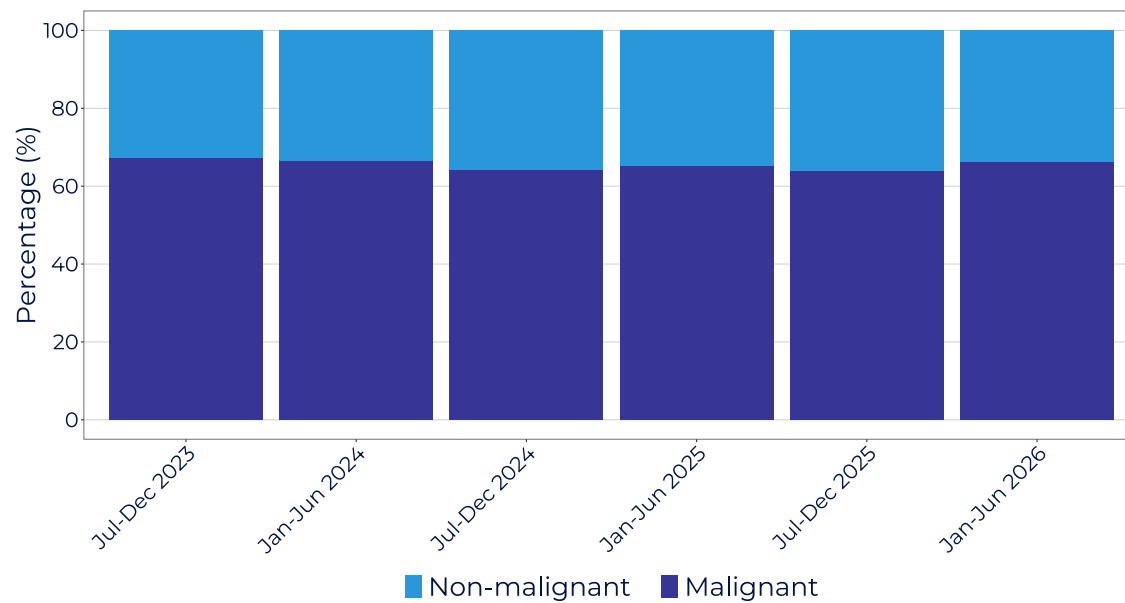


Figure 15: Principal diagnosis over time for NSW Services

Table 17 shows the breakdown of patient deaths in NSW Services and nationally for the reporting period. All inpatient deaths are reported in the hospital/hospice category while the non-admitted deaths are reported in the private residence and residential aged care facility categories.

Table 17: Place of death

Place of death	NSW Services		All Services	
	N	%	N	%
Private residence	535	10.5	2,809	15.3
Residential aged care facility	214	4.2	2,067	11.2
Hospital/hospice	4,261	84.0	12,943	70.4
Not stated/inadequately described	64	1.3	564	3.1
Total	5,074	100.0	18,383	100.0

Table 18 shows the place of death for the patients in NSW Services over time.

Table 18: Place of death for NSW Services over time

Place of death	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Private residence	12.6	12.8	9.6	9.9	9.0	10.5
Residential aged care facility	6.0	6.6	6.9	6.4	4.8	4.2
Hospital/hospice	80.5	79.6	82.5	82.7	85.2	84.0
Not stated/inadequately described	0.8	1.0	1.0	1.0	1.0	1.3
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

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 non-admitted 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 non-admitted 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 19 presents the number and percentage of episodes by age group and sex for the patients seen by NSW Services and at the national level. Age has been calculated as at episode start.

Table 19: Patient's age by sex

Age	NSW Services				All Services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	s	s	s	s	14	0.1	17	0.1
15 – 24	45	0.6	26	0.4	99	0.4	57	0.2
25 – 34	42	0.6	43	0.6	124	0.5	139	0.5
35 – 44	109	1.6	185	2.8	406	1.5	588	2.3
45 – 54	328	4.7	345	5.1	1,159	4.3	1,266	4.9
55 – 64	846	12.1	758	11.3	3,040	11.3	2,842	11.0
65 – 74	1,550	22.2	1,278	19.0	5,731	21.3	4,824	18.6
75 – 84	2,173	31.1	1,971	29.4	8,130	30.3	7,040	27.2
85 +	1,900	27.2	2,109	31.4	6,630	24.7	7,749	29.9
Unknown	0	0.0	0	0.0	1,523	5.7	1,402	5.4
Total	6,993	100.0	6,715	100.0	26,856	100.0	25,924	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 20 presents referral source by setting of care.

Table 20: Source of referral

Referral source	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Public hospital – palliative care unit/team	922	10.9	2,310	9.4	854	27.2	1,651	8.5
Public hospital - oncology unit/team	1,379	16.2	2,872	11.7	406	12.9	968	5.0
Public hospital - medical unit/team	3,098	36.5	8,209	33.6	339	10.8	1,263	6.5
Public hospital - surgical unit/team	436	5.1	1,017	4.2	20	0.6	76	0.4
Public hospital - emergency department	624	7.3	1,627	6.6	31	1.0	182	0.9
Public hospital - not further defined	24	0.3	2,520	10.3	0	0.0	5,048	25.9
Public hospital - Total	6,483	76.3	18,555	75.8	1,650	52.5	9,188	47.1
Private hospital - palliative care unit/team	55	0.6	167	0.7	74	2.4	523	2.7
Private hospital - oncology unit/team	296	3.5	525	2.1	96	3.1	170	0.9
Private hospital - medical unit/team	130	1.5	484	2.0	26	0.8	91	0.5
Private hospital - surgical unit/team	15	0.2	40	0.2	s	s	s	s
Private hospital - emergency department	10	0.1	62	0.3	s	s	9	0.0
Private hospital - not further defined	0	0.0	143	0.6	0	0.0	716	3.7
Private hospital - Total	506	6.0	1,421	5.8	196	6.2	1,509	7.7
Outpatient clinic	15	0.2	105	0.4	50	1.6	249	1.3
General medical practitioner	92	1.1	193	0.8	593	18.9	2,548	13.0
Specialist medical practitioner	214	2.5	500	2.0	382	12.2	2,006	10.3
Community-based palliative care agency	954	11.2	2,708	11.1	100	3.2	474	2.4
Community-based service	s	s	32	0.1	44	1.4	265	1.4
Residential aged care facility	9	0.1	70	0.3	41	1.3	1,745	8.9
Self, carer(s), family or friends	22	0.3	229	0.9	43	1.4	530	2.7
Other	61	0.7	387	1.6	45	1.4	818	4.2
Not stated/inadequately described	136	1.6	267	1.1	0	0.0	195	1.0
Total	8,492	100.0	24,467	100.0	3,144	100.0	19,527	100.0

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

Table 21 shows the referral source for the patients in NSW Services over time.

Table 21: Referral source for NSW Services over time

Referral source	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Public hospital - palliative care unit/team	16.1	16.4	17.9	17.2	17.2	15.3
Public hospital – oncology unit/team	12.5	11.8	12.3	12.4	14.0	15.3
Public hospital – medical unit/team	25.5	26.6	27.0	28.4	30.3	29.5
Public hospital – surgical unit/team	2.6	2.9	3.5	3.5	3.7	3.9
Public hospital – emergency department	5.7	5.8	5.4	6.3	6.6	5.6
Public hospital – not further defined	4.9	4.0	0.3	0.3	0.2	0.2
Public hospital – Total	67.3	67.5	66.4	68.1	72.0	69.8
Private hospital – palliative care unit/team	1.3	1.2	1.0	1.4	1.3	1.1
Private hospital – oncology unit/team	3.5	3.8	4.8	3.1	2.5	3.4
Private hospital – medical unit/team	1.2	1.0	2.0	1.9	1.7	1.3
Private hospital – surgical unit/team	0.2	0.1	0.3	0.1	0.1	0.1
Private hospital – emergency department	0.1	0.2	0.2	0.1	0.1	0.1
Private hospital – not further defined	0.3	0.3	0.0	0.0	0.0	0.0
Private hospital – Total	6.6	6.6	8.3	6.6	5.7	6.0
Outpatient clinic	0.4	0.4	0.4	0.6	0.5	0.6
General medical practitioner	7.7	7.4	6.8	6.9	5.1	5.9
Specialist medical practitioner	6.8	5.7	6.0	5.1	4.6	5.1
Community-based palliative care agency	9.3	9.8	10.0	10.0	9.7	9.1
Community-based service	0.4	0.4	0.3	0.7	0.4	0.4
Residential aged care facility	0.3	0.2	0.3	0.4	0.3	0.4
Self, carer(s), family or friends	0.5	0.9	0.8	0.4	0.6	0.6
Other	0.6	0.6	0.8	1.1	1.0	0.9
Not stated/inadequately described	0.2	0.5	0.1	0.1	0.0	1.2
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

Table 22 gives a summary of the length of episodes for patients in NSW Services and nationally.

Table 22: Length of episode (in days) summary by setting of care

Length of episode	Inpatient		Non-Admitted	
	NSW Services	All Services	NSW Services	All Services
Average length of episode	9.7	8.5	44.1	38
Median length of episode	5	4	35	27

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 23 shows a summary of the length of episodes for patients in NSW Services over time.

Table 23: Length of episode (in days) summary for NSW Services over time

Length of episode	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Average length of episode	21.2	21.9	19.4	20.2	18.3	19.1
Median length of episode	9	9	8	8	7	8

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 24 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 24: Length of episode (days)

Length of episode (days)	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Same day	726	8.6	2,466	10.0	74	2.0	1,411	6.2
1 – 2	1,875	22.2	6,198	25.0	213	5.8	1,428	6.3
3 – 4	1,260	14.9	3,999	16.2	169	4.6	1,171	5.2
5 – 7	1,359	16.1	3,807	15.4	263	7.2	1,631	7.2
8 – 14	1,604	19.0	4,158	16.8	404	11.0	2,629	11.6
15 – 21	672	8.0	1,778	7.2	291	8.0	1,998	8.8
22 – 30	438	5.2	1,079	4.4	293	8.0	1,947	8.6
31 – 60	402	4.8	963	3.9	601	16.4	3,778	16.7
61 – 90	76	0.9	183	0.7	338	9.2	1,830	8.1
91 +	39	0.5	117	0.5	1,014	27.7	4,801	21.2
Total	8,451	100.0	24,748	100.0	3,660	100.0	22,624	100.0

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

Table 25: How inpatient episodes start

Episode start mode	NSW Services		All Inpatient Services	
	N	%	N	%
Admitted from community^a	5,844	68.8	15,835	64.7
Admitted from another hospital	1,221	14.4	3,376	13.8
Admitted from acute care in another ward	605	7.1	3,179	13.0
Change from acute care to palliative care - same ward	289	3.4	845	3.5
Other^b	180	2.1	431	1.8
Not stated/inadequately described	355	4.2	801	3.3
Total	8,494	100.0	24,467	100.0

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

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

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

Table 26: How inpatient episodes end

Episode end mode	NSW Services		All Inpatient Services	
	N	%	N	%
Discharged to community^a	2,881	34.1	7,170	29.0
Discharged to another hospital	790	9.3	1,980	8.0
Death	4,261	50.4	12,943	52.3
Change from palliative care to acute care^b	142	1.7	248	1.0
Change in sub-acute care type	66	0.8	161	0.7
End of consultative episode - inpatient episode ongoing	28	0.3	1,111	4.5
Other	250	3.0	468	1.9
Not stated/inadequately described	33	0.4	667	2.7
Total	8,451	100.0	24,748	100.0

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

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

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

Table 27: How inpatient episodes start for NSW Services over time

Episode start mode (%)	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Admitted from community^a	62.7	66.8	62.0	61.8	67.9	68.8
Admitted from another hospital	17.8	17.8	18.8	17.7	15.7	14.4
Admitted from acute care on another ward	8.7	8.0	9.2	8.8	8.6	7.1
Change from acute care to palliative care - same ward	7.8	3.7	6.3	7.2	5.2	3.4
Other^b	3.0	3.7	3.2	4.3	2.6	2.1
Not stated/inadequately described	0.0	0.0	0.4	0.2	0.0	4.2
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

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

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

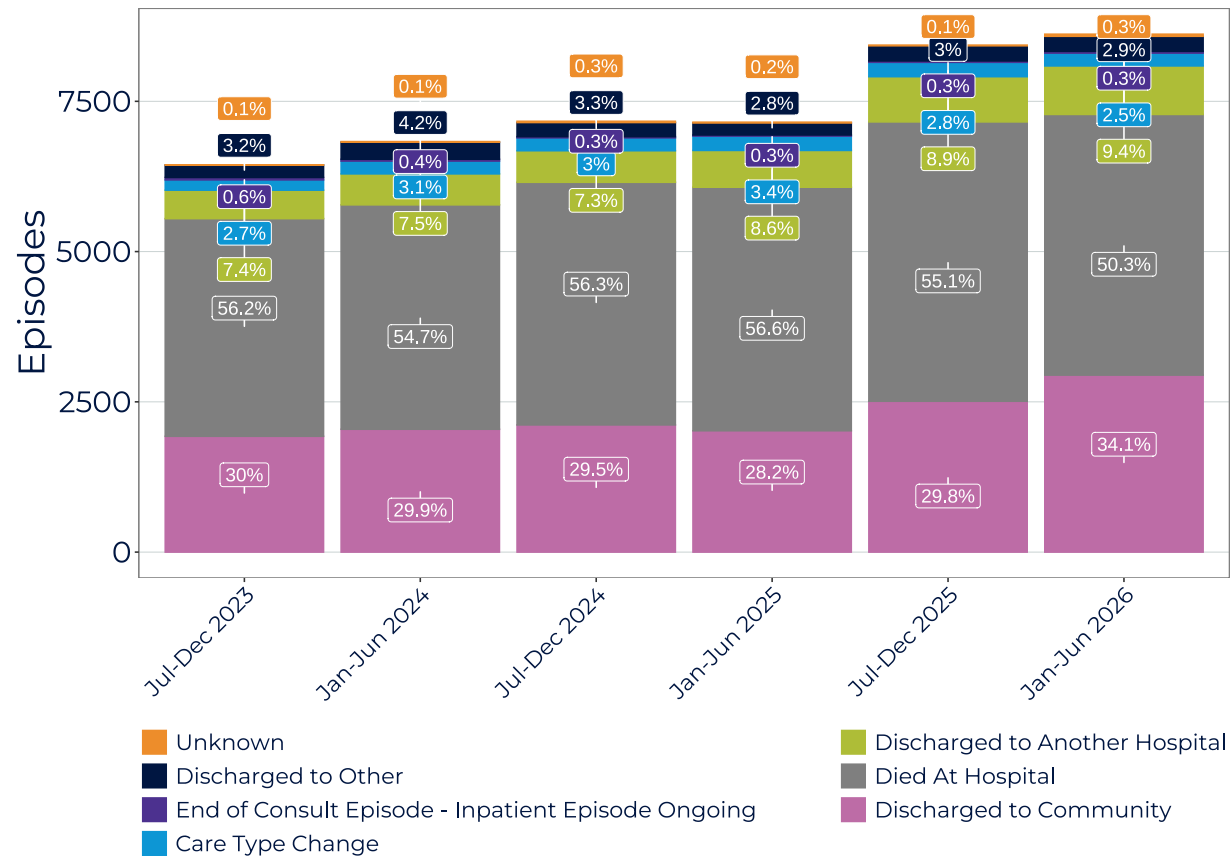
Table 28: How inpatient episodes end for NSW Services over time

Episode end mode (%)	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Discharged to community^a	29.9	29.7	29.6	28.1	29.7	34.1
Discharged to another hospital	7.4	7.6	7.3	8.4	9.0	9.3
Death	56.2	54.8	56.2	56.8	55.0	50.4
Change from palliative care to acute care^b	2.1	2.6	2.6	2.7	2.1	1.7
Change in sub-acute care type	0.6	0.5	0.5	0.7	0.7	0.8
End of consultative episode - inpatient episode ongoing	0.6	0.4	0.3	0.3	0.3	0.3
Other	3.2	4.1	3.3	2.8	3.0	3.0
Not stated/inadequately described	0.1	0.1	0.3	0.2	0.1	0.4
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

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

b. includes: change from palliative care to acute care - different ward, change from palliative care to acute care - same ward.



Inpatient setting

Figure 16: How episodes end for NSW Services over time - inpatient setting

Table 29: How non-admitted episodes start

Episode start mode	NSW Services		All Non-Admitted Services	
	N	%	N	%
Admitted from inpatient palliative care	721	22.9	6,048	31.0
Other^a	2,243	71.3	12,542	64.2
Not stated/inadequately described	183	5.8	941	4.8
Total	3,147	100.0	19,531	100.0

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

^a. includes: patient was not transferred from being an overnight patient.

Table 30: How non-admitted episodes end

Episode end mode	NSW Services		All Non-Admitted Services	
	N	%	N	%
Admitted for inpatient palliative care	991	27.1	5,945	26.3
Admitted for inpatient acute care	1,294	35.4	5,996	26.5
Admitted to another palliative care service	27	0.7	355	1.6
Admitted to primary health care	386	10.5	2,179	9.6
Discharged/case closure	64	1.7	1,698	7.5
Death	813	22.2	5,440	24.0
Other	58	1.6	206	0.9
Not stated/inadequately described	27	0.7	805	3.6
Total	3,660	100.0	22,624	100.0

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

Table 31: How non-admitted episodes start for NSW Services over time

Episode start mode (%)	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Admitted from inpatient palliative care	30.8	29.8	19.5	21.2	22.1	22.9
Other^a	67.2	68.6	78.9	75.7	73.3	71.3
Not stated/inadequately described	1.9	1.6	1.7	3.1	4.6	5.8
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

^a. includes: patient was not transferred from being an overnight admitted palliative care patient.

Table 32: How non-admitted episodes end for NSW Services over time

Episode end mode (%)	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Admitted for inpatient palliative care	22.2	23.6	25.7	24.5	24.8	27.1
Admitted for inpatient acute care	38.4	35.8	34.8	35.2	38.6	35.4
Admitted to another palliative care service	3.3	0.9	0.9	0.9	1.0	0.7
Admitted to primary health care	7.7	7.2	8.8	11.8	10.3	10.5
Discharged/case closure	4.1	7.7	1.5	1.6	1.6	1.7
Death	22.8	23.1	25.8	23.4	22.0	22.2
Other	1.3	1.5	1.8	2.5	1.5	1.6
Not stated/inadequately described	0.2	0.2	0.7	0.2	0.2	0.7
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

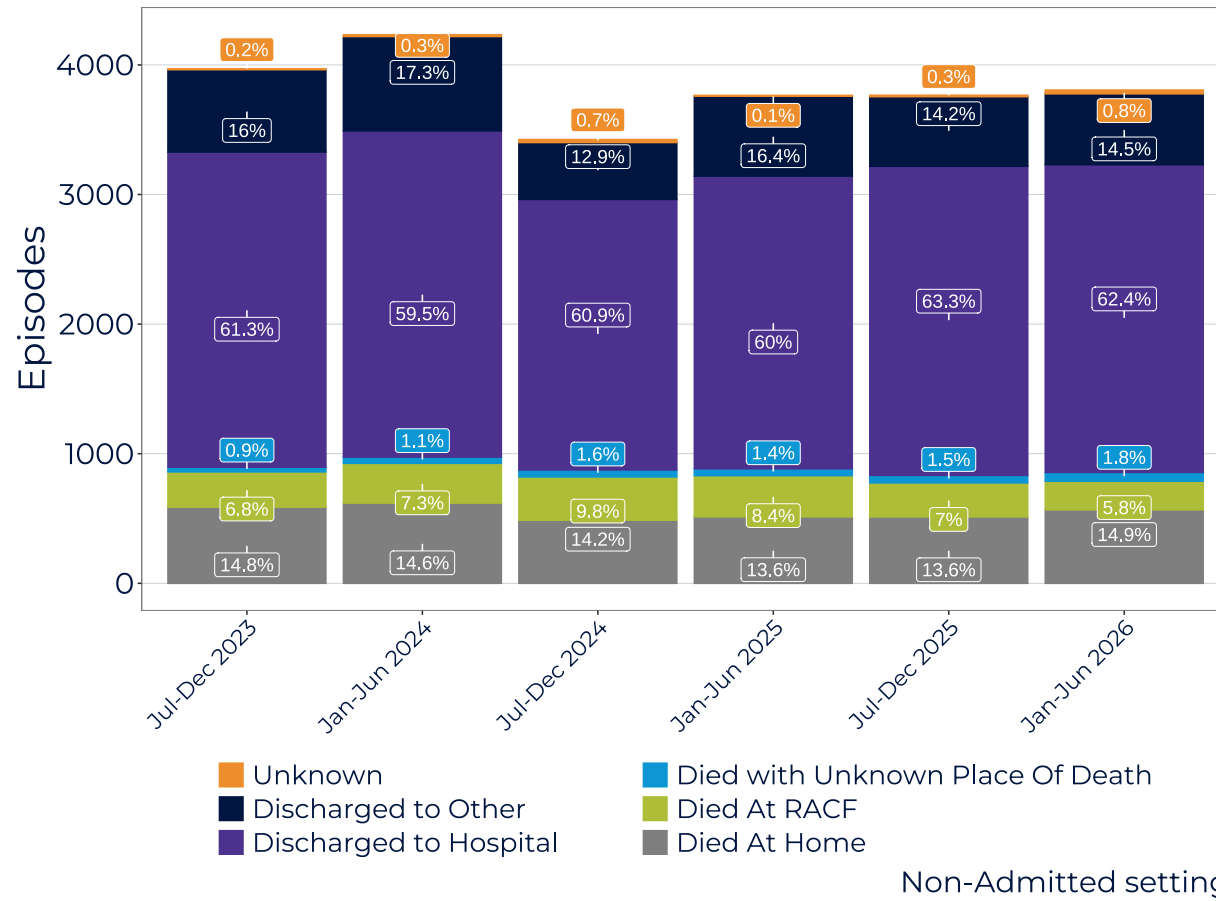


Figure 17: How episodes end for NSW Services over time - non-admitted setting

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 a patient's trajectory at specific points in time along their journey. These five assessment tools are completed daily for inpatient services, and at each contact for non-admitted 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 (difficulty sleeping, 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. Domains are scored separately and a total score between 4 and 18 is calculated.
- 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 non-admitted settings, and are reported on admission to the service, at phase changes and at discharge from the service.

Table 33: Number of patient phases by phase type and setting of care

Phase type	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Stable	6,237	29.5	13,669	25.5	4,747	44.5	22,038	40.1
Unstable	3,536	16.7	6,561	12.2	1,013	9.5	4,323	7.9
Deteriorating	7,545	35.7	21,137	39.4	4,331	40.6	24,566	44.6
Terminal	3,808	18.0	12,321	22.9	571	5.4	4,097	7.4
Total	21,126	100.0	53,688	100.0	10,662	100.0	55,024	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 34: Average phase length (in days) by phase type and setting of care

Phase type	Inpatient		Non-Admitted	
	NSW Services	All Services	NSW Services	All Services
Stable	6.1	6.1	23.9	22.9
Unstable	2.4	2.2	4.7	3.7
Deteriorating	4.2	4.6	13.1	14.9
Terminal	1.9	2.0	2.4	2.7

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

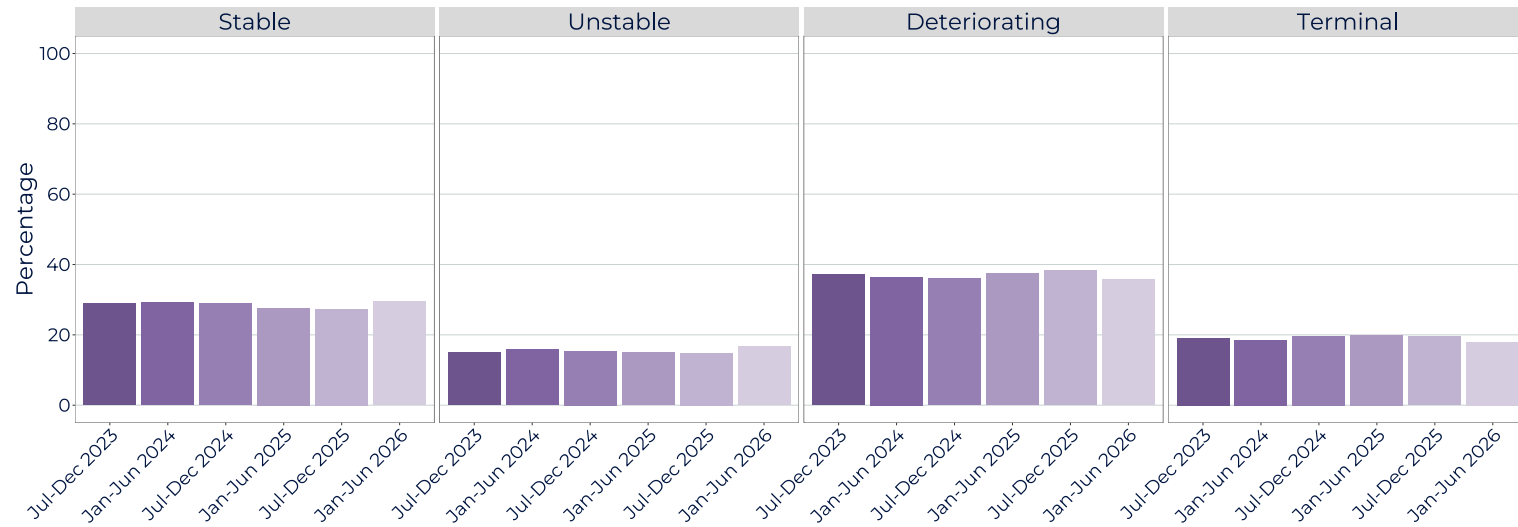


Figure 18: Patient phase profile over time - inpatient setting

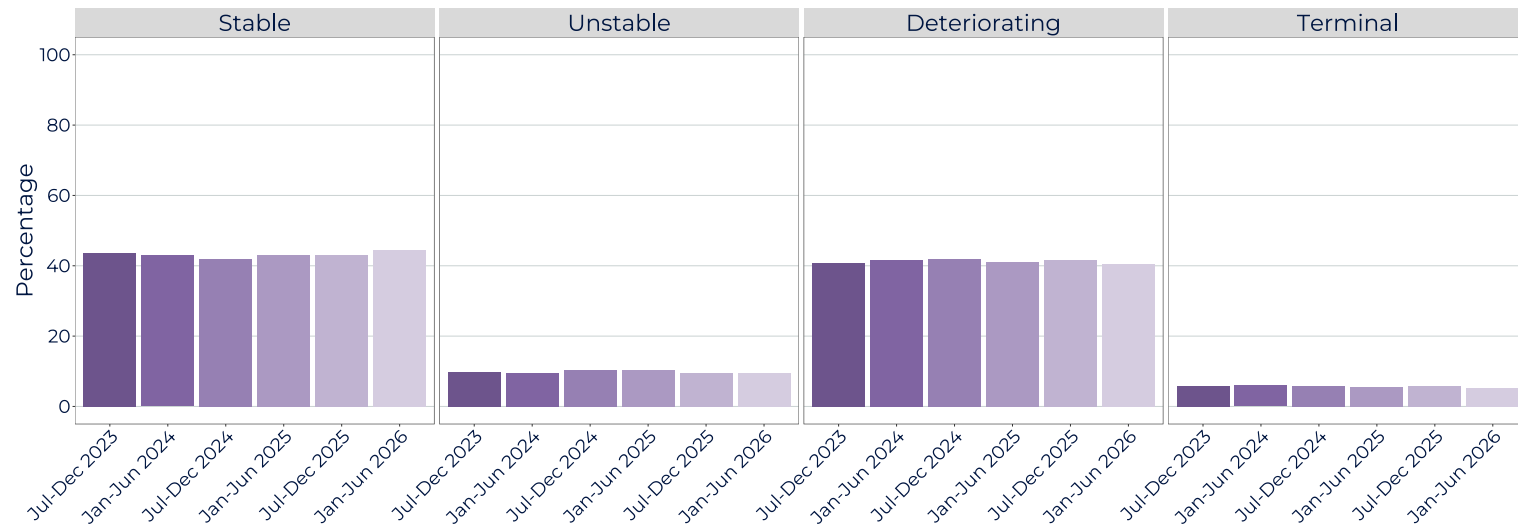


Figure 19: Patient phase profile over time - non-admitted setting

Table 35 presents the patients' first phase type for the episode, both for NSW Services and nationally. The first phase of the episode allows you to understand the type of patient, complexity and urgency of patient/family needs.

Table 35: First phase of episode by setting

Phase type	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Stable	1,763	20.8	4,220	17.3	1,562	49.7	7,441	38.1
Unstable	1,933	22.8	3,793	15.5	207	6.6	881	4.5
Deteriorating	3,769	44.4	12,456	50.9	1,293	41.1	10,330	52.9
Terminal	1,029	12.1	3,991	16.3	83	2.6	876	4.5
Total	8,494	100.0	24,460	100.0	3,145	100.0	19,528	100.0

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

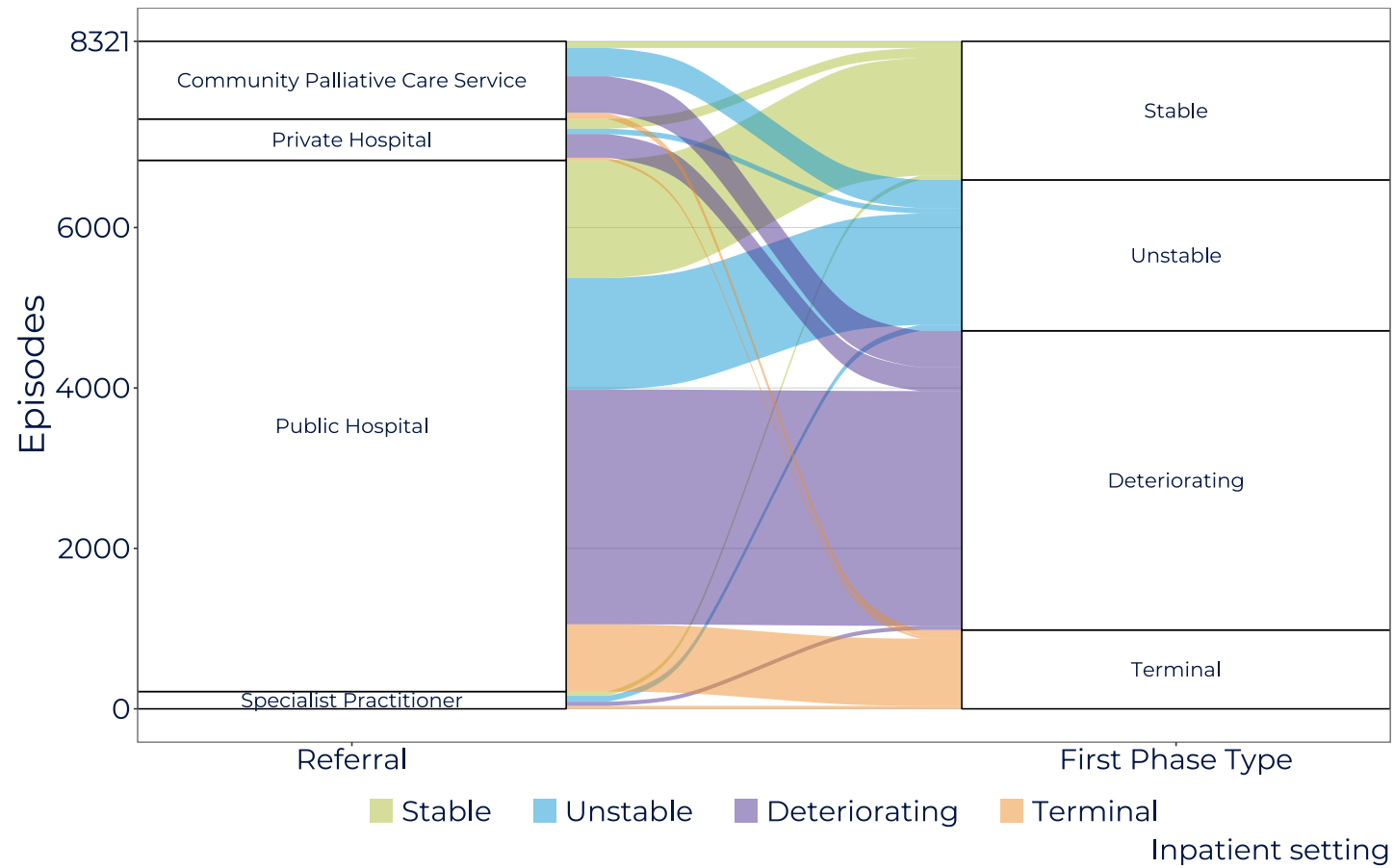


Figure 20: Alluvial plots showing referral source by first phase type – Inpatient setting

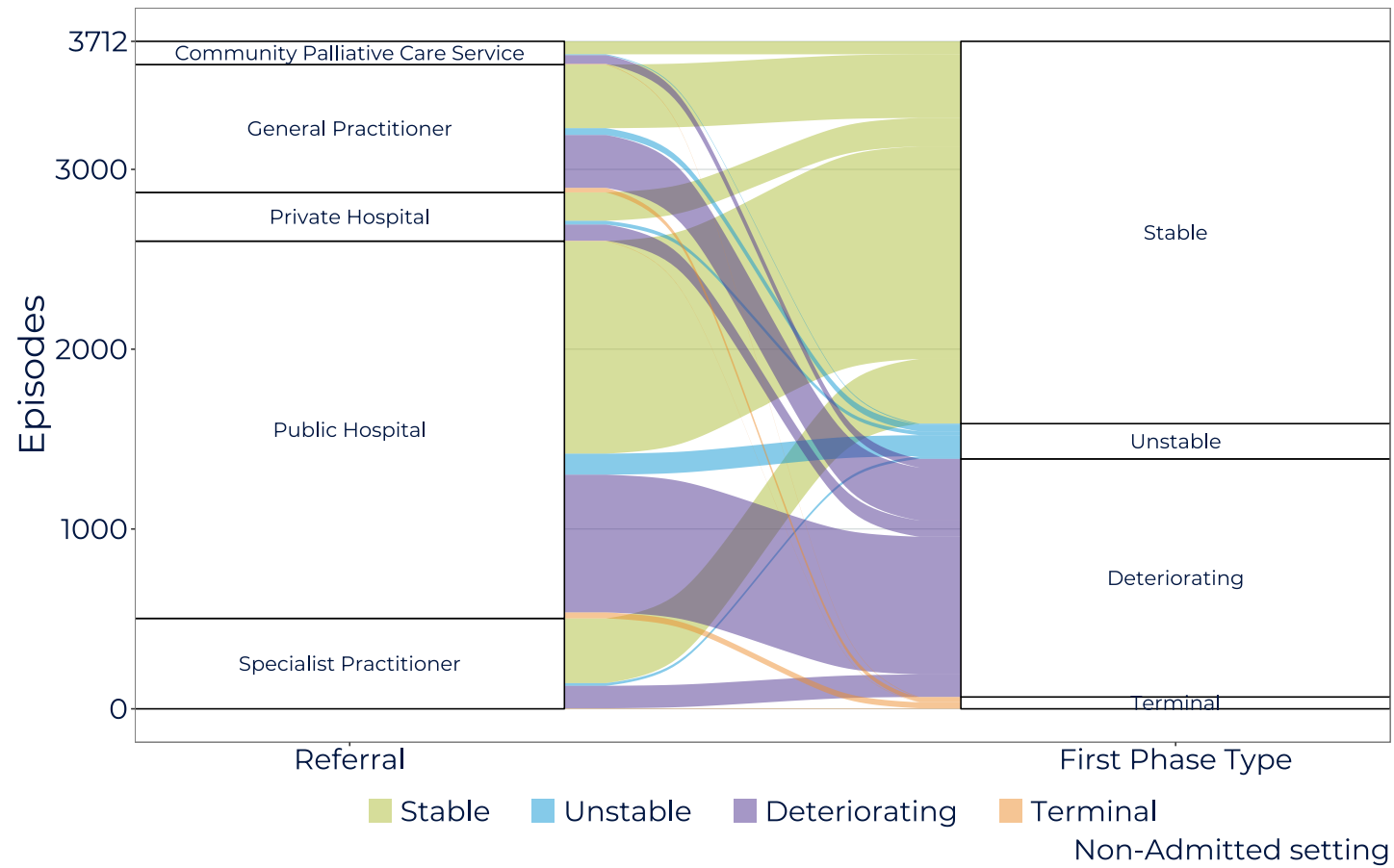


Figure 21: Alluvial plots showing referral source by first phase type – Non-Admitted setting

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 36 shows the percentage of phases that were rated absent, mild, moderate and severe at phase start for each key domain for NSW inpatient setting of care compared to all participating PCOC inpatient services. Table 37 shows the same for NSW non-admitted setting of care compared to all participating PCOC non-admitted services. Alternative graphical representations of PCPSS profile by phase type are shown in Appendix C.

Table 36: PCPSS at phase start by phase type - inpatient setting

Phase type	Problem	NSW Services (%)				All Services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	55.3	38.9	5.5	0.3	53.8	39.5	6.3	0.4
	Other symptoms	44.9	48.0	6.9	0.2	45.8	47.5	6.5	0.2
	Family/carer	68.2	28.1	3.5	0.2	63.8	32.4	3.5	0.3
	Psychological/spiritual	70.7	25.2	3.8	0.2	67.0	28.7	4.0	0.2
Unstable	Pain	32.2	36.6	25.8	5.4	28.5	35.3	28.5	7.7
	Other symptoms	21.7	45.5	28.1	4.7	22.9	42.0	29.5	5.5
	Family/carer	46.4	36.2	15.4	2.0	42.8	38.2	16.8	2.2
	Psychological/spiritual	53.5	30.1	13.9	2.5	49.2	33.8	14.5	2.4
Deteriorating	Pain	43.2	38.5	17.3	1.0	38.8	41.9	17.9	1.4
	Other symptoms	29.8	46.0	22.9	1.3	29.5	48.1	21.1	1.3
	Family/carer	54.0	35.6	9.6	0.7	48.2	41.0	10.1	0.7
	Psychological/spiritual	52.0	34.3	12.7	1.1	47.2	39.7	12.2	0.9
Terminal	Pain	55.2	33.7	10.0	1.1	45.3	39.8	13.3	1.6
	Other symptoms	46.2	37.1	14.7	1.9	41.8	40.3	16.0	1.9
	Family/carer	74.2	19.8	5.1	0.9	66.9	26.3	6.0	0.8
	Psychological/spiritual	43.3	37.0	17.7	2.0	38.3	43.8	16.0	2.0

Table 37: PCPSS at phase start by phase type - non-admitted setting

Phase type	Problem	NSW Services (%)				All Services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	49.4	45.8	4.6	0.2	44.8	50.3	4.8	0.1
	Other symptoms	25.3	66.0	8.6	0.1	26.4	66.6	6.8	0.1
	Family/carer	58.6	37.6	3.7	0.1	50.3	45.3	4.3	0.1
	Psychological/spiritual	57.2	37.1	5.2	0.4	47.7	46.1	5.8	0.3
Unstable	Pain	20.6	26.3	34.8	18.3	17.4	29.4	36.0	17.1
	Other symptoms	9.9	25.3	46.4	18.4	7.7	26.9	48.8	16.5
	Family/carer	29.3	37.9	27.8	5.0	21.9	41.2	32.1	4.8
	Psychological/spiritual	30.1	34.0	29.3	6.6	20.3	34.7	37.1	7.8
Deteriorating	Pain	32.2	41.3	25.6	0.8	29.1	47.9	21.8	1.1
	Other symptoms	10.1	44.0	44.4	1.4	11.0	52.2	35.7	1.2
	Family/carer	39.9	44.2	15.3	0.7	29.8	54.7	15.1	0.5
	Psychological/spiritual	33.3	43.6	21.8	1.4	25.7	51.3	21.9	1.0
Terminal	Pain	40.4	37.9	19.9	1.8	34.7	44.5	18.9	2.0
	Other symptoms	36.1	36.1	25.0	2.7	27.6	43.4	26.1	3.0
	Family/carer	65.5	23.3	10.4	0.7	52.3	35.3	11.3	1.1
	Psychological/spiritual	25.4	42.1	30.0	2.5	19.1	46.4	31.5	3.0

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 38 and Table 39 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 38: Symptom distress at phase start by phase type - inpatient setting

Phase type	Symptom	NSW Services (%)				All Services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Difficulty sleeping	82.9	14.1	2.8	0.2	82.4	14.8	2.6	0.2
	Appetite problems	78.7	18.7	2.4	0.2	78.7	18.6	2.4	0.3
	Nausea	86.0	12.2	1.7	0.0	86.9	11.4	1.6	0.1
	Bowel problems	76.5	19.9	3.5	0.1	75.8	20.5	3.4	0.3
	Breathing problems	77.3	19.3	3.3	0.1	77.1	19.3	3.3	0.3
	Fatigue	56.4	37.1	6.1	0.3	55.3	37.6	6.5	0.5
	Pain	53.6	38.6	7.4	0.4	53.9	38.0	7.4	0.6
Unstable	Difficulty sleeping	72.1	18.5	8.3	1.0	67.4	21.5	9.5	1.5
	Appetite problems	63.1	27.9	8.0	1.0	61.2	28.6	9.2	1.1
	Nausea	72.6	16.8	9.0	1.6	71.1	17.6	9.3	1.9
	Bowel problems	61.6	25.9	11.6	0.9	61.3	26.1	11.2	1.4
	Breathing problems	63.7	22.1	11.8	2.4	64.7	21.7	11.1	2.4
	Fatigue	39.7	38.3	19.8	2.2	36.4	39.9	21.5	2.3
	Pain	31.4	34.6	27.9	6.1	28.4	34.9	28.6	8.1
Deteriorating	Difficulty sleeping	77.8	16.6	5.2	0.3	75.8	18.2	5.5	0.5
	Appetite problems	71.7	23.1	4.7	0.5	69.9	24.1	5.4	0.6
	Nausea	79.9	14.8	4.9	0.4	78.7	15.6	5.1	0.6
	Bowel problems	72.6	21.3	5.7	0.3	69.9	23.1	6.4	0.6
	Breathing problems	66.0	22.9	10.4	0.7	65.2	23.7	10.2	0.9
	Fatigue	44.6	38.3	15.8	1.3	42.3	39.9	16.3	1.4
	Pain	41.9	38.8	18.1	1.2	38.8	40.4	19.2	1.6
Terminal	Difficulty sleeping	92.7	5.2	1.7	0.4	91.0	6.6	2.1	0.3
	Appetite problems	94.1	4.4	0.9	0.5	92.7	5.2	1.2	0.9
	Nausea	93.9	4.3	1.6	0.3	93.3	5.0	1.5	0.2
	Bowel problems	91.4	6.8	1.6	0.2	89.0	8.8	2.0	0.2
	Breathing problems	65.2	23.4	9.9	1.5	66.1	23.1	9.5	1.4
	Fatigue	78.4	15.7	5.3	0.6	74.9	17.3	6.5	1.4
	Pain	54.1	33.9	10.8	1.1	47.8	37.1	13.7	1.4

Table 39: Symptom distress at phase start by phase type - non-admitted setting

Phase type	Symptom	NSW Services (%)				All Services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Difficulty sleeping	66.9	29.1	3.8	0.2	72.8	23.8	3.3	0.2
	Appetite problems	60.9	36.1	2.8	0.2	62.0	34.5	3.3	0.2
	Nausea	81.8	16.7	1.5	0.0	83.7	15.1	1.2	0.1
	Bowel problems	67.2	29.4	3.2	0.2	72.1	24.7	2.9	0.2
	Breathing problems	60.6	33.6	5.5	0.3	61.6	32.6	5.5	0.2
	Fatigue	30.4	57.9	11.1	0.5	29.8	56.5	13.1	0.6
	Pain	46.0	47.0	6.7	0.3	44.9	48.2	6.6	0.3
Unstable	Difficulty sleeping	45.4	29.3	21.0	4.3	49.1	27.9	19.7	3.4
	Appetite problems	49.6	33.0	15.7	1.7	41.1	35.6	21.2	2.1
	Nausea	61.9	17.4	14.6	6.0	59.5	20.3	15.7	4.5
	Bowel problems	52.9	22.0	17.7	7.4	51.1	25.9	18.1	5.0
	Breathing problems	52.2	22.8	17.7	7.3	48.1	27.6	18.7	5.7
	Fatigue	26.5	34.6	31.1	7.8	18.7	35.2	39.1	7.1
	Pain	20.9	22.8	35.8	20.5	17.4	26.2	38.5	17.9
Deteriorating	Difficulty sleeping	54.9	33.2	11.3	0.7	64.3	27.4	7.8	0.5
	Appetite problems	48.5	41.2	9.9	0.5	47.2	42.1	10.2	0.5
	Nausea	71.1	21.0	7.3	0.6	72.9	21.2	5.6	0.4
	Bowel problems	56.1	31.8	11.4	0.7	61.5	29.4	8.6	0.6
	Breathing problems	50.7	31.4	16.7	1.2	53.5	32.8	13.0	0.8
	Fatigue	22.1	43.3	32.0	2.6	19.6	48.5	29.9	2.0
	Pain	31.3	38.9	27.7	2.1	30.4	45.1	22.9	1.6
Terminal	Difficulty sleeping	75.5	17.2	6.4	0.9	84.3	11.4	3.8	0.5
	Appetite problems	88.6	9.1	1.1	1.3	83.6	10.0	5.0	1.3
	Nausea	83.8	10.7	4.9	0.5	85.7	10.0	3.8	0.5
	Bowel problems	77.2	17.9	3.8	1.1	78.2	16.6	4.6	0.6
	Breathing problems	61.2	27.2	10.1	1.4	62.9	25.3	10.1	1.7
	Fatigue	72.6	15.0	9.9	2.6	64.3	16.8	15.4	3.5
	Pain	39.4	37.8	20.6	2.2	37.8	40.3	19.9	2.0

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 non-admitted patients. The items are reported at admission to the service, when the phase changes and at discharge.

Table 40 summarises the RUG-ADL items at phase start for inpatient and non-admitted patients.

Table 40: The Resource Utilisation Groups - Activities of Daily Living (RUG-ADL) at phase start by setting of care

Item	RUG-ADL assessment at phase start	Inpatient				Non-Admitted			
		NSW Services		All Services		NSW Services		All Services	
		N	%	N	%	N	%	N	%
Bed mobility	Independent or supervision only (1)	5,401	25.7	14,550	28.0	6,526	61.5	31,671	60.7
	Limited physical assistance (3)	3,503	16.7	7,500	14.5	1,444	13.6	6,227	11.9
	Other than two person physical assist (4)	2,694	12.8	5,888	11.4	928	8.8	4,297	8.2
	Two or more person physical assist (5)	9,417	44.8	23,936	46.1	1,707	16.1	9,947	19.1
Toileting	Independent or supervision only (1)	3,815	18.2	9,624	18.6	5,652	53.3	26,464	50.7
	Limited physical assistance (3)	4,031	19.2	9,211	17.8	1,946	18.3	8,946	17.1
	Other than two person physical assist (4)	3,220	15.3	7,669	14.8	1,175	11.1	6,012	11.5
	Two or more person physical assist (5)	9,949	47.3	25,362	48.9	1,832	17.3	10,786	20.7
Transfers	Independent or supervision only (1)	3,739	17.8	9,427	18.2	5,449	51.7	25,567	49.1
	Limited physical assistance (3)	4,016	19.1	9,098	17.5	2,061	19.6	9,549	18.4
	Other than two person physical assist (4)	3,148	15.0	7,379	14.2	1,122	10.7	5,919	11.4
	Two or more person physical assist (5)	10,111	48.1	25,951	50.0	1,898	18.0	10,995	21.1
Eating	Independent or supervision only (1)	8,337	39.8	21,450	41.5	7,153	67.5	34,132	66.1
	Limited physical assistance (2)	4,959	23.7	10,366	20.1	1,802	17.0	8,644	16.7
	Extensive assistance/total dependence/tube fed (3)	7,657	36.5	19,855	38.4	1,649	15.6	8,858	17.2



Figure 22: Distribution of patient's 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 41 shows the performance status of patients using the AKPS at phase start.

Table 41: Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting of care

AKPS assessment at phase start	Inpatient				Non-Admitted			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Comatose or barely rousable (10)	2,301	10.9	6,701	12.5	267	2.5	1,921	3.5
Totally bedfast and requiring extensive nursing care (20)	5,334	25.2	14,168	26.4	1,047	9.8	5,986	10.9
Almost completely bedfast (30)	2,974	14.1	7,639	14.2	908	8.5	4,774	8.7
In bed more than 50% of the time (40)	4,621	21.9	10,221	19.0	2,055	19.3	10,002	18.2
Requires considerable assistance (50)	3,110	14.7	6,625	12.3	2,650	24.9	12,961	23.6
Requires occasional assistance (60)	1,502	7.1	3,943	7.3	2,485	23.3	10,920	19.8
Cares for self (70)	558	2.6	1,310	2.4	872	8.2	4,830	8.8
Normal activity with effort (80)	132	0.6	379	0.7	187	1.8	1,144	2.1
Able to carry on normal activity; minor signs or symptoms (90)	46	0.2	115	0.2	31	0.3	228	0.4
Normal; no complaints; no evidence of disease (100)	11	0.1	28	0.1	s	s	9	0.0
Not stated/inadequately described^a	537	2.5	2,559	4.8	159	1.5	2,249	4.1
Total	21,126	100.0	53,688	100.0	10,661	100.0	55,024	100.0

Note: ^a This may include a small number of phases with AKPS assessment at phase start being Normal activity with effort (80) that have been mapped to an invalid score.



Figure 23: Distribution of AKPS for patients at episode start

Appendices

A Summary of data included in this report

During the reporting period, data were provided for a total of 42,545 patients who between them had 52,790 episodes of care and 108,712 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 42 shows the number of patients, episodes and phases included in this report - both for NSW Services and all participating PCOC services nationally.

Table 42: Summary of patients, episodes and phases by setting

	Inpatient		Non-Admitted		Total	
	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services
Patients (N)	7,742	21,786	4,272	22,252	11,662	42,545
Episodes (N)	8,876	25,555	4,840	27,235	13,716	52,790
Phases^a (N)	21,126	53,688	10,662	55,024	31,788	108,712
Patients (%)	66.4	51.2	36.6	52.3	100.0	100.0
Episodes (%)	64.7	48.4	35.3	51.6	100.0	100.0
Phases^a (%)	66.5	49.4	33.5	50.6	100.0	100.0
Average number of phases per episode^b	2.3	2.1	2.1	1.9	2.3	2.0

^a. Bereavement phases are excluded from this count.

^b. 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 43 shows the number of completed episodes and phases by setting of care for each month in the current reporting period for NSW Services. This table allows NSW Services to identify any significant change in the number of episodes and phases during the reporting period.

Table 43: Number of completed episodes and phases by month and setting

Setting		Jan	Feb	Mar	Apr	May	Jun
Inpatient	Completed episodes (N)	1,365	1,377	1,446	1,343	1,516	1,404
	Completed phases (N)	3,461	3,551	3,809	3,397	3,755	3,153
Non-Admitted	Completed episodes (N)	624	610	680	538	627	581
	Completed phases (N)	1,723	1,790	2,026	1,614	1,775	1,734

Table 44 shows the number of patients, episodes and phases for NSW 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 44: Number of patients, episodes and phases by setting and reporting period

	Inpatient						Non-Admitted					
	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026	Jul-Dec 2023	Jan-Jun 2024	Jul-Dec 2024	Jan-Jun 2025	Jul-Dec 2025	Jan-Jun 2026
Patients ^a	5,747	6,247	6,443	6,420	7,577	7,742	4,194	4,234	3,575	4,005	4,026	4,272
Episodes	6,544	7,131	7,286	7,289	8,608	8,876	4,787	4,929	4,123	4,579	4,645	4,840
Phases ^b	16,885	17,976	18,615	18,402	21,077	21,126	11,955	12,366	9,647	10,023	10,263	10,662
Phases per episode ^c	2.5	2.4	2.5	2.5	2.4	2.3	2.5	2.4	2.1	2.1	2.1	2.1

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

^b. Bereavement phases are excluded from this count.

^c. 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 45, Table 46, Table 47 and Table 48 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 45: Item completion (%) - patient level

Data item	NSW Services	All Services
Date of birth	100.0	94.6
Sex	100.0	100.0
Country of birth	99.3	98.3
Preferred language	98.5	98.8
Diagnosis	99.8	97.0

Table 46: Item completion (%) - episode level, by setting of care

Data item	Inpatient		Non-Admitted		Total	
	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services
Date of first contact	97.2	98.6	99.8	98.7	98.1	98.6
Referral date	99.9	100.0	99.7	99.5	99.8	99.7
Referral source	98.4	98.9	100.0	99.2	99.0	99.0
Date ready for care	94.9	97.8	93.7	97.2	94.5	97.5
Mode of episode start	95.9	96.7	94.5	95.6	95.4	96.2
Accommodation at episode start	100.0	99.1	100.0	96.9	100.0	97.8
Episode end date^a	97.1	98.2	78.6	85.5	90.6	91.6
Mode of episode end	99.6	97.3	99.2	96.4	99.5	96.9
Accommodation at episode end	98.1	98.2	99.6	97.7	98.3	98.0
Place of death	100.0	100.0	92.1	90.6	98.7	97.2

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

Table 47: Item completion (%) - phase level, by setting of care

Data item	Sub-Category (where applicable)	At phase start						At discharge					
		Inpatient		Non-Admitted		Total		Inpatient		Non-Admitted		Total	
		NSW	All Services	NSW	All Services	NSW	All Services	NSW	All Services	NSW	All Services	NSW	All Services
RUG-ADL	Bed mobility	99.5	96.6	99.5	94.8	99.5	95.7	55.6	61.9	25.1	47.7	43.0	53.4
	Toileting	99.5	96.6	99.5	94.9	99.5	95.7	58.3	62.8	25.1	47.9	44.6	54.0
	Transfers	99.5	96.6	98.8	94.6	99.2	95.6	55.6	61.8	25.1	47.7	43.0	53.5
	Eating	99.2	96.2	99.5	93.8	99.3	95.0	55.5	61.7	25.1	47.3	43.0	53.2
PCPSS	Pain	96.1	95.6	97.7	95.5	96.6	95.5	54.2	64.0	24.7	48.3	42.0	54.7
	Other symptoms	96.1	93.1	97.8	93.1	96.6	93.1	54.2	62.3	24.7	45.2	42.0	52.2
	Psychological/spiritual	95.9	95.0	97.5	94.0	96.5	94.5	54.1	63.3	24.6	47.5	41.9	53.9
	Family/carer	95.7	90.2	96.8	88.9	96.1	89.6	53.9	56.1	24.3	40.9	41.7	47.1
SAS	Difficulty sleeping	89.9	85.3	97.5	91.9	92.5	88.6	49.5	51.4	22.8	45.6	38.4	47.9
	Appetite problems	89.9	85.3	97.7	93.2	92.5	89.3	49.3	51.4	22.9	46.2	38.4	48.4
	Nausea	90.0	85.5	97.7	93.8	92.6	89.7	49.5	51.5	23.0	46.7	38.5	48.7
	Bowel problems	89.9	85.4	97.7	93.1	92.6	89.3	49.3	51.4	22.9	46.2	38.4	48.3
	Breathing problems	90.0	85.8	97.7	93.6	92.6	89.7	49.5	51.6	23.2	46.8	38.6	48.7
	Fatigue	89.8	85.4	97.7	94.0	92.5	89.8	49.3	51.5	23.0	47.0	38.5	48.9
	Pain	90.0	86.8	98.0	95.9	92.7	91.4	49.5	51.5	23.5	48.3	38.7	49.6
AKPS	-	97.5	95.2	98.5	95.9	97.8	95.6	54.7	61.1	28.1	49.1	43.7	54.0

Table 48: Item completion (%) - phase end, by setting of care

Data item	Inpatient		Non-Admitted		Total	
	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services
Phase End Reason	98.7	99.0	99.2	98.2	98.9	98.6

C Profile of patient symptoms and problems

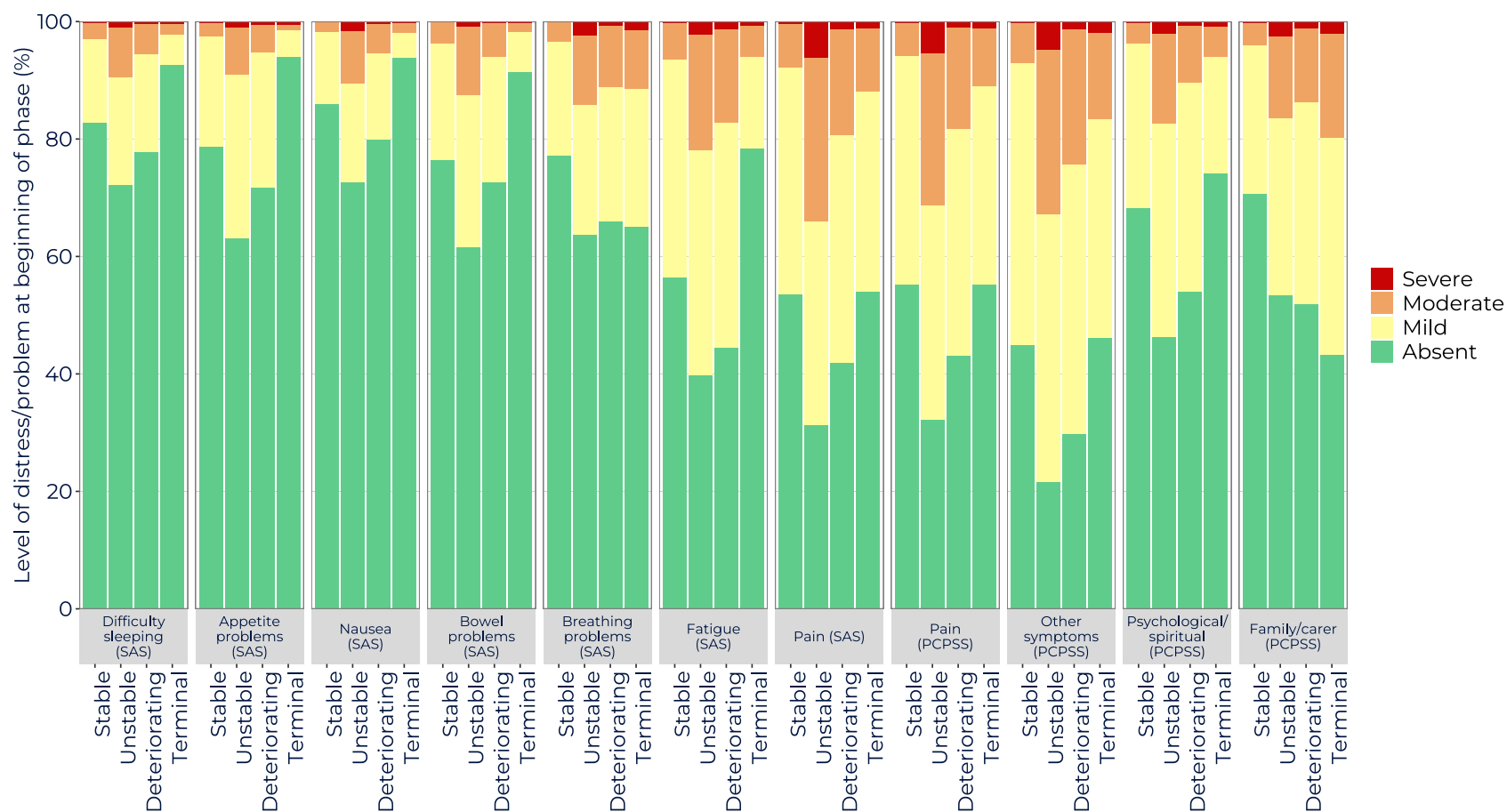


Figure 24: Profile of symptoms and problems by phase type for NSW Services- inpatient setting

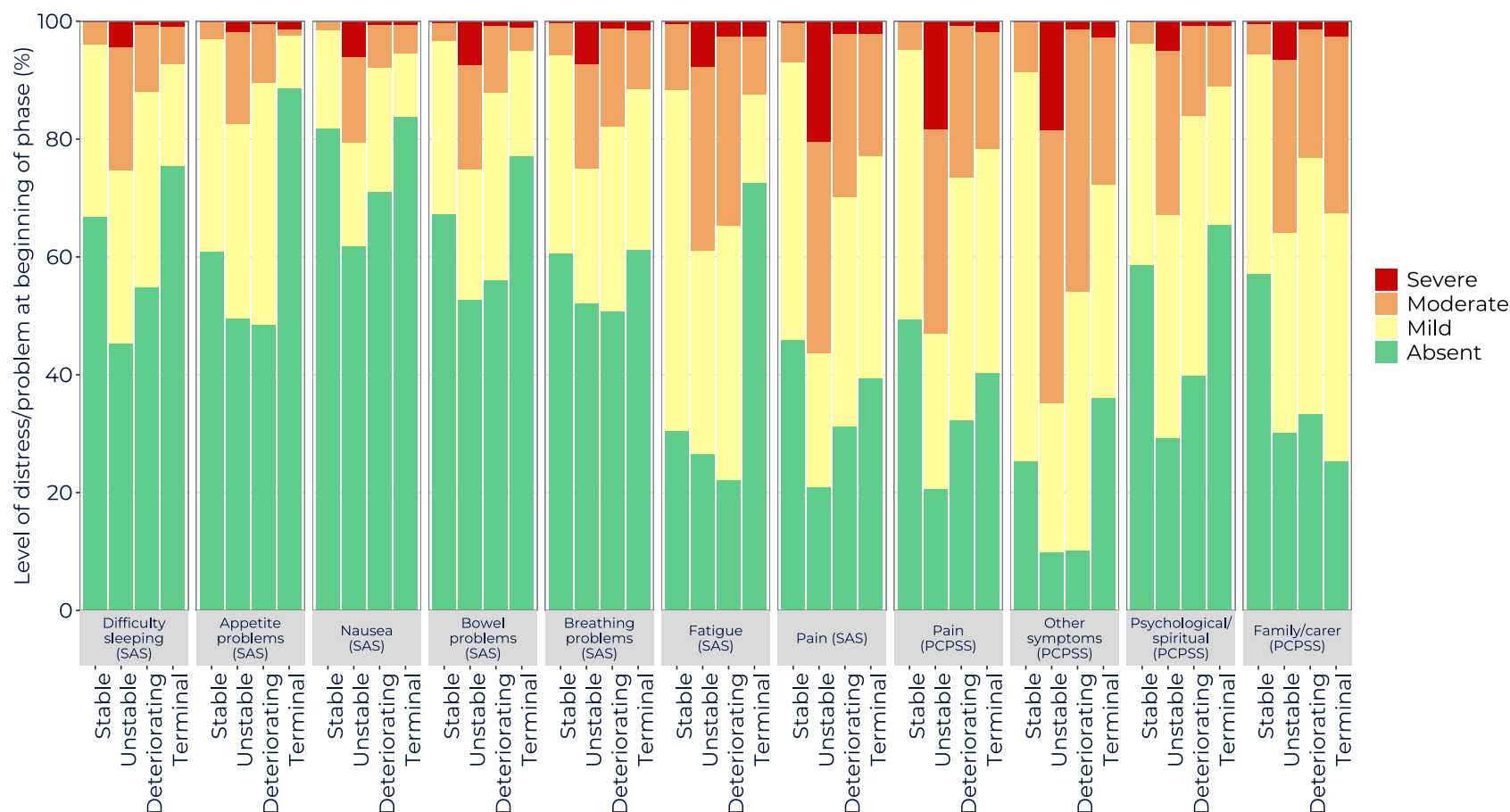


Figure 25: Profile of symptoms and problems by phase type for NSW Services- non-admitted setting

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 end 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 26 below displays four examples to help visualise this process.

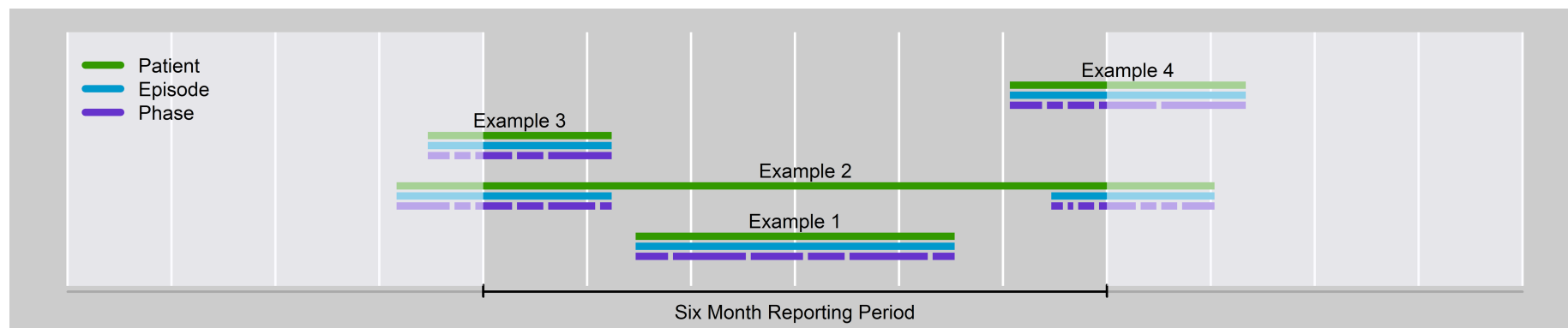


Figure 26: Diagram of the PCOC data scoping method

In Example 1, 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.

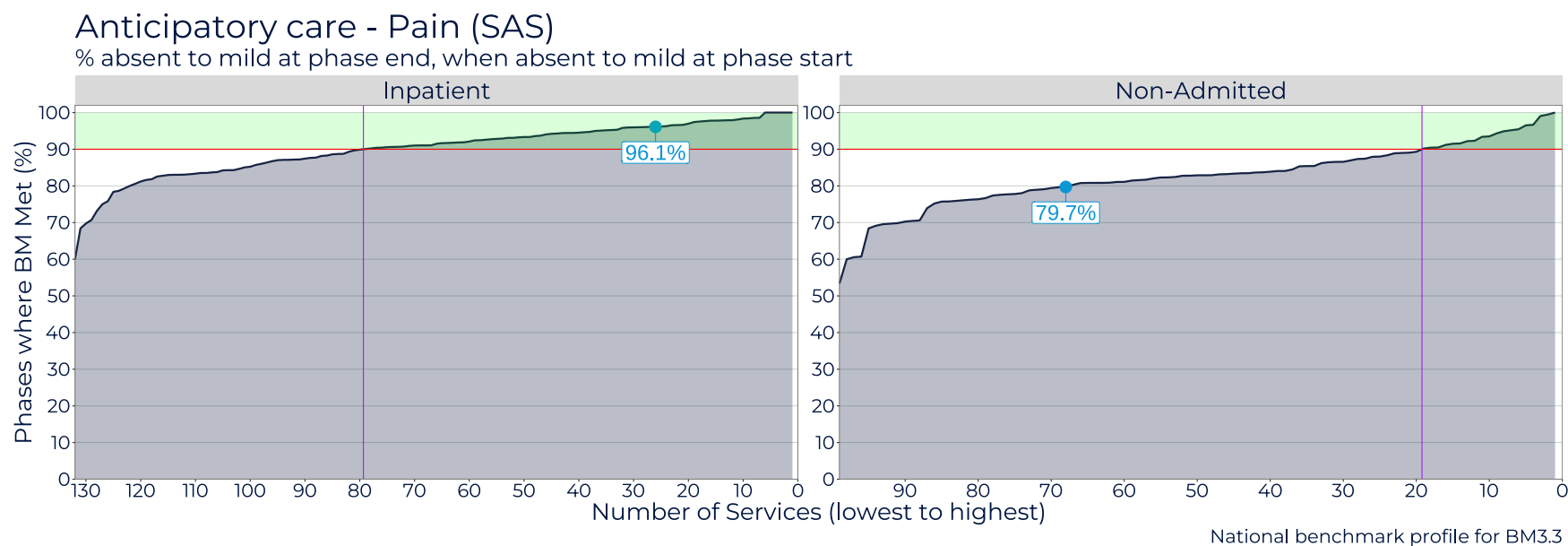
In Example 2, the patient has two episodes – the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in 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 Example 3, 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 Example 4, 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.

E Interpreting benchmark profile graphs

The figures used in this interpretation guide are only examples and do not show any real data. The national profile graphs present your service in comparison to all other palliative care services participating in PCOC. In each graph, the gray shaded region describes the national profile for that outcome measure.



- Inpatient NSW Services are represented by blue dots on the left figure.
- Non-admitted NSW Services are represented by blue dots on the right figure.
- The red line indicates the benchmark for this outcome measure.
- The gray region indicates the national profile. This contains all services across the country that have contributed to this benchmark ordered from the lowest percentage of phases meeting the BM to the highest percentage. The lowest percentage is on the left side of the graph and the highest percentage is on the right side of the graph.
- The green region contains the services that met this benchmark.
- The purple line indicates the number of services that met the benchmark.

F 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 • 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).

G Quality Improvement Guide

This guide is designed to help services and organisations identify opportunities for quality improvement within their Outcome Reports. It is intended for use alongside the PCOC Quality Improvement Guide for Services and is particularly useful for clinicians and managers responsible for applying PCOC data to drive improvement efforts.

When reviewing your report with your team, keep in mind that PCOC Benchmarks are aspirational and that meaningful quality improvement is a gradual process. This guide includes a step-by-step checklist to support teams in interpreting outcome data and pinpointing areas for targeted QI activities.

Instructions for use	
Gather relevant team members to complete this checklist. It is recommended that one to two QI activities are selected for each reporting period (bi-annual). Refer to the list of useful resources within this guide and the key reflection questions to help guide the review.	
Table / Figure	Process check ☐ QI activity ☐
Table 2 Summary of outcome measures by setting of care.	☐ How do your results compare against the state and national outcomes and benchmarks? How do you account for the difference? ☐ Have your areas identified for improvement from previous reports resulted in better outcomes this report? ☐ Consider which symptoms or problem area benchmarks continue to be a challenge for your service, given your patient cohort and referral source(s), as you read your report. This may inform which service processes might be changed, to improve patient outcomes.
Table 3 Figure 1 Time from date patient is ready for care to episode start by setting of care.	☐ If you meet this BM at 100%, do you think it is accurate that your service does a comprehensive PCOC assessment on all patients within 48 hours of the patient being ready and available to receive care? A patient is ready for care, when they can accept an offer of care from the service. For example, for inpatient services, if a patient would accept an offer of a bed today, they are ready for care today. ☐ If the patient is not available for assessment, does your service have a process for recognising the date a patient is ready for care has changed? ☐ If you do not meet the benchmark, consider addressing barriers, implementing, or reviewing triage processes. ☐ If you do not think it is accurate, review the definitions of date ready for care and how this information is recorded. ☐ If you do not meet this benchmark, consider how your IT system supports the recording of assessments and if improvements are required.

Table 4 Figure 2 Time in unstable Phase.	☐ Are patients moved out of the unstable phase, with unresolved moderate or severe symptoms? This could be indicated by meeting Benchmark 2 Responsiveness of care but not meeting some of the individual responsiveness Benchmarks for responsiveness of care. ☐ Are patients in an unstable phase reviewed daily? What is your procedure for managing patients in unstable phase? Is it followed? Consider a case review using your supplementary data. ☐ Do you think your team is assessing and changing phase correctly? ▷ If you do not meet the benchmark, consider implementing priority patient review process for review triage, case discussions and handover, based on patients in unstable phase. You may also consider a file audit. ▷ If there has been a significant increase in benchmark performance, consider if this is due to an improvement in performance e.g. responding more quickly to severe symptoms, or due to a process change.
Table 5 Anticipatory Care Benchmark.	☐ Does your service have processes to prevent problems escalating for common symptoms associated with the primary diagnosis? ☐ Does your service have anticipatory prescribing processes? ☐ Does the review of patients include carer education and planning for the preferred place of care and death? ☐ If a patient does not have a carer, what is the process to ensure they can report / escalate issues? How are patients without a carer flagged in your processes? ▷ If you do not meet the benchmark, consider implementing an anticipatory care process for patients in the deteriorating and terminal phase, to actively prevent scores escalating. ▷ Introduce a patient without a carer flagging process, to ensure their escalation of care needs are identified.
Table 6 Responsive Care Benchmark.	☐ What is your process for responding to patients with moderate to severe scores? ☐ How well are patient needs responded to, according to the PCOC Assessment and Response protocol? For example, are phases being changed / ended, when patients still have moderate to severe scores? ☐ Do moderate and severe scores trigger referrals, intervention, or review? ▷ Consider a case review for patients with severe pain and family/carers issues, utilising the moderate to severe symptoms tabs in the supplementary data spreadsheet. ▷ If you do not meet the benchmark, implement, or review your service escalation plan for patients with moderate and severe symptoms.
Tables 7, 8 Figures 13, 14 Casemix Adjusted Outcomes.	☐ Based on your performance in the last outcome report, what symptoms/problems are not improving? ☐ Are there any symptoms that are lower than the national average? Patients that do not meet these benchmarks have larger increases, or less improvement in the level of severity/distress than those in the reference period. ☐ Are there areas where you are consistently not meeting the benchmark e.g. bowel problems? Investigate why this might be. Is it a staff skills issue? ▷ Consider reviewing your symptom management processes. ▷ Consider undertaking a team learning needs assessment, to identify and address staff knowledge gaps. ▷ Consider reviewing supplementary data and auditing the care provided to several patients who did not meet the BM to determine whether the quality of the care provided could be improved.

Tables 11, 12 Indigenous Status.	☐ Consider what proportion of data is not stated / inadequately described. Why is this data not being asked / collected and recorded? Are your results representative of the population you provide care for? If not, why not? ☐ Review your outcomes dashboard. Compare your results with the state average. Could there be unmet need? ▷ Consider asking the question training and / or cultural awareness training for all staff. Also see Gwandalan National Palliative Care Project ▷ Consider whether intake processes or assessment forms/templates need to be revised to always include questions about whether patients identify as Aboriginal or Torres Strait Islanders. ▷ Consider working with local Aboriginal and/or Torres Strait Islander services/community members to improve referral pathways. ▷ Consider a community population mapping activity with your PHN and review access pathways.
Table 13 Country of birth.	☐ Are your results representative of the populations you provide care for? Are there barriers for diverse groups to access your service? ☐ What is your referral acceptance criteria? Are there unintended consequences for some populations? Who is missing out on care? ▷ Consider a non-admitted population mapping activity with your PHN, or other appropriate bodies, to review access pathways, acknowledging that the social determinants of health impact on population access to health services generally. ▷ Review Census data for the area that you serve to identify underserved populations.
Table 14 Preferred language.	☐ Country of birth is likely to inform preferred language. Consider whether this aligns with the data in Table 13. Are patients asked about their preferred language and provided with language specific resources? Do you provide SAS information in different SAS Translations ? ▷ Introduce a process when the identification of a preferred language (other than English) triggers the provision of resources in the preferred language, for the patient, carer, and family.
Tables 15, 16 Principal diagnosis – malignant, non-malignant.	☐ Are there specific diagnoses that account for more referrals than others? Why? Does your symptom prevalence align with common symptoms of your most prevalent malignant conditions? E.g. Lung cancer and breathlessness. If not, why not? ☐ Are there conditions that are under-represented? Consider expected causes of death in Australia. Who is missing out on accessing your care? ☐ Review 'other primary malignancy' and 'not further defined' rates. Does this account for a significant proportion of your results? What are these 'other' conditions and are they accurately recorded? ▷ Consider a file audit review for patients recorded as; other primary condition, not further defined. Undertake training to address knowledge gaps. Contact a PCOC Improvement Facilitator to request this bespoke data.
Table 20 Referral Source.	☐ Do your referral sources reflect your service model and setting of care? ☐ Which sources are under or overrepresented in your referral data? ☐ Refer to your Outcomes dashboard. Are there established trends between referral source and episode phase start? Can this help with service provision? ▷ Reach out to you PHN/ local palliative care consortia/Community of practice and explore a referral source collaboration QI activity. ▷ Meet with inpatient referral sources to improve referral pathway linkages, for inpatient / consult services. ▷ Consider what type of patient (e.g. phase type and / or diagnosis) come from each referral source.

Tables 22, 23, 24 Length of episode.	☐ Is the length of episode long enough, to allow you to create therapeutic relationships with patients? Are referrals timely? ☐ Has the episode length changed over time? If so, why? ▷ Review your 'deaths within three days of episode start' supplementary data to identify possible pathways for earlier referral. ▷ Consider how users of your service access your service, identify any barriers, and consider a QI activity to improve ease of access.
Figures 16, 17 How Episodes End.	☐ This displays how episodes end over time for your service. The vertical axis displays the number of episodes, and each column represents the proportion of episode end type, classified by color. "Discharge to Other" includes discharge home, discharge from a non-admitted service or discharge from a consult service (and remaining in hospital). The reason for this type of discharge is often due to the patient no longer requiring (or wanting) the level of specialist palliative care that the setting provides. "Unknown" includes the episode end modes 'not recorded' and 'other'. Open episodes have been omitted. ▷ What percentage of your non-admitted episodes are ending in 'Discharge to Inpatient' and inpatient episodes are ending in 'Discharge to Other'? ▷ Review your supplementary data to see if discharges are due to unmet need/ uncontrolled symptoms. Is there an opportunity for QI?
Table 33 Figures 18, 19 Phase type.	☐ This table represents the patient and/or family/carer needs of your service. How do the needs of your patients/ family/carers compare to all services nationally? ▷ If the data does not reflect your teams time spent on supporting these needs, check that phases are being assessed accurately according to definitions. Note that the unstable phase can be triggered by severe family / carer problems.
Table 34 Phase length.	☐ Consider the average length of each phase at your service compared to national figures. Is your phase length longer or shorter? If your phases are longer for unstable and deteriorating phase, this may indicate that care plans are taking longer to be effective in reducing symptoms/problems. Is the Assessment and Response protocol being followed? Is your team phasing correctly? ▷ Undertake a team skills and knowledge survey and address identified staff needs, for example, clinical skills development, phasing education or implementation of an escalation of care protocol. ▷ Reach out to your Improvement facilitator for additional support.
Table 35 First phase of episode by setting.	☐ This table represents needs at admission to your service. How do these needs compare against services nationally? Does this seem accurate? ☐ Does phase type at admission reflect your service model e.g. Unstable for consult services? ▷ Conduct a file review to understand whether these phases align with the severity of symptoms/problems on admission. Introduce a process or staff training, to address the discrepancy. ▷ Meet with inpatient referral settings of care to improve referral pathway linkages and awareness of your service admission criteria.
Figure 21 Alluvial plot of Referral Source by First Phase Type.	☐ The left-hand side shows the referral source with the height of the box representing the volume of referrals. Similarly on the right-hand side, the size of the boxes represents the proportion of first phases. The referral source is then linked to the first phase phase of an episode with coloured lines/bands representing phase type (see key below, and box on the right-hand side). ☐ Does phase type at admission by referral source reflect your service model? ▷ Is the percentage of phase at episode start expected? ▷ Should referral type be considered at intake/triage?

Table 36, 37 PCPSS at phase start by phase type.	☐ Does the severity of scores align with phases as per the PCOC Assessment and Response protocol? ☐ How does the severity of scores for your patients compare to those for all services? ▷ Conduct a file audit on patients with severe PCPSS scores and the corresponding phase recorded. Is your team phasing correctly? Consider whether the assessment and response protocol is followed, as documented in the patient notes. Address issues found in team assessments or processes.
Table 38, 39 Symptom distress at phase start by phase type.	☐ Does the level of symptom distress align with phases as per the PCOC Assessment and Response protocol? Is your team phasing correctly? ☐ How does the level of symptom distress of your patients compare to those for all services? ▷ Conduct a file audit on patients with severe SAS scores and phase. Assess whether the assessment and response protocol were followed, in the patient notes. Address issues found in team assessments or processes. For example, staff education around phasing and applying the Assessment and Response protocol.
Table 40 Figure 22 RUG - ADL.	☐ Do most of your patients have RUG ADL score of 10 or more at admission? Are your referrals timely, given your setting of care, model of care and service type? ▷ Consider the impact of proportion of patients with a RUG - ADL score of 10 or more on admission, considering resources required and type of care provided (e.g. equipment needs, staff requirements).
Table 41 Figure 23 AKPS at phase start by setting of care.	☐ Do most of your patients have AKPS scores below 50 at admission? Are your referrals timely, given your setting of care, model of care and service type? ▷ Consider the impact of proportion of patients with AKPS of less than 50 on admission on the resources required and type of care provided (e.g. symptom management vs. end-of-life care). ▷ Reach out to you PHN/local palliative care consortia/Community of practice and explore a timeliness of referral collaboration QI activity or engage in a project around the value of palliative care with referring teams / sources.
Tables 45, 46, 47, 48 Data item completion.	☐ Does your service type explain the missing data? ☐ Is your service using the suite of tools at point of care? ☐ Who in your team is responsible for entering data? Is this an IT system and / or administration process issue? ▷ Identify in your team processes, from referral receipt until discharge. What assessment and collection points are missed? ▷ Consider introducing a routine check for PCOC item completion. ▷ If there are IT system issues, work with your IT team to resolve the issues before the next submission.