

2012

Outcomes in Palliative Care, Report 12 (July - December 2011) - New South Wales

Samuel F. Allingham
University of Wollongong, samallin@uow.edu.au

Sonia Bird
University of Wollongong, marcolin@uow.edu.au

Follow this and additional works at: <https://ro.uow.edu.au/ahsri>

Recommended Citation

Allingham, Samuel F. and Bird, Sonia, "Outcomes in Palliative Care, Report 12 (July - December 2011) - New South Wales" (2012). *Australian Health Services Research Institute*. 156.
<https://ro.uow.edu.au/ahsri/156>

Research Online is the open access institutional repository for the University of Wollongong. For further information contact the UOW Library: research-pubs@uow.edu.au

Outcomes in Palliative Care, Report 12 (July - December 2011) - New South Wales

Abstract

Introduction PCOC aims to assist services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this, the twelfth PCOC report, data submitted for the July - December 2011 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

This report is broken into three sections:

Section 1 summarises each of the four major benchmark measures and subsets and presents national benchmarking results for these benchmarks

Section 2 presents additional analysis for each of the sixteen benchmarks

Section 3 provides descriptive analysis of the data items at each of the patient, episode and phase levels. In each of the three sections, data and analysis for NSW is presented alongside the national figures for comparative purposes.

The national figures reflect all palliative care services who submitted data for the July - December 2011 period. A full list of these services can be found at www.pcoc.org.au

Keywords

2011, december, wales, july, south, 12, report, care, palliative, outcomes

Publication Details

S. F. Allingham & S. Bird, Outcomes in Palliative Care, Report 12 (July - December 2011) - New South Wales (Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong, 2012).

Outcomes in Palliative Care

Report 12, July – December 2011



New South Wales

About the Palliative Care Outcomes Collaboration (PCOC)

PCOC is a unique national program that utilises standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in PCOC is voluntary and assists palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) *Standards for Providing Quality Palliative Care for all Australians*. PCOC is funded under the *National Palliative Care Program* and is supported by the Australian Government Department of Health and Ageing.

PCOC is a collaboration between four centres, each with a Chief Investigator, and is divided into four zones for the purpose of engaging with palliative care service providers. The four PCOC zones and their Chief Investigators are:



Central Zone		Professor Kathy Eagar , Australian Health Services Research Institute, University of Wollongong
North Zone		Professor Patsy Yates , Institute of Health and Biomedical Innovation, Queensland University of Technology
South Zone		Professor David Currow , Department of Palliative and Supportive Services, Flinders University
West Zone		Assistant Professor Claire Johnson , Cancer and Palliative Care Research and Evaluation Unit, University of WA

The National office is located within the Australian Health Services Research Institute at the University of Wollongong.

The items included in the PCOC dataset (Version 2) serve the dual purpose of:

- Defining a common clinical language to allow communication between palliative care providers
- Facilitating the routine collection of national palliative care data for the purpose of reporting and benchmarking to drive quality improvement

The dataset includes the clinical assessment tools: Phase Type of Care, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status Scale (AKPS) and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL). These are used to measure the quality and outcomes of palliative care. For more information on the PCOC clinical tools or data items please visit www.pcoc.org.au

Contents

Introduction.....	1
Section 1 – NSW at a Glance.....	2
Section 2 – Benchmark Analysis	13
Measure 1 – Time from referral to first contact	13
Measure 2 – Time in unstable phase.....	15
Measure 3 – Change in pain	17
Measure 4 – Change in symptoms relative to the baseline national average (X-CAS)	20
Section 3 - Descriptive analysis.....	23
Profile of palliative care patients.....	24
Profile of palliative care episodes.....	26
Profile of palliative care phases.....	29
Appendix A – Summary of data included in this report	39
A1 – Data Summary	39
A2 – Data Item Completion	40
A3 – Data scoping methodology.....	42
Appendix B – Benchmark Notes	43
B1 – Outline of Benchmark Measures and Targets.....	43
B2 – National profile graphs	44
B3 – X-CAS technical notes	44
Acknowledgements	45

List of Tables

Table 1 Summary of benchmark measures 1-3	2
Table 2 Summary of benchmark measure 4: Average improvement on the 2008 baseline national average (X-CAS)	2
Table 3 Time from referral to first contact by episode type	13
Table 4 Time in unstable phase by episode type and occurrence in episode	16
Table 5 Trends in Benchmark 3.1: Phases with absent or mild pain at start, which end with absent or mild pain (PCPSS)	17
Table 6 Trends in Benchmark 3.2: Phases with moderate or severe pain at start, which end with absent or mild pain (PCPSS).....	17
Table 7 Trends in Benchmark 3.3: Phases with absent or mild pain at start, which end with absent or mild pain (SAS)	18
Table 8 Trends in Benchmark 3.4: Phases with moderate or severe pain at start, which end with absent or mild pain (SAS).....	18
Table 9 Indigenous Status - all patients.....	24
Table 10 Primary diagnosis.....	25
Table 11 Referral source by episode type	27
Table 12 Place of death – ambulatory and community episodes	27
Table 13 Length of episode summary (elapsed days)	28
Table 14 Length of episode breakdown (elapsed days)	28
Table 15 Number of phases by phase type and episode type.....	29
Table 16 Average phase length (in days) by phase and episode type.....	29
Table 17 Profile of PC Problem Severity Scores at beginning of phase by phase type – inpatient episodes (percentages).....	30
Table 18 Profile of PC Problem Severity Scores at beginning of phase by phase type – ambulatory and community episodes (percentages)	31
Table 19 Karnofsky score at phase start by episode type	34
Table 20 How stable phases end	35
Table 21 How unstable phases end	36
Table 22 How deteriorating phases end.....	37
Table 23 How terminal phases end	38
Table 24 Number and percentage of patients, episodes and phases - by episode type.....	39
Table 25 Item completion- patient level	40
Table 26 Item completion- episode level	40
Table 27 Item completion - phase level.....	41

List of Figures

Figure 1 Trend in time from referral to first contact measure	14
Figure 2 Change in pain benchmark measures - all phases.....	19
Figure 4 Trend in average improvement on 2008 baseline - Palliative Care Problem Severity Score	21
Figure 5 Trend in average improvement on 2008 baseline - Symptom Assessment Scale.....	22
Figure 6 Total RUG-ADL at beginning of phase – inpatients.....	32
Figure 7 Total RUG-ADL at beginning of phase – ambulatory and community patients.....	33
Figure 8 Stable phase progression – inpatient	35
Figure 9 Stable phase progression - ambulatory & community	35
Figure 10 Unstable phase progression - inpatient.....	36
Figure 11 Unstable phase progression - ambulatory & community.....	36
Figure 12 Deteriorating phase progression - inpatient	37
Figure 13 Deteriorating phase progression - ambulatory & community	37
Figure 14 Terminal phase progression - inpatient.....	38
Figure 15 Terminal phase progression - ambulatory & community.....	38
Figure 16 Diagram of the PCOC data scoping process.....	42

Introduction

PCOC aims to assist services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this, the twelfth PCOC report, data submitted for the July – December 2011 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

This report is broken into three sections:

Section 1 summarises each of the four major benchmark measures and subsets and presents national benchmarking results for these benchmarks

Section 2 presents additional analysis for each of the sixteen benchmarks

Section 3 provides descriptive analysis of the data items at each of the patient, episode and phase levels

In each of the three sections, data and analysis for NSW is presented alongside the national figures for comparative purposes. The national figures reflect all palliative care services who submitted data for the July - December 2011 period. A full list of these services can be found at www.pcoc.org.au

If you would like more information regarding this report please contact:

The PCOC National Director, email: pcoc@uow.edu.au or phone (02) 4221 4411

“PCOC is an excellent example of a national and voluntary programme using benchmarking to measure outcomes in palliative care”

PRISMA (Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-Life Care) in their recent publication

Outcome Measurement in Palliative Care – The Essentials, www.prismafp7.eu

Section 1 – NSW at a Glance

Table 1 Summary of benchmark measures 1-3

Measure	Description	Benchmark	Inpatient		Ambulatory & Community	
			NSW Score	Benchmark Met?	NSW Score	Benchmark Met?
1. Time from referral to contact	Benchmark 1: Patients contacted on same or following day	90%	90.4	Yes	62.3	No
2. Time in unstable phase	Benchmark 2.1: Unstable phases lasting for less than 7 days - first phase of episode	85%	78.5	No	28.2	No
	Benchmark 2.2: Unstable phases lasting for less than 7 days - not first phase of episode	90%	84.9	No	43.9	No
	Benchmark 2.3: Median time in unstable phase	2 days	3 days	No	10 days	No
3. Change in pain PC Problem Severity Score (PCPSS) Symptom Assessment Score (SAS)	Benchmark 3.1: Phases starting with absent/mild pain, that end with absent/mild pain	90%	77.3	No	78.2	No
	Benchmark 3.2: Phases starting with moderate/severe pain, that end with absent/mild pain	60%	44.4	No	64.8	Yes
	Benchmark 3.3: Phases starting with absent/mild pain, that end with absent/mild pain	90%	82.0	No	80.6	No
	Benchmark 3.4: Phases starting with moderate/severe pain, that end with absent/mild pain	60%	47.2	No	61.0	Yes

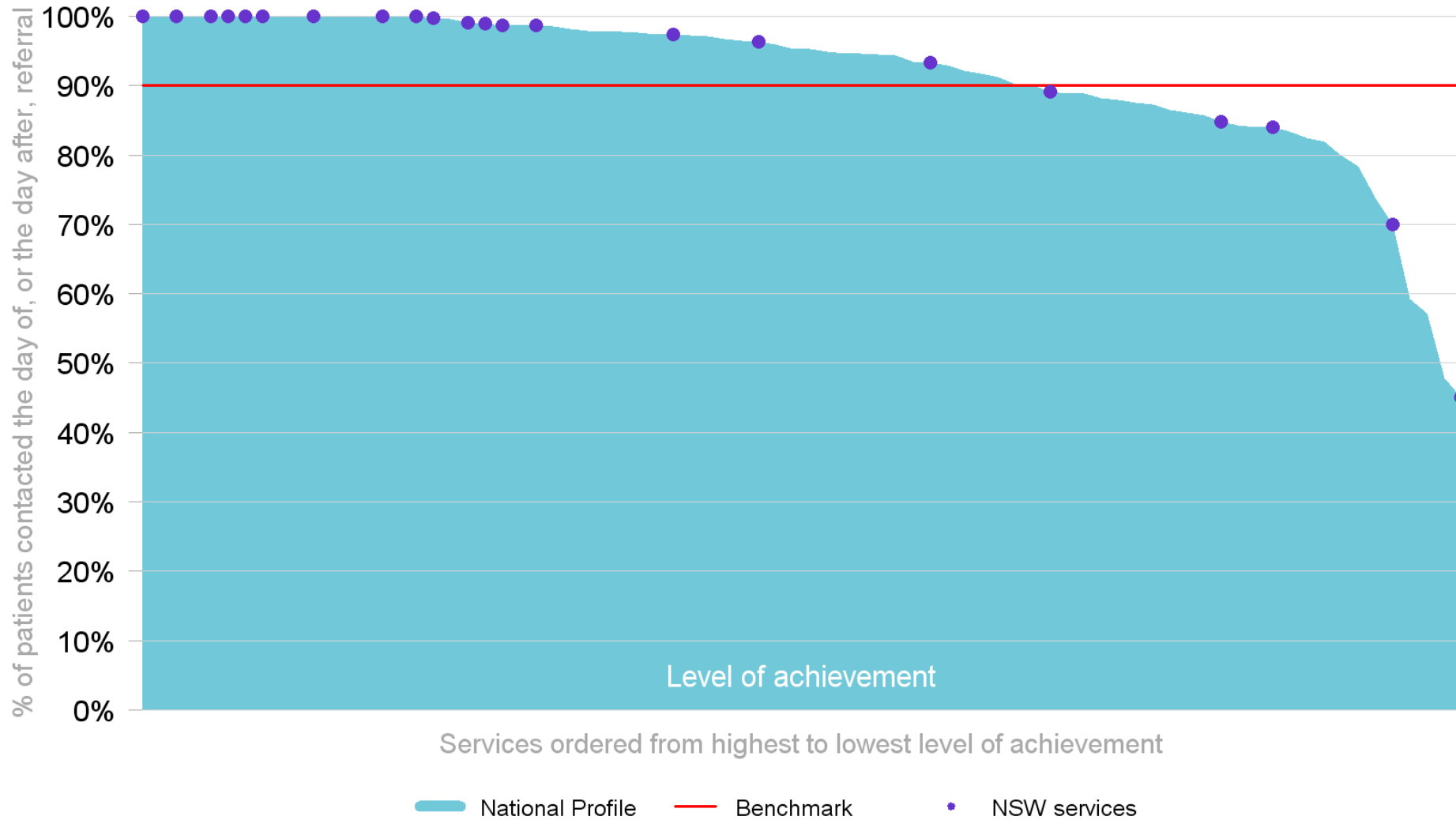
Table 2 Summary of benchmark measure 4: Average improvement on the 2008 baseline national average (X-CAS)

Clinical Tool	Description	Average improvement on baseline	Benchmark met?
PCPSS	Benchmark 4.1: Pain	0.06	Yes
	Benchmark 4.2: Other symptoms	0.05	Yes
	Benchmark 4.3: Family/carer	0.03	Yes
	Benchmark 4.4: Psychological/spiritual	-0.05	No
SAS	Benchmark 4.5: Pain	0.25	Yes
	Benchmark 4.6: Nausea	0.01	Yes
	Benchmark 4.7: Breathing	0.26	Yes
	Benchmark 4.8: Bowels	-0.05	No

For more information on the benchmark measures, see Section 2 and Appendix B

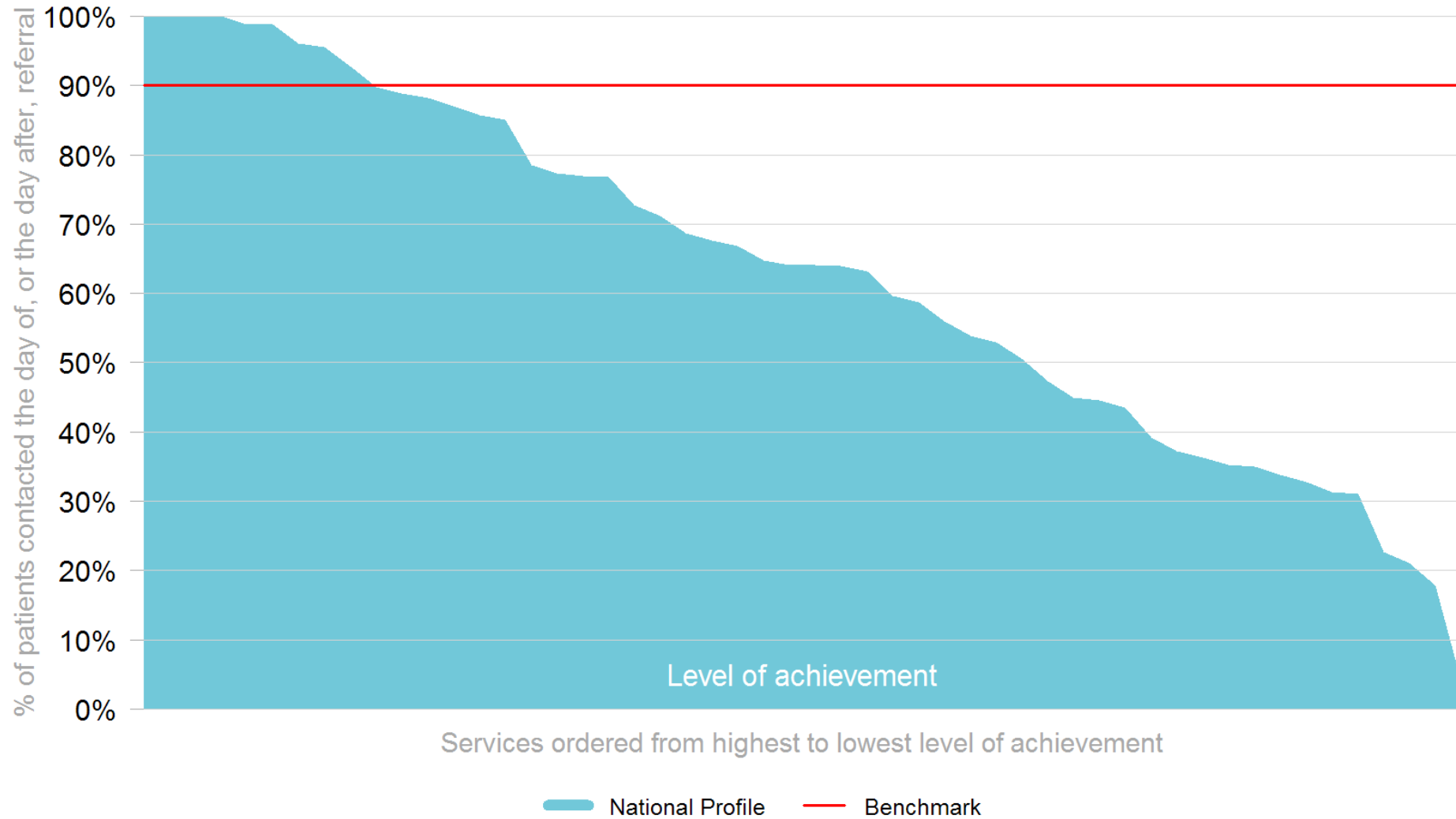
Measure 1: Time from referral to first contact - Inpatient Setting

Benchmark 1: 90% of patients contacted the day of, or the day after, referral



Measure 1: Time from referral to first contact - Ambulatory & Community Settings

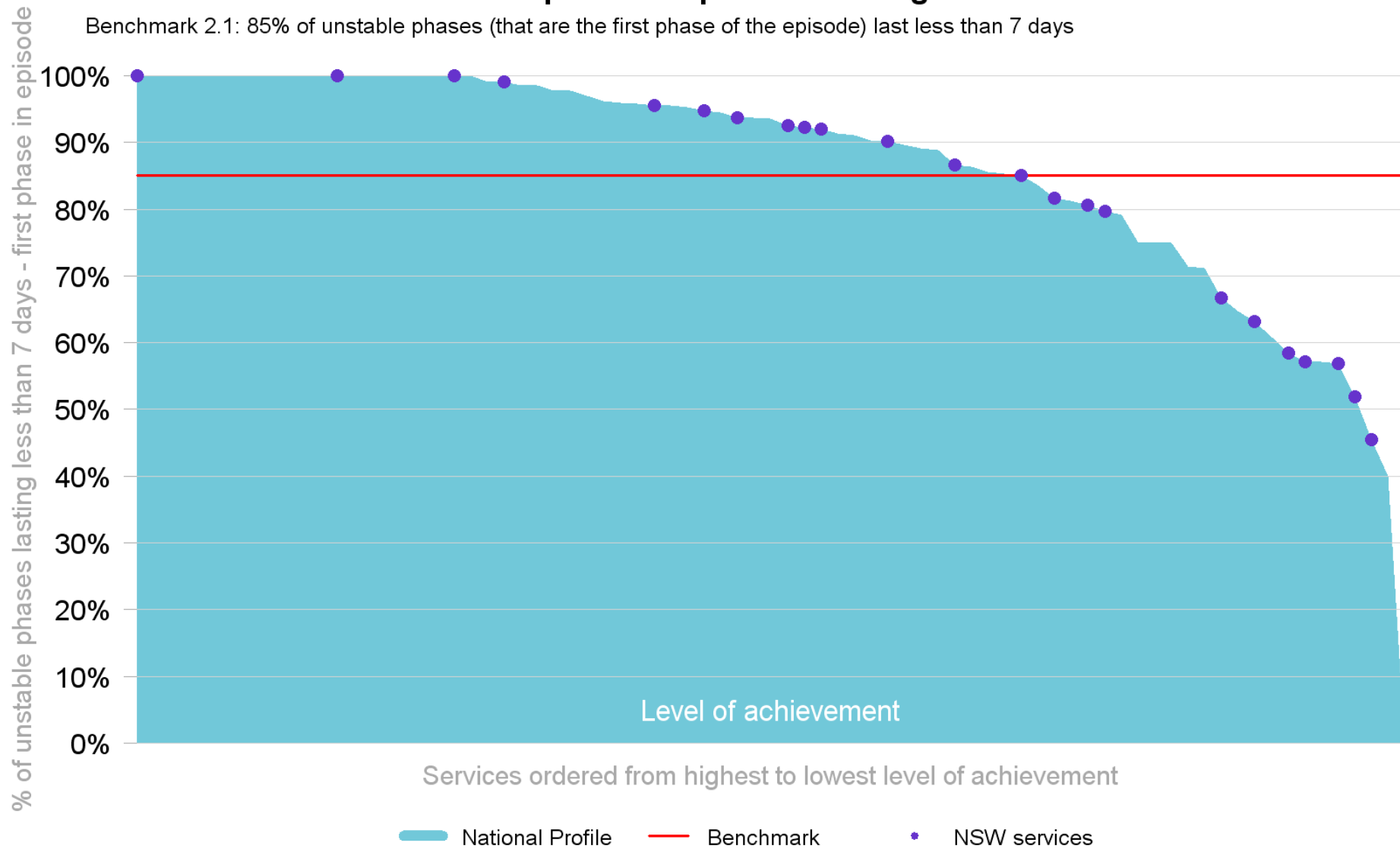
Benchmark 1: 90% of patients contacted the day of, or the day after, referral



NOTE: Data submitted by NSW services in the ambulatory and community settings are suppressed in the above graph due to their small number.

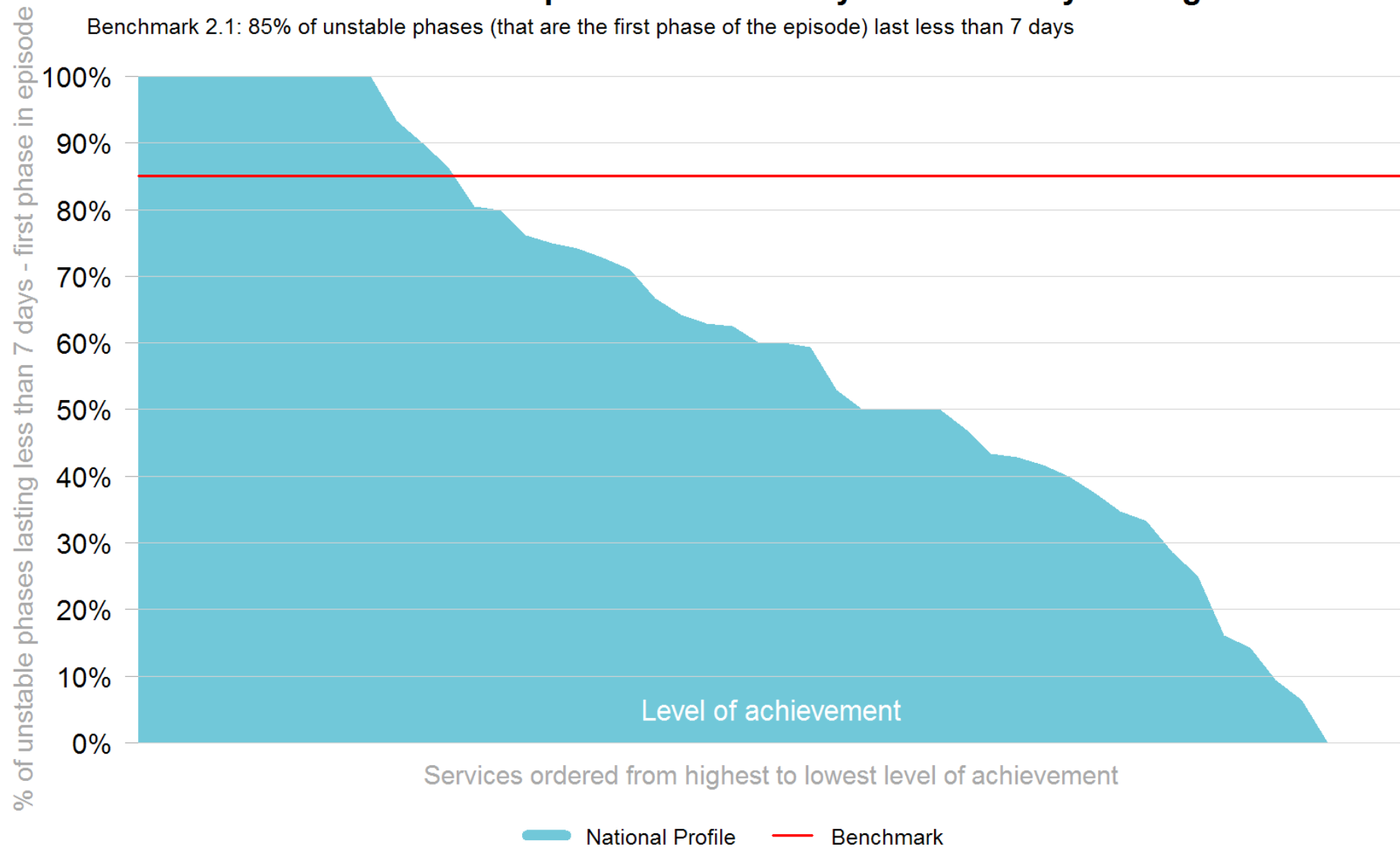
Measure 2: Time in unstable phase - Inpatient Setting

Benchmark 2.1: 85% of unstable phases (that are the first phase of the episode) last less than 7 days



Measure 2: Time in unstable phase - Ambulatory & Community Settings

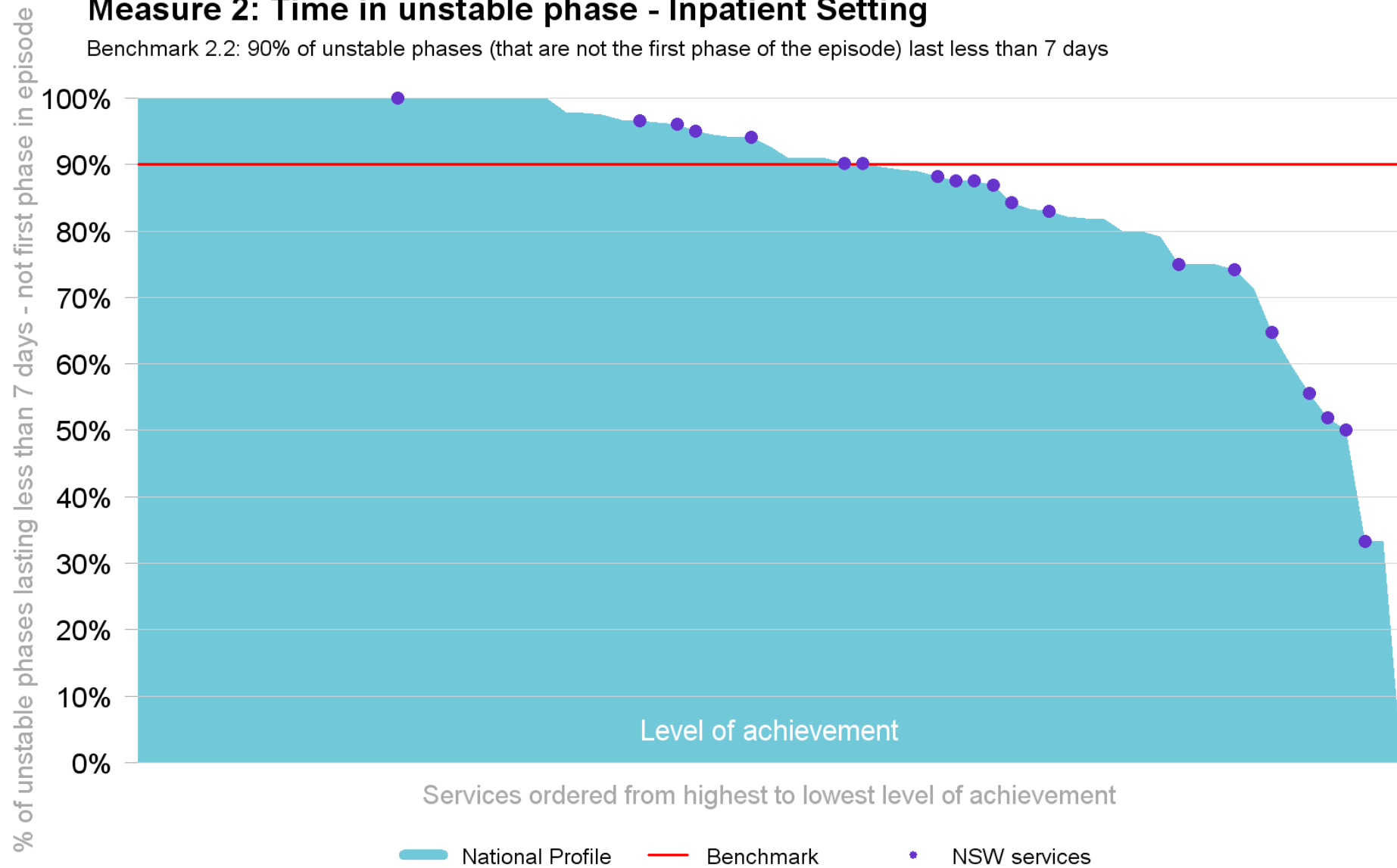
Benchmark 2.1: 85% of unstable phases (that are the first phase of the episode) last less than 7 days



NOTE: Data submitted by NSW services in the ambulatory and community settings are suppressed in the above graph due to their small number.

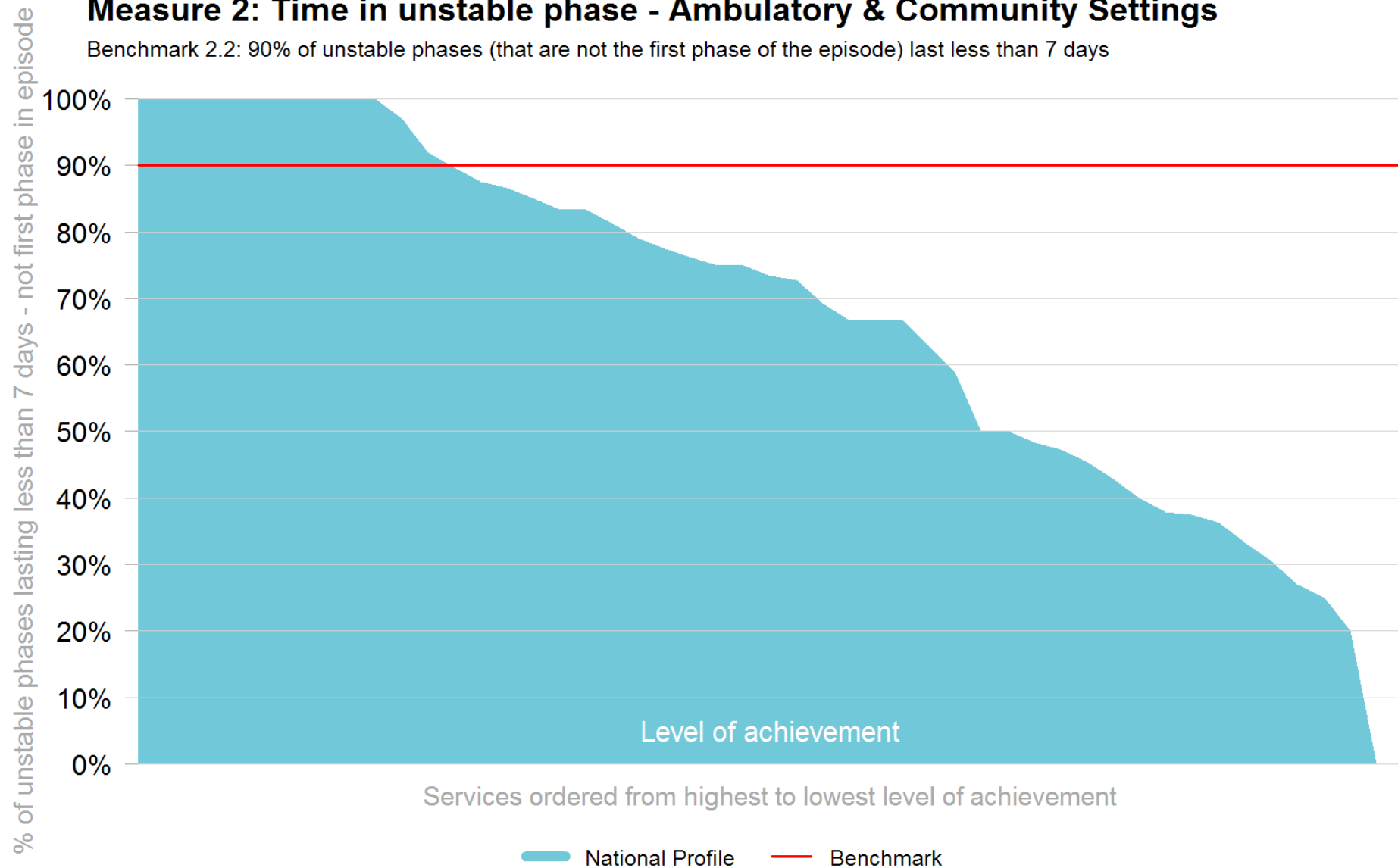
Measure 2: Time in unstable phase - Inpatient Setting

Benchmark 2.2: 90% of unstable phases (that are not the first phase of the episode) last less than 7 days



Measure 2: Time in unstable phase - Ambulatory & Community Settings

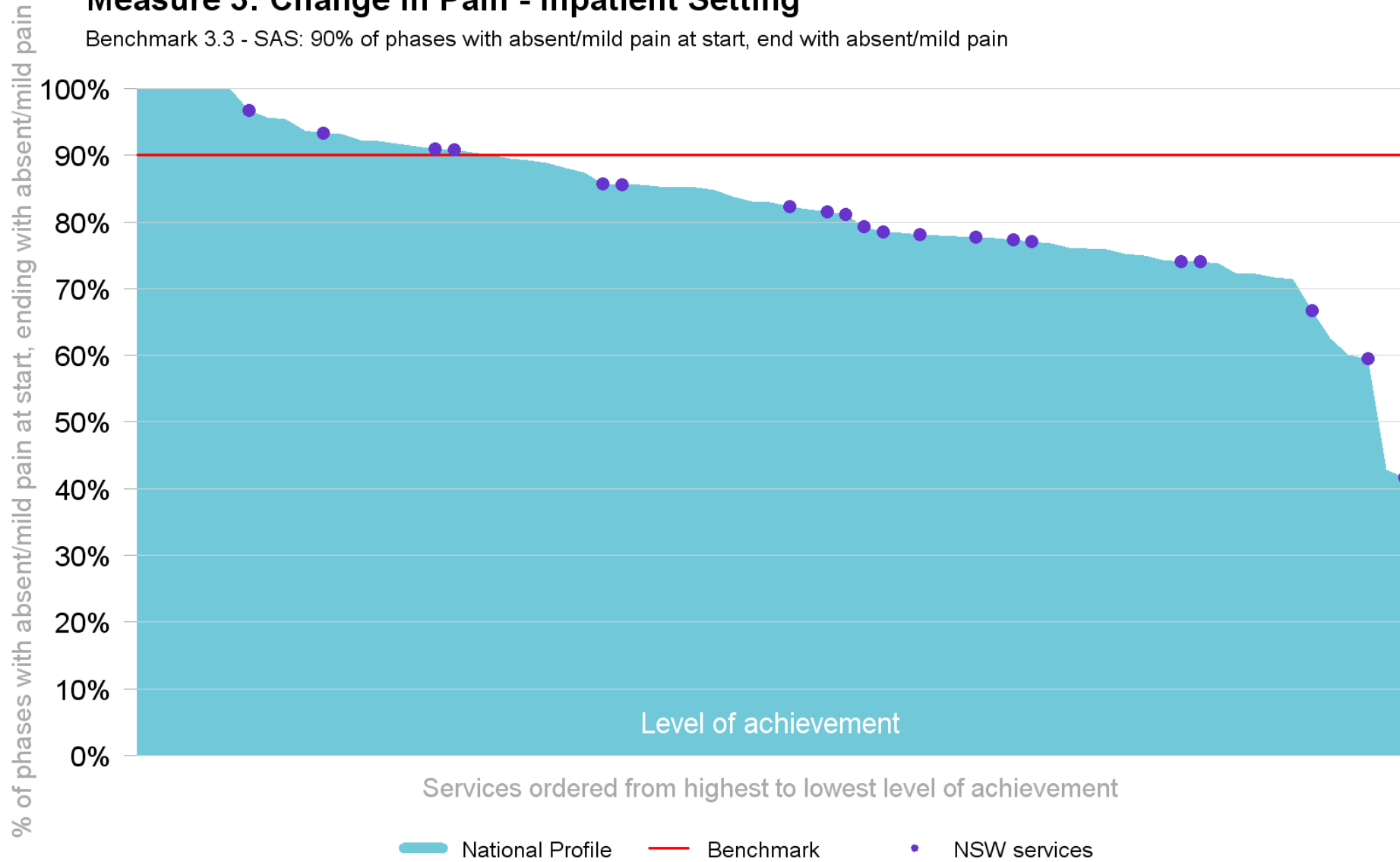
Benchmark 2.2: 90% of unstable phases (that are not the first phase of the episode) last less than 7 days



NOTE: Data submitted by NSW services in the ambulatory and community settings are suppressed in the above graph due to their small number.

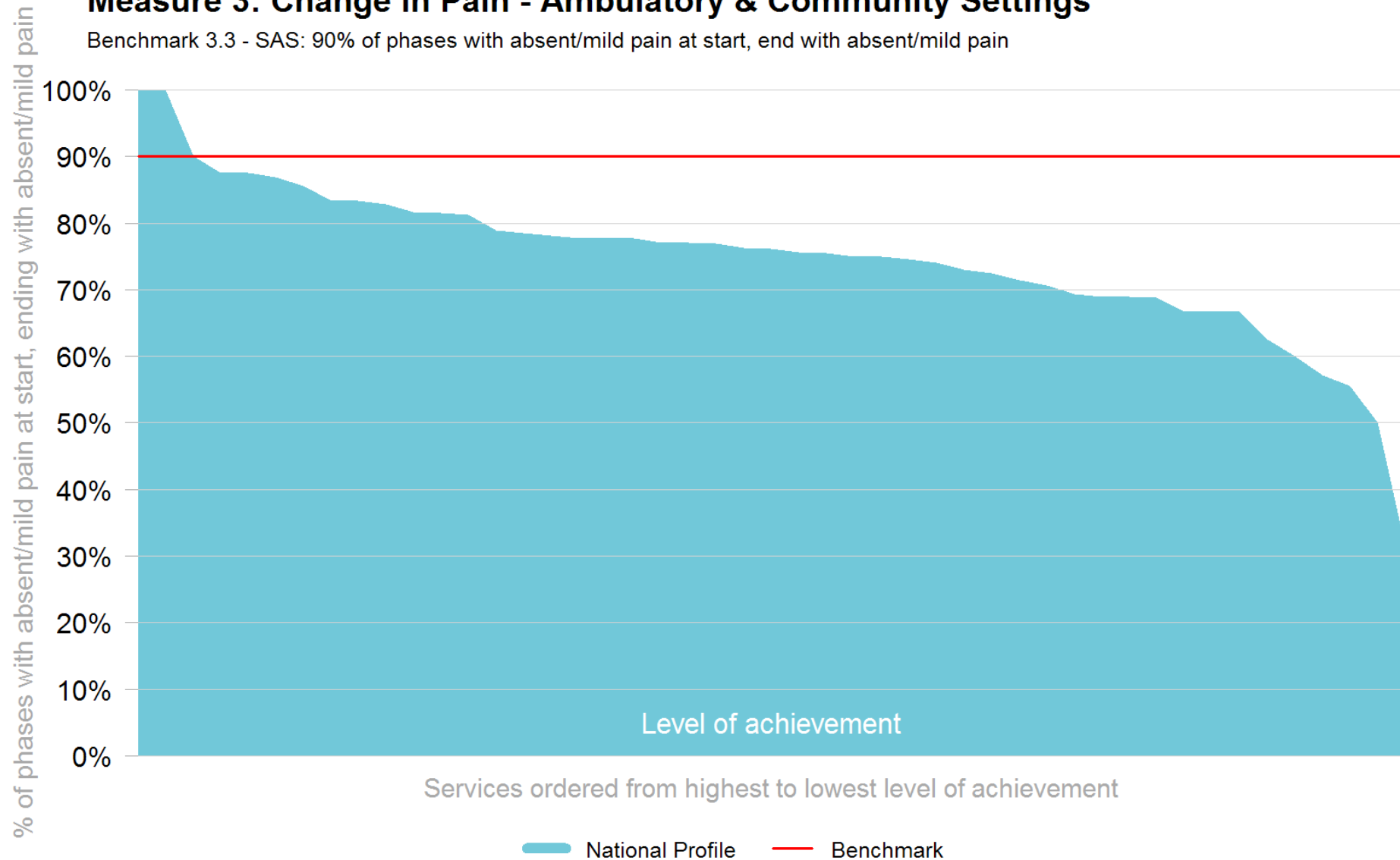
Measure 3: Change in Pain - Inpatient Setting

Benchmark 3.3 - SAS: 90% of phases with absent/mild pain at start, end with absent/mild pain



Measure 3: Change in Pain - Ambulatory & Community Settings

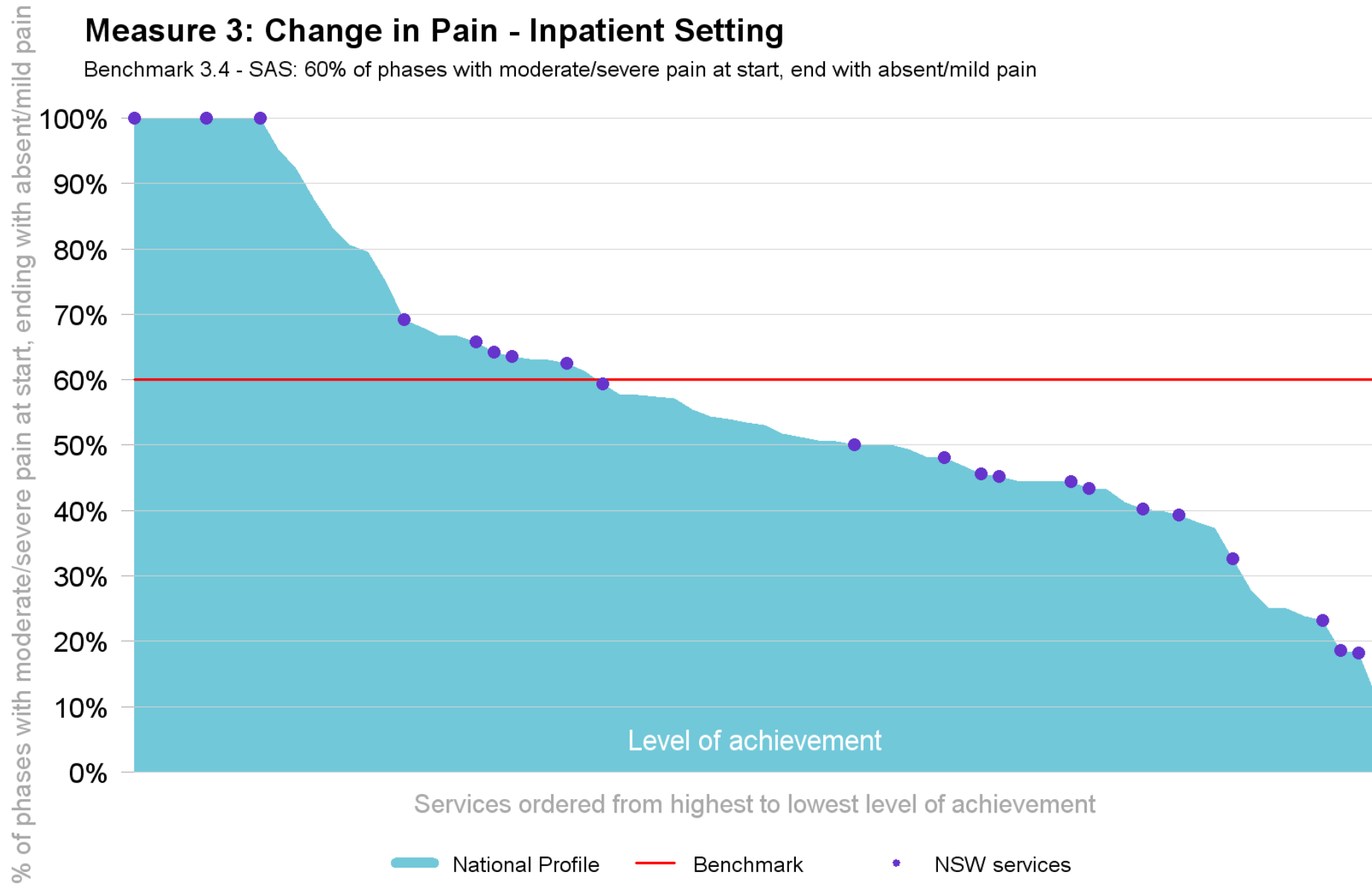
Benchmark 3.3 - SAS: 90% of phases with absent/mild pain at start, end with absent/mild pain



NOTE: Data submitted by NSW services in the ambulatory and community settings are suppressed in the above graph due to their small number.

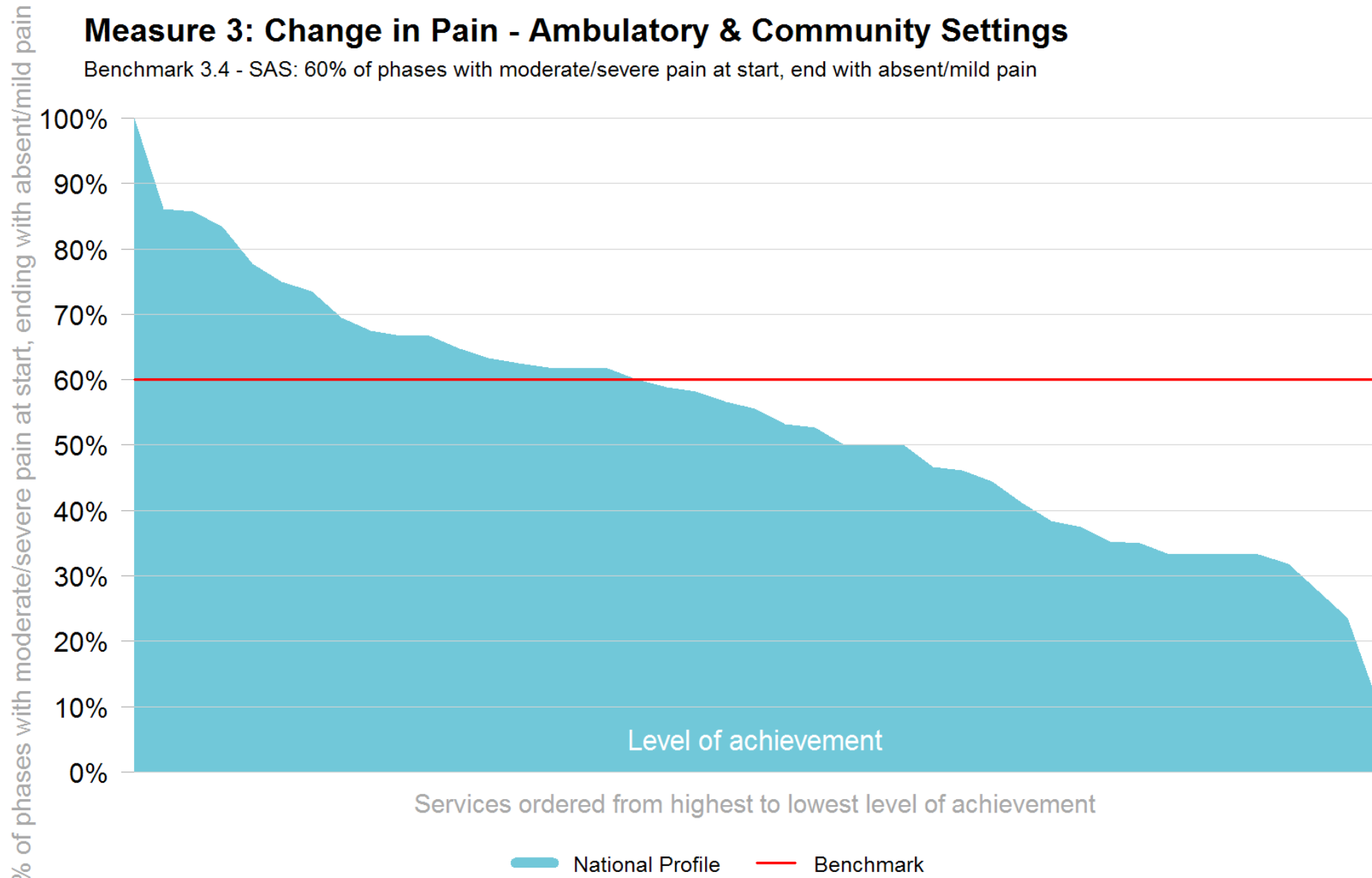
Measure 3: Change in Pain - Inpatient Setting

Benchmark 3.4 - SAS: 60% of phases with moderate/severe pain at start, end with absent/mild pain



Measure 3: Change in Pain - Ambulatory & Community Settings

Benchmark 3.4 - SAS: 60% of phases with moderate/severe pain at start, end with absent/mild pain



NOTE: Data submitted by NSW services in the ambulatory and community settings are suppressed in the above graph due to their small number.

Section 2 – Benchmark Analysis

Measure 1 – Time from referral to first contact

Time from referral to first contact reports responsiveness of palliative care services to patient needs. This benchmark was set after consultation with participants at the PCOC national benchmarking workshops in 2008. Participants acknowledged 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 5 days a week (Monday-Friday) are benchmarked against services operating 7 days a week.

Benchmark 1: This measure relates to the time taken for patients to be contacted and clinically assessed, once the palliative care team has received the patient’s referral. To meet this benchmark, at least 90% of patients must be contacted within two days of receipt of referral.

The time from referral to first contact is calculated as the time from the date referral received to either the date of first contact (if provided) or the episode start date.

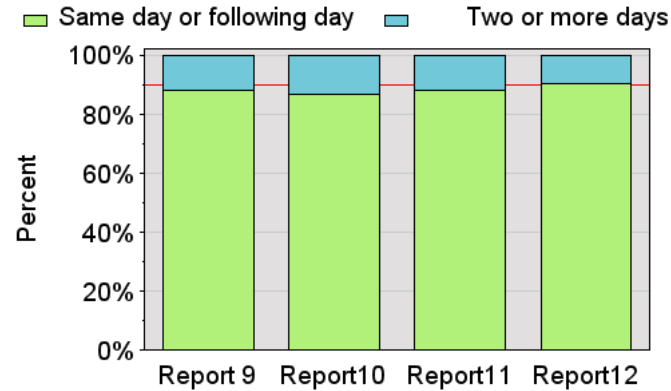
Table 3 Time from referral to first contact by episode type

Time (in days)	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Within 2 days	2583	90.4	9503	90.6	226	62.3	3521	53.0
2-7 days	244	8.5	798	7.6	99	27.3	2028	30.5
8-14 days	18	0.6	72	0.7	25	6.9	655	9.9
Greater than 14 days	11	0.4	112	1.1	13	3.6	440	6.6
Average	1.3	Na	1.3	Na	2.4	Na	2.9	Na
Median	1	Na	1	Na	1	Na	1	na

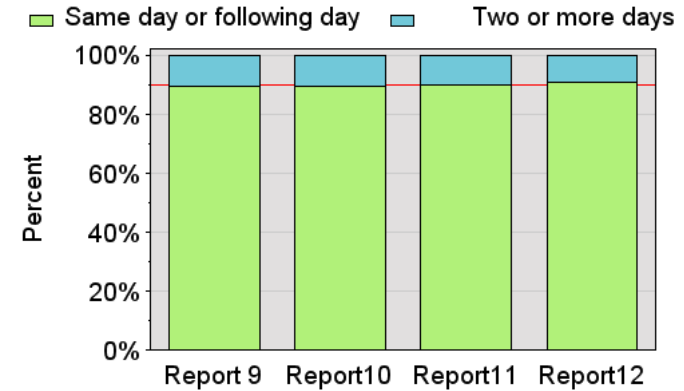
Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact or time from first contact to episode start was greater than 7 days were considered to be atypical and were assumed to equal 7 days for the purpose of calculating the average and median time.

Figure 1 Trend in time from referral to first contact measure

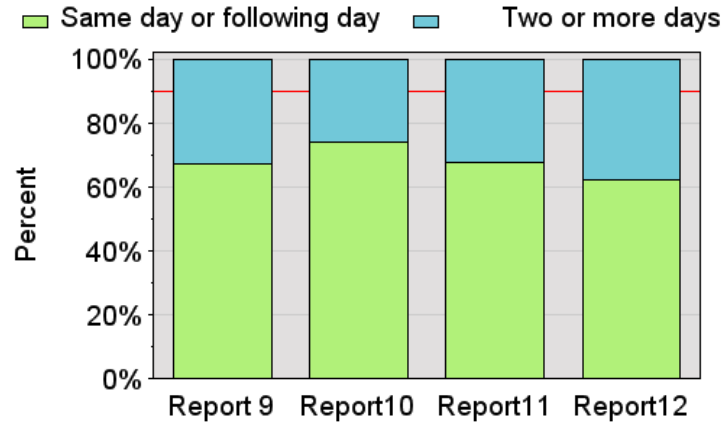
Inpatient episodes for **NSW**



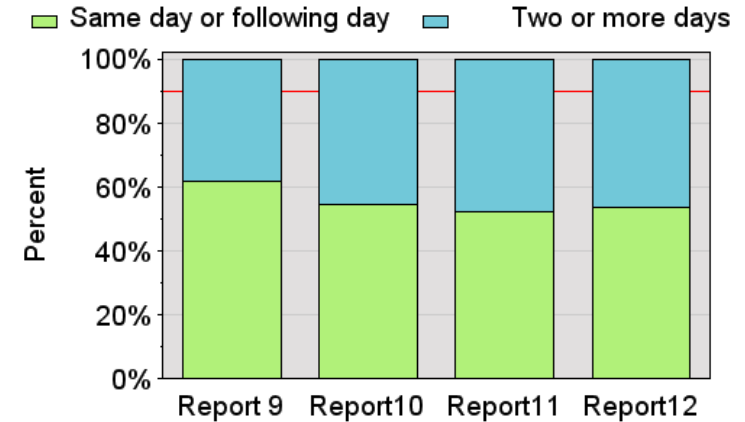
Inpatient episodes for **all services**



Ambulatory and community episodes for **NSW**



Ambulatory and community episodes for **all services**



Measure 2 – Time in unstable phase

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

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

Unstable phases are ended 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 Terminal Phase

There are three benchmarks relating to the time in unstable phase measure:

- Benchmark 2.1:** This benchmark relates to unstable phases that are the first phase in an episode of care (for example, a patient is admitted to an inpatient palliative care unit and is immediately assessed as being in the unstable phase). To meet this benchmark, at least **85%** of these unstable phases must last for less than 7 days.
- Benchmark 2.2:** This benchmark relates to unstable phases that are not the first phase in an episode of care (for example, a patient’s condition changes during an episode of care, and the patient’s phase type is changed to unstable). To meet this benchmark, at least **90%** of these unstable phases must last for less than 7 days.
- Benchmark 2.3:** This benchmark relates to all unstable phases, regardless of where they occur in the episode. To meet this benchmark, the median length of all unstable phases must be **2 days or less**.

Table 4 presents descriptive data for these three benchmarks.

Table 4 Time in unstable phase by episode type and occurrence in episode

Episode type	Occurrence of unstable phase	Number of unstable phases		Percent unstable for < 7 days		Median days in unstable phase	
		NSW	All Services	NSW	All Services	NSW	All Services
Inpatient	First phase of episode	1948	4958	78.5	84.8	3	2
	Not first phase of episode	866	2356	84.9	90.3	2	2
	Total unstable phases	2814	7314	80.5	86.5	3	2
Ambulatory & Community	First phase of episode	85	1123	28.2	59.6	13	4
	Not first phase of episode	107	1180	43.9	68.5	10	3
	Total unstable phases	192	2303	37.0	64.1	10	3

Interpretation hint:

For NSW, **1948** patients commenced their **inpatient episode** of care in the unstable phase. Of these unstable phases, **78.5%** lasted for less than 7 days. This was **lower** than the **84.8%** seen across all participating services.

Measure 3 – Change in pain

Pain management is acknowledged as a core business of palliative care services. The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS) provide two different perspectives of pain: the SAS is patient rated, while the PCPSS is clinician rated. There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain, and the other relating to the management of pain for patients with moderate or severe pain.

Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to be included in the benchmarks.

Benchmark 3.1: This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild pain. Table 5 shows trends in this benchmark over the last four reports.

Table 5 Trends in Benchmark 3.1: Phases with absent or mild pain at start, which end with absent or mild pain (PCPSS)

Episode type		NSW				All Services			
		Report 9	Report 10	Report 11	Report 12	Report 9	Report 10	Report 11	Report 12
Inpatient	Number	833	1024	1232	1545	2860	3969	5153	5577
	%	79.1	75.1	77.4	77.3	79.0	79.0	82.1	81.6
Ambulatory & Community	Number	228	213	138	183	1441	2415	2176	2339
	%	71.9	75.0	67.3	78.2	75.8	74.9	75.1	77.5

Benchmark 3.2: This benchmark relates to patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 60% of these phases must end with the patient's pain reduced to being absent or mild. Table 6 shows trends in this benchmark over the last four reports.

Table 6 Trends in Benchmark 3.2: Phases with moderate or severe pain at start, which end with absent or mild pain (PCPSS)

Episode type		NSW				All Services			
		Report 9	Report 10	Report 11	Report 12	Report 9	Report 10	Report 11	Report 12
Inpatient	Number	319	409	449	512	1257	1655	1858	1986
	%	30.1	34.2	36.0	44.4	44.0	46.6	48.0	53.6
Ambulatory & Community	Number	99	81	52	57	485	806	646	697
	%	52.1	59.1	57.8	64.8	55.7	57.5	57.3	55.4

Benchmark 3.3: This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 90% of these phases end with the patient still experiencing only absent or mild pain. Table 7 shows trends in this benchmark over the last four reports.

Table 7 Trends in Benchmark 3.3: Phases with absent or mild pain at start, which end with absent or mild pain (SAS)

Episode type		NSW				All Services			
		Report 9	Report 10	Report 11	Report 12	Report 9	Report 10	Report 11	Report 12
Inpatient	Number	1001	1570	1980	2322	3370	4672	5902	6476
	%	79.8	74.4	80.4	82.0	79.8	78.8	81.8	82.5
Ambulatory & Community	Number	196	176	146	191	1978	2825	2566	2816
	%	77.8	77.5	71.9	80.6	78.2	76.4	76.8	78.1

Benchmark 3.4: This benchmark relates to patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 60% of these phases must end with the patient's pain reduced to being absent or mild. Table 8 shows trends in this benchmark over the last four reports.

Table 8 Trends in Benchmark 3.4: Phases with moderate or severe pain at start, which end with absent or mild pain (SAS)

Episode type		NSW				All Services			
		Report 9	Report 10	Report 11	Report 12	Report 9	Report 10	Report 11	Report 12
Inpatient	Number	404	643	642	690	1453	1912	2159	2216
	%	35.8	45.0	45.3	47.2	41.3	45.7	46.4	49.6
Ambulatory & Community	Number	72	67	49	50	591	846	708	787
	%	45.0	54.9	54.4	61.0	53.1	55.3	57.0	56.2

Figure 2 Change in pain benchmark measures - all phases



Measure 4 – Change in symptoms relative to the baseline national average (X-CAS)

Measure 4 includes a suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included this report:

4.1. Pain - PCPSS	4.2. Other symptoms- PCPSS	4.3. Family/carer - PCPSS	4.4. Psychological/spiritual- PCPSS
4.5. Pain - SAS	4.6 Nausea - SAS	4.7. Breathing - SAS	4.8. Bowels - SAS

The suite of benchmarks included in Measure 4 are generally referred to as X-CAS – CAS standing for *Case-mix Adjusted Score*, and the X to represent that multiple symptoms are included.

How to interpret X-CAS:

The X-CAS benchmarks are calculated relative to a baseline reference period (currently July-December 2008). As a result:

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

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

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

As the X-CAS measures look at change in symptom, they are only able to be calculated on phases which ended in phase change or discharge (as the phase end scores are required to determine the change). Bereavement phases are excluded from the analysis.

A more technical explanation of X-CAS is included in Appendix B.

Figure 3 Trend in average improvement on 2008 baseline - Palliative Care Problem Severity Score

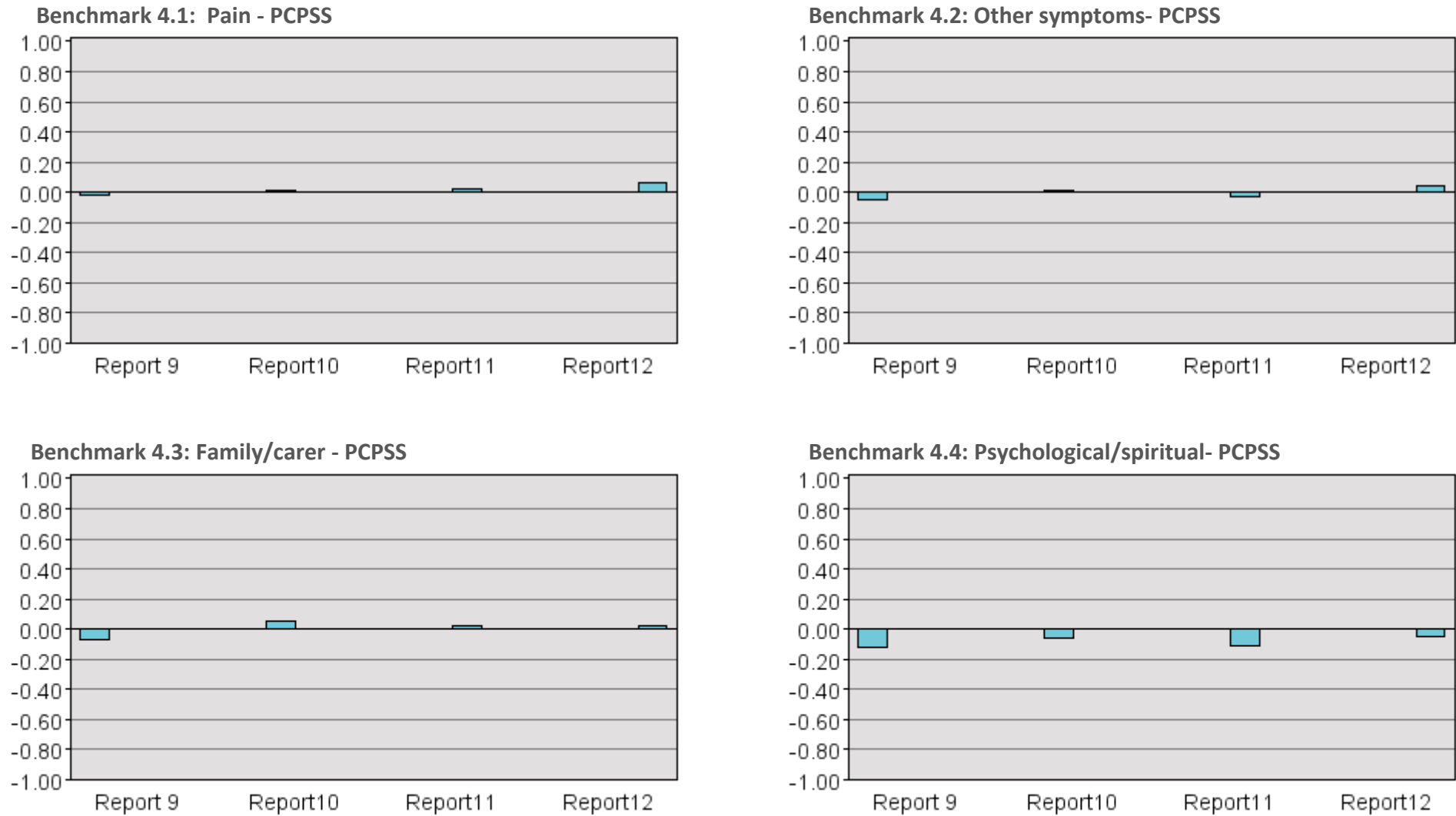
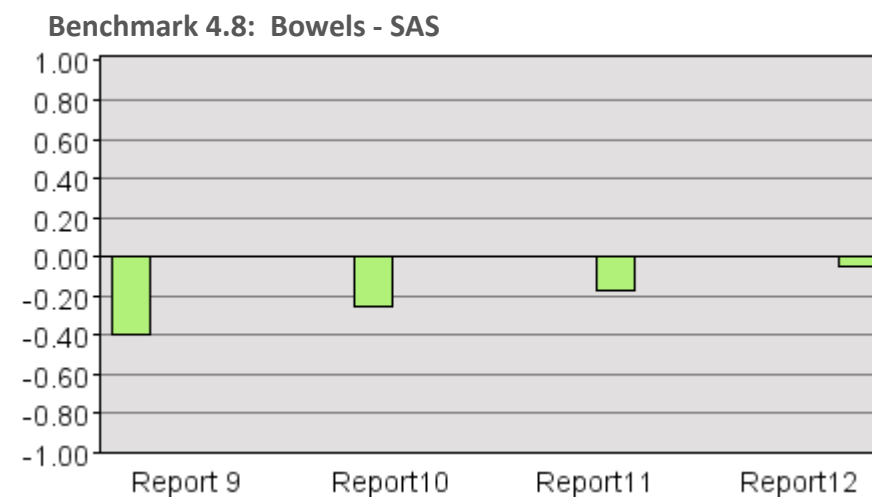
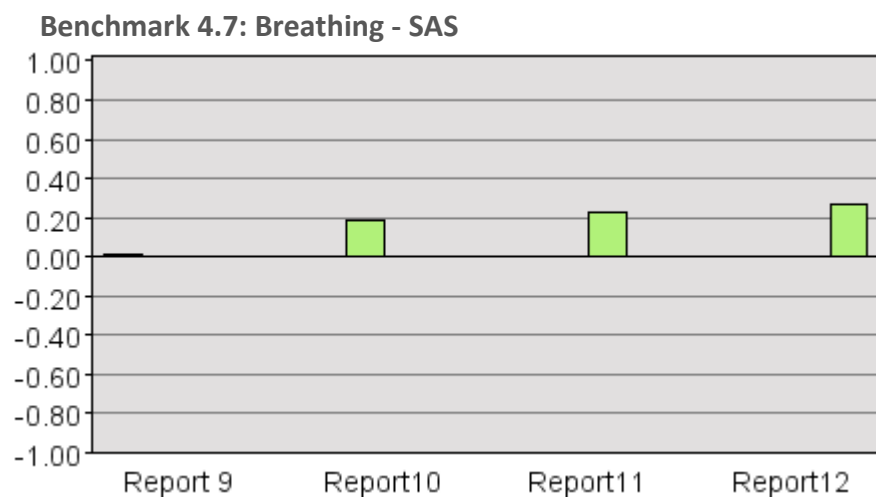
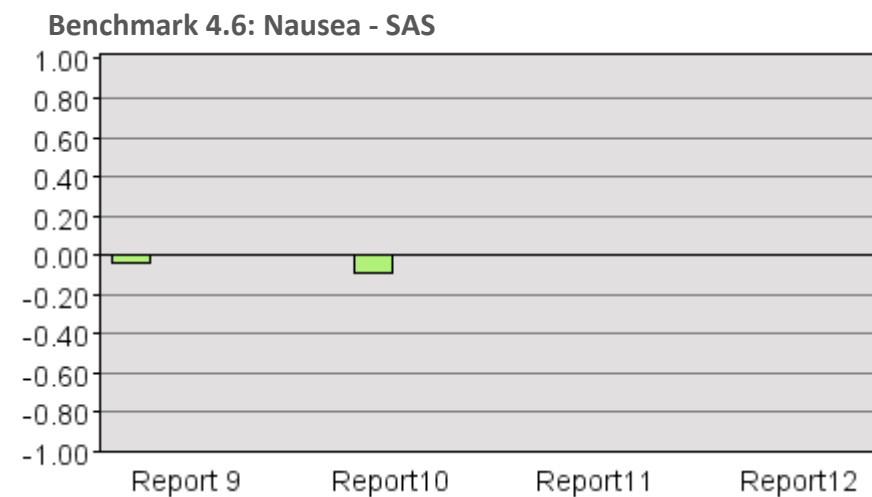
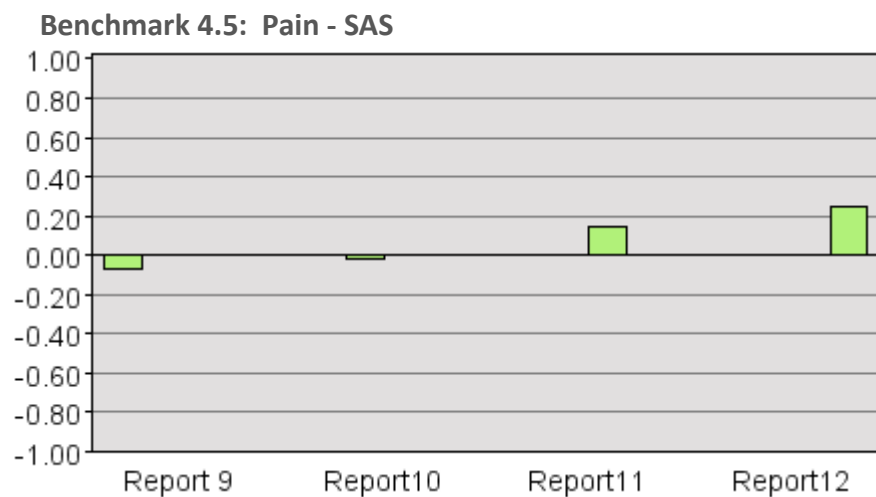


Figure 4 Trend in average improvement on 2008 baseline - Symptom Assessment Scale



Section 3 - Descriptive analysis

There are three levels of PCOC data items – Patient, Episode and Phase.

The broad detail is found at the **patient level**, where the data items look at patient demographics.

At the **episode level**, the items focus on characterising each setting of palliative care. They also describe the reasons behind why and how palliative care episodes start/end, the level of support patients receive both before and after an episode and (where applicable) the setting in which the patient died.

The clinical focus of PCOC is at the **phase level**. The items at this level describe the patient's stage of illness, functional impairment as well as their levels of pain and symptom distress. The items at the phase level are used to quantify patient outcomes, and are the focus of the PCOC Benchmarks in the previous sections.

This section provides an overview of the data submitted by NSW at each level for the current reporting period. Summaries of the national data are included for comparative purposes.

Some tables throughout this section may be incomplete. This is because some items may not be applicable to a particular service or it may be due to data quality issues.

Please use the following key when interpreting the tables:

na The item is not applicable

u The item was unavailable/unable to be calculated due to missing or invalid data.

In addition, interpret all figures carefully as results may appear distorted due to low frequencies being represented as percentages.

Profile of palliative care patients

The information collected on each patient includes Indigenous status, sex, main language spoken at home and country of birth. Table 9 shows the Indigenous status for all patients for NSW and nationally. Non-disclosure of Indigenous status can result in cultural issues not being identified. A number of programs exist that can assist services to encourage Indigenous persons to identify.

Table 9 Indigenous Status - all patients

Indigenous Status	NSW	%	All Services	%
Aboriginal but not Torres Strait Islander origin	28	1.0	133	0.9
Torres Strait Islander but not Aboriginal origin	1	0.0	25	0.2
Both Aboriginal and Torres Strait Islander origin	2	0.1	13	0.1
Neither Aboriginal nor Torres Strait Islander origin	2731	93.1	13749	93.0
Not stated/inadequately described	172	5.9	867	5.9
Total	2934	100.0	14787	100.0

Table 10 shows a breakdown of malignant and non-malignant diagnosis for the patients for NSW and at the national level. The development of Version 3 Data Set will include further opportunity to expand on diagnosis for both malignant and non-malignant categories.

Table 10 Primary diagnosis

Diagnosis category	Primary diagnosis	NSW	% of category	% of total	All Services	% of category	% of total	
Malignant	Bone and soft tissue	57	2.4	1.9	244	2.1	1.7	
	Breast	200	8.3	6.8	990	8.4	6.7	
	CNS	41	1.7	1.4	194	1.6	1.3	
	Colorectal	260	10.8	8.9	1297	11.0	8.8	
	Gynaecological	115	4.8	3.9	530	4.5	3.6	
	Haematological	97	4.0	3.3	659	5.6	4.5	
	Head and neck	138	5.7	4.7	679	5.8	4.6	
	Lung	538	22.3	18.3	2310	19.6	15.6	
	Pancreas	161	6.7	5.5	650	5.5	4.4	
	Prostate	150	6.2	5.1	780	6.6	5.3	
	Skin	97	4.0	3.3	444	3.8	3.0	
	Other GIT	203	8.4	6.9	929	7.9	6.3	
	Other urological	82	3.4	2.8	485	4.1	3.3	
	Other malignancy	186	7.7	6.3	622	5.3	4.2	
	Unknown primary	84	3.5	2.9	335	2.8	2.3	
	Malignant - not further defined	0	0.0	0.0	660	5.6	4.5	
	All malignant		2409	100.0	82.1	11808	100.0	79.9
	Non-malignant	Cardiovascular	85	22.4	2.9	530	20.7	3.6
HIV/AIDS		0	0.0	0.0	2	0.1	0.0	
Kidney failure		50	13.2	1.7	272	10.6	1.8	
Neurological disease		69	18.2	2.4	540	21.1	3.7	
Respiratory failure		64	16.8	2.2	434	17.0	2.9	
Other non-malignancy		112	29.5	3.8	685	26.8	4.6	
Non-malignant - not further defined		0	0.0	0.0	95	3.7	0.6	
All non-malignant			380	100.0	13.0	2558	100.0	17.3
Not Stated	-	145	100.0	4.9	421	100.0	2.8	

Profile of palliative care episodes

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as an Inpatient or an Ambulatory and Community patient.

An episode of care refers to the care received within one setting. An episode of palliative care begins on the day the patient is assessed face to face by the palliative care provider and there is agreement between the patient and the service.

An episode of palliative care ends when:

- the principal clinical intent of the care changes and the patient is no longer receiving palliative care
- the patient is formally separated from the hospital/hospice/community or,
- the patient dies

Referral source refers to the service or organisation from which the patient was referred to for each individual episode of care. Table 11 presents referral source by episode type. Review of referral source can identify opportunities to connect with referral sources that are currently lower than the national referral profile (e.g. a community service with few GP referrals may want to re-address referral or triage practices and look to working more collaboratively).

Table 11 Referral source by episode type

Referral source	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Public hospital - other than inpatient palliative care unit	1215	38.7	4927	45.6	202	54.2	3367	43.4
Self, carer(s), family or friends	100	3.2	268	2.5	5	1.3	205	2.6
Private hospital - other than inpatient palliative care unit	69	2.2	761	7.0	5	1.3	1262	16.3
Public palliative care inpatient unit/hospice	166	5.3	363	3.4	18	4.8	318	4.1
Private palliative care inpatient unit/hospice	15	0.5	93	0.9	0	0.0	135	1.7
General medical practitioner	204	6.5	555	5.1	49	13.1	1046	13.5
Specialist medical practitioner	113	3.6	382	3.5	63	16.9	459	5.9
Community-based palliative care agency	678	21.6	2186	20.2	16	4.3	98	1.3
Community-based service	229	7.3	405	3.7	5	1.3	168	2.2
Residential aged care facility	14	0.4	81	0.7	0	0.0	232	3.0
Other	53	1.7	104	1.0	0	0.0	149	1.9
Not stated/inadequately described	286	9.1	679	6.3	10	2.7	312	4.0
Total	3142	100.0	10804	100.0	373	100.0	7751	100.0

Table 12 Place of death – ambulatory and community episodes

Place of death	NSW	%	All Services	%
Private residence	35	23.0	1152	54.8
Residential aged care setting	20	13.2	360	17.1
Other location*	90	59.2	390	18.5
Not stated/inadequately described	7	4.6	201	9.6
Total	152	100.0	2103	100.0

* Includes patients who have died in a hospital setting without the episode of non-admitted palliative care being ended. Patients whose community episode has ended when admitted to hospital are excluded from this table.

Table 13 gives a summary of the length of episode for patients for NSW and nationally. The term “elapsed days” refers to the number of days between the episode starting and ending. For inpatient episodes, elapsed days and length of stay are equivalent. In the ambulatory and community settings, the number of elapsed days may more than the number of occasions of service.

Table 13 Length of episode summary (elapsed days)

Length of episode	Inpatient		Ambulatory & Community	
	NSW	All Services	NSW	All Services
Average length of episode	13.3	11.9	58.0	33.7
Median length of episode	8.0	7.0	61.0	21.0

Note: Bereavement phase records are excluded and episodes that remain open at the end of the reporting period (and hence do not have an episode end date), are also excluded. In addition, any records where LOS was greater than 180 days were considered to be atypical and are excluded from the average calculations. The number of episodes excluded can be seen in Table 14.

Table 14 details the length of episode in the number of elapsed days.

Table 14 Length of episode breakdown (elapsed days)

Length of episode	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Same day	88	2.8	454	4.3	6	1.9	629	8.7
1-2 days	486	15.5	1980	18.9	11	3.4	545	7.5
3-4 days	381	12.2	1382	13.2	7	2.2	419	5.8
5-7 days	507	16.2	1670	15.9	12	3.7	563	7.8
8-14 days	723	23.1	2304	22.0	37	11.5	912	12.6
15-21 days	396	12.6	1104	10.5	15	4.6	590	8.2
22-30 days	228	7.3	671	6.4	23	7.1	630	8.7
31-60 days	253	8.1	691	6.6	49	15.2	1163	16.1
61-90 days	50	1.6	139	1.3	40	12.4	621	8.6
Greater than 90 days	19	0.6	80	0.8	123	38.1	1152	15.9
Total	3131	100.0	10475	100.0	323	100.0	7224	100.0

Note: Bereavement phase records are excluded and episodes that remain open at the end of the reporting period (and hence do not have an episode end date), are also excluded.

Profile of palliative care phases

The palliative care phase is the stage of the patient's illness. Palliative care phases are not sequential and a patient may move back and forth between phases. Palliative care phases provide a clinical indication of the level of care required. There are five palliative care phases; stable, unstable, deteriorating, terminal and bereaved.

Table 15 Number of phases by phase type and episode type

Phase	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Stable	2005	24.6	7181	26.5	283	43.5	5246	38.1
Unstable	2814	34.6	7314	27.0	192	29.5	2303	16.7
Deteriorating	1957	24.0	7088	26.1	154	23.7	4864	35.4
Terminal	1316	16.2	4234	15.6	19	2.9	1208	8.8
Bereaved	51	0.6	1318	4.9	2	0.3	134	1.0
All phases	8143	100.0	27135	100.0	650	100.0	13755	100.0

Table 16 Average phase length (in days) by phase and episode type

Phase	Inpatient		Ambulatory & Community	
	NSW	All Services	NSW	All Services
Stable	8.4	6.9	29.4	21.8
Unstable	4.4	3.6	16.2	8.6
Deteriorating	4.4	5.5	16.1	15.6
Terminal	2.0	2.2	2.7	2.8
Bereaved	1.3	1.2	1.0	2.3

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

Table 17 Profile of PC Problem Severity Scores at beginning of phase by phase type – inpatient episodes (percentages)

Phase	Problem severity	NSW				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	36.6	36.2	19.7	7.4	43.0	38.3	14.8	4.0
	Other Symptom	11.2	29.6	38.7	20.5	21.1	43.7	26.4	8.9
	Psychological/Spiritual	18.7	35.4	30.8	15.1	24.5	46.7	21.5	7.3
	Family/Carer	21.2	37.3	26.2	15.3	34.1	39.7	18.7	7.5
Unstable	Pain	29.3	28.8	25.4	16.5	26.9	28.7	28.7	15.6
	Other Symptom	7.9	21.0	37.4	33.7	8.7	27.4	40.2	23.8
	Psychological/Spiritual	14.3	32.2	31.6	21.9	14.3	38.3	32.7	14.7
	Family/Carer	13.7	33.7	28.9	23.7	21.1	34.0	29.5	15.3
Deteriorating	Pain	30.4	30.6	24.8	14.2	34.9	33.3	22.4	9.4
	Other Symptom	10.5	18.4	32.5	38.6	11.7	30.4	36.3	21.6
	Psychological/Spiritual	19.7	26.9	26.6	26.8	18.8	39.9	28.3	13.0
	Family/Carer	16.2	26.5	25.4	31.9	22.3	33.1	28.5	16.1
Terminal	Pain	27.9	31.5	23.7	16.9	39.4	32.1	18.5	10.1
	Other Symptom	14.3	17.2	29.2	39.3	24.2	26.3	27.4	22.1
	Psychological/Spiritual	25.0	23.0	25.8	26.2	38.0	27.8	20.4	13.7
	Family/Carer	10.6	23.0	26.0	40.3	15.4	26.5	31.9	26.1

Table 18 Profile of PC Problem Severity Scores at beginning of phase by phase type – ambulatory and community episodes (percentages)

Phase	Problem severity	NSW				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	47.3	41.3	9.2	2.1	37.1	47.6	13.6	1.8
	Other Symptom	8.5	53.4	30.4	7.8	16.1	54.0	26.0	3.9
	Psychological/Spiritual	17.7	46.3	30.7	5.3	23.0	53.6	20.0	3.3
	Family/Carer	18.7	38.2	33.6	9.5	24.0	45.9	24.9	5.1
Unstable	Pain	29.7	26.0	30.7	13.5	19.5	31.3	31.6	17.6
	Other Symptom	5.2	18.8	48.4	27.6	5.9	24.6	45.8	23.7
	Psychological/Spiritual	6.3	29.7	42.2	21.9	11.8	36.0	35.2	17.0
	Family/Carer	8.3	22.9	42.2	26.6	14.8	25.4	39.1	20.7
Deteriorating	Pain	33.1	30.5	27.9	8.4	26.6	42.0	26.0	5.4
	Other Symptom	3.2	8.4	42.2	46.1	5.9	31.4	48.8	13.9
	Psychological/Spiritual	9.1	15.6	42.9	32.5	14.6	46.2	31.0	8.2
	Family/Carer	11.7	9.7	33.8	44.8	11.3	31.9	43.3	13.5
Terminal	Pain	52.6	15.8	21.1	10.5	35.3	38.2	17.9	8.6
	Other Symptom	10.5	5.3	31.6	52.6	19.5	31.3	30.4	18.9
	Psychological/Spiritual	26.3	15.8	26.3	31.6	40.2	29.8	20.9	9.1
	Family/Carer	0.0	10.5	21.1	68.4	8.0	26.6	41.6	23.9

Figure 5 Total RUG-ADL at beginning of phase – inpatients

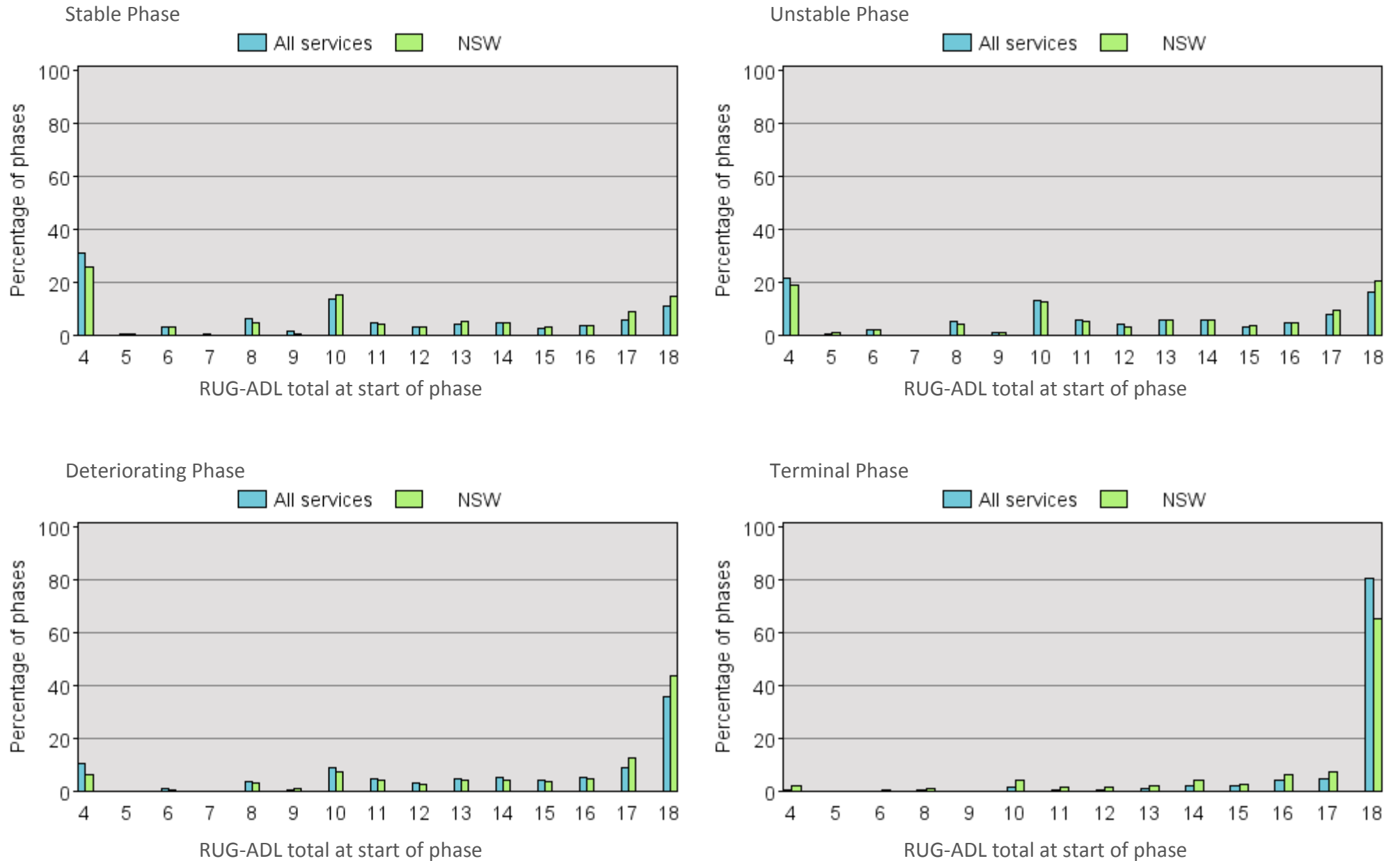
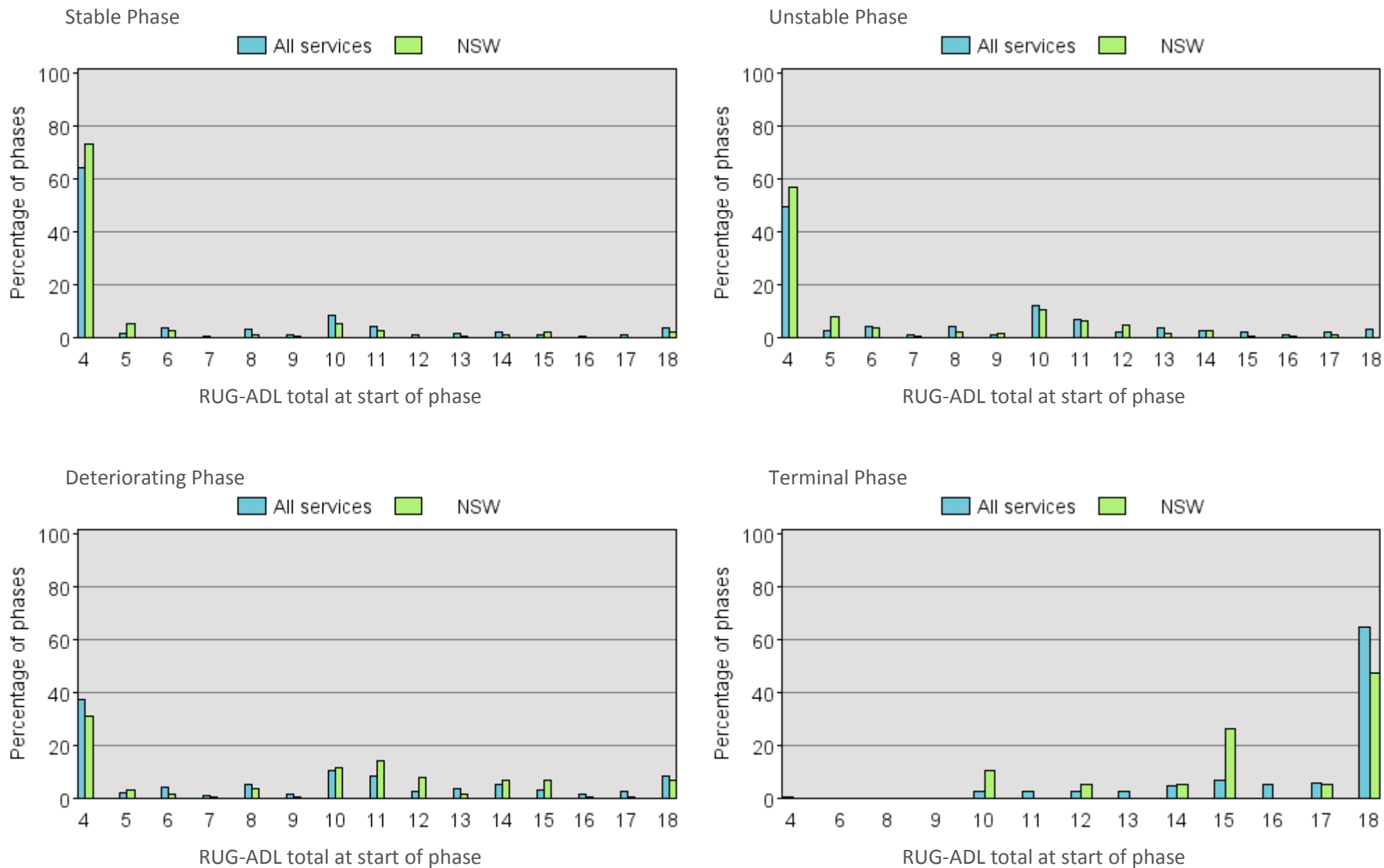


Figure 6 Total RUG-ADL at beginning of phase – ambulatory and community patients



RUG-ADL (shown on the previous two pages) consists of 4 items (bed mobility, toileting, transfers and eating) and should be assessed on admission, at phase change and at episode end.

The Karnofsky Performance Status Scale used in PCOC is the Australia-modified version which is applicable to both inpatient and community palliative care. The Karnofsky Performance Scale assesses patient/client functioning and performance and can be used in determining prognosis /survival times.

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

Table 19 Karnofsky score at phase start by episode type

Karnofsky score	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Comatose or barely rousable	728	9.1	2416	9.4	7	1.1	573	4.2
Totally bedfast and requiring extensive nursing care	1452	18.1	4899	19.1	31	4.8	1200	8.9
Almost completely bedfast	856	10.7	2920	11.4	31	4.8	863	6.4
In bed more than 50% of the time	1165	14.5	4130	16.1	83	12.8	1539	11.4
Requires considerable assistance	1493	18.6	5102	19.9	168	26.0	3164	23.4
Requires occasional assistance	769	9.6	3341	13.0	154	23.8	3114	23.0
Cares for self	172	2.1	1048	4.1	94	14.6	1864	13.8
Normal activity with effort	97	1.2	391	1.5	55	8.5	680	5.0
Able to carry on normal activity; minor signs or symptoms	28	0.3	113	0.4	12	1.9	199	1.5
Normal; no complaints; no evidence of disease	2	0.0	4	0.0	2	0.3	15	0.1
Not stated/inadequately described	1257	15.7	1333	5.2	9	1.4	334	2.5
Total	8019	100.0	25697	100.0	646	100.0	13545	100.0

Table 20 presents information relating to the manner in which stable phases ended, both for NSW and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or the patient dies. For those stable phases that ended because the patient was deemed to be in another phase (phase change), Figure 7 and Figure 8 summarise subsequent the phase that the patient moved into, for both the Inpatient and Ambulatory & Community settings respectively. This movement from one phase to another is referred to as Phase Progression. The phase progression information is derived by PCOC. The “Unknown” category has been included to account for situations where subsequent phase records have not been submitted to PCOC, meaning the phase progression cannot be determined.

Similar information is presented for the unstable, deteriorating and terminal phases on the following pages.

Table 20 How stable phases end

Phase end reason	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Phase change (see figures below)	1122	56.0	4121	57.4	138	48.8	3482	66.4
Discharge/case closure	839	41.8	2903	40.4	72	25.4	1384	26.4
Died	44	2.2	118	1.6	67	23.7	332	6.3
Bereavement phase end	0	0.0	7	0.1	0	0.0	2	0.0
Not stated/inadequately described	0	0.0	32	0.4	6	2.1	46	0.9
Total	2005	100.0	7181	100.0	283	100.0	5246	100.0

Figure 7 Stable phase progression – inpatient



Figure 8 Stable phase progression - ambulatory & community



Table 21 How unstable phases end

Phase end reason	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Phase change (see figures below)	2400	85.3	6389	87.4	117	60.9	1553	67.4
Discharge/case closure	204	7.2	495	6.8	39	20.3	606	26.3
Died	210	7.5	347	4.7	26	13.5	121	5.3
Bereavement phase end	0	0.0	11	0.2	0	0.0	3	0.1
Not stated/inadequately described	0	0.0	72	1.0	10	5.2	20	0.9
Total	2814	100.0	7314	100.0	192	100.0	2303	100.0

Figure 9 Unstable phase progression - inpatient



Figure 10 Unstable phase progression - ambulatory & community



Table 22 How deteriorating phases end

Phase end reason	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Phase change (see figures below)	1450	74.1	4817	68.0	52	33.8	2699	55.5
Discharge/case closure	61	3.1	1040	14.7	29	18.8	1346	27.7
Died	443	22.6	1183	16.7	60	39.0	780	16.0
Bereavement phase end	3	0.2	37	0.5	0	0.0	5	0.1
Not stated/inadequately described	0	0.0	11	0.2	13	8.4	34	0.7
Total	1957	100.0	7088	100.0	154	100.0	4864	100.0

Figure 11 Deteriorating phase progression - inpatient



Figure 12 Deteriorating phase progression - ambulatory & community

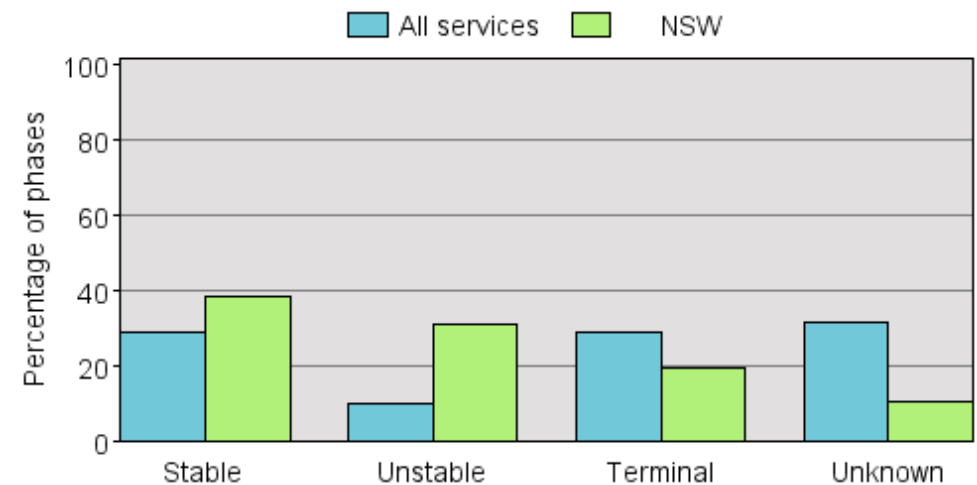


Table 23 How terminal phases end

Phase end reason	Inpatient				Ambulatory & Community			
	NSW	%	All Services	%	NSW	%	All Services	%
Phase change (see figures below)	83	6.3	489	11.5	2	10.5	275	22.8
Discharge/case closure	6	0.5	93	2.2	1	5.3	88	7.3
Died	1225	93.1	3437	81.2	14	73.7	837	69.3
Bereavement phase end	2	0.2	212	5.0	1	5.3	4	0.3
Not stated/inadequately described	0	0.0	3	0.1	1	5.3	4	0.3
Total	1316	100.0	4234	100.0	19	100.0	1208	100.0

Figure 13 Terminal phase progression - inpatient



Figure 14 Terminal phase progression - ambulatory & community



Appendix A – Summary of data included in this report

A1 – Data Summary

This report includes data from a total of 102 services. During the reporting period, data were provided for a total of 14787 patients who between them had 18555 episodes of care and 40890 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 (Section A3 contains a more detailed explanation of this process). Table 24 shows the number of patients, episodes and phases included in this report – both for NSW and nationally.

A consequence of the data scoping method is that it is likely that not all phases related to a particular episode are included in this report. Hence, the average number of phases per episode calculation shown in Table 24 may be an underestimate (due to episodes that cross-over 2 or more reporting periods) as it only includes phases that ended within the current reporting period.

Table 24 Number and percentage of patients, episodes and phases - by episode type

Episode Type	Inpatient		Ambulatory & Community		Total	
	NSW	All Services	NSW	All Services	NSW	All Services
Number of patients*	2746	9247	336	6405	2934	14787
Number of episodes	3142	10804	373	7751	3515	18555
Number of phases	8143	27135	650	13755	8793	40890
Percentage of patients*	93.6	62.5	11.5	43.3	100	100
Percentage of episodes	89.4	58.2	10.6	41.8	100	100
Percentage of phases	92.6	66.4	7.4	33.6	100	100
Average number of phases per episode**	2.6	2.4	1.7	1.7	2.5	2.1

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

** Average number of phases per episode is only calculated for closed episodes and excludes bereavement phases.

A2 – Data Item Completion

Overall, the quality of data submitted to PCOC is very good and, as shown in Tables 25, 26 and 27 below, the rate of data completion is very high. In reviewing this table, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for non-admitted patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

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

Table 25 Item completion- patient level

Data item	% Complete	
	NSW	All Services
Date of birth	100.0	100.0
Sex	100.0	99.9
Indigenous status	94.1	94.1
Country of birth	98.8	93.0
Main language	91.8	90.6
Primary diagnosis	95.1	97.2

Table 26 Item completion- episode level

Data item	% Complete	
	NSW	All Services
Date of first contact/assessment	79.6	95.6
Referral date	91.6	92.3
Referral source	91.6	94.7
Episode start date	100.0	100.0
Mode of episode start	99.4	99.2
Accommodation at episode start	96.0	97.2
Episode end date	100.0	99.6
Level of support at episode start	45.8	81.9
Mode of episode end	98.8	98.2
Accommodation at episode end	93.8	84.8
Level of support at episode end	96.3	96.7
Place of death	95.4	90.4

Table 27 Item completion - phase level

Data item	Sub-Category (where applicable)	% Complete	
		NSW	All Services
Phase start date	-	100.0	100.0
Phase	-	100.0	100.0
RUG-ADL at phase start	Bed Mobility	100.0	95.2
	Toileting	100.0	95.1
	Transfers	100.0	94.9
	Eating	100.0	94.4
PC Problem Severity at phase start	Pain	67.7	81.5
	Other Symptom	90.0	85.3
	Psychological/Spiritual	94.7	92.5
	Family/Carer	94.7	91.7
Symptom Assessment Score at phase start	Insomnia	88.0	88.5
	Appetite	88.0	90.1
	Nausea	88.0	90.5
	Bowels	88.0	89.9
	Breathing	88.0	90.4
	Fatigue	88.0	90.5
	Pain	88.0	90.9
Phase end reason	-	99.6	99.4
Karnofsky at phase start	-	85.5	95.8

Some tables throughout this report may be incomplete. This is because some items may not be applicable to a particular service or it may be due to data quality issues.

Please use the following key when interpreting the tables:

na The item is not applicable

u The item was unavailable/unable to be calculated due to missing or invalid data.

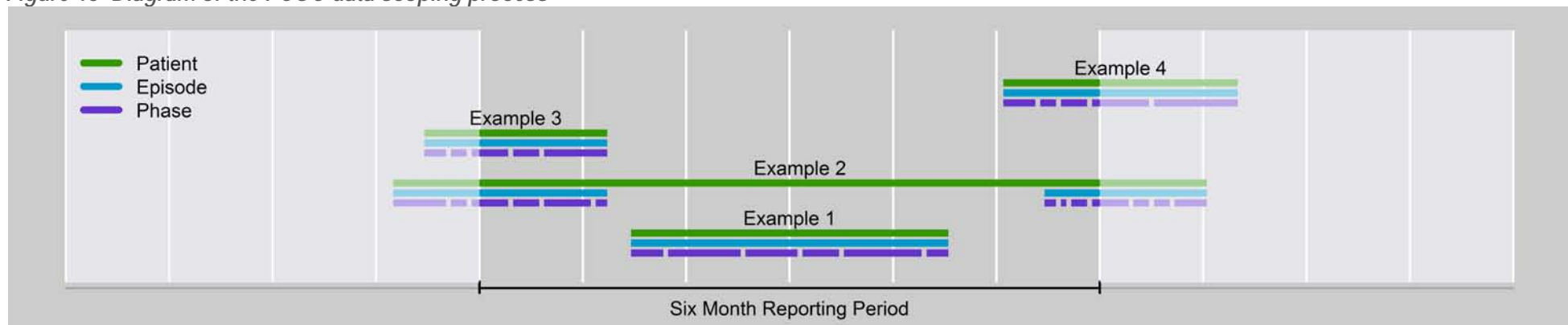
In addition, interpret all figures carefully as results may appear distorted due to low frequencies being represented as percentages.

A3 – Data scoping methodology

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 15 below displays four examples to help visualize this process.

Figure 15 Diagram of the PCOC data scoping process



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). For the phases relating to the second episode, only the first three end within the period, so only these would be included in the report. Both of the episode records and the patient record would also be reported on.

In Example 3, the patient has one episode and five phases. Only the last three phases will be reported on as they are the only ones ending within the reporting period. 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. Again, the episode and patient records would be included in the report on as they have associated phases ending within the period.

Appendix B – Benchmark Notes

B1 – Outline of Benchmark Measures and Targets

There is strong sectoral support for national benchmarks and a consensus that such benchmarks can drive service innovation regardless of model of care. Benchmarking provides opportunities to understand the services that are provided, the outcomes patients experience and also to generate research opportunities focused on how to demonstrate variations in practice and outcomes.

Beginning in the reporting period January to June 2009 (Report 7), PCOC introduced four benchmark measures into the routine PCOC reports:

Measure	Benchmark
1. Time from referral to first contact	90% of patients are contacted on the day of, or the day after referral
2. Time in unstable phase	85% in their first phase remain unstable for less than 7 days 90% in a subsequent phase remain unstable for less than 7 days The median time in unstable phase is 2 days or less
3. Change in pain (both PCSS and SAS)	90% of phases that start with absent/mild pain start pain have absent/mild end pain 60% of phases with moderate/severe start pain have absent/mild end pain
4. Change in symptoms relative to the national average (8 symptoms are included)	A score of 0 or above

It is recognised that services aspire to achieve best practice, and to reflect this, current benchmarks have intentionally been set at a high level. Where a service does not meet the benchmark, PCOC has adopted a target of improvement of 10% per year.

B2 – National profile graphs

In each national profile graph, the shaded region describes the national profile for that benchmark. NSW services are highlighted as dots on the graph. Graphs may have differing numbers of dots, caused by services not qualifying for inclusion in a particular benchmark. This may be caused by insufficient data item completion, or services not having any records falling into a particular category, for example, no phases starting with moderate/severe SAS pain.

B3 – X-CAS technical notes

The procedure for calculating X-CAS is as follows:

- Step 1.** Using the baseline data, calculate the average change in symptom for all patients in the same phase, having the same symptom start score. This is called the **expected** change.
- Step 2.** For each individual phase, calculate the change in symptom score (start score minus end score)
- Step 3.** For each individual phase, calculate the difference between their change in symptom score (calculated in step 2) and the relevant expected change (calculated in step 1).
- Step 4.** Average all of the values calculated in step 3 to produce the service’s Symptom Casemix-Adjusted Score (e.g. PCAS).

Example:

Phase	PCPSS Pain at start	PCPSS Pain at end	Step 1: Expected PCPSS Pain change (from Report 6 National Database)	Step2: PCPSS Pain change (start score minus end score)	Step 3: Difference (Step 2 minus Step 1)	Step 4: Average of values in step 3
Stable	0	1	-0.8	-1	-0.2	$\frac{-0.2+0.9+0.4-0.4}{4} = .175$
Stable	1	1	-0.9	0	0.9	
Unstable	3	1	1.6	2	0.4	
Deteriorating	2	1	1.4	1	-0.4	

Acknowledgements

Contributions PCOC wishes to acknowledge the valuable contribution made by:

- Members of the Management Advisory Board of PCOC
- 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
- The PCOC National staff at the Australian Health Services Research Institute, University of Wollongong, for the collation, analysis and reporting of the data
- The PCOC Quality Improvement Facilitators for working closely with services to support the data collection and data quality improvement processes
- The Australian Government Department of Health and Ageing for funding this initiative

Disclaimer PCOC has made every effort to ensure that the data used in this report are accurate. Data submitted to PCOC are checked for anomalies and services are asked to re-submit data prior to the production of the PCOC report. We would advise readers to use their professional judgement in considering all information contained in this report.

Copyright This work is copyright. It may be produced in whole or in part for study or training purposes subject to the inclusion of an acknowledgement of the source. It is not for commercial usage or sale. Reproduction for purposes other than those above requires the written permission of PCOC.

Suggested Citation Allingham S. & Bird S. (2012) Outcomes in Palliative Care, Report 12 (July – December 2011) – New South Wales. Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong.