

# Outcomes in Palliative Care

## Report 11 January – June 2011



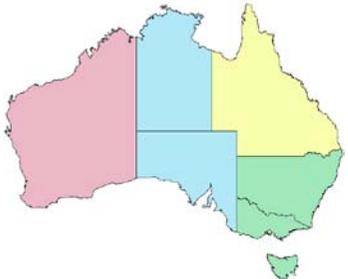
## Palliative Care in Australia



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

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

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

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

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

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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 eleventh PCOC report, data submitted for the January – June 2011 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

This report is broken into three sections:

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

Section 2 presents additional analysis for each of the four benchmark measures

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

The national figures included in this report reflect the 100 palliative care services who submitted data for the January – June 2011 period. A full list of these services can be found at [www.pcoc.org.au](http://www.pcoc.org.au)

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

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

*Outcome Measurement in Palliative Care – The Essentials*, [www.prismafp7.eu](http://www.prismafp7.eu)

## Section 1 – Australia at a Glance

Table 1 Summary of benchmark measures 1-3

Measure	Description	Benchmark	Overnight admitted		Not admitted overnight	
			Score	Benchmark Met?	Score	Benchmark Met?
1. Time from referral to contact	Patients contacted on same or following day	90%	89.6	No	52.1	No
2. Time in unstable phase	Patients unstable less than 7 days - first phase	85%	79.8	No	59.6	No
	Patients unstable less than 7 days - Not first phase	90%	86.4	No	67.8	No
	Median time in unstable phase	2 days or less	3 days	No	3 days	No
3. Change in pain PC Problem Severity Score (PCPSS)	Patients with absent/mild pain at phase start remaining absent/mild at phase end	90%	82.1	No	75.1	No
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	48.0	No	57.3	No
Symptom Assessment Score (SAS)	Patients with absent/mild pain at phase start remaining absent/mild at phase end	90%	81.8	No	76.8	No
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	46.4	No	57.0	No

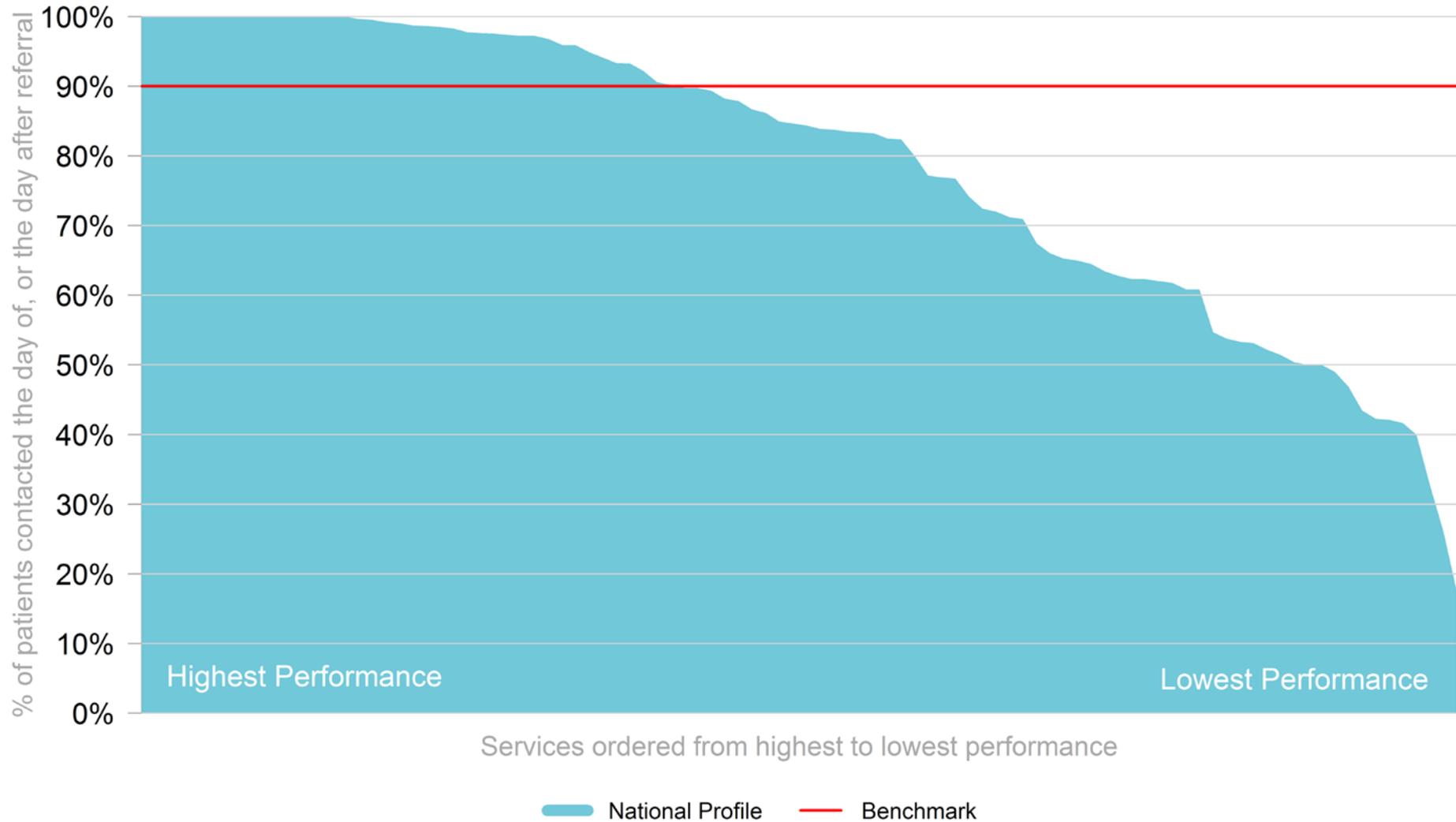
Table 2 Summary of benchmark measure 4: Change in symptoms relative to the national average (X-CAS)

Clinical Tool	Symptom	Benchmark	Score	Benchmark met?
PC PSS	Pain	0 or above	0.13	Yes
	Other symptoms	0 or above	0.23	Yes
	Family/carer	0 or above	0.12	Yes
	Psychological/spiritual	0 or above	0.09	Yes
SAS	Pain	0 or above	0.21	Yes
	Nausea	0 or above	0.15	Yes
	Breathing	0 or above	0.28	Yes
	Bowels	0 or above	0.16	Yes

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

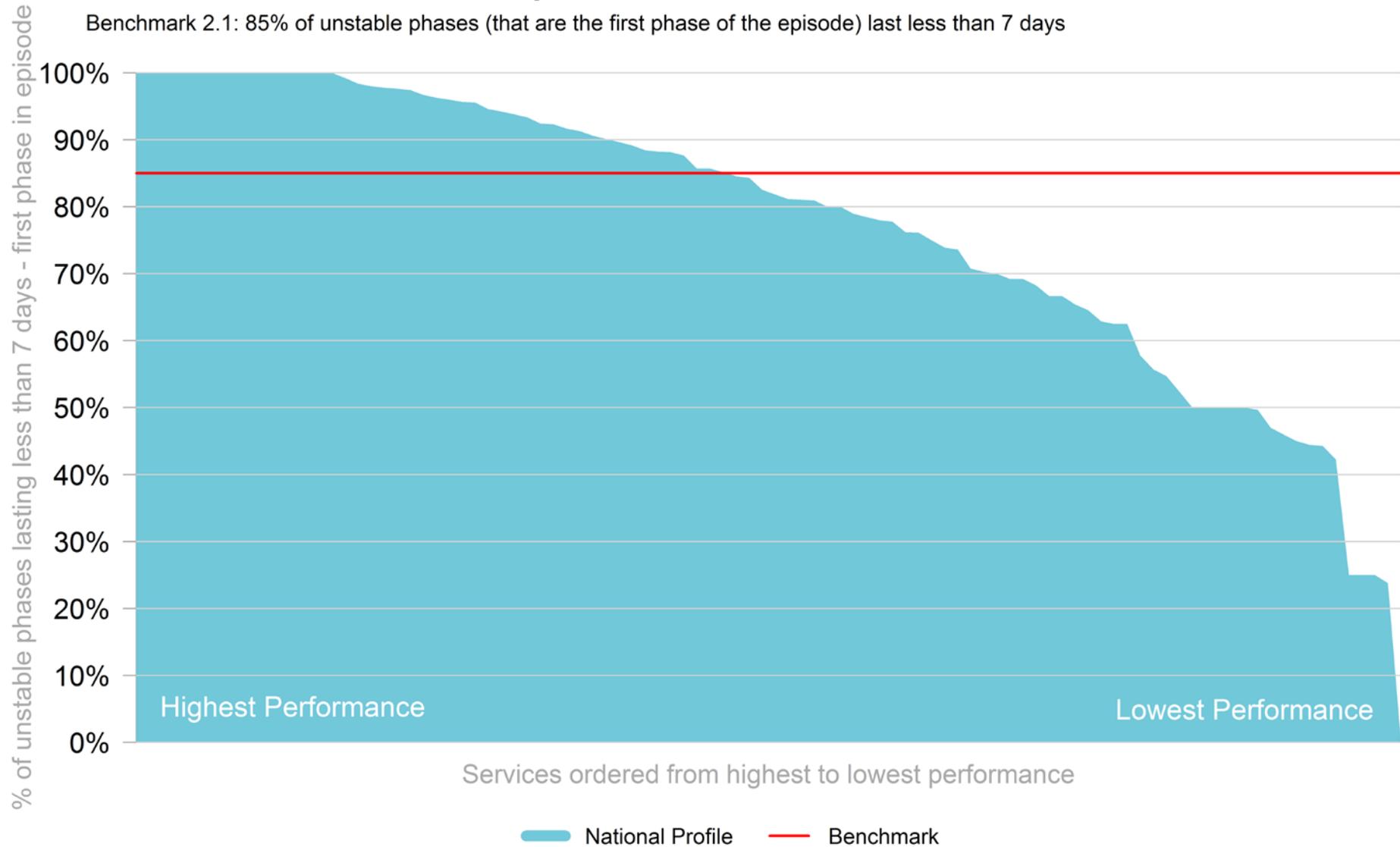
## Measure 1: Time from referral to first contact

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



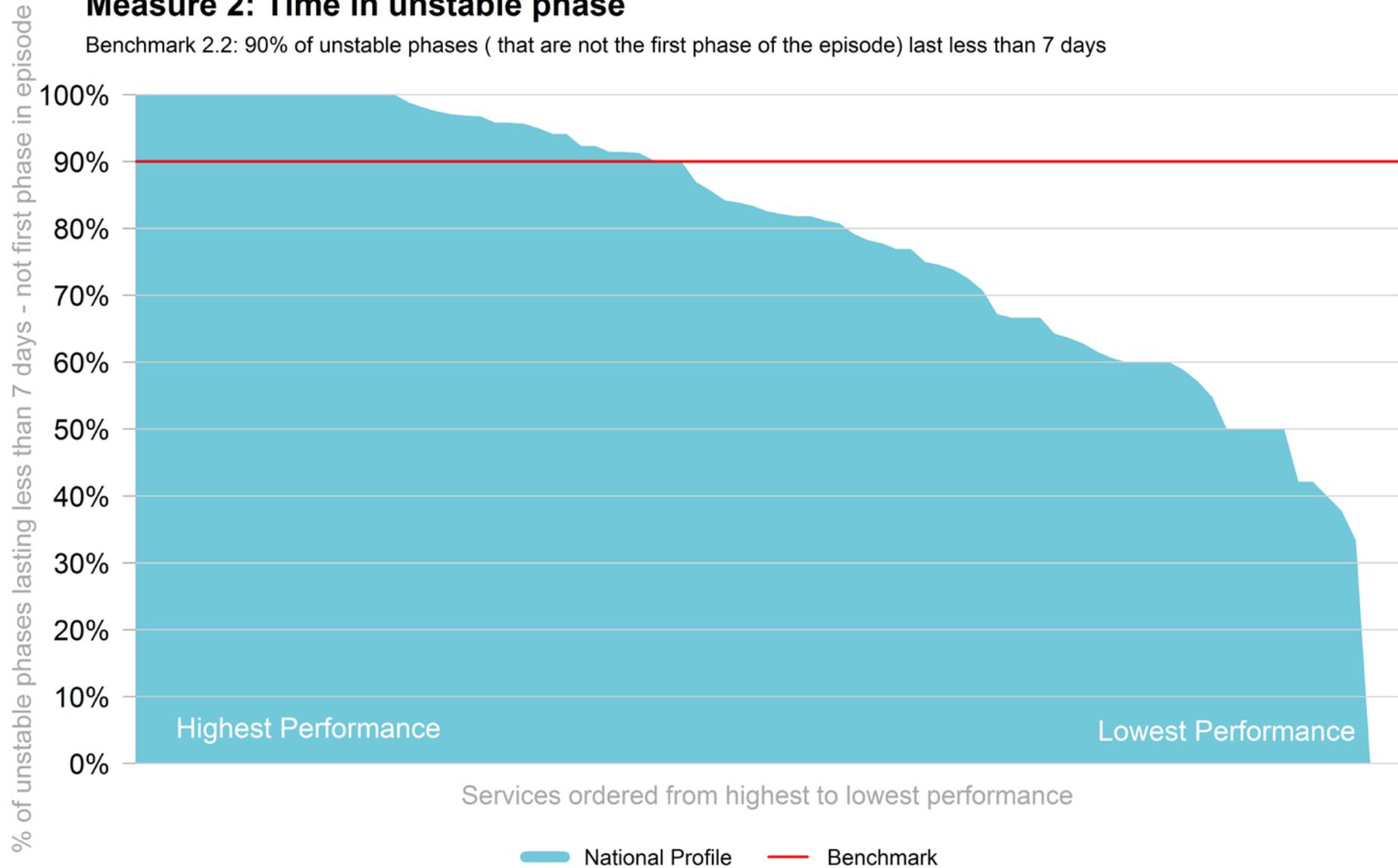
## Measure 2: Time in unstable phase

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



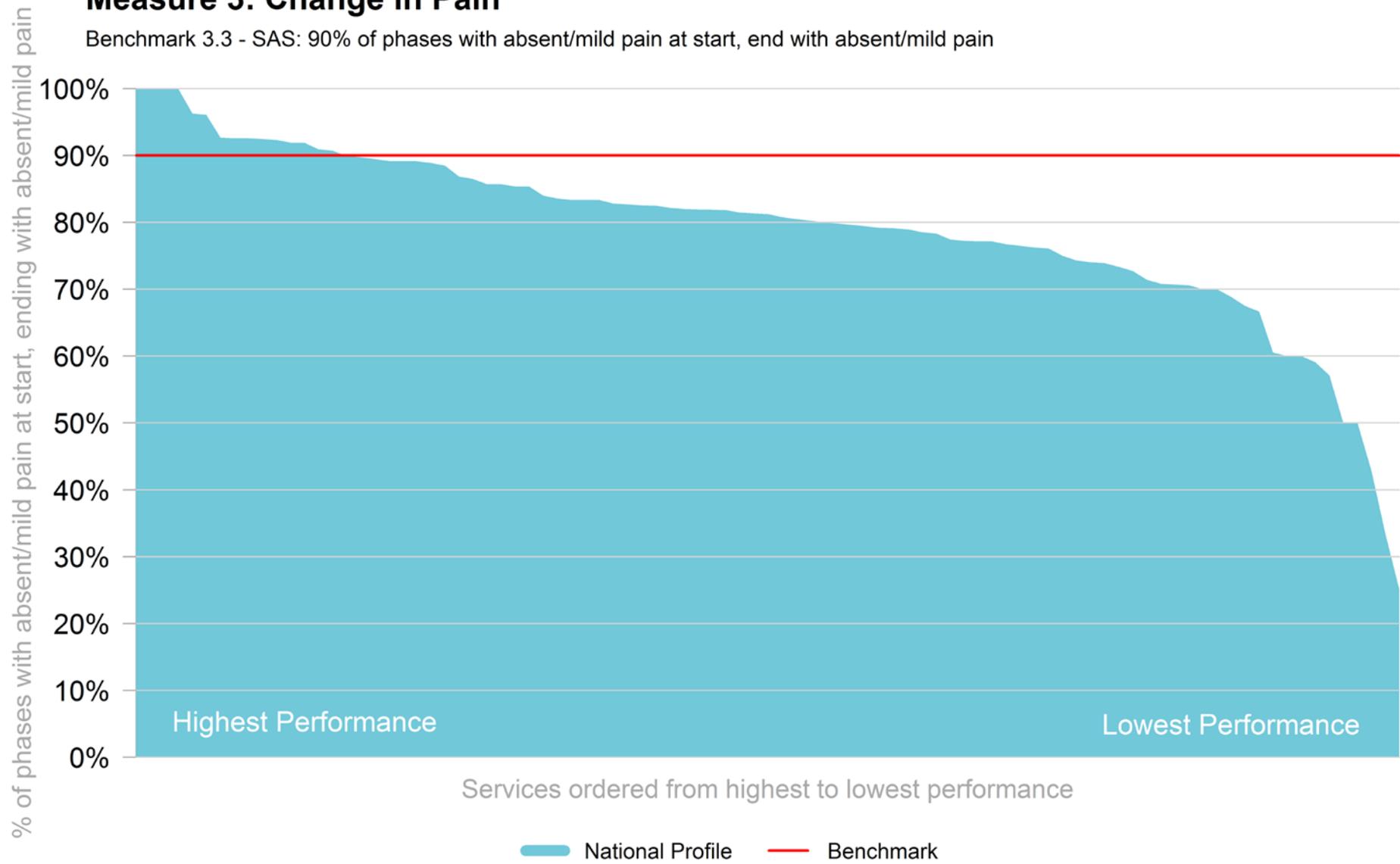
## Measure 2: Time in unstable phase

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



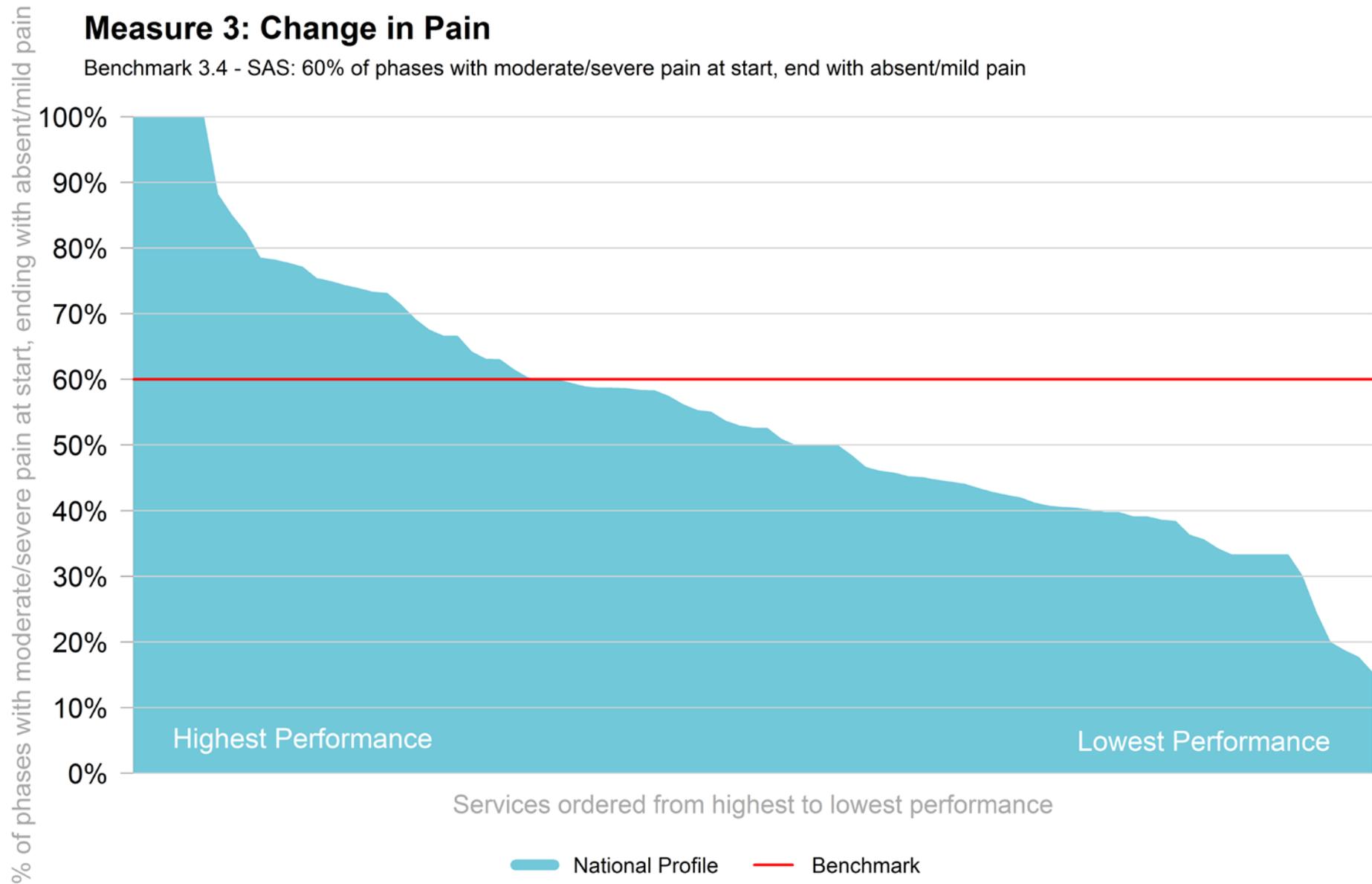
### Measure 3: Change in Pain

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



### Measure 3: Change in Pain

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



## Section 2 – Benchmark Analysis

### Measure 1 - Time from referral to first contact

Time from referral to first contact was selected as a benchmark measure as it reports responsiveness of palliative care services to patient needs. This benchmark was set acknowledging there is wide variation in delivery of palliative care service provision across the country. It was agreed at the 2008 national benchmarking workshops that access to palliative care service should be based on patient need rather than service availability. In other words services operating a 5 day week (Monday-Friday) are benchmarked against services operating 7 days a week.

Table 3 and Figure 1 below present descriptive data on the first benchmark measure. This measure is the percentage of patients seen either on the day of, or the day following the referral. The benchmark is **90%**.

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

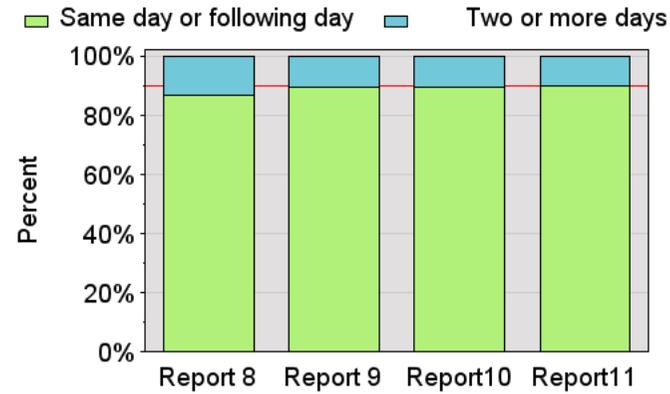
*Table 3 Time from referral to first contact by episode type*

Time (in days)	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Same day or following day	9127	89.6	3058	52.1
2-7 days	878	8.6	1856	31.6
8-14 days	110	1.1	560	9.5
Greater than 14 days	74	0.7	395	6.7
Average	1.3	na	2.9	na
Median	1	na	1	na

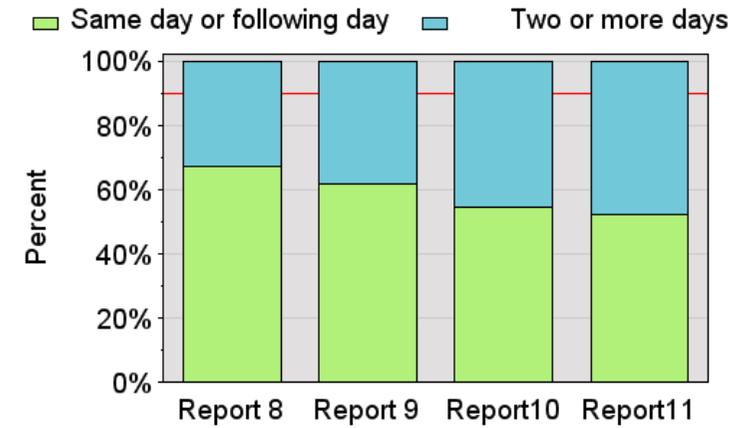
Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact or time from first contact to episode start was greater than 7 days were considered to be outliers and were assumed to equal 7 days for the purpose of calculating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

Figure 1 Time from referral to first contact

Overnight admitted episodes for all services



Not admitted overnight episodes for all services



## Measure 2 - Time in unstable phase

The unstable phase, by nature of its definition, alerts clinical staff to the need for urgent or emergency intervention. This phase shows the effectiveness of the intervention(s) implemented for a specific new or exacerbation of existing problem. Those patients determined as being in the unstable phase require intense review for a short period of time. This period of time was considered less than 7 days – that is, any patient who is deemed unstable should have their problem(s) managed and under control within this period of time regardless of the setting of care.

The following table presents descriptive data on the second benchmark measure. The first part of this measure is the percentage of patients remaining unstable for less than 7 days and is split by occurrence of unstable phase. The benchmark for patients in their first phase is **85%** and for patients in a subsequent phase is **90%**. The second part of this measure is the median time spent in the unstable phase and the benchmark is **2 days or less**.

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

Episode type	Occurrence of unstable phase	Number	Percent unstable for < 7 days	Median days in unstable phase
		All Services	All Services	All Services
Overnight admitted	First phase	5088	79.8	3
	Subsequent phase	2461	86.4	2
	<i>Total</i>	<i>7549</i>	<i>82.0</i>	<i>3</i>
Not admitted overnight	First phase	847	59.6	4
	Subsequent phase	1146	67.8	3
	<i>Total</i>	<i>1993</i>	<i>64.3</i>	<i>3</i>

## Measure 3 - Change in pain

The management of patients with pain is acknowledged as core business for palliative care services. Hence measuring the distress from pain was agreed at the 2008 National Benchmarking workshops as an important outcome for palliative care services. Two of the five assessment tools used in PCOC are used to measure pain, the Symptom Assessment Score (SAS) is a patient rated tool and the palliative Care Problem Severity Score (PCPSS) is a clinician rated tool. At the 2008 benchmarking workshops it was agreed that the outcomes for pain are at 2 levels: Patients with absent/mild pain at phase start and patients with moderate/severe pain at phase start.

### Change in pain - PC Problem Severity Score (PCPSS)

The following two tables present data on the third benchmark measure in relation to pain PCPSS. The first measure is the percentage of patients with absent/mild pain at phase start remaining with absent/mild pain at phase end and the benchmark is **90%**. The second measure is the percentage of patients with moderate/severe pain at phase start with absent/mild pain at phase end and the benchmark is **60%**. Note that only phases with a valid pain score at both the start and the end of the phase are included in the following analysis.

*Table 5 Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase*

Episode type	All Services				
		Report 8	Report 9	Report 10	Report 11
Overnight admitted	Number	2166	2860	3969	5153
	%	75.9	79.0	79.0	82.1
Not admitted overnight	Number	1336	1441	2415	2176
	%	77.1	75.8	74.9	75.1

*Table 6 Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase*

Episode type	All Services				
		Report 8	Report 9	Report 10	Report 11
Overnight admitted	Number	1031	1257	1655	1858
	%	40.8	44.0	46.6	48.0
Not admitted overnight	Number	382	485	806	646
	%	54.0	55.7	57.5	57.3

## Change in pain - Symptom Assessment Score (SAS)

The following two tables present data on the third benchmark measure in relation to pain SAS. The first measure is the percentage of patients who commenced with absent/mild pain at phase start and have absent/mild pain at phase end and the benchmark is **90%**. The second measure is the percentage of patients with moderate/severe pain at phase start with absent/mild pain at phase end and the benchmark is **60%**. Note that only phases with a valid pain score at both the start and the end of the phase are included in the following analysis.

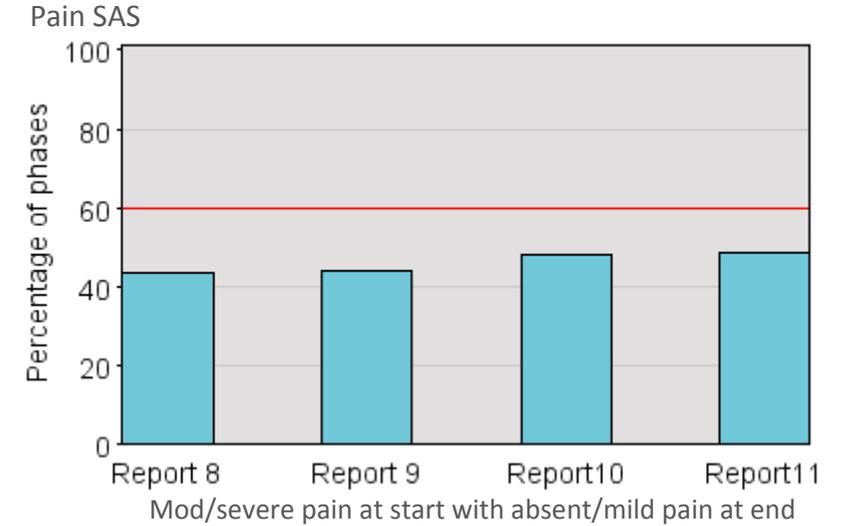
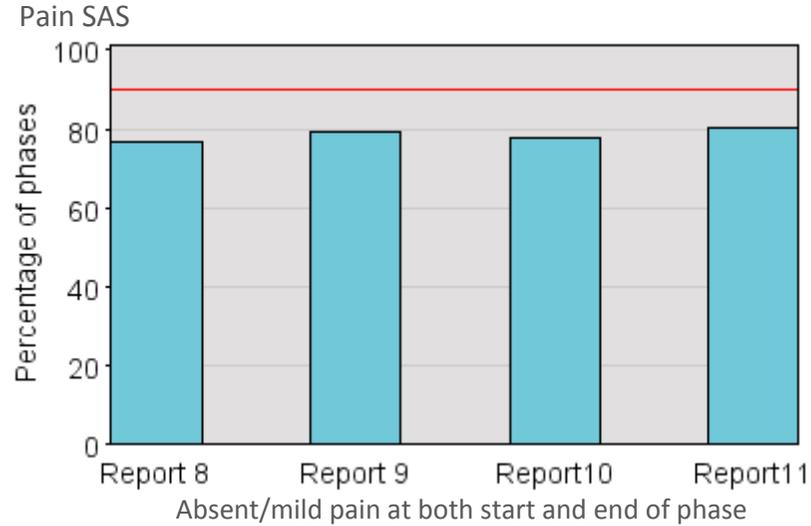
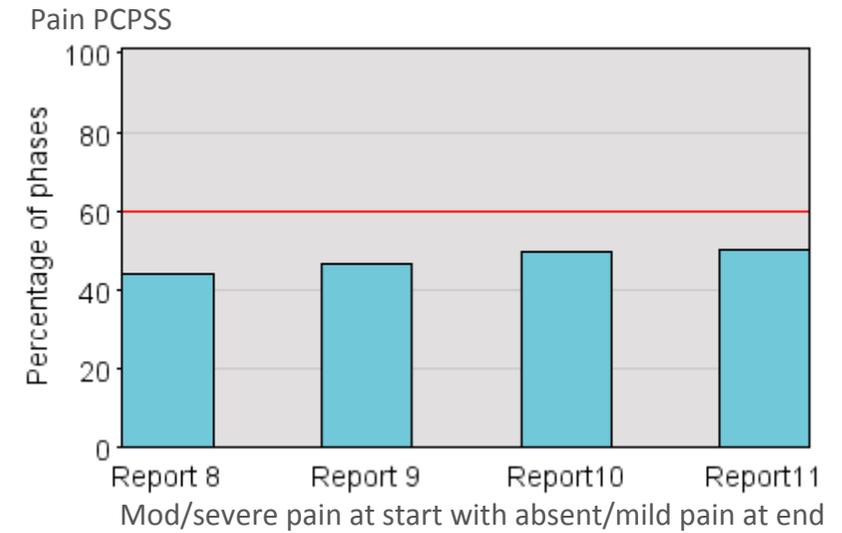
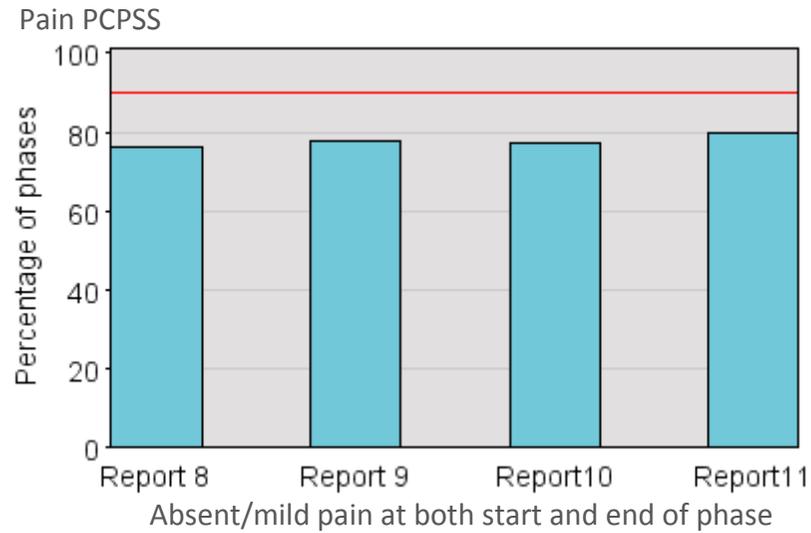
*Table 7 Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase*

Episode type	All Services				
		Report 8	Report 9	Report 10	Report 11
Overnight admitted	Number	2950	3370	4672	5902
	%	76.7	79.8	78.8	81.8
Not admitted overnight	Number	2008	1978	2825	2566
	%	76.8	78.2	76.4	76.8

*Table 8 Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase*

Episode type	All Services				
		Report 8	Report 9	Report 10	Report 11
Overnight admitted	Number	1339	1453	1912	2159
	%	41.0	41.3	45.7	46.4
Not admitted overnight	Number	598	591	846	708
	%	50.1	53.1	55.3	57.0

Figure 2 Change in pain benchmark measures - all phases



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

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

1. PCPSS Pain	2. PCPSS Other symptoms	3. PCPSS Psychological/spiritual	4. PCPSS Family/carer
5. SAS Pain	6. SAS Nausea	7. SAS Bowels	8. SAS Breathing

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

### How to interpret X-CAS:

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

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

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

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

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

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

Figure 3 PCPSS mean change adjusted for phase and symptom score at start of phase

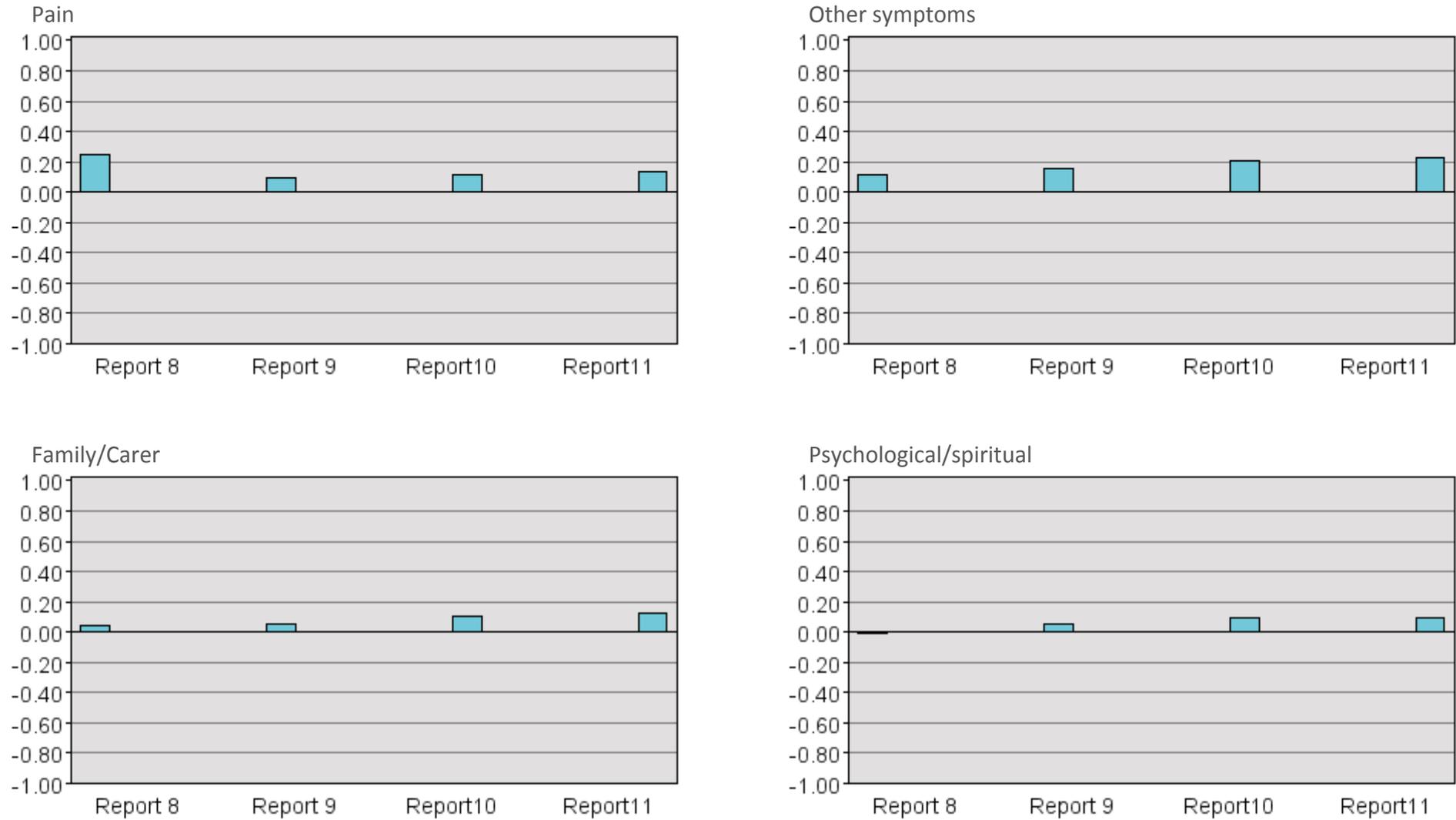
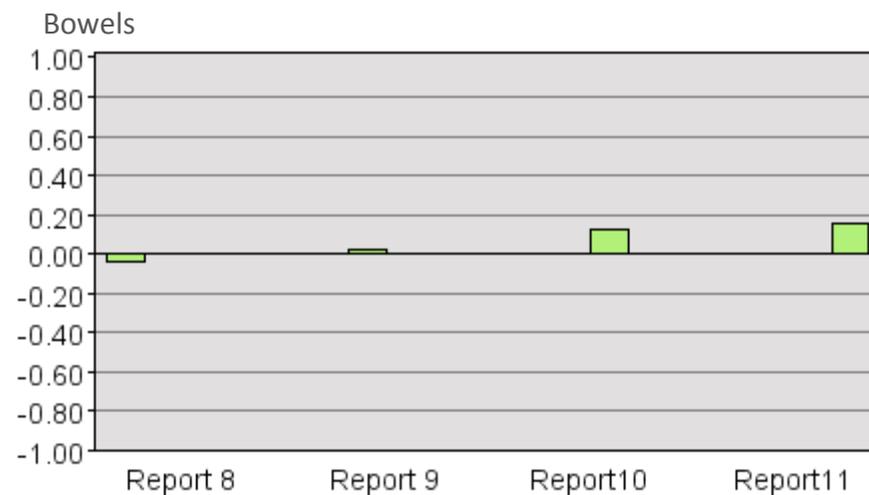
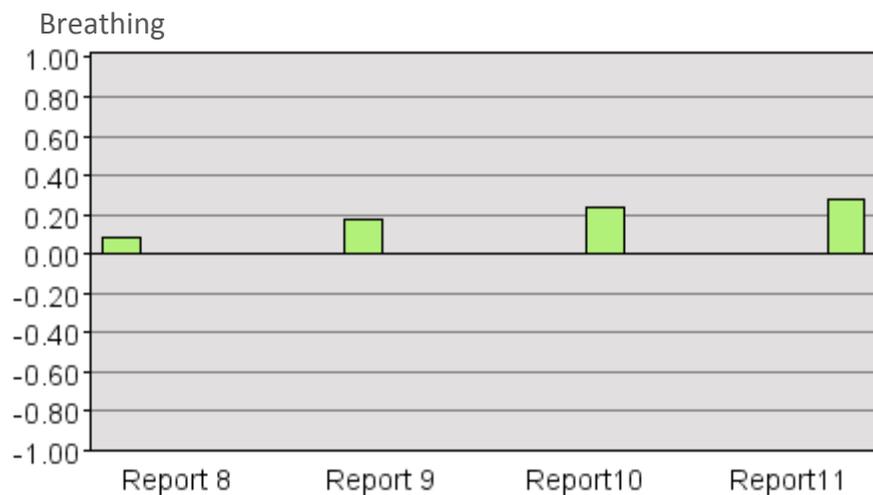
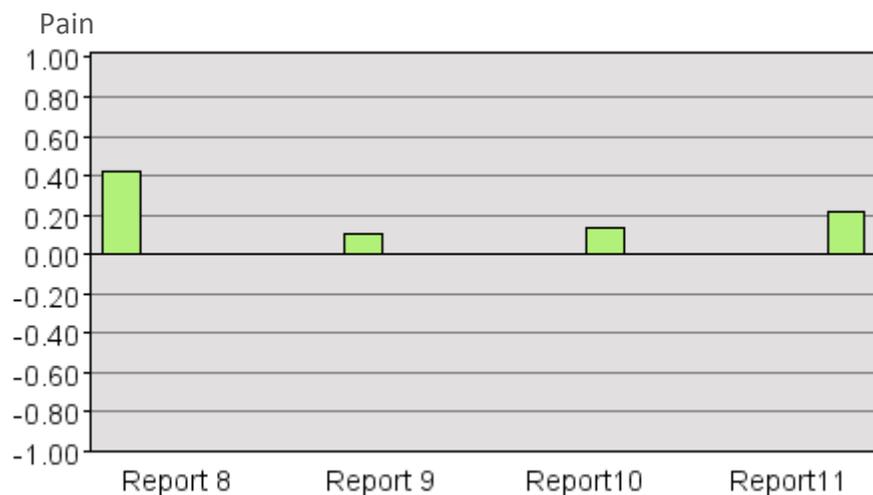


Figure 4 SAS mean change adjusted for phase and symptom score at start of phase



## Section 3 - Descriptive analysis

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

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

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

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

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

## 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. Non-disclosure of Indigenous status can result in cultural issues not being identified. A number of programs exist that can assist services to encourage Indigenous persons to identify.

*Table 9 Indigenous Status - all patients*

Indigenous Status	All Services
Aboriginal but not Torres Strait Islander origin	141
Torres Strait Islander but not Aboriginal origin	25
Both Aboriginal and Torres Strait Islander origin	17
Neither Aboriginal nor Torres Strait Islander origin	12982
Not stated/inadequately described	720
<b>Total</b>	<b>13885</b>

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

Table 10 Primary diagnosis

Primary diagnosis		All Services	%
Malignant	Bone and soft tissue	215	1.9
	Breast	883	7.7
	CNS	196	1.7
	Colorectal	1260	11.0
	Gynaecological	546	4.8
	Haematological	607	5.3
	Head and neck	656	5.7
	Lung	2245	19.6
	Pancreas	619	5.4
	Prostate	764	6.7
	Skin	429	3.8
	Other GIT	965	8.4
	Other urological	453	4.0
	Other malignancy	604	5.3
	Unknown primary	328	2.9
	Malignant - not further defined	662	5.8
	<b>All malignant</b>	<b>11432</b>	<b>100.0</b>
	Non-malignant	Cardiovascular	440
HIV/AIDS		9	0.4
Kidney failure		285	13.0
Neurological disease		491	22.4
Respiratory failure		322	14.7
Other non-malignancy		567	25.8
Non-malignant - not further defined		82	3.7
<b>All non-malignant</b>		<b>2196</b>	<b>100.0</b>

Note: All patients where diagnosis was not stated/inadequately described are excluded from the table.

## 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 overnight admitted patient or not admitted overnight patient.

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

An episode of palliative care ends when:

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

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

*Table 11 Referral source by episode type*

Referral source	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Public hospital - other than inpatient palliative care unit	4741	45.2	3305	47.9
Self, carer(s), family or friends	315	3.0	227	3.3
Private hospital - other than inpatient palliative care unit	714	6.8	862	12.5
Public palliative care inpatient unit/hospice	306	2.9	411	6.0
Private palliative care inpatient unit/hospice	48	0.5	39	0.6
General medical practitioner	620	5.9	847	12.3
Specialist medical practitioner	332	3.2	366	5.3
Community-based palliative care agency	2206	21.0	89	1.3
Community-based service	393	3.7	185	2.7
Residential aged care facility	83	0.8	184	2.7
Other	88	0.8	174	2.5
Not stated/inadequately described	654	6.2	205	3.0
<b>Total</b>	<b>10500</b>	<b>100.0</b>	<b>6894</b>	<b>100.0</b>

*Table 12 Place of death - patients not admitted overnight*

Place of death	All Services	%
Private residence	1055	56.9
Residential aged care setting	288	15.5
Other location*	345	18.6
Not stated/inadequately described	165	8.9
<b>Total</b>	<b>1853</b>	<b>100.0</b>

\* 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 nationally.

*Table 13 Length of episode summary*

Length of episode	Overnight admitted	Not admitted overnight
	All Services	All Services
Average length of episode	11.6	23.3
Median length of episode	7.0	22.0

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 90 days were considered to be outliers and are excluded from the average calculations.

Table 14 details the length of episodes by number of days.

*Table 14 Length of episode breakdown*

Length of episode	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Same day	367	3.6	535	8.3
1-2 days	1902	18.5	506	7.9
3-4 days	1387	13.5	305	4.7
5-7 days	1730	16.8	459	7.1
8-14 days	2167	21.1	788	12.2
15-21 days	1079	10.5	610	9.5
22-30 days	704	6.8	553	8.6
31-60 days	718	7.0	1003	15.6
61-90 days	158	1.5	552	8.6
Greater than 90 days	74	0.7	1131	17.6
<b>Total</b>	<b>10286</b>	<b>100.0</b>	<b>6442</b>	<b>100.0</b>

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

## Profile of palliative care phases

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

*Table 15 Number of phases by phase type and episode type*

Phase	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Stable	6914	26.1	4338	36.6
Unstable	7549	28.5	1993	16.8
Deteriorating	6595	24.9	4383	37.0
Terminal	4084	15.4	1036	8.8
Bereaved	1381	5.2	90	0.8
All phases	26523	100.0	11840	100.0

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

Phase	Overnight admitted	Not admitted overnight
	All Services	All Services
Stable	7.0	23.6
Unstable	4.3	8.6
Deteriorating	5.3	16.1
Terminal	2.2	2.9
Bereaved	1.1	2.1

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

*Table 17 Profile of PC Problem Severity Scores at beginning of phase by phase type - overnight admitted (percentages)*

Phase	Problem severity	All Services			
		Absent	Mild	Moderate	Severe
Stable	Pain	43.0	37.5	15.5	4.0
	Other Symptom	20.2	42.7	27.3	9.8
	Psychological/Spiritual	24.7	45.9	21.8	7.6
	Family/Carer	33.4	37.9	19.9	8.9
Unstable	Pain	25.2	27.6	30.5	16.6
	Other Symptom	8.1	24.4	41.8	25.7
	Psychological/Spiritual	13.9	34.9	34.8	16.4
	Family/Carer	21.0	31.0	30.5	17.6
Deteriorating	Pain	30.7	32.4	26.3	10.6
	Other Symptom	9.2	26.2	40.0	24.6
	Psychological/Spiritual	17.3	35.9	30.5	16.2
	Family/Carer	21.1	30.2	30.1	18.6
Terminal	Pain	38.2	28.4	21.9	11.6
	Other Symptom	21.0	22.5	28.9	27.5
	Psychological/Spiritual	35.3	26.5	21.5	16.6
	Family/Carer	15.0	24.8	31.8	28.4

*Table 18 Profile of PC Problem Severity Scores at beginning of phase by phase type - not admitted overnight (percentages)*

Phase	Problem severity	All Services			
		Absent	Mild	Moderate	Severe
Stable	Pain	36.8	48.9	13.0	1.3
	Other Symptom	15.7	55.3	26.5	2.4
	Psychological/Spiritual	24.8	52.4	20.5	2.3
	Family/Carer	23.8	46.0	26.5	3.7
Unstable	Pain	17.3	27.5	35.4	19.8
	Other Symptom	6.4	27.0	45.4	21.2
	Psychological/Spiritual	13.4	39.9	34.4	12.2
	Family/Carer	15.0	29.7	38.0	17.4
Deteriorating	Pain	26.2	45.6	22.8	5.5
	Other Symptom	6.5	34.6	46.3	12.6
	Psychological/Spiritual	18.2	46.1	28.7	7.1
	Family/Carer	13.8	32.1	41.9	12.2
Terminal	Pain	36.4	38.9	17.3	7.4
	Other Symptom	21.2	33.1	30.1	15.6
	Psychological/Spiritual	42.7	34.8	15.2	7.2
	Family/Carer	12.7	29.6	37.1	20.5

Figure 5 Total RUG-ADL at beginning of phase – overnight admitted patients

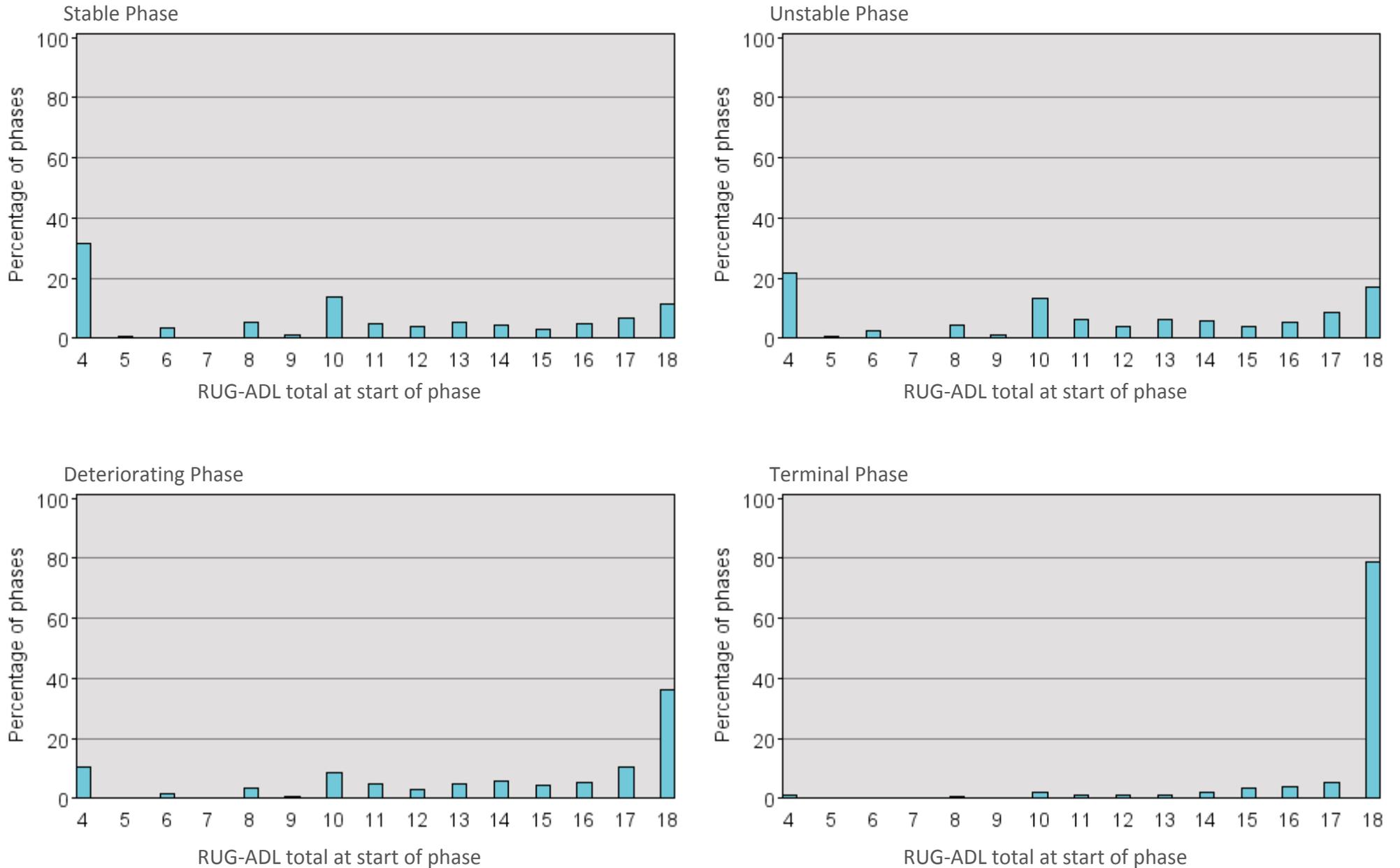
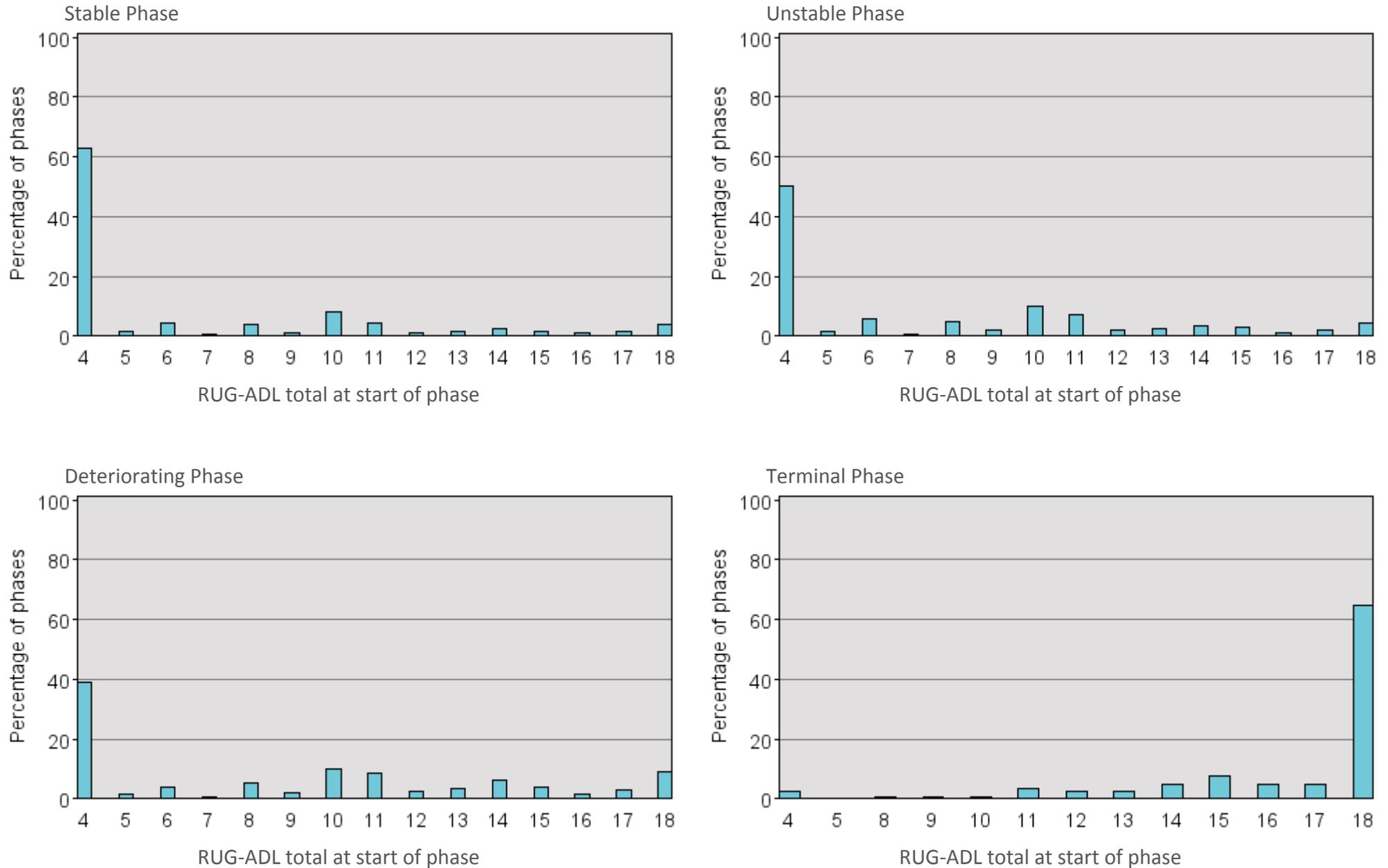


Figure 6 Total RUG-ADL at beginning of phase – patients not admitted overnight



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

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

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

*Table 19 Karnofsky score at phase start by episode type*

Karnofsky score	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Comatose or barely rousable	2298	9.2	453	3.9
Totally bedfast and requiring extensive nursing care	5020	20.0	1049	9.0
Almost completely bedfast	2887	11.5	742	6.4
In bed more than 50% of the time	4035	16.1	1473	12.6
Requires considerable assistance	4837	19.3	2626	22.5
Requires occasional assistance	3311	13.2	2651	22.7
Cares for self	1003	4.0	1670	14.3
Normal activity with effort	377	1.5	588	5.0
Able to carry on normal activity; minor signs or symptoms	117	0.5	157	1.3
Normal; no complaints; no evidence of disease	7	0.0	8	0.1
Not stated/inadequately described	1165	4.6	265	2.3
<b>Total</b>	<b>25057</b>	<b>100.0</b>	<b>11682</b>	<b>100.0</b>

Table 20 How stable phases end

Phase end reason	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Phase change	3926	56.8	2843	65.5
Discharge/case closure	2841	41.1	1169	26.9
Died	117	1.7	266	6.1
Bereavement phase end	10	0.1	1	0.0
Not stated/inadequately described	20	0.3	59	1.4
<b>Total</b>	<b>6914</b>	<b>100.0</b>	<b>4338</b>	<b>100.0</b>

Figure 7 Stable phase progression - overnight admitted

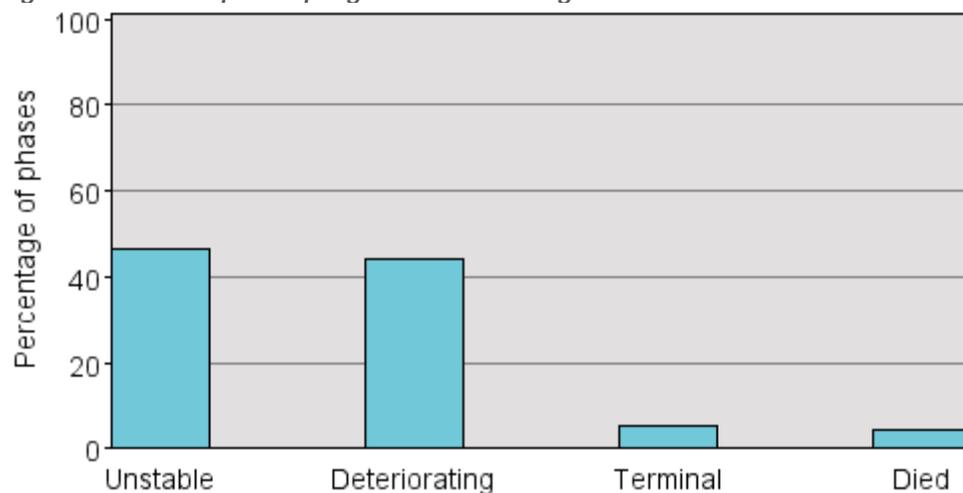


Figure 8 Stable phase progression - not admitted overnight

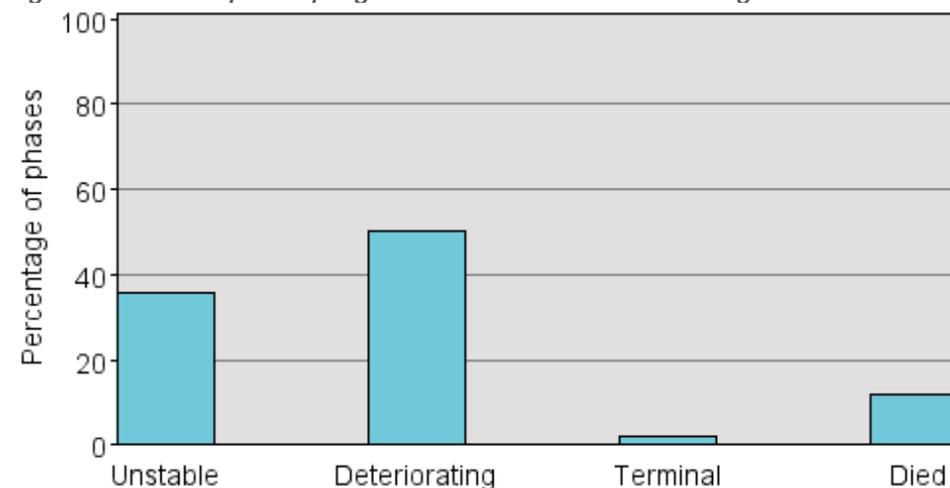


Table 21 How unstable phases end

Phase end reason	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Phase change	6464	85.6	1406	70.5
Discharge/case closure	721	9.6	462	23.2
Died	345	4.6	89	4.5
Bereavement phase end	12	0.2	4	0.2
Not stated/inadequately described	7	0.1	32	1.6
<b>Total</b>	<b>7549</b>	<b>100.0</b>	<b>1993</b>	<b>100.0</b>

Figure 9 Unstable phase progression - overnight admitted

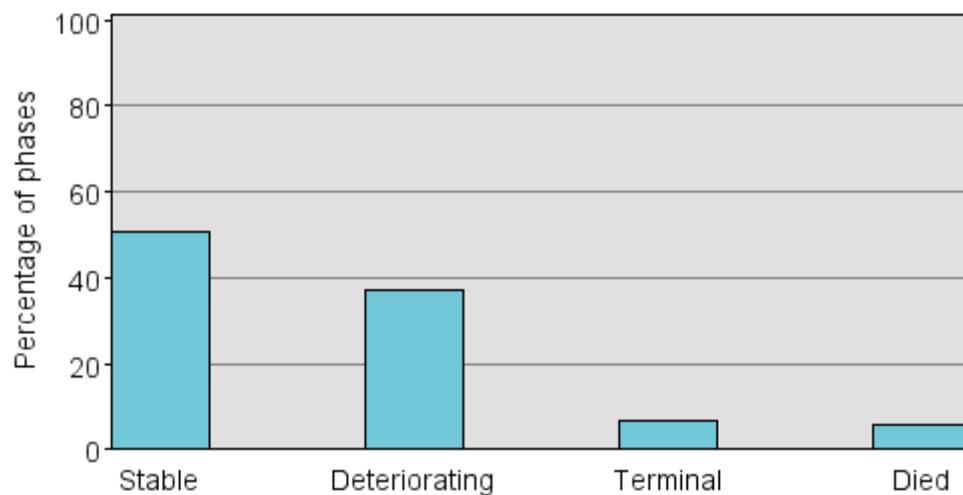


Figure 10 Unstable phase progression - not admitted overnight

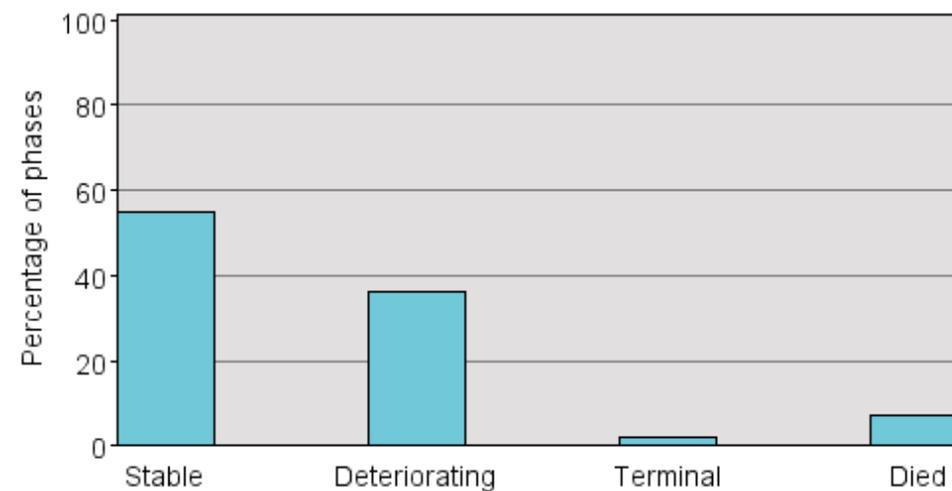


Table 22 How deteriorating phases end

Phase end reason	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Phase change	4595	69.7	2304	52.6
Discharge/case closure	844	12.8	1366	31.2
Died	1110	16.8	679	15.5
Bereavement phase end	37	0.6	4	0.1
Not stated/inadequately described	9	0.1	30	0.7
<b>Total</b>	<b>6595</b>	<b>100.0</b>	<b>4383</b>	<b>100.0</b>

Figure 11 Deteriorating phase progression - overnight admitted

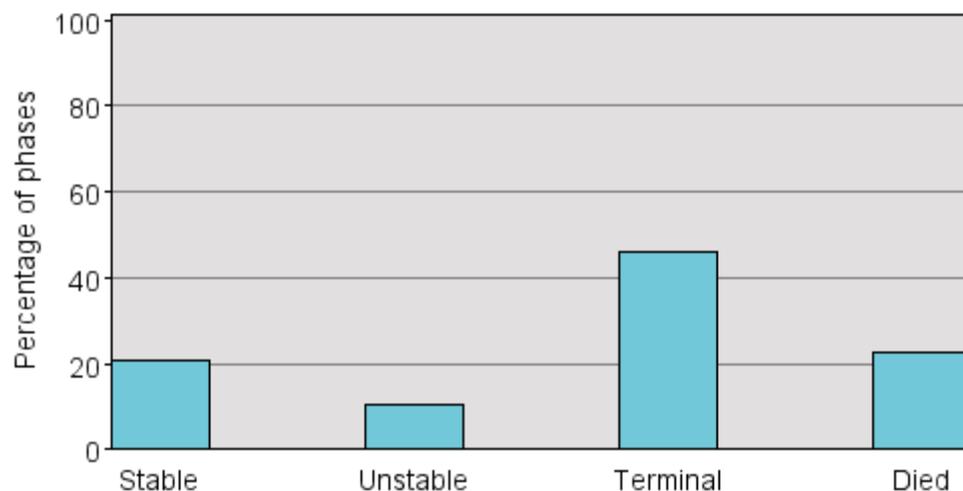


Figure 12 Deteriorating phase progression - not admitted overnight

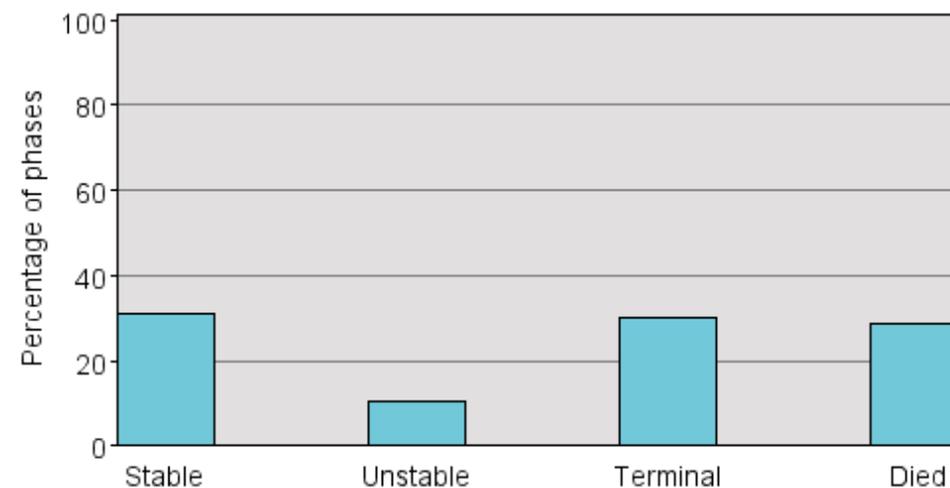


Table 23 How *terminal* phases end

Phase end reason	Overnight admitted		Not admitted overnight	
	All Services	%	All Services	%
Phase change	480	11.8	224	21.6
Discharge/case closure	75	1.8	75	7.2
Died	3416	83.6	724	69.9
Bereavement phase end	106	2.6	6	0.6
Not stated/inadequately described	7	0.2	7	0.7
<b>Total</b>	<b>4084</b>	<b>100.0</b>	<b>1036</b>	<b>100.0</b>

Figure 13 Terminal phase progression - overnight admitted

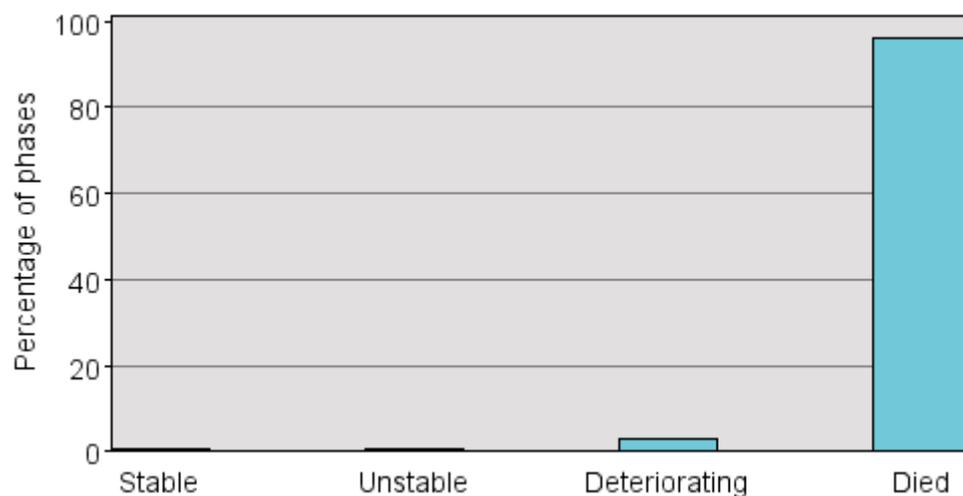
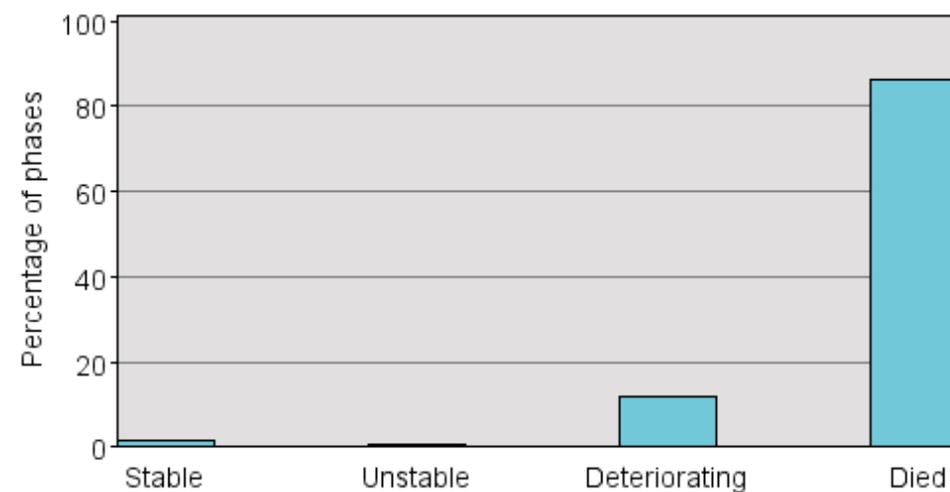


Figure 14 Terminal phase progression - not admitted overnight



## Appendix A – Summary of data included in this report

### A1 – Data Summary

This report includes data from a total of 100 services. During the reporting period, data were provided for a total of 13885 patients who between them had 17394 episodes of care and 38363 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 episode type*

Episode Type	Overnight admitted	Not admitted overnight	Total
	All Services	All Services	All Services
Number of patients*	8890	5750	13885
Number of episodes	10500	6894	17394
Number of phases	26523	11840	38363
Percentage of patients*	64.0	41.4	100
Percentage of episodes	60.4	39.6	100
Percentage of phases	69.1	30.9	100
Average number of phases per episode**	2.4	1.7	2.1

\* Patients seen in both an overnight admitted and not admitted overnight setting are only counted once in the total column and hence numbers/percentages may not add to the total.

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

## A2 – Data Item Completion

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

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

*Table 25 Item completion- patient level*

Data item	% Complete
	All Services
Date of birth	100.0
Sex	99.9
Indigenous status	94.8
Country of birth	94.1
Main language	91.5
Primary diagnosis	98.6

*Table 26 Item completion- episode level*

Data item	% Complete
	All Services
Date of first contact/assessment	96.2
Referral date	92.3
Referral source	95.1
Episode start date	100.0
Mode of episode start	99.0
Accommodation at episode start	97.4
Episode end date	99.9
Level of support at episode start	82.9
Mode of episode end	98.1
Accommodation at episode end	88.1
Level of support at episode end	97.1
Place of death	91.1

*Table 27 Item completion - phase level*

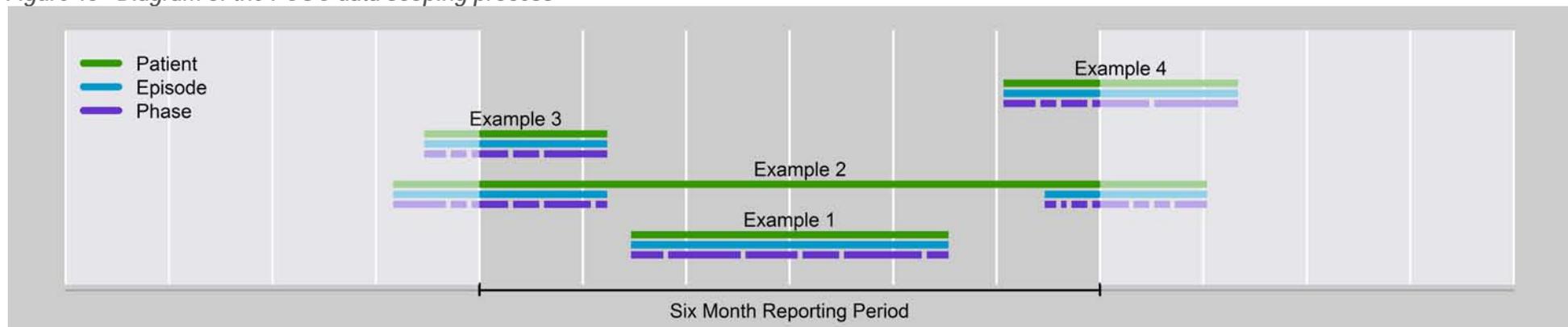
Data item	Sub-Category	% Complete
	(where applicable)	All Services
Phase start date	-	100.0
Phase	-	100.0
RUG-ADL at phase start	Bed Mobility	95.2
	Toileting	95.1
	Transfers	95.0
	Eating	94.4
PC Problem Severity at phase start	Pain	79.1
	Other Symptom	83.1
	Psychological/Spiritual	92.8
	Family/Carer	91.6
Symptom Assessment Score at phase start	Insomnia	86.7
	Appetite	89.2
	Nausea	89.5
	Bowels	88.9
	Breathing	89.5
	Fatigue	89.7
	Pain	90.0
Phase end reason	-	99.5
Karnofsky at phase start	-	96.1

### A3 – Data scoping methodology

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

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

Figure 15 Diagram of the PCOC data scoping process



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

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

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

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

## Appendix B – Benchmark Notes

### B1 – Outline of Benchmark Measures and Targets

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

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

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

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

## B2 – National profile graphs

In each national profile graph, the shaded region describes the national profile for that benchmark.

## B3 – X-CAS technical notes

The procedure for calculating X-CAS is as follows:

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