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PCOC National Report on Outcomes in Palliative Care in Australia July to December 2011

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Abstract

The Palliative Care Outcomes Collaboration (PCOC) was established in mid-2005 and is funded under the National Palliative Care Program supported by the Australian Government Department of Health and Ageing. The goal of the PCOC is to use standardised, validated, clinical assessment tools to benchmark and measure outcomes in palliative care; and assist palliative care services to improve the quality of care. Further information on the tools can be found at www.pcoc.org.au. Each service involved in PCOC submits data every six months. The data are then collated and fed back to services to inform service improvement. Participation in PCOC is voluntary. There are three levels of 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 the data is at the phase level. The items at this level describe the patient's stage of illness, functional impairment as well as their levels of pain and symptom distress. The items at the phase level are used to quantify patient outcomes, and are the focus of the PCOC benchmarks. The current PCOC data set (Version 2) was introduced in July 2007 following consultation with palliative care services and approval by PCOC's Scientific and Clinical Advisory Committee. The data set includes five clinical assessment tools: Phases of Care, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status Scale (AKPS) and Resource Utilisation Groups - Activities of Daily Living (RUG-ADL). The items included in the PCOC data set serve the dual purpose of: - defining a common clinical language to allow communication between palliative care providers - facilitating the routine collection of national palliative care data for the purpose of reporting and benchmarking to drive quality improvement. Revised phase definitions were implemented in January 2012 but the data in this report does not reflect the revised definitions.

Keywords

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National Report on Outcomes in Palliative Care in Australia

About the Palliative Care Outcomes Collaboration (PCOC)

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

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



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

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

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Introduction

The Palliative Care Outcomes Collaboration (PCOC) was established in mid-2005 and is funded under the National Palliative Care Program supported by the Australian Government Department of Health and Ageing. The goal of the PCOC is to use standardised, validated, clinical assessment tools to benchmark and measure outcomes in palliative care; and assist palliative care services to improve the quality of care. Further information on the tools can be found at www.pcoc.org.au. Each service involved in PCOC submits data every six months. The data are then collated and fed back to services to inform service improvement. Participation in PCOC is voluntary.

There are three levels of 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 the data is at the phase level. The items at this level describe the patient's stage of illness, functional impairment as well as their levels of pain and symptom distress. The items at the phase level are used to quantify patient outcomes, and are the focus of the PCOC benchmarks.

The current PCOC data set (Version 2) was introduced in July 2007 following consultation with palliative care services and approval by PCOC's Scientific and Clinical Advisory Committee. The data set includes five clinical assessment tools: Phases of Care, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status Scale (AKPS) and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL). The items included in the PCOC data set serve the dual purpose of:

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

Revised phase definitions were implemented in January 2012 but the data in this report does not reflect the revised definitions.

This report, for the period July to December 2011, includes data from 102 palliative care services across Australia, ranging from large, metropolitan, services through to relatively small, rural, services. Data were provided for a total of 14,787 patients who between them had 18,555 episodes of care and 40,890 palliative care phases. The average number of phases per episode was 2.4 for inpatients and 1.7 for ambulatory/community. Overall, the quality of data submitted to PCOC was very good and the rate of data completion very high. The focus of this report is the current reporting period, with some data presented for the previous three reporting periods. The national figures reflect all palliative care services who submitted data.

There is strong sectoral support for national benchmarks and a consensus that such benchmarks can drive service innovation regardless of model of care. Benchmarking provides opportunities to understand the services that are provided, the outcomes patients experience and also to generate research opportunities focused on how to demonstrate variations in practice and outcomes. Beginning in the reporting period January to June 2009, four benchmarks were introduced into the PCOC reports. It is recognised that services aspire to achieve best practice, and to reflect this, current benchmarks have intentionally been set at a high level. Where a service does not meet the benchmark, PCOC has adopted a target of improvement of 10% per year. In each national profile graph (pages 6-15), the shaded region describes the national profile for that benchmark.

This report is broken 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 levels.

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

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

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

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

Section 1 – Australia at a glance

Table 1 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 contact	Benchmark 1: Patients contacted on same or following day	90%	90.6%	Yes	53.0%	No
2. Time in unstable phase	Benchmark 2.1: Unstable phases lasting for less than 7 days - first phase of episode	85%	84.8%	No	59.6%	No
	Benchmark 2.2: Unstable phases lasting for less than 7 days - not first phase of episode	90%	90.3%	Yes	68.5%	No
	Benchmark 2.3: Median time in unstable phase	2 days	2 days	Yes	3 days	No
3. Change in pain PC Problem Severity Score (PCPSS) Symptom Assessment Scale (SAS)	Benchmark 3.1: Phases starting with absent/mild pain, that end with absent/mild pain	90%	81.6%	No	77.5%	No
	Benchmark 3.2: Phases starting with moderate/severe pain, that end with absent/mild pain	60%	53.6%	No	55.4%	No
	Benchmark 3.3: Phases starting with absent/mild pain, that end with absent/mild pain	90%	82.5%	No	78.1%	No
	Benchmark 3.4: Phases starting with moderate/severe pain, that end with absent/mild pain	60%	49.6%	No	56.2%	No

Table 2 Summary of outcome measure 4: Average improvement from baseline

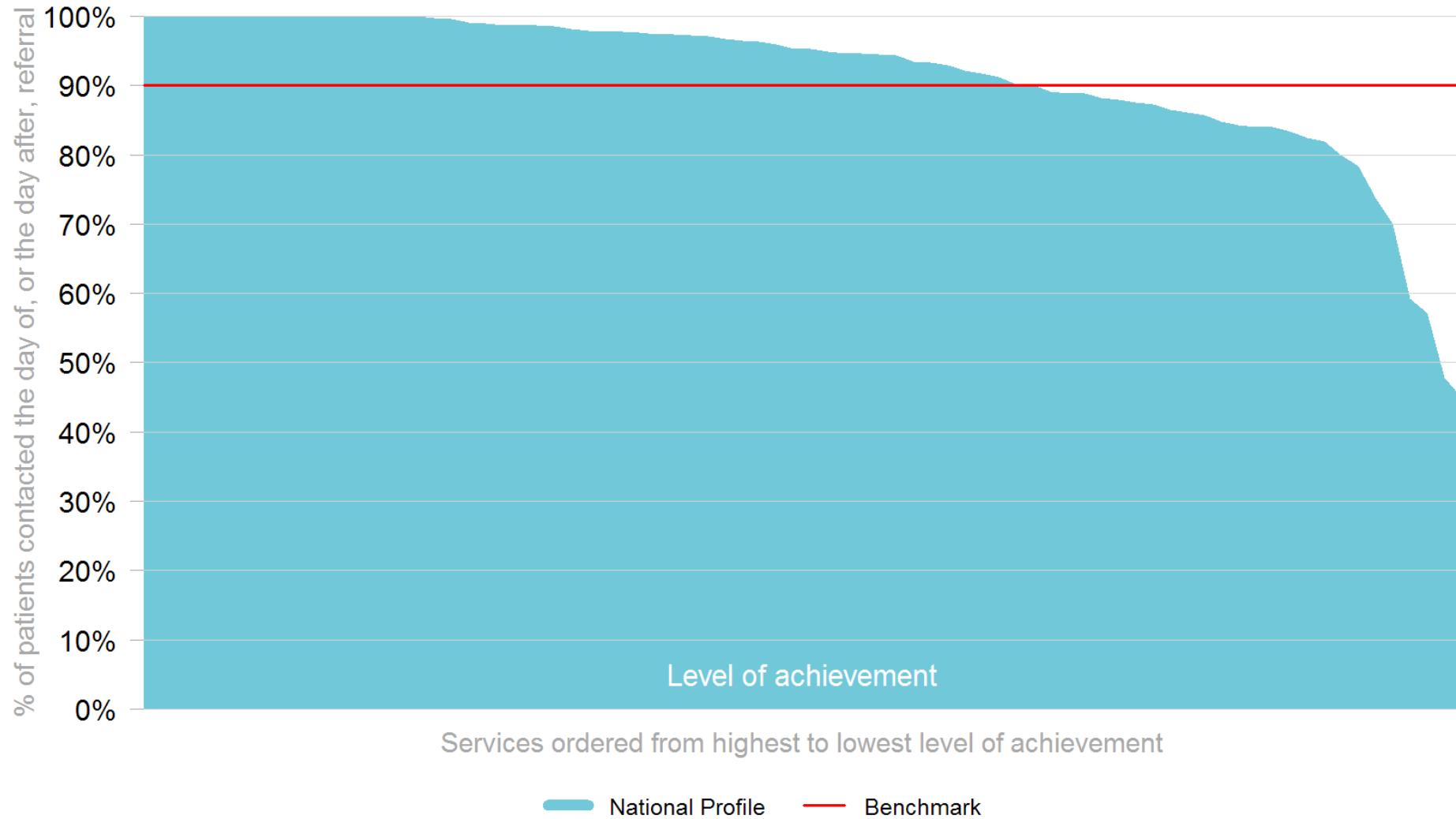
Clinical Tool	Description	Average improvement from baseline	Benchmark met?
PCPSS (rated by clinicians)	Benchmark 4.1: Pain	0.15	Yes
	Benchmark 4.2: Other symptoms	0.27	Yes
	Benchmark 4.3: Family/carer	0.14	Yes
	Benchmark 4.4: Psychological/spiritual	0.11	Yes
SAS (rated by patients)	Benchmark 4.5: Pain	0.28	Yes
	Benchmark 4.6: Nausea	0.15	Yes
	Benchmark 4.7: Breathing	0.34	Yes
	Benchmark 4.8: Bowels	0.23	Yes

The benchmark for this measure is zero.

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

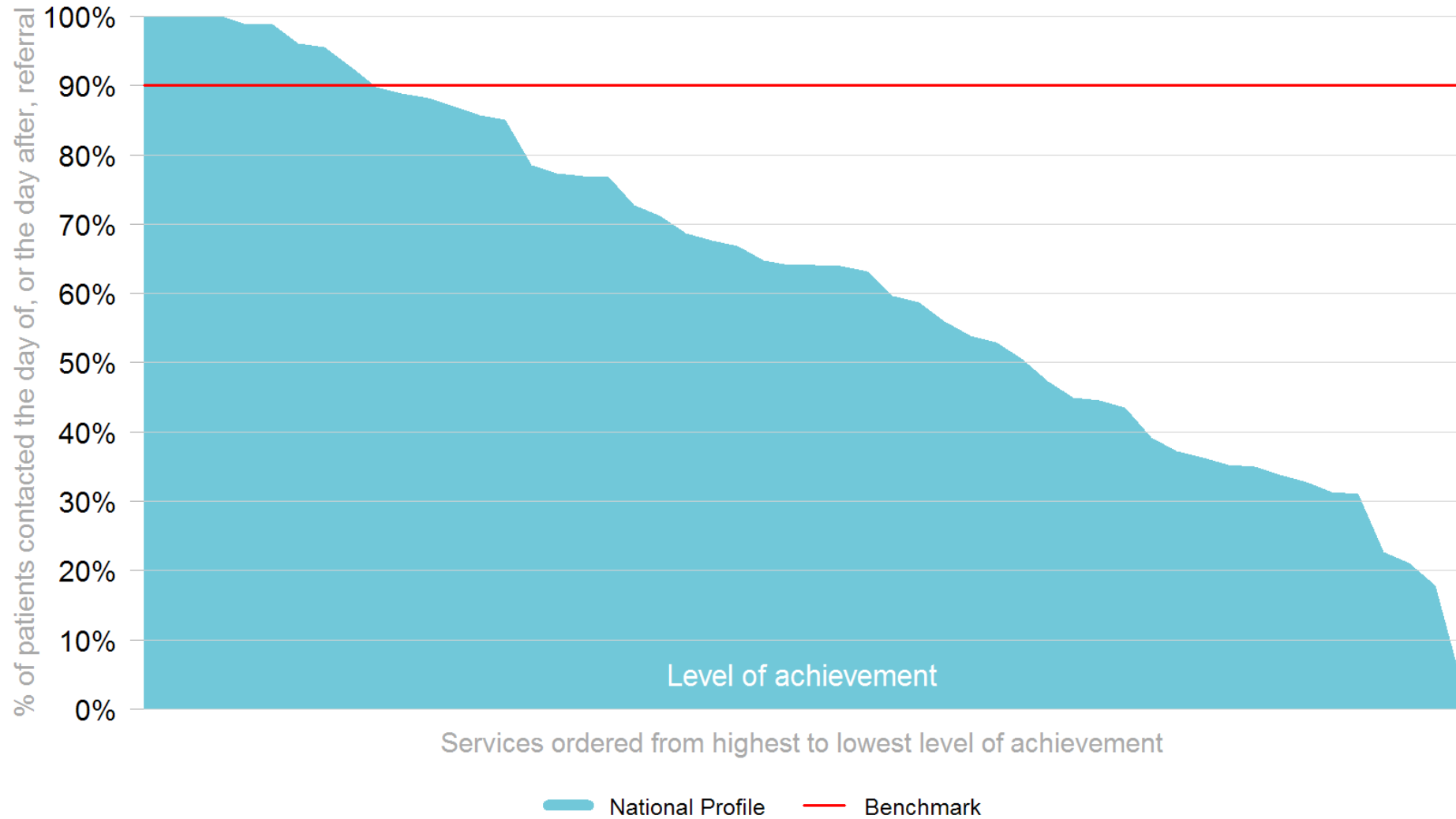
Measure 1: Time from referral to first contact - Inpatient Setting

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



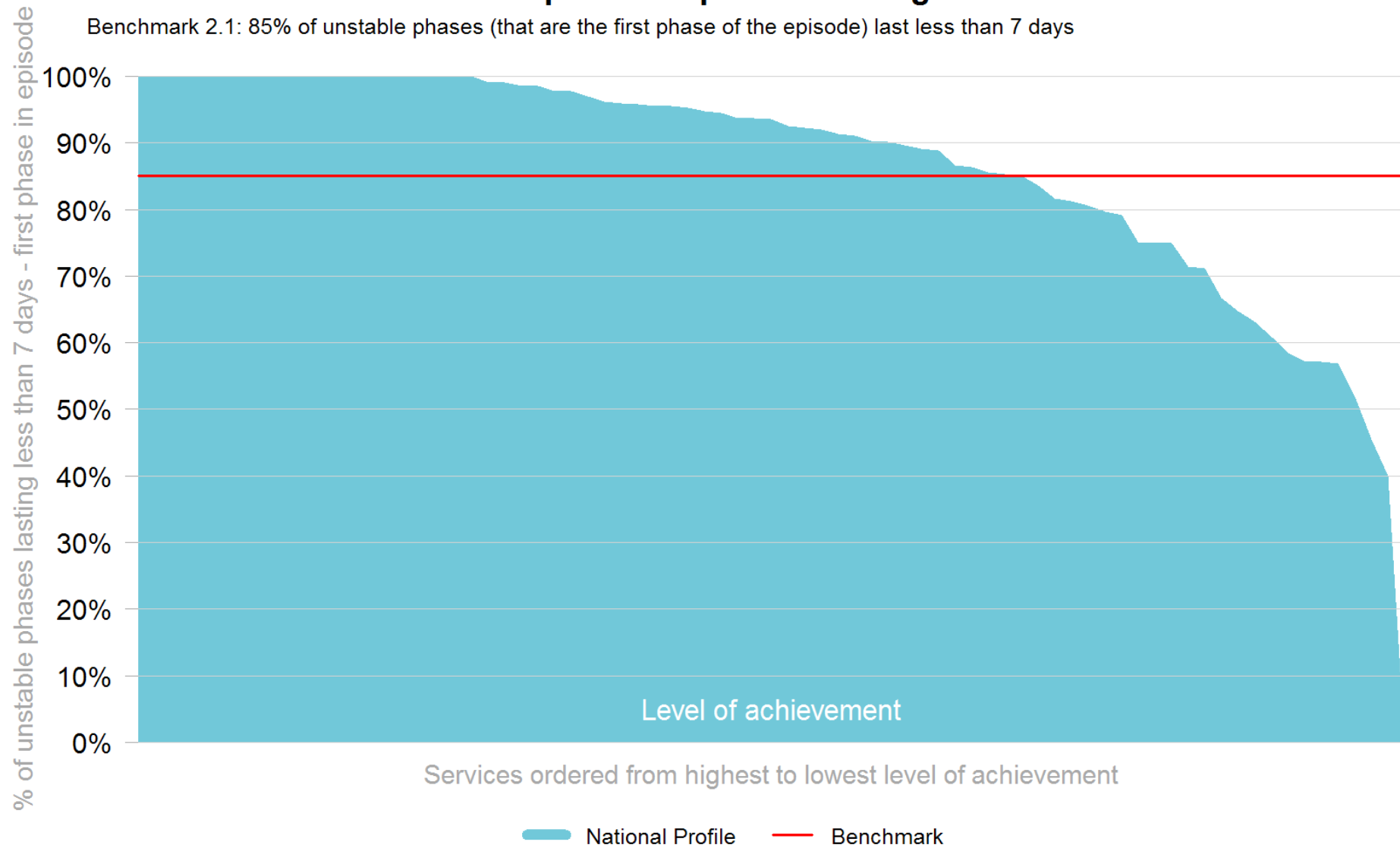
Measure 1: Time from referral to first contact - Ambulatory & Community Settings

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



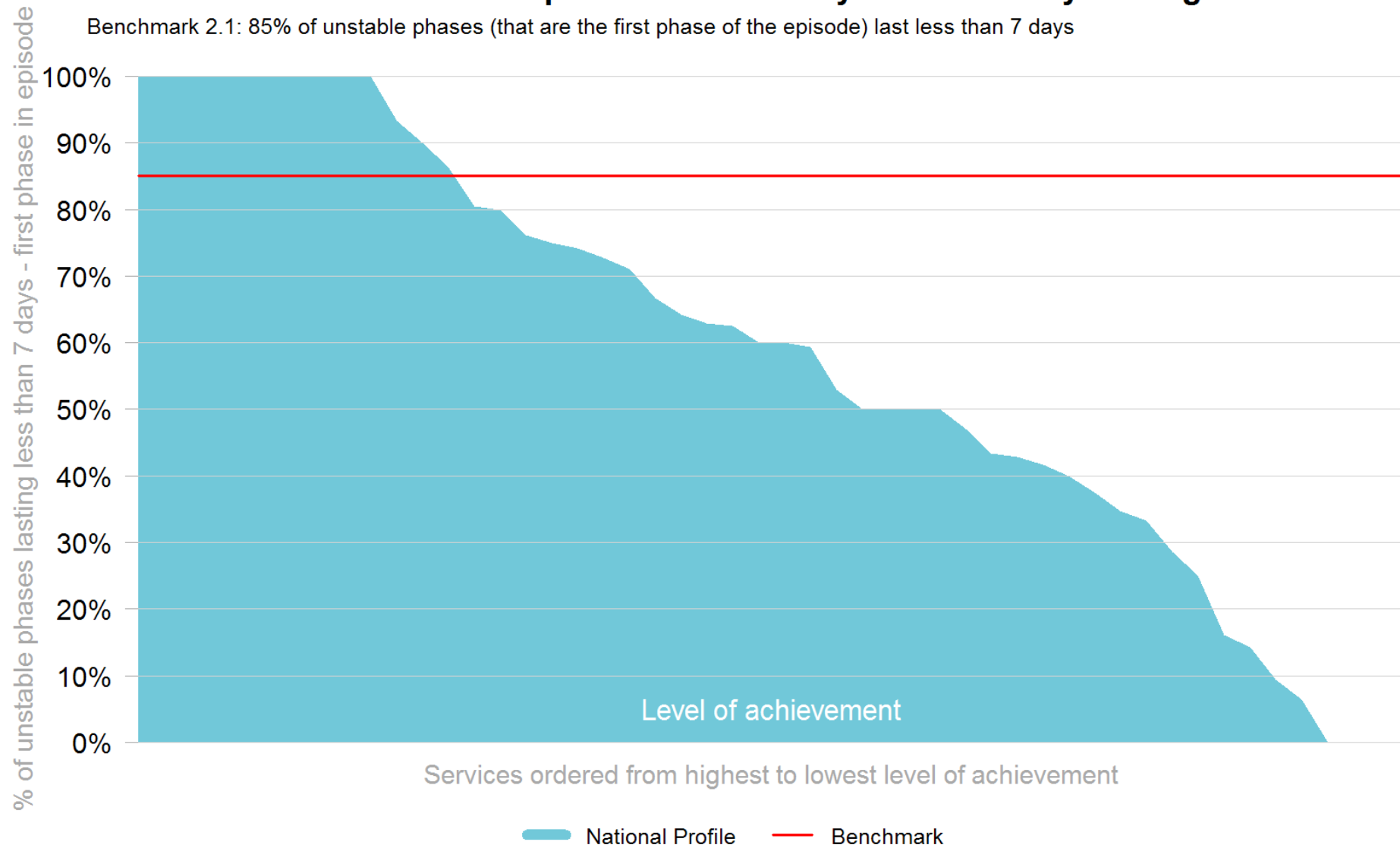
Measure 2: Time in unstable phase - Inpatient Setting

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



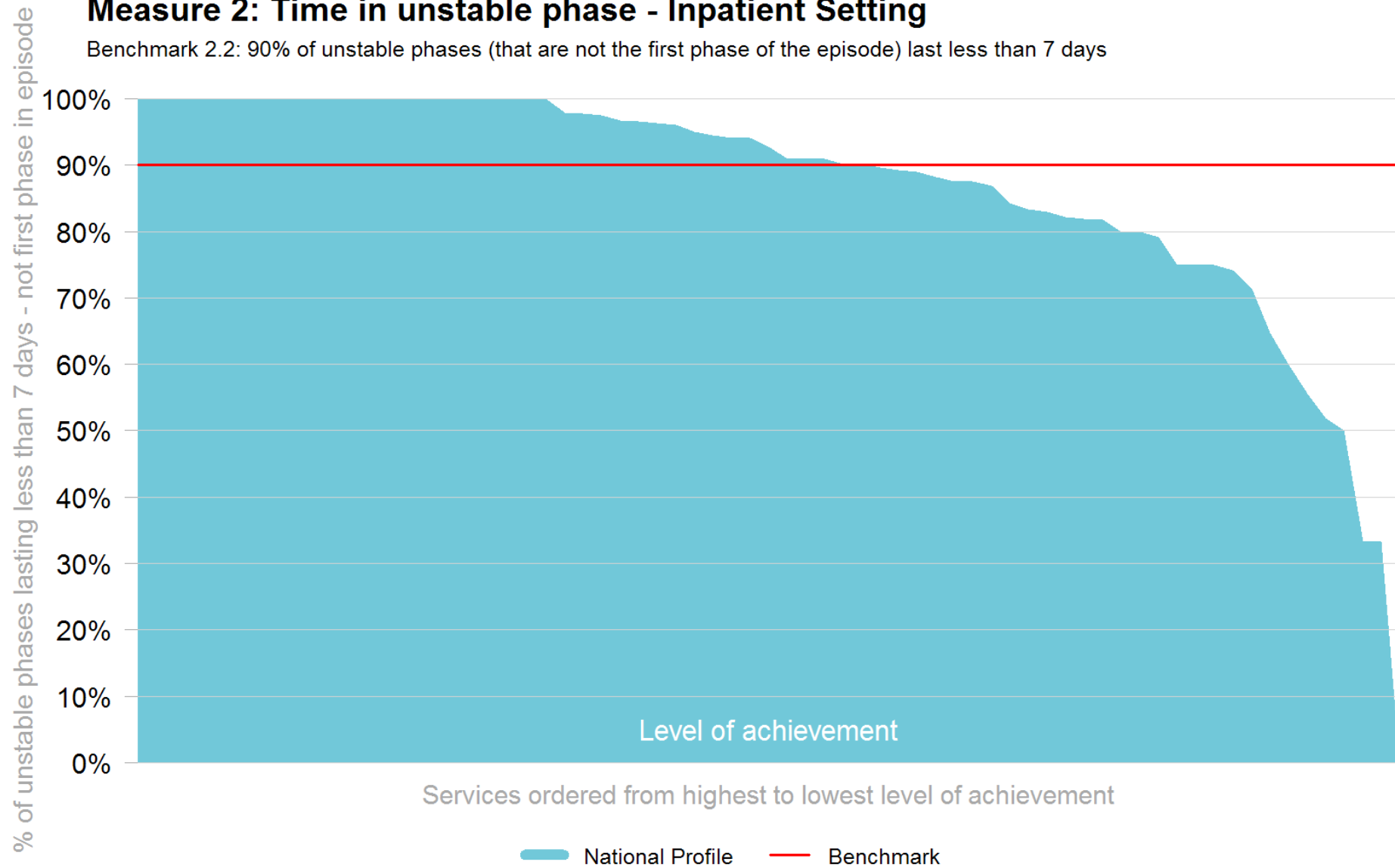
Measure 2: Time in unstable phase - Ambulatory & Community Settings

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



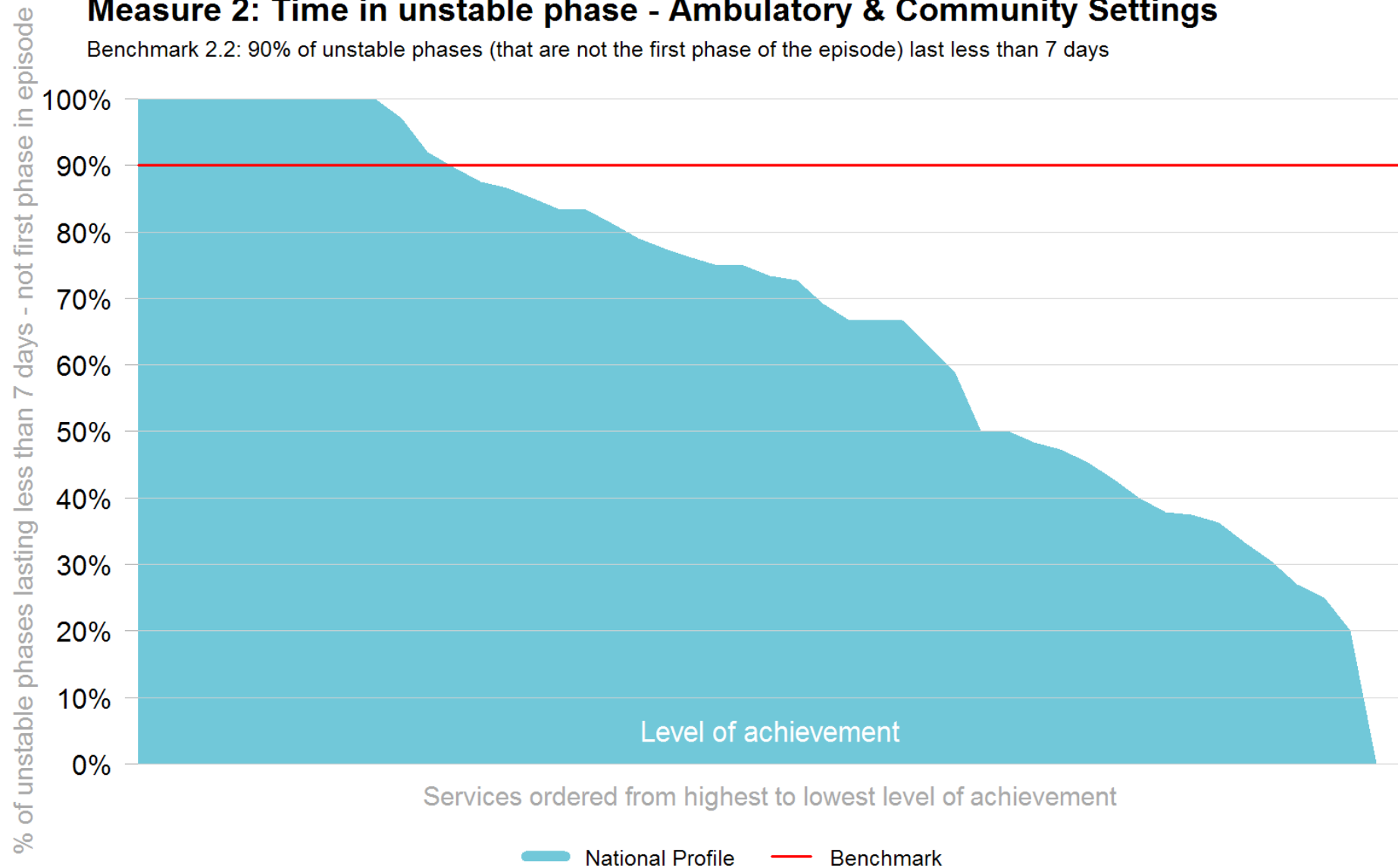
Measure 2: Time in unstable phase - Inpatient Setting

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



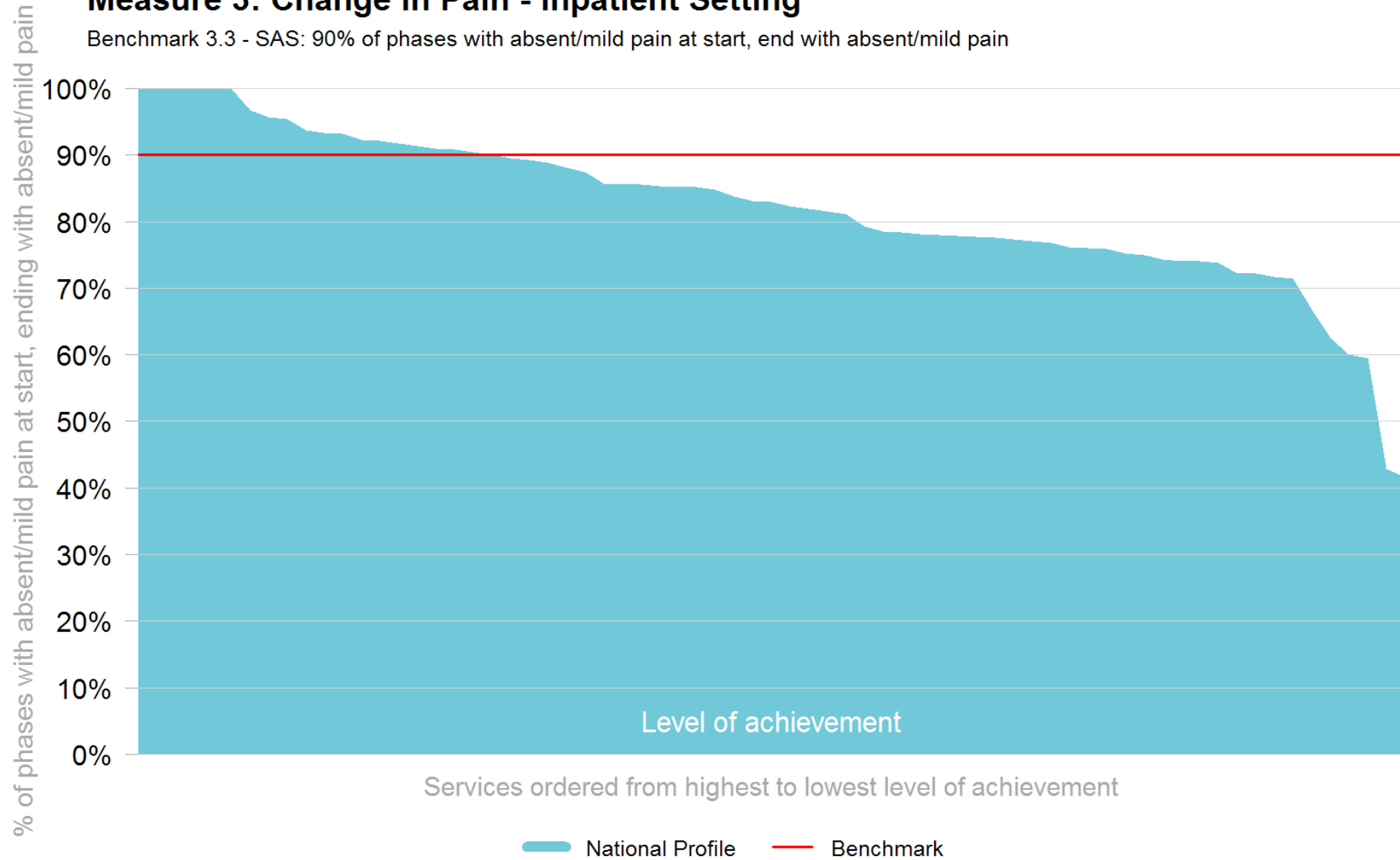
Measure 2: Time in unstable phase - Ambulatory & Community Settings

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



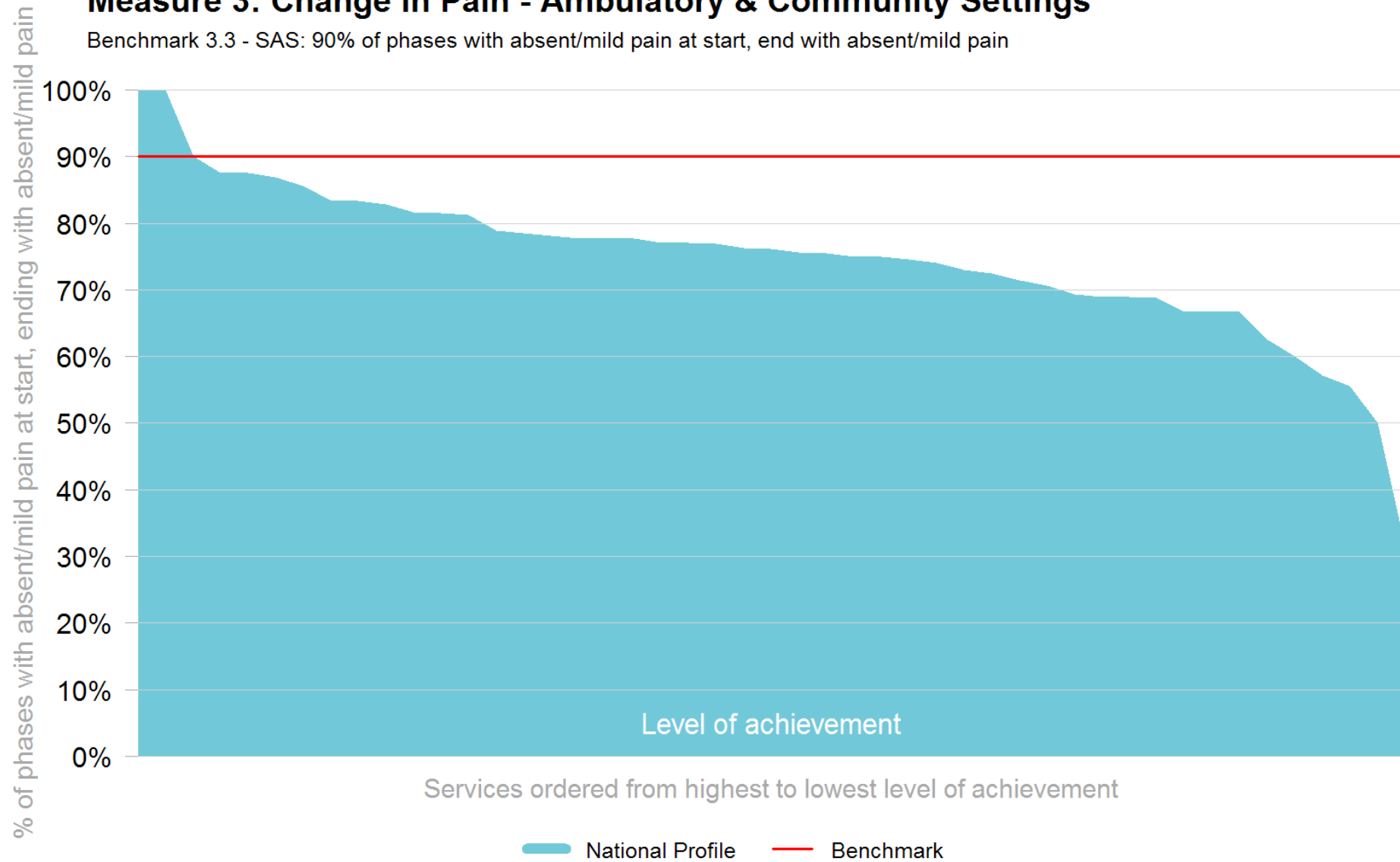
Measure 3: Change in Pain - Inpatient Setting

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



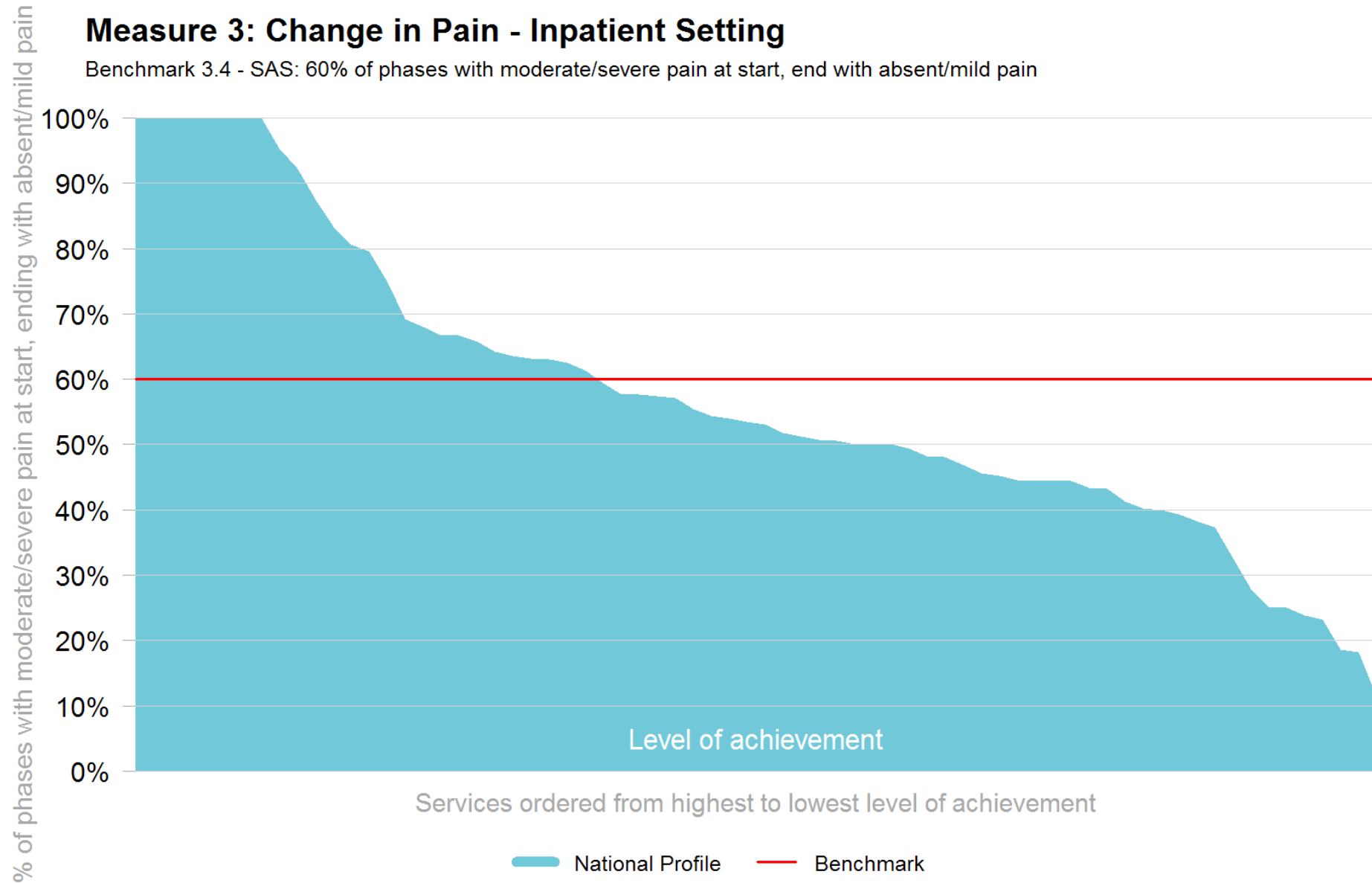
Measure 3: Change in Pain - Ambulatory & Community Settings

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



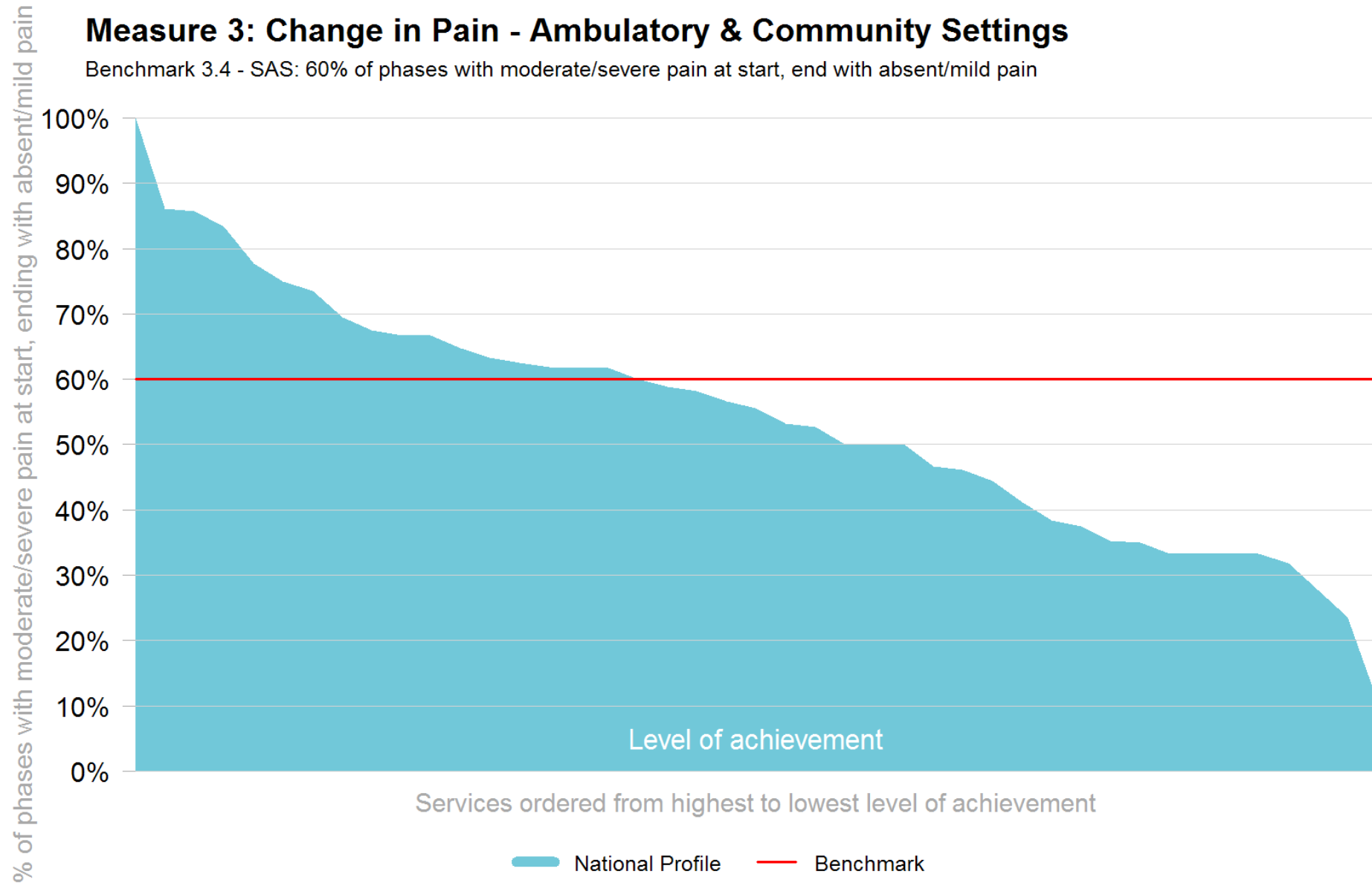
Measure 3: Change in Pain - Inpatient Setting

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



Measure 3: Change in Pain - Ambulatory & Community Settings

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



Section 2 – Outcome measures in detail

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 2008. Participants acknowledged that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday-Friday) are benchmarked against services operating seven days a week.

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

The time from referral to first contact is calculated as the time from the date referral was received to either the date of first contact (if provided) or the episode start date. Across all services the average time from referral to first contact was 1.3 days for inpatient services and 2.9 days for ambulatory and community, with a median of 1 day for both episode types.

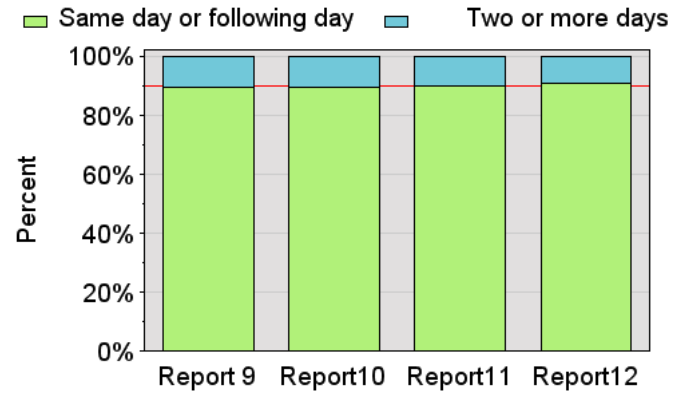
Table 3 Time from referral to first contact by setting

Time (in days)	Inpatient		Ambulatory & community	
	n	%	n	%
Within 2 days	9,503	90.6	3,521	53.0
2-7 days	798	7.6	2,028	30.5
8-14 days	72	0.7	655	9.9
Greater than 14 days	112	1.1	440	6.6
Total	10,485	100	6,644	100

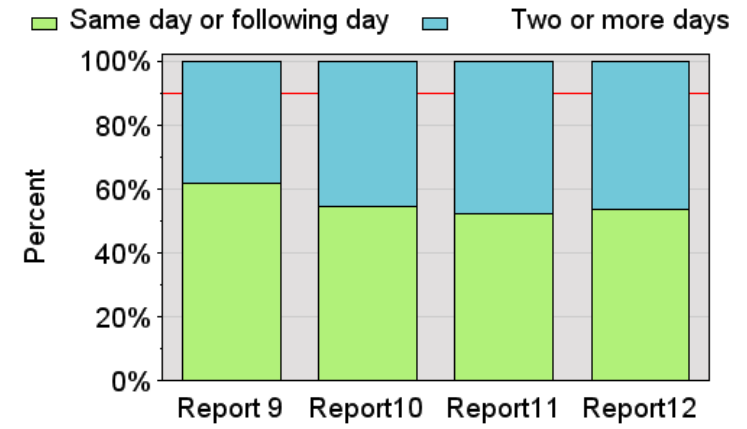
Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact or time from first contact to episode start was greater than 7 days were considered to be atypical and were assumed to equal 7 days for the purpose of calculating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

Figure 1 Trend in time from referral to first contact by setting

Inpatient setting



Ambulatory and community settings



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 but there is a clear diagnosis and plan of 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 move to the terminal phase.

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

Benchmark 2.1: This benchmark relates to unstable phases that are the first phase in an episode of care (for example, a patient is admitted to an inpatient palliative care unit and is immediately assessed as being in the unstable phase). To meet this benchmark, at least **85%** of these unstable phases must last for less than 7 days.

Benchmark 2.2: This benchmark relates to unstable phases that are not the first phase in an episode of care (for example, a patient's condition changes during an episode of care, and the patient's phase type is changed to unstable). To meet this benchmark, at least **90%** of these unstable phases must last for less than 7 days.

Benchmark 2.3: This benchmark relates to all unstable phases, regardless of where they occur in the episode. To meet this benchmark, the median length of all unstable phases must be **2 days or less**.

Table 4 presents descriptive data for these three benchmarks.

Table 4 Time in unstable phase for all services by setting and occurrence in episode

Setting	Occurrence of unstable phase	Number of unstable phases	Percent unstable for < 7 days	Median days in unstable phase
Inpatient	First phase of episode	4,958	84.8	2
	Not first phase of episode	2,356	90.3	2
	Total unstable phases	7,314	86.5	2
Ambulatory & Community	First phase of episode	1,123	59.6	4
	Not first phase of episode	1,180	68.5	3
	Total unstable phases	2,303	64.1	3

Interpretation hint:

Across participating services:

4,958 patients commenced their **inpatient episode** of care in the unstable phase.

Of these unstable phases, **84.8%** lasted for less than 7 days.

1,123 patients commenced their **ambulatory/community episode** of care in the unstable phase.

Of these unstable phases, **59.6%** lasted for less than 7 days.

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 rated by clinicians, the SAS is rated by patients. There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain, and the other relating to the management of pain for patients with moderate or severe pain.

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

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

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

Setting		Jan-Jun 2010 (Report 9)	Jul-Dec 2010 (Report 10)	Jan-Jun 2011 (Report 11)	Jul-Dec 2011 (Report 12)
Inpatient	n	2,860	3,969	5,153	5,577
	%	79.0	79.0	82.1	81.6
Ambulatory & Community	n	1,441	2,415	2,176	2,339
	%	75.8	74.9	75.1	77.5

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

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

Setting		Jan-Jun 2010 (Report 9)	Jul-Dec 2010 (Report 10)	Jan-Jun 2011 (Report 11)	Jul-Dec 2011 (Report 12)
Inpatient	n	1,257	1,655	1,858	1,986
	%	44.0	46.6	48.0	53.6
Ambulatory & Community	n	485	806	646	697
	%	55.7	57.5	57.3	55.4

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

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

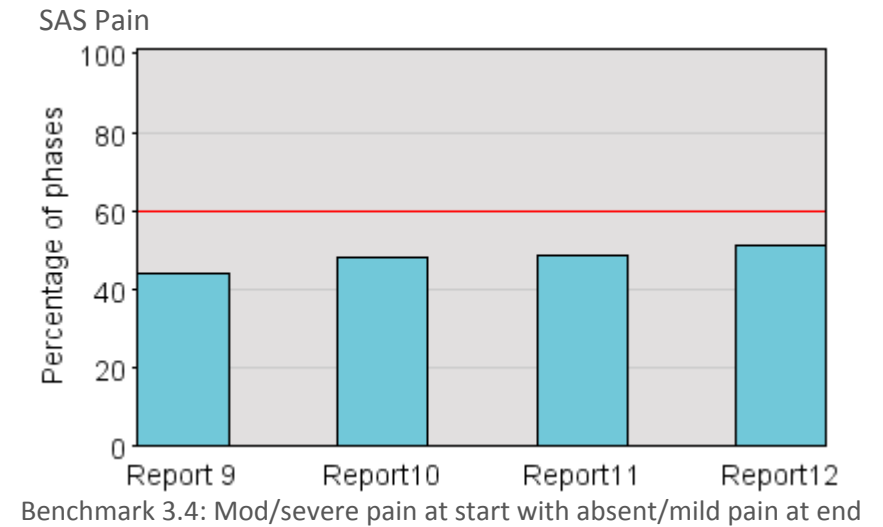
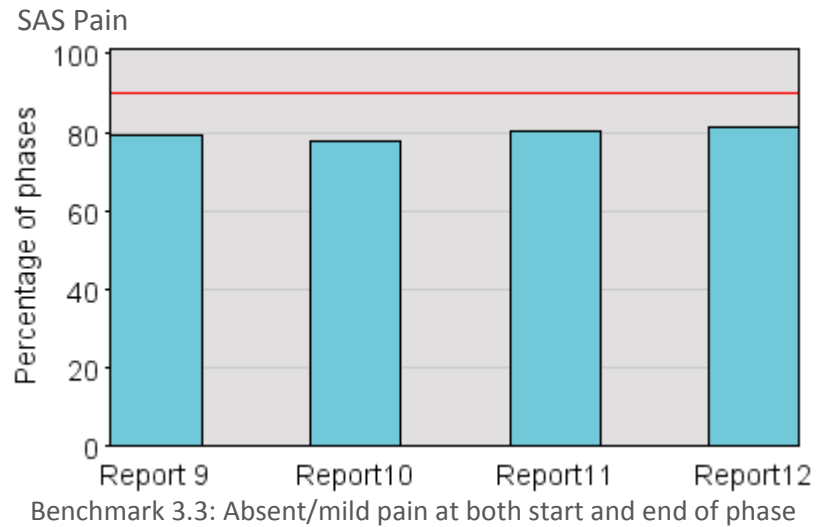
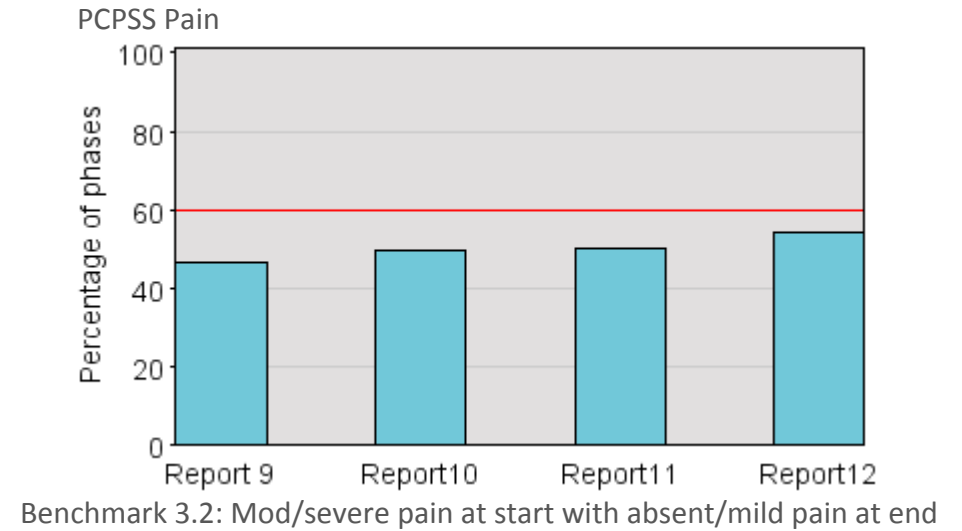
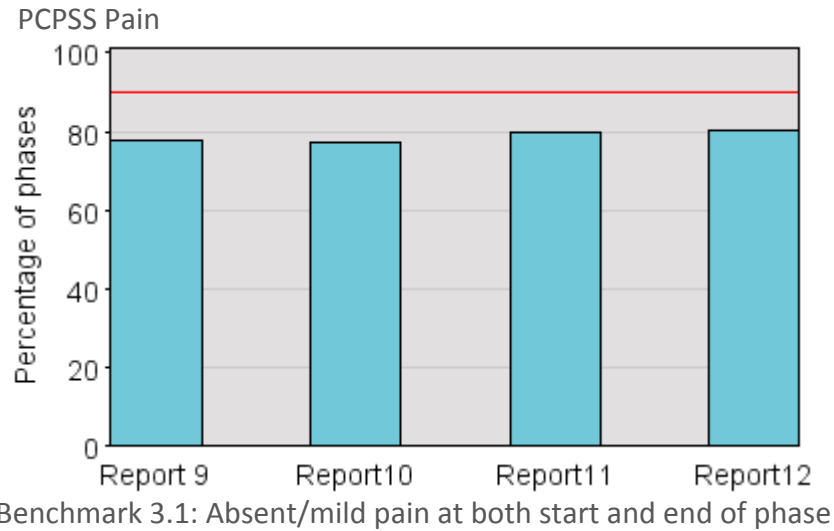
Setting		Jan-Jun 2010 (Report 9)	Jul-Dec 2010 (Report 10)	Jan-Jun 2011 (Report 11)	Jul-Dec 2011 (Report 12)
Inpatient	n	3,370	4,672	5,902	6,476
	%	79.8	78.8	81.8	82.5
Ambulatory & Community	n	1,978	2,825	2,566	2,816
	%	78.2	76.4	76.8	78.1

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

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

Setting		Jan-Jun 2010 (Report 9)	Jul-Dec 2010 (Report 10)	Jan-Jun 2011 (Report 11)	Jul-Dec 2011 (Report 12)
Inpatient	n	1,453	1,912	2,159	2,216
	%	41.3	45.7	46.4	49.6
Ambulatory & Community	n	591	846	708	787
	%	53.1	55.3	57.0	56.2

Figure 2 Change in pain benchmarks



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

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

Palliative Care Problem Severity Score	Symptom Assessment Scale
4.1. Pain	4.5. Pain
4.2. Other symptoms	4.6. Nausea
4.3. Family/carer	4.7. Breathing
4.4. Psychological/spiritual	4.8. Bowels

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. 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 Symptom Casemix-Adjusted Score (e.g. PCAS).

Figure 3 Trend in average improvement from baseline - Palliative Care Problem Severity Score (PCPSS)

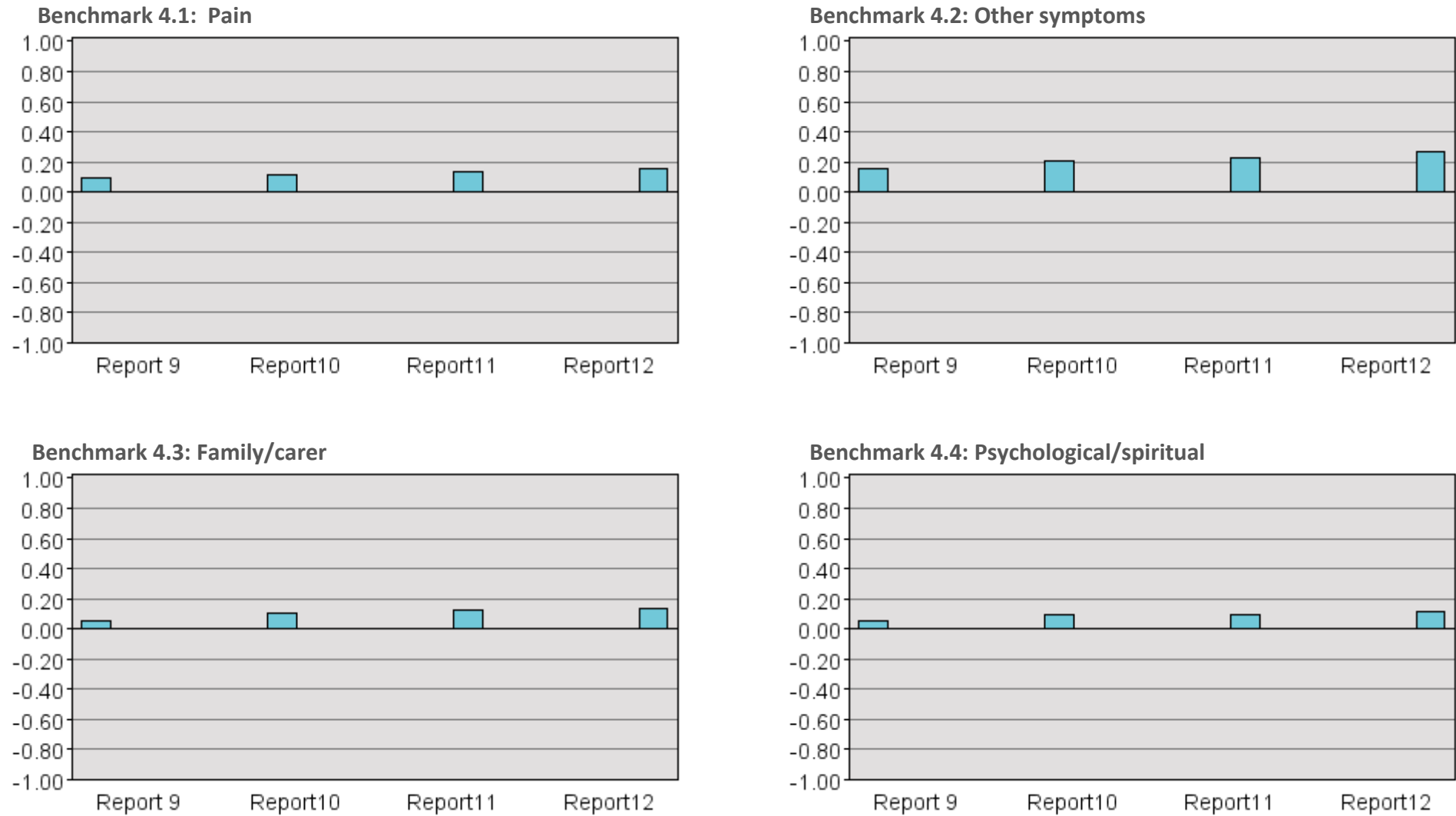
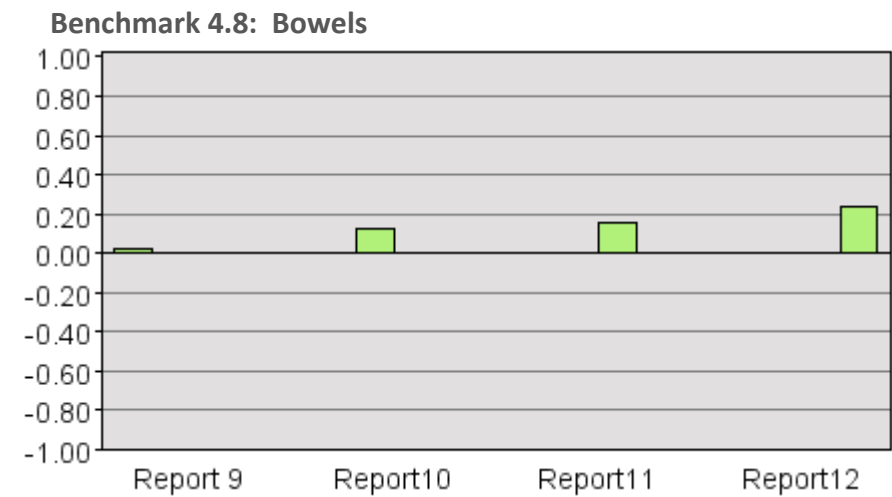
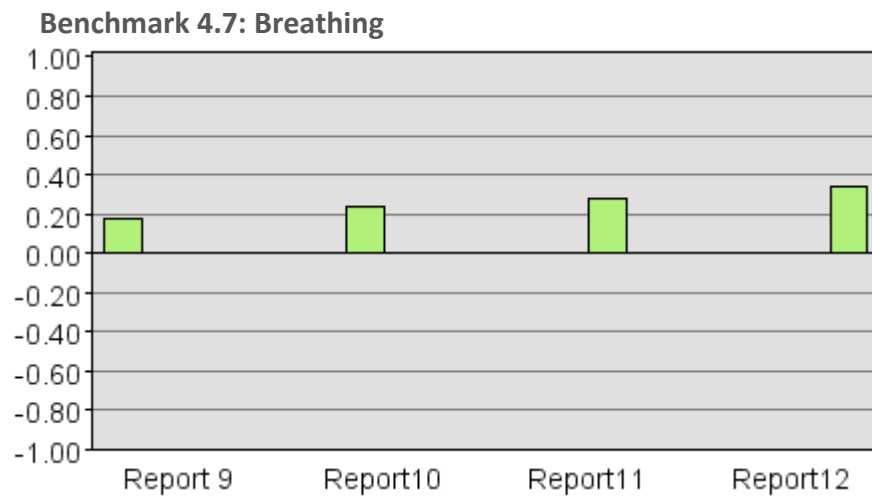
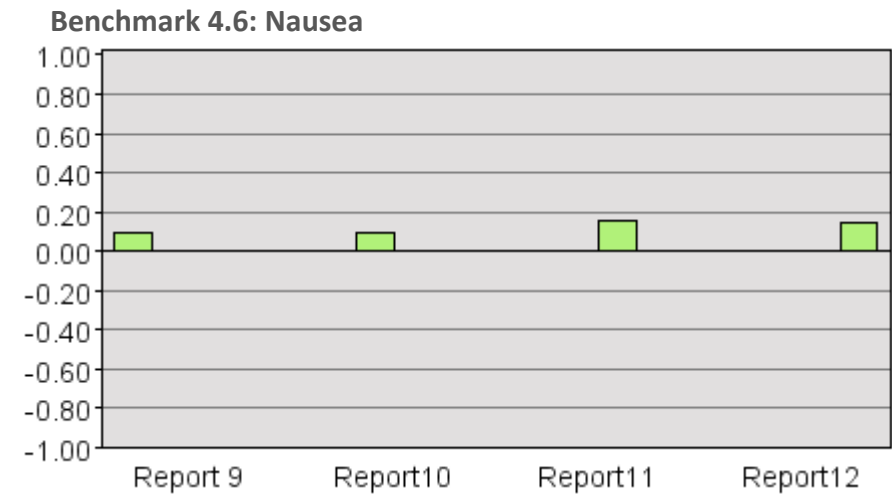
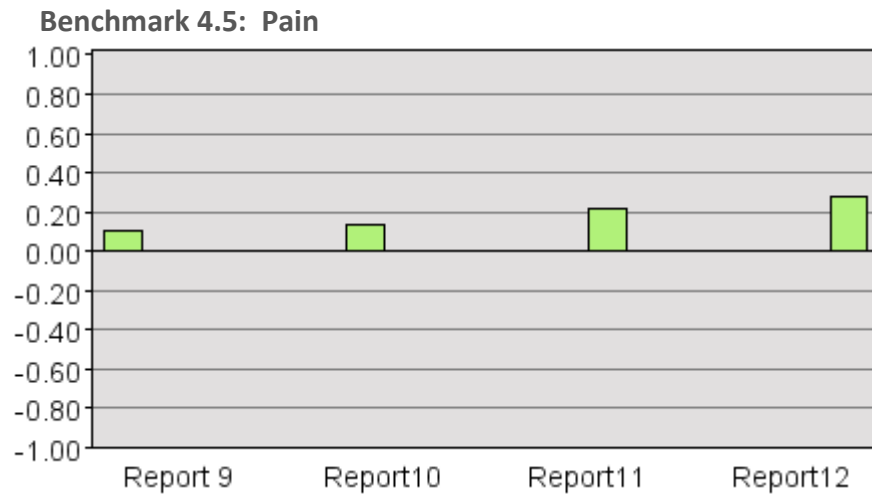


Figure 4 Trend in average improvement from baseline - Symptom Assessment Scale (SAS)



Section 3 – Descriptive analysis

Profile of palliative care patients

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

Table 9 Indigenous status

Indigenous status	n	%
Aboriginal but not Torres Strait Islander origin	133	0.9
Torres Strait Islander but not Aboriginal origin	25	0.2
Both Aboriginal and Torres Strait Islander origin	13	0.1
Neither Aboriginal nor Torres Strait Islander origin	13,749	93.0
Not stated/inadequately described	867	5.9
Total	14,787	100.0

Table 10 on the following page shows a breakdown of malignant and non-malignant diagnoses. The implementation of the Version 3.0 Data Set will include further opportunity to expand on diagnosis for both malignant and non-malignant categories.

Table 10 Primary diagnosis

Diagnosis category	Primary diagnosis	n	% of category	% of total
Malignant	Bone and soft tissue	244	2.1	1.7
	Breast	990	8.4	6.7
	CNS	194	1.6	1.3
	Colorectal	1,297	11.0	8.8
	Gynaecological	530	4.5	3.6
	Haematological	659	5.6	4.5
	Head and neck	679	5.8	4.6
	Lung	2,310	19.6	15.6
	Pancreas	650	5.5	4.4
	Prostate	780	6.6	5.3
	Skin	444	3.8	3.0
	Other GIT	929	7.9	6.3
	Other urological	485	4.1	3.3
	Other malignancy	622	5.3	4.2
	Unknown primary	335	2.8	2.3
	Malignant - not further defined	660	5.6	4.5
	All malignant		11,808	100.0
Non-malignant	Cardiovascular	530	20.7	3.6
	HIV/AIDS	2	0.1	0.0
	Kidney failure	272	10.6	1.8
	Neurological disease	540	21.1	3.7
	Respiratory failure	434	17.0	2.9
	Other non-malignancy	685	26.8	4.6
	Non-malignant - not further defined	95	3.7	0.6
	All non-malignant		2,558	100.0
Not Stated	-	421	100.0	2.8

Profile of palliative care episodes

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting, either as an inpatient or a community/ambulatory patient.

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

An episode of palliative care ends when:

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

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

Table 11 Referral source by setting

Referral source	Inpatient		Ambulatory & community	
	n	%	n	%
Public hospital - other than inpatient palliative care unit	4,927	45.6	3,367	43.4
Self, carer(s), family or friends	268	2.5	205	2.6
Private hospital - other than inpatient palliative care unit	761	7.0	1,262	16.3
Public palliative care inpatient unit/hospice	363	3.4	318	4.1
Private palliative care inpatient unit/hospice	93	0.9	135	1.7
General medical practitioner	555	5.1	1,046	13.5
Specialist medical practitioner	382	3.5	459	5.9
Community-based palliative care agency	2,186	20.2	98	1.3
Community-based service	405	3.7	168	2.2
Residential aged care facility	81	0.7	232	3.0
Other	104	1.0	149	1.9
Not stated/inadequately described	679	6.3	312	4.0
Total	10,804	100.0	7,751	100.0

Table 12 Place of death – ambulatory and community settings

Place of death	n	%
Private residence	1,152	54.8
Residential aged care setting	360	17.1
Other location*	390	18.5
Not stated/inadequately described	201	9.6
Total	2,103	100.0

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

Table 13 gives a summary of the length of episode for patients.

Table 13 Length of episode summary by setting

Length of episode	Inpatient	Ambulatory & community
Average length of episode	11.9	33.7
Median length of episode	7.0	21.0

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

Table 14 details the length of episode in days. Comparison of these numbers and percentages to the national figures gives the service an opportunity to review themselves against other palliative care services nationally.

Table 14 Breakdown of length of episode by setting

Length of episode	Inpatient		Ambulatory & community	
	n	%	n	%
Same day	454	4.3	629	8.7
1-2 days	1,980	18.9	545	7.5
3-4 days	1,382	13.2	419	5.8
5-7 days	1,670	15.9	563	7.8
8-14 days	2,304	22.0	912	12.6
15-21 days	1,104	10.5	590	8.2
22-30 days	671	6.4	630	8.7
31-60 days	691	6.6	1,163	16.1
61-90 days	139	1.3	621	8.6
Greater than 90 days	80	0.8	1,152	15.9
Total	10,475	100.0	7,224	100.0

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

Profile of palliative care phases

Palliative care phases describe the stages of the patient's illness. Palliative care phases are not sequential and a patient may move back and forth between them. Palliative care phases provide a clinical indication of the level of care required. There are five palliative care phases: stable, unstable, deteriorating, terminal and bereaved.

When looking at the profile of palliative care phases, individual services can compare their results to the national average. A difference in these results may be reflective of the model of care employed.

Table 15 Number of phases by phase type and setting

Phase type	Inpatient		Ambulatory & community	
	n	%	n	%
Stable	7,181	26.5	5,246	38.1
Unstable	7,314	27.0	2,303	16.7
Deteriorating	7,088	26.1	4,864	35.4
Terminal	4,234	15.6	1,208	8.8
Bereaved	1,318	4.9	134	1.0
All phases	27,135	100.0	13,755	100.0

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

Phase type	Inpatient	Ambulatory & community
Stable	6.9	21.8
Unstable	3.6	8.6
Deteriorating	5.5	15.6
Terminal	2.2	2.8
Bereaved	1.2	2.3

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

Table 17 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 the patient dies. For those stable phases that ended because the patient was deemed to be in another phase (phase change), Figure 5 and Figure 6 summarise the phase that the patient moved into, for inpatient and ambulatory/community settings respectively. This movement from one phase to another is referred to as phase progression. The phase progression information is derived by PCOC. The 'Unknown' category has been included to account for situations where subsequent phase records have not been submitted to PCOC, meaning the phase progression cannot be determined.

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

Table 17 How stable phases end – by setting

Phase end reason	Inpatient		Ambulatory & community	
	n	%	n	%
Phase change (see figures below)	4,121	57.4	3,482	66.4
Discharge/case closure	2,903	40.4	1,384	26.4
Died	118	1.6	332	6.3
Bereavement phase end	7	0.1	2	0.0
Not stated/inadequately described	32	0.4	46	0.9
Total	7,181	100.0	5,246	100.0

Figure 5 Stable phase progression – inpatient setting

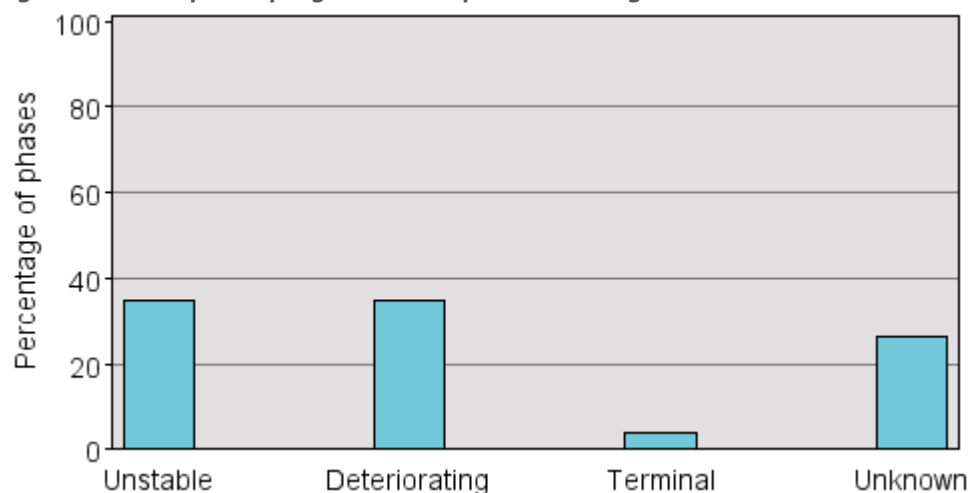


Figure 6 Stable phase progression – ambulatory & community settings

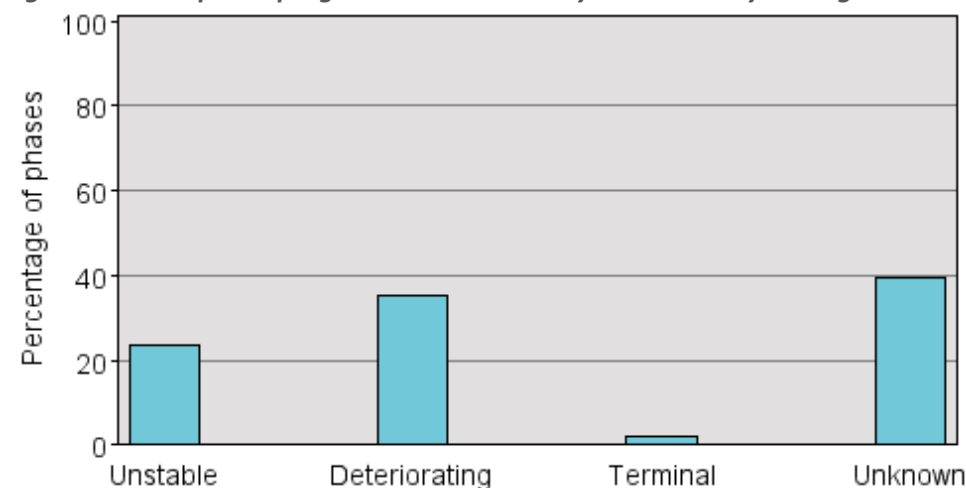


Table 18 How unstable phases end – by setting

Phase end reason	Inpatient		Ambulatory & community	
	n	%	n	%
Phase change (see figures below)	6,389	87.4	1,553	67.4
Discharge/case closure	495	6.8	606	26.3
Died	347	4.7	121	5.3
Bereavement phase end	11	0.2	3	0.1
Not stated/inadequately described	72	1.0	20	0.9
Total	7,314	100.0	2,303	100.0

Figure 7 Unstable phase progression – inpatient setting

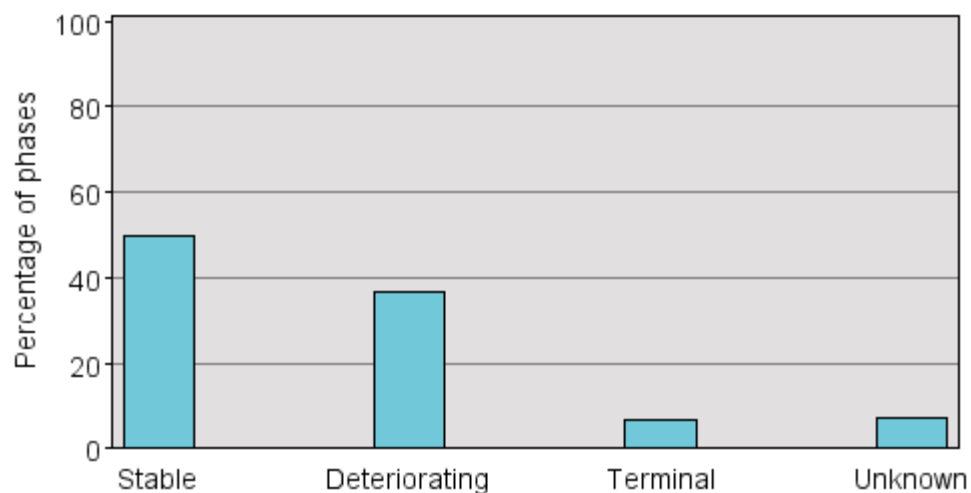


Figure 8 Unstable phase progression – ambulatory & community settings

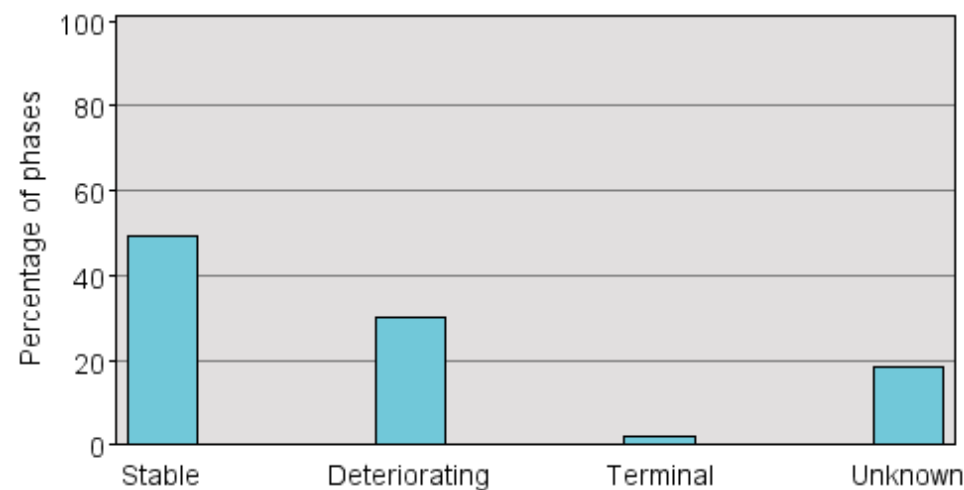


Table 19 How deteriorating phases end – by setting

Phase end reason	Inpatient		Ambulatory & community	
	n	%	n	%
Phase change (see figures below)	4,817	68.0	2,699	55.5
Discharge/case closure	1,040	14.7	1,346	27.7
Died	1,183	16.7	780	16.0
Bereavement phase end	37	0.5	5	0.1
Not stated/inadequately described	11	0.2	34	0.7
Total	7,088	100.0	4,864	100.0

Figure 9 Deteriorating phase progression – inpatient setting

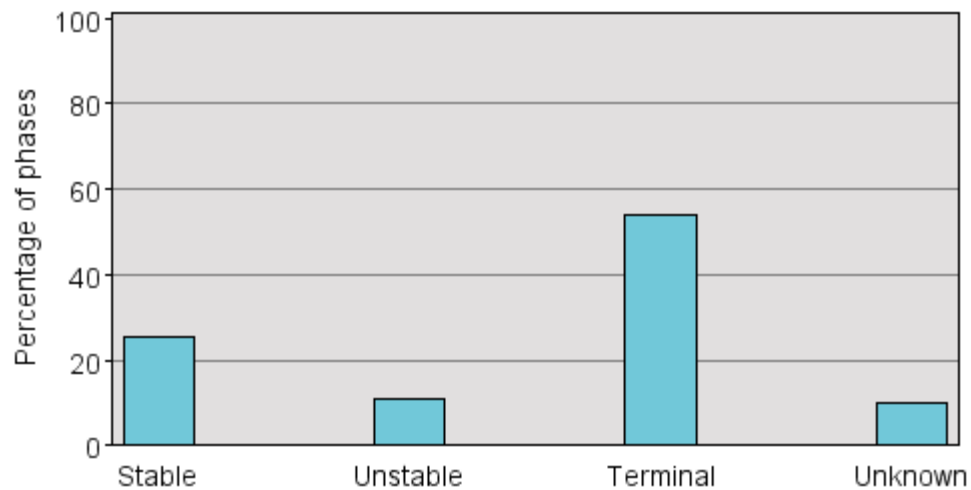


Figure 10 Deteriorating phase progression – ambulatory & community settings

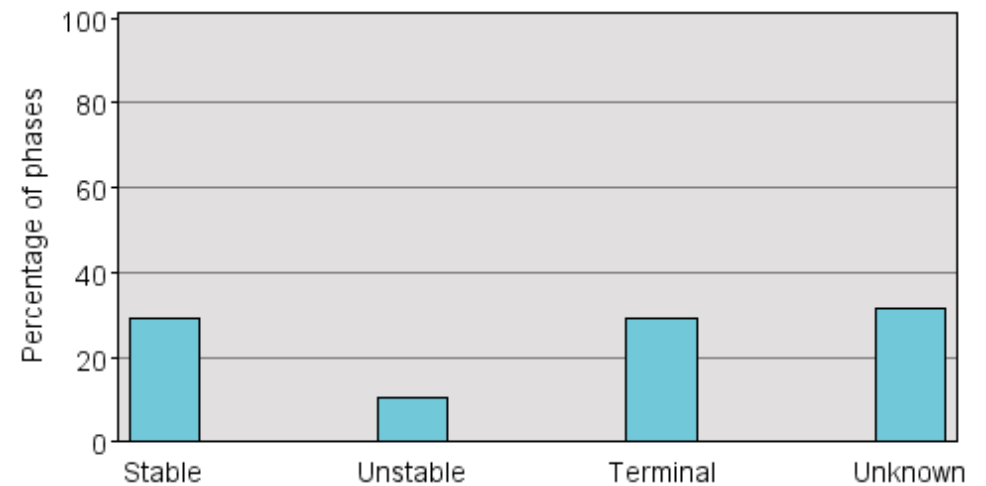


Table 20 How terminal phases end – by setting

Phase end reason	Inpatient		Ambulatory & community	
	n	%	n	%
Phase change (see figures below)	489	11.5	275	22.8
Discharge/case closure	93	2.2	88	7.3
Died	3,437	81.2	837	69.3
Bereavement phase end	212	5.0	4	0.3
Not stated/inadequately described	3	0.1	4	0.3
Total	4,234	100.0	1,208	100.0

Figure 11 Terminal phase progression – inpatient setting

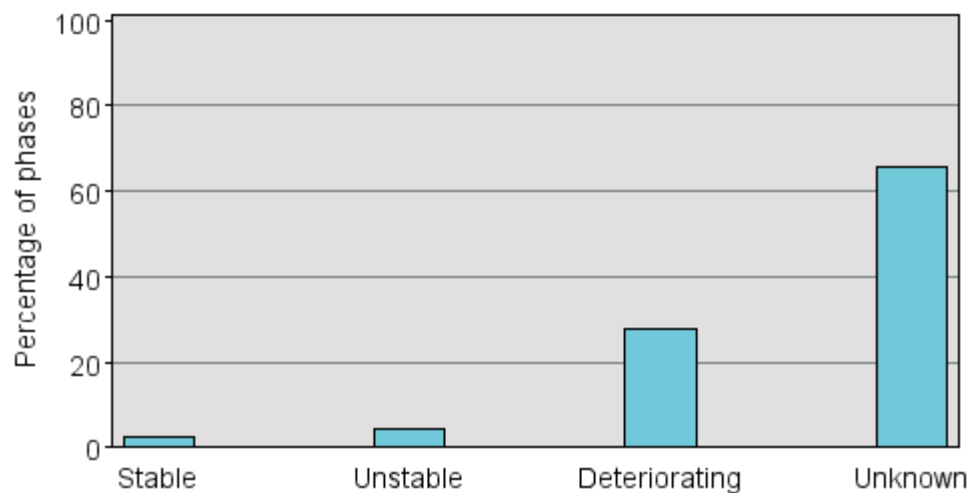


Figure 12 Terminal phase progression – ambulatory & community settings

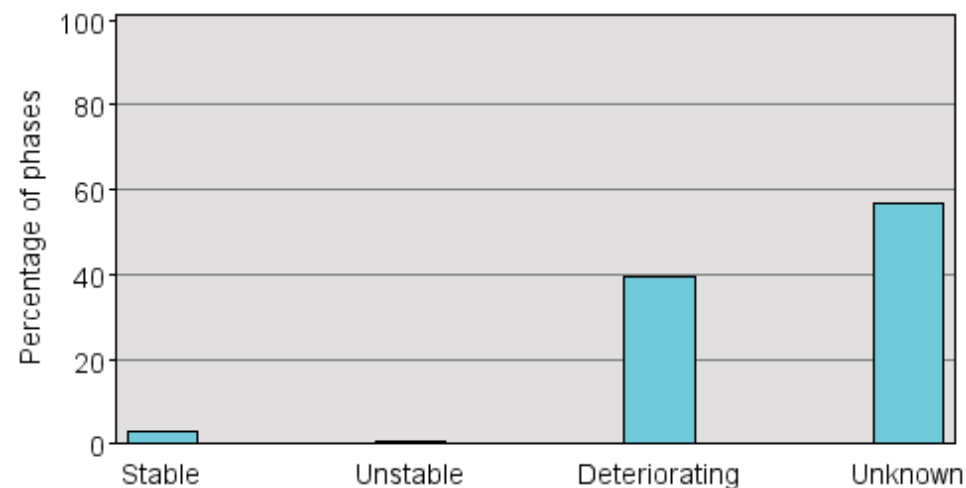


Table 21 Profile of PC Problem Severity Scores at beginning of phase by phase type (percentages) – inpatient setting

Phase type	Problem severity	Absent	Mild	Moderate	Severe	Total
Stable	Pain	43.0	38.3	14.8	4.0	100
	Other symptoms	21.1	43.7	26.4	8.9	100
	Psychological/spiritual	24.5	46.7	21.5	7.3	100
	Family/carer	34.1	39.7	18.7	7.5	100
Unstable	Pain	26.9	28.7	28.7	15.6	100
	Other symptoms	8.7	27.4	40.2	23.8	100
	Psychological/spiritual	14.3	38.3	32.7	14.7	100
	Family/carer	21.1	34.0	29.5	15.3	100
Deteriorating	Pain	34.9	33.3	22.4	9.4	100
	Other symptoms	11.7	30.4	36.3	21.6	100
	Psychological/spiritual	18.8	39.9	28.3	13.0	100
	Family/carer	22.3	33.1	28.5	16.1	100
Terminal	Pain	39.4	32.1	18.5	10.1	100
	Other symptoms	24.2	26.3	27.4	22.1	100
	Psychological/spiritual	38.0	27.8	20.4	13.7	100
	Family/carer	15.4	26.5	31.9	26.1	100

Table 22 Profile of PC Problem Severity Scores at beginning of phase by phase type (percentages) – ambulatory and community settings

Phase type	Problem severity	Absent	Mild	Moderate	Severe	Total
Stable	Pain	37.1	47.6	13.6	1.8	100
	Other symptoms	16.1	54.0	26.0	3.9	100
	Psychological/spiritual	23.0	53.6	20.0	3.3	100
	Family/carer	24.0	45.9	24.9	5.1	100
Unstable	Pain	19.5	31.3	31.6	17.6	100
	Other symptoms	5.9	24.6	45.8	23.7	100
	Psychological/spiritual	11.8	36.0	35.2	17.0	100
	Family/carer	14.8	25.4	39.1	20.7	100
Deteriorating	Pain	26.6	42.0	26.0	5.4	100
	Other symptoms	5.9	31.4	48.8	13.9	100
	Psychological/spiritual	14.6	46.2	31.0	8.2	100
	Family/carer	11.3	31.9	43.3	13.5	100
Terminal	Pain	35.3	38.2	17.9	8.6	100
	Other symptoms	19.5	31.3	30.4	18.9	100
	Psychological/spiritual	40.2	29.8	20.9	9.1	100
	Family/carer	8.0	26.6	41.6	23.9	100

The Australia-modified Karnofsky Performance Scale (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 23 Australia-modified Karnofsky Performance Scale (AKPS) at phase start by setting

AKPS assessment	Inpatient		Ambulatory & community	
	n	%	n	%
10 - Comatose or barely rousable	2,416	9.4	573	4.2
20 - Totally bedfast and requiring extensive nursing care	4,899	19.1	1,200	8.9
30 - Almost completely bedfast	2,920	11.4	863	6.4
40 - In bed more than 50% of the time	4,130	16.1	1,539	11.4
50 - Requires considerable assistance	5,102	19.9	3,164	23.4
60 - Requires occasional assistance	3,341	13.0	3,114	23.0
70 - Cares for self	1,048	4.1	1,864	13.8
80 - Normal activity with effort	391	1.5	680	5.0
90 - Able to carry on normal activity; minor signs or symptoms	113	0.4	199	1.5
100 - Normal; no complaints; no evidence of disease	4	0.0	15	0.1
Not stated/inadequately described	1,333	5.2	334	2.5
Total	25,697	100.0	13,545	100.0

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 RUG-ADL should be assessed on admission, at phase change and at episode end.

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

Figure 13 Total RUG-ADL at beginning of phase – inpatient setting

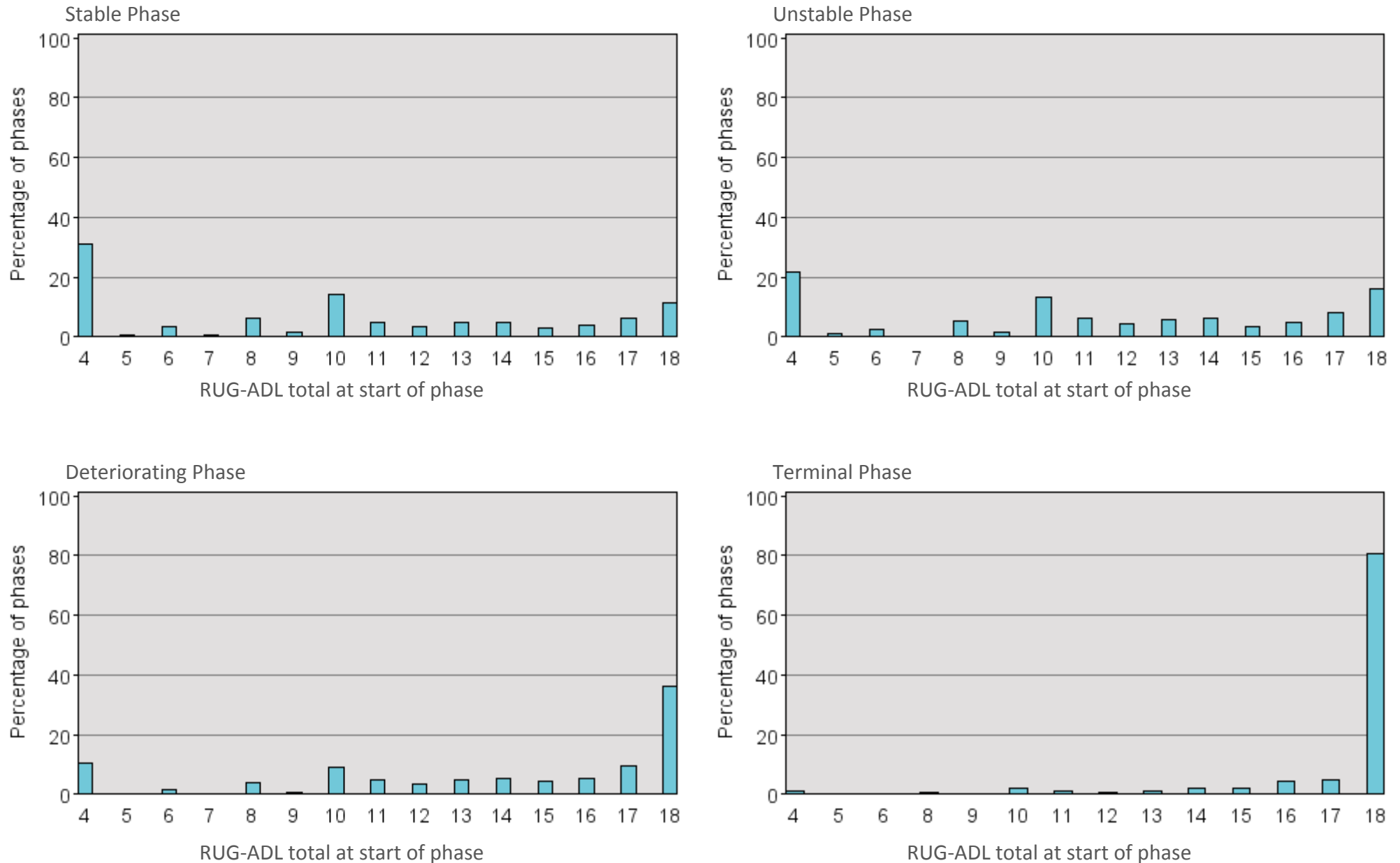
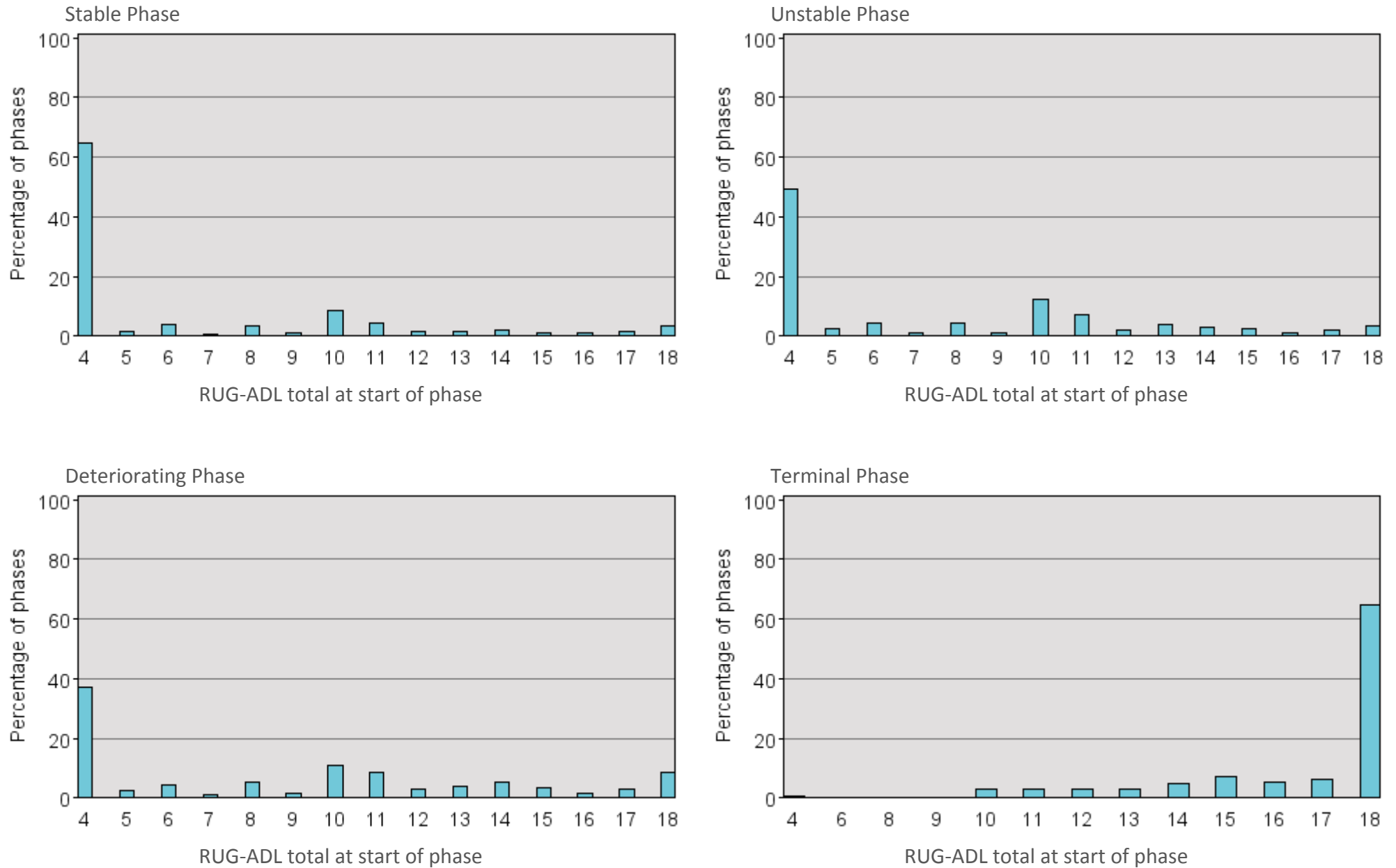


Figure 14 Total RUG-ADL at beginning of phase – ambulatory & community settings



Appendix A – Summary of data included in this report

A1 – Data summary

This report includes data from a total of 102 services. During the reporting period, data were provided for a total of 14,787 patients who between them had 18,555 episodes of care and 40,890 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Section A3 contains a more detailed explanation of this process). Table 24 shows the number of patients, episodes and phases included in this report.

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

Table 24 *Number and percentage of patients, episodes and phases by setting*

	Inpatient	Ambulatory & community	Total
Number of patients*	9,247	6,405	14,787
Number of episodes	10,804	7,751	18,555
Number of phases	27,135	13,755	40,890
Percentage of patients*	62.5	43.3	100
Percentage of episodes	58.2	41.8	100
Percentage of phases	66.4	33.6	100
Average number of phases per episode**	2.4	1.7	2.1

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

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

A2 – Data item completion

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

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

Table 25 Item completion- patient level

Data item	% complete
Date of birth	100.0
Sex	99.9
Indigenous status	94.1
Country of birth	93.0
Main language	90.6
Primary diagnosis	97.2

Table 26 Item completion- episode level

Data item	% complete
Date of first contact/assessment	95.6
Referral date	92.3
Referral source	94.7
Episode start date	100.0
Mode of episode start	99.2
Accommodation at episode start	97.2
Episode end date	99.6
Level of support at episode start	81.9
Mode of episode end	98.2
Accommodation at episode end	84.8
Level of support at episode end	96.7
Place of death	90.4

Table 27 Item completion - phase level

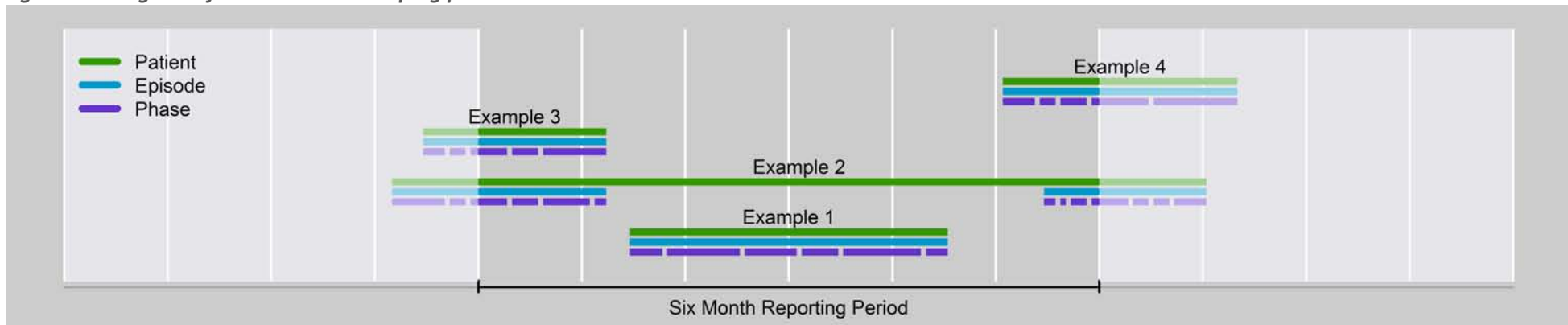
Data item	Sub-Category (where applicable)	% complete
Phase start date	-	100.0
Phase	-	100.0
RUG-ADL at phase start	Bed Mobility	95.2
	Toileting	95.1
	Transfers	94.9
	Eating	94.4
PC Problem Severity at phase start	Pain	81.5
	Other symptoms	85.3
	Psychological/Spiritual	92.5
	Family/carer	91.7
Symptom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

A3 – Data scoping methodology

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be 'in scope' and would be included in the report. The episode and patient records associated with these phases are also deemed to be 'in scope' and hence would also be included in the report.

Figure 15 below displays four examples to help visualize this process.

Figure 15 Diagram of the PCOC data scoping process



In Example 1, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

In Example 2, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). For the phases relating to the second episode, only the first three end within the period, so only these would be included in the report. Both of the episode records and the patient record would also be reported on.

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

In Example 4, the patient again has one episode and five phases. This time, only the first three phases will be included in the report. Again, the episode and patient records would be included in the report on as they have associated phases ending within the period.

Acknowledgements

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- Members of the Management Advisory Board of PCOC
- The many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible
- The PCOC National staff at the Australian Health Services Research Institute, University of Wollongong, for the collation, analysis and reporting of the data
- The PCOC Quality Improvement Facilitators for working closely with services to support the data collection and data quality improvement processes
- The Australian Government Department of Health and Ageing for funding this initiative

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

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