2014

National report on patient outcomes in palliative care in Australia: July - December 2013

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National report on patient outcomes in palliative care in Australia: July - December 2013

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 sixteenth PCOC report, data submitted for the July to December 2013 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, december, 2013, report, patient, outcomes, national, palliative, care, australia, july

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PCOC
palliative care
outcomes collaboration

National Report on Patient Outcomes in Palliative Care in Australia

July – December 2013

Report 16

March 2014

Australian Government
Department of Health

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www.pcoc.org.au

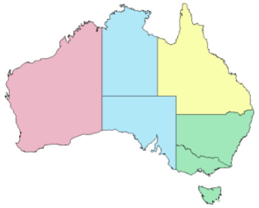
About the Palliative Care Outcomes Collaboration

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.

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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 sixteenth PCOC report, data submitted for the July to December 2013 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

In this report, the data item 'Date ready for care' will be used in outcome measure one to indicate responsiveness of service for the first time. The new outcome measure is 'Time from date ready for care to episode start'. This replaces the previous outcome measure 'Time from referral to first contact'. For more information about this change please contact your quality improvement facilitator.

This report is divided into three sections:

- Section 1 summarises each of the four outcome measures and presents national benchmarking results for a selection of these measures.
- Section 2 presents a more detailed analysis of the outcome measures and benchmarks.
- Section 3 provides descriptive analysis at each of the patient, episode and phase data levels.

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

The four outcome measures included in this report were first introduced in the reporting period January to June 2009 (Report 7). 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.

Interpretation hint:

Some tables throughout this report may be incomplete. This is because some items may not be applicable 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 or unable to be calculated due to missing, invalid or insufficient data**

Section 1 Benchmark summary

1.1 Australian Outcomes at a glance

Table 1 Summary of outcome measures 1 to 3 by setting

Outcome measure	Description	Benchmark	Inpatient		Ambulatory & community	
			Your Score	Benchmark Met?	Your 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%	96.5	Yes	78.0	No
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	79.9	No	70.3	No
3. Change in pain	Benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end	90%	88.5	No	83.2	No
	Benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild pain at phase end	60%	53.8	No	51.8	No
	Benchmark 3.3: SAS Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end	90%	87.0	No	81.2	No
	Benchmark 3.4: SAS Patients with moderate/severe distress from pain at phase start, with absent/mild at phase end	60%	50.4	No	48.7	No

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	0.19	Yes
	Benchmark 4.2: Other symptoms	0.37	Yes
	Benchmark 4.3: Family/carer	0.23	Yes
	Benchmark 4.4: Psychological/spiritual	0.20	Yes
SAS	Benchmark 4.5: Pain	0.34	Yes
	Benchmark 4.6: Nausea	0.21	Yes
	Benchmark 4.7: Breathing problems	0.41	Yes
	Benchmark 4.8: Bowel problems	0.36	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 ambulatory and 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 allow 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. 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

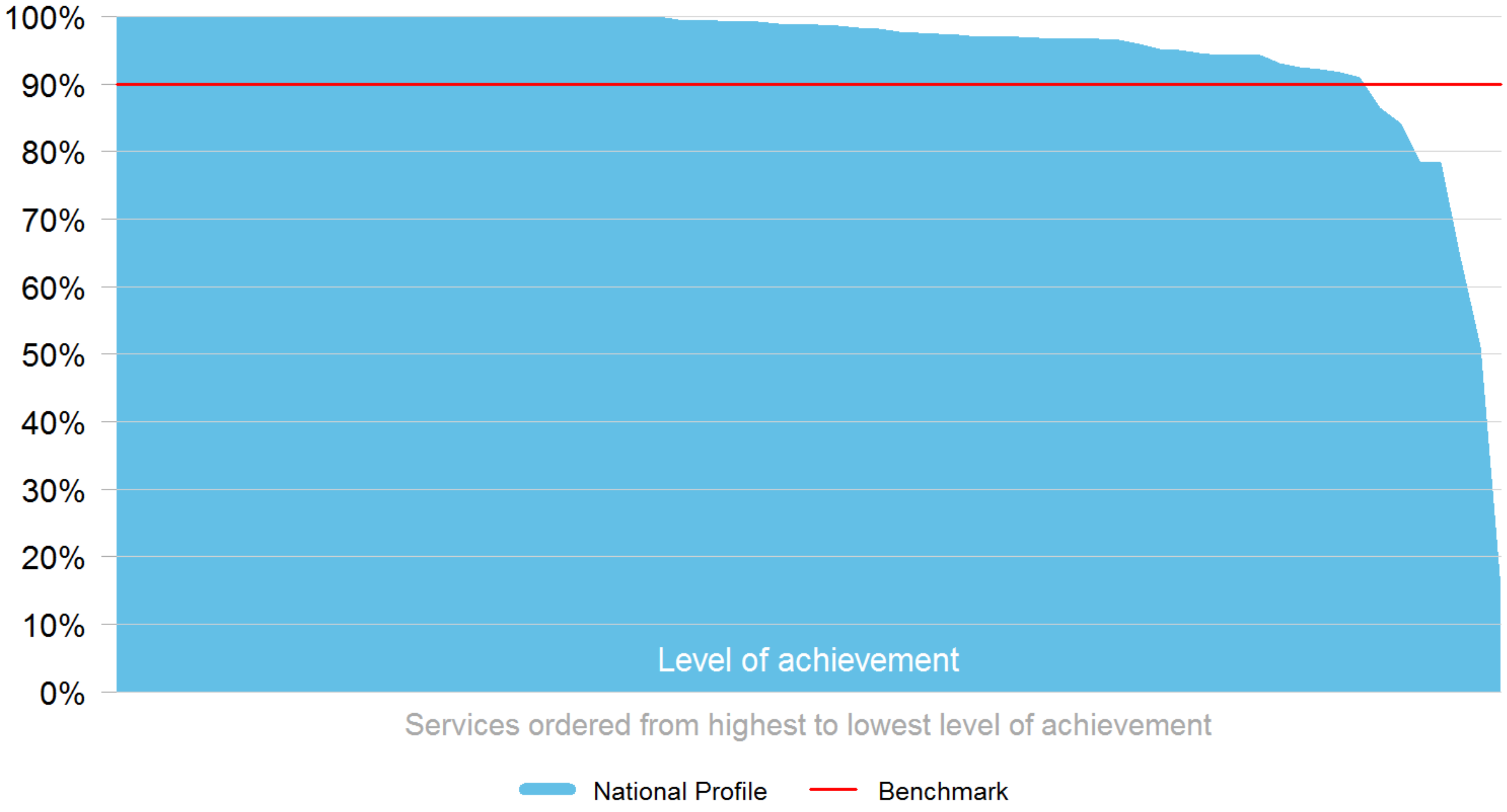
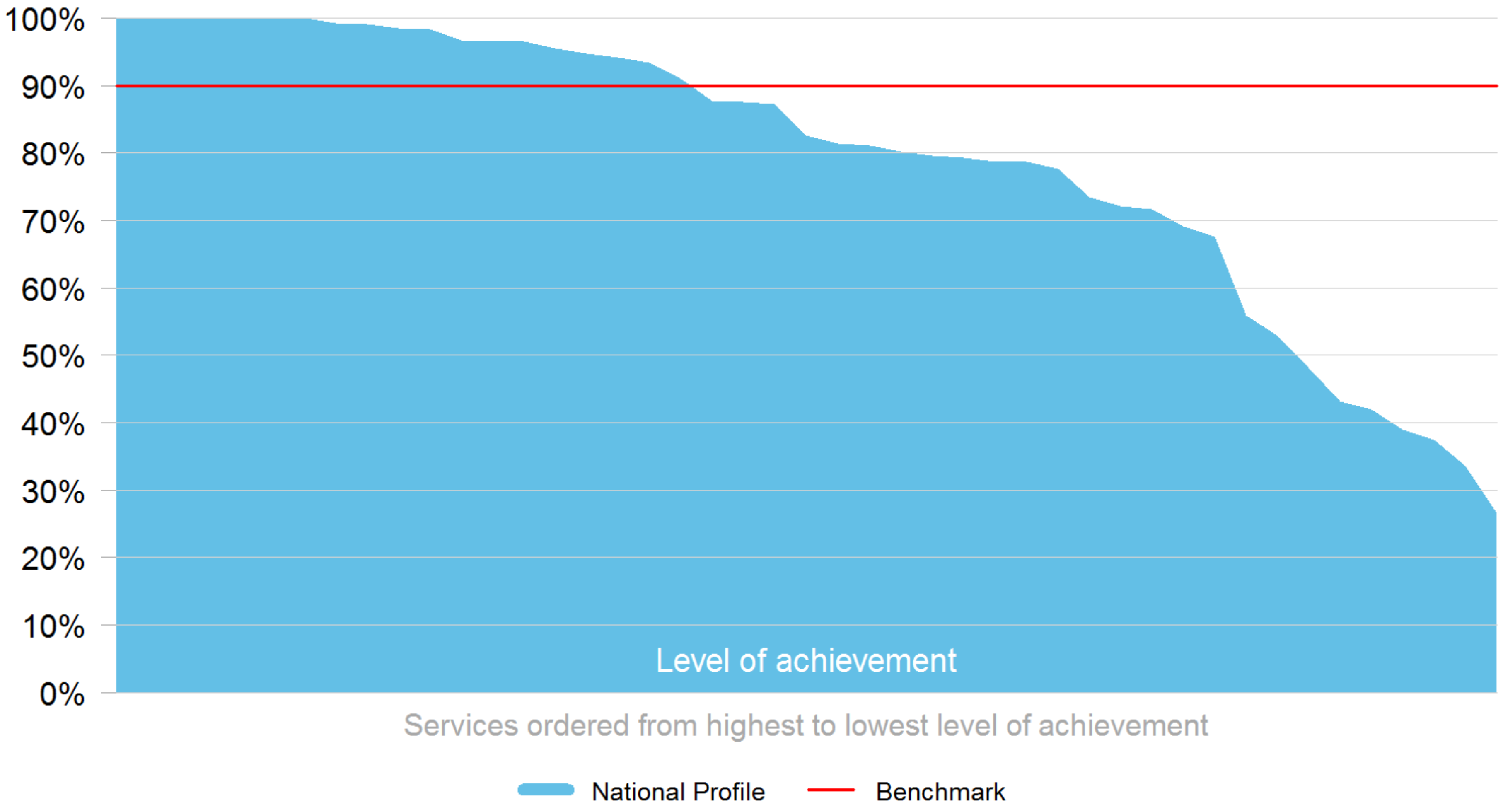


Figure 2 Percentage of patients with episodes started on the day of, or the day after date ready for care – ambulatory & community settings



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

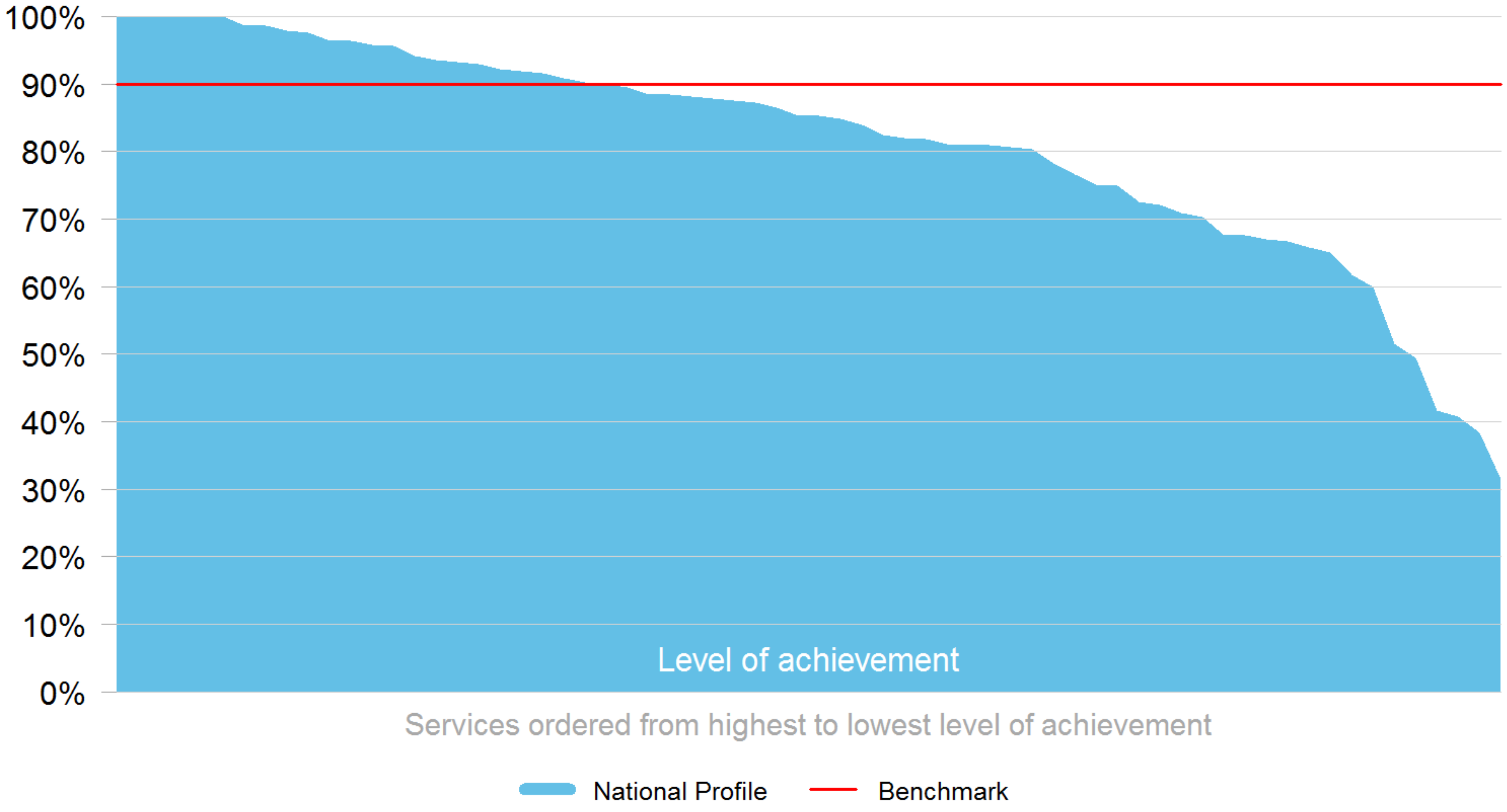
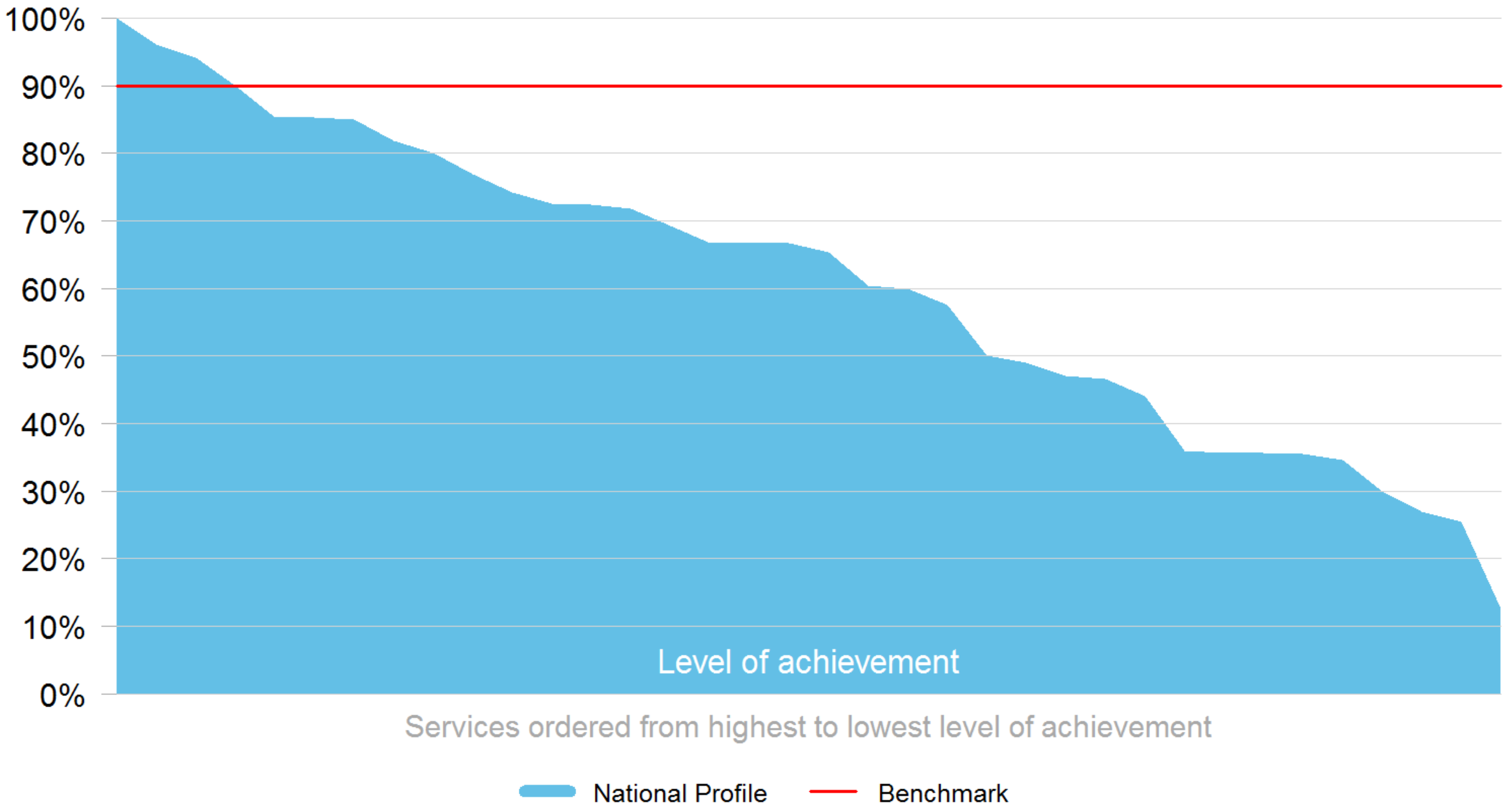


Figure 4 Percentage of patients in the unstable phase for 3 days or less – ambulatory & community settings



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

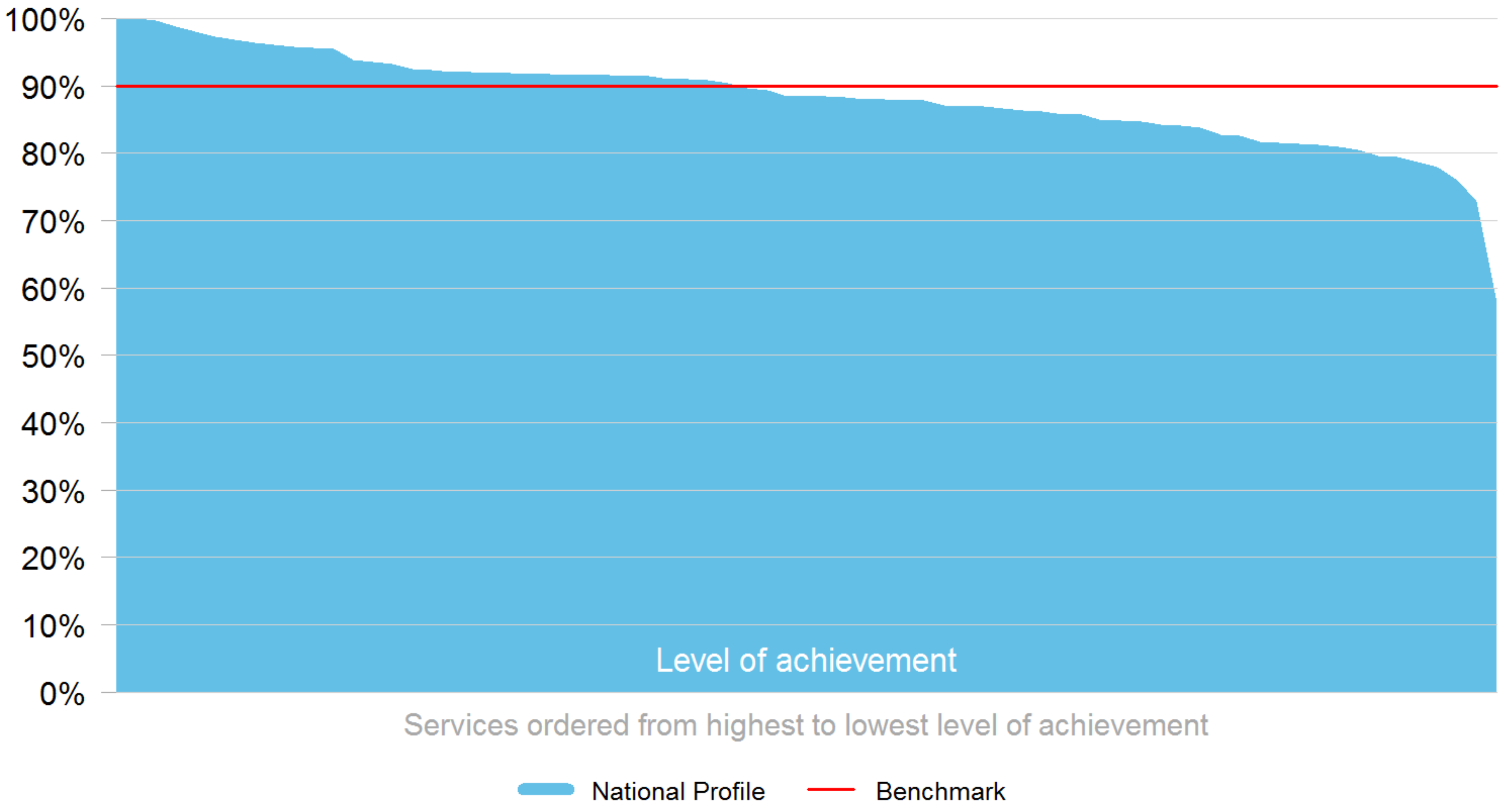
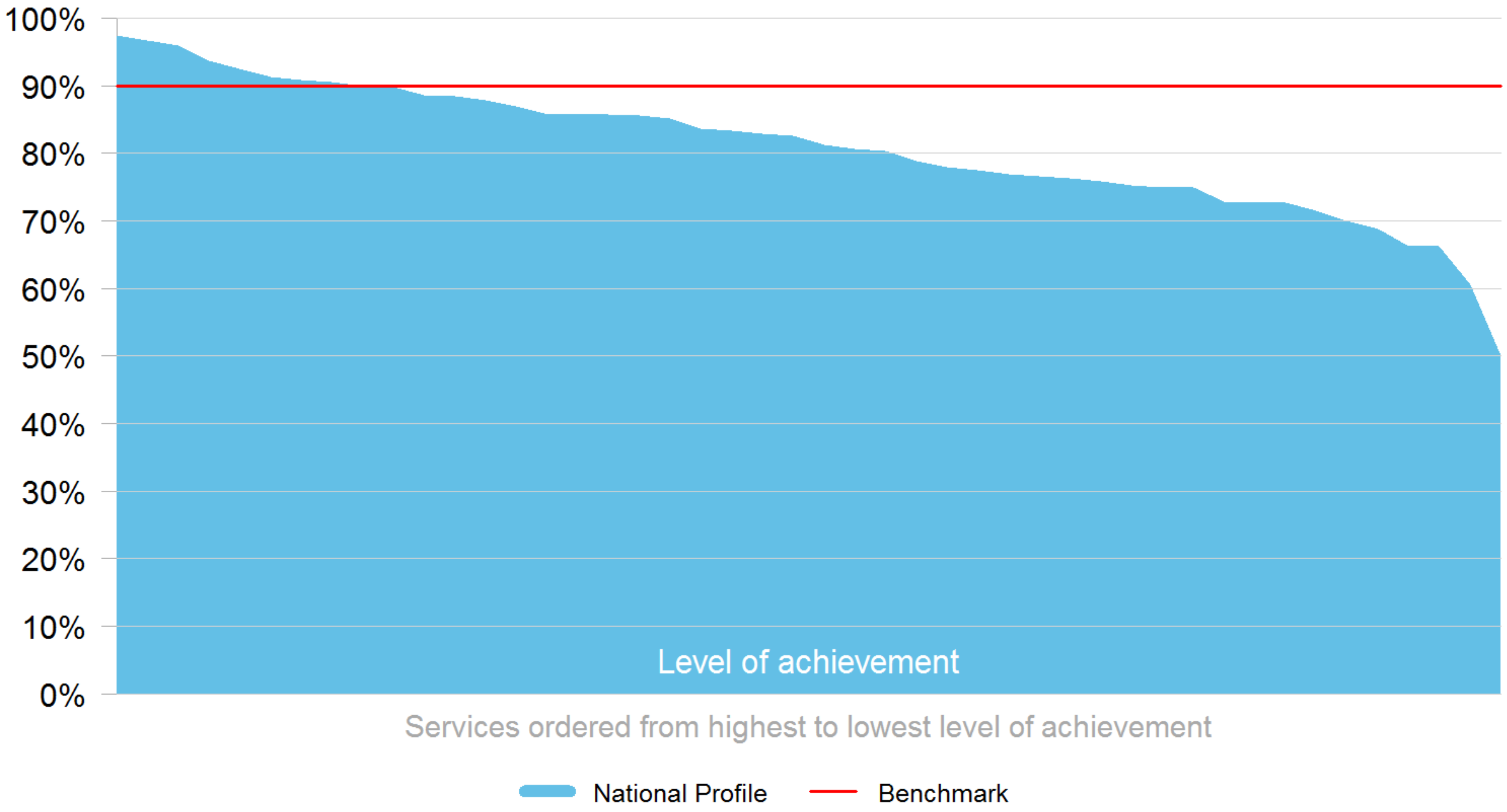


Figure 6 PCPSS: Percentage of patients with absent/mild pain at phase start, remaining absent/mild at phase end – ambulatory & community settings



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

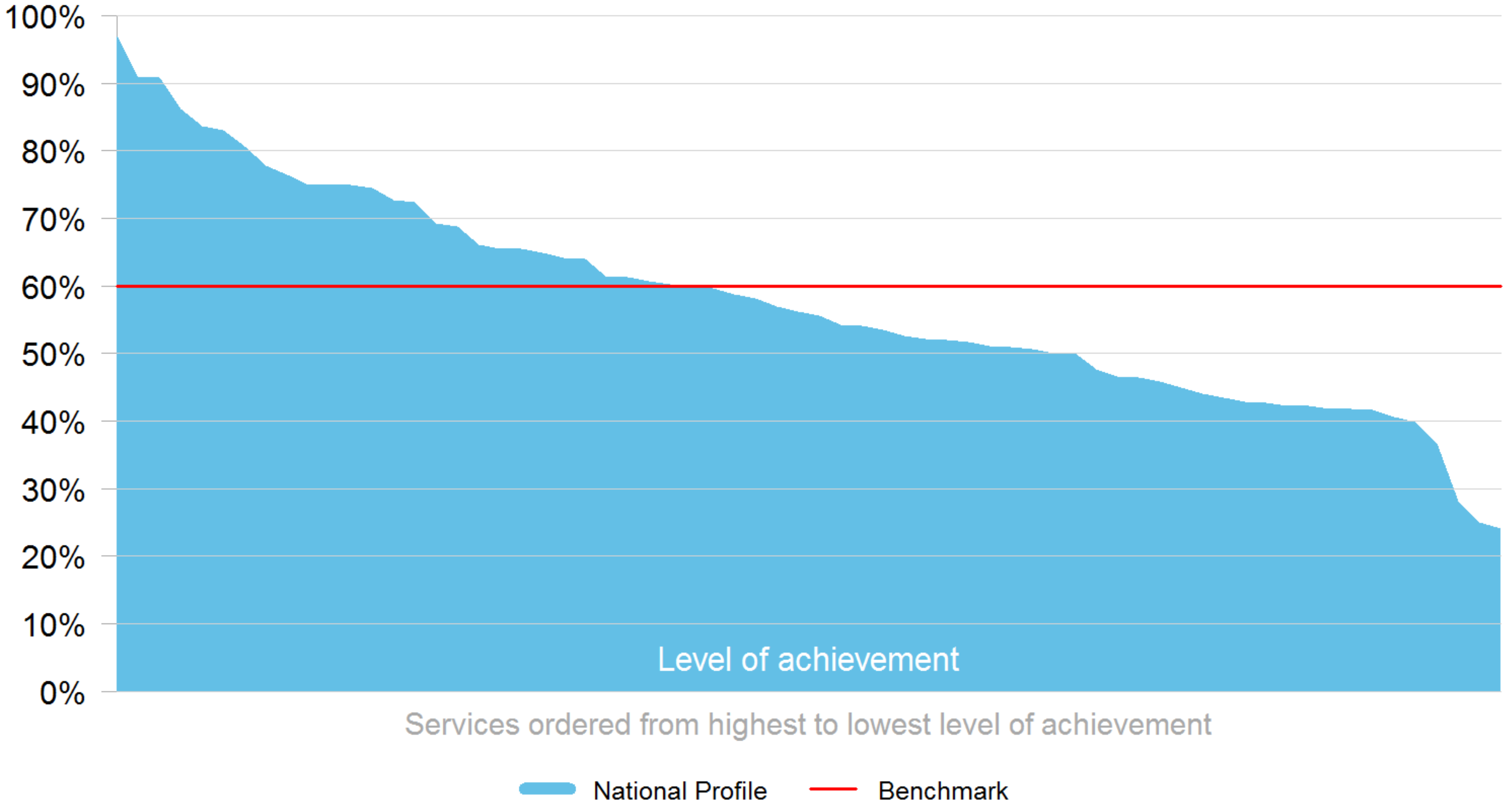
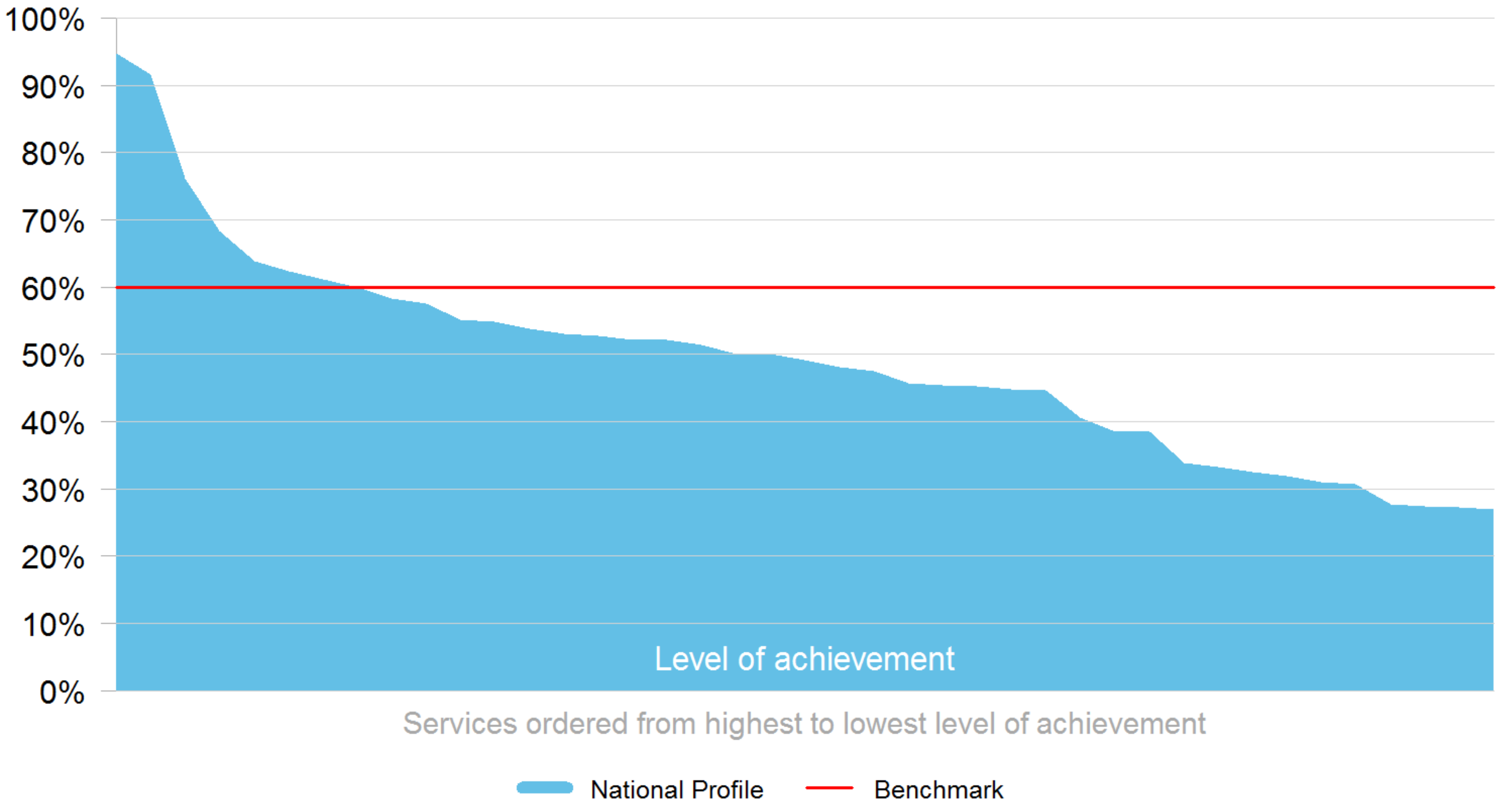


Figure 8 PCPSS: Percentage of patients with moderate/severe pain at phase start, with absent/mild pain at phase end – ambulatory & community settings



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

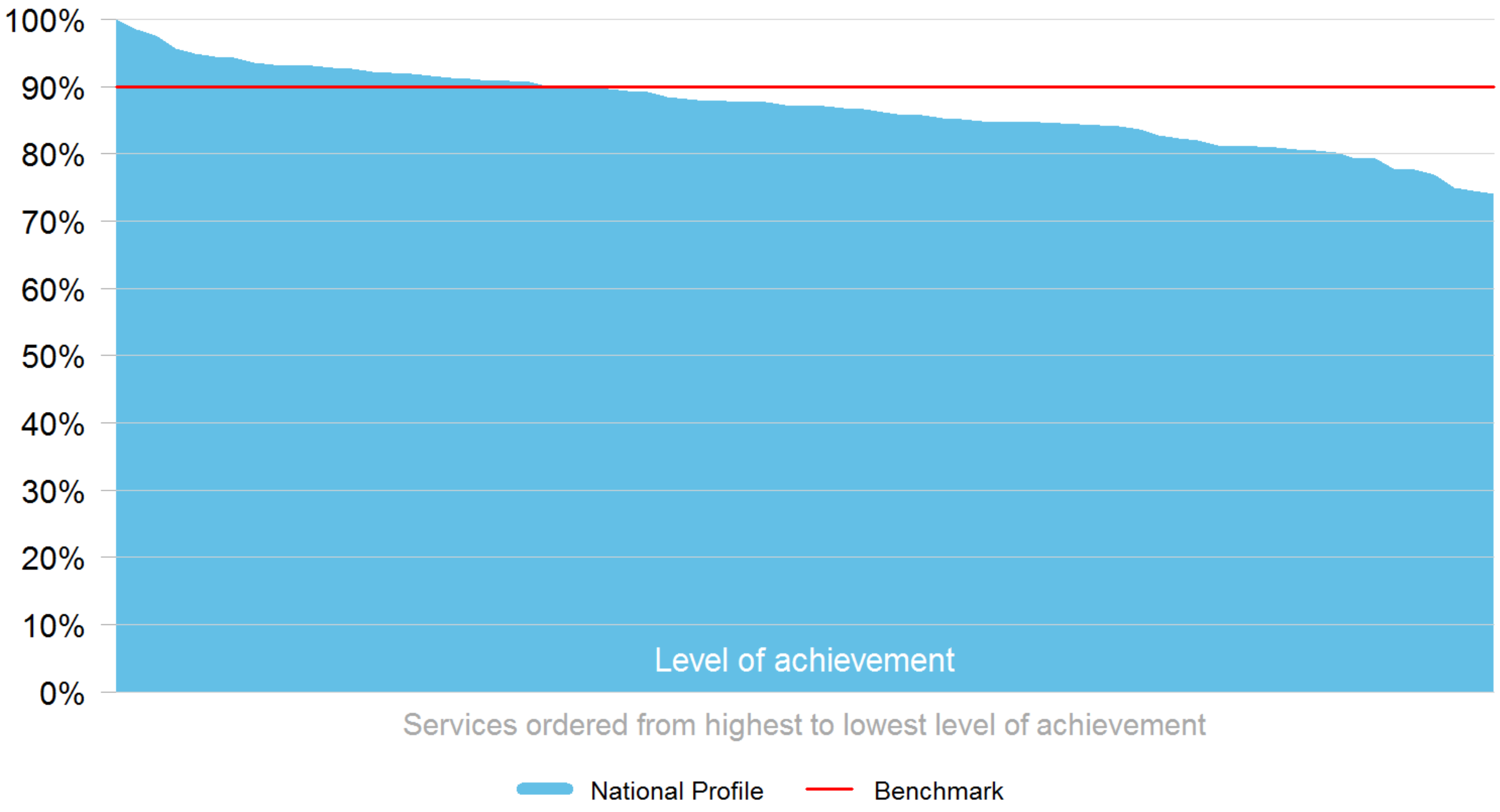
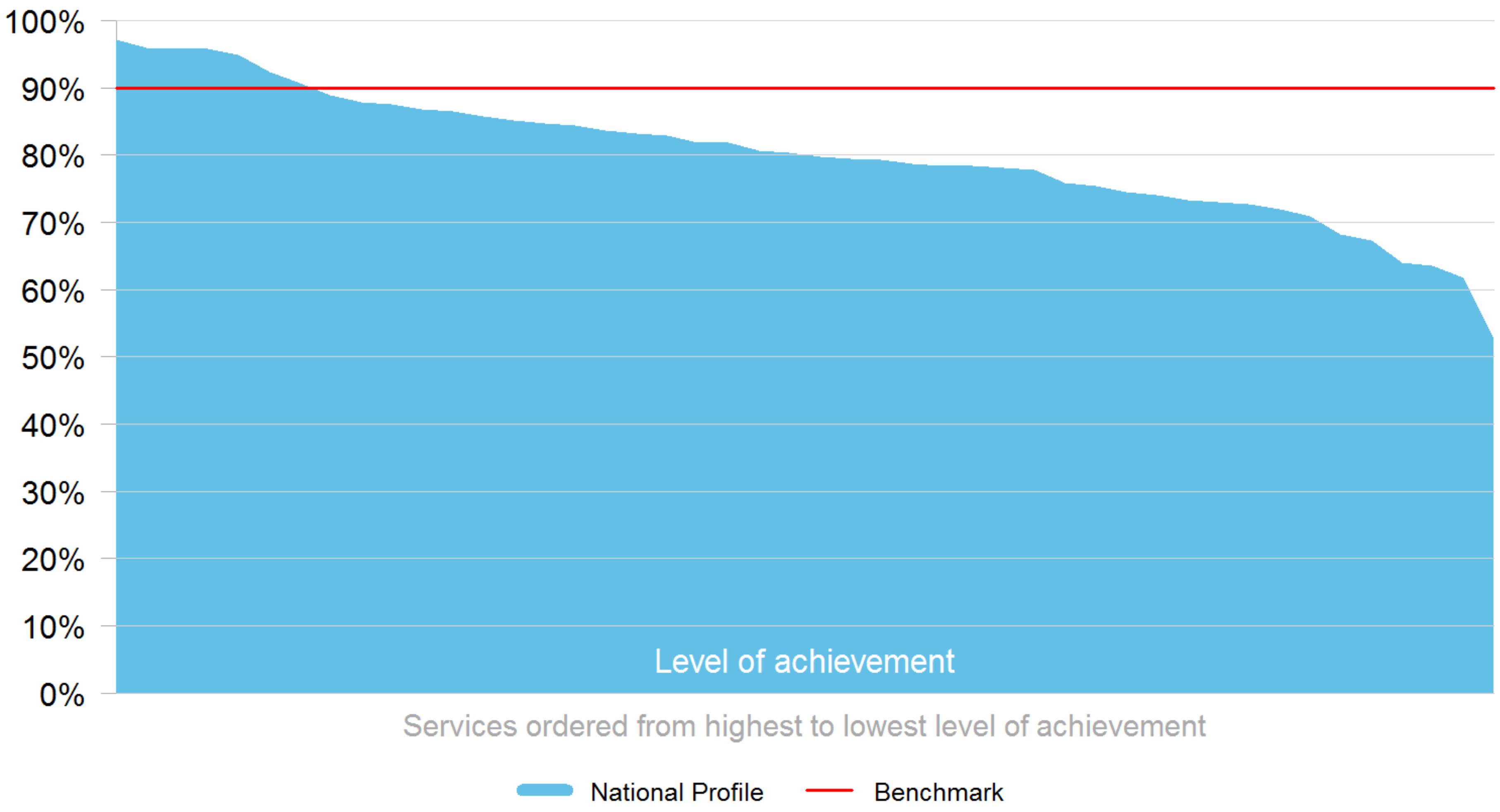


Figure 10 SAS: Percentage of patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end – ambulatory & community settings



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

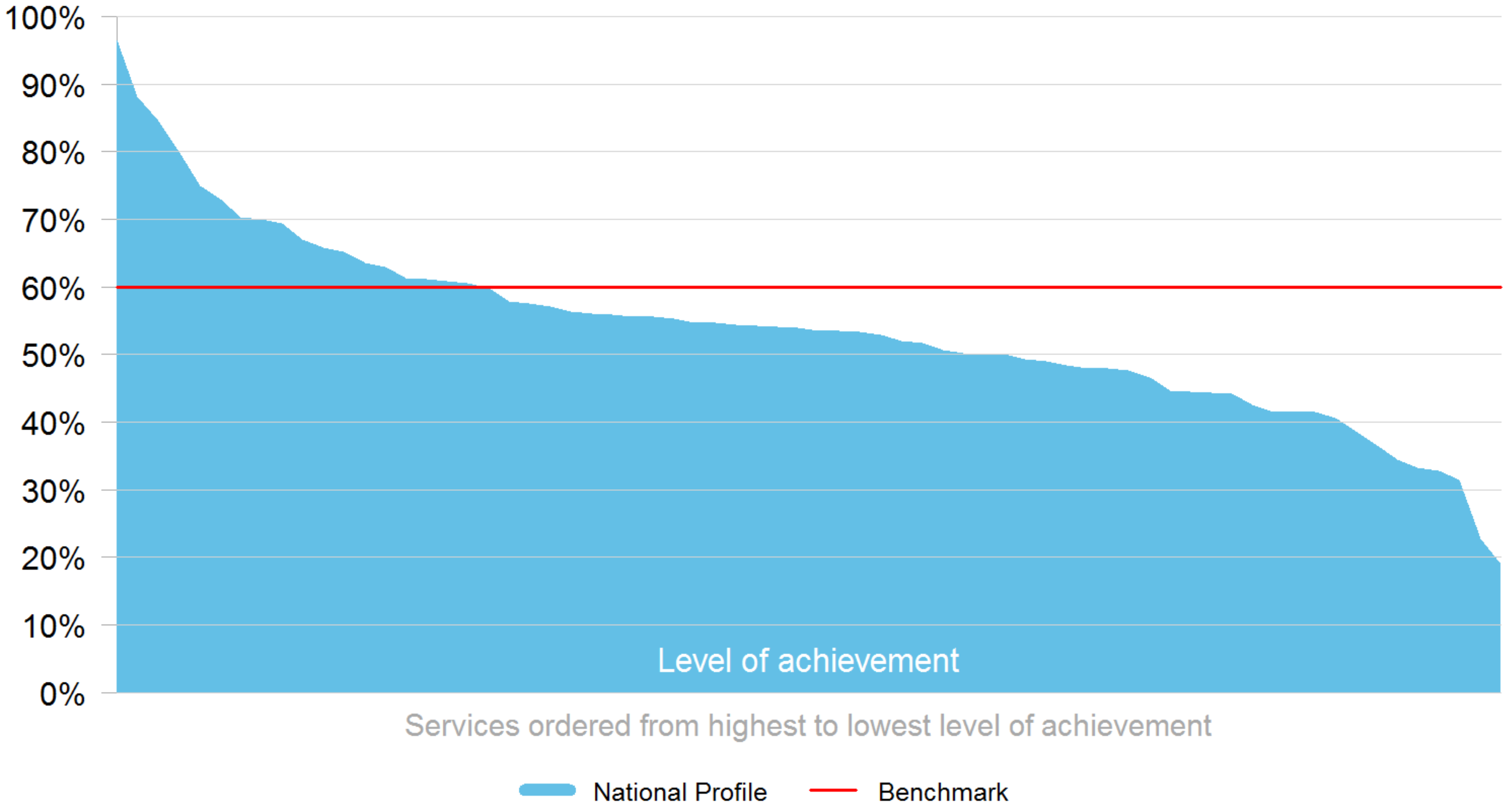
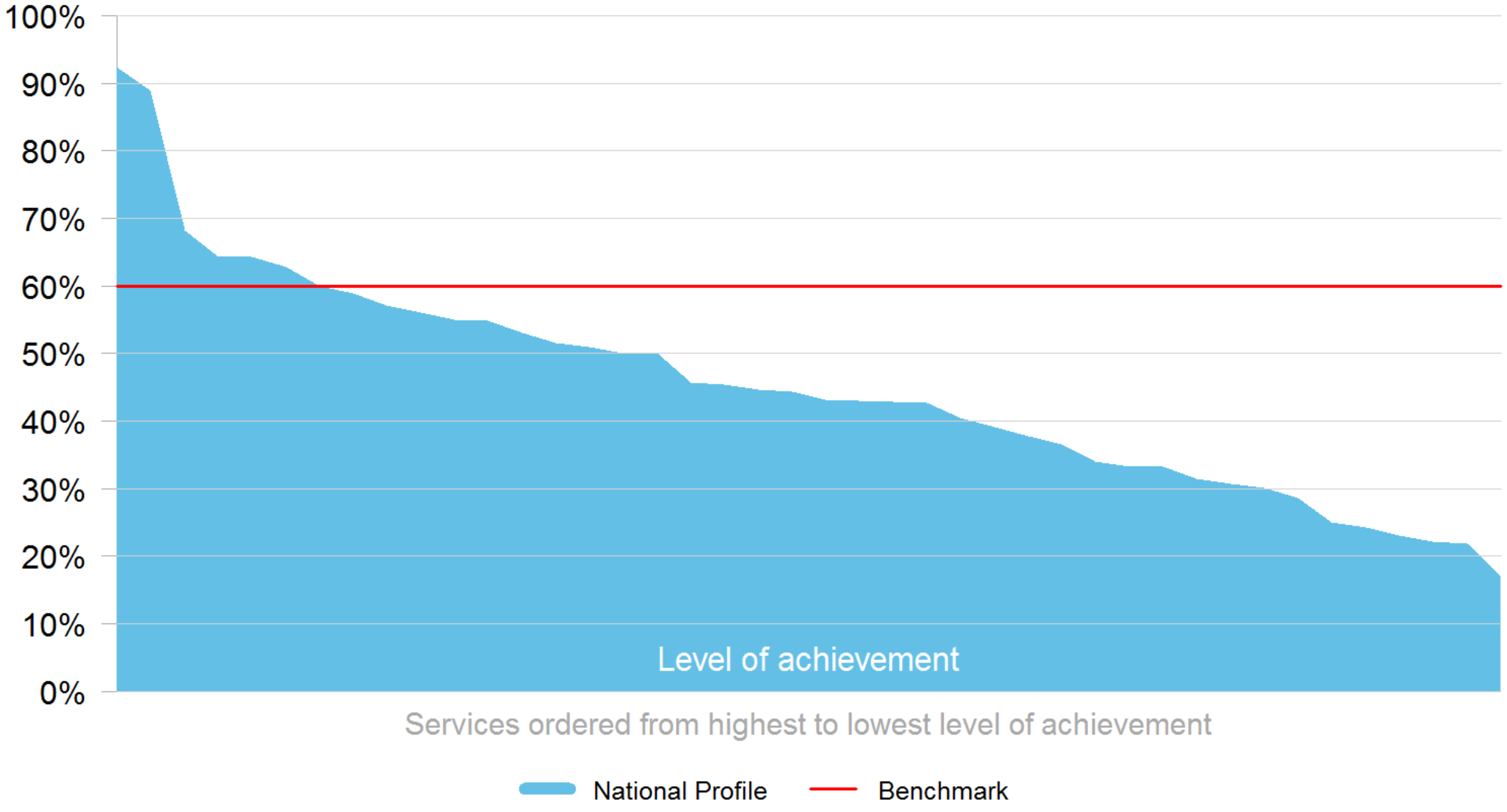


Figure 12 SAS: Percentage of patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end – ambulatory & community settings



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

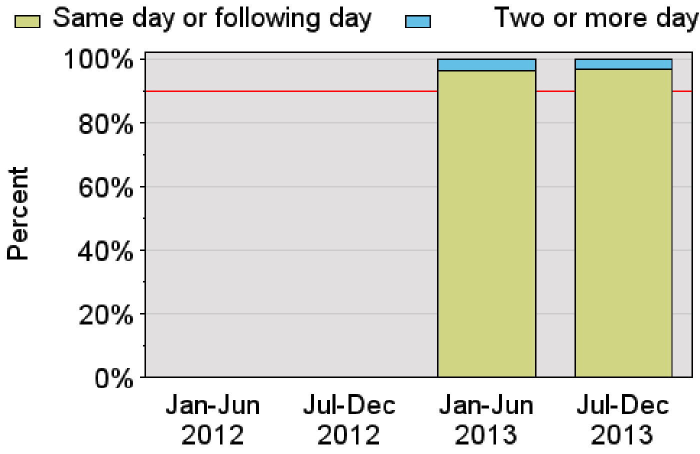
Time (in days)	Inpatient		Ambulatory & community	
	N	%	N	%
Same day	9,798	91.2	7,277	71.0
Following day	568	5.3	714	7.0
2-7 days	283	2.6	1,538	15.0
8-14 days	14	0.1	386	3.8
Greater than 14 days	78	0.7	336	3.3
Average	1.6	na	3.3	na
Median	1	na	1	na

Note: 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.

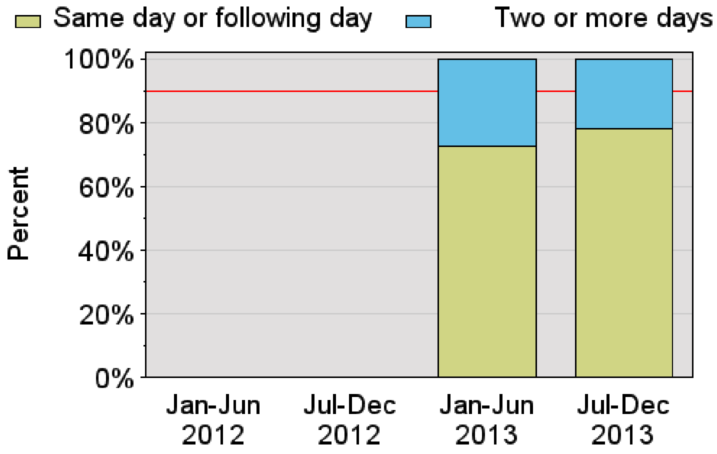
Outcome measure 1 has changed for this report. Table 16 on page 34 gives a summary of 'Time from referral to first contact', which has been replaced by the new outcome measure 'Time from date ready for care to episode start'.

Figure 13 Trends in time from date ready for care to episode start by setting

Inpatient setting



Ambulatory & community settings



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 patients care.

Patients move out of the unstable phases 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.

Prior to Report 14 (July to December 2012), there were three benchmarks relating to the time a patient spent in the unstable phase. In Report 14, these three benchmarks were replaced by the following as shown in Table 4:

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 and occurrence in episode

Setting	Occurrence of unstable phase	Number of unstable phases	Per cent unstable for 7 days or less	Per cent unstable for 3 days or less
Inpatient	First phase of episode	5,142	94.3	79.8
	Not first phase of episode	2,147	93.4	80.1
	Total unstable phases	***7,289***	***94.1***	***79.9***
Ambulatory & community	First phase of episode	745	67.8	54.6
	Not first phase of episode	2,183	84.1	75.7
	Total unstable phases	***2,928***	***79.9***	***70.3***

Interpretation hint:

Nationally, a total of **7289** patients in the **inpatient** setting were in the unstable phase. Of these unstable phases, **79.9%** remained for 3 days or less.

Nationally, a total of **2928** patients in the **ambulatory and community** setting were in the unstable phase. Of these unstable phases, **70.3%** remained for 3 days or less.

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		Jan-Jun 2012	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013
Inpatient	Number	7,362	8,738	10,243	13,296
	%	86.2	86.0	88.5	88.5
Ambulatory & community	Number	3,276	8,698	8,842	11,200
	%	80.0	83.4	82.6	83.2

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		Jan-Jun 2012	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013
Inpatient	Number	2,220	2,457	2,740	3,131
	%	51.1	52.8	56.2	53.8
Ambulatory & community	Number	742	1,552	1,625	2,017
	%	48.3	51.6	51.7	51.8

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

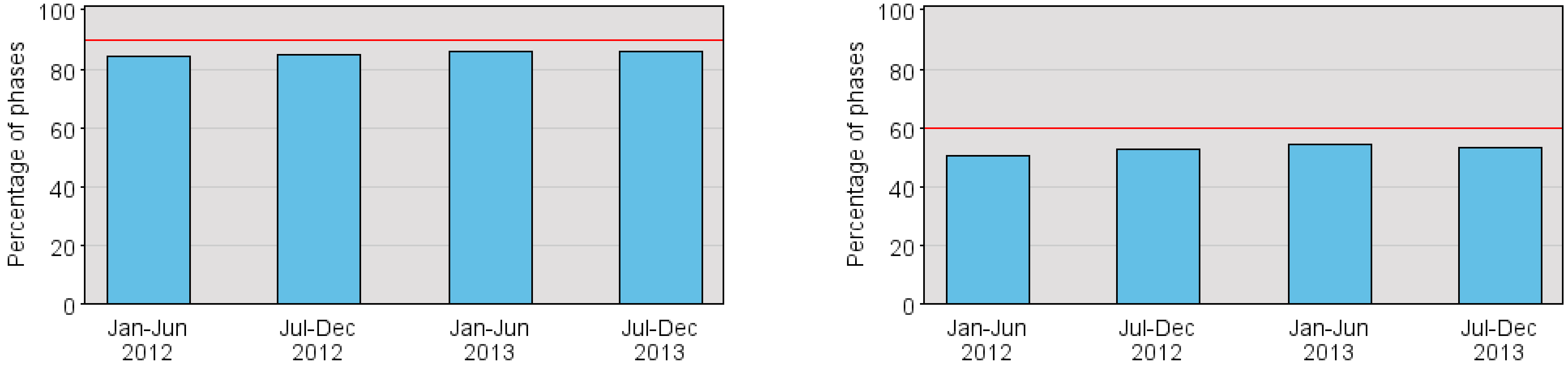
Setting		Jan-Jun 2012	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013
Inpatient	Number	8,179	9,638	10,228	12,002
	%	84.5	85.3	87.8	87.0
Ambulatory & community	Number	4,112	8,221	8,255	10,359
	%	80.9	81.8	81.2	81.2

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

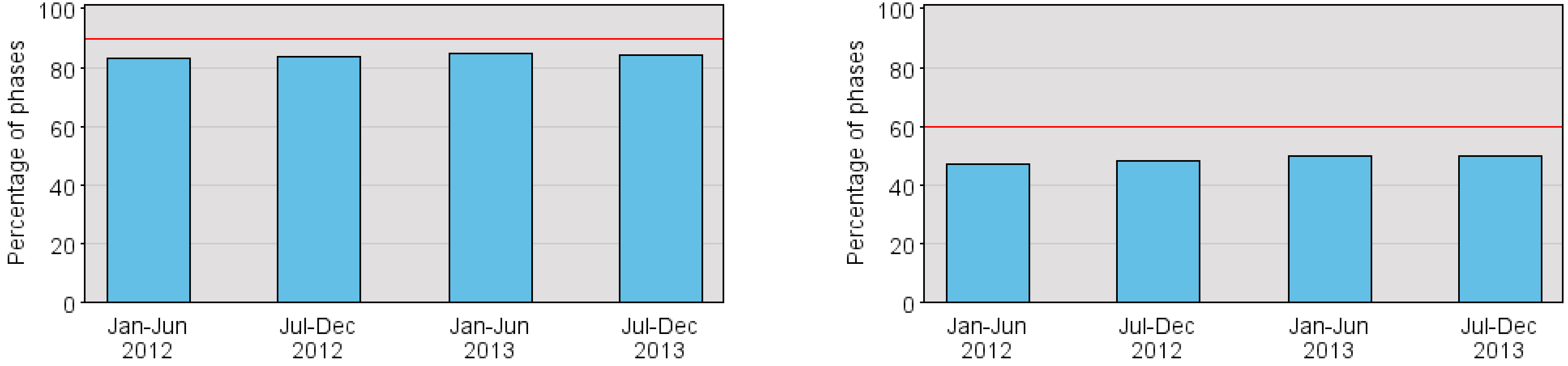
Setting		Jan-Jun 2012	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013
Inpatient	Number	2,789	2,870	3,028	3,506
	%	47.9	49.0	51.4	50.4
Ambulatory & community	Number	911	1,666	1,746	2,316
	%	45.1	46.8	47.5	48.7

Figure 14 Trends in outcome measure 3



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

Benchmark 3.2: PCPSS - Mod/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 - Mod/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:

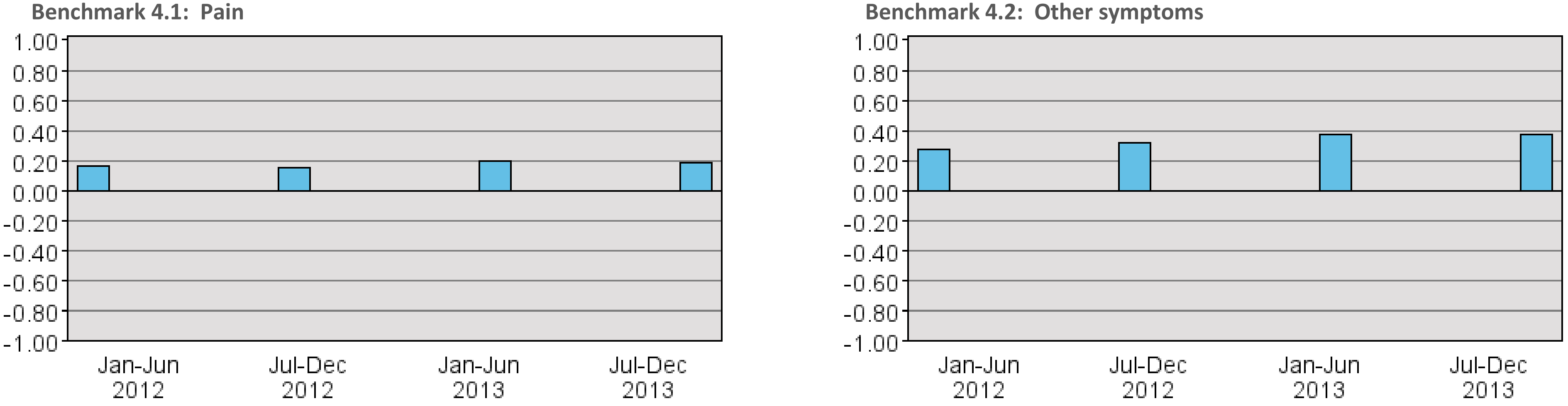
The X-CAS measures are calculated relative to a baseline reference period (currently July to December 2008). As a result:

If X-CAS 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 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.

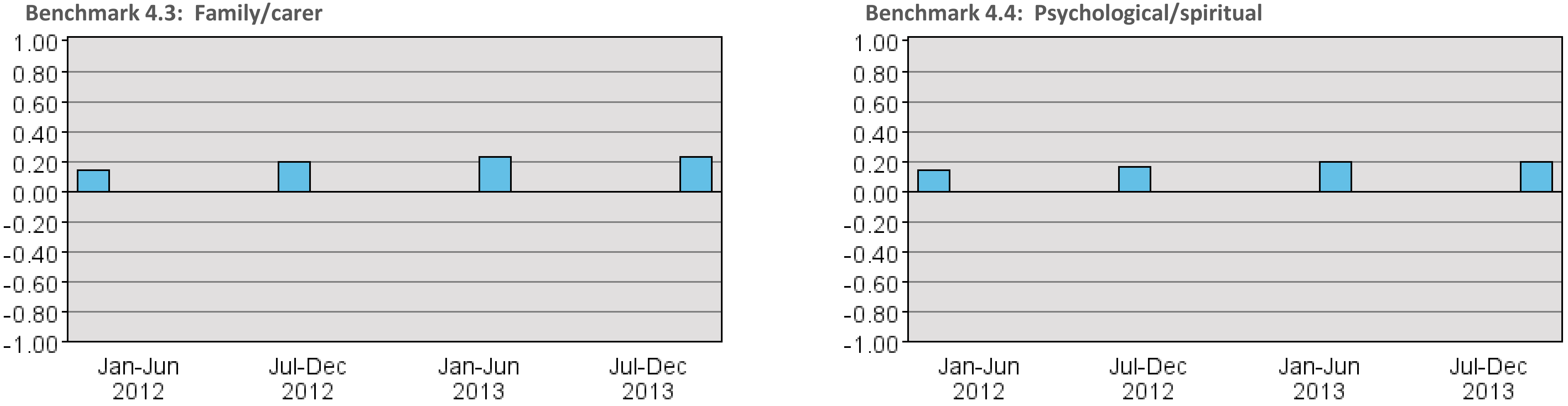
A more technical explanation of X-CAS is included in Appendix C.

Figure 15 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

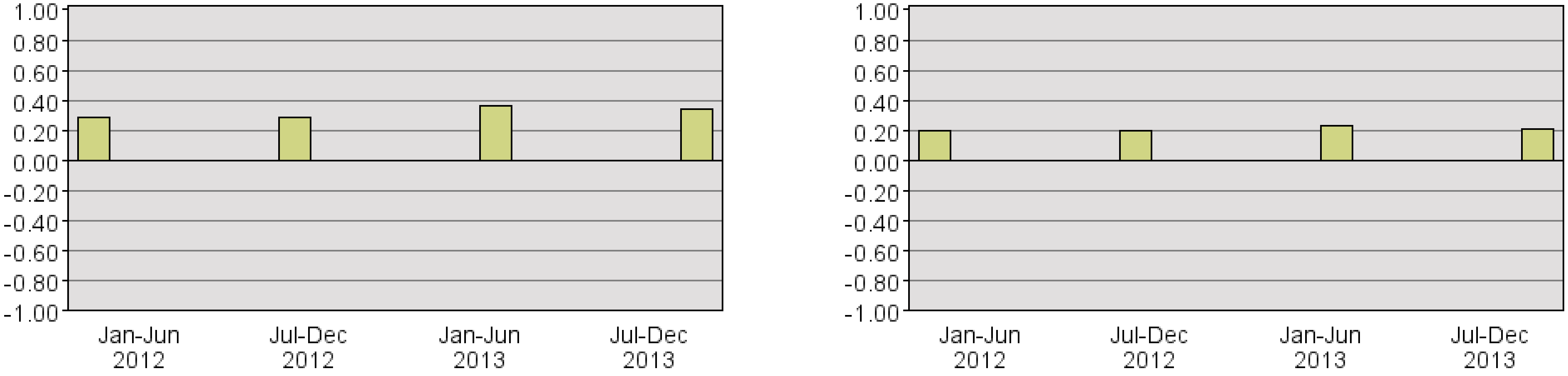
Benchmark 4.4: Psychological/spiritual

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

Figure 16 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)

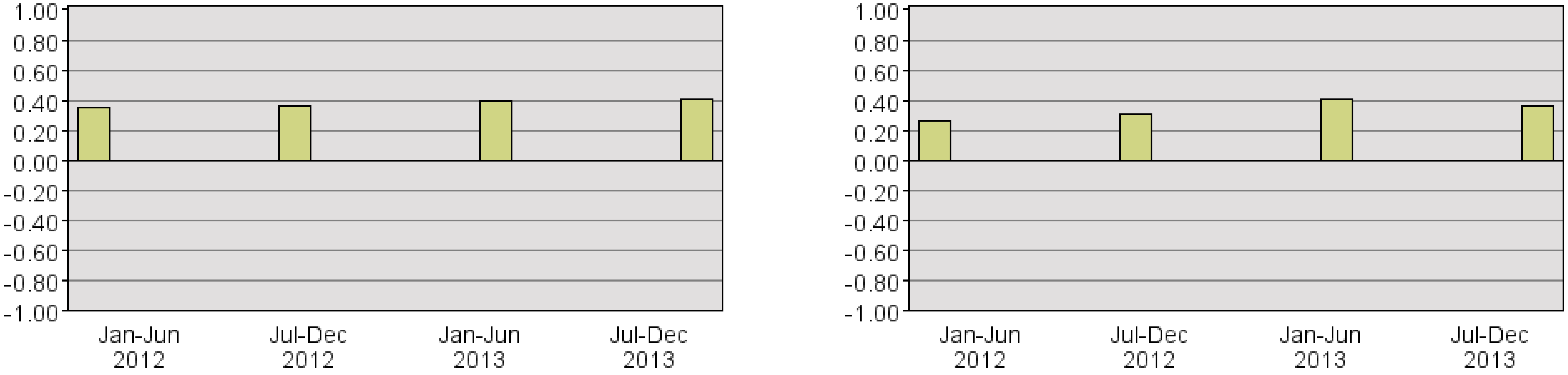
Benchmark 4.5: Pain

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.

Episode level includes data items which focus on characterising the setting of palliative care service provision. They also provide information relating to the reasons why and how a palliative care episodes starts/ends, the level of support a palliative care patient received both before and after an episode and (where applicable) the setting in which the patient died.

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 at each level for the current reporting period.

3.1 Profile of palliative care patients

PCOC defines a patient as a person for whom a palliative care services 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).

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 nationally. Non-disclosure can result in cultural issues not being identified.

Table 9 Indigenous status

Indigenous status	N	%
Aboriginal but not Torres Strait Islander origin	183	1.1
Torres Strait Islander but not Aboriginal origin	7	0.0
Both Aboriginal and Torres Strait Islander origin	12	0.1
Neither Aboriginal nor Torres Strait Islander origin	16,644	96.9
Not stated/inadequately described	330	1.9
Total	**17,176**	**100.0**

The following two tables show the preferred language spoken at home and the country of birth respectively for all patients nationally. To allow for comparison with the broader Australian community the list of languages in Table 10 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 11 (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 10 Preferred language spoken at home

Preferred language	N	%
English	15,335	89.3
Italian	353	2.1
Greek	291	1.7
Cantonese/Mandarin	163	0.9
Arabic	98	0.6
Vietnamese	61	0.4
Spanish/Portuguese	41	0.2
Filipino	16	0.1
German	24	0.1
Hindi	5	0.0
Macedonian/Croatian	108	0.6
Korean	8	0.0
Turkish	35	0.2
Polish	28	0.2
Maltese	25	0.1
All other languages	470	2.7
Not stated/inadequately described	115	0.7
Total	***17,176***	***100.0***

Table 11 Country of birth

Country of birth	N	%
Australia	10,842	63.1
England	1,259	7.3
New Zealand	295	1.7
China	189	1.1
Italy	689	4.0
Vietnam	127	0.7
India	115	0.7
Scotland	263	1.5
Philippines	71	0.4
Greece	394	2.3
Germany	192	1.1
South Africa	81	0.5
Malaysia	54	0.3
Netherlands	148	0.9
Lebanon	78	0.5
All other countries	2,102	12.2
Not stated/inadequately described	277	1.6
Total	***17,176***	***100.0***

Table 12 and Table 13 present a breakdown of malignant and non-malignant diagnosis for all patients nationally. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 54 (0.3%) patients nationally.

Table 12 Primary diagnosis - malignant

Primary diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	190	1.4	1.1
Breast	1,114	8.3	6.5
CNS	262	1.9	1.5
Colorectal	1,549	11.5	9.0
Other GIT	1,240	9.2	7.2
Haematological	857	6.4	5.0
Head and neck	693	5.1	4.0
Lung	2,875	21.4	16.7
Pancreas	808	6.0	4.7
Prostate	952	7.1	5.5
Other urological	613	4.6	3.6
Gynaecological	664	4.9	3.9
Skin	581	4.3	3.4
Unknown primary	351	2.6	2.0
Other primary malignancy	541	4.0	3.1
Malignant – not further defined	167	1.2	1.0
All malignant	***13,457***	***100.0***	***78.3***

Table 13 Primary diagnosis - non-malignant

Primary diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	681	18.6	4.0
HIV/AIDS	11	0.3	0.1
End stage kidney disease	356	9.7	2.1
Stroke	162	4.4	0.9
Motor neurone disease	135	3.7	0.8
Alzheimer’s dementia	107	2.9	0.6
Other dementia	187	5.1	1.1
Other neurological disease	398	10.9	2.3
Respiratory failure	621	16.9	3.6
End stage liver disease	111	3.0	0.6
Diabetes and its complications	12	0.3	0.1
Sepsis	75	2.0	0.4
Multiple organ failure	73	2.0	0.4
Other non-malignancy	652	17.8	3.8
Non-malignant – not further defined	84	2.3	0.5
All non-malignant	***3,665***	***100.0***	***21.3***

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 ambulatory and 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 14 below presents the number and percentage of episodes by age group and gender. Age has been calculated as at the beginning of each episode.

Table 14 Age group by gender

Age group	Male		Female	
	N	%	N	%
< 15	26	0.2	24	0.2
15 - 24	31	0.3	24	0.2
25 - 34	97	0.8	106	1.0
35 - 44	251	2.1	320	3.1
45 - 54	765	6.5	908	8.8
55 - 64	1,859	15.9	1,685	16.3
65 - 74	3,140	26.8	2,298	22.3
75 - 84	3,493	29.8	2,714	26.3
85+	2,057	17.6	2,230	21.6
Not stated/inadequately described	0	0.0	1	0.0
Total	***11,719***	***100.0***	***10,310***	***100.0***

Note: Records where gender 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 15 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 15 Referral source by setting

Referral source	Inpatient		Ambulatory & community	
	N	%	N	%
Public hospital - other than inpatient palliative care unit	3,995	35.0	4,285	40.3
Private hospital - other than inpatient palliative care unit	1,298	11.4	843	7.9
Public palliative care inpatient unit/hospice	1,482	13.0	1,141	10.7
Private palliative care inpatient unit/hospice	215	1.9	346	3.3
Outpatient clinic	33	0.3	17	0.2
General medical practitioner	442	3.9	1,436	13.5
Specialist medical practitioner	432	3.8	524	4.9
Community-based palliative care agency	2,758	24.2	162	1.5
Community-based service	108	0.9	143	1.3
Residential aged care facility	125	1.1	982	9.2
Self, carer(s), family or friends	280	2.5	304	2.9
Other	147	1.3	250	2.4
Not stated/inadequately described	94	0.8	188	1.8
Total	***11,409***	***100.0***	***10,621***	***100.0***

In this report, for the first time, date ready for care has replaced time from referral to first contact in outcome measure one. Table 16 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 16 Referral to first contact by episode setting

Time (in days)	Inpatient		Ambulatory & community	
	N	%	N	%
Same day or following day	10,435	91.6	5,793	54.6
2-7 days	810	7.1	3,320	31.3
8-14 days	82	0.7	749	7.1
Greater than 14 days	68	0.6	749	7.1
Average	1.2	na	2.7	na
Median	1	na	1	na

Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact was greater than 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 17 gives a summary of the length of episode for patients nationally. Table 18 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 17 Length of episode (in days) summary by setting

Length of episode	Inpatient	Ambulatory & community
Average length of episode	11.6	39.8
Median length of episode	7.0	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.

Table 18 Length of episode (in days) by setting

Length of episode	Inpatient		Ambulatory & community	
	N	%	N	%
Same day	546	4.8	547	5.6
1-2 days	2,129	18.8	531	5.4
3-4 days	1,636	14.4	486	4.9
5-7 days	1,849	16.3	685	7.0
8-14 days	2,359	20.8	1,182	12.0
15-21 days	1,082	9.5	887	9.0
22-30 days	781	6.9	849	8.6
31-60 days	752	6.6	1,772	18.0
61-90 days	146	1.3	966	9.8
Greater than 90 days	52	0.5	1,947	19.8
Total	***11,332***	***100.0***	***9,852***	***100.0***

Table 19 How episodes start and end – inpatient setting

How episode started	How episodes ended											
	Discharged to:						Death		All other reasons**		Total	
	Usual accommodation		Other than usual accommodation		Another hospital							
Admitted from:	N	%	N	%	N	%	N	%	N	%	N	%
- usual accommodation	2,704	39.7	237	3.5	584	8.6	3,036	44.6	246	3.6	6,807	100.0
- other than usual accommodation	34	16.7	35	17.2	18	8.9	106	52.2	10	4.9	203	100.0
- another hospital (transferred)	508	17.2	99	3.4	135	4.6	2,134	72.3	77	2.6	2,953	100.0
- acute care in other ward (transferred)	194	18.1	32	3.0	50	4.7	774	72.3	20	1.9	1,070	100.0
All other reasons*	86	30.2	16	5.6	29	10.2	147	51.6	7	2.5	285	100.0
Total	***3,526***	***31.2***	***419***	***3.7***	***816***	***7.2***	***6,197***	***54.8***	***360***	***3.2***	***11,318***	***100.0***

Note: All episodes where episode start mode or episode end mode was not stated/inadequately described are excluded from the table. Episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

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

** Includes: Change from palliative care to acute care - different ward; Change from palliative care to acute care - same ward.

Table 20 How episodes start and end – ambulatory and community setting

How episode started	How episodes ended									
	Admitted for inpatient:				Death		All other reasons*		Total	
	Palliative care		Acute care							
	N	%	N	%	N	%	N	%	N	%
Transferred from inpatient palliative care	1,086	29.0	1,241	33.1	980	26.1	443	11.8	3,750	100.0
Other	1,626	26.9	1,191	19.7	1,957	32.4	1,269	21.0	6,043	100.0
Total	***2,712***	***27.7***	***2,432***	***24.8***	***2,937***	***30.0***	***1,712***	***17.5***	***9,793***	***100.0***

Note: All episodes where episode start mode or episode end mode was not stated/inadequately described are excluded from the table. Episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

* Includes: Discharged/case closure, admitted to another palliative care service, admitted to primary health care and other categories.

Table 21 Place of death – ambulatory and community setting

Place of death	N	%
Private residence	1,894	64.1
Residential aged care setting	632	21.4
Not stated/inadequately described	427	14.5
Total	***2,953***	***100.0***

Interpretation hint:

Place of death is only recorded for the ambulatory and community setting. Table 23 only relates to this setting. All inpatients deaths occur in hospital and are not recorded in this table.

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. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence.

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

Table 22 Number of phases by phase type and setting

Phase type	Inpatient		Ambulatory & community	
	N	%	N	%
Stable	7,533	25.6	9,016	38.9
Unstable	7,289	24.8	2,928	12.6
Deteriorating	8,328	28.3	9,386	40.5
Terminal	5,209	17.7	1,631	7.0
Bereaved	1,021	3.5	237	1.0
All phases	**29,380**	**100.0**	**23,198**	**100.0**

Table 23 Average phase length (in days) by phase type and setting

Phase type	Inpatient	Ambulatory & community
Stable	7.1	20.8
Unstable	2.5	5.0
Deteriorating	5.1	13.4
Terminal	2.1	3.0
Bereaved	1.2	23.3

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

Table 24 presents information relating to the manner in which stable phases ended. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 17 and Figure 18 summarise the movement of patients out of the stable phase for the inpatient and ambulatory 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 25, Figure 19 and Figure 20), deteriorating (Table 26, Figure 21 and Figure 22) and terminal (Table 26, Figure 23 and Figure 24) phases on the following pages.

Table 24 How stable phases end – by setting

How stable phases end	Inpatient		Ambulatory & community	
	N	%	N	%
Patient moved into another phase	3,978	52.8	5,687	63.1
Discharge/case closure	3,416	45.3	2,878	31.9
Died	114	1.5	407	4.5
Not stated/inadequately described	25	0.3	44	0.5
Total	***7,533***	***100.0***	***9,016***	***100.0***

Figure 17 Stable phase progression – inpatient setting

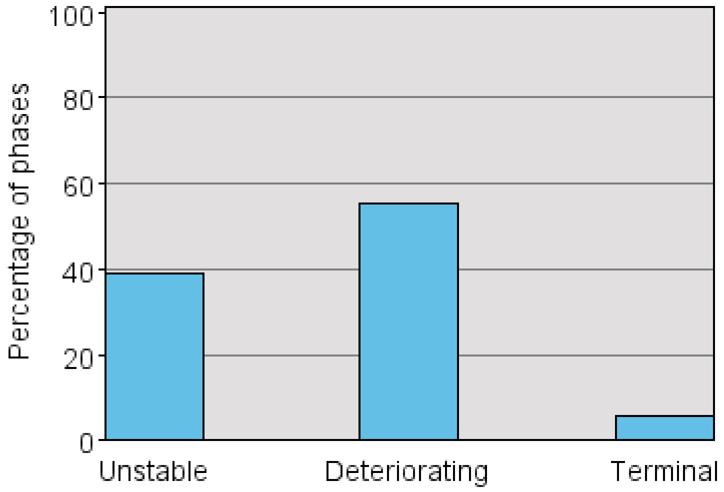


Figure 18 Stable phase progression – ambulatory & community settings

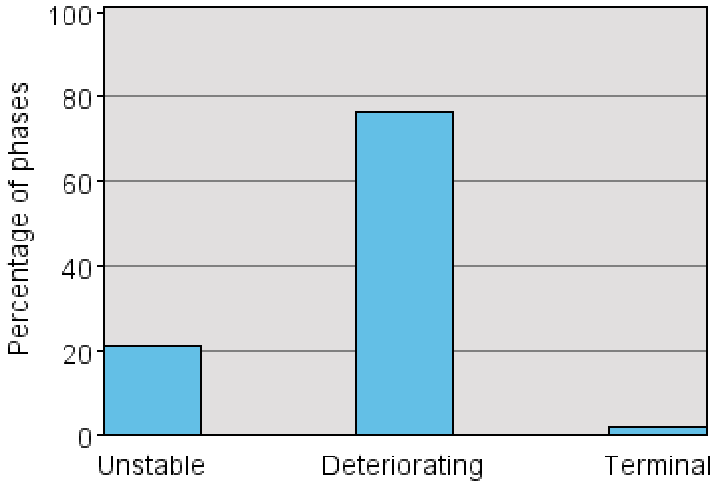


Table 25 How unstable phases end – by setting

How unstable phases end	Inpatient		Ambulatory & community	
	N	**%**	**N**	**%**
Patient moved into another phase	6,685	91.7	1,940	66.3
Discharge/case closure	405	5.6	853	29.1
Died	183	2.5	126	4.3
Not stated/inadequately described	16	0.2	9	0.3
Total	***7,289***	***100.0***	***2,928***	***100.0***

Figure 19 Unstable phase progression – inpatient setting

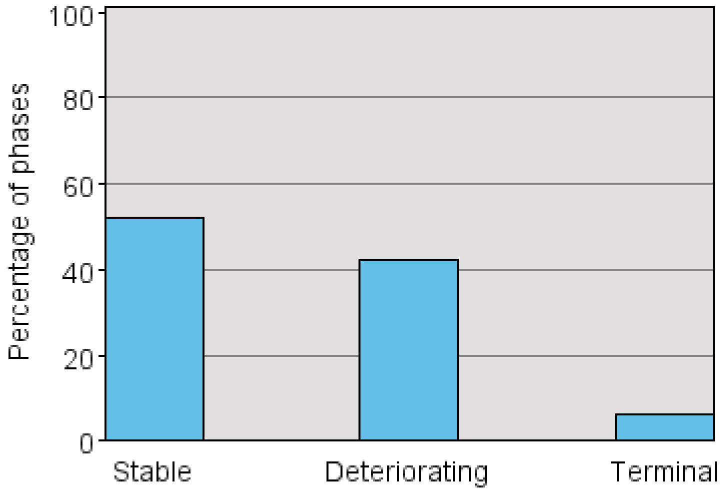


Figure 20 Unstable phase progression – ambulatory & community settings

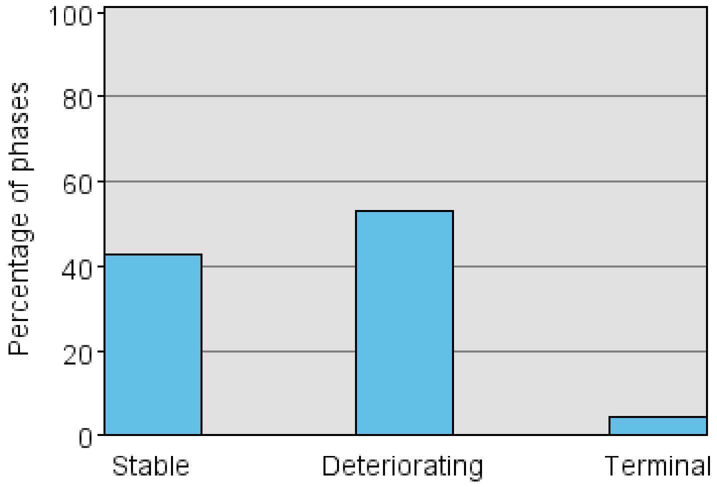


Table 26 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient		Ambulatory & community	
	N	%	N	%
Patient moved into another phase	6,214	74.6	5,610	59.8
Discharge/case closure	1,129	13.6	2,753	29.3
Died	966	11.6	1,004	10.7
Not stated/inadequately described	19	0.2	19	0.2
Total	***8,328***	***100.0***	***9,386***	***100.0***

Figure 21 Deteriorating phase progression – inpatient setting

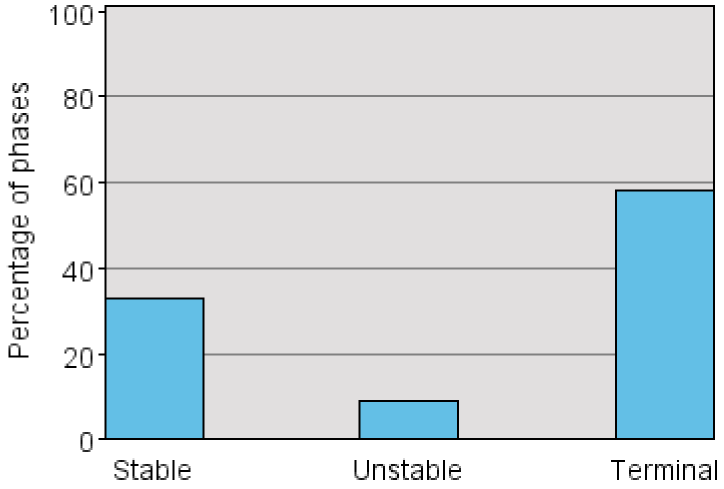


Figure 22 Deteriorating phase progression – ambulatory & community settings

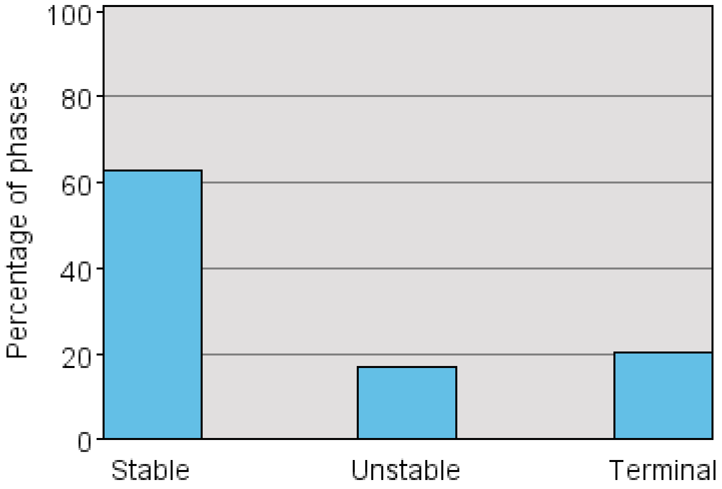


Table 27 How terminal phases end – by setting

How terminal phases end	Inpatient		Ambulatory & community	
	N	%	N	%
Patient moved into another phase	265	5.1	189	11.6
Discharge/case closure	94	1.8	117	7.2
Died	4,836	92.8	1,322	81.1
Not stated/inadequately described	14	0.3	3	0.2
Total	***5,209***	***100.0***	***1,631***	***100.0***

Figure 23 Terminal phase progression – inpatient setting

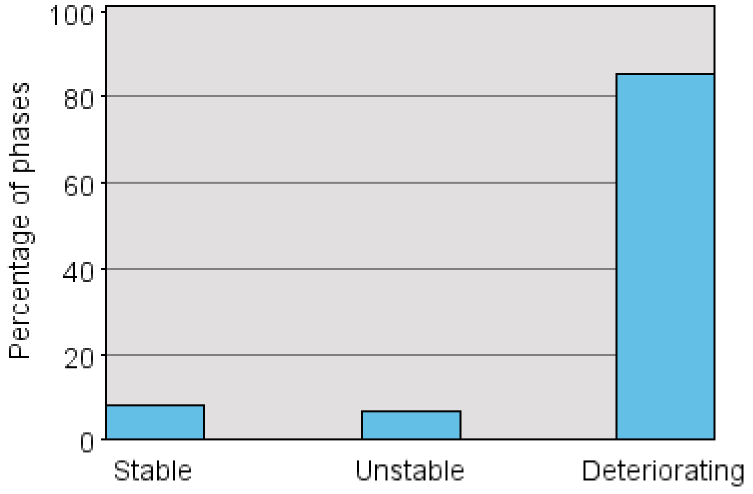
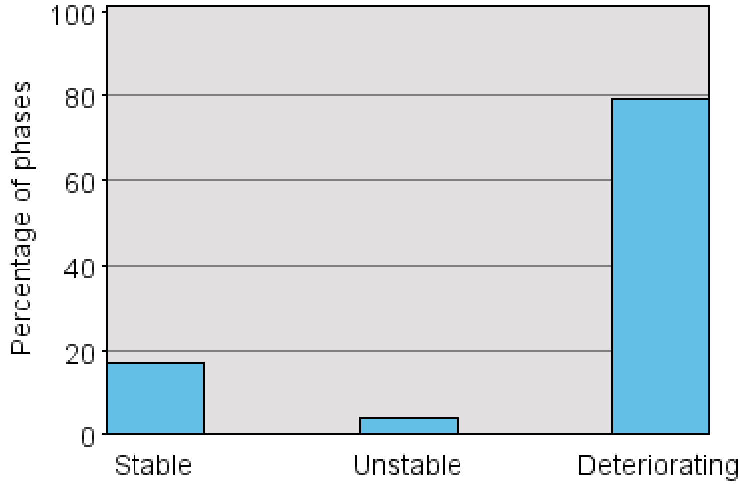


Figure 24 Terminal phase progression – ambulatory & community settings



The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall degree 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 28 and Table 29 show the percentage scores for the inpatient and ambulatory and community settings respectively.

Table 28 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	45.8	38.3	12.9	3.0
	Other symptoms	23.5	47.9	23.6	5.0
	Psychological/spiritual	29.7	49.1	17.2	4.0
	Family/carer	34.7	43.0	16.9	5.4
Unstable	Pain	31.0	30.3	26.5	12.3
	Other symptoms	12.4	32.4	39.5	15.7
	Psychological/spiritual	20.7	41.7	27.9	9.7
	Family/carer	24.4	37.1	26.8	11.7
Deteriorating	Pain	37.5	34.5	20.7	7.3
	Other symptoms	14.6	36.2	36.1	13.1
	Psychological/spiritual	24.2	43.2	24.2	8.4
	Family/carer	24.8	37.3	26.1	11.8
Terminal	Pain	47.7	28.7	16.0	7.6
	Other symptoms	33.9	27.8	24.4	13.9
	Psychological/spiritual	47.7	29.6	15.0	7.7
	Family/carer	20.4	30.5	30.6	18.5

Table 29 Profile of PCPSS at beginning of phase by phase type – ambulatory and community settings (percentages)

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	38.8	51.3	8.9	1.0
	Other symptoms	13.9	62.2	21.9	2.0
	Psychological/spiritual	28.3	57.2	13.2	1.3
	Family/carer	30.2	49.8	17.8	2.2
Unstable	Pain	20.0	27.3	32.8	19.9
	Other symptoms	5.5	26.3	48.5	19.8
	Psychological/spiritual	13.1	43.1	34.4	9.3
	Family/carer	13.8	33.7	40.4	12.2
Deteriorating	Pain	27.9	47.4	21.4	3.3
	Other symptoms	7.1	43.0	44.1	5.8
	Psychological/spiritual	19.0	53.1	24.7	3.2
	Family/carer	20.3	41.2	33.3	5.2
Terminal	Pain	33.2	42.9	19.3	4.5
	Other symptoms	17.7	37.4	32.8	12.1
	Psychological/spiritual	37.9	41.3	15.9	4.9
	Family/carer	12.4	33.3	39.9	14.3

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 identified as the main cancer and palliative care problems (difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain). It provides a clinical picture of these seven symptoms from the patients perspective e.g. a patient may rate their nausea at 8, hence an alert for further review. The SAS scores are grouped in Table 30 and

Table 31 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 30 Profile of SAS scores at beginning of phase by phase type – inpatient setting (percentages)

Phase type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	64.5	20.8	12.4	2.3
	Appetite problems	50.5	25.4	20.0	4.1
	Nausea	78.5	13.7	6.6	1.3
	Bowel problems	57.7	24.3	14.4	3.6
	Breathing problems	62.8	20.1	13.6	3.6
	Fatigue	24.8	23.8	41.8	9.6
	Pain	44.3	32.5	20.0	3.3
Unstable	Difficulty sleeping	55.0	19.6	19.5	5.8
	Appetite problems	38.5	22.9	28.5	10.1
	Nausea	66.0	15.4	13.1	5.4
	Bowel problems	48.4	23.5	20.9	7.2
	Breathing problems	53.5	18.6	19.5	8.4
	Fatigue	19.0	16.8	44.5	19.7
	Pain	30.8	26.1	30.8	12.3
Deteriorating	Difficulty sleeping	65.1	17.3	14.1	3.4
	Appetite problems	47.6	20.0	23.5	9.0
	Nausea	74.8	13.3	9.2	2.7
	Bowel problems	56.0	22.3	16.8	4.8
	Breathing problems	53.4	19.1	19.8	7.6
	Fatigue	23.3	12.3	42.2	22.3
	Pain	37.7	29.0	26.3	7.0
Terminal	Difficulty sleeping	87.2	6.4	4.9	1.4
	Appetite problems	83.0	4.7	6.7	5.6
	Nausea	91.2	4.5	3.1	1.1
	Bowel problems	79.5	9.5	8.2	2.8
	Breathing problems	64.1	12.4	14.9	8.6
	Fatigue	66.0	4.5	12.0	17.5
	Pain	54.9	21.6	19.0	4.6

Table 31 Profile of SAS scores at beginning of phase by phase type – ambulatory and community settings (percentages)

Phase type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	60.8	26.9	11.3	1.0
	Appetite problems	44.1	33.6	19.5	2.8
	Nausea	77.9	17.6	4.0	0.5
	Bowel problems	65.3	25.5	7.8	1.4
	Breathing problems	51.5	30.9	15.3	2.4
	Fatigue	12.8	32.3	47.4	7.5
	Pain	41.0	43.6	14.0	1.3
Unstable	Difficulty sleeping	42.7	26.4	25.2	5.7
	Appetite problems	30.2	23.9	34.8	11.0
	Nausea	57.5	19.8	15.9	6.8
	Bowel problems	51.2	25.0	17.6	6.2
	Breathing problems	44.7	27.4	21.2	6.8
	Fatigue	8.4	17.1	53.1	21.5
	Pain	21.2	23.6	35.5	19.8
Deteriorating	Difficulty sleeping	54.9	27.3	15.5	2.2
	Appetite problems	35.5	28.7	29.3	6.4
	Nausea	71.9	19.0	8.0	1.1
	Bowel problems	59.1	26.8	11.8	2.2
	Breathing problems	44.5	30.2	21.2	4.2
	Fatigue	9.2	17.5	56.9	16.4
	Pain	31.0	39.6	25.6	3.8
Terminal	Difficulty sleeping	71.6	15.2	10.6	2.6
	Appetite problems	67.8	8.9	10.1	13.2
	Nausea	82.4	11.3	5.6	0.7
	Bowel problems	70.1	18.0	9.4	2.5
	Breathing problems	48.8	25.1	20.2	5.9
	Fatigue	45.7	4.7	18.3	31.3
	Pain	38.7	34.0	23.3	4.0

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. Table 32 shows the data for the AKPS at phase start.

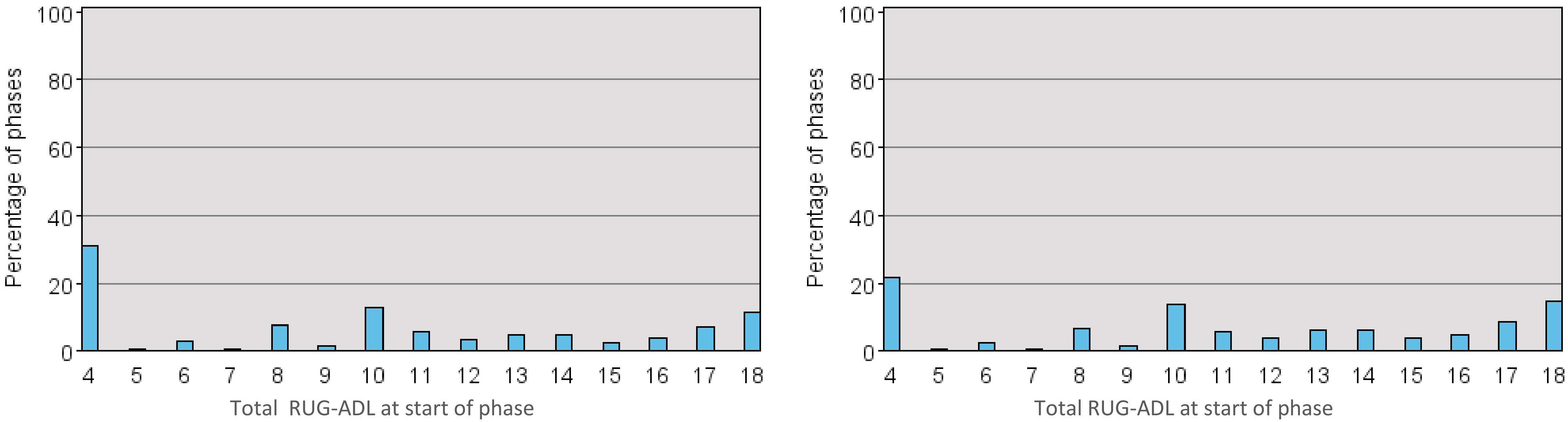
Table 32 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting

AKPS assessment	Inpatient		Ambulatory & community	
	N	%	N	%
10 - Comatose or barely rousable	2,818	9.9	653	2.8
20 - Totally bedfast and requiring extensive nursing care	6,249	22.0	2,120	9.2
30 - Almost completely bedfast	3,663	12.9	1,548	6.7
40 - In bed more than 50% of the time	5,164	18.2	2,518	11.0
50 - Requires considerable assistance	5,015	17.7	5,323	23.2
60 - Requires occasional assistance	3,070	10.8	5,880	25.6
70 - Cares for self	679	2.4	3,457	15.1
80 - Normal activity with effort	244	0.9	866	3.8
90 - Able to carry on normal activity; minor signs or symptoms	71	0.3	209	0.9
100 - Normal; no complaints; no evidence of disease	2	0.0	15	0.1
Not stated/inadequately described	1,384	4.9	372	1.6
Total	***28,359***	***100.0***	***22,961***	***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 should be assessed on admission, at phase change and at discharge. Figure 25 and Figure 26 on the following two pages summarise the total RUG-ADL at the beginning of each phase for inpatients and ambulatory 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).

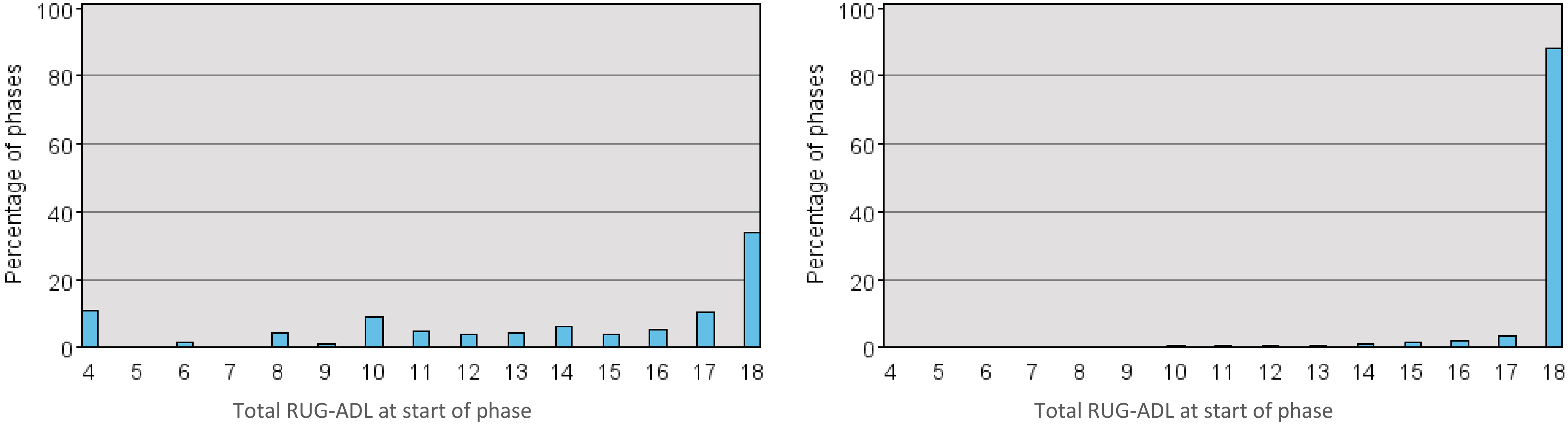
AKPS & RUG-ADL can be used together to provide a profile of both patient dependency, equipment requirements, need for allied health referrals and carer burden/respite requirements.

Figure 25 Total RUG-ADL at beginning of phase by phase type – inpatient setting



Stable Phase

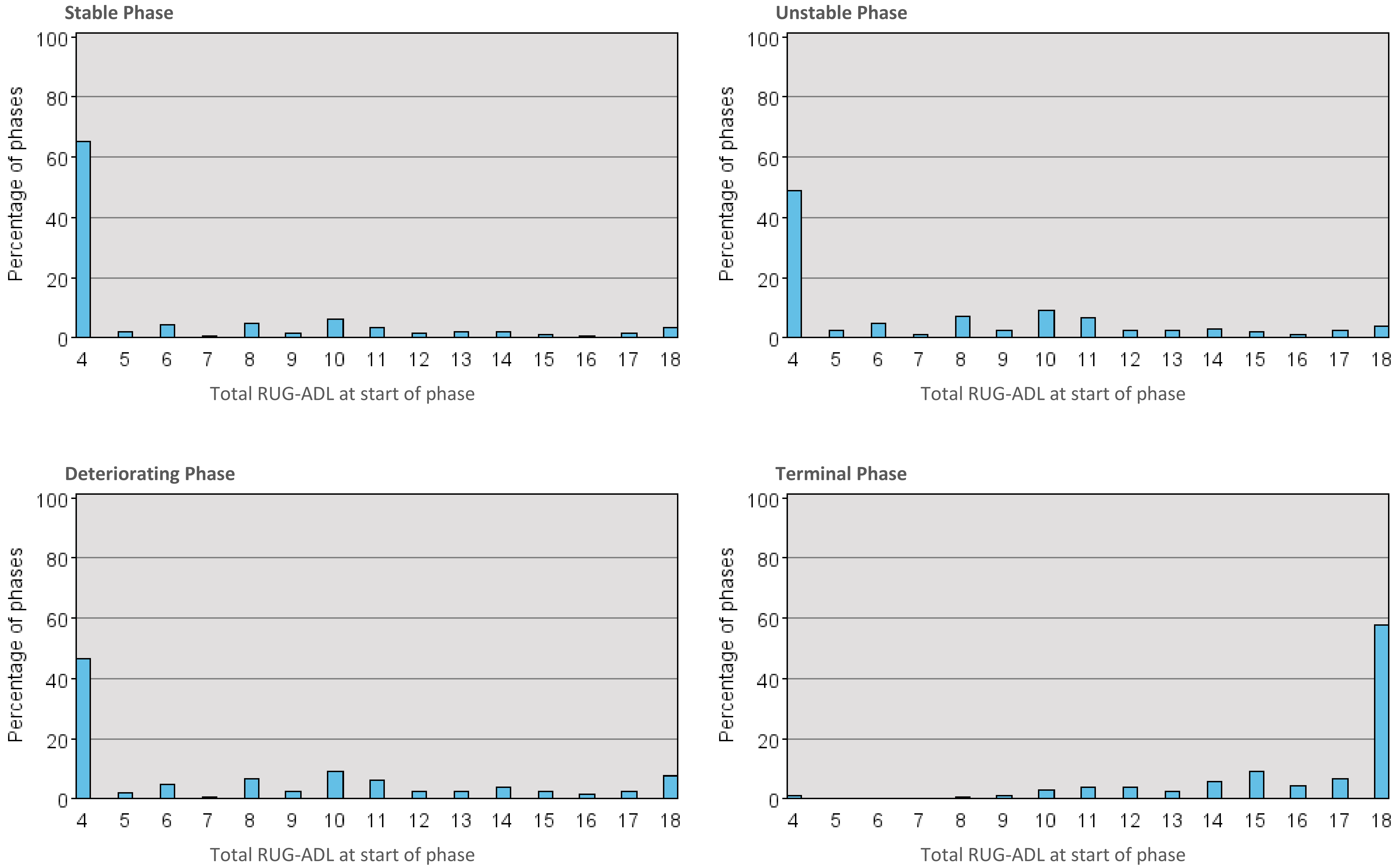
Unstable Phase



Deteriorating Phase

Terminal Phase

Figure 26 Total RUG-ADL at beginning of phase by phase type – ambulatory & community settings



Appendix A Summary of data included in this report

A1 Data summary

During the reporting period, data were provided for a total of 17,176 patients who between them had 22,030 episodes of care and 52,578 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 33 shows the number of patients, episodes and phases included in this report.

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 33 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 33 Number and percentage of patients, episodes and phases by setting

	Inpatient	Ambulatory & community	Total
Number of patients*	9,648	8,583	17,176
Number of episodes	11,409	10,621	22,030
Number of phases	29,380	23,198	52,578
Percentage of patients*	56.2	50.0	100
Percentage of episodes	51.8	48.2	100
Percentage of phases	55.9	44.1	100
Average number of phases per episode**	2.5	2.0	2.3

* 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.

A2 Data item completion

Overall, the quality of data submitted to PCOC is very good. As shown in Table 34, Table 35 and Table 36 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 ambulatory and 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 34 Item completion (per cent complete) - patient level

Data item	Total
Date of birth	100.0
Sex	100.0
Indigenous status	98.1
Country of birth	98.4
Preferred language	99.3
Primary diagnosis	99.7

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

Table 35 Item completion by setting (per cent complete) - episode level

Data item	Inpatient	Ambulatory & community	Total
Date of first contact	98.7	97.7	98.2
Referral date	99.9	99.9	99.9
Referral source	99.2	98.2	98.7
Date ready for care	94.1	96.5	95.3
Mode of episode start	99.9	99.4	99.7
Accommodation at episode start	98.6	97.7	98.1
Episode end date	99.4	92.9	96.3
Mode of episode end	99.9	99.8	99.9
Accommodation at episode end	97.4	94.7	96.7
Place of death	na	97.4	97.4

Table 36 Item completion by setting (per cent complete) - phase level

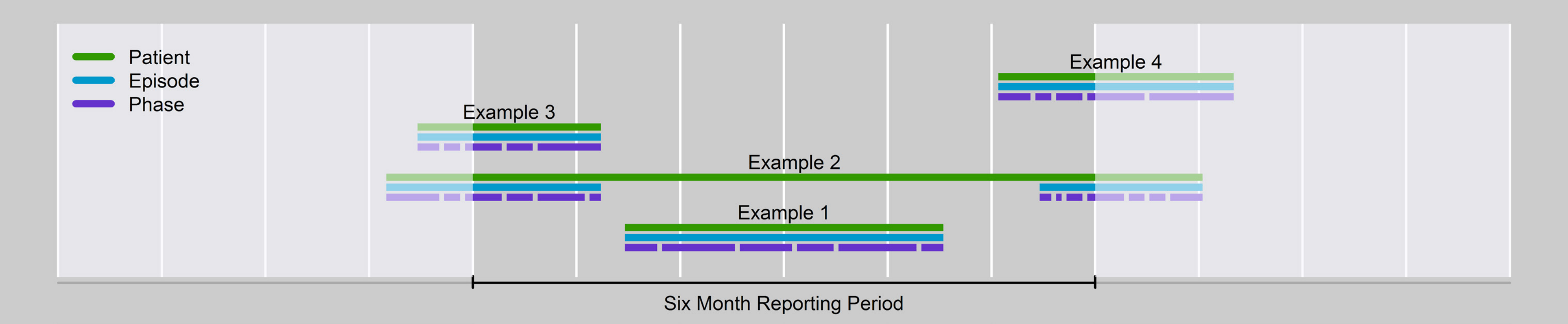
Data item	Sub-Category	At phase start			At discharge		
		Inpatient	Ambulatory & community	Total	Inpatient	Ambulatory & community	Total
RUG-ADL	Bed mobility	99.8	97.5	98.8	78.6	58.4	67.2
	Toileting	99.8	97.1	98.6	78.6	58.3	67.1
	Transfers	99.8	96.5	98.3	78.7	58.3	67.1
	Eating	99.6	94.7	97.4	78.5	57.6	66.7
PCPSS	Pain	97.2	97.8	97.5	76.8	58.1	66.2
	Other symptom	97.0	96.9	97.0	76.8	57.4	65.8
	Psychological/spiritual	99.1	97.5	98.4	78.1	58.0	66.7
	Family/carer	96.9	96.8	96.8	72.9	57.3	64.1
SAS	Difficulty sleeping	96.4	93.5	95.1	75.5	55.7	64.3
	Appetite problems	96.6	94.6	95.7	75.7	57.5	65.4
	Nausea	96.7	96.3	96.5	75.8	58.1	65.8
	Bowel problems	96.5	94.8	95.8	75.6	57.2	65.2
	Breathing problems	96.7	96.1	96.4	75.8	58.1	65.8
	Fatigue	96.6	96.0	96.3	75.7	58.3	65.8
	Pain	96.7	97.4	97.0	75.7	59.3	66.4
AKPS	-	95.1	98.4	96.6	77.4	59.1	67.0

	Inpatient	Ambulatory & community	Total
Phase End Reason	99.2	99.4	99.3

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 27 below displays four examples to help visualize this process.

Figure 27 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	

Acknowledgements

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