

National Report on Patient Outcomes in Palliative Care in Australia

July – December 2012

Report 14

May 2013






About the Palliative Care Outcomes Collaboration (PCOC)

PCOC is a unique 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
- 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 Scale (AKPS) 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 four 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 office is located within the Australian Health Services Research Institute at the University of Wollongong. If you would like more information about PCOC please visit our website www.pcoc.org.au or email us at pcoc@uow.edu.au or phone (02) 4221 4411.

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

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

Outcome Measurement in Palliative Care – The Essentials

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Introduction

PCOC aims to assist services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this, the fourteenth PCOC report, data submitted for the July - December 2012 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

This report is broken into four sections:

Section 1 provides a summary of the data included in this report.

Section 2 summarises each of the four outcome measures and presents national benchmarking results for a selection of these measures.

Section 3 presents a more detailed analysis of the outcome measures and benchmarks.

Section 4 provides descriptive analysis at each of the patient, episode and phase data levels.

The national figures reflect all palliative care services who submitted data for the July - December 2012 period.

A full list of these services 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.

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

na **The item is not applicable**

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

Section 1 – Summary of data included in this report

1.1 Data summary

This report includes data from a total of 103 services. During the reporting period, data were provided for a total of 16,608 patients who between them had 20,679 episodes of care and 48,180 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Section A contains a more detailed explanation of this process). Table 1 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 1 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 1 *Number and percentage of patients, episodes and phases by setting*

	Inpatient	Ambulatory & community	Total
Number of patients*	9,767	7,718	16,608
Number of episodes	11,280	9,399	20,679
Number of phases	28,401	19,779	48,180
Percentage of patients*	58.8	46.5	100
Percentage of episodes	54.5	45.5	100
Percentage of phases	58.9	41.1	100
Average number of phases per episode**	2.4	1.9	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.

1.2 Data Item Completion

Overall, the quality of data submitted to PCOC is very good and, as shown in Tables 2, 3 and 4 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 2 Item completion (per cent complete) - patient level

Data item	Total
Date of birth	100.0
Sex	99.8
Indigenous status	97.0
Country of birth	95.7
Main language	93.9
Primary diagnosis	96.7

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

Table 3 Item completion by setting (per cent complete) - episode level

Data item	Inpatient	Ambulatory & community	Total
Date of first contact/assessment	95.5	96.4	95.9
Referral date	96.9	99.3	98.0
Referral source	95.5	95.0	95.2
Mode of episode start	100.0	99.0	99.5
Accommodation at episode start	94.9	97.9	96.3
Episode end date	98.6	93.5	96.3
Mode of episode end	97.3	99.1	98.1
Accommodation at episode end	93.4	86.7	91.6
Place of death	na	93.8	93.8

Table 4 Item completion by setting (per cent complete) - phase level

Data item	Sub-Category (where applicable)	Inpatient	Ambulatory & community	Total
RUG-ADL at phase start	Bed mobility	100.0	98.4	99.3
	Toileting	100.0	97.9	99.1
	Transfers	100.0	97.3	98.8
	Eating	100.0	95.3	98.0
PC Problem Severity at phase start	Pain	82.5	97.8	89.0
	Other symptoms	90.3	97.5	93.3
	Psychological/spiritual	99.3	97.7	98.6
	Family/carer	99.3	97.5	98.5
Symptom Assessment Scale at phase start	Insomnia	93.5	94.2	93.8
	Appetite problems	93.5	95.1	94.2
	Nausea	93.5	97.1	95.0
	Bowel problems	93.4	95.9	94.5
	Breathing problems	93.5	96.9	94.9
	Fatigue	93.4	96.7	94.8
	Pain	93.5	98.0	95.4
Phase end reason	-	95.7	98.3	96.8
Karnofsky at phase start	-	94.6	98.8	96.4

Section 2 – Benchmark summary

2.1 Australian outcomes at a glance

Table 5 Summary of outcome measures 1-3 by setting

Outcome measure	Description	Benchmark	Inpatient		Ambulatory & community	
			Score	Benchmark Met?	Score	Benchmark Met?
1. Time from referral to first contact	Benchmark 1: Patients contacted on the day of, or the day after referral	90%	90.9%	Yes	53.0%	No
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	72.4%	No	58.5%	No
3. Change in pain	Benchmark 3.1: PCPSS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end	90%	86.0%	No	83.4%	No
	Benchmark 3.2: PCPSS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end	60%	52.8%	No	51.6%	No
	Benchmark 3.3: SAS: Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end	90%	85.3%	No	81.8%	No
	Benchmark 3.4: SAS: Patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end	60%	49.0%	No	46.8%	No

Table 6 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	0.16	Yes
	Benchmark 4.2: Other symptoms	0.31	Yes
	Benchmark 4.3: Family/carer	0.20	Yes
	Benchmark 4.4: Psychological/spiritual	0.16	Yes
SAS	Benchmark 4.5: Pain	0.28	Yes
	Benchmark 4.6: Nausea	0.19	Yes
	Benchmark 4.7: Breathing problems	0.37	Yes
	Benchmark 4.8: Bowel problems	0.31	Yes

→ The benchmark for measure 4 is zero.

For more information on the outcome measures and benchmarks, see Section 3 and Appendix B

2.2 National benchmark profiles

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

The selected benchmarks included are:

- Benchmark 1 Patients contacted on the day of, or the day after referral
- Benchmark 2 Patients in the unstable phase for 3 days or less
- 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

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.

Outcome measure 1 – Time from referral to first contact

Benchmark 1

Figure 1 Percentage of patients contacted on the day of, or the day after referral – inpatient setting

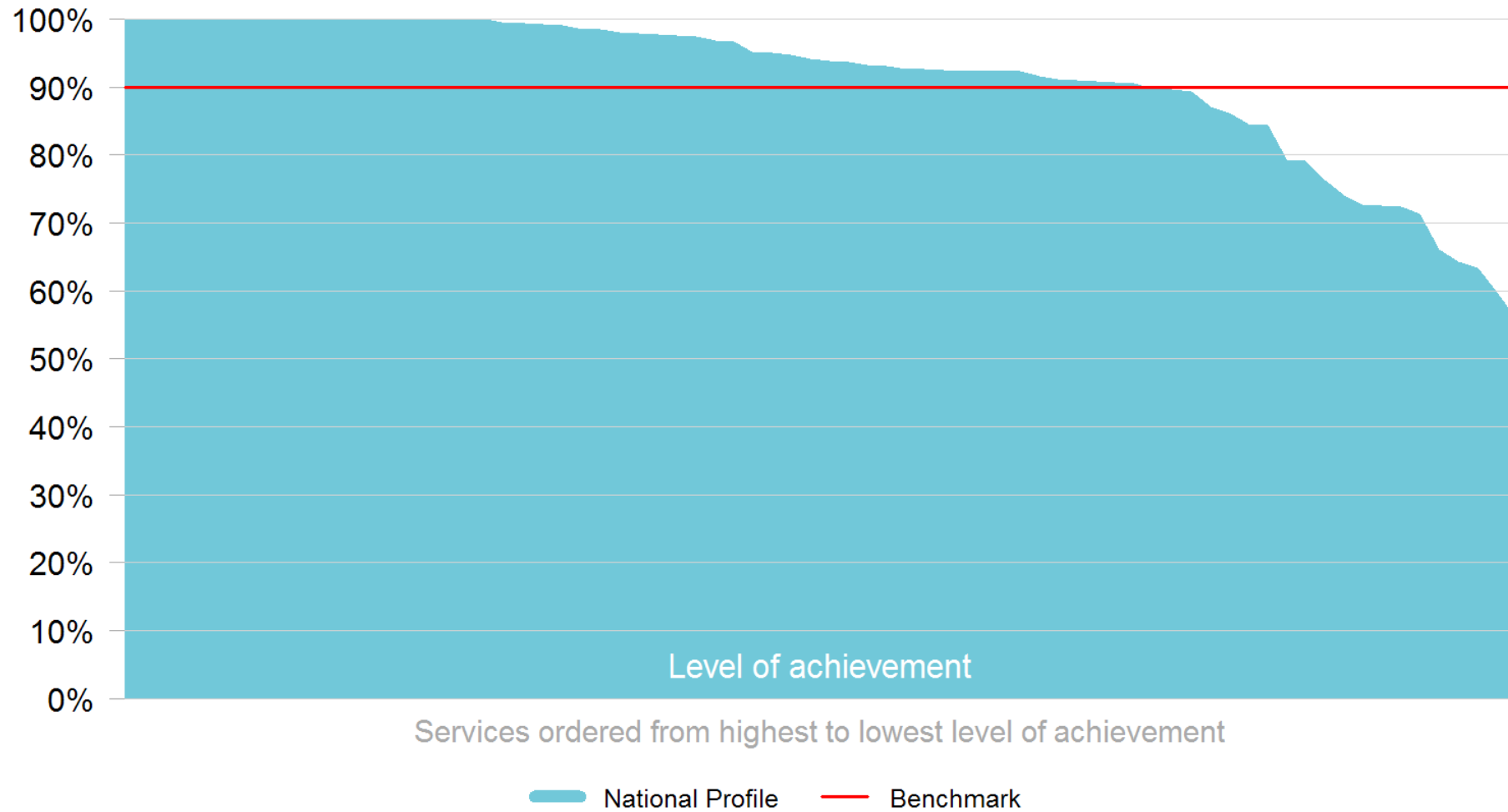
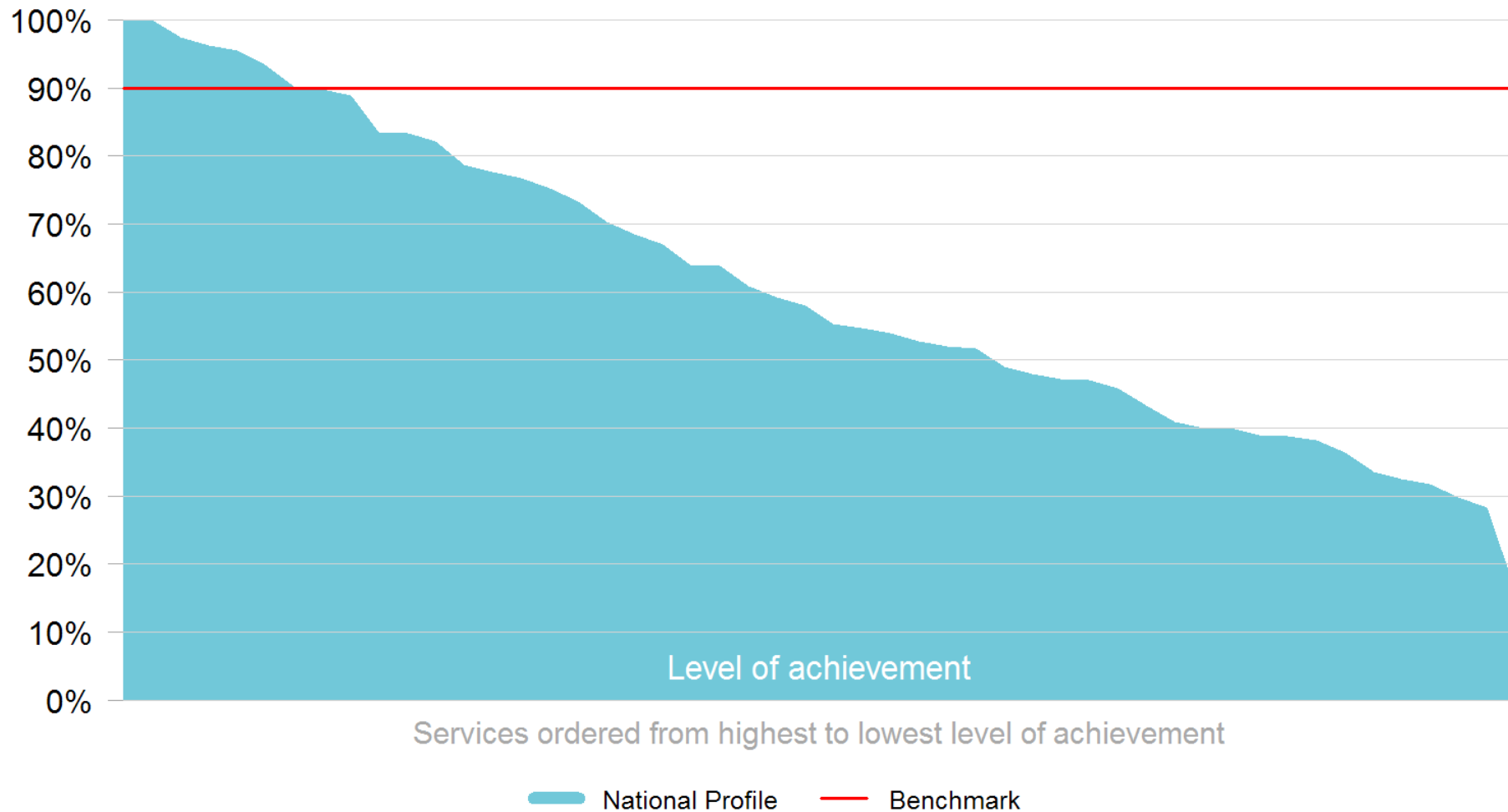


Figure 2 Percentage of patients contacted on the day of, or the day after referral – ambulatory & community settings



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

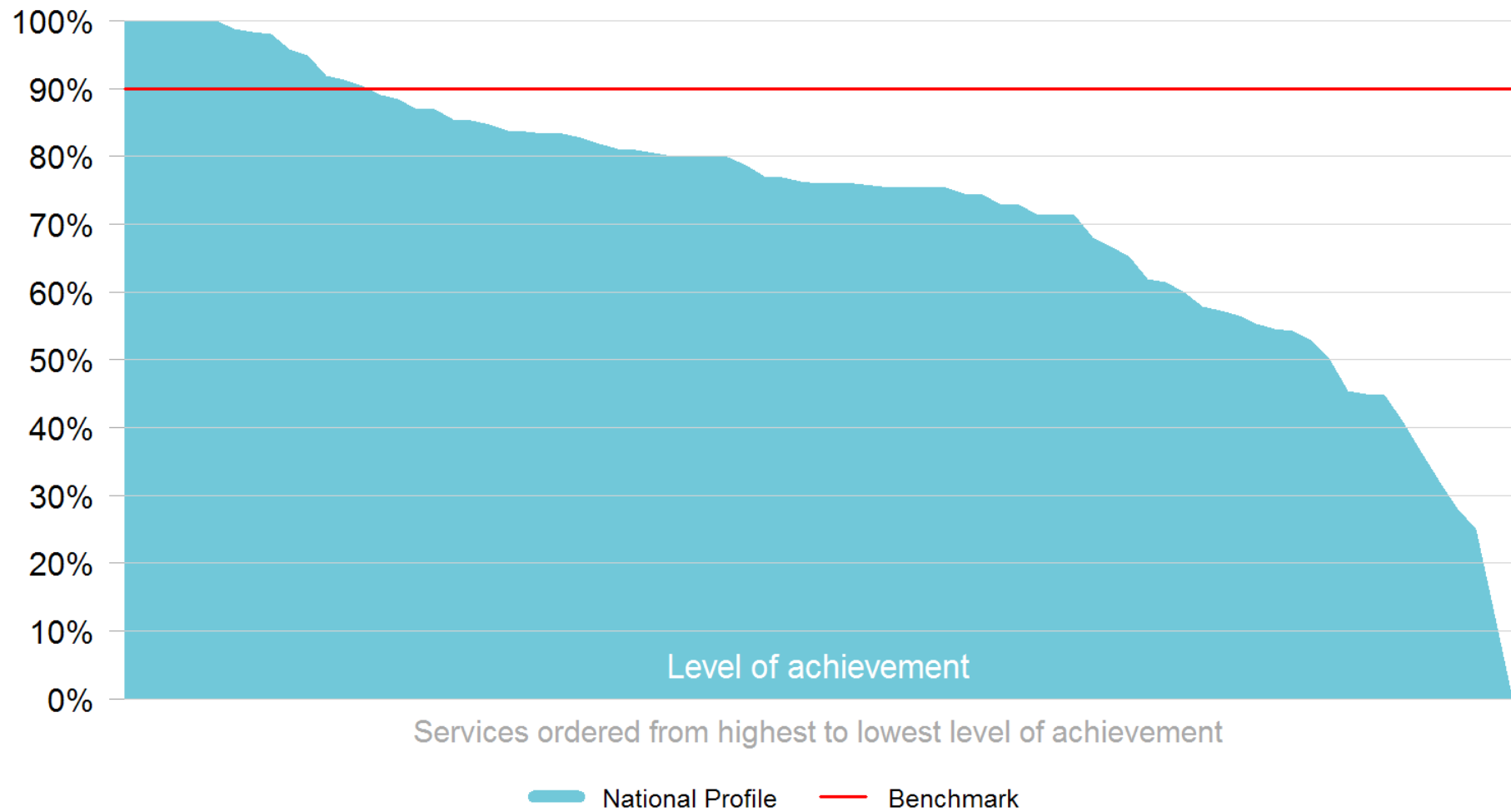
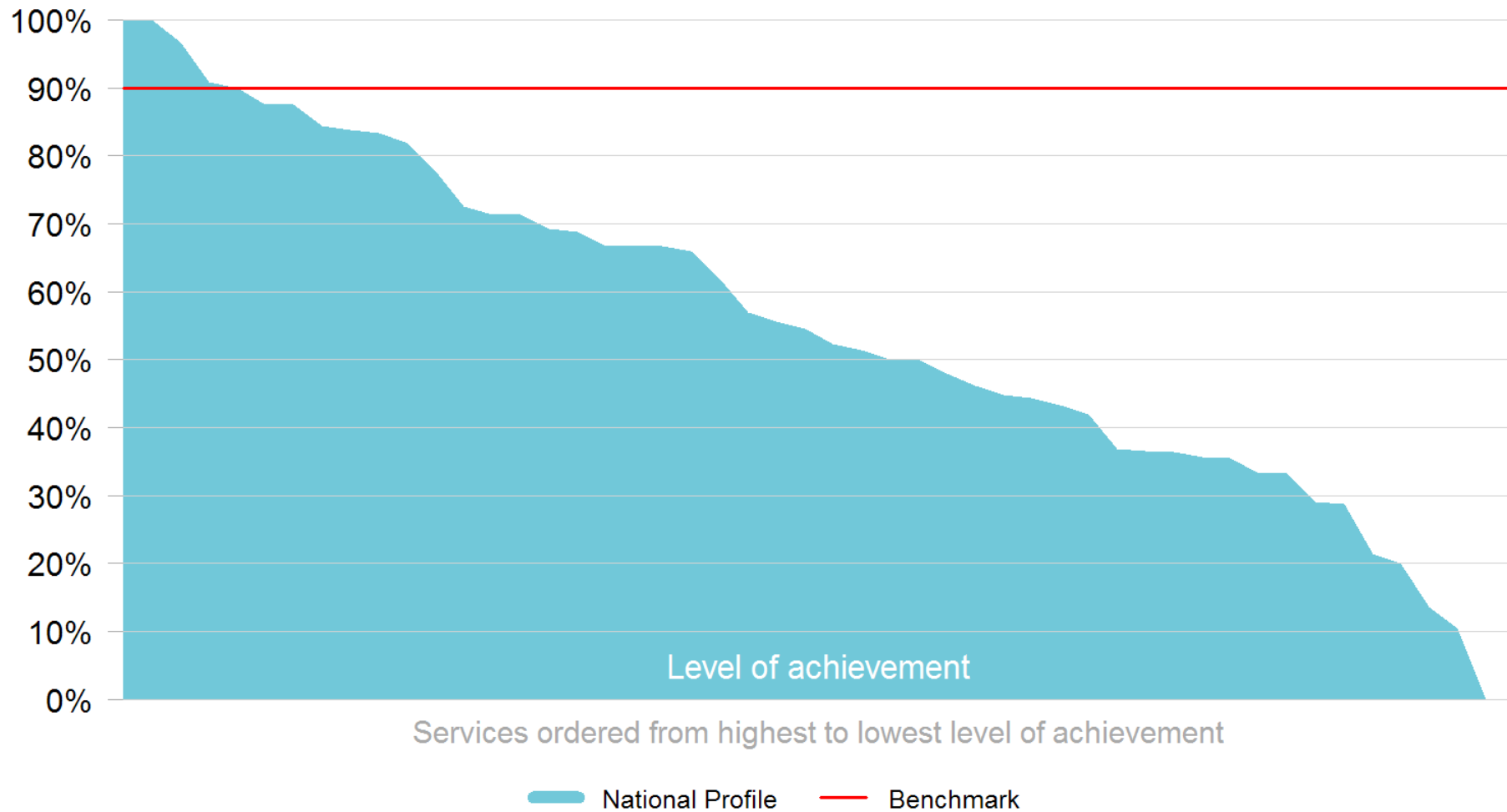


Figure 4 Percentage of patients in the unstable phase for 3 days or less – ambulatory & community settings



Outcome measure 3 – Change in pain (SAS pain)

Benchmark 3.3

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

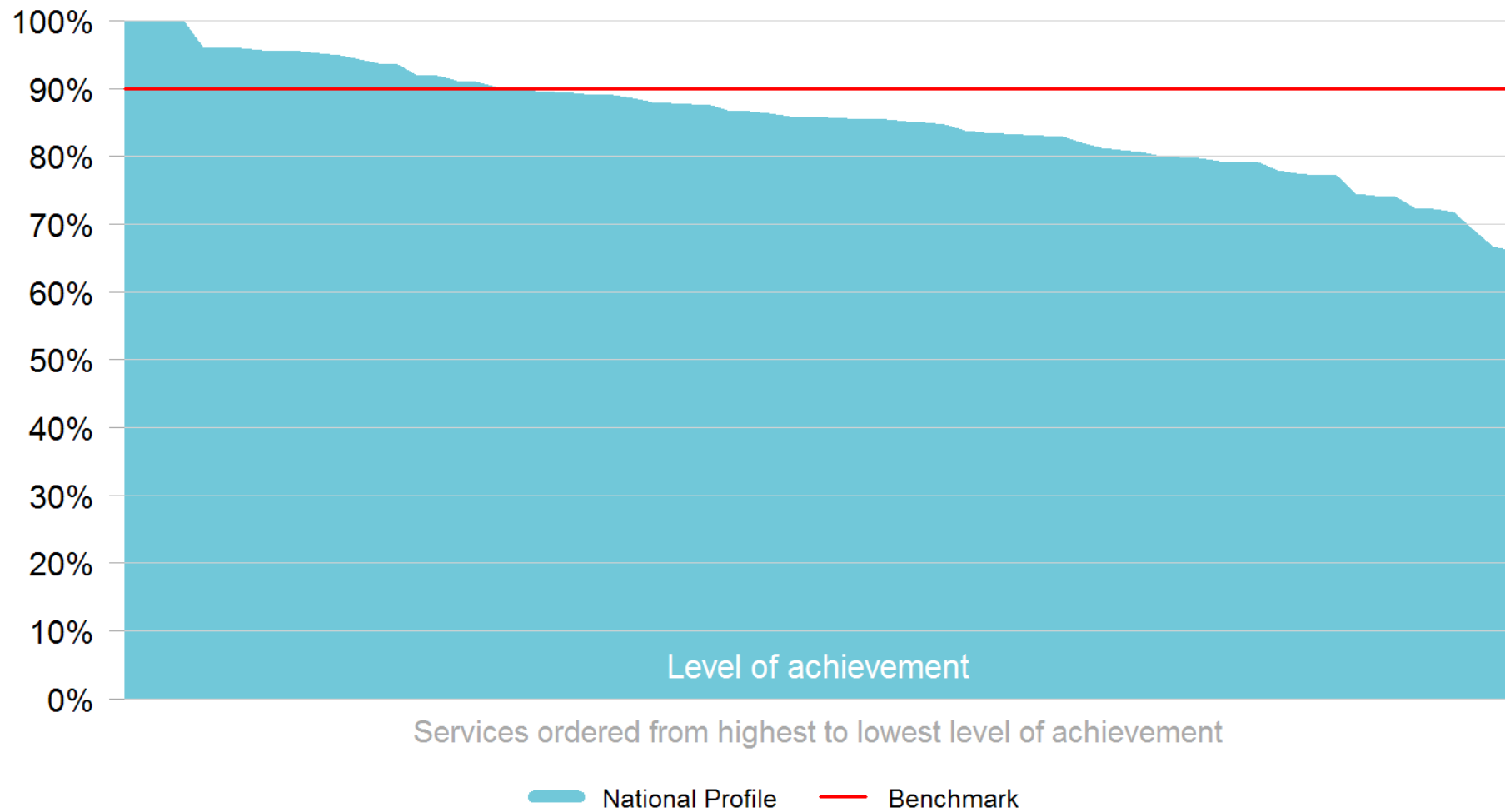
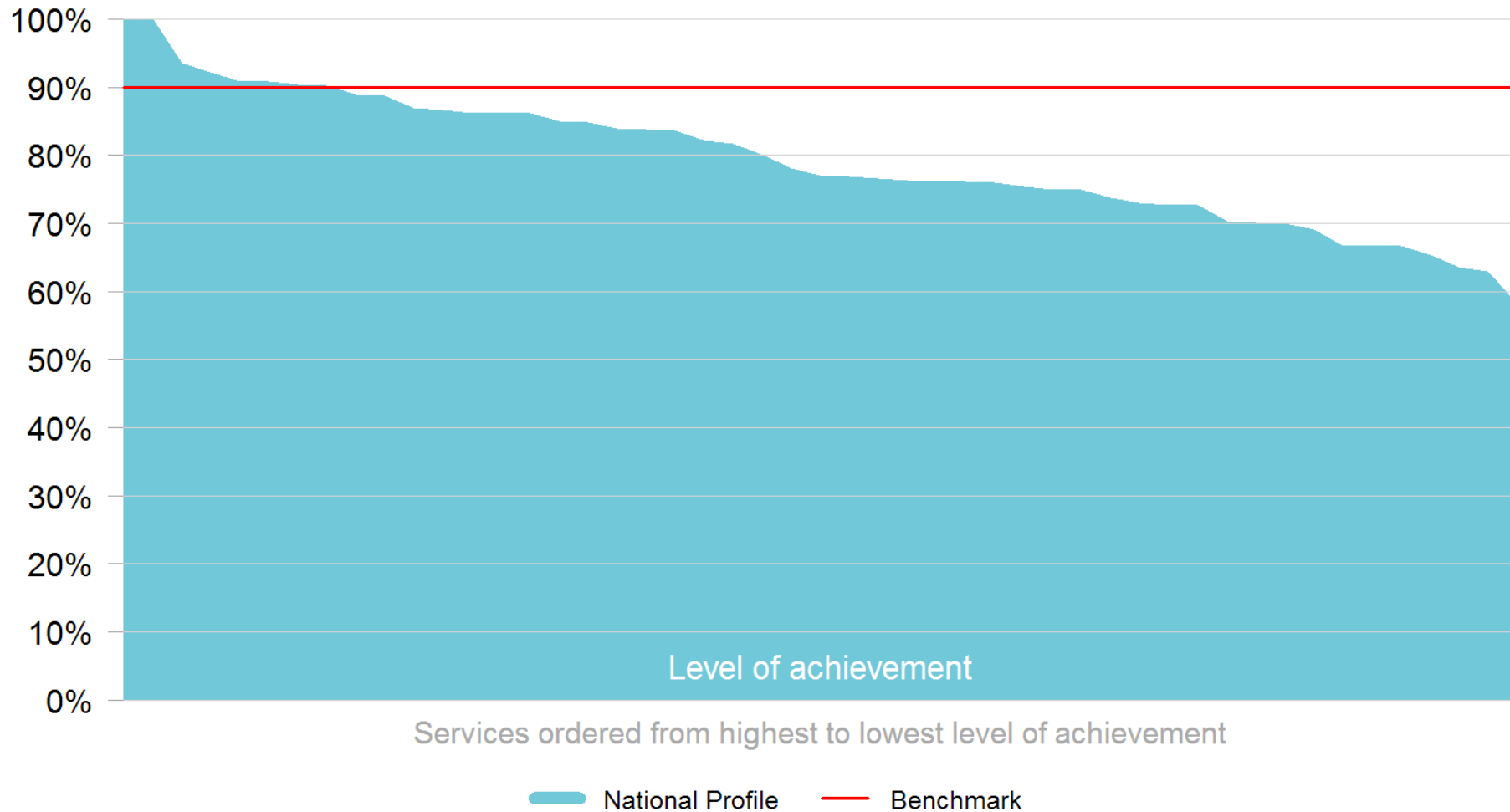


Figure 6 Percentage of patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end – ambulatory & community settings



Benchmark 3.4

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

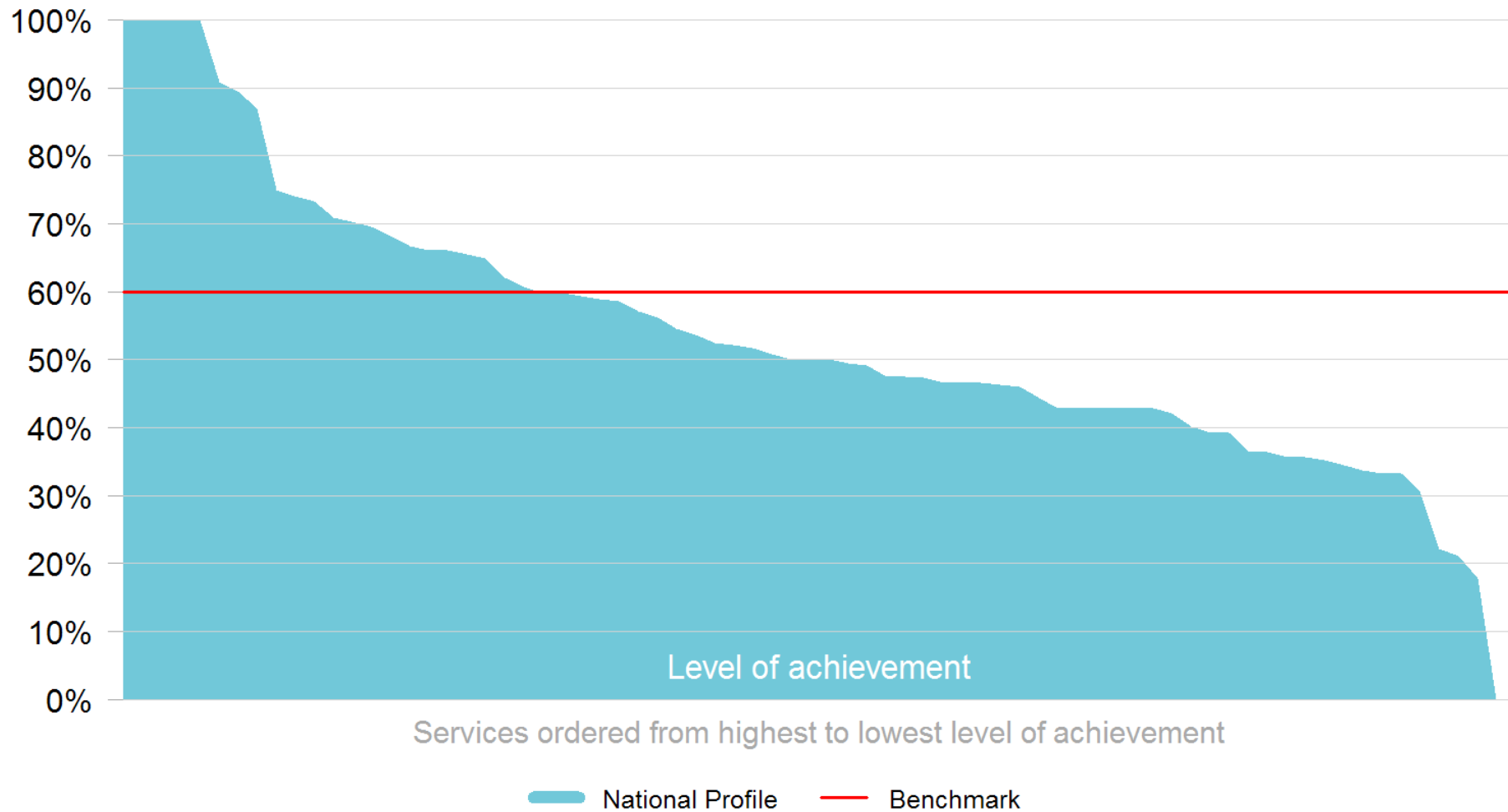
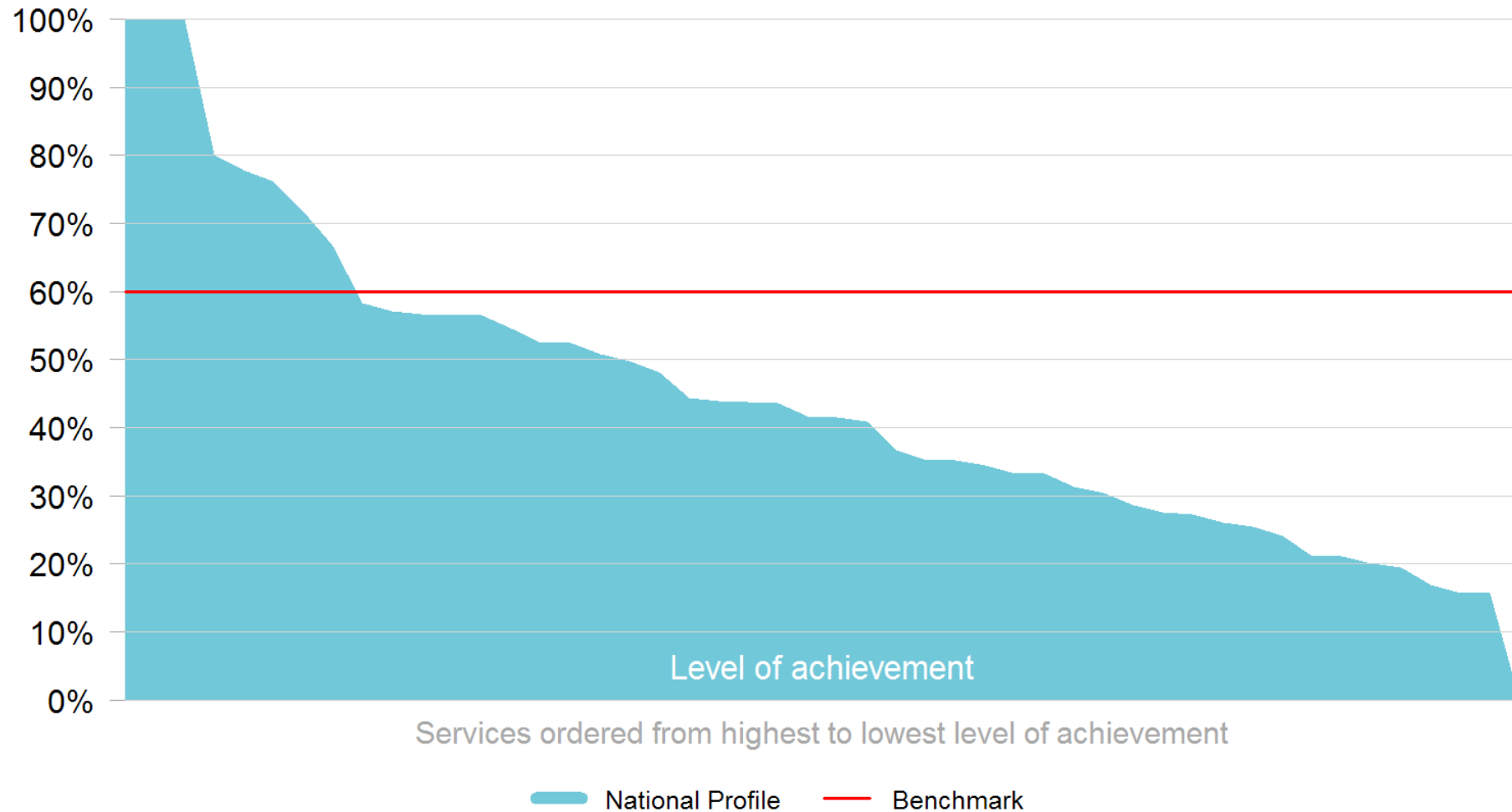


Figure 8 Percentage of patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end – ambulatory & community settings



Section 3 – Outcome measures in detail

3.1 Outcome measure 1 – Time from referral to first contact

Time from referral to first contact reports responsiveness of palliative care services to patient needs. This benchmark was set after consultation with participants at the PCOC national benchmarking workshops in 2009. Participants acknowledged that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating 5 days a week (Monday-Friday) are not distinguished from services operating 7 days a week (all services are being benchmarked together).

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

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.

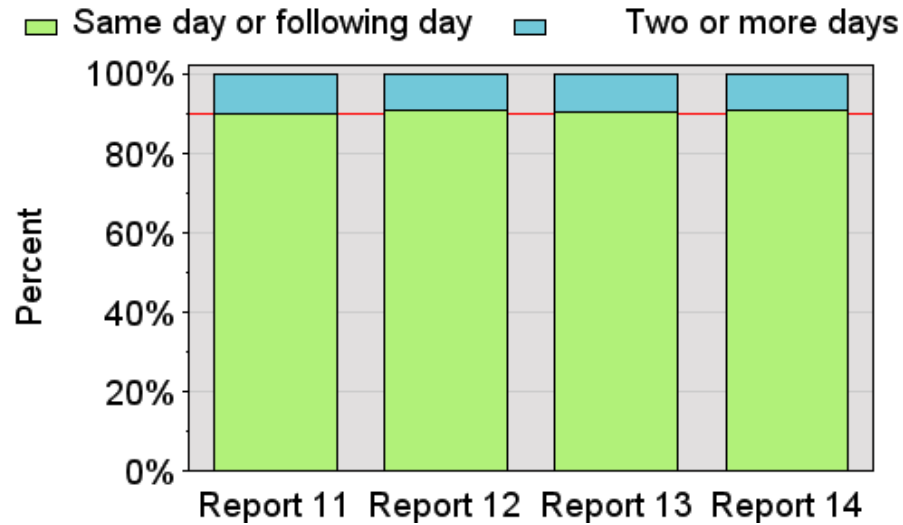
Table 7 Time from referral to first contact by setting

Time (in days)	Inpatient		Ambulatory & community	
	N	%	N	%
Same day or following day	9,939	90.9	4,947	53.0
2-7 days	811	7.4	3,118	33.4
8-14 days	94	0.9	775	8.3
Greater than 14 days	91	0.8	493	5.3
Average	1.3	na	2.8	na
Median	1	na	1	na

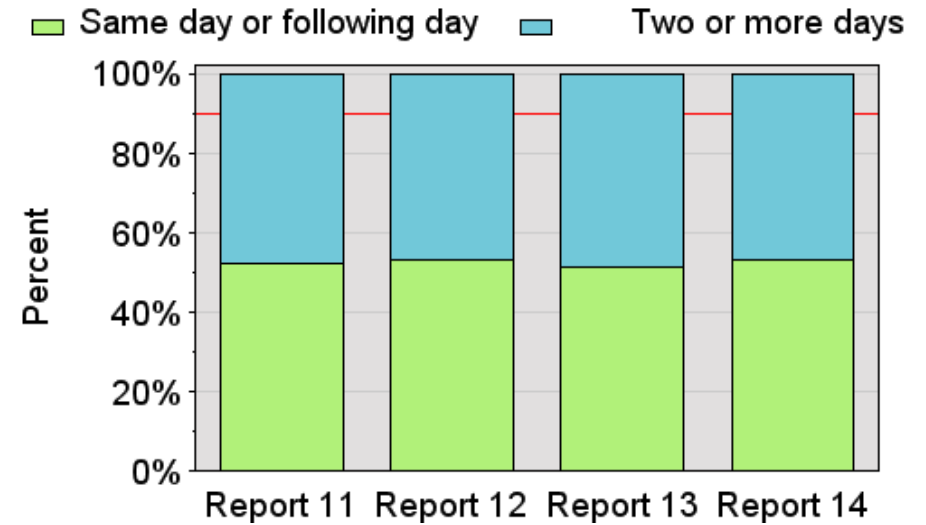
Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact was greater than 7 days were considered to be atypical and were assumed to equal 7 days for the purpose of calculating the average and median time.

Figure 9 Trends in time from referral to first contact by setting

Inpatient setting



Ambulatory & community settings



3.2 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

Unstable phases are ended in one of two ways:

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

In previous PCOC reports, there were three benchmarks relating to the time a patient spent in the unstable phase. This report sees the three replaced by one:

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.

Why has this benchmark changed?

Feedback from services attending the 2012 PCOC Benchmarking workshops was that benchmarks 2.1 & 2.2 should be combined as the first phase/not first phase split did not provide any additional information. There was also general feedback that the ‘within 7 days’ timeframe did not represent best practice and that it should be reduced. PCOC undertook analysis to determine the target time frame by looking at the top 10 services participating during January – June 2012. This analysis identified ‘3 days or less’ as the target time frame when 90% was used as the benchmark. Benchmark 2.3 (median time) is now considered to be redundant and has been removed from the suite of PCOC benchmarks.

Table 8 presents descriptive data for the new benchmark. Previous benchmarks 2.1 and 2.2 have also been included for comparison with results previous reports.

Table 8 Time in unstable phase by setting and occurrence in episode

Setting	Occurrence of unstable phase	Number of unstable phases	Percent unstable for < 7 days	Percent unstable for 3 days or less
Inpatient	First phase of episode	5,304	89.6	70.8
	Not first phase of episode	2,224	91.8	76.3
	Total unstable phases	7,528	90.3	72.4
Ambulatory & community	First phase of episode	721	63.1	46.7
	Not first phase of episode	1,810	74.1	63.1
	Total unstable phases	2,531	71.0	58.5

3.3 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 SAS is patient rated, while the PCPSS is clinician rated. There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain, and the other relating to the management of pain for patients with moderate or severe pain. The PCPSS is rated from 0 to 3 (absent, mild, moderate and severe) whereas the SAS is rated on a scale of 0 to 10 (0 = absent and 10 = the worst possible). For the analysis in this report SAS scores have been grouped as 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 9 shows trends in this benchmark over the last four reports.

Table 9 Trends in Benchmark 3.1: Patients with absent/mild pain at phase start, remaining absent/mild at phase end (PCPSS) by setting

Setting		All Services			
		Report 11	Report 12	Report 13	Report 14
Inpatient	Number	5,153	5,577	7,362	8,738
	%	82.1	81.6	86.2	86.0
Ambulatory & community	Number	2,176	2,339	3,276	8,698
	%	75.1	77.5	80.0	83.4

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 10 shows trends in this benchmark over the last four reports.

Table 10 Trends in Benchmark 3.2: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end (PCPSS) by setting

Setting		All Services			
		Report 11	Report 12	Report 13	Report 14
Inpatient	Number	1,858	1,986	2,220	2,457
	%	48.0	53.6	51.1	52.8
Ambulatory & community	Number	646	697	742	1,552
	%	57.3	55.4	48.3	51.6

Benchmark 3.3: This benchmark relates to patients who have reported an absent or mild level of distress due to 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 an absent or mild level of distress due to pain. Table 11 shows trends in this benchmark over the last four reports.

Table 11 Trends in Benchmark 3.3: Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end (SAS) by setting

Setting		All Services			
		Report 11	Report 12	Report 13	Report 14
Inpatient	Number	5,902	6,476	8,179	9,638
	%	81.8	82.5	84.5	85.3
Ambulatory & community	Number	2,566	2,816	4,112	8,221
	%	76.8	78.1	80.9	81.8

Benchmark 3.4: This benchmark relates to patients who have reported a moderate or severe level of distress due to 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 level of distress due to pain reduced to being absent or mild. Table 12 shows trends in this benchmark over the last four reports.

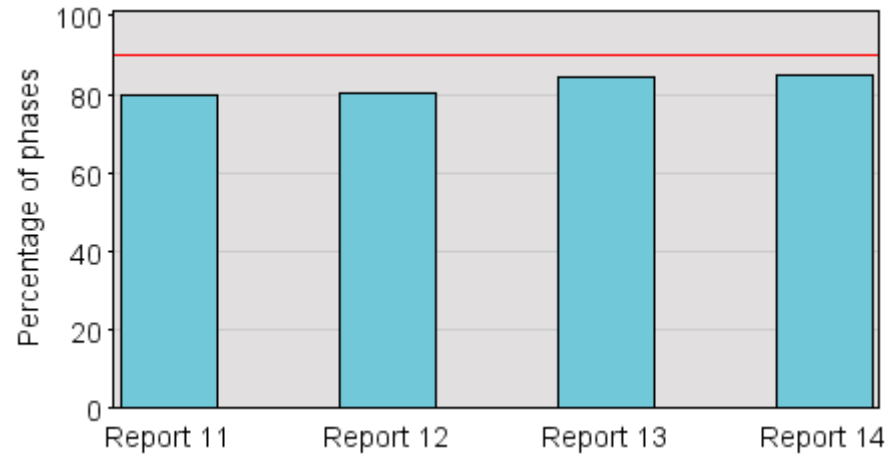
Table 12 Trends in Benchmark 3.4: Patients with moderate/severe distress from pain at phase start, with absent/mild distress at phase end (SAS) by setting

Setting		All Services			
		Report 11	Report 12	Report 13	Report 14
Inpatient	Number	2,159	2,216	2,789	2,870
	%	46.4	49.6	47.9	49.0
Ambulatory & community	Number	708	787	911	1,666
	%	57.0	56.2	45.1	46.8

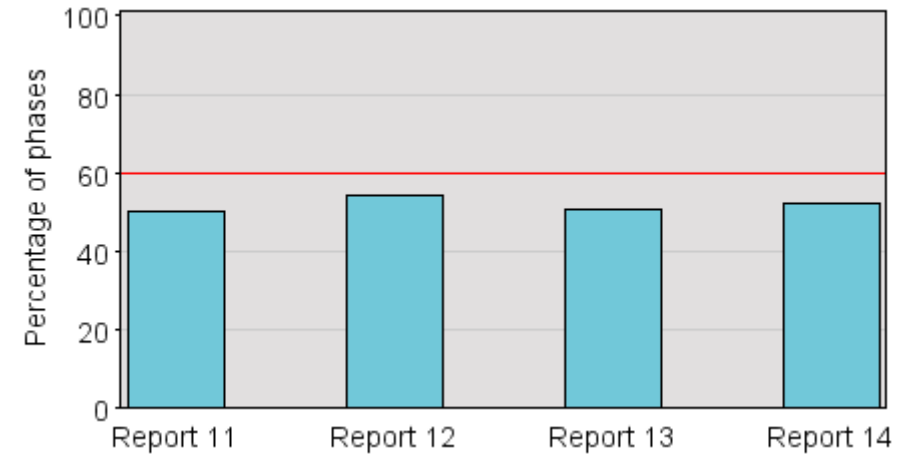
* Following a review of the quality of the data submitted to PCOC for January – June 2012 an improvement was made to the calculation of the Change in Pain outcome measure. The new calculation included situations where episodes (and hence phases) end due to discharge or a change in the setting/type of care where the SAS and PCPSS pain assessments have been provided to PCOC. Services may notice a change in their benchmark scores from prior reports and should be cautious when comparing their scores.

Figure 10 Trends in outcome measure 3

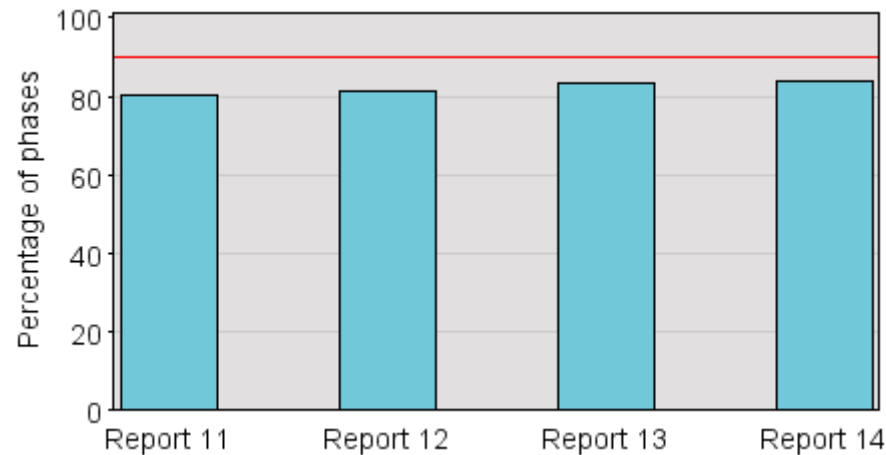
Benchmark 3.1: Absent/mild pain at both start and end of phase (using PCPSS)



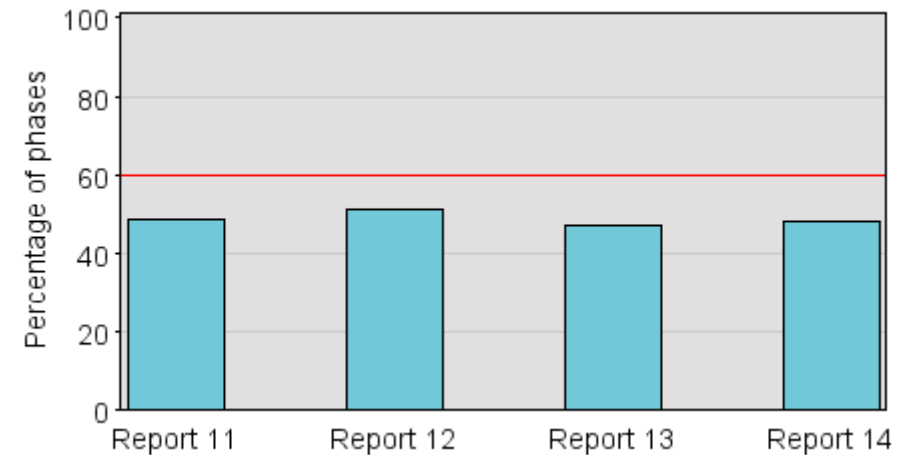
Benchmark 3.2: Mod/severe pain at start with absent/mild pain at end (using PCPSS)



Benchmark 3.3: Absent/mild pain at both start and end of phase (using SAS)



Benchmark 3.4: Mod/severe pain at start with absent/mild pain at end (using SAS)



3.4 Outcome measure 4 – Average improvement on the 2008 baseline national average (X-CAS)

Measure 4 includes a suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included 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 Measure 4 are generally referred to as X-CAS – CAS standing for *Case-mix Adjusted Score*, and the X to represent that multiple symptoms are included.

How to interpret X-CAS:

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

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

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

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

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

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

Figure 11 Trends in outcome measure 4 – Palliative Care Problem Severity Score (PCPSS)

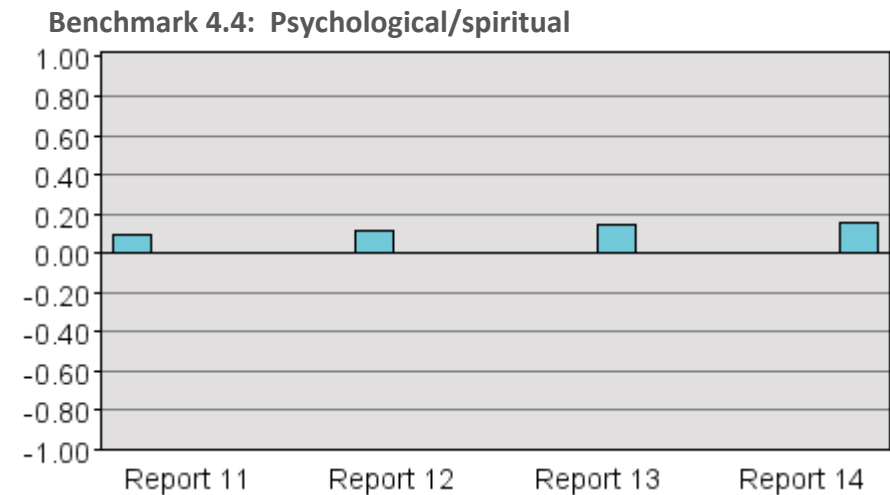
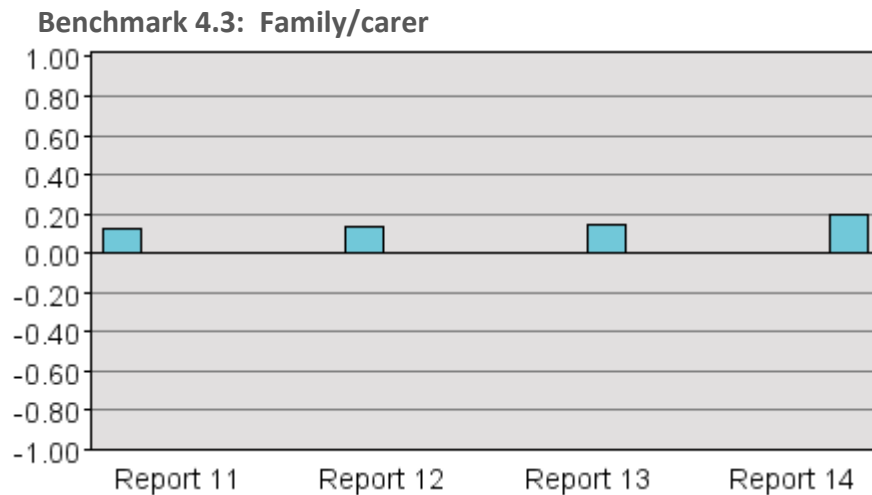
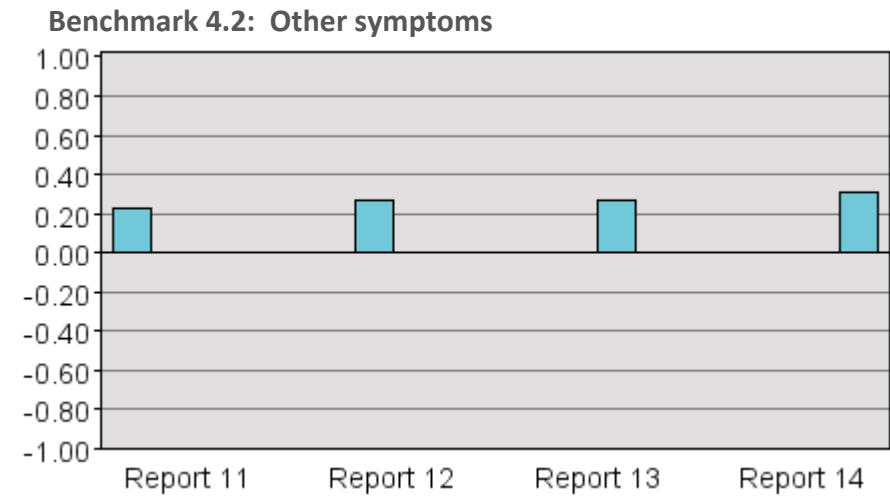
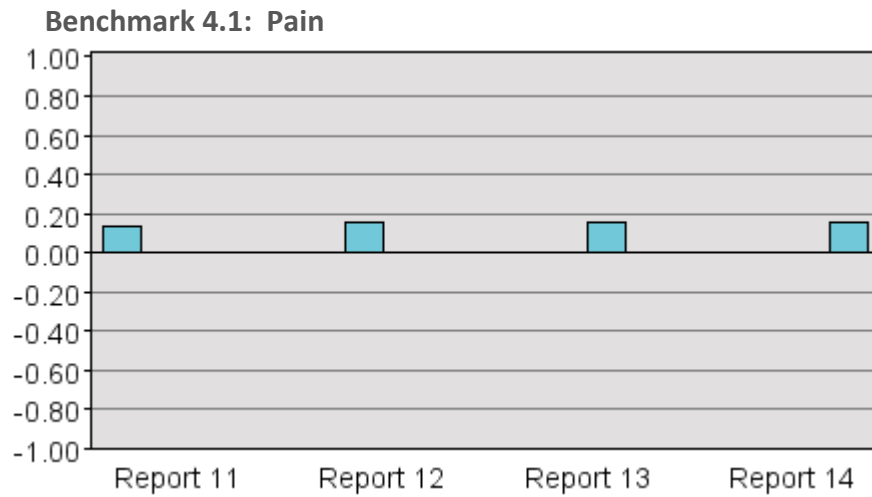
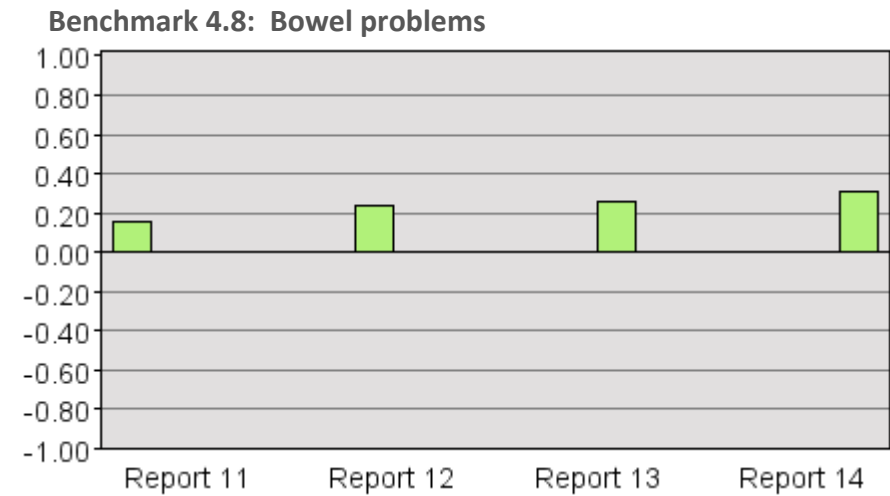
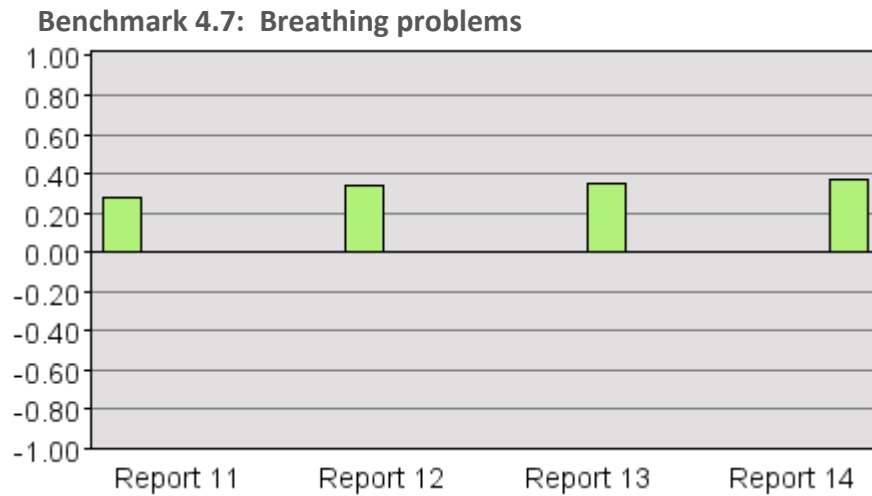
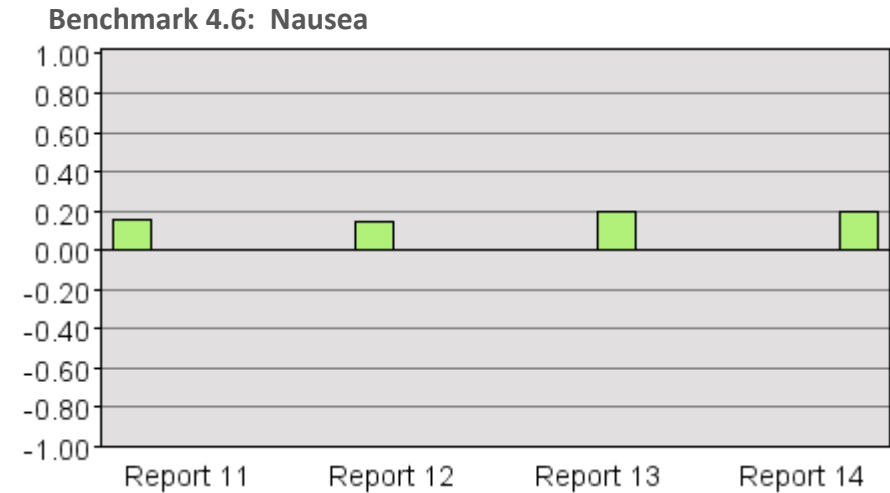
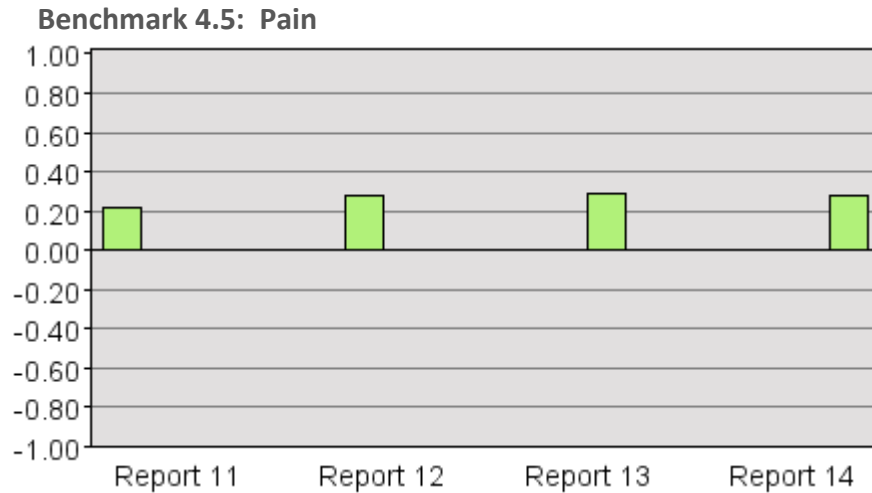


Figure 12 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)



Section 4 - Descriptive analysis

There are three levels of PCOC data items – patient, episode and phase.

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

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

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

This section provides an overview of the data at each level for the current reporting period.

4.1 Profile of palliative care patients

The information collected on each patient includes Indigenous status, sex, main language spoken at home and country of birth. Table 13 shows the Indigenous status for all patients nationally. Non-disclosure of Indigenous status can result in cultural issues not being identified.

Table 13 Indigenous status

Indigenous status	N	%
Aboriginal but not Torres Strait Islander origin	148	0.9
Torres Strait Islander but not Aboriginal origin	25	0.2
Both Aboriginal and Torres Strait Islander origin	16	0.1
Neither Aboriginal nor Torres Strait Islander origin	15,918	95.8
Not stated/inadequately described	501	3.0
Total	16,608	100.0

The following two tables show the main 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 14 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 15 (e.g. Italy was the third 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 14 Main language spoken at home

Main language spoken at home	N	%
English	14,097	84.9
Italian	299	1.8
Greek	162	1.0
Cantonese	119	0.7
Arabic (including Lebanese)	84	0.5
Mandarin	39	0.2
Vietnamese	72	0.4
Spanish	52	0.3
German	30	0.2
Hindi	10	0.1
Macedonian	84	0.5
Croatian	40	0.2
Korean	17	0.1
Turkish	31	0.2
Polish	36	0.2
All other languages	455	2.7
Not stated/inadequately described	981	5.9
Total	16,608	100.0

Table 15 Country of birth

Country of birth	N	%
Australia	10,144	61.1
England	1,247	7.5
New Zealand	222	1.3
China	171	1.0
Italy	683	4.1
Vietnam	104	0.6
India	88	0.5
Scotland	245	1.5
Philippines	33	0.2
Greece	339	2.0
Germany	221	1.3
South Africa	95	0.6
Malaysia	64	0.4
Netherlands	168	1.0
Lebanon	83	0.5
All other countries	2,207	13.3
Not stated/inadequately described	494	3.0
Total	16,608	100.0

Table 16 presents a breakdown of malignant and non-malignant diagnosis at the national level.

Table 16 Primary diagnosis

Diagnosis category	Primary diagnosis	N	% of category	% of total	
Malignant	Bone and soft tissue	182	1.4	1.1	
	Breast	1,032	8.0	6.2	
	CNS	252	1.9	1.5	
	Colorectal	1,473	11.4	8.9	
	Gynaecological	664	5.1	4.0	
	Haematological	731	5.7	4.4	
	Head and neck	671	5.2	4.0	
	Lung	2,780	21.5	16.7	
	Pancreas	839	6.5	5.1	
	Prostate	879	6.8	5.3	
	Skin	499	3.9	3.0	
	Other GIT	1,245	9.6	7.5	
	Other urological	584	4.5	3.5	
	Other malignancy	745	5.8	4.5	
	Unknown primary	348	2.7	2.1	
	All malignant		12,924	100.0	77.8
	Non-malignant	Cardiovascular	641	20.4	3.9
HIV/AIDS		7	0.2	0.0	
Kidney failure		327	10.4	2.0	
Neurological disease		570	18.2	3.4	
Respiratory failure		539	17.2	3.2	
Other non-malignancy		1,056	33.6	6.4	
All non-malignant			3,140	100.0	18.9
Not Stated	-	544	100.0	3.3	

4.2 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 begins on the day the patient is assessed using the five PCOC assessment tools either by face to face or phone contact with the palliative care service and there is agreement between the patient and the service.

An episode of palliative care ends when:

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

Table 17 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 17 Age group by gender

Age group	Male		Female	
	N	%	N	%
< 15	31	0.3	27	0.3
15-24	14	0.1	21	0.2
25-34	66	0.6	102	1.1
35-44	210	1.9	291	3.0
45-54	697	6.4	842	8.7
55-64	1,683	15.4	1,596	16.5
65-74	3,023	27.6	2,181	22.5
75-84	3,427	31.3	2,597	26.8
85+	1,811	16.5	2,031	21.0
Not stated/inadequately described	0	0.0	1	0.0
Total	10,962	100.0	9,689	100.0

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

Referral source refers to the service or organisation from which the patient was referred for each episode of care. Table 18 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 18 Referral source by setting

Referral source	Inpatient		Ambulatory & community	
	N	%	N	%
Public hospital - other than inpatient palliative care unit	5,277	46.8	4,086	43.5
Private hospital - other than inpatient palliative care unit	785	7.0	1,134	12.1
Public palliative care inpatient unit/hospice	251	2.2	390	4.1
Private palliative care inpatient unit/hospice	125	1.1	153	1.6
General medical practitioner	560	5.0	1,375	14.6
Specialist medical practitioner	376	3.3	463	4.9
Community-based palliative care agency	2,432	21.6	118	1.3
Community-based service	464	4.1	193	2.1
Residential aged care facility	92	0.8	643	6.8
Self, carer(s), family or friends	288	2.6	274	2.9
Other	117	1.0	98	1.0
Not stated/inadequately described	513	4.5	472	5.0
Total	11,280	100.0	9,399	100.0

Table 19 Place of death – ambulatory & community setting

Place of death	N	%
Private residence	1,605	55.8
Residential aged care setting	492	17.1
Other location*	600	20.9
Not stated/inadequately described	177	6.2
Total	2,874	100.0

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

Table 20 gives a summary of the length of episode. Table 21 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 20 Length of episode summary by setting

Length of episode	Inpatient	Ambulatory & community
Average length of episode	11.8	39.9
Median length of episode	7.0	27.0

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

Table 21 Length of episode by setting

Length of episode	Inpatient		Ambulatory & community	
	N	%	N	%
Same day	416	3.8	501	5.7
1-2 days	2,078	18.8	594	6.8
3-4 days	1,560	14.1	421	4.8
5-7 days	1,890	17.1	642	7.3
8-14 days	2,307	20.8	1,016	11.6
15-21 days	1,167	10.5	760	8.7
22-30 days	740	6.7	681	7.8
31-60 days	701	6.3	1,478	16.9
61-90 days	135	1.2	777	8.9
Greater than 90 days	77	0.7	1,891	21.6
Total	11,071	100.0	8,761	100.0

4.3 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 stable, unstable, deteriorating and terminal phase types can occur in any sequence and a patient may move back and forth between them.

Table 22 *Number of phases by phase type and setting*

Phase type	Inpatient		Ambulatory & community	
	N	%	N	%
Stable	7,024	24.7	7,700	38.9
Unstable	7,528	26.5	2,531	12.8
Deteriorating	7,529	26.5	7,938	40.1
Terminal	4,767	16.8	1,452	7.3
Bereaved	1,553	5.5	158	0.8
All phases	28,401	100.0	19,779	100.0

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

Phase type	Inpatient	Ambulatory & community
Stable	7.5	19.8
Unstable	3.1	6.9
Deteriorating	5.2	15.0
Terminal	2.1	2.9
Bereaved	1.1	2.5

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

Table 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 13 and Figure 14 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. The “Unknown” category has been included to account for situations where subsequent phase records have not been submitted to PCOC, meaning the phase progression cannot be determined.

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

Table 24 How stable phases end – by setting

Phase end reason	Inpatient		Ambulatory & community	
	N	%	N	%
Phase change (see figures below)	3,589	51.1	4,669	60.6
Discharge/case closure	3,170	45.1	2,448	31.8
Died	128	1.8	447	5.8
Bereavement phase end	0	0.0	0	0.0
Not stated/inadequately described	137	2.0	136	1.8
Total	7,024	100.0	7,700	100.0

Figure 13 Stable phase progression – inpatient setting

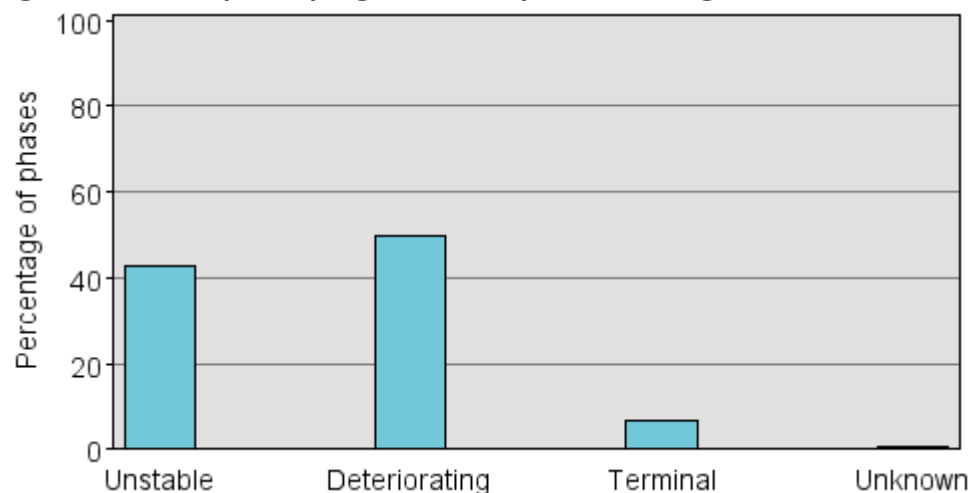


Figure 14 Stable phase progression – ambulatory & community settings

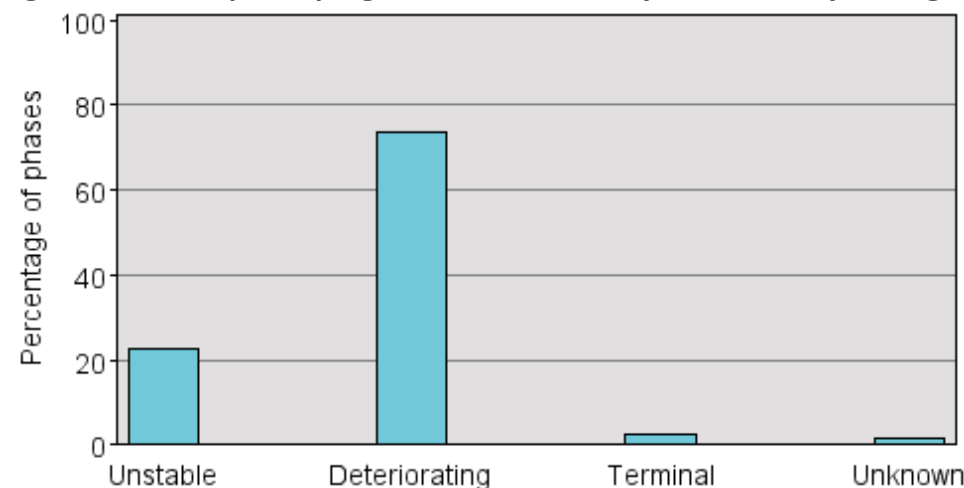


Table 25 How *unstable phases end* – by setting

Phase end reason	Inpatient		Ambulatory & community	
	N	%	N	%
Phase change (see figures below)	6,803	90.4	1,733	68.5
Discharge/case closure	426	5.7	602	23.8
Died	230	3.1	149	5.9
Bereavement phase end	0	0.0	0	0.0
Not stated/inadequately described	69	0.9	47	1.9
<i>Total</i>	<i>7,528</i>	<i>100.0</i>	<i>2,531</i>	<i>100.0</i>

Figure 15 Unstable phase progression – inpatient setting

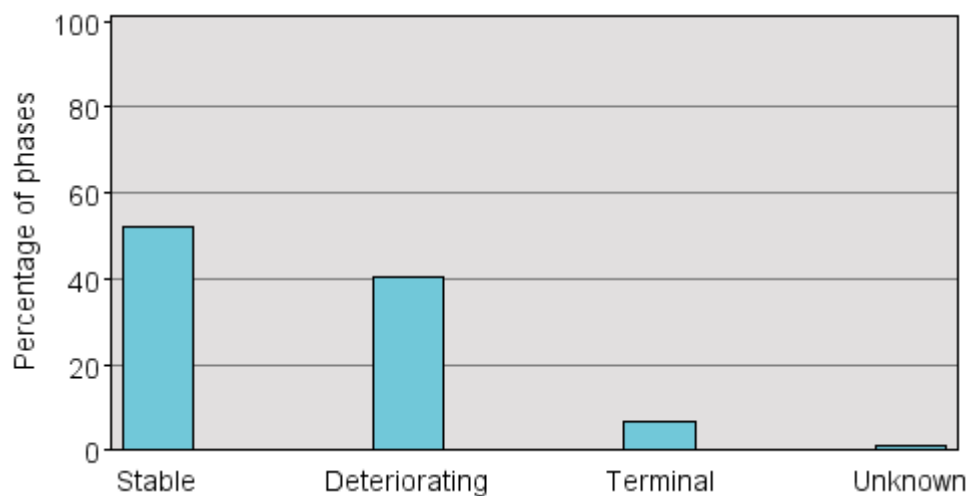


Figure 16 Unstable phase progression – ambulatory & community settings

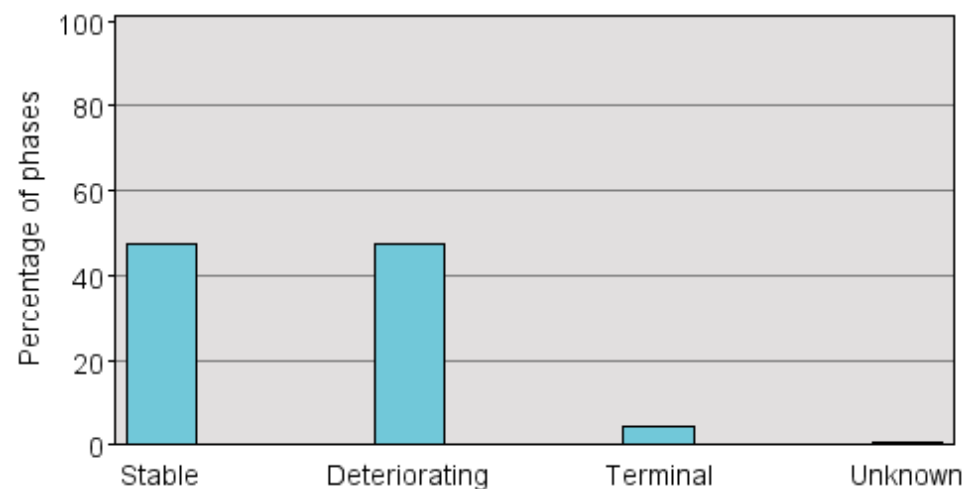


Table 26 How *deteriorating* phases end – by setting

Phase end reason	Inpatient		Ambulatory & community	
	N	%	N	%
Phase change (see figures below)	5,173	68.7	4,651	58.6
Discharge/case closure	1,065	14.1	2,202	27.7
Died	1,083	14.4	1,017	12.8
Bereavement phase end	0	0.0	0	0.0
Not stated/inadequately described	208	2.8	68	0.9
<i>Total</i>	<i>7,529</i>	<i>100.0</i>	<i>7,938</i>	<i>100.0</i>

Figure 17 Deteriorating phase progression – inpatient setting

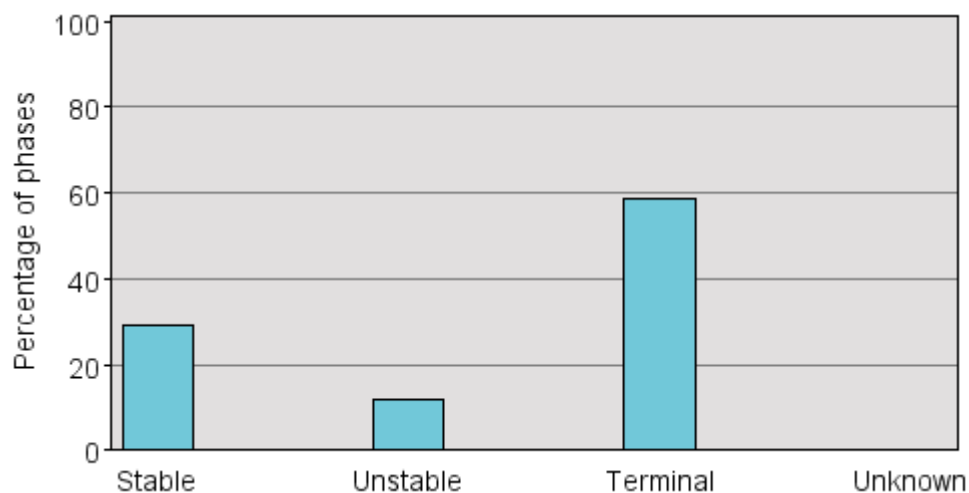


Figure 18 Deteriorating phase progression – ambulatory & community settings

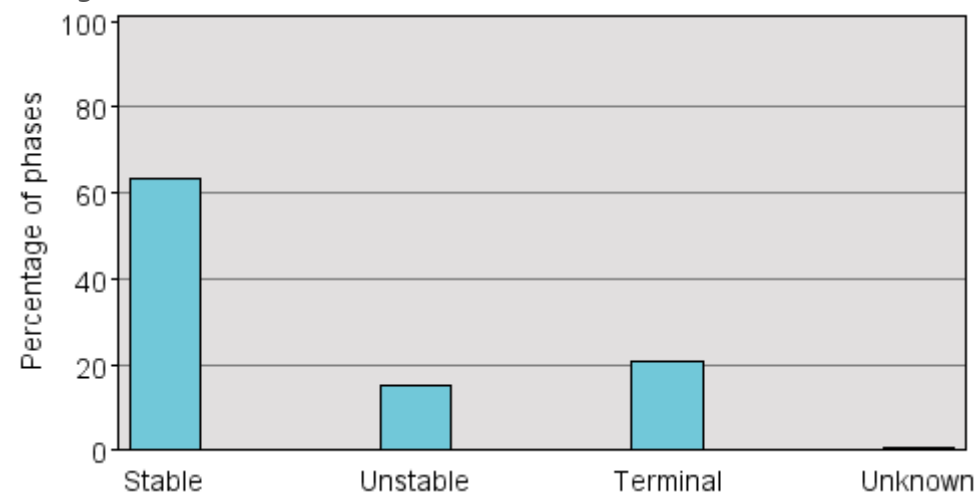


Table 27 How terminal phases end – by setting

Phase end reason	Inpatient		Ambulatory & community	
	N	%	N	%
Phase change (see figures below)	179	3.8	137	9.4
Discharge/case closure	86	1.8	102	7.0
Died	4,107	86.2	1,184	81.5
Bereavement phase end	0	0.0	0	0.0
Not stated/inadequately described	395	8.3	29	2.0
<i>Total</i>	<i>4,767</i>	<i>100.0</i>	<i>1,452</i>	<i>100.0</i>

Figure 19 Terminal phase progression – inpatient setting

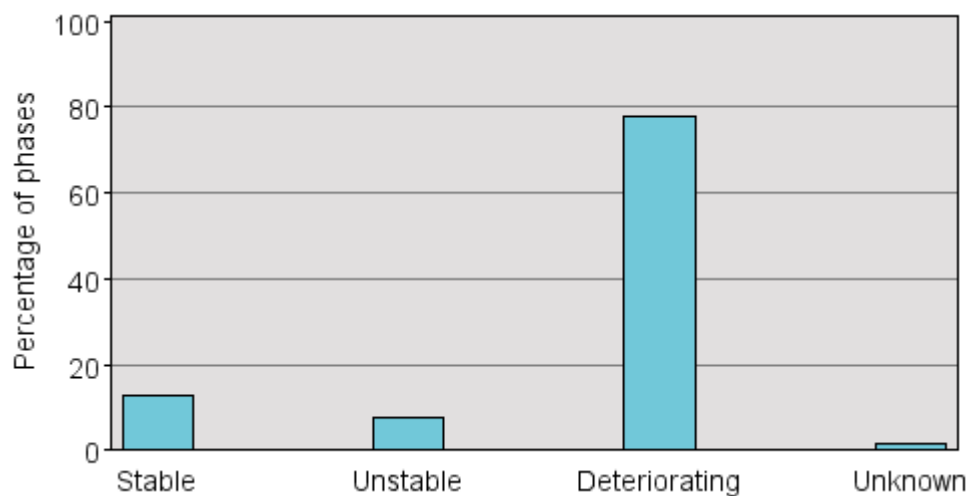
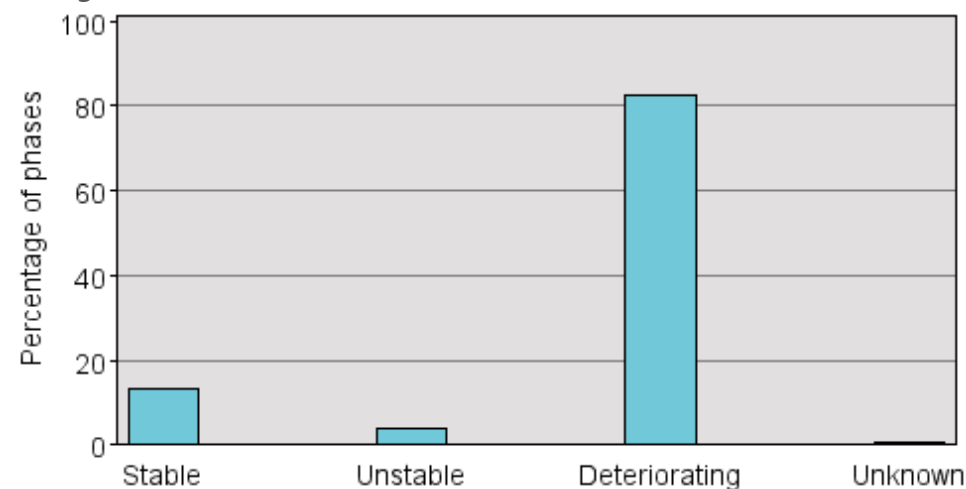


Figure 20 Terminal phase progression – ambulatory & community settings



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 e.g. a score of severe in the family/carer domain could trigger a more detailed assessment by a skilled social worker or pastoral care worker to establish appropriate treatment or intervention.

Tables 28 and 29 show the percentage scores for the inpatient and ambulatory and community settings respectively.

Table 28 Profile of PC Problem Severity scores at beginning of phase by phase type – inpatient setting (percentages)

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	44.0	37.5	14.8	3.8
	Other symptoms	19.0	45.2	27.6	8.2
	Psychological/spiritual	27.4	48.0	19.4	5.3
	Family/carer	36.9	39.4	17.5	6.3
Unstable	Pain	28.0	30.1	27.8	14.1
	Other symptoms	10.4	29.4	40.3	19.9
	Psychological/spiritual	18.5	40.2	29.8	11.6
	Family/carer	25.2	34.7	27.7	12.4
Deteriorating	Pain	38.4	31.8	22.1	7.6
	Other symptoms	14.3	31.7	37.5	16.5
	Psychological/spiritual	24.0	41.0	25.6	9.5
	Family/carer	27.2	34.2	26.3	12.4
Terminal	Pain	43.2	32.3	16.8	7.7
	Other symptoms	27.8	28.7	25.9	17.7
	Psychological/spiritual	42.4	30.9	17.1	9.6
	Family/carer	19.1	30.8	31.0	19.1

Table 29 Profile of PC Problem Severity scores at beginning of phase by phase type – ambulatory and community settings (percentages)

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	41.6	46.5	10.7	1.2
	Other symptoms	16.5	57.3	23.5	2.8
	Psychological/spiritual	30.1	51.5	15.6	2.7
	Family/carer	32.7	44.0	18.4	5.0
Unstable	Pain	19.8	27.9	34.4	18.0
	Other symptoms	6.0	25.3	48.6	20.0
	Psychological/spiritual	13.8	39.9	35.4	10.9
	Family/carer	18.7	30.0	35.9	15.3
Deteriorating	Pain	29.9	45.3	21.3	3.5
	Other symptoms	8.7	40.3	42.9	8.1
	Psychological/spiritual	21.5	49.5	24.6	4.4
	Family/carer	24.0	38.4	30.3	7.4
Terminal	Pain	37.1	40.0	18.2	4.8
	Other symptoms	19.6	34.1	30.7	15.6
	Psychological/spiritual	43.5	32.3	18.0	6.2
	Family/carer	13.1	31.1	36.3	19.5

The Symptom Assessment Scale (SAS) is a ‘patient rated’ assessment tool capturing the patient’s level of symptom distress. It uses a visual analogue scale where 0 = no problems and 1 - 10 = level of distress, with 10 being the worst possible experience. 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). In tables 30 and 31 on the following pages, the SAS scores are grouped into the following categories: absent (0), mild (1-3), moderate (4-7) and severe (8-10).

Table 30 Profile of Symptom Assessment Scale 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	Insomnia	64.4	19.6	13.2	2.8
	Appetite problems	49.6	22.3	22.8	5.3
	Nausea	77.8	13.5	7.2	1.5
	Bowel problems	58.8	22.9	14.5	3.7
	Breathing problems	61.8	19.2	14.5	4.6
	Fatigue	24.3	21.1	42.9	11.7
	Pain	45.2	30.8	20.5	3.5
Unstable	Insomnia	54.8	18.2	20.8	6.2
	Appetite problems	37.8	19.8	30.3	12.1
	Nausea	66.0	14.3	14.3	5.4
	Bowel problems	49.8	21.4	21.4	7.4
	Breathing problems	51.4	19.0	20.3	9.3
	Fatigue	19.0	15.0	42.9	23.2
	Pain	31.9	25.7	29.2	13.2
Deteriorating	Insomnia	66.4	15.6	14.6	3.4
	Appetite problems	47.1	17.0	25.0	10.9
	Nausea	74.8	12.4	9.9	2.9
	Bowel problems	57.0	20.0	17.7	5.3
	Breathing problems	55.1	17.0	19.4	8.5
	Fatigue	24.7	10.6	39.3	25.3
	Pain	39.8	26.3	26.9	6.9
Terminal	Insomnia	84.1	8.0	6.2	1.7
	Appetite problems	79.0	6.4	8.2	6.4
	Nausea	89.1	6.1	3.8	1.0
	Bowel problems	75.9	11.6	9.1	3.5
	Breathing problems	60.9	13.7	16.3	9.1
	Fatigue	61.2	5.5	15.3	17.9
	Pain	53.2	23.2	18.7	4.8

Table 31 Profile of Symptom Assessment Scale 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	Insomnia	59.5	28.1	11.0	1.3
	Appetite problems	42.2	33.1	21.5	3.2
	Nausea	77.5	17.5	4.4	0.7
	Bowel problems	63.1	26.0	9.5	1.4
	Breathing problems	51.6	30.5	15.5	2.4
	Fatigue	11.3	28.7	51.5	8.5
	Pain	43.6	40.2	14.6	1.6
Unstable	Insomnia	43.3	27.4	23.7	5.5
	Appetite problems	29.3	24.2	34.7	11.8
	Nausea	59.4	18.8	15.8	6.0
	Bowel problems	51.3	25.4	17.8	5.4
	Breathing problems	47.0	25.8	21.2	5.9
	Fatigue	7.0	13.9	56.1	23.1
	Pain	19.8	24.9	37.4	17.9
Deteriorating	Insomnia	54.3	28.3	14.8	2.6
	Appetite problems	35.0	27.5	29.2	8.3
	Nausea	70.2	20.2	8.2	1.4
	Bowel problems	58.6	26.9	12.0	2.4
	Breathing problems	42.5	30.9	22.2	4.4
	Fatigue	7.5	16.7	56.8	19.0
	Pain	33.3	39.3	23.3	4.2
Terminal	Insomnia	72.4	12.8	11.2	3.7
	Appetite problems	64.7	6.1	10.2	18.9
	Nausea	85.5	8.8	4.5	1.2
	Bowel problems	72.0	16.6	8.9	2.4
	Breathing problems	49.0	21.9	21.0	8.0
	Fatigue	41.9	4.6	12.2	41.3
	Pain	42.4	33.8	20.0	3.9

The RUG-ADL consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence, based on what a person actually does, rather than what they are capable of doing. The figures 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).

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. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status. The AKPS is often used in assessment of prognosis and is applicable to both inpatient and community palliative care. Table 32 shows the data for the AKPS at phase start.

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

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

AKPS assessment	Inpatient		Ambulatory & community	
	N	%	N	%
10 - Comatose or barely rousable	2,581	9.7	607	3.1
20 - Totally bedfast and requiring extensive nursing care	5,620	21.0	1,588	8.1
30 - Almost completely bedfast	3,276	12.3	1,010	5.2
40 - In bed more than 50% of the time	4,702	17.6	1,974	10.1
50 - Requires considerable assistance	4,824	18.0	4,466	22.8
60 - Requires occasional assistance	3,264	12.2	5,217	26.6
70 - Cares for self	706	2.6	3,390	17.3
80 - Normal activity with effort	244	0.9	920	4.7
90 - Able to carry on normal activity; minor signs or symptoms	82	0.3	197	1.0
100 - Normal; no complaints; no evidence of disease	1	0.0	11	0.1
Not stated/inadequately described	1,438	5.4	227	1.2
Total	26,738	100.0	19,607	100.0

Figure 21 Total RUG-ADL at beginning of phase by phase type – inpatient setting

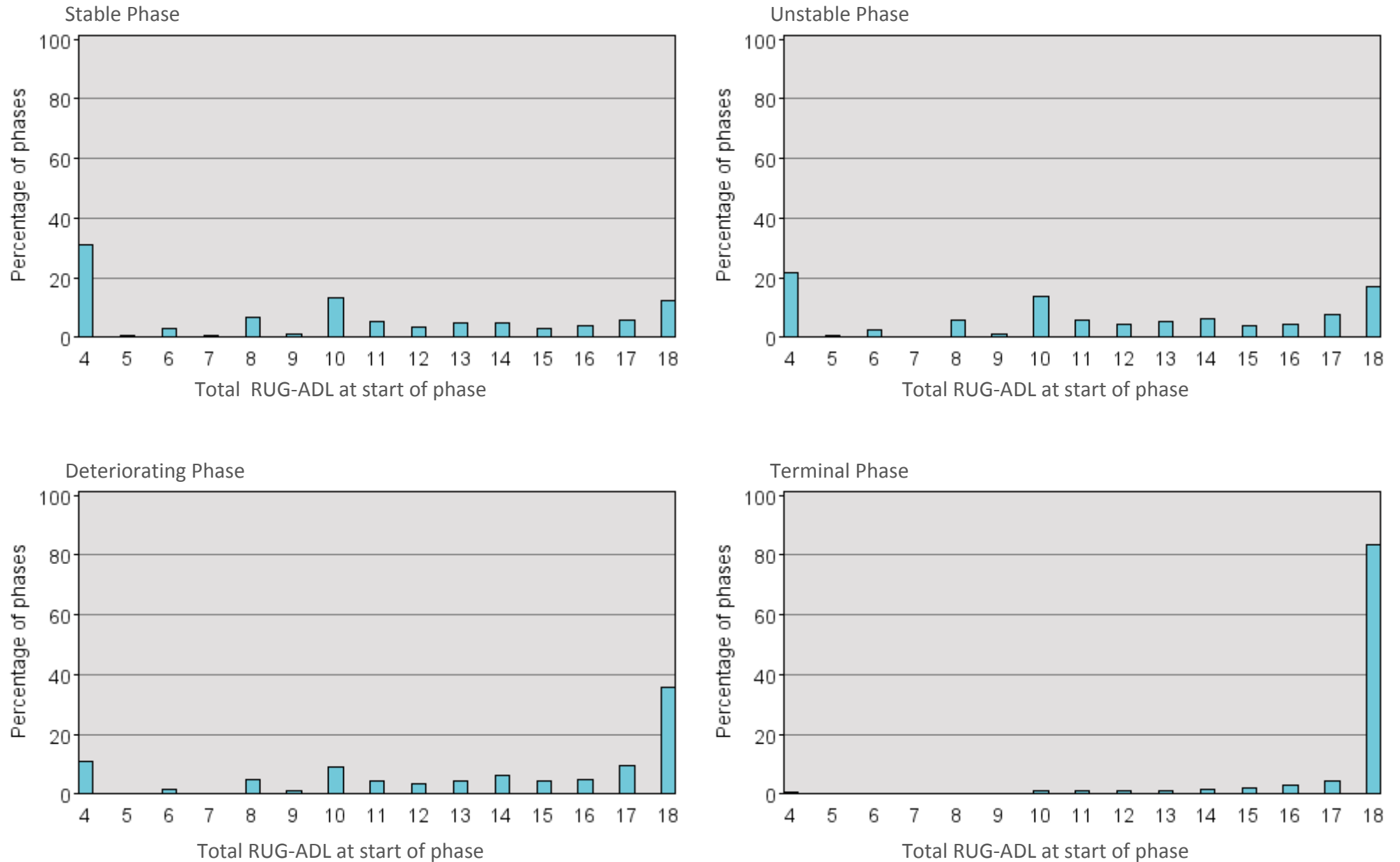
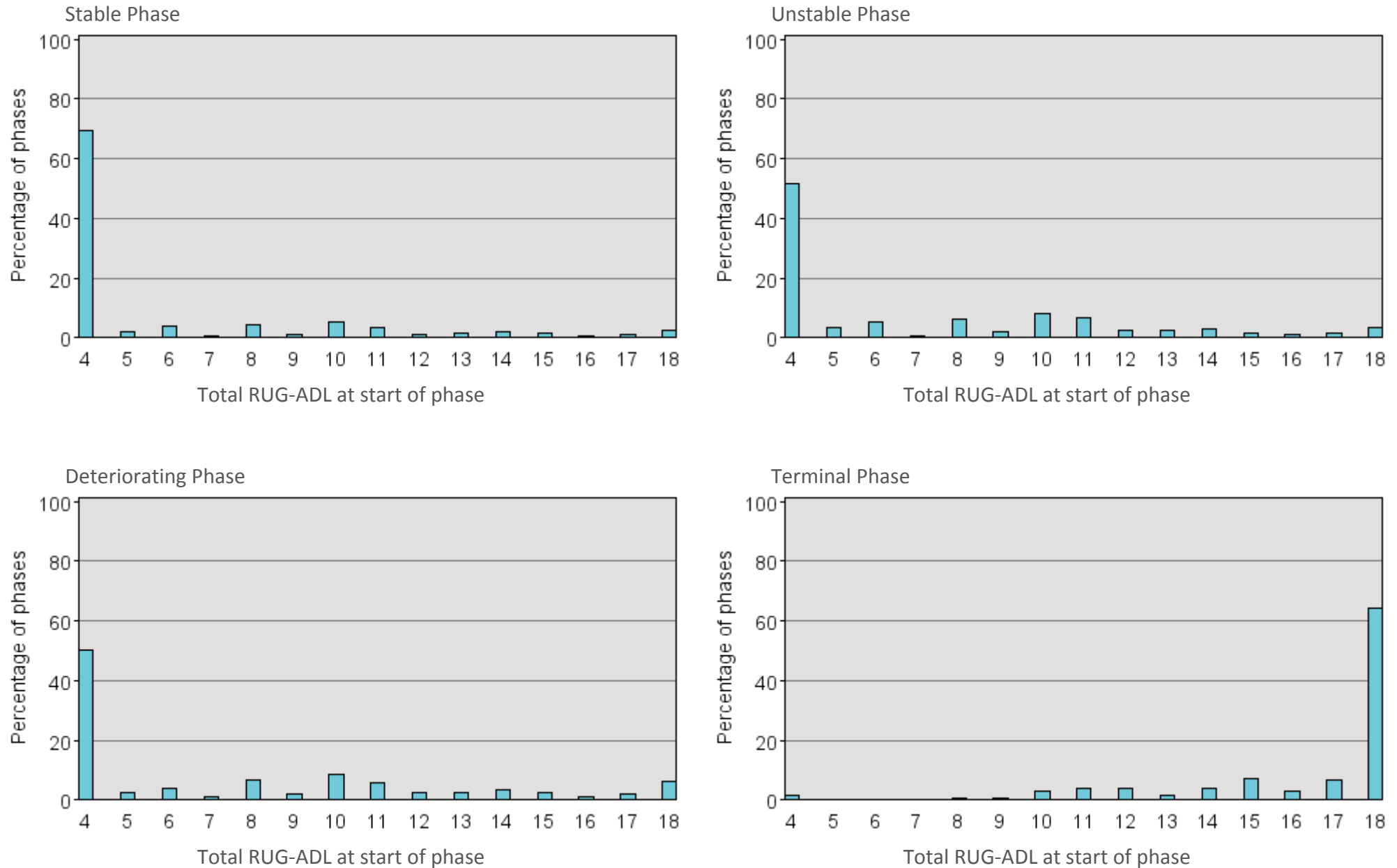


Figure 22 Total RUG-ADL at beginning of phase by phase type – ambulatory & community settings

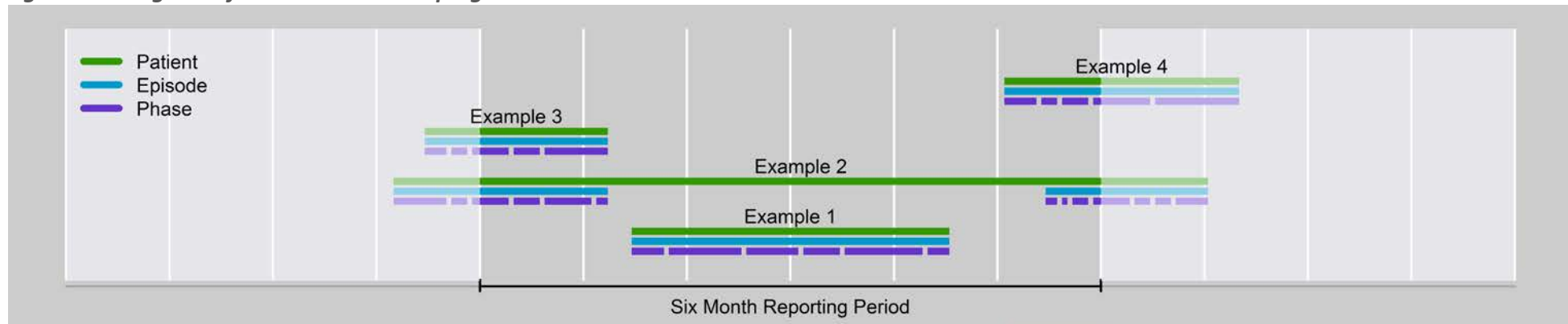


Appendix A – Data scoping method

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 23 below displays four examples to help visualize this process.

Figure 23 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 B – 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	

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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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