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Western Australia: patient outcomes in palliative care: January - June 2014: report 17

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Western Australia: patient outcomes in palliative care: January - June 2014: report 17

Abstract

The Palliative Care Outcomes Collaboration (PCOC) assists services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this, the seventeenth PCOC report, data submitted for the January to June 2014 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

Keywords

PCOC, outcomes, palliative, care, western, patient, australia, 2014, report, 17, january, june

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PCOC
palliative care
outcomes collaboration

Western Australia

Patient Outcomes in Palliative Care

January – June 2014

Report 17

September 2014

Australian Government
Department of Health

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Australian Government Department of Health

www.pcoc.org.au

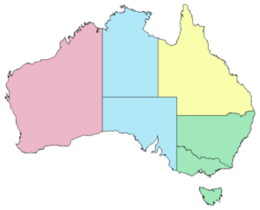
About the Palliative Care Outcomes Collaboration

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) *Standards for Providing Quality Palliative Care for all Australians*. This is achieved via the PCOC dataset; a multi-purpose framework designed to:

- provide clinicians with an approach to systematically assess individual patient experiences,
- define a common clinical language to streamline communication between palliative care providers and
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking.

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

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



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

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

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

Table of Contents

List of Tables

List of Figures

Introduction

The Palliative Care Outcomes Collaboration (PCOC) assists services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this, the seventeenth PCOC report, data submitted for the January to June 2014 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

Patient outcomes are reported for a total of 16,833 patients, with 21,518 episodes of care and 49,643 palliative care phases. The information included in this report is determined by a data scoping methods. See Appendix A for more information on the data included in this report.

Throughout this report, patient information for Western Australia is presented alongside the national figures for comparative purposes. The national figures are based on information submitted by 93 services, of which:

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

A full list of the services included in the national figures can be found at www.pcoc.org.au.

Interpretation hint:

Some tables throughout this report may be incomplete. This is because some items may not be applicable to Western Australia or it may be due to data quality issues.
Please use the following key when interpreting the tables:

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

Section 1 Benchmark summary

1.1 WA at a glance

Table 1 Summary of outcome measures 1 to 3 by setting

Outcome measure	Description	Benchmark	Inpatient		Community	
			WA Score	Benchmark Met?	WA Score	Benchmark Met?
1. Time from ready for care to episode start	Benchmark 1: Patients episode commences on the day of, or the day after date ready for care	90%	95.3	Yes	96.6	Yes
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	90.7	Yes	93.5	Yes
3. Change in pain	Benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end	90%	91.2	Yes	85.3	No
	Benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild pain at phase end	60%	46.9	No	68.0	Yes
	Benchmark 3.3: SAS Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end	90%	87.0	No	82.4	No
	Benchmark 3.4: SAS Patients with moderate/severe distress from pain at phase start, with absent/mild at phase end	60%	47.6	No	60.7	Yes

Table 2 Summary of outcome 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	0.17	Yes
	Benchmark 4.2: Other symptoms	0.39	Yes
	Benchmark 4.3: Family/carer	0.31	Yes
	Benchmark 4.4: Psychological/spiritual	0.21	Yes
SAS	Benchmark 4.5: Pain	0.34	Yes
	Benchmark 4.6: Nausea	0.29	Yes
	Benchmark 4.7: Breathing problems	0.48	Yes
	Benchmark 4.8: Bowel problems	0.50	Yes

The benchmark for
outcome measure 4 is zero.

For more information on the outcome measures and benchmarks, see
Section 2 and Appendix C.

1.2 National benchmark profiles

In this section, the national profiles for selected benchmarks are split by setting (inpatient or community) and presented graphically.

The selected benchmarks included are:

Benchmark 1	Patients episode commences on the day of or the day after date ready for care
Benchmark 2	Patients in the unstable phase for 3 days or less
Benchmark 3.1	PCPSS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end
Benchmark 3.2	PCPSS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end
Benchmark 3.3	SAS: Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end
Benchmark 3.4	SAS: Patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end

Interpretation hint:

The national profile graphs below allows services to see how they are performing in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. Western Australia services are highlighted as dots on the graph.

If no dots are present on a particular graph, this means that Western Australian services has not met the criteria for inclusion in this measure. This may be caused by insufficient data item completion, or not having any data falling into a particular category, for example, no phases starting with moderate/severe SAS pain.

The red line on the graph indicates the benchmark for that outcome measure.

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

Benchmark 1

Figure 1 Percentage of patients with episode started on the day of, or the day after date ready for care – inpatient setting

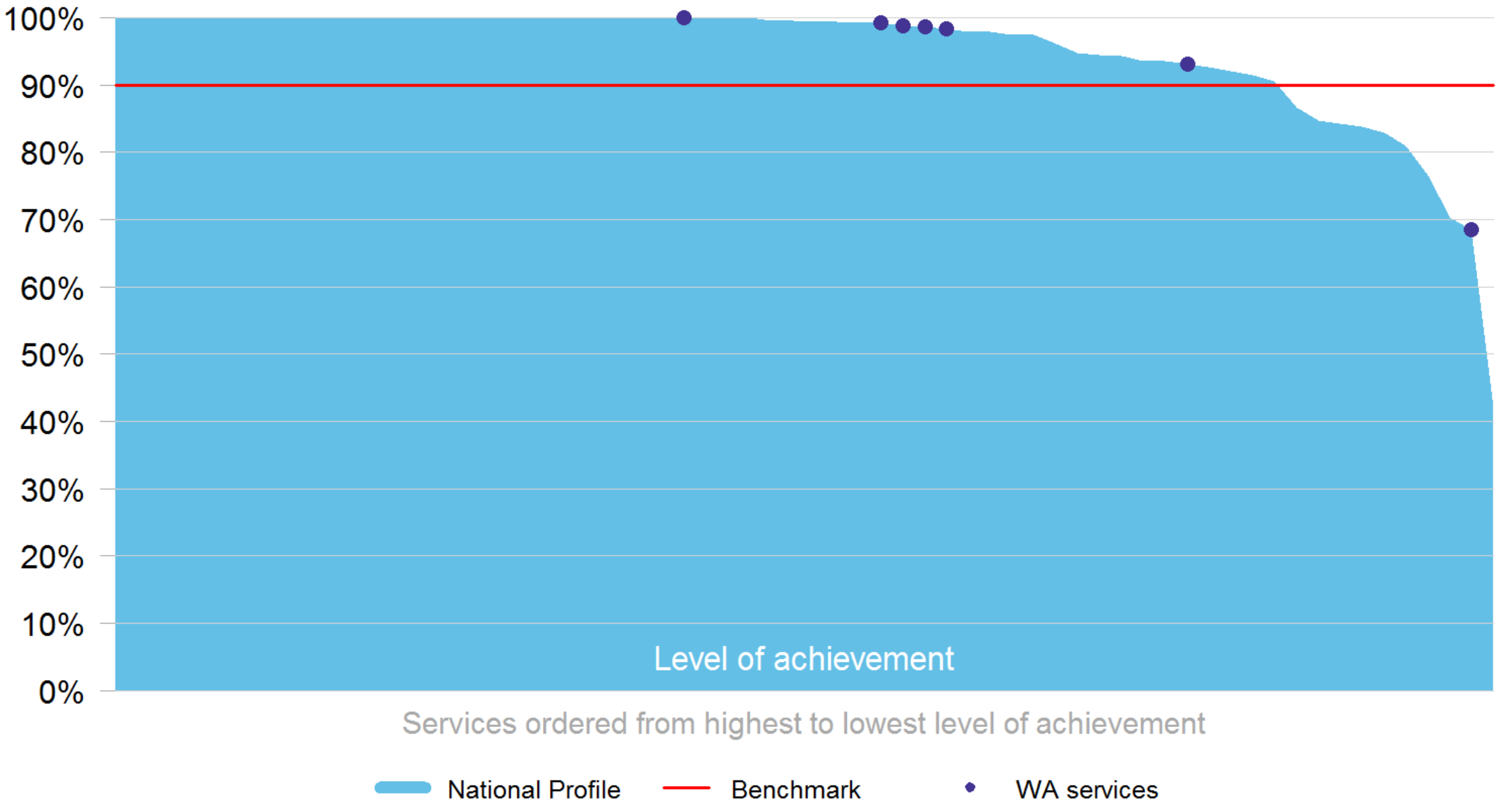
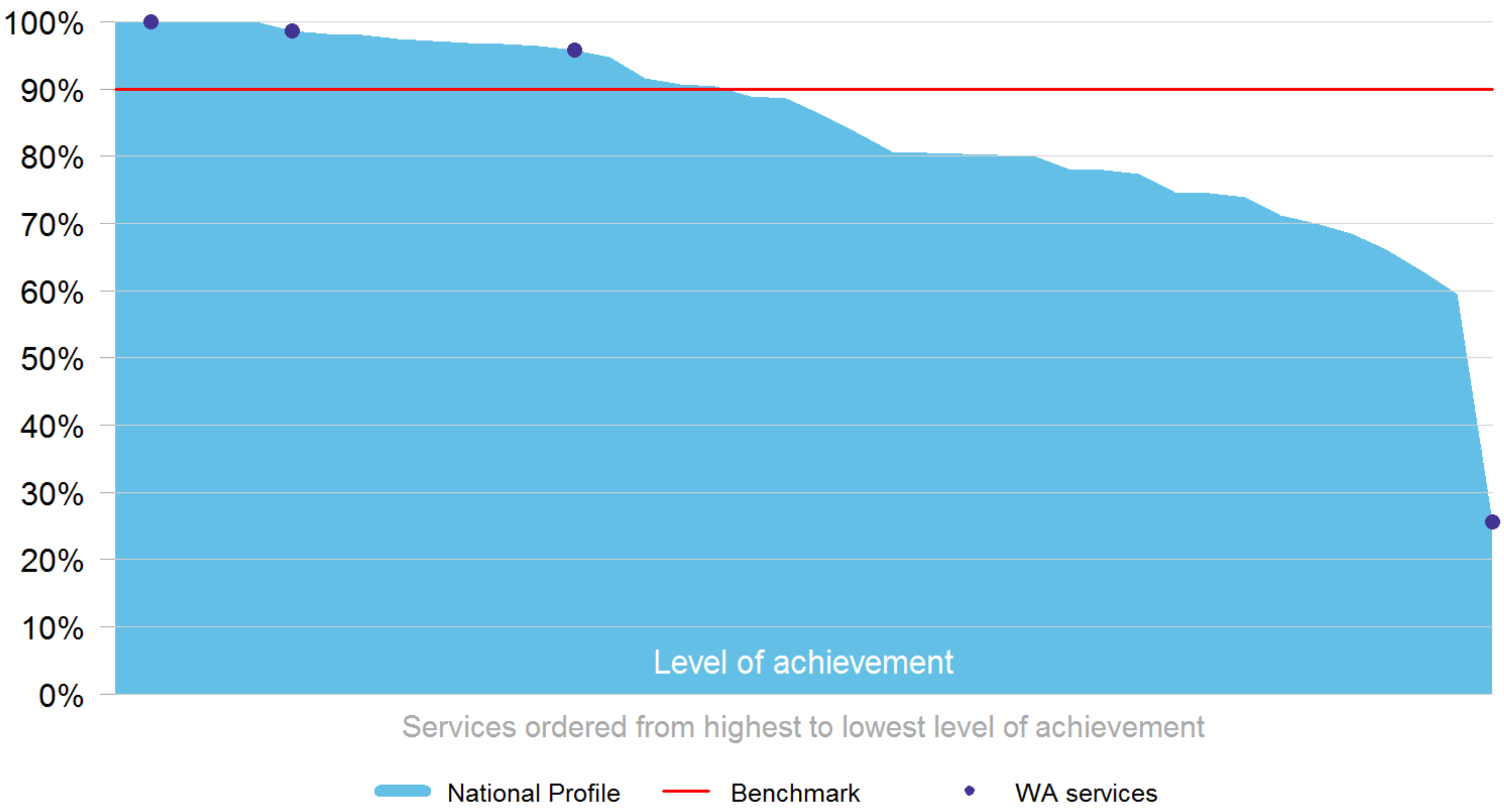


Figure 2 Percentage of patients with episodes started on the day of, or the day after date ready for care – community setting



Outcome measure 2 – Time in unstable phase

Benchmark 2

Figure 3 Percentage of patients in the unstable phase for 3 days or less – inpatient setting

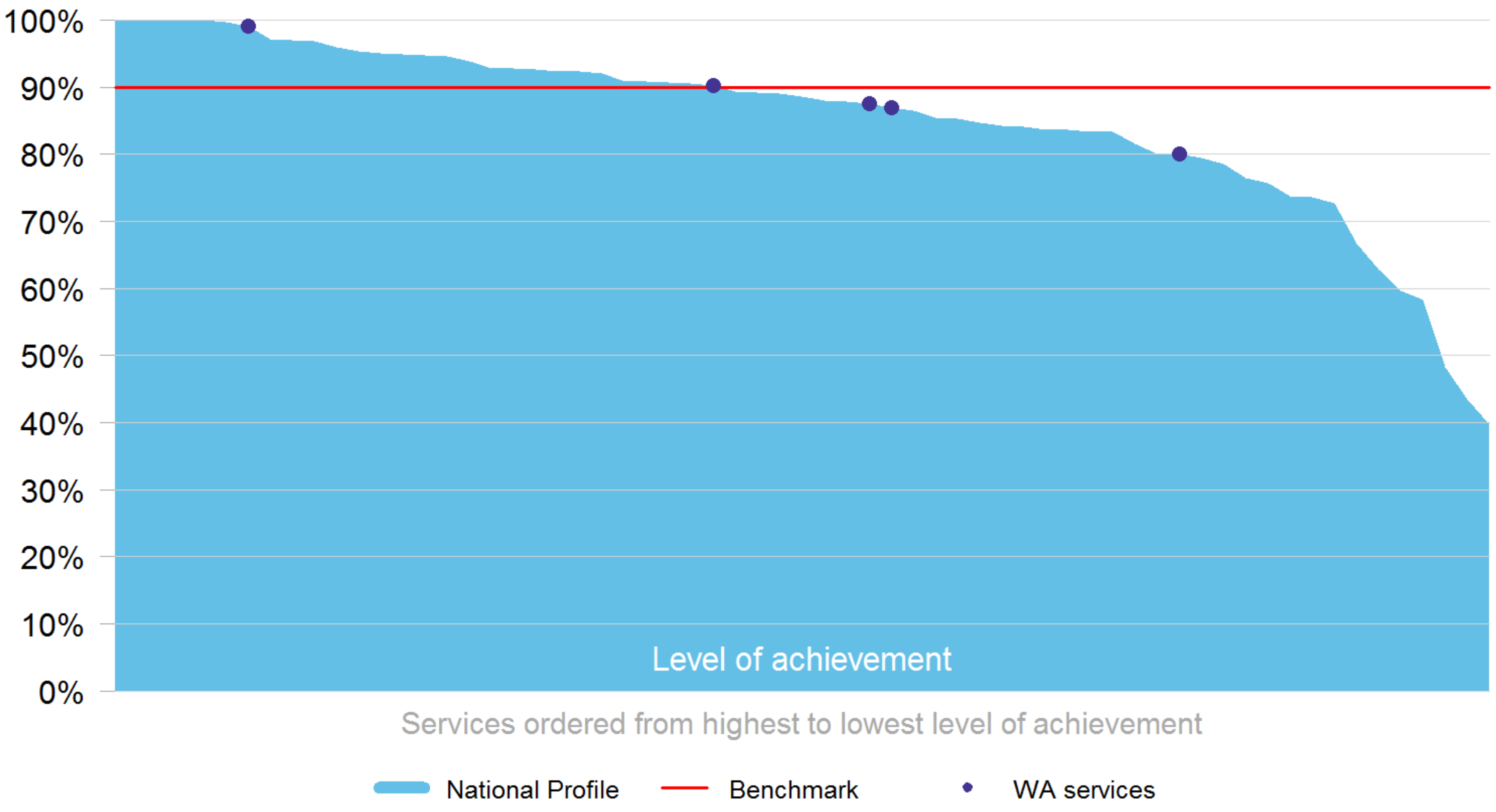
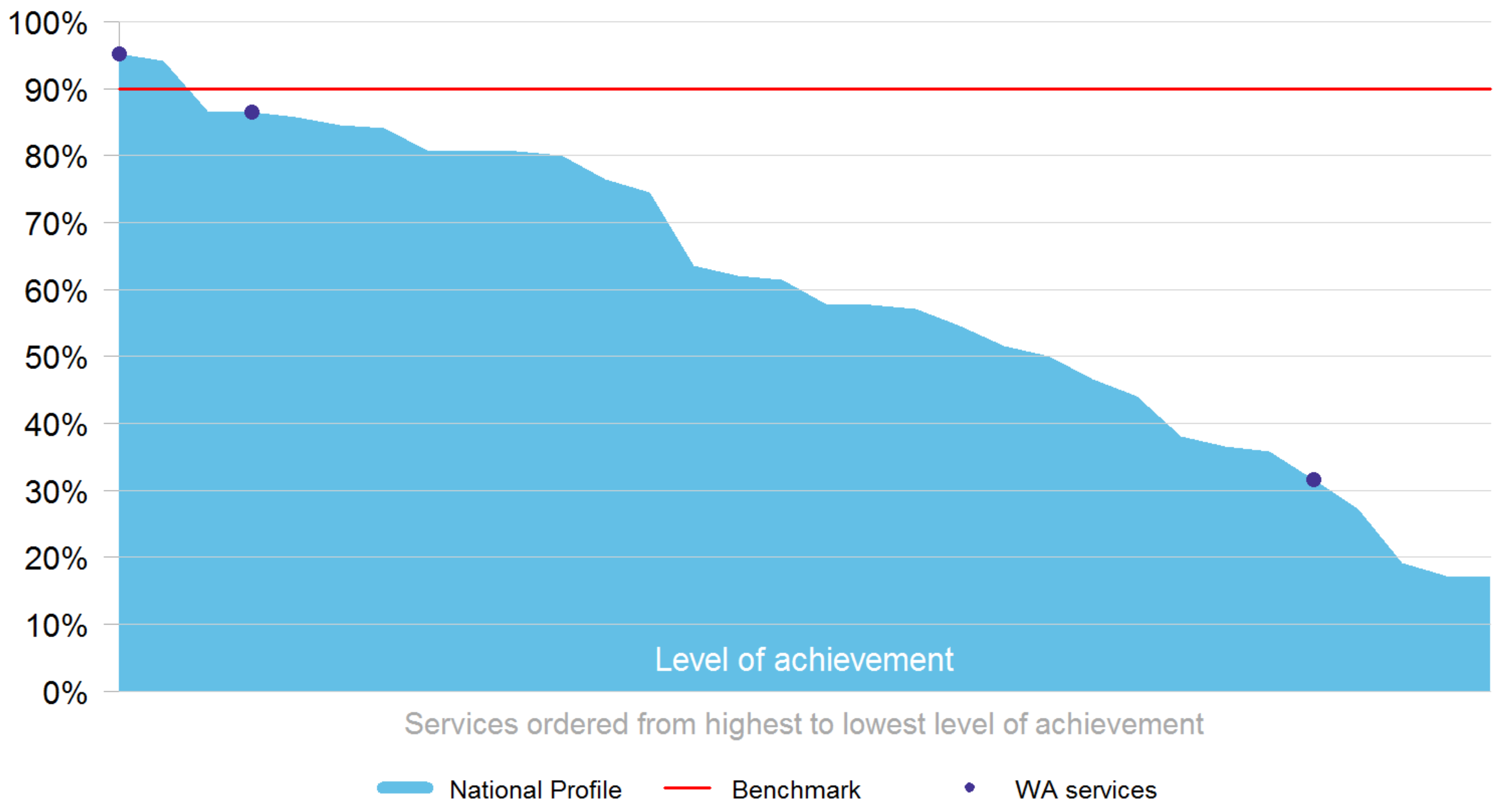


Figure 4 Percentage of patients in the unstable phase for 3 days or less – community setting



Outcome measure 3 – Change in pain

Benchmark 3.1

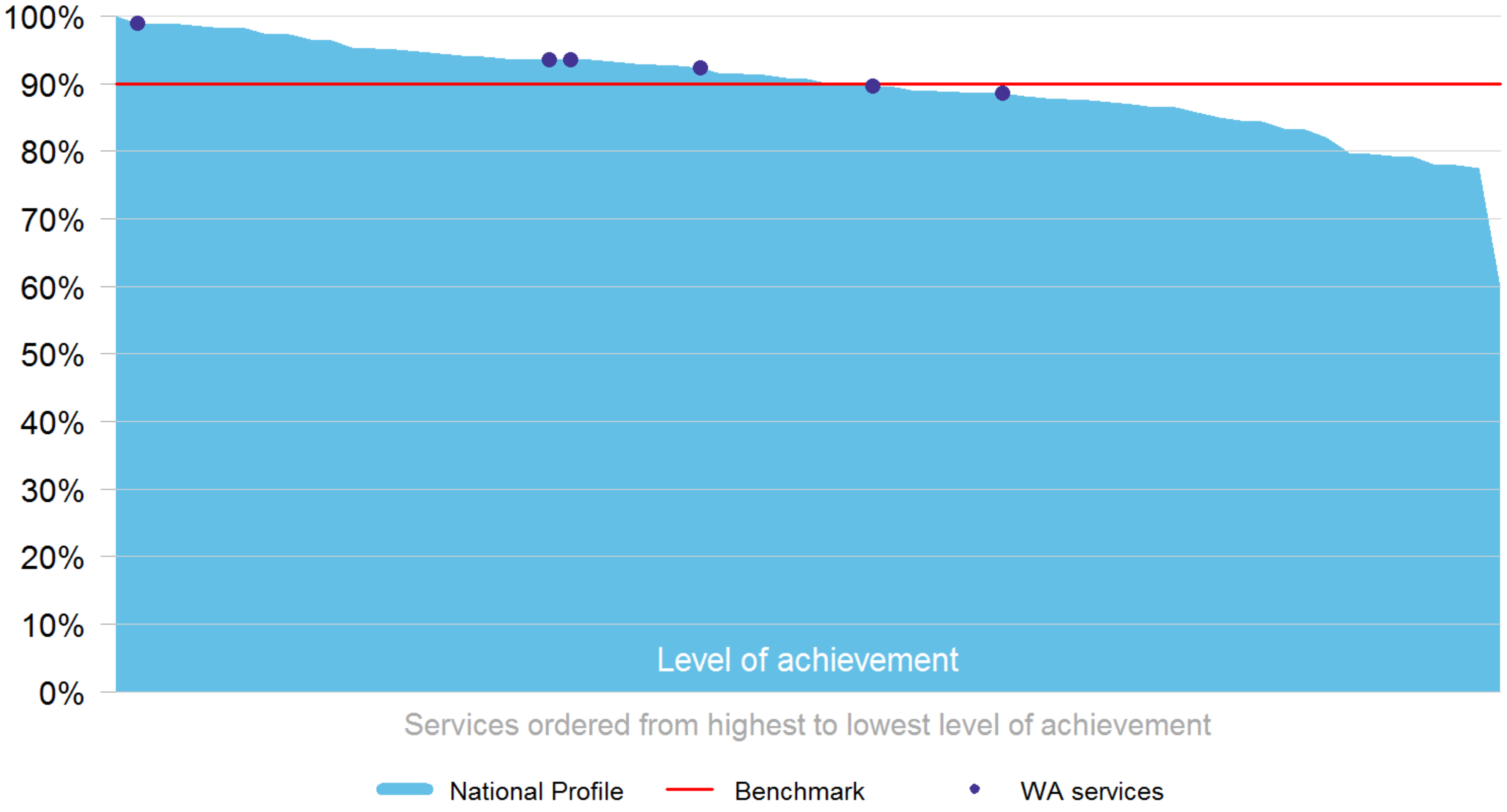
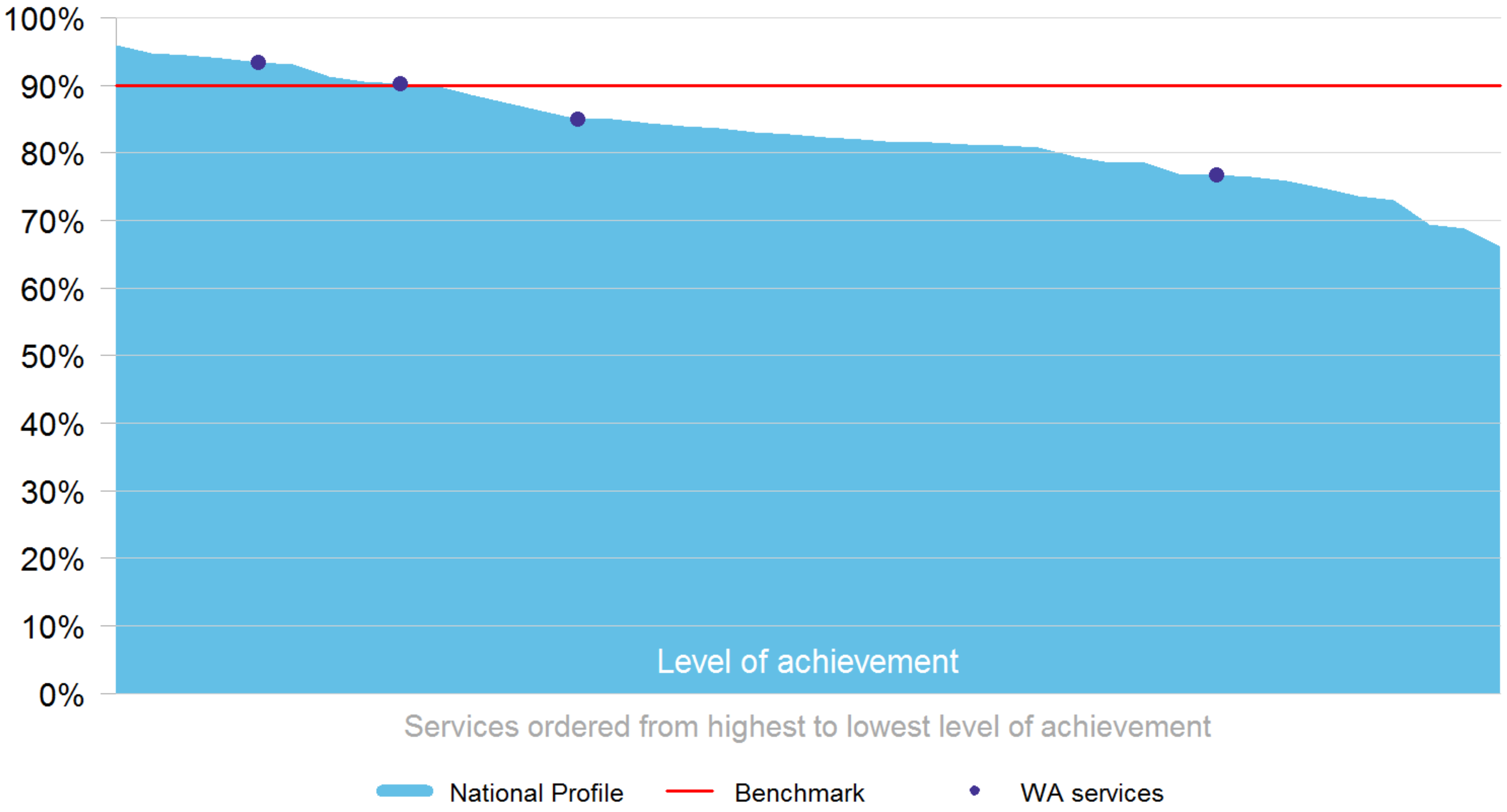


Figure 5 PCPSS: Percentage of patients with absent/mild pain at phase start, remaining absent/mild at phase end – inpatient setting

Figure 6 PCPSS: Percentage of patients with absent/mild pain at phase start, remaining absent/mild at phase end – community setting



Benchmark 3.2

Figure 7 PCPSS: Percentage of patients with moderate/severe pain at phase start, with absent/mild pain at phase end – inpatient setting

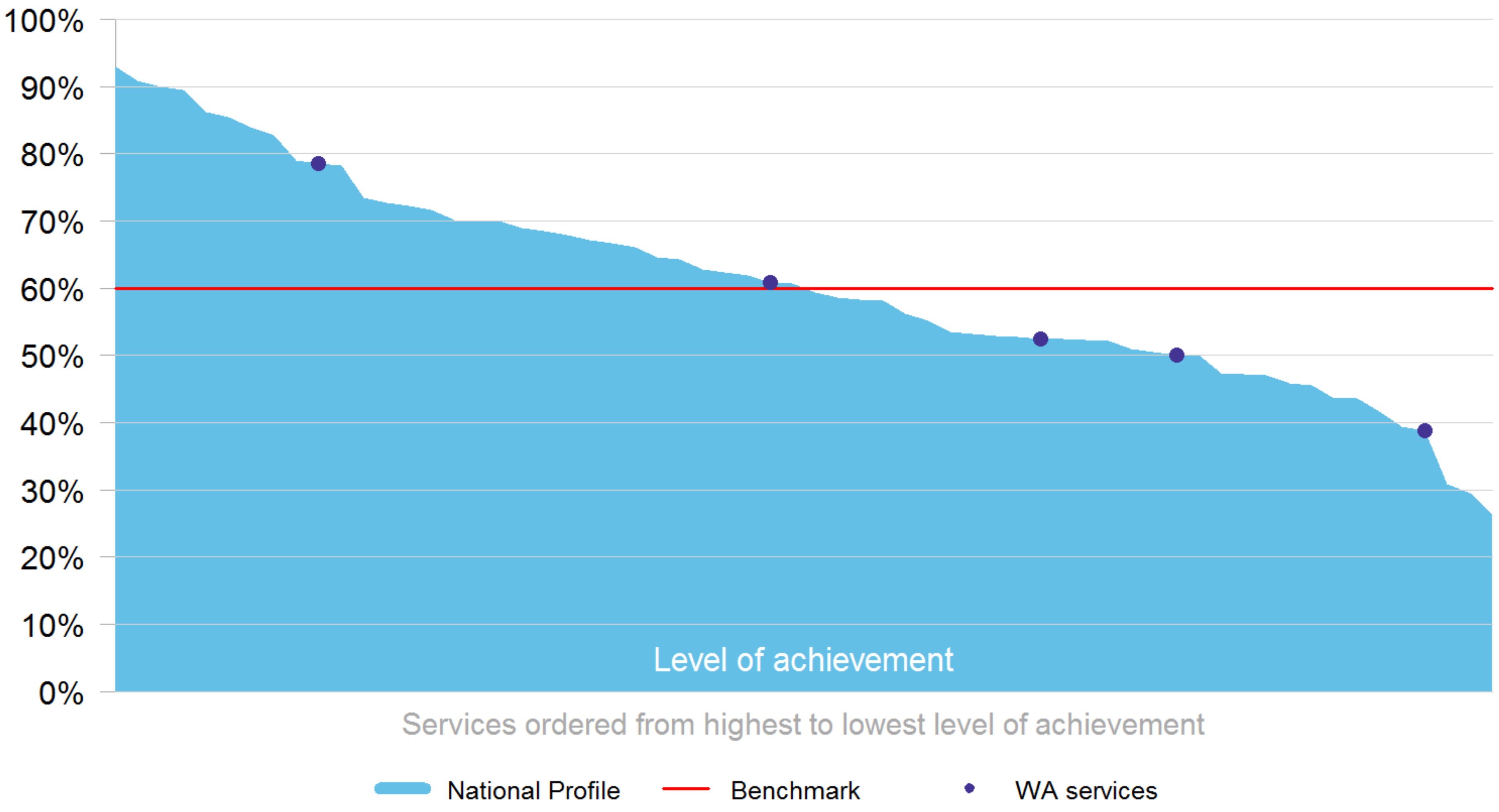
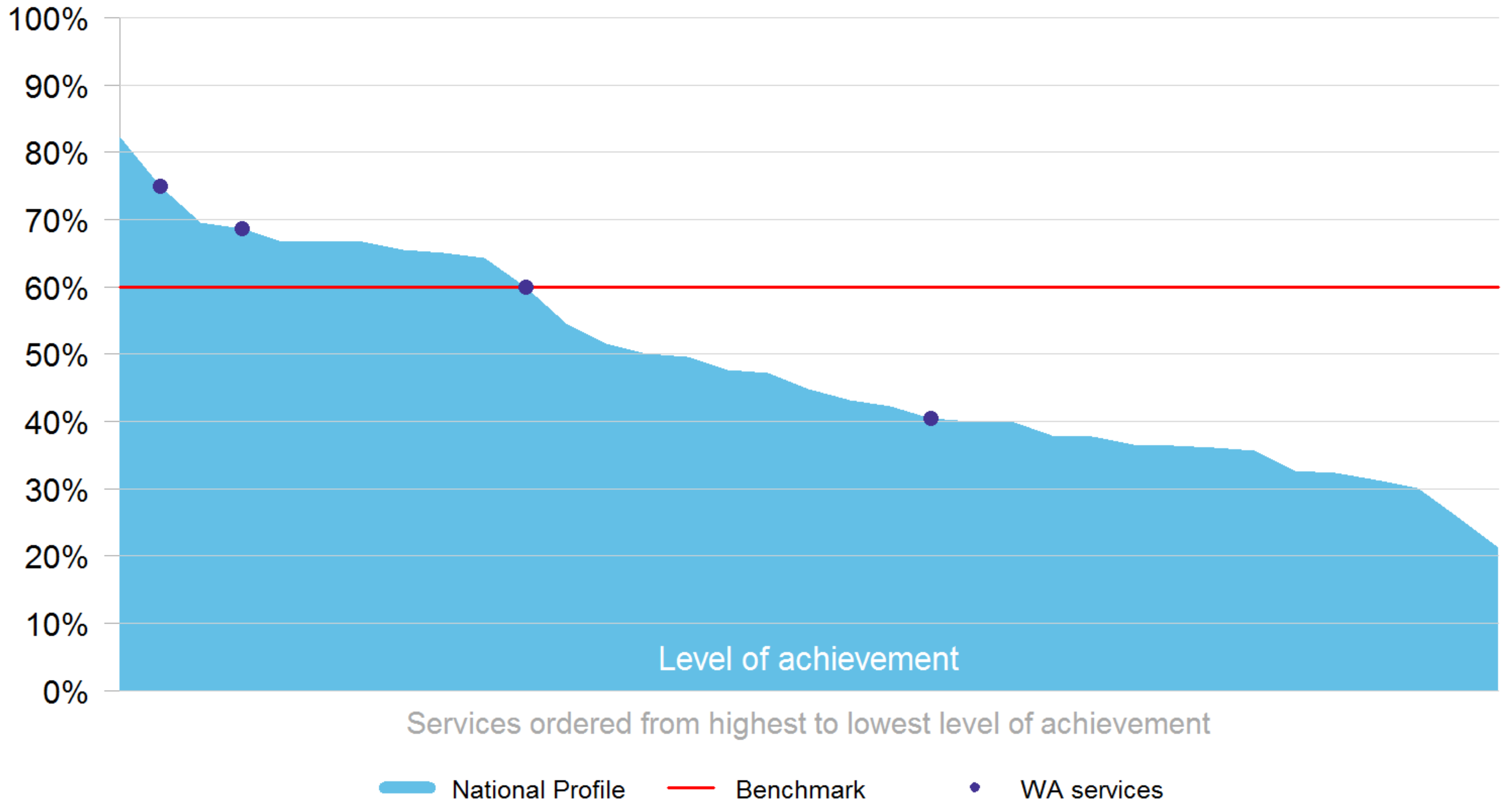


Figure 8 PCPSS: Percentage of patients with moderate/severe pain at phase start, with absent/mild pain at phase end – community setting



Benchmark 3.3

Figure 9 SAS: Percentage of patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end – inpatient setting

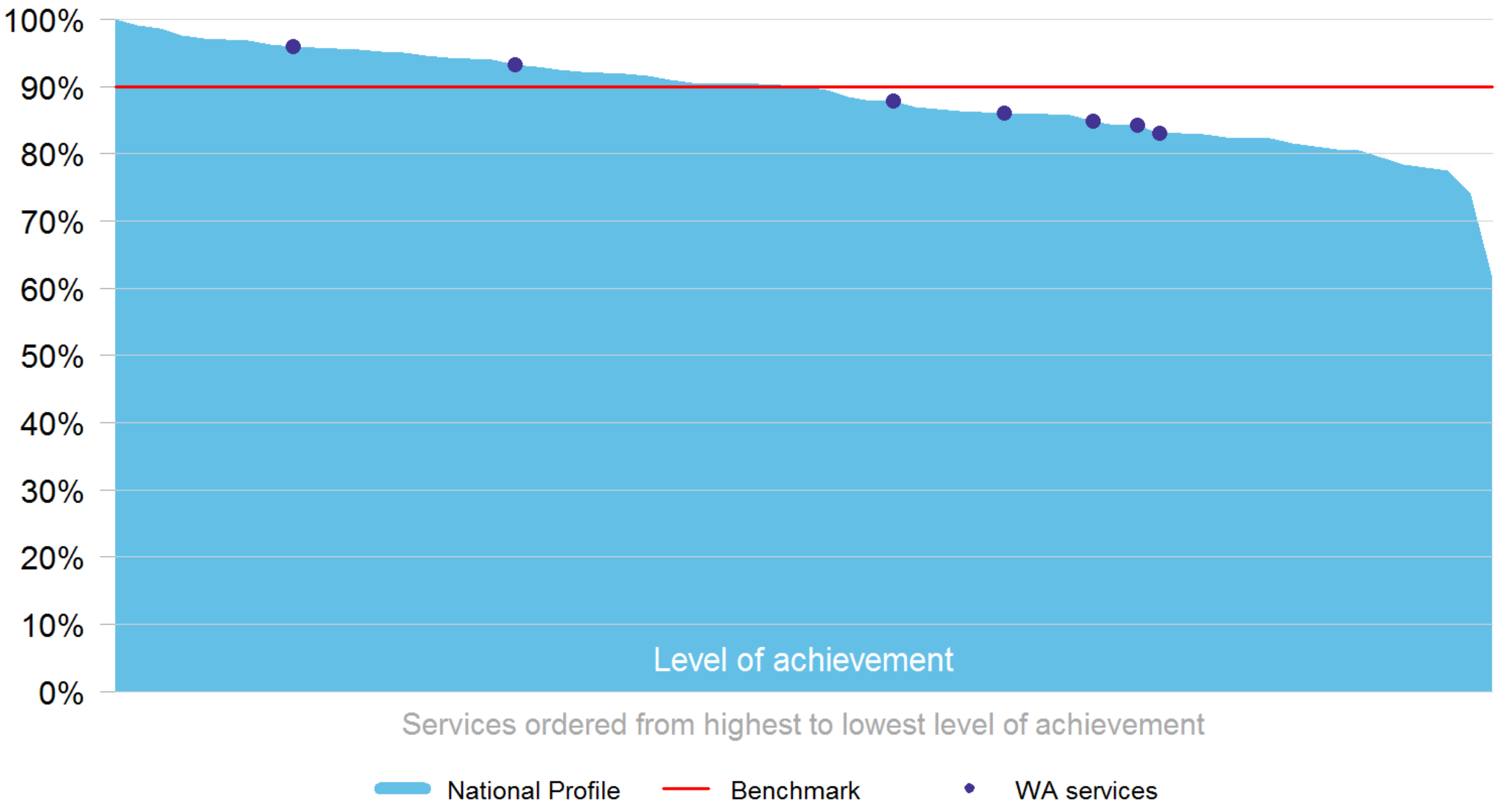
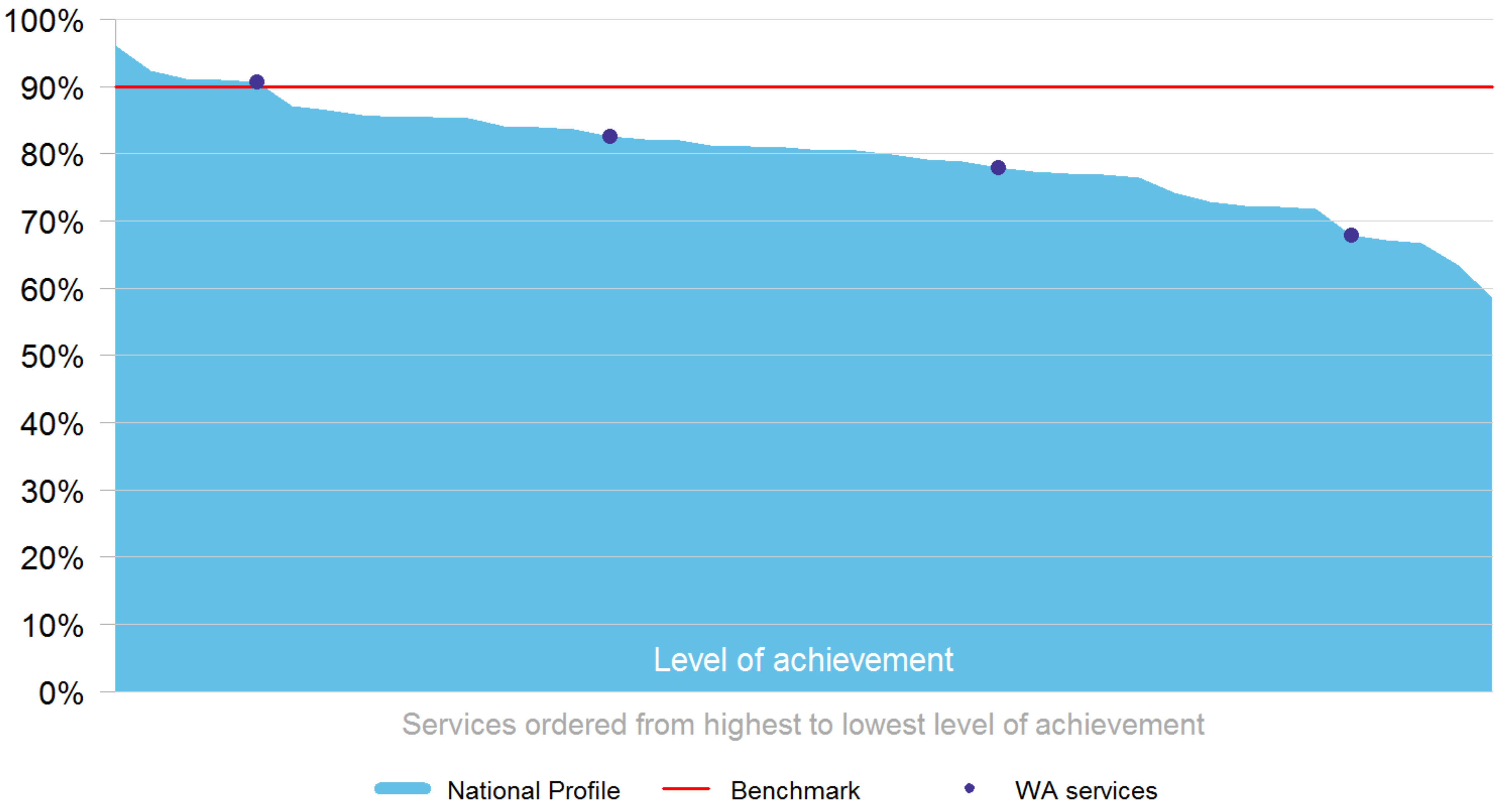


Figure 10 SAS: Percentage of patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end – community setting



Benchmark 3.4

Figure 11 SAS: Percentage of patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end – inpatient setting

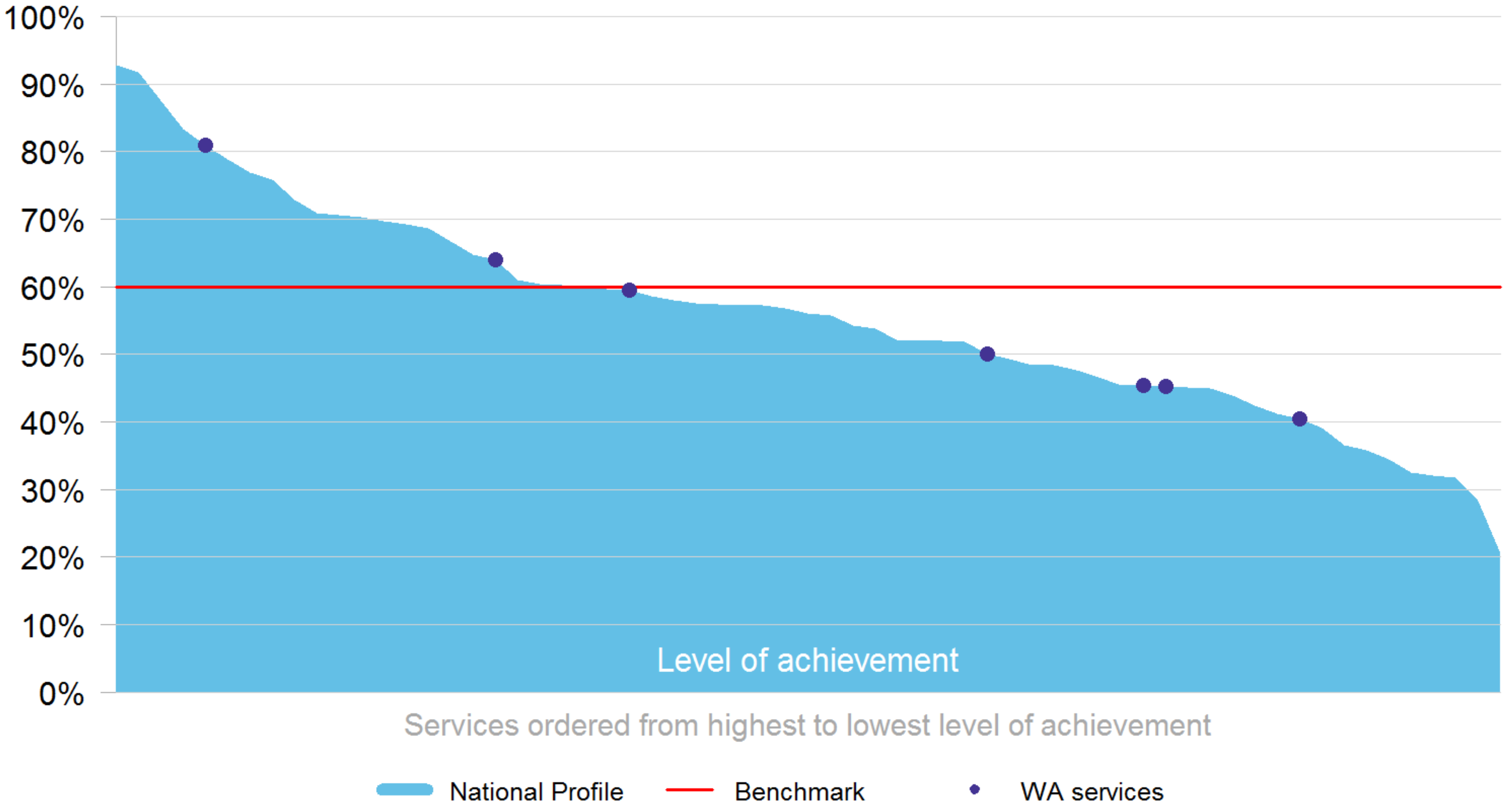
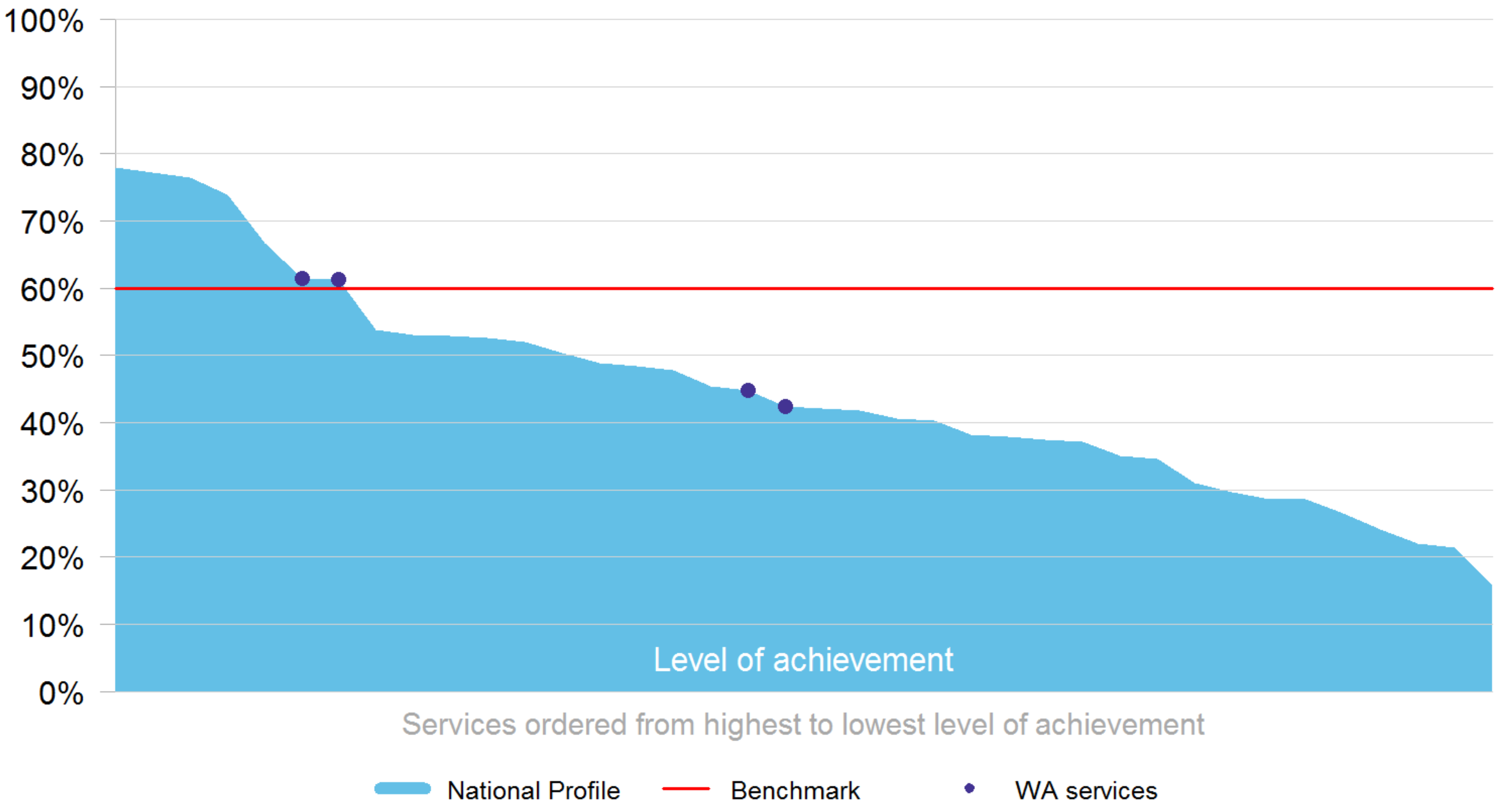


Figure 12 SAS: Percentage of patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end – community setting



Section 2 Outcome measures in detail

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

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

Benchmark 1: This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following date ready for care.

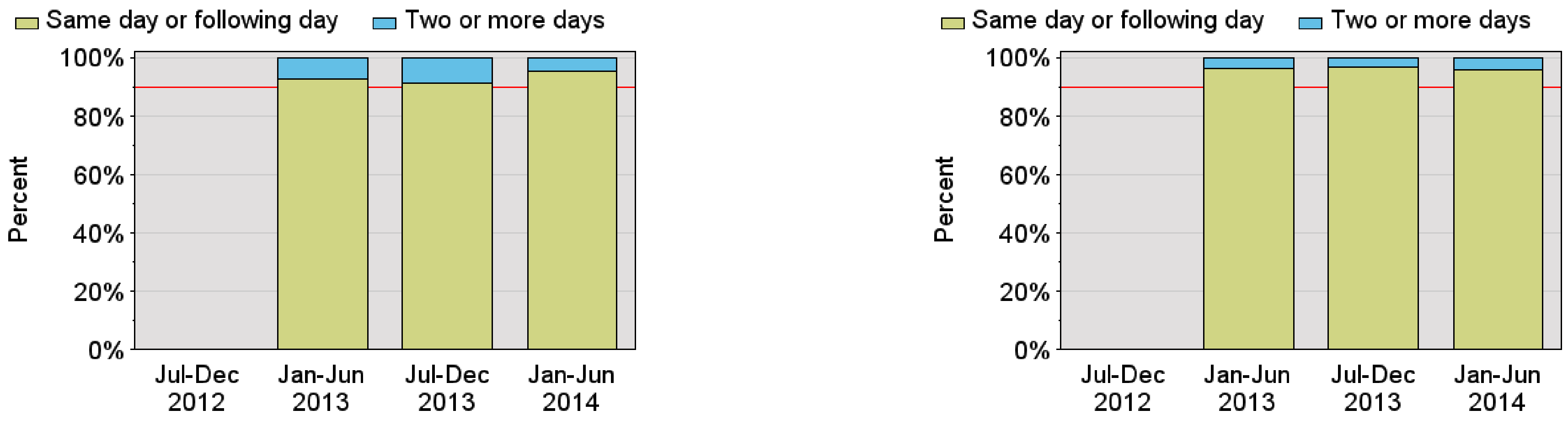
Table 3 Time from date ready for care to episode start by setting

Time (in days)	Inpatient				Community			
	WA	%	All Services	%	WA	%	All Services	%
Same day	927	82.0	9,348	88.9	1,944	95.7	7,167	79.1
Following day	150	13.3	712	6.8	19	0.9	474	5.2
2-7 days	47	4.2	397	3.8	46	2.3	1,008	11.1
8-14 days	2	0.2	42	0.4	17	0.8	210	2.3
Greater than 14 days	4	0.4	18	0.2	6	0.3	203	2.2
Average	1.1	na	1.2	na	1.2	na	2.4	na
Median	1	na	1	na	1	na	1	na

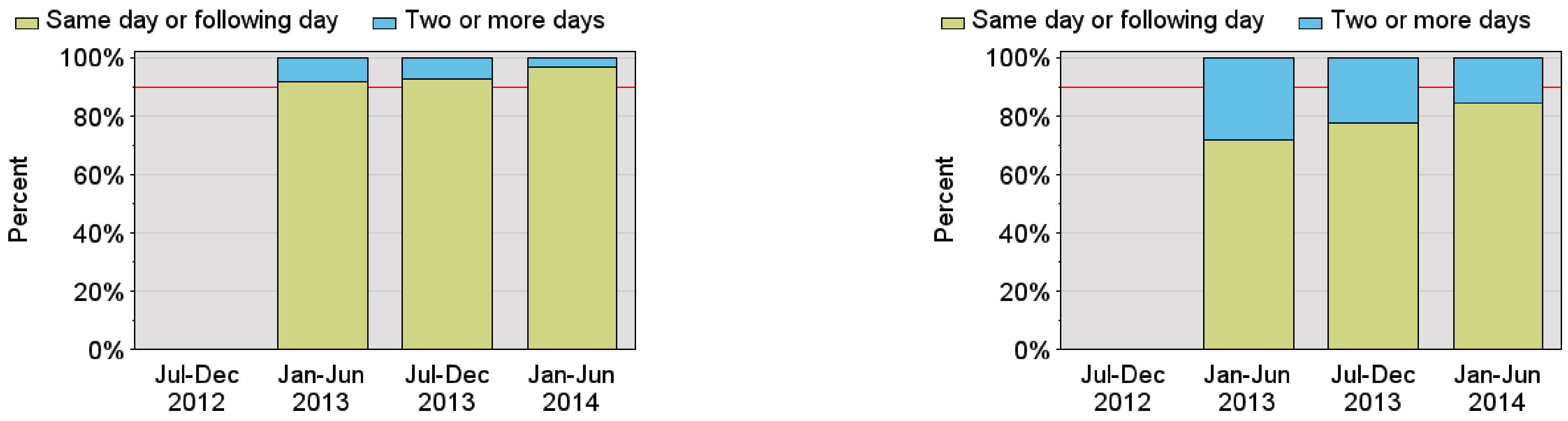
Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical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

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

Figure 13 Trends in outcome measure 1


Inpatient setting for **WA services**

Inpatient setting for **all services**


Community settings for **WA services**

Community settings for **all services**

2.2 Outcome measure 2 – Time in unstable phase

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

An unstable phase is triggered if:

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

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

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

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

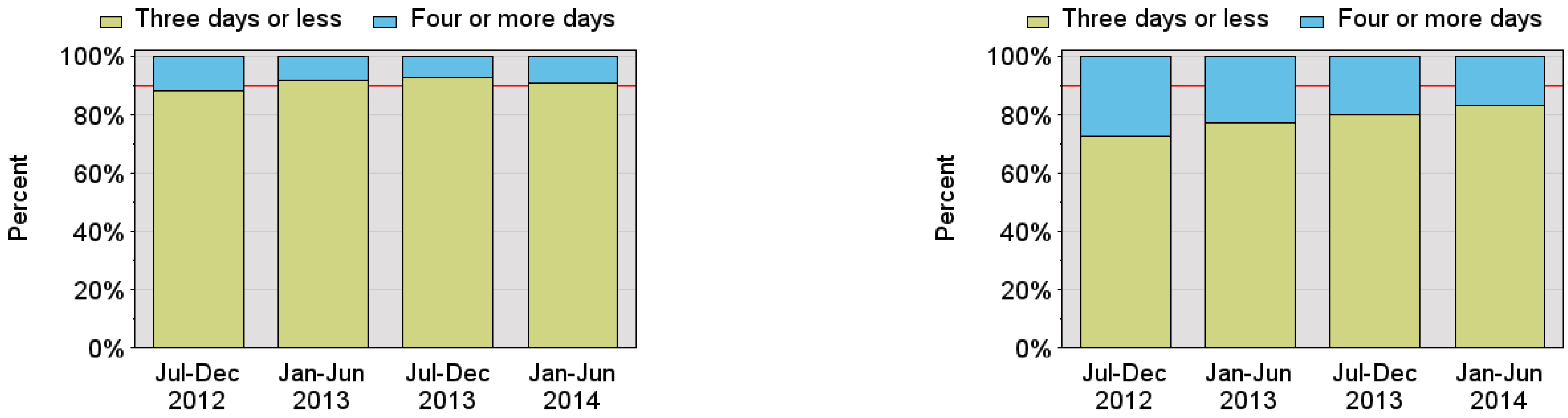
Table 4 Time in unstable phase by setting

Length of unstable phase	Inpatient				Community			
	WA	%	All Services	%	WA	%	All Services	%
Same day	23	6.5	241	3.8	256	27.6	555	20.6
1 day	191	53.8	2,684	42.8	493	53.1	885	32.9
2 days	76	21.4	1,515	24.2	89	9.6	285	10.6
3 days	32	9.0	752	12.0	31	3.3	175	6.5
4-5 days	26	7.3	621	9.9	31	3.3	193	7.2
6-7 days	4	1.1	246	3.9	16	1.7	127	4.7
8-14 days	3	0.8	177	2.8	10	1.1	170	6.3
Greater than 14 days	0	0.0	37	0.6	3	0.3	299	11.1
Total	***355***	***100.0***	***6,273***	***100.0***	***929***	***100.0***	***2,689***	***100.0***

Figure 14 Trends in outcome measure 2

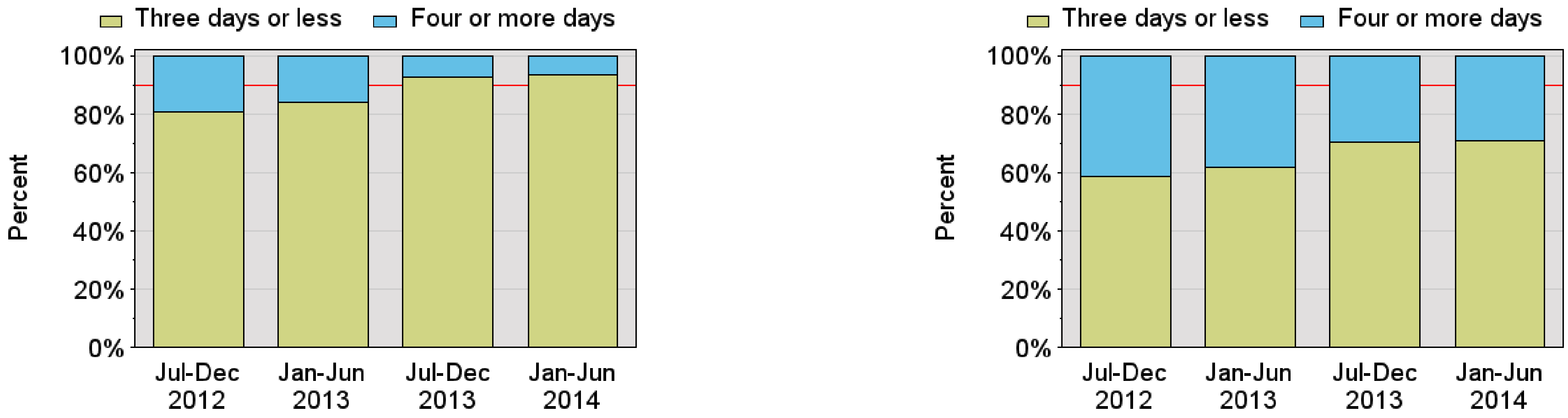
Inpatient setting for **WA services**

Inpatient setting for **all services**



Community settings for **WA services**

Community settings for **all services**



2.3 Outcome 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 PCPSS is clinician rated and measures the severity of pain as a clinical problem while the SAS is patient rated and measures distress caused by pain. There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain (Table 5 and Table 7), and the other relating to the management of pain for patients with moderate or severe pain (Table 6 and Table 8). For the analysis in this report SAS scores have been grouped as 0 absent, 1-3 mild, 4-7 moderate and 8-10 severe. 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 Trends in benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end by setting

Setting	PCPSS	WA				All Services			
		Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014
Inpatient	Start absent/mild (N)*	928	1,237	1,442	975	10,155	11,577	15,025	14,142
	End absent/mild (%)	90.1	90.8	91.7	91.2	86.0	88.5	88.5	90.1
Community	Start absent/mild (N)*	5,192	5,641	6,511	6,776	10,424	10,700	13,454	13,873
	End absent/mild (%)	85.1	84.6	83.6	85.3	83.4	82.6	83.2	84.9

*Total number of phases included in this benchmark.

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 Trends in benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild pain at phase end by setting

Setting	PCPSS	WA				All Services			
		Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014
Inpatient	Start moderate/severe (N)*	475	600	619	522	4,653	4,876	5,822	5,181
	End absent/mild (%)	47.6	51.5	50.4	46.9	52.8	56.2	53.8	56.1
Community	Start moderate/severe (N)*	1,111	1,364	1,600	1,424	3,006	3,144	3,896	3,612
	End absent/mild (%)	60.4	60.4	61.4	68.0	51.6	51.7	51.8	52.5

*Total number of phases included in this benchmark.

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 must end with the patient still experiencing only absent or mild pain.

Table 7 Trends in benchmark 3.3: SAS Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end by setting

Setting	SAS	WA				All Services			
		Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014
Inpatient	Start absent/mild (N)*	1,361	1,366	1,473	1,112	11,302	11,646	13,788	12,669
	End absent/mild (%)	87.1	86.7	86.9	87.0	85.3	87.8	87.0	88.7
Community	Start absent/mild (N)*	5,020	5,350	6,137	6,448	10,052	10,171	12,752	13,209
	End absent/mild (%)	83.4	82.5	80.6	82.4	81.8	81.2	81.2	82.4

*Total number of phases included in this benchmark.

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 Trends in benchmark 3.4: SAS Patients experience moderate/severe distress from pain at phase start, with absent/mild pain at phase end by setting

Setting	SAS	WA				All Services			
		Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014
Inpatient	Start moderate/severe (N)*	940	794	922	670	5,858	5,890	6,956	6,027
	End absent/mild (%)	42.0	48.6	45.6	47.6	49.0	51.4	50.4	52.1
Community	Start moderate/severe (N)*	1,426	1,623	1,963	1,728	3,557	3,676	4,756	4,287
	End absent/mild (%)	52.3	54.2	58.5	60.7	46.8	47.5	48.7	48.4

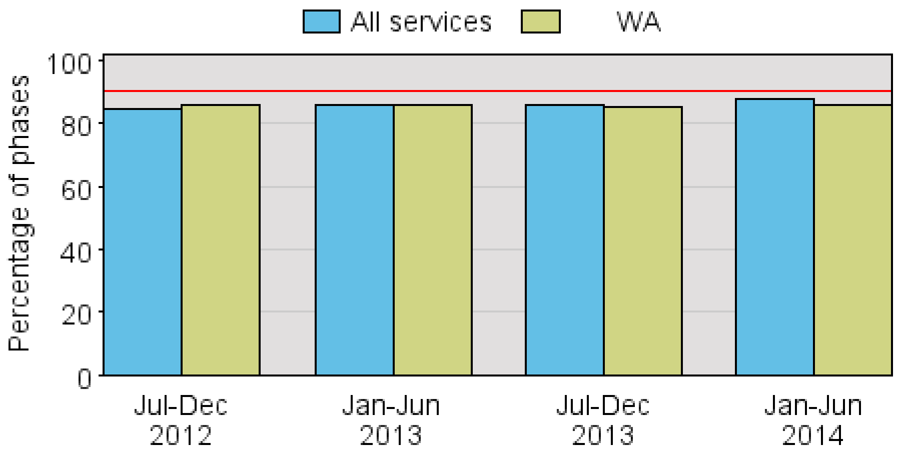
*Total number of phases included in this benchmark.

Interpretation hint:

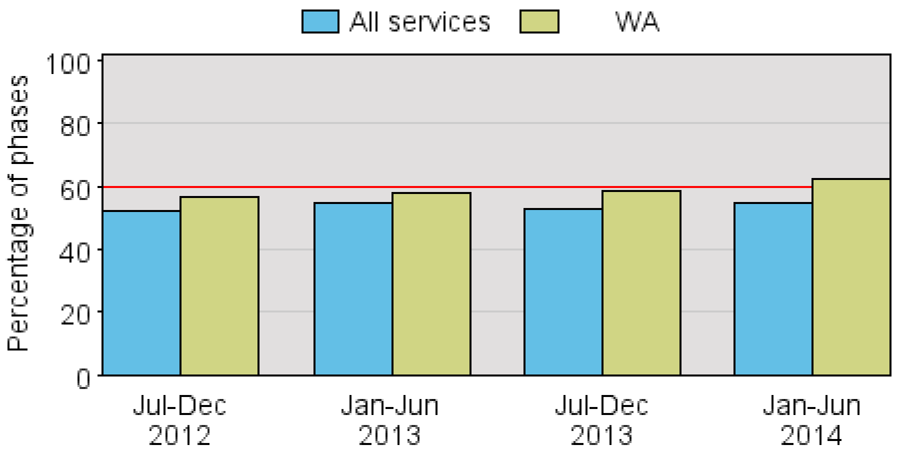
For this report, the number (N) shown in Table 5 to Table 8 has changed. In past reports, only the number of phases that met the benchmark was shown. This has been changed to report on the total number of phases included in the benchmark. As a result of this change, past reports will display a different number but the percentage remains the same.

Figure 15 Trends in outcome measure 3

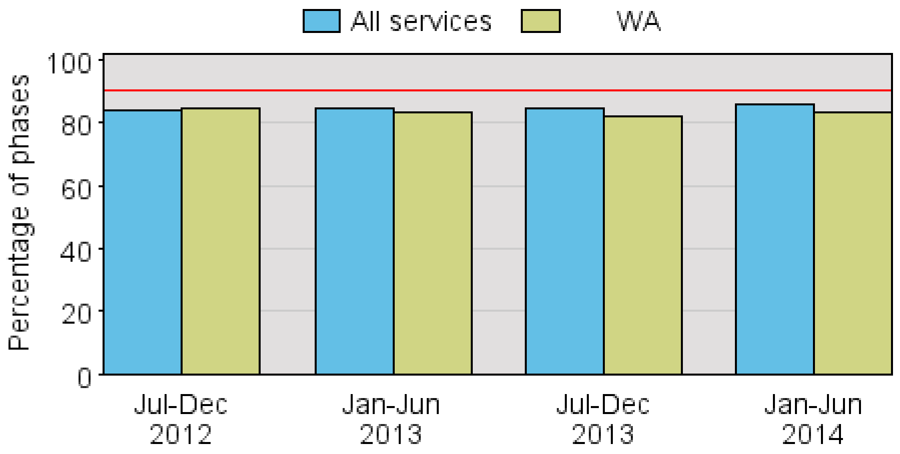
Benchmark 3.1: PCPSS - Absent/mild pain at both start and end of phase



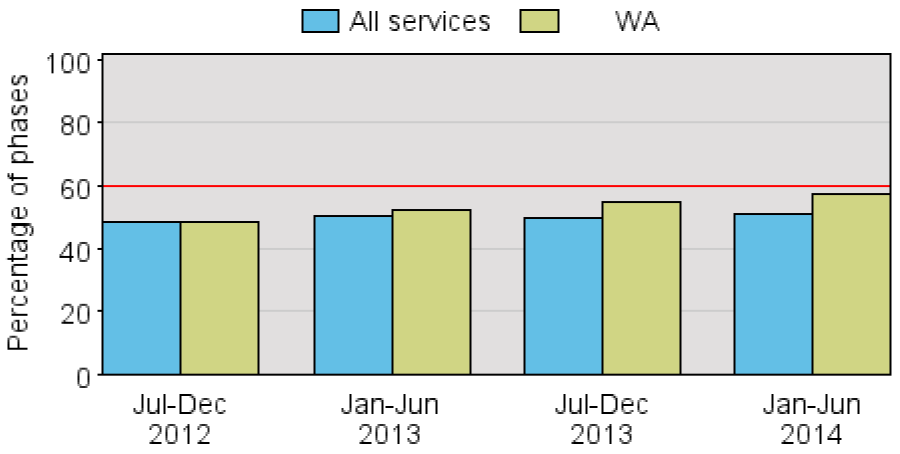
Benchmark 3.2: PCPSS - Moderate/severe pain at start with absent/mild pain at end



Benchmark 3.3: SAS - Absent/mild pain at both start and end of phase



Benchmark 3.4: SAS - Moderate/severe pain at start with absent/mild pain at end



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

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

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

The suite of benchmarks included in outcome 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.

Interpretation hint:

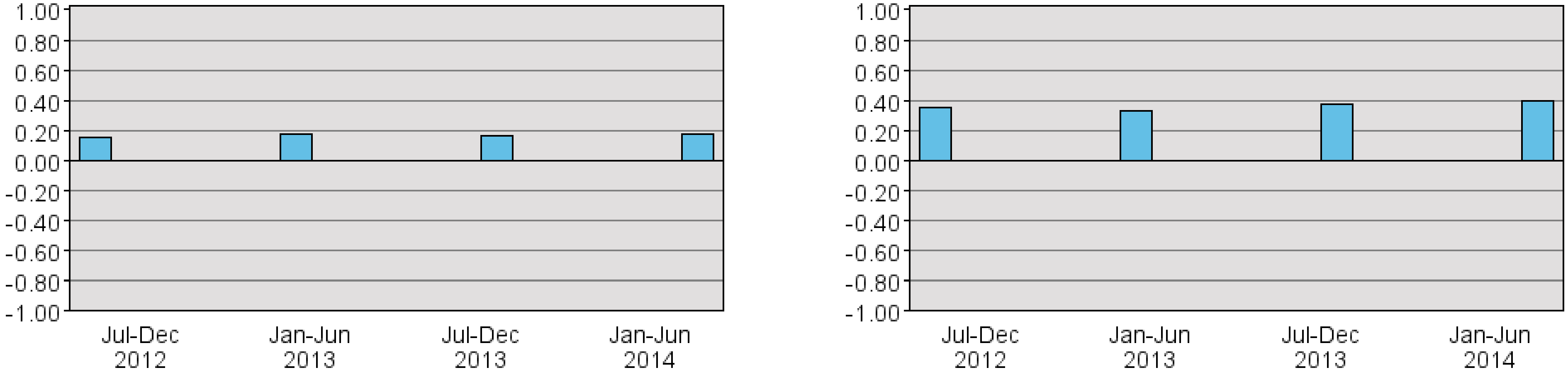
The X-CAS measures are calculated relative to a baseline reference period (currently July to December 2008). As a result:

If X-CAS for WA is greater than 0 then on average, your patients' change in symptom was better than similar patients in the baseline reference period.
If X-CAS for WA is equal to 0 then on average, your patients' change in symptom was about the same as similar patients in the baseline reference period.
If X-CAS for WA is less than 0 then on average, your patients' change in symptom was worse than similar patients in the baseline reference period.

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

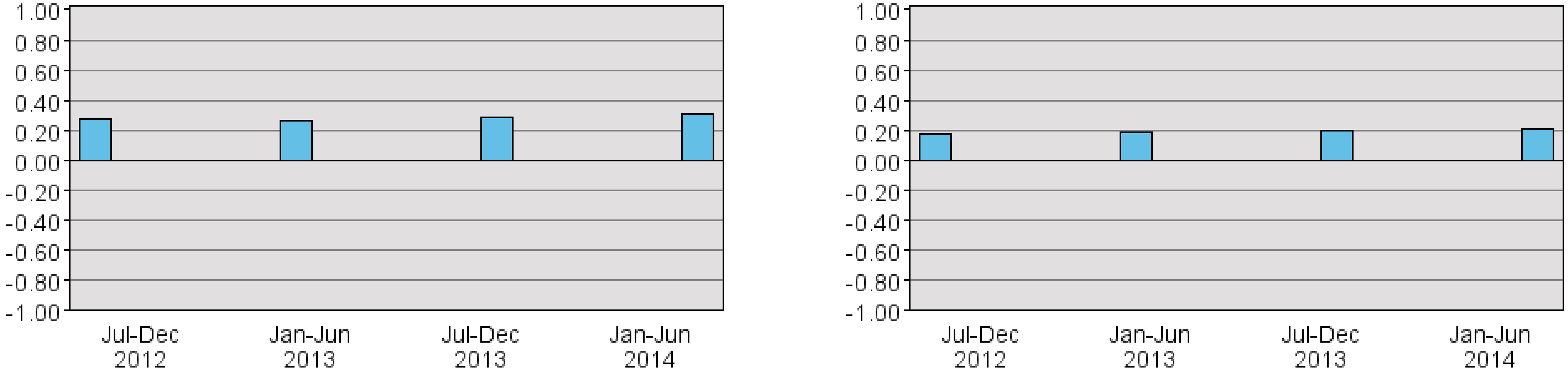
A more technical explanation of X-CAS is included in Appendix C.

Figure 16 Trends in outcome measure 4 – Palliative Care Problem Severity Score (PCPSS)



Benchmark 4.1: Pain

Benchmark 4.2: Other symptoms



Benchmark 4.3: Family/carer

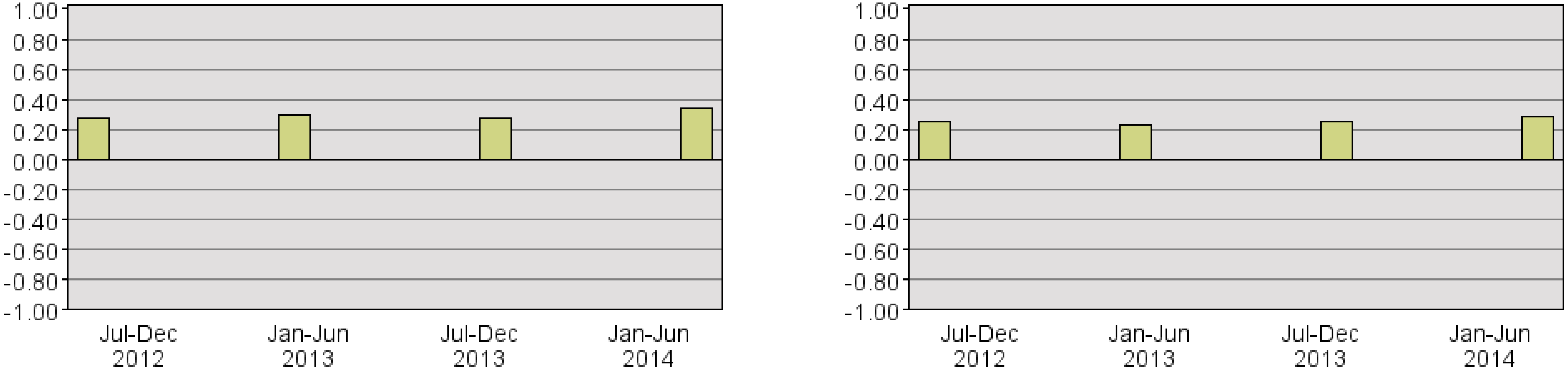
Benchmark 4.4: Psychological/spiritual

Note: Only services with 10 or more valid assessments are included in the above graphs.

Figure 17 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)

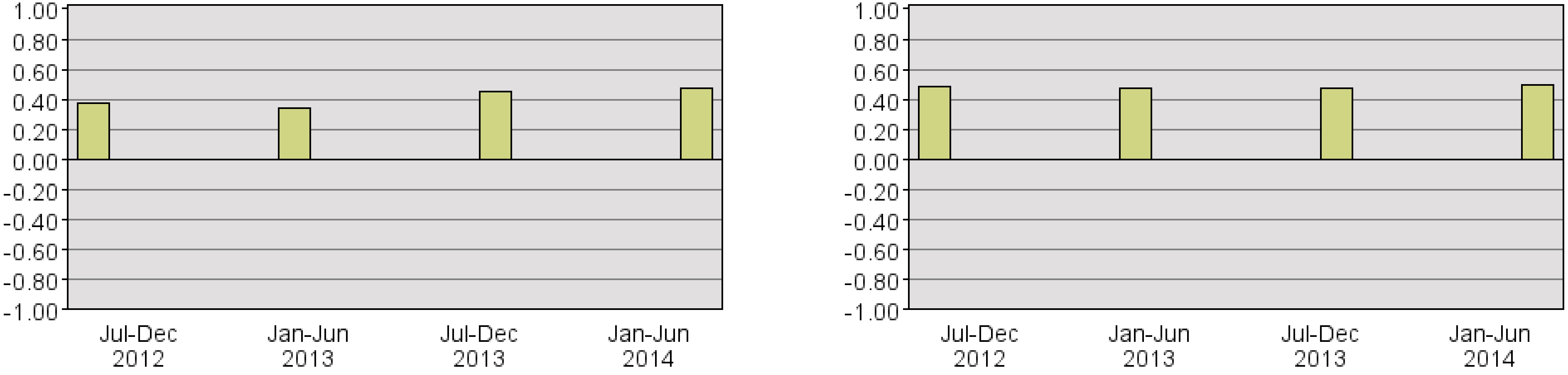
Benchmark 4.5: Pain

Benchmark 4.6: Nausea



Benchmark 4.7: Breathing problems

Benchmark 4.8: Bowel problems



Note: Only services with 10 or more valid assessments are included in the above graphs.

Section 3 Descriptive analysis

Information is collected at three levels – patient, episode and phase.

Patient level includes data items relating to patient demographic. The information collected on each patient includes Indigenous status, sex, preferred language and country of birth.

Episode level includes data items which focus on characterising the setting of palliative care service provision. It also provides information relating to the facility or organisation that has referred the patient as well as how a palliative care episode starts and ends.

Phase level data items describe a palliative care patient's stage of illness, functional impairment and levels of pain and symptom distress, using five clinical assessment tools.

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

3.1 Profile of palliative care patients

PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record. Family/carers are included in this definition if interventions relating to them are recorded in the patient medical record. For the purpose of palliative care this includes the bereaved family of the deceased patient (particularly for the bereavement phase).

Table 9 shows the Indigenous status for all the patients in Western Australia and nationally.

Table 9 Indigenous status

Indigenous status	WA	%	All Services	%
Aboriginal but not Torres Strait Islander origin	37	1.3	141	0.8
Torres Strait Islander but not Aboriginal origin	0	0.0	14	0.1
Both Aboriginal and Torres Strait Islander origin	3	0.1	13	0.1
Neither Aboriginal nor Torres Strait Islander origin	2,620	94.8	16,333	97.0
Not stated/inadequately described	105	3.8	332	2.0
Total	**2,765**	**100.0**	**16,833**	**100.0**

Table 10 shows the breakdown of deaths for all patients in Western Australia and nationally for the reporting period. All inpatient deaths are reported in the hospital category while the community deaths can be found in the private residence and residential aged care facility categories.

Table 10 Place of death

Place of death	WA	%	All Services	%
Private residence	580	51.2	1,714	20.7
Residential aged care facility	116	10.2	548	6.6
Hospital	432	38.2	5,829	70.3
Not stated/inadequately described	4	0.4	205	2.5
Total	***1,132***	***100.0***	***8,296***	***100.0***

The following two tables show the preferred language and the country of birth respectively for all patients in Western Australia and nationally. To allow for comparison with the broader Australian community the list of languages in Table 11 is in descending order of the most frequently spoken languages according to the 2006 Census (e.g. Greek was the third most frequently spoken language in the 2006 Census). The same approach has been taken with Table 12 (e.g. Italy was the fifth highest country of birth in the 2006 Census). All other languages and countries have been grouped together to form the categories 'All other languages' and 'All other countries' respectively.

Table 11 Preferred language

Preferred language	WA	%	All Services	%
English	2,559	92.5	15,092	89.7
Italian	44	1.6	373	2.2
Greek	15	0.5	261	1.6
Cantonese/Mandarin	13	0.5	141	0.8
Arabic	5	0.2	116	0.7
Vietnamese	11	0.4	57	0.3
Spanish/Portuguese	8	0.3	44	0.3
Filipino	6	0.2	23	0.1
German	3	0.1	34	0.2
Hindi	5	0.2	25	0.1
Macedonian/Croatian	23	0.8	121	0.7
Korean	1	0.0	16	0.1
Turkish	1	0.0	33	0.2
Polish	6	0.2	21	0.1
Maltese	0	0.0	19	0.1
All other languages	65	2.4	447	2.7
Not stated/inadequately described	0	0.0	10	0.1
Total	***2,765***	***100.0***	***16,833***	***100.0***

Table 12 Country of birth

Country of birth	WA	%	All Services	%
Australia	1,518	54.9	10,640	63.2
England	390	14.1	1,190	7.1
New Zealand	58	2.1	274	1.6
China	11	0.4	156	0.9
Italy	105	3.8	700	4.2
Vietnam	19	0.7	107	0.6
India	39	1.4	127	0.8
Scotland	70	2.5	228	1.4
Philippines	4	0.1	66	0.4
Greece	32	1.2	364	2.2
Germany	39	1.4	235	1.4
South Africa	34	1.2	94	0.6
Malaysia	14	0.5	46	0.3
Netherlands	35	1.3	170	1.0
Lebanon	1	0.0	88	0.5
All other countries	316	11.4	2,139	12.7
Not stated/inadequately described	80	2.9	209	1.2
Total	***2,765***	***100.0***	***16,833***	***100.0***

Table 13 and Table 14 present a breakdown of malignant and non-malignant diagnosis for the patients seen by Western Australia and at the national level. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 39 (1.4%) patients in Western Australia and was not stated for 60 (0.4%) patients nationally.

Table 13 Primary diagnosis - malignant

Primary diagnosis	WA	% malignant diagnosis	% all diagnosis	All Services	% malignant diagnosis	% all diagnosis
Bone and soft tissue	16	0.8	0.6	195	1.5	1.2
Breast	162	7.8	5.9	1,041	7.9	6.2
CNS	59	2.9	2.1	304	2.3	1.8
Colorectal	229	11.1	8.3	1,559	11.8	9.3
Other GIT	207	10.0	7.5	1,263	9.5	7.5
Haematological	118	5.7	4.3	829	6.3	4.9
Head and neck	68	3.3	2.5	689	5.2	4.1
Lung	510	24.6	18.4	2,927	22.1	17.4
Pancreas	115	5.6	4.2	790	6.0	4.7
Prostate	145	7.0	5.2	919	6.9	5.5
Other urological	101	4.9	3.7	562	4.2	3.3
Gynaecological	91	4.4	3.3	666	5.0	4.0
Skin	119	5.7	4.3	509	3.8	3.0
Unknown primary	64	3.1	2.3	375	2.8	2.2
Other primary malignancy	60	2.9	2.2	514	3.9	3.1
Malignant – not further defined	6	0.3	0.2	93	0.7	0.6
All malignant	***2,070***	***100.0***	***74.9***	***13,235***	***100.0***	***78.6***

Table 14 Primary diagnosis - non-malignant

Primary diagnosis	WA	% non-malignant diagnosis	% all diagnosis	All Services	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	111	16.9	4.0	652	18.4	3.9
HIV/AIDS	5	0.8	0.2	11	0.3	0.1
End stage kidney disease	54	8.2	2.0	342	9.7	2.0
Stroke	45	6.9	1.6	171	4.8	1.0
Motor neurone disease	25	3.8	0.9	140	4.0	0.8
Alzheimer’s dementia	30	4.6	1.1	97	2.7	0.6
Other dementia	57	8.7	2.1	183	5.2	1.1
Other neurological disease	33	5.0	1.2	367	10.4	2.2
Respiratory failure	111	16.9	4.0	623	17.6	3.7
End stage liver disease	16	2.4	0.6	136	3.8	0.8
Diabetes and its complications	2	0.3	0.1	17	0.5	0.1
Sepsis	21	3.2	0.8	93	2.6	0.6
Multiple organ failure	19	2.9	0.7	77	2.2	0.5
Other non-malignancy	122	18.6	4.4	577	16.3	3.4
Non-malignant – not further defined	5	0.8	0.2	52	1.5	0.3
All non-malignant	***656***	***100.0***	***23.7***	***3,538***	***100.0***	***21.0***

3.2 Profile of palliative care episodes

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

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

An episode of palliative care ends when:

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

Table 15 below presents the number and percentage of episodes by age group and sex for the patients seen in Western Australia and at the national level. Age has been calculated as at the beginning of each episode.

Table 15 Age group by sex

Age group	WA				All Services			
	Male	%	Female	%	Male	%	Female	%
< 15	8	0.4	6	0.4	36	0.3	23	0.2
15 - 24	5	0.3	8	0.5	36	0.3	39	0.4
25 - 34	13	0.7	9	0.5	77	0.7	94	0.9
35 - 44	71	3.8	59	3.4	227	2.0	315	3.2
45 - 54	130	6.9	160	9.3	704	6.1	832	8.3
55 - 64	305	16.2	275	16.1	1,752	15.2	1,545	15.5
65 - 74	455	24.1	349	20.4	3,046	26.4	2,311	23.1
75 - 84	563	29.8	457	26.7	3,508	30.4	2,654	26.6
85+	338	17.9	389	22.7	2,135	18.5	2,182	21.8
Not stated/inadequately described	0	0.0	0	0.0	0	0.0	0	0.0
Total	*1,888*	*100.0*	*1,712*	*100.0*	*11,521*	*100.0*	*9,995*	*100.0*

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

Referral source refers to the facility or organisation from which the patient was referred for each episode of care. Table 16 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 16 Referral source by setting

Referral source	Inpatient				Community			
	WA	%	All Services	%	WA	%	All Services	%
Public hospital	793	68.4	5,859	51.9	1,090	44.7	5,075	49.6
Private hospital	20	1.7	1,352	12.0	433	17.7	1,106	10.8
Outpatient clinic	0	0.0	37	0.3	0	0.0	32	0.3
General medical practitioner	78	6.7	353	3.1	722	29.6	1,504	14.7
Specialist medical practitioner	33	2.8	626	5.5	24	1.0	466	4.6
Community-based palliative care agency	204	17.6	2,460	21.8	1	0.0	181	1.8
Community-based service	1	0.1	51	0.5	9	0.4	141	1.4
Residential aged care facility	9	0.8	105	0.9	133	5.5	914	8.9
Self, carer(s), family or friends	13	1.1	237	2.1	3	0.1	391	3.8
Other	3	0.3	133	1.2	20	0.8	254	2.5
Not stated/inadequately described	6	0.5	73	0.6	5	0.2	168	1.6
Total	*1,160*	*100.0*	*11,286*	*100.0*	*2,440*	*100.0*	*10,232*	*100.0*

Table 17 provides a summary of the time between referral to first contact by setting of care. The time from referral to first contact is calculated as the time from the date of referral received to either the date of first contact (if provided) or the episode start date.

Table 17 Referral to first contact by episode setting

Time (in days)	Inpatient				Community			
	WA	%	All Services	%	WA	%	All Services	%
Same day or following day	1,024	88.3	10,418	92.3	1,207	49.5	5,245	51.3
2-7 days	109	9.4	742	6.6	1,102	45.2	3,596	35.2
8-14 days	16	1.4	80	0.7	95	3.9	797	7.8
Greater than 14 days	11	0.9	45	0.4	36	1.5	587	5.7
Average	1.3	na	1.2	na	2.5	na	2.8	na
Median	1	na	1	na	2	na	1	na

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

Table 18 gives a summary of the length of episode for patients in Western Australia and nationally. Table 19 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 18 Length of episode (in days) summary by setting

Length of episode	Inpatient		Community	
	WA	All Services	WA	All Services
Average length of episode	9.5	10.9	40.0	40.0
Median length of episode	5.0	6.0	29.0	28.0

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

Table 19 Length of episode (in days) by setting

Length of episode	Inpatient				Community			
	WA	%	All Services	%	WA	%	All Services	%
Same day	103	9.1	657	5.9	25	1.2	487	5.3
1-2 days	298	26.2	2,248	20.1	139	6.9	558	6.1
3-4 days	163	14.3	1,609	14.4	103	5.1	456	5.0
5-7 days	196	17.2	1,794	16.1	132	6.6	624	6.8
8-14 days	197	17.3	2,337	20.9	258	12.8	1,062	11.6
15-21 days	67	5.9	1,030	9.2	188	9.4	805	8.8
22-30 days	42	3.7	630	5.6	180	9.0	769	8.4
31-60 days	42	3.7	653	5.9	422	21.0	1,628	17.9
61-90 days	18	1.6	142	1.3	203	10.1	877	9.6
Greater than 90 days	12	1.1	57	0.5	359	17.9	1,854	20.3
Total	***1,138***	***100.0***	***11,157***	***100.0***	***2,009***	***100.0***	***9,120***	***100.0***

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

Table 20 How episodes start – inpatient setting

Episode start mode	WA		All Services	
	N	%	N	%
Admitted from community	872	75.2	7,172	63.5
Admitted from another hospital	260	22.4	2,854	25.3
Admitted from acute care in another ward	16	1.4	1,049	9.3
Other*	11	0.9	201	1.8
Not stated/inadequately described	1	0.1	10	0.1
Total	***1,160***	***100.0***	***11,286***	***100.0***

* includes: change from acute care to palliative care while remaining on same ward; change of sub-acute/non-acute care type.

Table 21 How episodes end – inpatient setting

Episode end mode	WA		All Services	
	N	%	N	%
Discharged to community	510	44.8	3,781	33.9
Discharged to another hospital	69	6.1	825	7.4
Death	432	38.0	5,829	52.2
Other*	126	11.1	386	3.5
Not stated/inadequately described	1	0.1	336	3.0
Total	***1,138***	***100.0***	***11,157***	***100.0***

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

* includes: change from palliative care to acute care - different ward; change from palliative care to acute care - same ward; change in sub-acute care type; end of consultative episode – inpatient episode ongoing.

Table 22 How episodes start – community setting

Episode start mode	WA		All Services	
	N	%	N	%
Admitted from inpatient palliative care	1,662	68.1	3,961	38.7
Other	777	31.8	6,208	60.7
Not stated/inadequately described	1	0.0	63	0.6
Total	***2,440***	***100.0***	***10,232***	***100.0***

Table 23 How episodes end – community setting

Episode end mode	WA		All Services	
	N	%	N	%
Admitted for inpatient palliative care	148	7.4	2,562	28.1
Admitted for inpatient acute care	943	46.9	2,515	27.6
Discharged/case closure	193	9.6	874	9.6
Death	700	34.8	2,467	27.1
Other*	25	1.2	698	7.7
Not stated/inadequately described	0	0.0	4	0.0
Total	***2,009***	***100.0***	***9,120***	***100.0***

Note: Only episode ending during the reporting period are included.
* includes: admitted to another palliative care service, admitted to primary health care and other categories.

3.3 Profile of palliative care phases

The palliative care phase type describes the stage of the patient's illness and provides a clinical indication of the level of care a patient requires. There are five palliative care phase types; stable, unstable, deteriorating, terminal and bereaved. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence. See Appendix D for more information on the definition of palliative care phase.

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

Table 24 Number of phases by phase type and setting

Phase type	Inpatient				Community			
	WA	%	All Services	%	WA	%	All Services	%
Stable	664	28.2	6,664	24.8	3,240	35.1	8,497	37.3
Unstable	355	15.1	6,273	23.3	929	10.1	2,689	11.8
Deteriorating	892	37.8	8,105	30.1	4,258	46.1	9,585	42.1
Terminal	378	16.0	4,971	18.5	668	7.2	1,796	7.9
Bereaved	69	2.9	874	3.3	138	1.5	189	0.8
Total phases	***2,358***	***100.0***	***26,887***	***100.0***	***9,233***	***100.0***	***22,756***	***100.0***

Table 25 Average phase length (in days) by phase type and setting

Phase type	Inpatient		Community	
	WA	All Services	WA	All Services
Stable	6.7	7.1	13.4	20.7
Unstable	1.8	2.4	1.6	5.5
Deteriorating	4.2	5.6	9.5	13.5
Terminal	1.9	2.0	2.4	3.2
Bereaved	12.2	1.8	35.2	25.5

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

Table 26 presents information relating to the manner in which stable phases ended, both for Western Australia and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 18 and Figure 19 summarise the movement of patients out of the stable phase for the inpatient and community settings. This movement from one phase to another is referred to as phase progression. The phase progression information is derived by PCOC.

Similar information is presented for the unstable (Table 27, Figure 20 and Figure 21), deteriorating (Table 28, Figure 22 and Figure 23) and terminal (Table 28, Figure 24 and Figure 25) phases on the following pages.

Table 26 How stable phases end – by setting

How stable phases end	Inpatient				Community			
	WA	%	All Services	%	WA	%	All Services	%
Patient moved into another phase	271	40.8	3,366	50.5	2,762	85.2	5,469	64.4
Discharge/case closure	385	58.0	3,208	48.1	437	13.5	2,756	32.4
Died	8	1.2	88	1.3	41	1.3	260	3.1
Not stated/inadequately described	0	0.0	2	0.0	0	0.0	12	0.1
Total	*664*	*100.0*	*6,664*	*100.0*	*3,240*	*100.0*	*8,497*	*100.0*

Figure 18 Stable phase progression – inpatient setting

Figure 19 Stable phase progression – community setting

Table 27 How unstable phases end – by setting

How unstable phases end	Inpatient				Community			
	WA	**%**	**All Services**	**%**	**WA**	**%**	**All Services**	**%**
Patient moved into another phase	308	86.8	5,665	90.3	711	76.5	1,795	66.8
Discharge/case closure	35	9.9	467	7.4	187	20.1	812	30.2
Died	12	3.4	140	2.2	31	3.3	79	2.9
Not stated/inadequately described	0	0.0	1	0.0	0	0.0	3	0.1
Total	***355***	***100.0***	***6,273***	***100.0***	***929***	***100.0***	***2,689***	***100.0***

Figure 20 Unstable phase progression – inpatient setting

Figure 21 Unstable phase progression – community setting

Table 28 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient				Community			
	WA	**%**	**All Services**	**%**	**WA**	**%**	**All Services**	**%**
Patient moved into another phase	550	61.7	5,579	68.8	3,443	80.9	5,870	61.2
Discharge/case closure	245	27.5	1,541	19.0	652	15.3	2,952	30.8
Died	97	10.9	978	12.1	163	3.8	762	7.9
Not stated/inadequately described	0	0.0	7	0.1	0	0.0	1	0.0
Total	***892***	***100.0***	***8,105***	***100.0***	***4,258***	***100.0***	***9,585***	***100.0***

Figure 22 Deteriorating phase progression – inpatient setting

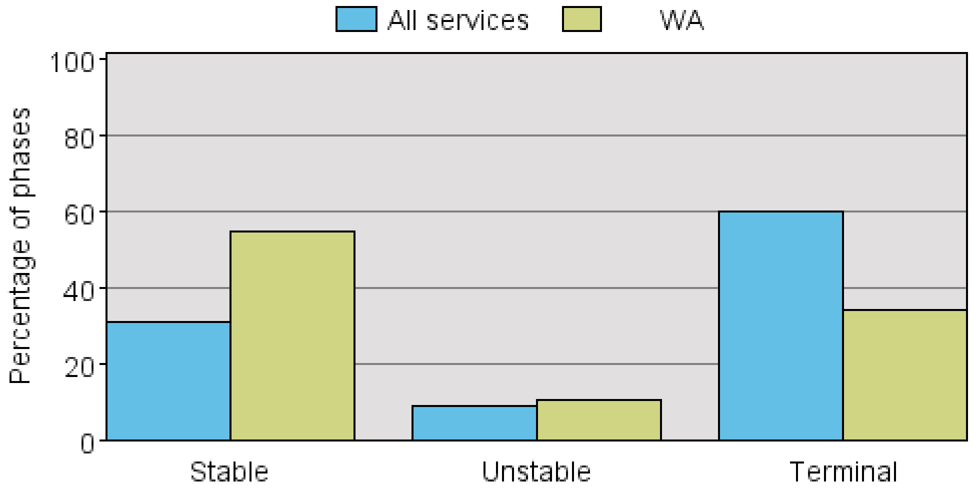


Figure 23 Deteriorating phase progression – community setting

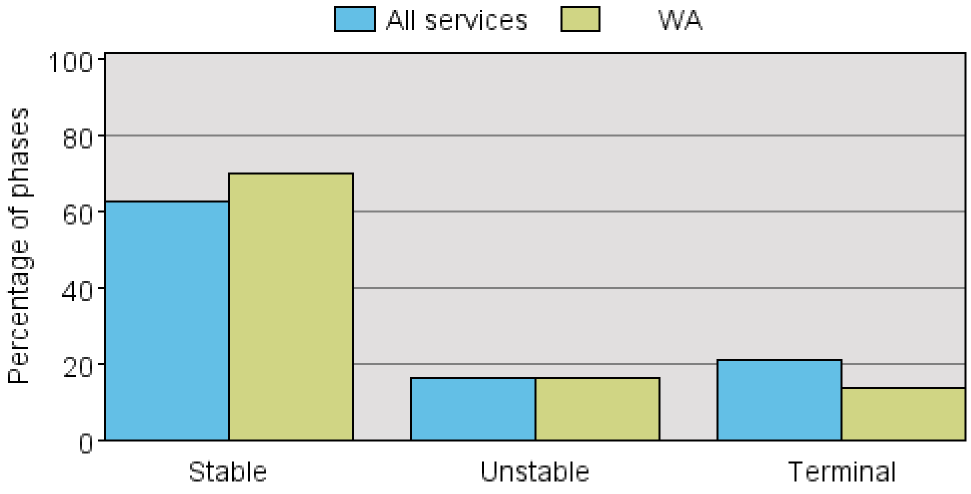


Table 29 How terminal phases end – by setting

How terminal phases end	Inpatient				Community			
	WA	**%**	**All Services**	**%**	**WA**	**%**	**All Services**	**%**
Patient moved into another phase	16	4.2	221	4.4	171	25.6	247	13.8
Discharge/case closure	41	10.8	101	2.0	33	4.9	148	8.2
Died	320	84.7	4,644	93.4	464	69.5	1,400	78.0
Not stated/inadequately described	1	0.3	5	0.1	0	0.0	1	0.1
Total	***378***	***100.0***	***4,971***	***100.0***	***668***	***100.0***	***1,796***	***100.0***

Figure 24 Terminal phase progression – inpatient setting

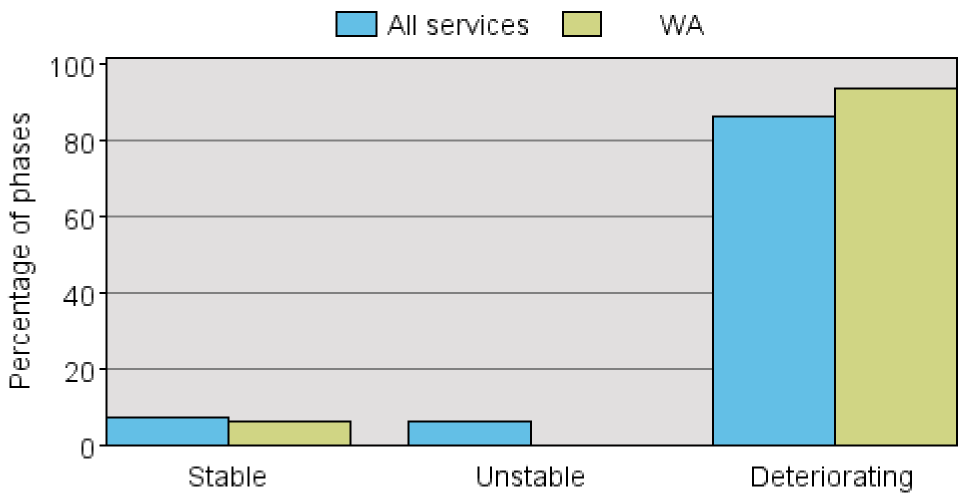
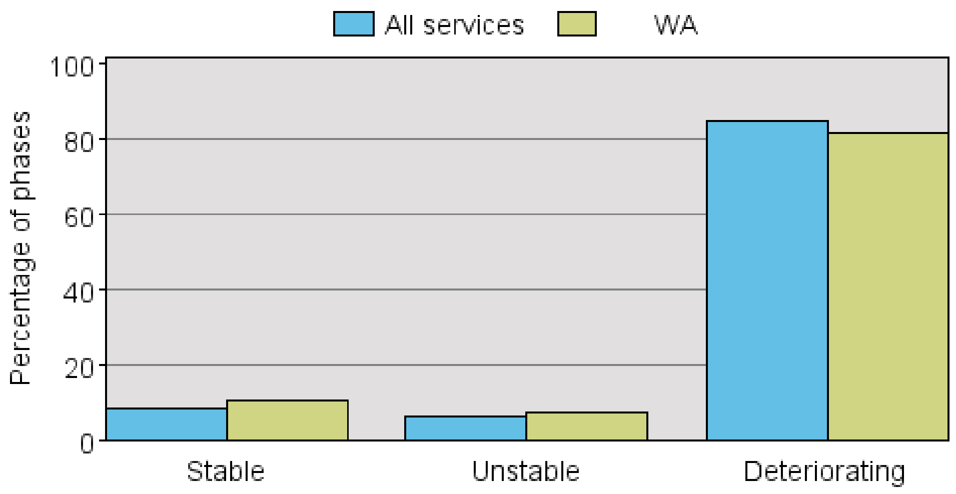


Figure 25 Terminal phase progression – community setting



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

Table 30 and Table 31 show the percentage scores for the inpatient and community settings respectively for both Western Australia and nationally.

Table 30 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)

Phase type		WA				All Services			
	Problem severity	**Absent**	**Mild**	**Moderate**	**Severe**	**Absent**	**Mild**	**Moderate**	**Severe**
Stable	Pain	42.8	41.1	14.3	1.8	47.8	36.9	12.6	2.7
	Other symptoms	22.8	54.6	20.2	2.4	24.8	49.6	21.6	4.0
	Psychological/spiritual	26.2	57.2	15.4	1.2	30.2	51.6	15.1	3.1
	Family/carer	36.1	41.8	18.8	3.3	38.0	41.9	15.9	4.2
Unstable	Pain	24.0	23.1	27.7	25.1	29.8	30.4	27.4	12.5
	Other symptoms	8.5	28.4	38.0	25.1	11.5	32.7	40.9	14.9
	Psychological/spiritual	12.2	36.4	37.5	13.9	19.8	42.8	27.7	9.7
	Family/carer	16.9	30.7	39.3	13.1	24.1	36.2	28.2	11.4
Deteriorating	Pain	28.7	32.2	28.7	10.4	38.0	36.3	19.6	6.2
	Other symptoms	9.9	31.5	46.8	11.7	14.9	40.0	34.9	10.2
	Psychological/spiritual	18.3	43.0	33.7	5.0	23.4	46.8	23.5	6.3
	Family/carer	21.0	35.5	36.0	7.6	26.4	39.2	25.3	9.1
Terminal	Pain	57.4	27.6	11.0	4.0	48.9	30.8	14.8	5.5
	Other symptoms	39.8	23.0	23.7	13.5	34.3	31.2	23.6	10.9
	Psychological/spiritual	59.1	24.1	12.3	4.5	50.8	29.8	13.7	5.7
	Family/carer	17.6	28.8	43.0	10.6	23.7	32.1	29.6	14.7

Table 31 Profile of PCPSS at beginning of phase by phase type –community setting (percentages)

Phase type		WA				All Services			
	Problem severity	**Absent**	**Mild**	**Moderate**	**Severe**	**Absent**	**Mild**	**Moderate**	**Severe**
Stable	Pain	43.0	51.9	4.9	0.2	40.8	50.3	8.2	0.7
	Other symptoms	15.0	68.9	15.7	0.3	15.1	63.9	19.6	1.4
	Psychological/spiritual	35.5	56.0	8.2	0.3	30.4	57.4	11.1	1.1
	Family/carer	46.5	45.8	7.2	0.5	31.3	51.3	15.5	1.8
Unstable	Pain	22.4	27.7	30.3	19.6	19.5	29.8	32.4	18.4
	Other symptoms	5.4	24.2	52.5	17.9	5.2	26.2	49.0	19.6
	Psychological/spiritual	14.8	42.2	36.4	6.6	13.3	43.7	34.3	8.6
	Family/carer	19.3	36.3	38.5	6.0	14.5	34.9	38.3	12.2
Deteriorating	Pain	30.9	49.4	18.1	1.6	28.9	48.8	19.5	2.8
	Other symptoms	7.4	53.9	36.6	2.1	6.7	47.1	40.4	5.8
	Psychological/spiritual	21.6	58.0	19.1	1.4	18.1	56.3	22.7	2.9
	Family/carer	31.5	48.3	18.9	1.3	20.3	44.5	30.1	5.1
Terminal	Pain	39.9	39.6	17.5	3.0	36.8	41.5	16.7	5.0
	Other symptoms	24.8	41.7	27.3	6.2	20.3	38.8	30.7	10.2
	Psychological/spiritual	48.1	36.2	13.7	2.0	40.8	39.7	15.3	4.2
	Family/carer	16.2	44.4	34.9	4.5	11.5	38.4	36.5	13.6

The Symptom Assessment Scale (SAS) is a patient rated assessment tool and reports a level of distress using a numerical rating scale from 0 - no problems to 10 - worst possible problems. The SAS reports on 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 32 and Table 33 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).

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

Phase type		WA				All Services			
	Symptom distress	**0 (Absent)**	**1-3 (Mild)**	**4-7 (Moderate)**	**8-10 (Severe)**	**0 (Absent)**	**1-3 (Mild)**	**4-7 (Moderate)**	**8-10 (Severe)**
Stable	Difficulty sleeping	58.9	22.7	15.9	2.6	66.1	19.1	12.8	2.1
	Appetite problems	56.0	25.0	16.2	2.9	51.9	24.8	19.3	4.0
	Nausea	81.7	12.7	4.8	0.8	78.4	13.8	6.4	1.4
	Bowel problems	60.1	24.1	13.6	2.3	60.8	22.7	13.3	3.1
	Breathing problems	59.9	21.6	15.5	3.0	64.5	18.3	13.7	3.5
	Fatigue	27.8	26.0	35.7	10.4	27.8	23.9	39.3	9.0
	Pain	40.7	34.2	21.4	3.6	45.6	32.6	19.1	2.6
Unstable	Difficulty sleeping	42.1	17.2	31.5	9.2	56.5	18.7	19.6	5.2
	Appetite problems	42.6	20.2	29.0	8.2	39.2	22.5	29.2	9.1
	Nausea	68.2	15.9	10.5	5.4	65.6	16.0	13.7	4.7
	Bowel problems	54.6	21.0	17.8	6.6	51.3	22.2	19.9	6.6
	Breathing problems	46.9	18.2	20.5	14.5	53.5	17.7	20.0	8.8
	Fatigue	20.8	13.5	47.4	18.4	20.2	15.6	45.9	18.3
	Pain	24.9	20.3	31.6	23.2	30.4	25.5	33.0	11.1
Deteriorating	Difficulty sleeping	57.2	20.6	18.6	3.6	66.9	16.1	14.2	2.8
	Appetite problems	53.1	19.8	22.0	5.1	49.1	20.6	22.7	7.6
	Nausea	73.8	16.3	8.5	1.5	74.8	13.3	9.7	2.1
	Bowel problems	55.2	25.4	15.7	3.8	58.6	21.5	16.1	3.8
	Breathing problems	51.3	21.9	20.2	6.6	56.4	17.6	18.8	7.2
	Fatigue	22.4	16.9	39.3	21.5	25.1	13.9	41.2	19.8
	Pain	29.1	29.9	32.6	8.5	38.5	29.6	25.9	5.9
Terminal	Difficulty sleeping	85.9	8.2	3.7	2.1	89.6	5.1	4.1	1.2
	Appetite problems	92.5	1.6	4.0	1.9	85.8	3.9	5.5	4.7
	Nausea	94.4	2.4	2.9	0.3	92.2	3.9	2.9	0.9
	Bowel problems	85.3	8.0	4.3	2.4	82.7	8.9	6.5	1.9
	Breathing problems	57.7	15.4	18.4	8.5	65.4	12.9	14.0	7.7
	Fatigue	78.1	1.6	5.1	15.2	69.6	4.2	11.6	14.5
	Pain	55.9	24.2	16.8	3.2	57.0	22.6	16.5	3.9

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

Phase type		WA				All Services			
	Symptom distress	**0 (Absent)**	**1-3 (Mild)**	**4-7 (Moderate)**	**8-10 (Severe)**	**0 (Absent)**	**1-3 (Mild)**	**4-7 (Moderate)**	**8-10 (Severe)**
Stable	Difficulty sleeping	75.0	18.7	5.8	0.4	62.5	26.3	10.1	1.1
	Appetite problems	60.3	28.0	10.8	0.9	45.7	34.3	17.9	2.1
	Nausea	88.3	10.6	1.1	0.0	79.8	16.0	3.8	0.4
	Bowel problems	77.0	19.1	3.5	0.5	67.0	24.8	7.2	1.0
	Breathing problems	64.7	25.2	9.6	0.6	55.1	29.8	13.1	2.0
	Fatigue	15.7	32.2	47.7	4.3	12.2	34.1	46.6	7.1
	Pain	51.0	40.4	8.2	0.4	43.6	43.1	12.1	1.2
Unstable	Difficulty sleeping	52.8	19.7	22.2	5.3	43.6	27.0	23.9	5.5
	Appetite problems	42.6	18.7	29.6	9.1	30.8	25.7	32.9	10.6
	Nausea	65.4	14.0	14.0	6.6	58.8	19.7	14.5	7.0
	Bowel problems	68.0	14.8	13.8	3.5	53.2	25.5	16.0	5.3
	Breathing problems	58.7	18.4	15.8	7.1	47.2	25.2	20.5	7.1
	Fatigue	11.8	12.3	52.9	23.0	7.8	16.4	52.3	23.5
	Pain	25.1	21.9	32.9	20.1	19.9	25.6	36.8	17.8
Deteriorating	Difficulty sleeping	67.0	20.0	12.0	1.0	56.3	27.2	14.6	2.0
	Appetite problems	52.1	25.0	19.4	3.5	37.5	30.0	26.6	5.9
	Nausea	80.6	14.7	4.2	0.6	71.6	19.9	7.1	1.4
	Bowel problems	69.4	20.9	8.4	1.2	59.7	27.6	10.9	1.8
	Breathing problems	57.9	24.9	15.5	1.7	47.9	30.0	18.7	3.4
	Fatigue	11.5	20.4	58.5	9.6	8.9	20.5	55.3	15.2
	Pain	38.3	37.6	21.5	2.6	33.0	41.0	22.8	3.2
Terminal	Difficulty sleeping	76.8	10.9	10.5	1.9	74.1	13.4	9.8	2.7
	Appetite problems	84.1	2.7	4.8	8.4	73.8	7.1	7.2	12.0
	Nausea	89.9	7.1	2.6	0.5	84.9	10.2	3.9	1.0
	Bowel problems	86.1	8.9	4.1	0.8	74.1	16.9	7.9	1.0
	Breathing problems	62.8	18.3	14.6	4.4	54.3	22.5	16.9	6.4
	Fatigue	64.8	1.3	14.9	19.0	54.3	4.5	15.0	26.2
	Pain	47.5	27.4	21.7	3.3	41.7	34.1	20.2	4.1

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. Table 34 shows the data for the AKPS at phase start.

Table 34 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting

AKPS assessment	Inpatient				Community			
	WA	%	All Services	%	WA	%	All Services	%
10 - Comatose or barely rousable	234	10.2	2,623	10.1	277	3.0	727	3.2
20 - Totally bedfast and requiring extensive nursing care	445	19.4	5,848	22.5	847	9.3	2,079	9.2
30 - Almost completely bedfast	257	11.2	3,515	13.5	511	5.6	1,563	6.9
40 - In bed more than 50% of the time	289	12.6	4,637	17.8	735	8.1	2,576	11.4
50 - Requires considerable assistance	594	26.0	4,594	17.7	1,689	18.6	5,121	22.7
60 - Requires occasional assistance	334	14.6	2,571	9.9	2,659	29.2	5,782	25.6
70 - Cares for self	82	3.6	622	2.4	1,975	21.7	3,394	15.0
80 - Normal activity with effort	16	0.7	182	0.7	350	3.8	805	3.6
90 - Able to carry on normal activity; minor signs or symptoms	5	0.2	59	0.2	46	0.5	171	0.8
100 - Normal; no complaints; no evidence of disease	0	0.0	3	0.0	0	0.0	7	0.0
Not stated/inadequately described	33	1.4	1,359	5.2	6	0.1	342	1.5
Total	***2,289***	***100.0***	***26,013***	***100.0***	***9,095***	***100.0***	***22,567***	***100.0***

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. Figure 26 and Figure 27 on the following two pages summarise the total RUG-ADL at the beginning of each phase for inpatients and community patients. The total score on the RUG-ADL ranges from a minimum of 4 (lowest level of functional dependency) to a maximum of 18 (highest level of functional dependency).

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

Figure 26 Total RUG-ADL at beginning of phase by phase type – inpatient setting

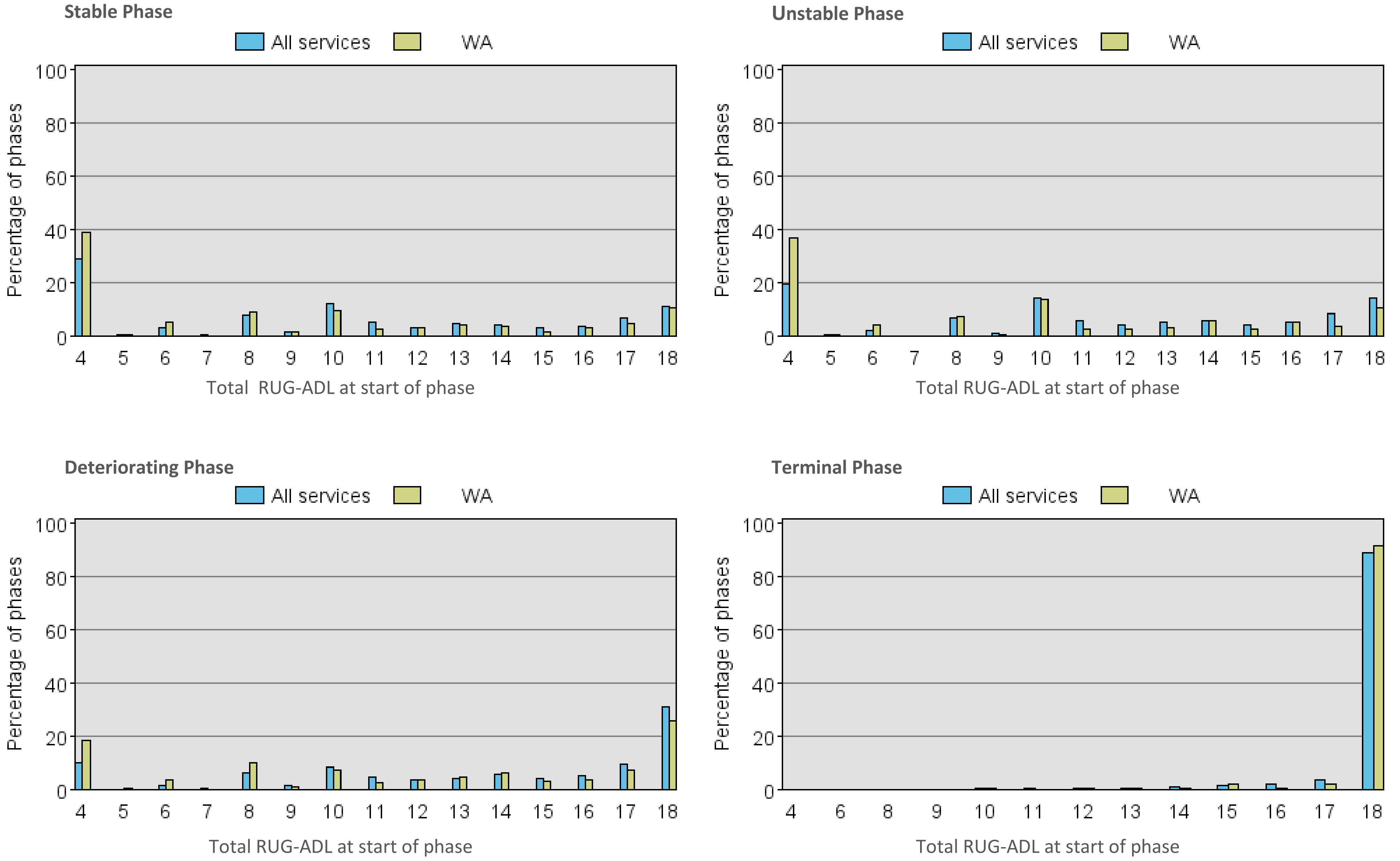
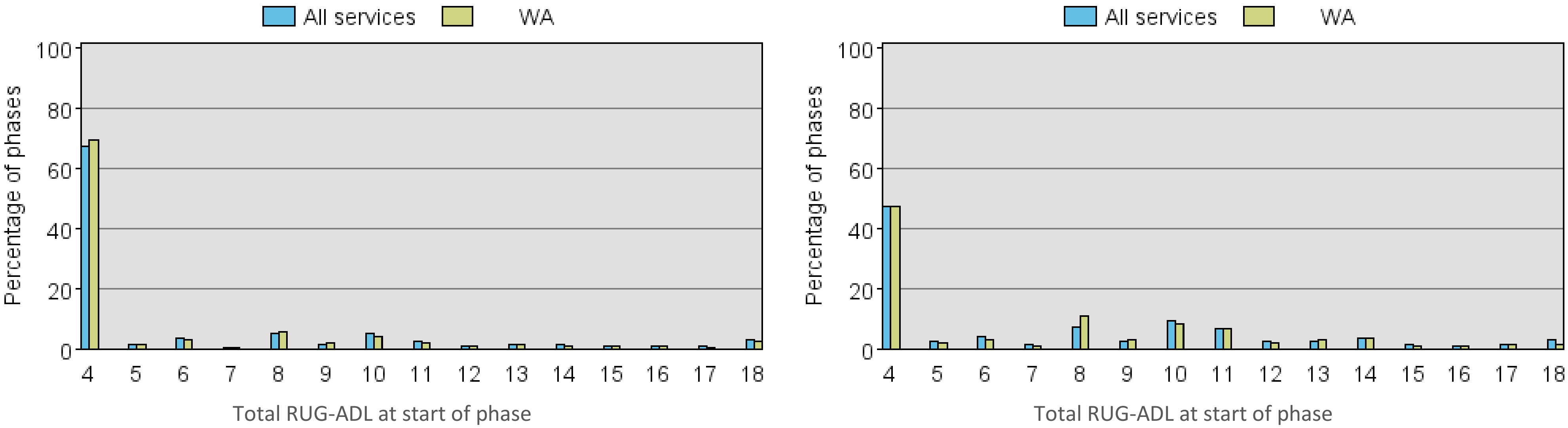
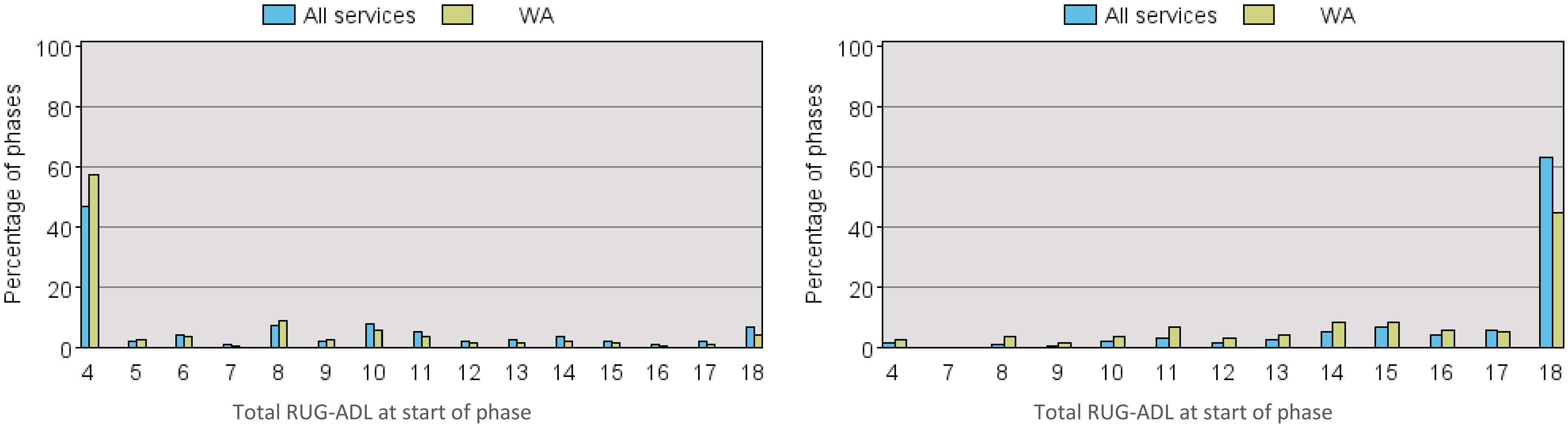


Figure 27 Total RUG-ADL at beginning of phase by phase type – community setting



Stable Phase **Unstable Phase**



Deteriorating Phase **Terminal Phase**

Appendix A Summary of data included in this report

A1 Data summary

During the reporting period, data were provided for a total of 16,833 patients who between them had 21,518 episodes of care and 49,643 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 B contains a more detailed explanation of this process). Table 35 shows the number of patients, episodes and phases included in this report – both for Western Australia 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 35 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 35 Number and percentage of patients, episodes and phases by setting

	Inpatient		Community		Total	
	WA	**All Services**	**WA**	**All Services**	**WA**	**All Services**
Number of patients*	950	9,509	1,883	8,234	2,765	16,833
Number of episodes	1,160	11,286	2,440	10,232	3,600	21,518
Number of phases	2,358	26,887	9,233	22,756	11,591	49,643
Percentage of patients*	34.4	56.5	68.1	48.9	100	100
Percentage of episodes	32.2	52.4	67.8	47.6	100	100
Percentage of phases	20.3	54.2	79.7	45.8	100	100
Average number of phases per episode**	2.0	2.3	3.6	2.1	2.9	2.2

* 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 that started and ended within the reporting period and excludes bereavement phases.

Table 36 shows the number of completed episodes and phases by setting in the current reporting period for Western Australia. This table identifies any change in patient numbers during the reporting period.

Table 36 Number of completed episodes and phases by month and setting

		Jan	Feb	Mar	Apr	May	Jun
Inpatient	No. of completed episodes	184	173	200	189	203	189
	No. of completed phases	407	371	422	386	407	365
Community	No. of completed episodes	297	330	352	339	370	321
	No. of completed phases	1,482	1,433	1,504	1,518	1,756	1,540

A2 Data item completion

As shown in Table 37, Table 38 and Table 39 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for community patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

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

Table 37 Item completion (per cent complete) - patient level

Data item	WA	All Services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	96.2	98.0
Country of birth	97.1	98.8
Preferred language	100.0	99.9
Primary diagnosis	98.6	99.6

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

Table 38 Item completion by setting (per cent complete) - episode level

Data item	Inpatient		Community		Total	
	WA	All Services	WA	All Services	WA	All Services
Date of first contact	100.0	100.0	100.0	99.9	100.0	99.9
Referral date	100.0	100.0	100.0	99.9	100.0	100.0
Referral source	99.5	99.4	99.8	98.4	99.7	98.9
Date ready for care	100.0	96.3	100.0	99.9	100.0	98.0
Mode of episode start	99.9	99.9	100.0	99.4	99.9	99.7
Accommodation at episode start	99.3	99.7	99.8	97.0	99.7	98.2
Episode end date	99.0	99.6	87.2	92.8	91.0	96.4
Mode of episode end	99.9	97.0	100.0	99.9	100.0	98.4
Accommodation at episode end	97.1	98.3	99.6	93.1	97.9	96.8
Place of death	na	na	100.0	97.7	100.0	97.7

Table 39 Item completion by setting (per cent complete) - phase level

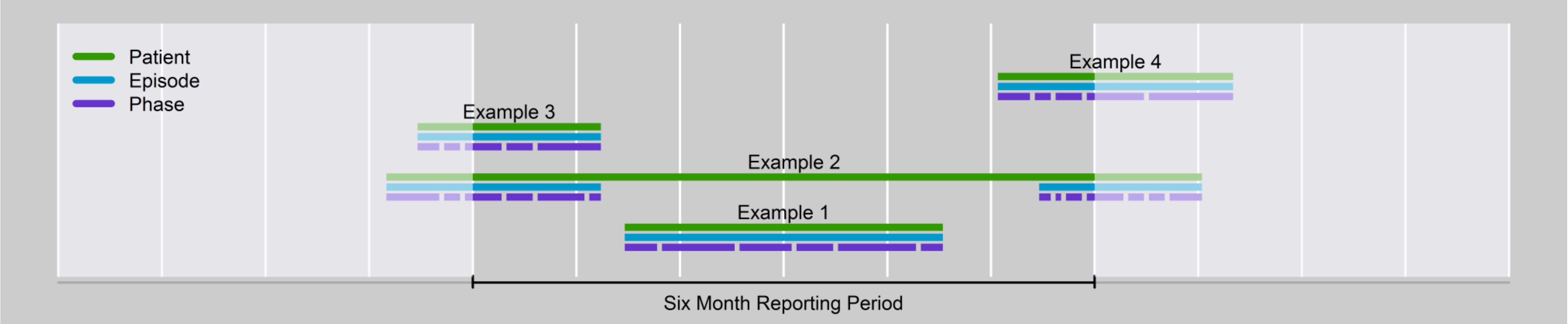
Data item	Sub-Category	At phase start						At discharge					
		Inpatient		Community		Total		Inpatient		Community		Total	
	(where applicable)	WA	All Services	WA	All Services	WA	All Services	WA	All Services	WA	All Services	WA	All Services
RUG-ADL	Bed mobility	99.8	99.6	98.4	97.9	98.7	98.8	91.4	83.8	53.9	60.9	67.0	71.0
	Toileting	99.7	99.6	97.5	97.5	98.0	98.6	91.4	83.8	53.7	60.8	66.9	71.0
	Transfers	99.7	99.6	95.9	96.8	96.7	98.3	91.4	83.8	53.8	60.8	66.9	71.0
	Eating	99.6	99.4	92.6	95.2	94.0	97.4	91.4	83.8	52.3	60.3	66.0	70.7
PCPSS	Pain	81.3	98.0	100.0	98.1	96.2	98.0	84.8	82.8	54.5	60.4	65.1	70.3
	Other symptom	80.6	97.8	99.8	97.4	96.0	97.6	84.3	82.7	54.5	59.9	64.9	70.0
	Psychological/spiritual	98.8	99.5	99.9	97.8	99.7	98.7	90.4	83.5	54.5	60.2	67.0	70.6
	Family/carer	72.4	96.7	99.5	96.8	94.1	96.7	55.9	77.8	54.4	59.7	54.9	67.7
SAS	Difficulty sleeping	99.0	93.3	97.5	94.1	97.8	93.7	90.4	77.4	53.8	58.4	66.6	66.8
	Appetite problems	99.0	93.7	95.0	95.0	95.8	94.3	90.8	77.5	52.6	59.9	66.0	67.7
	Nausea	99.4	93.7	98.8	96.9	98.9	95.2	90.9	77.5	53.8	60.4	66.8	68.0
	Bowel problems	98.7	93.5	96.7	95.3	97.1	94.4	90.8	77.5	53.1	59.5	66.3	67.5
	Breathing problems	99.4	93.7	98.4	96.5	98.6	95.0	90.8	77.5	53.9	60.4	66.8	68.0
	Fatigue	98.7	93.6	96.8	96.2	97.2	94.8	90.8	77.6	53.5	60.4	66.6	68.0
	Pain	99.6	93.7	99.5	97.7	99.6	95.6	91.1	77.6	54.3	61.1	67.2	68.4
AKPS	-	98.6	94.8	99.9	98.5	99.7	96.5	89.7	81.2	54.4	60.6	66.7	69.8

Data item	Inpatient		Community		Total	
	WA	All Services	WA	All Services	WA	All Services
Phase End Reason	100.0	99.9	100.0	99.9	100.0	99.9

Appendix B 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 28 below displays four examples to help visualize this process.

Figure 28 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.

Appendix C 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	$\frac{-0.2+0.9+0.4-0.4}{4} = 0.175$
Stable	1	1	-0.9	0	0.9	
Unstable	3	1	1.6	2	0.4	
Deteriorating	2	1	1.4	1	-0.4	

Appendix D Palliative Care Phase definitions

START	END
1. 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.
2. 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).
3. 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).
4. 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).
5. Bereavement – post death support	
▪ The patient has died ▪ Bereavement support provided to family/carers is documented in the deceased patient's clinical record.	▪ Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

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