Patient Outcomes in Palliative Care

Report 13, January - June 2012

Queensland

Australian Government
Department of Health and Ageing

www.pcoc.org.au

About the Palliative Care Outcomes Collaboration (PCOC)

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

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

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

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

Central Zone — **Professor Kathy Eagar**, Australian Health Services Research Institute, University of Wollongong

North Zone — **Professor Patsy Yates**, Institute of Health and Biomedical Innovation, Queensland University of Technology

South Zone — **Professor David Currow**, Department of Palliative and Supportive Services, Flinders University

West Zone — **Assistant Professor Claire Johnson**, Cancer and Palliative Care Research and Evaluation Unit, University of WA

Each zone is also represented by one or more quality improvement facilitators, whose role includes supporting services to participate in PCOC and facilitating ongoing service development and quality improvement.

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

"PCOC is an excellent example of a national and voluntary programme using benchmarking to measure outcomes in palliative care"
PRISMA (Reflecting the Positive Diversities of European Priorities for ReSearch and Measurement in End-of-Life CAre) in their publication
Outcome Measurement in Palliative Care – The Essentials

Contents

List of Tables

List of Figures

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 thirteenth PCOC report, data submitted for the January - June 2012 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

This report is broken into four sections:

Section 1 provides a summary of the data included in this report.
Section 2 summarises each of the four outcome measures and presents national benchmarking results for a selection of these measures.
Section 3 presents a more detailed analysis of the outcome measures and benchmarks.
Section 4 provides descriptive analysis at each of the patient, episode and phase data levels.

In each of the four sections, data and analysis for services in QLD is presented alongside the national figures for comparative purposes. The national figures reflect all palliative care services who submitted data for the January - June 2012 period. A full list of these services can be found at www.pcoc.org.au

The four outcome measures included in this report were first introduced in the reporting period January to June 2009 (Report 7). There is strong sectoral support for national benchmarks and a consensus that such benchmarks can drive service innovation regardless of model of care. Benchmarking provides opportunities to understand the services that are provided, the outcomes patients experience and also to generate research opportunities focused on how to demonstrate variations in practice and outcomes.

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

na   **The item is not applicable**
u   **The item was unavailable/unable to be calculated due to missing or invalid data.**

Section 1 – Summary of data included in this report

1.1 Data summary

This report includes data from a total of 103 services. During the reporting period, data were provided for a total of 15,505 patients who between them had 19,157 episodes of care and 41,947 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Section A contains a more detailed explanation of this process). Table 1 shows the number of patients, episodes and phases included in this report – both for QLD and nationally.

A consequence of the data scoping method is that it is likely that not all phases related to a particular episode are included in this report. Hence, the average number of phases per episode calculation shown in Table 1 may be an underestimate (due to episodes that cross-over 2 or more reporting periods) as it only includes phases that ended within the current reporting period.

Table 1 Number and percentage of patients, episodes and phases by setting

Setting	Inpatient		Ambulatory & community		Total	
	QLD	All Services	QLD	All Services	QLD	All Services
Number of patients*	2,691	9,501	1,100	6,794	3,472	15,505
Number of episodes	3,196	10,983	1,270	8,174	4,466	19,157
Number of phases	7,414	27,814	2,100	14,133	9,514	41,947
Percentage of patients*	77.5	61.3	31.7	43.8	100	100
Percentage of episodes	71.6	57.3	28.4	42.7	100	100
Percentage of phases	77.9	66.3	22.1	33.7	100	100
Average number of phases per episode**	2.1	2.4	1.6	1.7	2.0	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, excludes bereavement phases and may also be an underestimate due to the data scoping methodology (see Section A).

1.2 Data Item Completion

Overall, the quality of data submitted to PCOC is very good and, as shown in Tables 2, 3 and 4 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for ambulatory and community patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

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

Table 2 Item completion (per cent complete) - patient level

Data item	QLD	All Services
Date of birth	100.0	100.0
Sex	100.0	99.9
Indigenous status	96.9	96.1
Country of birth	97.4	95.4
Main language	98.4	93.4
Primary diagnosis	99.5	96.8

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

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

Data item	Inpatient		Ambulatory & community		Total	
	QLD	All Services	QLD	All Services	QLD	All Services
Date of first contact/assessment	98.9	96.0	99.1	97.5	98.9	96.7
Referral date	99.6	97.4	99.5	86.3	99.6	92.7
Referral source	98.4	94.4	99.2	98.9	98.6	96.3
Mode of episode start	99.3	99.7	95.2	98.9	98.1	99.4
Accommodation at episode start	99.4	94.6	97.9	97.4	99.0	95.8
Episode end date	98.1	99.3	99.6	99.9	98.5	99.6
Level of support at episode start	98.9	81.3	99.1	83.1	98.9	82.1
Mode of episode end	99.1	97.9	99.8	99.6	99.3	98.6
Accommodation at episode end	80.7	84.7	92.1	77.9	82.9	83.0
Level of support at episode end	99.0	98.2	100.0	89.5	99.2	96.1
Place of death	na	na	73.0	91.8	73.0	91.8

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

Data item	Sub-Category	Inpatient		Ambulatory & community		Total	
	(where applicable)	QLD	All Services	QLD	All Services	QLD	All Services
RUG-ADL at phase start	Bed mobility	87.9	96.8	100.0	97.1	90.7	96.9
	Toileting	87.9	96.9	100.0	96.9	90.7	96.9
	Transfers	87.9	96.8	100.0	96.6	90.7	96.7
	Eating	87.9	96.8	100.0	94.9	90.7	96.1
PC Problem Severity at phase start	Pain	86.6	79.5	100.0	84.2	89.7	81.2
	Other symptom	82.5	87.1	100.0	83.5	86.6	85.8
	Psychological/spiritual	96.5	98.2	100.0	84.1	97.3	93.3
	Family/carer	96.5	98.2	100.0	83.9	97.3	93.2
Symptom Assessment Scale at phase start	Insomnia	84.1	92.2	99.4	90.2	87.7	91.5
	Appetite problems	84.1	92.2	99.4	94.5	87.7	93.0
	Nausea	84.1	92.2	99.4	95.5	87.7	93.3
	Bowel problems	84.1	92.2	99.4	94.0	87.7	92.8
	Breathing problems	84.1	92.2	99.4	95.5	87.7	93.4
	Fatigue	84.1	92.2	99.4	95.9	87.7	93.5
	Pain	84.1	92.2	99.4	96.7	87.7	93.8
Phase end reason	-	99.3	99.7	98.7	99.7	99.2	99.7
Karnofsky at phase start	-	99.8	94.9	99.7	97.7	99.7	95.9

Section 2 – Benchmark summary

2.1 QLD at a glance

Table 5 Summary of outcome measures 1-3 by setting

Outcome measure	Description	Benchmark	Inpatient		Ambulatory & community	
			QLD Score	Benchmark Met?	QLD Score	Benchmark Met?
1. Time from referral to first contact	Benchmark 1: Patients contacted on the day of, or the day after referral	90%	95.2	Yes	57.8	No
2. Time in unstable phase	Benchmark 2.1: Patients in the unstable phase for less than 7 days – first phase of episode	85%	84.1	No	70.2	No
	Benchmark 2.2: Patients in the unstable phase for less than 7 days - not first phase of episode	90%	86.1	No	64.9	No
	Benchmark 2.3: Median time patients are in the unstable phase	2 days	2 days	Yes	3 days	No
3. Change in pain	Benchmark 3.1: PCPSS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end	90%	88.6	No	72.5	No
	Benchmark 3.2: PCPSS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end	60%	58.6	No	45.4	No
	Benchmark 3.3: SAS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end	90%	87.6	No	70.7	No
	Benchmark 3.4: SAS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end	60%	47.7	No	36.3	No

Table 6 Summary of outcome measure 4: Average improvement on the 2008 baseline national average (X-CAS)

Clinical Tool	Description	Average improvement on baseline	Benchmark met?
PCPSS	Benchmark 4.1: Pain	0.20	Yes
	Benchmark 4.2: Other symptoms	0.44	Yes
	Benchmark 4.3: Family/carer	0.18	Yes
	Benchmark 4.4: Psychological/spiritual	0.24	Yes
SAS	Benchmark 4.5: Pain	0.33	Yes
	Benchmark 4.6: Nausea	0.21	Yes
	Benchmark 4.7: Breathing problems	0.46	Yes
	Benchmark 4.8: Bowel problems	0.32	Yes

→ **The benchmark for measure 4 is zero.**

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

2.2 National benchmark profiles

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

The selected benchmarks included are:

- Benchmark 1   Patients contacted on the day of, or the day after referral
- Benchmark 2.1   Patients in the unstable phase for less than 7 days – first phase of episode
- Benchmark 2.2   Patients in the unstable phase for less than 7 days - not first phase of episode
- Benchmark 3.3   SAS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end
- Benchmark 3.4   SAS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end

The national profile graphs below allow a comparison of the performance of QLD services to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. QLD services are highlighted as dots on the graph. If no dots are present on a particular graph, this means that no services in QLD met the criteria for inclusion in this measure. This may be caused by insufficient data item completion, or not having any data falling into a particular category, for example, no phases starting with moderate/severe SAS pain. The red line on the graph indicates the benchmark for that measure.

Outcome measure 1 – Time from referral to first contact

Benchmark 1

Figure 1 Percentage of patients contacted on the day of, or the day after referral – inpatient setting
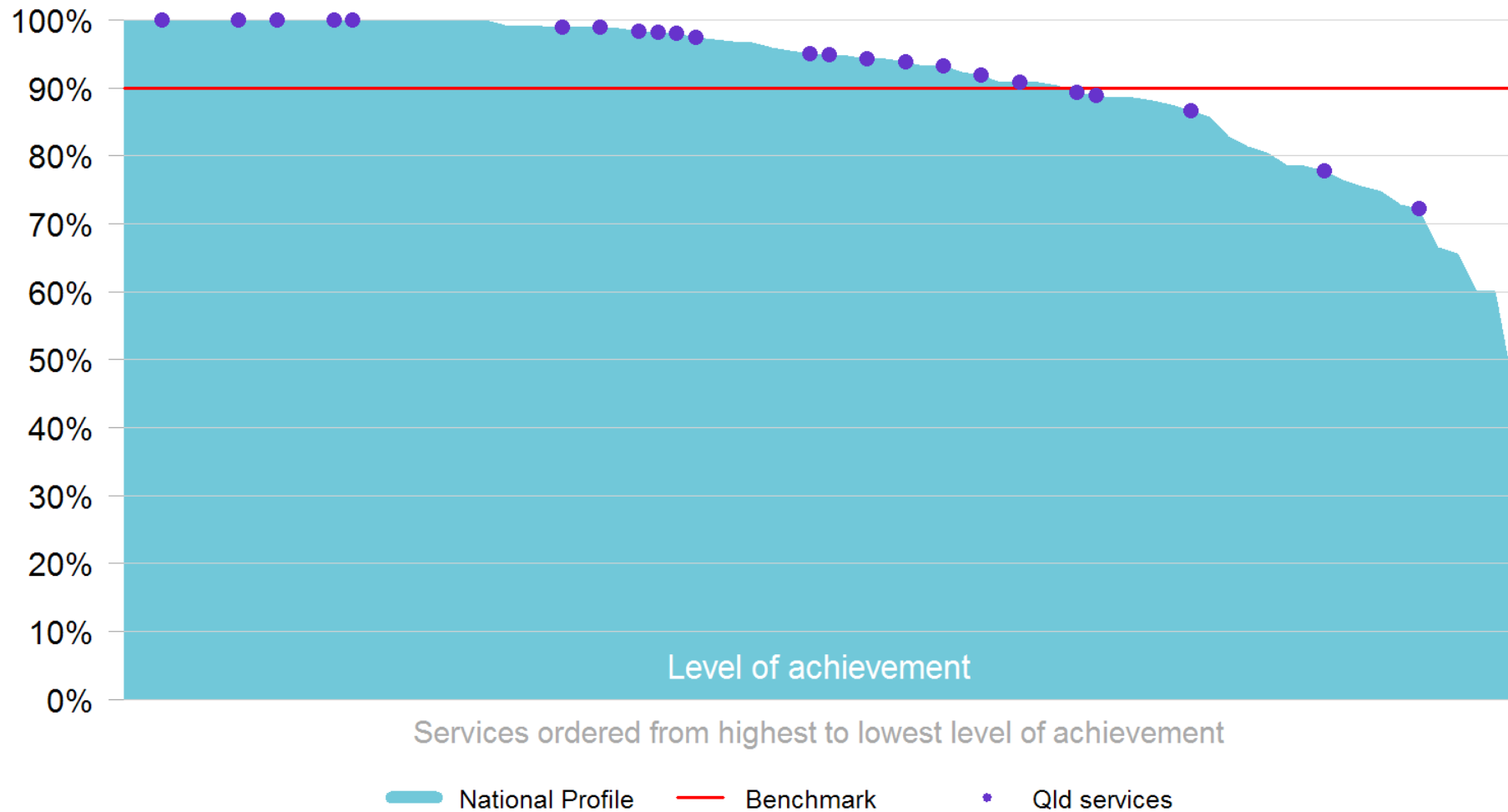
Figure 2 *Percentage of patients contacted on the day of, or the day after referral – ambulatory & community settings*

Level of achievement

Services ordered from highest to lowest level of achievement

— National Profile   — Benchmark   • Qld services
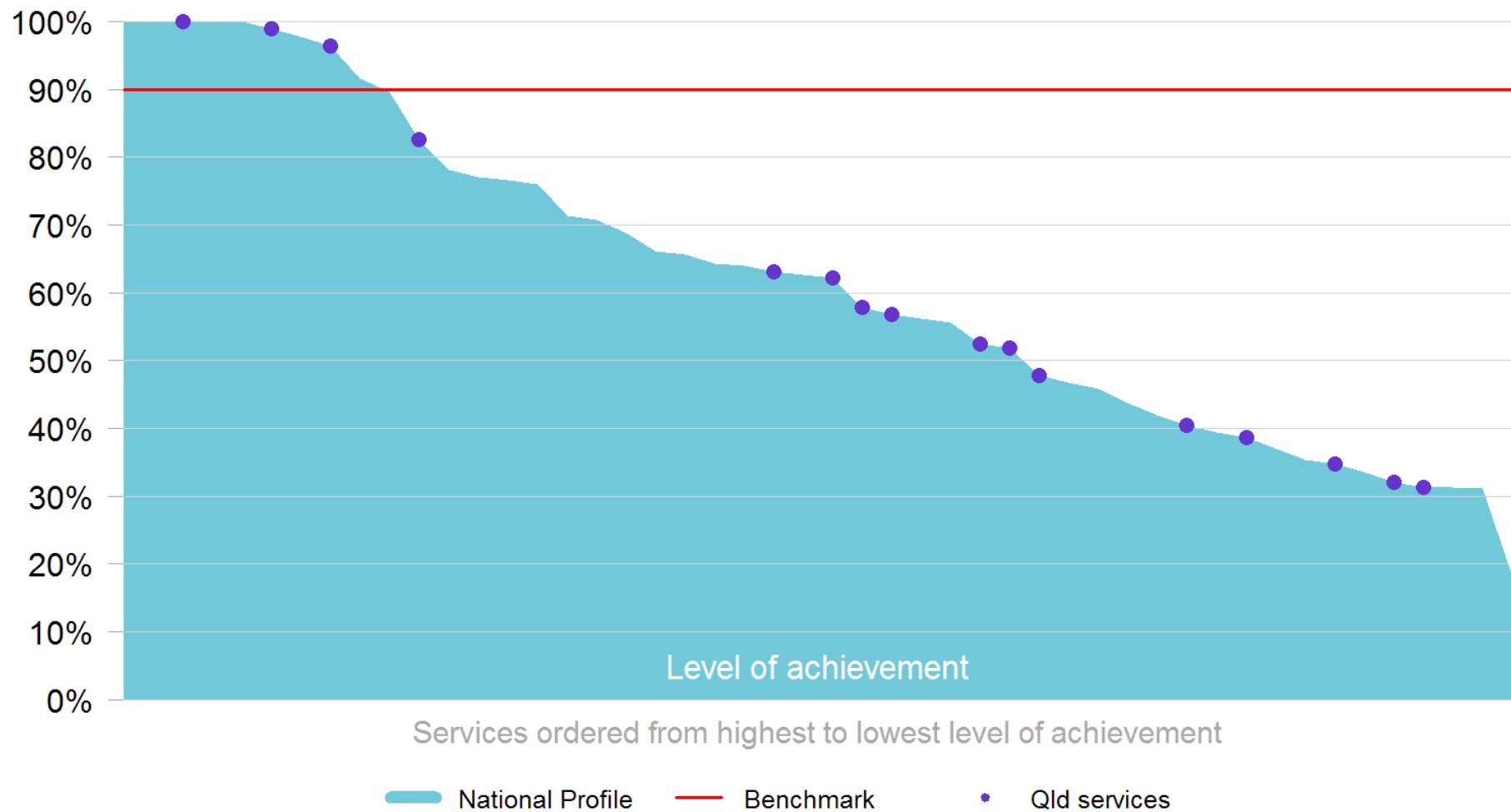
Outcome measure 2 – Time in unstable phase

Benchmark 2.1

Figure 3 Percentage of patients in the unstable phase for less than 7 days - 1st phase of episode – inpatient setting
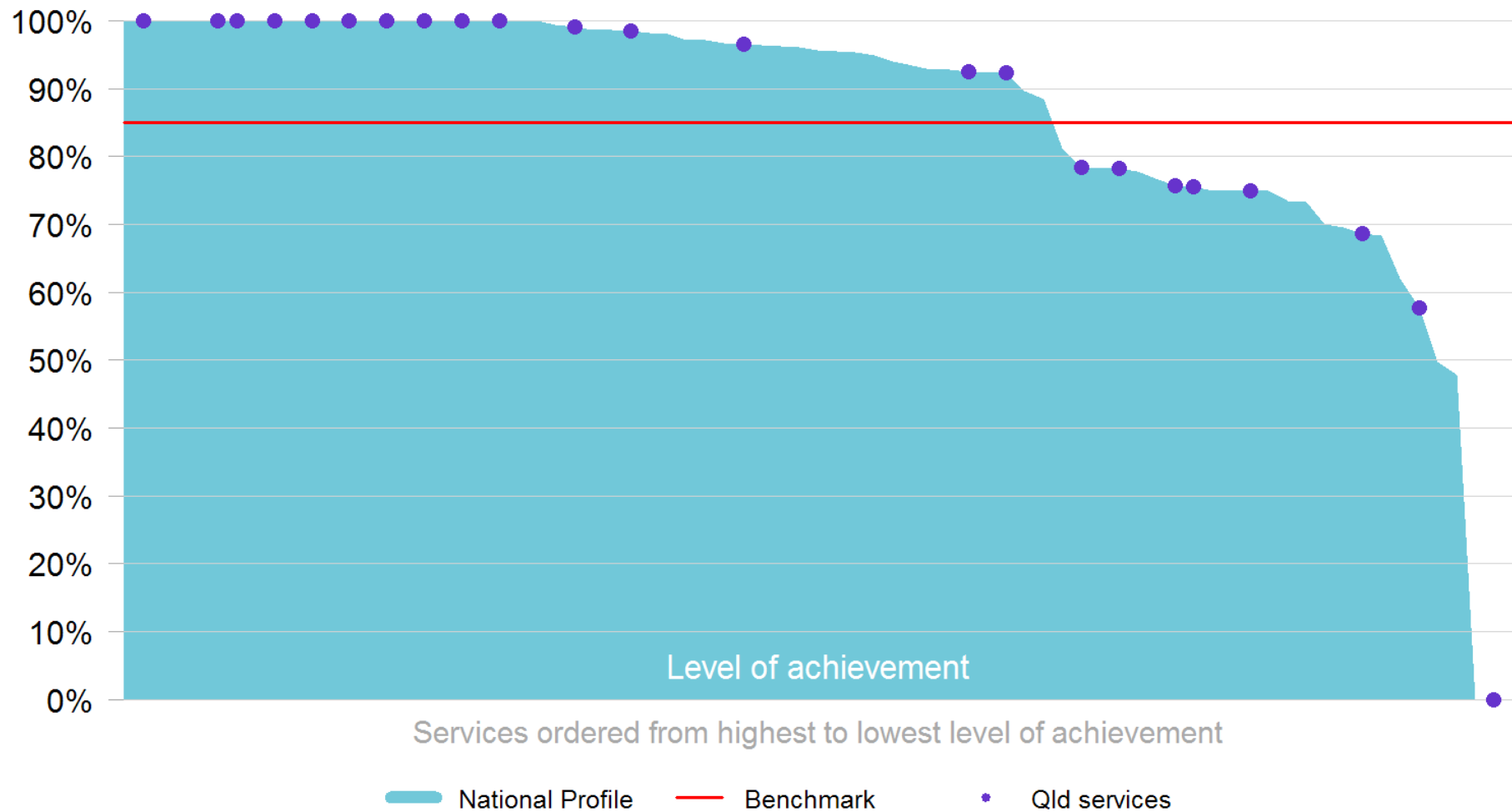
Figure 4 Percentage of patients in the unstable phase for less than 7 days - 1st phase of episode – ambulatory & community settings

National Profile ━━━ Benchmark • Qld services
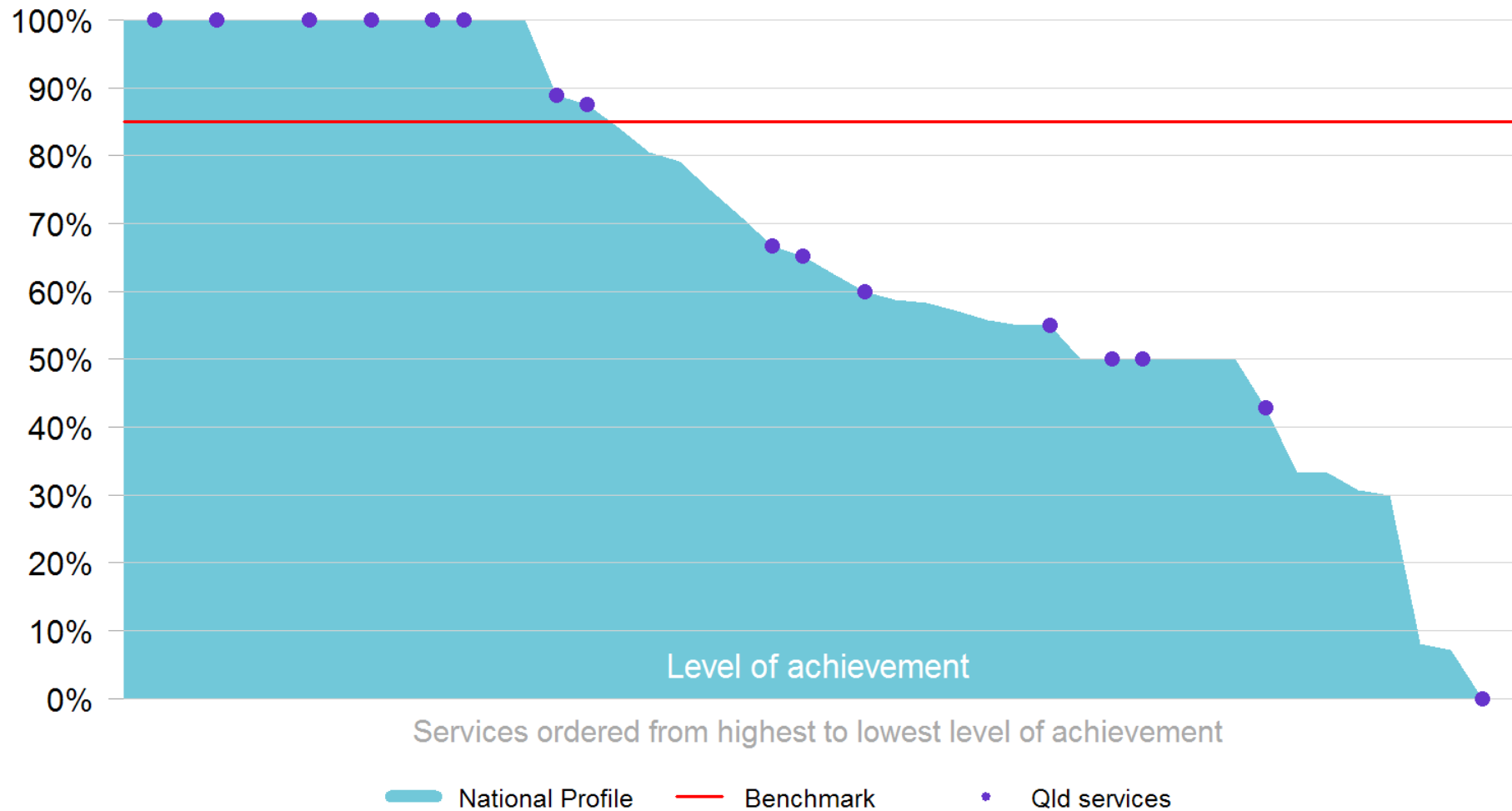
Benchmark 2.2

Figure 5 Percentage of patients in the unstable phase for less than 7 days - not 1st phase of episode – inpatient setting
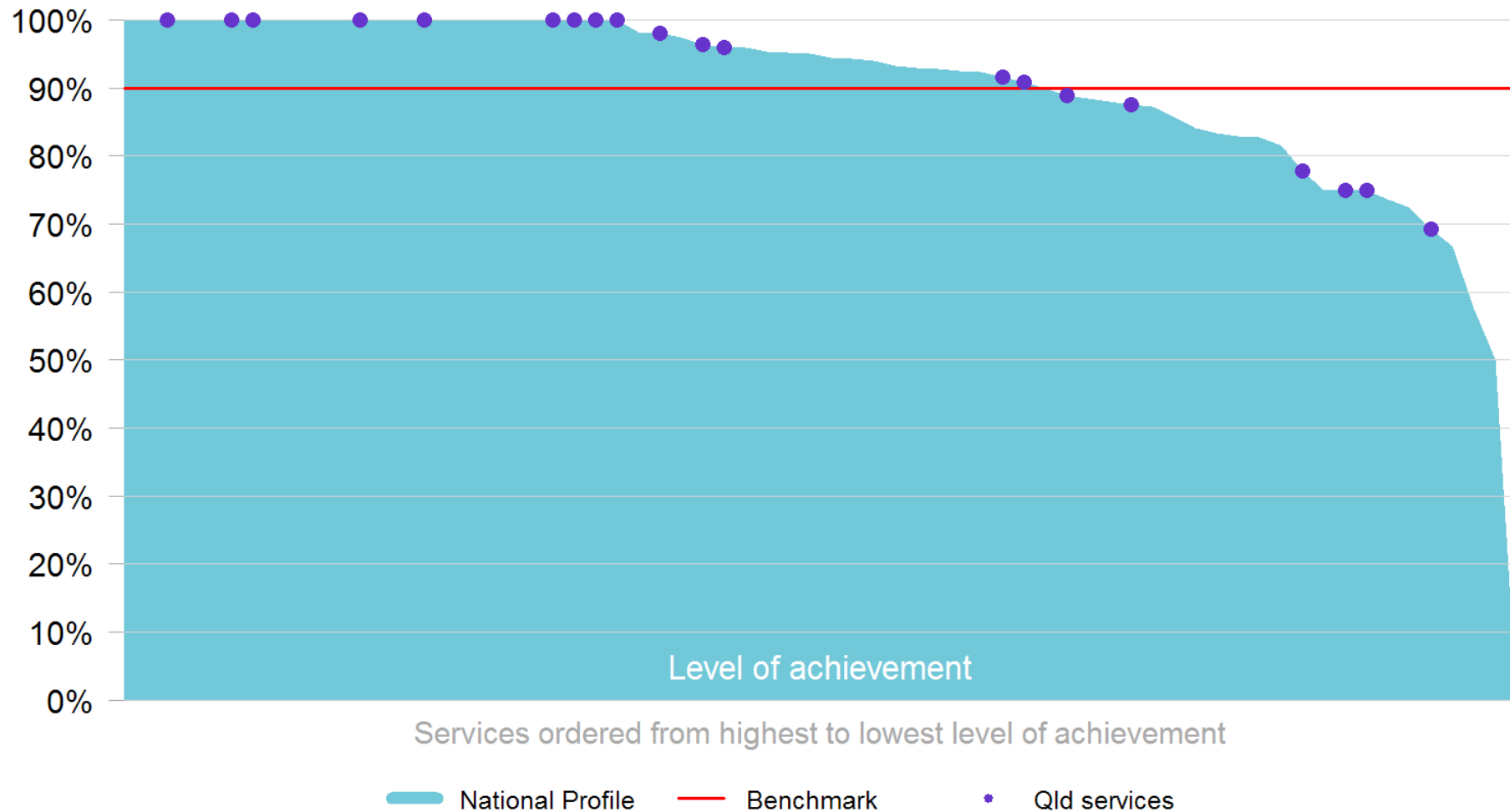
Figure 6 Percentage of patients in the unstable phase for less than 7 days - not 1st phase of episode – ambulatory & community settings

Level of achievement

Services ordered from highest to lowest level of achievement

National Profile   Benchmark   • Qld services
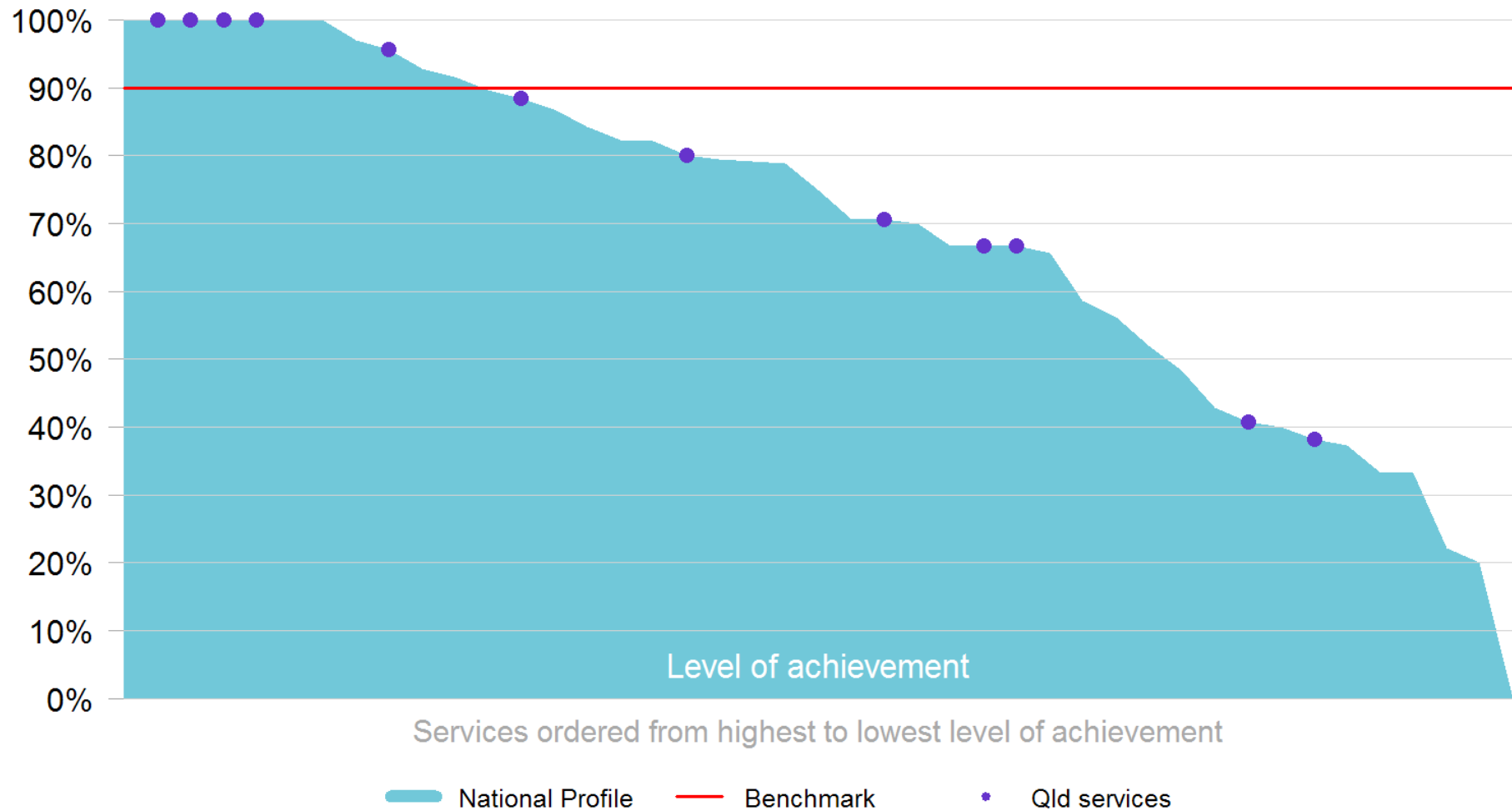
Outcome measure 3 – Change in pain (SAS pain)

Benchmark 3.3

Figure 7 Percentage of patients with absent/mild pain at phase start, remaining absent/mild at phase end – inpatient setting
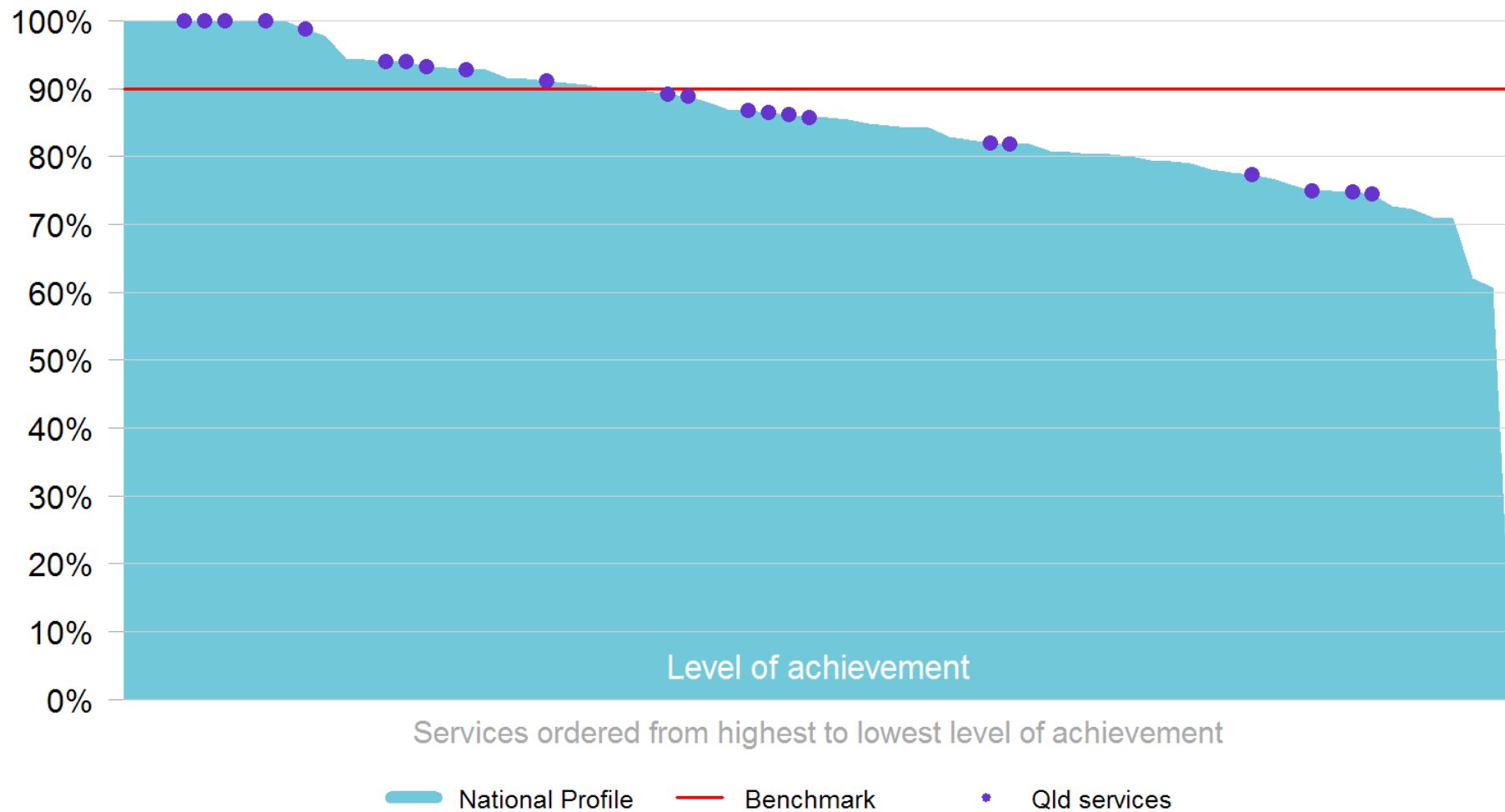
Figure 8 Percentage of patients with absent/mild pain at phase start, remaining absent/mild at phase end – ambulatory & community settings
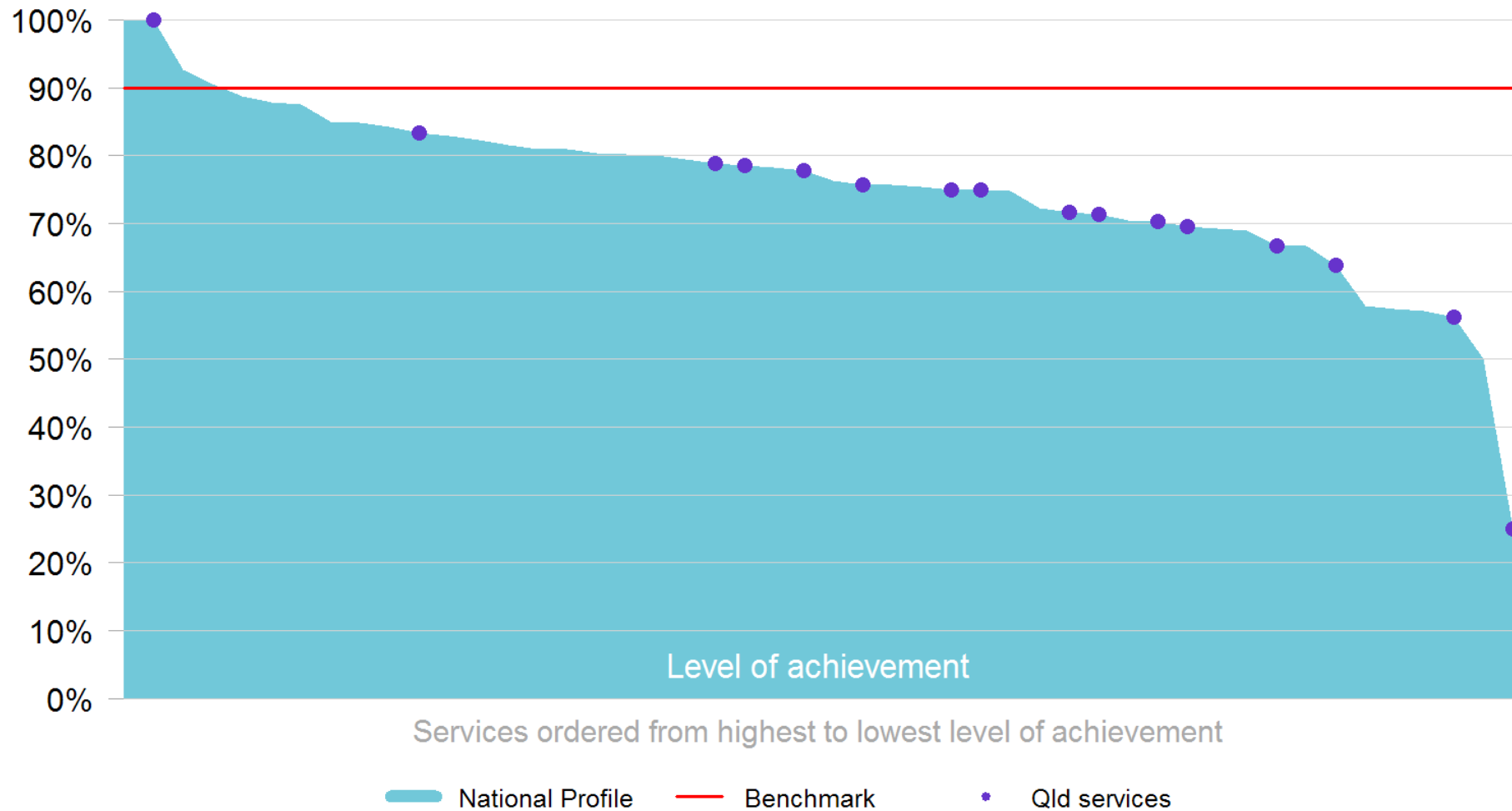
Benchmark 3.4

Figure 9 Percentage of patients with moderate/severe pain at phase start, with absent/mild pain at phase end – inpatient setting
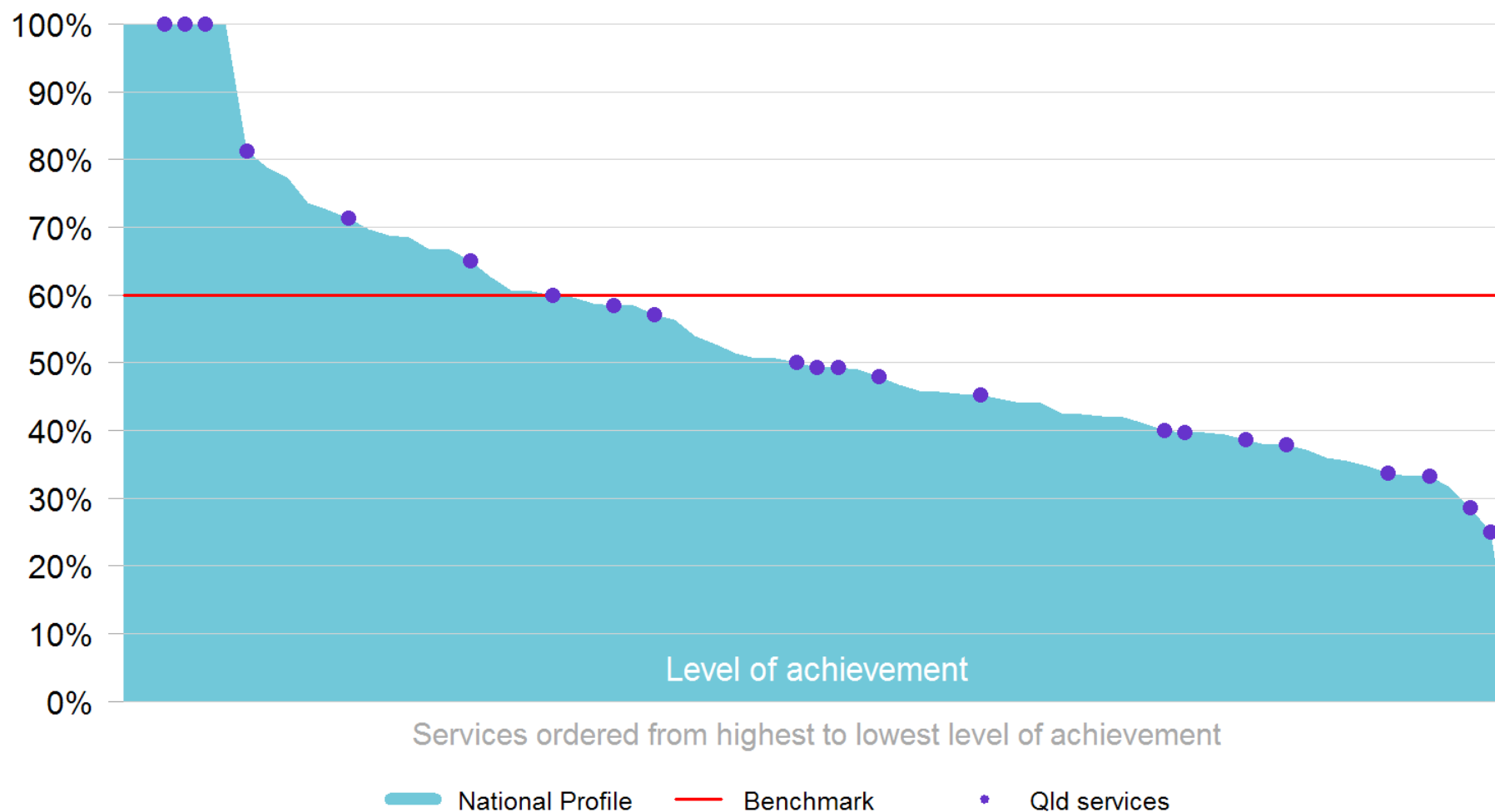
Figure 10 Percentage of patients with moderate/severe pain at phase start, with absent/mild pain at phase end – ambulatory & community settings
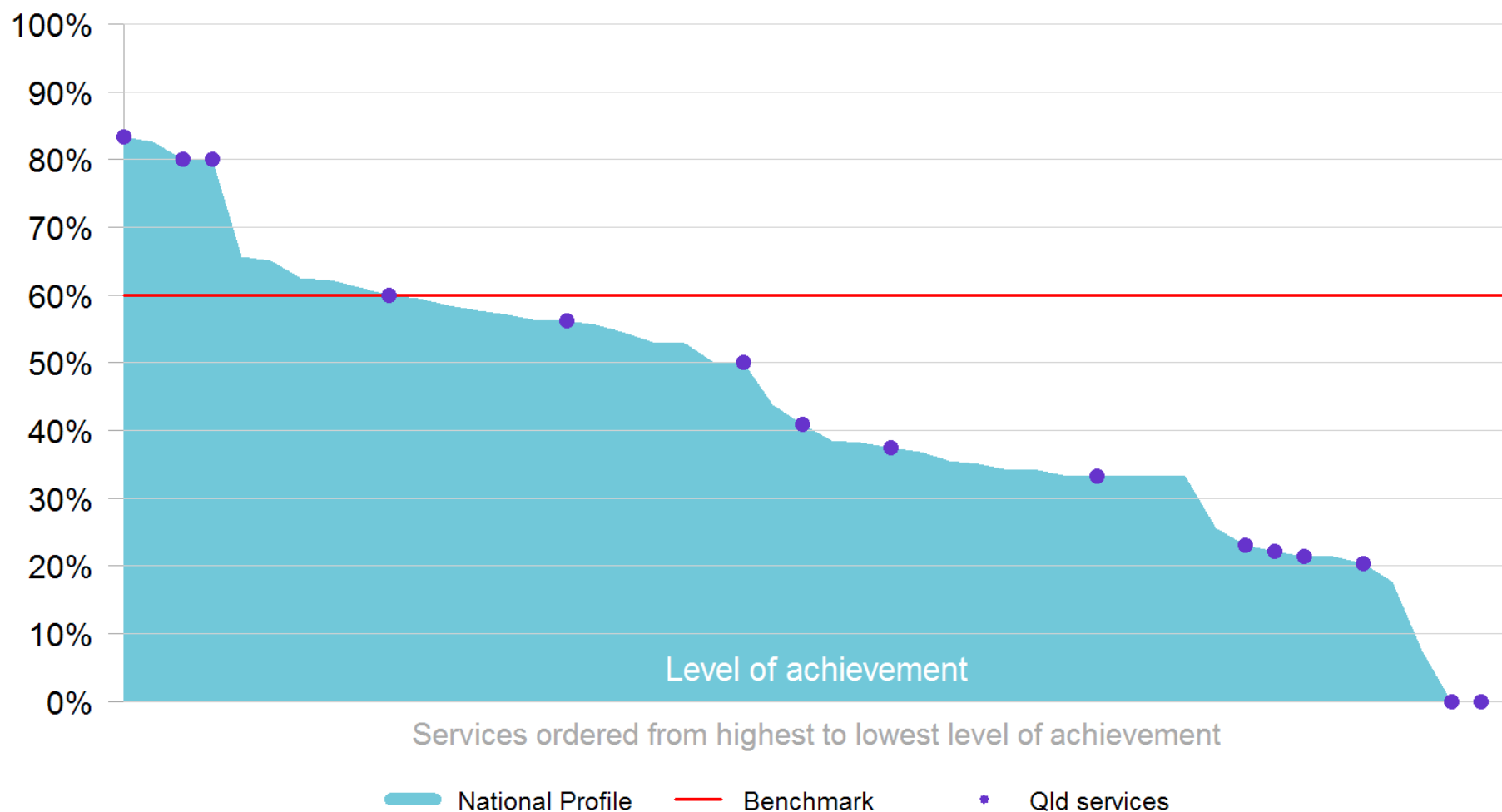
Section 3 – Outcome measures in detail

3.1   Outcome measure 1 – Time from referral to first contact

Time from referral to first contact reports responsiveness of palliative care services to patient needs. This benchmark was set after consultation with participants at the PCOC national benchmarking workshops in 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 5 days a week (Monday-Friday) are not distinguished from services operating 7 days a week (all services are being benchmarked together).

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

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

Table 7 Time from referral to first contact by setting

Time (in days)	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
Same day or following day	3028	95.2	9,657	90.3	731	57.8	3,605	51.1
2-7 days	139	4.4	845	7.9	349	27.6	2,259	32.0
8-14 days	6	0.2	97	0.9	110	8.7	716	10.2
Greater than 14 days	9	0.3	101	0.9	74	5.9	471	6.7
Average	1.1	na	1.3	na	2.7	na	3.0	na
Median	1	na	1	na	1	na	1	na

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

Figure 11 Trends in time from referral to first contact by setting

Inpatient setting for **QLD**
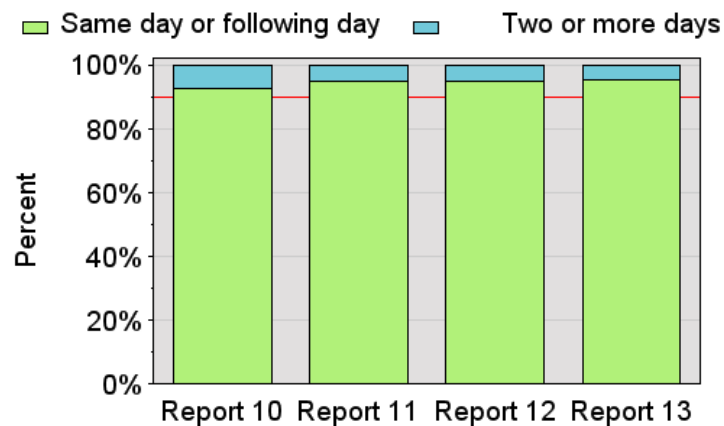
Inpatient setting for **all services**
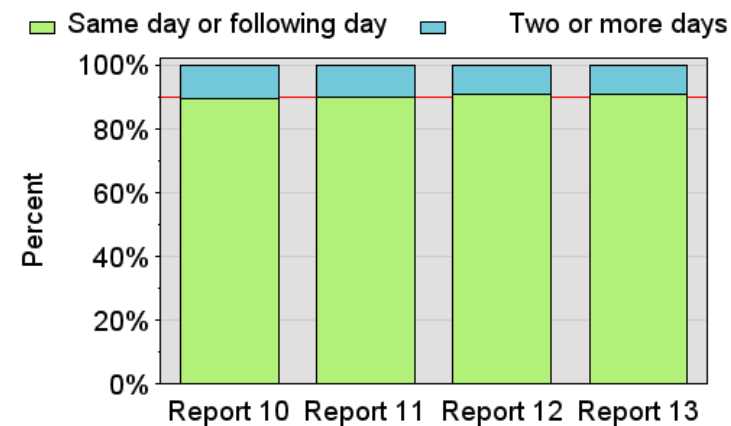
Ambulatory & community settings for **QLD**
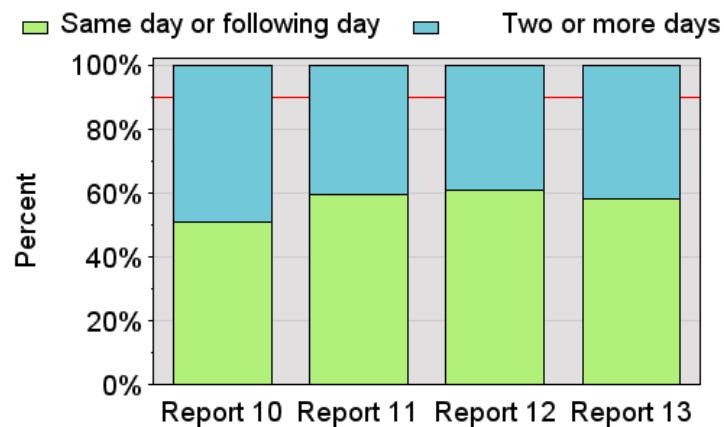
Ambulatory & community settings for **all services**
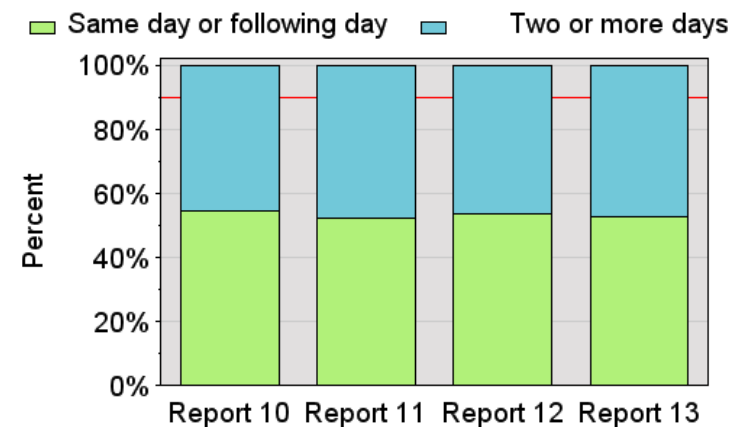
3.2 Outcome measure 2 – Time in unstable phase

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

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

Unstable phases are ended in one of two ways:

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

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 a patient's 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 a patient's 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 a patient's episode of care. To meet this benchmark, the median length of all unstable phases must be **2 days or less**.

Table 8 presents descriptive data for these three benchmarks.

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

Setting	Occurrence of unstable phase	Number of unstable phases		Percent unstable for < 7 days		Median days in unstable phase	
		QLD	All Services	QLD	All Services	QLD	All Services
Inpatient	First phase of episode	1,449	5,046	84.1	85.5	2	2
	Not first phase of episode	380	2,275	86.1	90.2	2	2
	Total unstable phases	*1,829*	*7,321*	*84.5*	*86.9*	*2*	*2*
Ambulatory & community	First phase of episode	131	846	70.2	64.7	2	4
	Not first phase of episode	208	1,141	64.9	70.7	3	2
	Total unstable phases	*339*	*1,987*	*67.0*	*68.1*	*3*	*3*

Interpretation hint:

For QLD, **1,449** patients commenced their **inpatient episode** of care in the unstable phase. Of these unstable phases, **84.1%** remained for less than 7 days. This was **lower** than the **85.5%** seen across all participating services.

For QLD, **131** patients commenced their **ambulatory/community episode** of care in the unstable phase. Of these unstable phases, **70.2%** remained for less than 7 days. This was **higher** than the **64.7%** seen across all participating services.

3.3 Outcome measure 3 – Change in pain

Pain management is acknowledged as a core business of palliative care services. The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS) provide two different perspectives of pain: the SAS is patient rated, while the PCPSS is clinician rated. There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain, and the other relating to the management of pain for patients with moderate or severe pain. The PCPSS is rated from 0 to 3 (absent, mild, moderate and severe) whereas the SAS is rated on a scale of 0 to 10 (0 = absent and 10 = the worst possible). For the analysis in this report SAS scores have been grouped as 1-3 mild, 4-7 moderate and 8-10 severe.

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

Benchmark 3.1: This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild pain. Table 9 shows trends in this benchmark over the last four reports.

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

Setting		QLD				All Services			
		Report 10	Report 11	Report 12	Report 13*	Report 10	Report 11	Report 12	Report 13*
Inpatient	Number	898	1,162	1,311	1,533	3,969	5,153	5,577	7,362
	%	83.1	88.0	86.4	88.6	79.0	82.1	81.6	86.2
Ambulatory & community	Number	406	312	340	346	2,415	2,176	2,339	3,276
	%	75.5	76.3	74.7	72.5	74.9	75.1	77.5	80.0

Benchmark 3.2: This benchmark relates to patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 60% of these phases must end with the patient's pain reduced to being absent or mild. Table 10 shows trends in this benchmark over the last four reports.

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

Setting		QLD				All Services			
		Report 10	Report 11	Report 12	Report 13*	Report 10	Report 11	Report 12	Report 13*
Inpatient	Number	510	562	575	581	1,655	1,858	1,986	2,220
	%	52.4	57.6	62.5	58.6	46.6	48.0	53.6	51.1
Ambulatory & community	Number	110	82	88	108	806	646	697	742
	%	53.9	53.2	47.3	45.4	57.5	57.3	55.4	48.3

Benchmark 3.3: This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild pain. Table 11 shows trends in this benchmark over the last four reports.

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

Setting		QLD				All Services			
		Report 10	Report 11	Report 12	Report 13*	Report 10	Report 11	Report 12	Report 13*
Inpatient	Number	836	940	1,112	1,268	4,672	5,902	6,476	8,179
	%	84.6	87.5	87.6	87.6	78.8	81.8	82.5	84.5
Ambulatory & community	Number	356	287	304	307	2,825	2,566	2,816	4,112
	%	74.2	77.2	74.3	70.7	76.4	76.8	78.1	80.9

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

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

Setting		QLD				All Services			
		Report 10	Report 11	Report 12	Report 13*	Report 10	Report 11	Report 12	Report 13*
Inpatient	Number	512	523	511	624	1,912	2,159	2,216	2,789
	%	46.6	45.1	51.7	47.7	45.7	46.4	49.6	47.9
Ambulatory & community	Number	125	80	94	98	846	708	787	911
	%	48.1	46.8	43.5	36.3	55.3	57.0	56.2	45.1

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

Figure 12 Trends in outcome measure 3

Benchmark 3.1: Absent/mild pain at both start and end of phase (using PCPSS)
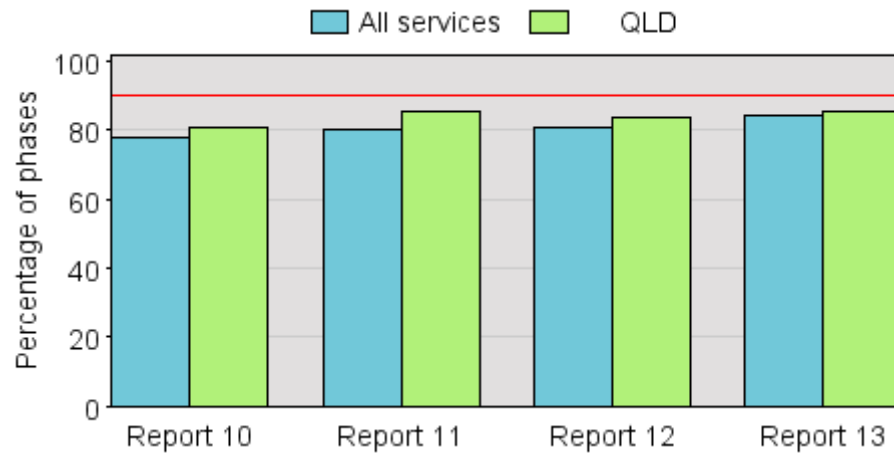
Benchmark 3.2: Mod/severe pain at start with absent/mild pain at end (using PCPSS)
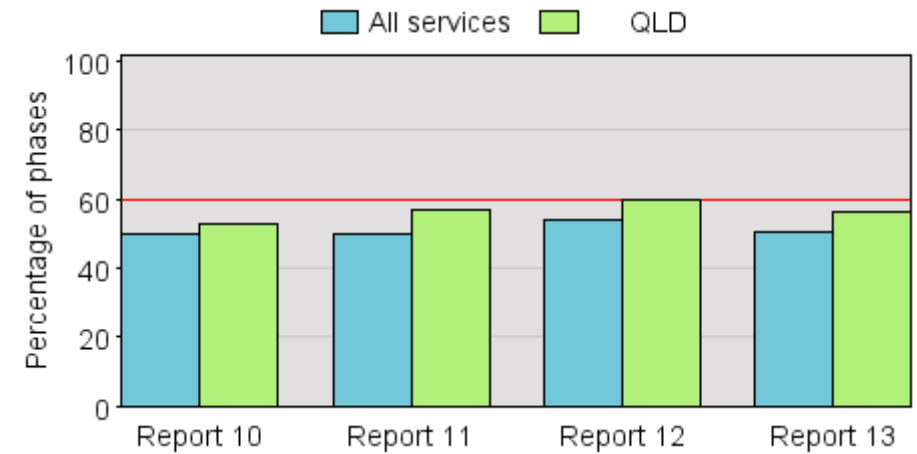
Benchmark 3.3: Absent/mild pain at both start and end of phase (using SAS)
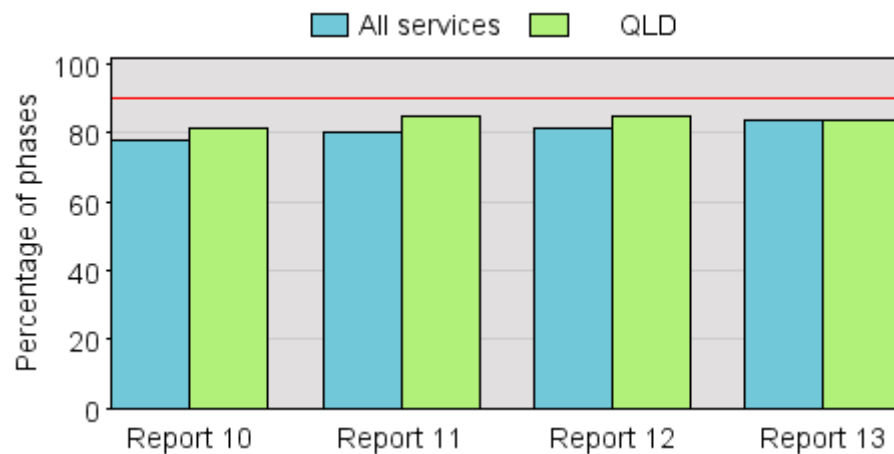
Benchmark 3.4: Mod/severe pain at start with absent/mild pain at end (using SAS)

3.4   Outcome measure 4 – 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 in this report:

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

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

Interpretation hint:

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

If X-CAS for QLD is greater than 0 then on average, patients' change in symptom was better than similar patients in the baseline reference period.
If X-CAS for QLD is equal to 0 then on average, patients' change in symptom was about the same as similar patients in the baseline reference period.
If X-CAS for QLD is less than 0 then on average, 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 13 Trends in outcome measure 4 – Palliative Care Problem Severity Score (PCPSS)

Benchmark 4.1: Pain

Benchmark 4.2: Other symptoms

Benchmark 4.3: Family/carer

Benchmark 4.4: Psychological/spiritual
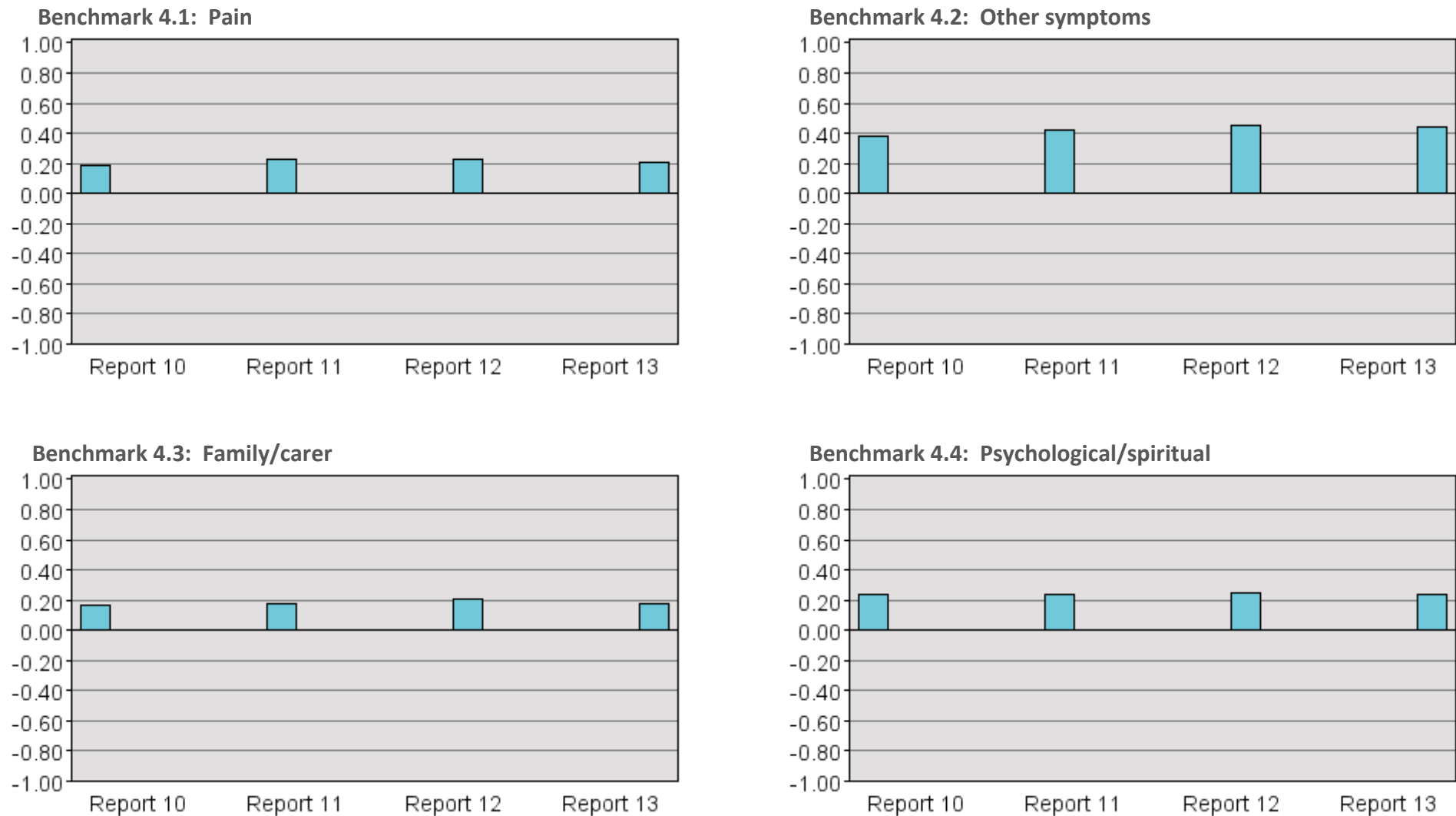
Figure 14 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)

Benchmark 4.5: Pain

Benchmark 4.6: Nausea

Benchmark 4.7: Breathing problems

Benchmark 4.8: Bowel problems
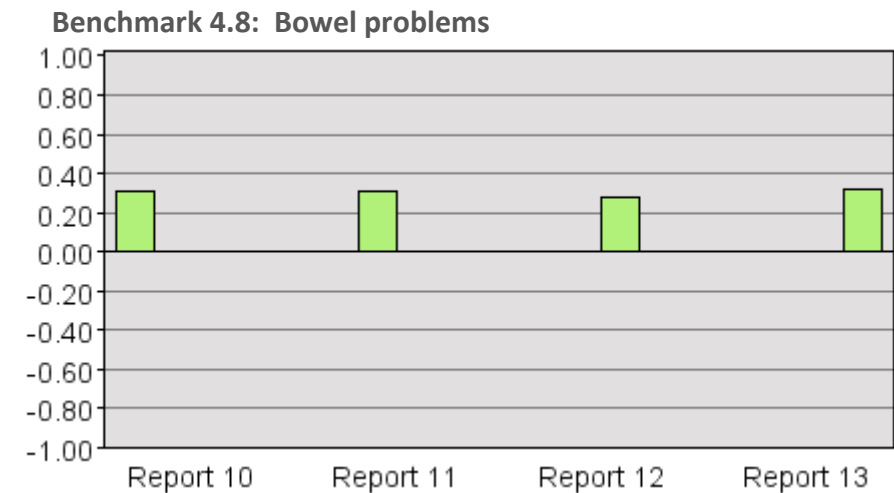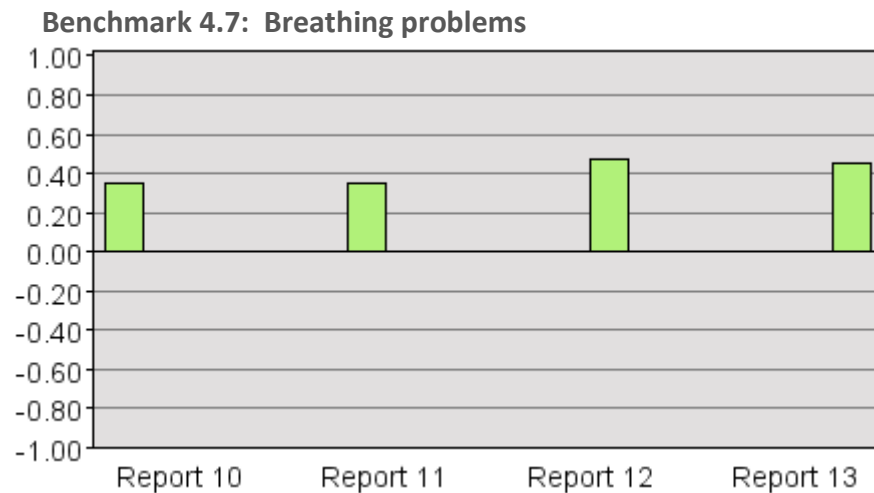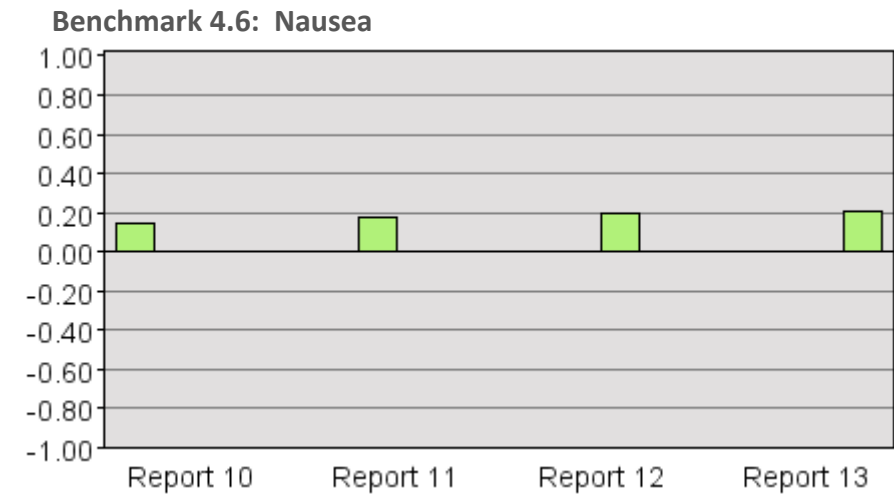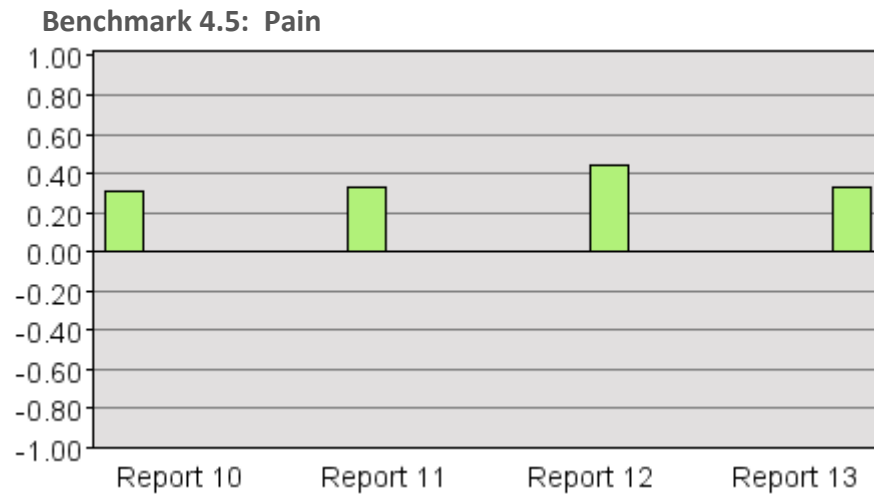
Section 4 - Descriptive analysis

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

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

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

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

4.1 Profile of palliative care patients

The information collected on each patient includes Indigenous status, sex, main language spoken at home and country of birth. Table 13 shows the Indigenous status for all patients in QLD and 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 13 Indigenous status

Indigenous status	QLD	%	All Services	%
Aboriginal but not Torres Strait Islander origin	31	0.9	137	0.9
Torres Strait Islander but not Aboriginal origin	7	0.2	15	0.1
Both Aboriginal and Torres Strait Islander origin	4	0.1	15	0.1
Neither Aboriginal nor Torres Strait Islander origin	3,322	95.7	14,732	95.0
Not stated/inadequately described	108	3.1	606	3.9
Total	3,472	100.0	15,505	100.0

The following two tables show the main language spoken at home and the country of birth respectively for all patients in QLD and nationally. To allow for comparison with the broader Australian community the list of languages in Table 14 is in descending order of the most frequently spoken languages according to the 2006 Census (e.g. Greek was the third most frequently spoken language in the 2006 Census). The same approach has been taken with Table 15 (e.g. Italy was the third highest country of birth in the 2006 Census). All other languages and countries have been grouped together to form the categories *All other languages* and *All other countries* respectively.

Table 14 Main language spoken at home

Main language spoken at home	QLD	%	All Services	%
English	3,336	96.1	13,181	85.0
Italian	17	0.5	268	1.7
Greek	11	0.3	194	1.3
Cantonese	1	0.0	80	0.5
Arabic (including Lebanese)	0	0.0	59	0.4
Mandarin	1	0.0	63	0.4
Vietnamese	5	0.1	69	0.4
Spanish	4	0.1	45	0.3
German	5	0.1	15	0.1
Hindi	1	0.0	6	0.0
Macedonian	1	0.0	54	0.3
Croatian	4	0.1	52	0.3
Korean	0	0.0	10	0.1
Turkish	0	0.0	15	0.1
Polish	3	0.1	45	0.3
All other languages	27	0.8	322	2.1
Not stated/inadequately described	56	1.6	1,027	6.6
Total	3,472	100.0	15,505	100.0

Table 15 Country of birth

Country of birth	QLD	%	All Services	%
Australia	2,640	76.0	9,768	63.0
England	227	6.5	1,124	7.2
Italy	108	3.1	249	1.6
Scotland	5	0.1	145	0.9
New Zealand	34	1.0	572	3.7
Greece	6	0.2	95	0.6
Netherlands	4	0.1	92	0.6
Germany	44	1.3	200	1.3
China	12	0.3	38	0.2
Poland	10	0.3	327	2.1
Malta	42	1.2	205	1.3
Croatia	6	0.2	60	0.4
Ireland	5	0.1	40	0.3
India	39	1.1	168	1.1
Vietnam	2	0.1	68	0.4
All other countries	197	5.7	1,635	10.5
Not stated/inadequately described	91	2.6	719	4.6
Total	3,472	100.0	15,505	100.0

Table 16 on the following page presents a breakdown of malignant and non-malignant diagnosis.

Table 16 Primary diagnosis

Diagnosis category	Primary diagnosis	QLD	% of category	% of total	All Services	% of category	% of total
Malignant	Bone and soft tissue	46	1.6	1.3	238	1.9	1.5
	Breast	241	8.4	6.9	958	7.8	6.2
	CNS	47	1.6	1.4	194	1.6	1.3
	Colorectal	310	10.8	8.9	1,370	11.2	8.8
	Gynaecological	168	5.8	4.8	585	4.8	3.8
	Haematological	173	6.0	5.0	623	5.1	4.0
	Head and neck	166	5.8	4.8	671	5.5	4.3
	Lung	616	21.4	17.7	2,470	20.1	15.9
	Pancreas	159	5.5	4.6	767	6.2	4.9
	Prostate	239	8.3	6.9	794	6.5	5.1
	Skin	137	4.8	3.9	432	3.5	2.8
	Other GIT	199	6.9	5.7	995	8.1	6.4
	Other urological	123	4.3	3.5	442	3.6	2.9
	Other malignancy	168	5.8	4.8	724	5.9	4.7
	Unknown primary	84	2.9	2.4	338	2.8	2.2
	Malignant - not further defined	0	0.0	0.0	677	5.5	4.4
	All malignant	*2,876*	*100.0*	*82.8*	*12,278*	*100.0*	*79.2*
Non-malignant	Cardiovascular	138	23.8	4.0	555	20.3	3.6
	HIV/AIDS	2	0.3	0.1	4	0.1	0.0
	Kidney failure	58	10.0	1.7	290	10.6	1.9
	Neurological disease	127	21.9	3.7	558	20.4	3.6
	Respiratory failure	93	16.1	2.7	439	16.1	2.8
	Other non-malignancy	161	27.8	4.6	804	29.4	5.2
	Non-malignant - not further defined	0	0.0	0.0	82	3.0	0.5
	All non-malignant	*579*	*100.0*	*16.7*	*2,732*	*100.0*	*17.6*
Not Stated	-	*17*	*100.0*	*0.5*	*495*	*100.0*	*3.2*

4.2   Profile of palliative care episodes

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

An episode of palliative care begins on the day the patient is assessed 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

Table 17 below presents the number and percentage of episodes by age group and gender for the patients in QLD and at the national level. Age has been calculated as at the beginning of each episode.

Table 17 Age group by gender

Age group	QLD				All Services			
	Male	%	Female	%	Male	%	Female	%
< 15	14	0.6	9	0.4	40	0.4	44	0.5
15-24	10	0.4	11	0.5	31	0.3	28	0.3
25-34	20	0.8	19	0.9	48	0.5	68	0.8
35-44	65	2.6	70	3.5	245	2.4	272	3.1
45-54	153	6.2	232	11.6	630	6.1	800	9.0
55-64	470	19.1	428	21.3	1,822	17.8	1,645	18.5
65-74	731	29.7	486	24.2	2,761	26.9	1,995	22.5
75-84	710	28.9	454	22.6	3,160	30.8	2,335	26.3
85+	287	11.7	296	14.8	1,517	14.8	1,699	19.1
Not stated/inadequately described	0	0.0	0	0.0	1	0.0	0	0.0
Total	2,460	100.0	2,005	100.0	10,255	100.0	8,886	100.0

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

Referral source refers to the service or organisation from which the patient was referred for each episode of care. Table 18 presents referral source by episode type. Review of referral source can identify opportunities to connect with referral sources that are currently lower than the national referral profile (e.g. a community service with few GP referrals may want to re-address referral or triage practices and look to working more collaboratively).

Table 18 Referral source by setting

Referral source	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
Public hospital - other than inpatient palliative care unit	1,799	56.3	5,063	46.1	469	36.9	3,531	43.2
Self, carer(s), family or friends	142	4.4	323	2.9	52	4.1	235	2.9
Private hospital - other than inpatient palliative care unit	280	8.8	714	6.5	64	5.0	1,349	16.5
Public palliative care inpatient unit/hospice	98	3.1	220	2.0	193	15.2	322	3.9
Private palliative care inpatient unit/hospice	21	0.7	83	0.8	43	3.4	114	1.4
General medical practitioner	174	5.4	537	4.9	180	14.2	1,166	14.3
Specialist medical practitioner	147	4.6	567	5.2	152	12.0	588	7.2
Community-based palliative care agency	430	13.5	2,225	20.3	55	4.3	151	1.8
Community-based service	32	1.0	461	4.2	37	2.9	193	2.4
Residential aged care facility	12	0.4	75	0.7	7	0.6	265	3.2
Other	10	0.3	99	0.9	8	0.6	169	2.1
Not stated/inadequately described	51	1.6	616	5.6	10	0.8	91	1.1
Total	3,196	100.0	10,983	100.0	1,270	100.0	8,174	100.0

Table 19 Place of death – ambulatory & community setting

Place of death	QLD	%	All Services	%
Private residence	90	32.0	1,237	53.1
Residential aged care setting	15	5.3	449	19.3
Other location*	100	35.6	452	19.4
Not stated/inadequately described	76	27.0	190	8.2
Total	281	100.0	2,328	100.0

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

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

Table 20 Length of episode summary by setting

Length of episode	Inpatient		Ambulatory & community	
	QLD	All Services	QLD	All Services
Average length of episode	10.1	11.9	32.6	34.7
Median length of episode	6.0	7.0	19.0	22.0

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

Table 21 Length of episode by setting

Length of episode	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
Same day	130	4.2	389	3.7	266	23.8	713	9.4
1-2 days	651	21.2	2,047	19.4	52	4.7	529	7.0
3-4 days	499	16.2	1,497	14.2	34	3.0	418	5.5
5-7 days	552	18.0	1,730	16.4	49	4.4	570	7.5
8-14 days	614	20.0	2,120	20.1	101	9.0	896	11.9
15-21 days	269	8.7	1,067	10.1	87	7.8	612	8.1
22-30 days	158	5.1	742	7.0	66	5.9	631	8.4
31-60 days	160	5.2	742	7.0	150	13.4	1,194	15.8
61-90 days	23	0.7	125	1.2	95	8.5	643	8.5
Greater than 90 days	19	0.6	83	0.8	218	19.5	1,348	17.8
Total	3,075	100.0	10,542	100.0	1,118	100.0	7,554	100.0

4.3 Profile of palliative care phases

The palliative care phase type describes the stage of the patient's illness and provides a clinical indication of the level of care a patient requires. There are five palliative care phase types; stable, unstable, deteriorating, terminal and bereaved. The stable, unstable, deteriorating and terminal phase types can occur in any sequence and a patient may move back and forth between them.

Table 22 Number of phases by phase type and setting

Phase type	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
Stable	1,351	18.2	6,797	24.4	770	36.7	5,193	36.7
Unstable	1,829	24.7	7,321	26.3	339	16.1	1,987	14.1
Deteriorating	2,304	31.1	7,634	27.4	792	37.7	5,421	38.4
Terminal	1,188	16.0	4,480	16.1	115	5.5	1,373	9.7
Bereaved	742	10.0	1,582	5.7	84	4.0	159	1.1
All phases	7,414	100.0	27,814	100.0	2,100	100.0	14,133	100.0

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

Phase type	Inpatient		Ambulatory & community	
	QLD	All Services	QLD	All Services
Stable	6.0	7.5	22.4	23.2
Unstable	3.8	3.6	8.7	8.0
Deteriorating	6.0	5.5	14.7	16.2
Terminal	2.2	2.2	5.6	3.1
Bereaved	1.0	1.2	1.8	3.0

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

Table 24 presents information relating to the manner in which stable phases ended, both for QLD and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 15 and Figure 16 summarise the movement of patients out of the stable phase for the inpatient and ambulatory & community settings. This movement from one phase to another is referred to as phase progression. The phase progression information is derived by PCOC. The "Unknown" category has been included to account for situations where subsequent phase records have not been submitted to PCOC, meaning the phase progression cannot be determined.

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

Table 24 How stable phases end – by setting

Phase end reason	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
Phase change (see figures below)	616	45.6	3,986	58.6	355	46.1	3,062	59.0
Discharge/case closure	712	52.7	2,651	39.0	340	44.2	1,704	32.8
Died	20	1.5	151	2.2	58	7.5	401	7.7
Bereavement phase end	1	0.1	5	0.1	0	0.0	4	0.1
Not stated/inadequately described	2	0.1	4	0.1	17	2.2	22	0.4
Total	1,351	100.0	6,797	100.0	770	100.0	5,193	100.0

Figure 15 Stable phase progression – inpatient setting

Figure 16 Stable phase progression – ambulatory & community settings
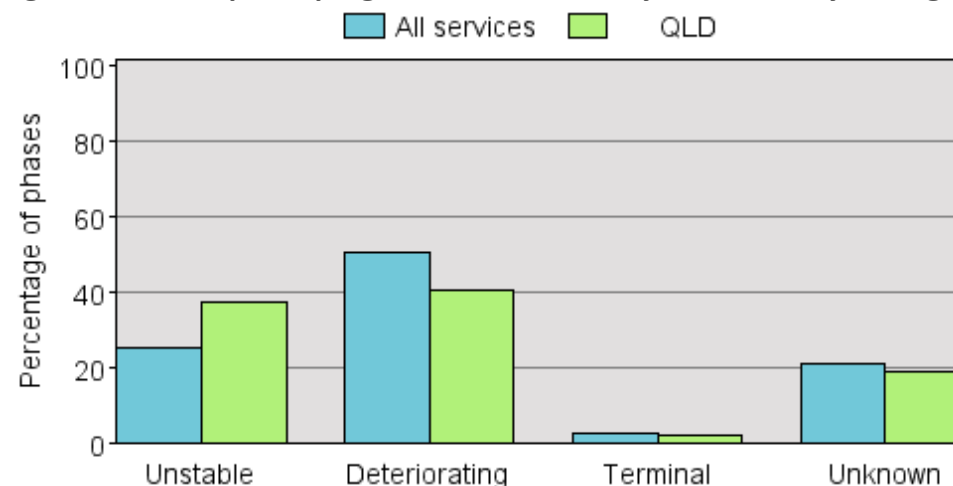
Table 25 How _unstable_ phases end – by setting

Phase end reason	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
Phase change (see figures below)	1,593	87.1	6,498	88.8	203	59.9	1,323	66.6
Discharge/case closure	177	9.7	483	6.6	125	36.9	557	28.0
Died	36	2.0	296	4.0	8	2.4	101	5.1
Bereavement phase end	0	0.0	14	0.2	1	0.3	1	0.1
Not stated/inadequately described	23	1.3	30	0.4	2	0.6	5	0.3
Total	_1,829_	_100.0_	_7,321_	_100.0_	_339_	_100.0_	_1,987_	_100.0_

Figure 17 Unstable phase progression – inpatient setting
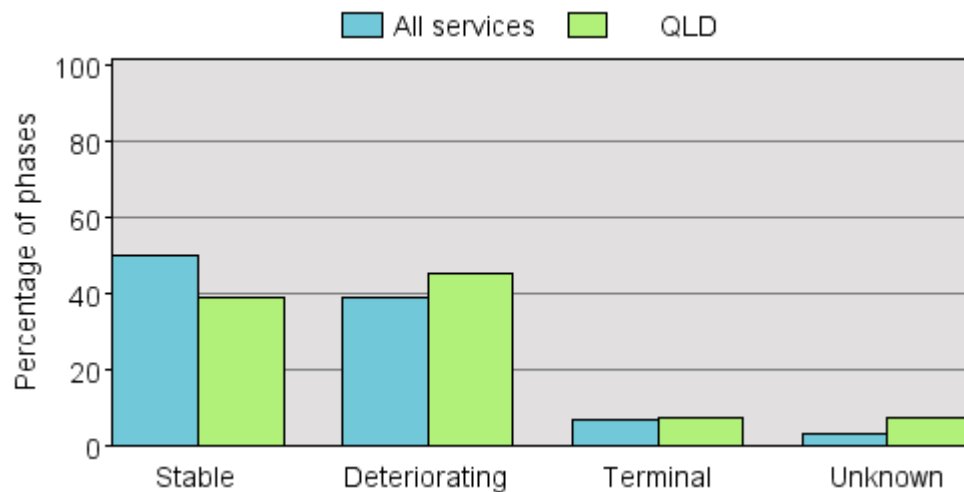
Figure 18 Unstable phase progression – ambulatory & community settings
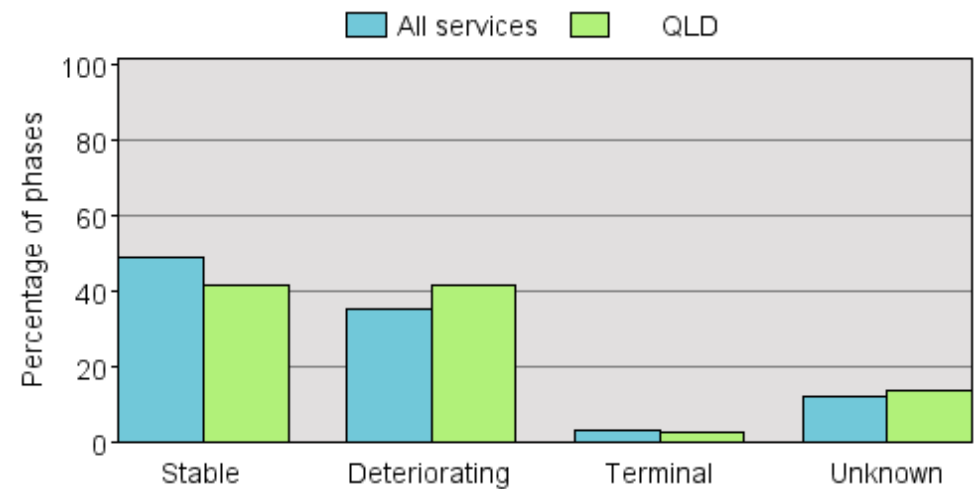
Table 26 How _deteriorating_ phases end – by setting

Phase end reason	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
Phase change (see figures below)	1,272	55.2	5,211	68.3	344	43.4	2,577	47.5
Discharge/case closure	769	33.4	1,178	15.4	338	42.7	2,043	37.7
Died	236	10.2	1,185	15.5	104	13.1	792	14.6
Bereavement phase end	13	0.6	40	0.5	0	0.0	2	0.0
Not stated/inadequately described	14	0.6	20	0.3	6	0.8	7	0.1
Total	_2,304_	_100.0_	_7,634_	_100.0_	_792_	_100.0_	_5,421_	_100.0_

Figure 19 Deteriorating phase progression – inpatient setting

Figure 20 Deteriorating phase progression – ambulatory & community settings
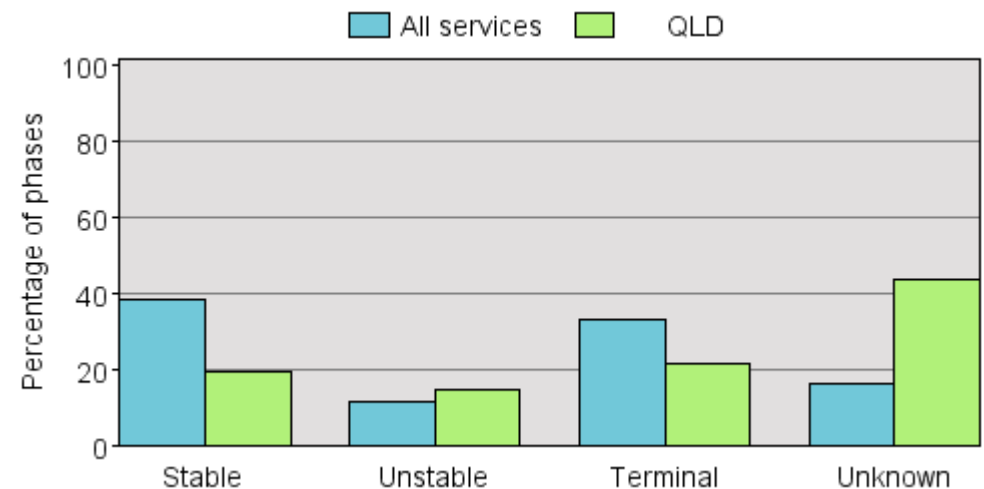
Table 27 How terminal phases end – by setting

Phase end reason	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
Phase change (see figures below)	97	8.2	519	11.6	28	24.3	293	21.3
Discharge/case closure	31	2.6	95	2.1	16	13.9	157	11.4
Died	972	81.8	3,720	83.0	69	60.0	917	66.8
Bereavement phase end	84	7.1	135	3.0	1	0.9	2	0.1
Not stated/inadequately described	4	0.3	11	0.2	1	0.9	4	0.3
Total	*1,188*	*100.0*	*4,480*	*100.0*	*115*	*100.0*	*1,373*	*100.0*

Figure 21 Terminal phase progression – inpatient setting

Figure 22 Terminal phase progression – ambulatory & community settings

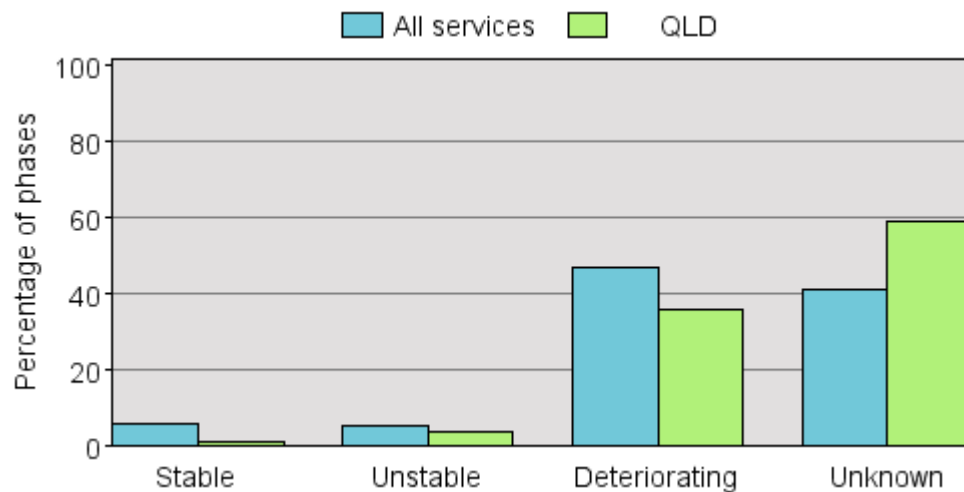The Palliative Care Problem Severity Score (PCPSS) is a '**clinician rated' screening tool** to assess the overall degree of problems within four key palliative care domains (pain, other symptoms, psychological/spiritual and family/carer). The ratings are: 0 = absent, 1 = mild, 3 = moderate and 4 = severe. The use of this tool provides an opportunity to assist in the need or urgency of intervention e.g. a score of severe in the family/carer domain could trigger a more detailed assessment by a skilled social worker or pastoral care worker to establish appropriate treatment or intervention.

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

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

Phase type	Problem severity	QLD				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	41.4	44.8	10.9	2.9	44.0	38.5	14.1	3.5
	Other symptoms	30.4	47.8	18.9	3.0	21.7	44.0	26.2	8.1
	Psychological/spiritual	35.7	47.9	13.5	2.8	27.5	47.5	18.7	6.3
	Family/carer	37.8	42.2	16.7	3.4	36.3	40.1	17.1	6.5
Unstable	Pain	19.8	32.9	31.7	15.5	25.5	29.0	30.1	15.5
	Other symptoms	10.4	30.2	41.5	17.9	9.4	26.9	40.3	23.4
	Psychological/spiritual	18.7	39.5	29.2	12.7	16.2	38.0	31.4	14.4
	Family/carer	23.5	33.5	30.2	12.7	22.4	34.6	28.6	14.5
Deteriorating	Pain	33.0	39.6	19.3	8.1	36.3	33.3	21.6	8.7
	Other symptoms	13.7	41.1	33.1	12.1	13.1	30.7	36.1	20.0
	Psychological/spiritual	23.9	46.3	21.9	7.9	21.7	40.6	25.8	11.9
	Family/carer	22.5	40.9	25.8	10.9	25.3	33.9	26.4	14.5
Terminal	Pain	47.5	33.6	13.3	5.6	44.9	29.7	17.0	8.4
	Other symptoms	39.5	29.1	20.0	11.4	30.2	23.7	24.0	22.1
	Psychological/spiritual	53.3	27.0	13.0	6.8	44.3	28.5	15.8	11.5
	Family/carer	18.2	32.0	32.0	17.7	16.9	28.6	29.8	24.8

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

Phase type	Problem severity	QLD				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	43.0	42.2	12.5	2.3	37.8	48.3	12.0	1.9
	Other symptoms	22.3	53.5	22.1	2.1	14.1	55.3	27.2	3.4
	Psychological/spiritual	39.6	44.3	14.7	1.4	24.0	53.2	19.2	3.6
	Family/carer	43.8	37.6	16.1	2.5	22.7	47.0	24.5	5.8
Unstable	Pain	14.5	28.0	35.7	21.8	15.9	30.7	34.2	19.2
	Other symptoms	7.1	29.2	44.8	18.9	4.9	23.9	46.6	24.6
	Psychological/spiritual	18.3	38.1	31.6	12.1	12.0	35.6	35.5	16.9
	Family/carer	22.4	30.7	33.0	13.9	14.9	25.5	33.9	25.7
Deteriorating	Pain	24.0	39.9	26.5	9.5	24.5	45.7	24.1	5.7
	Other symptoms	4.3	33.8	48.9	13.0	5.4	34.1	47.6	12.9
	Psychological/spiritual	19.3	40.2	33.1	7.4	15.7	45.6	30.6	8.1
	Family/carer	17.4	35.4	39.0	8.2	12.3	33.9	40.7	13.1
Terminal	Pain	43.5	34.8	13.9	7.8	32.3	43.1	19.7	4.9
	Other symptoms	24.3	33.0	25.2	17.4	18.0	32.9	30.9	18.2
	Psychological/spiritual	44.3	32.2	19.1	4.3	41.6	34.7	15.9	7.8
	Family/carer	9.6	33.0	40.0	17.4	10.8	24.9	39.2	25.1

The Symptom Assessment Scale (SAS) is a 'patient rated' assessment tool and reports a level of distress using a visual analogue scale from 0 = no problems to 10 = worst possible problems. The SAS reports on seven symptoms identified as the main cancer and palliative care problems (difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain). It provides a clinical picture of these seven symptoms from the patients perspective e.g. a patient may rate their nausea at 8, hence an alert for further review. The SAS scores are grouped in tables 30 and 31 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10).

Table 30 Profile of Symptom Assessment Scale scores at beginning of phase by phase type – inpatient setting (percentages)

Phase type	Symptom severity	QLD				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Insomnia	59.5	27.2	11.0	2.3	63.2	20.9	13.7	2.1
	Appetite problems	51.5	25.5	19.7	3.3	47.5	23.0	24.4	5.1
	Nausea	72.3	20.2	6.8	0.7	79.0	13.1	6.7	1.2
	Bowel problems	53.3	29.5	14.4	2.8	57.7	23.2	15.4	3.7
	Breathing problems	61.0	22.6	13.1	3.4	62.2	19.6	13.6	4.6
	Fatigue	26.1	26.7	38.3	8.8	22.9	22.3	42.2	12.6
	Pain	38.2	37.5	21.6	2.7	44.2	32.4	20.0	3.4
Unstable	Insomnia	38.2	24.2	28.5	9.2	50.4	19.7	23.2	6.8
	Appetite problems	27.2	22.9	36.3	13.5	32.8	19.7	33.5	14.0
	Nausea	50.5	21.6	20.4	7.5	63.6	15.7	15.0	5.8
	Bowel problems	35.1	24.8	28.8	11.4	44.6	22.6	23.7	9.1
	Breathing problems	43.4	21.3	23.6	11.7	51.2	19.1	19.3	10.4
	Fatigue	13.2	12.9	47.5	26.4	15.2	12.9	46.0	25.9
	Pain	19.1	23.2	37.3	20.4	28.1	24.0	32.6	15.3
Deteriorating	Insomnia	59.7	18.2	17.6	4.5	64.8	15.9	15.9	3.5
	Appetite problems	42.3	20.2	25.1	12.4	43.6	17.0	26.1	13.3
	Nausea	65.8	17.8	12.0	4.4	74.2	12.8	9.5	3.5
	Bowel problems	48.3	21.1	23.1	7.5	53.2	19.9	20.6	6.3
	Breathing problems	48.2	19.0	22.9	9.9	53.5	17.3	19.5	9.7
	Fatigue	23.0	12.5	39.7	24.8	21.4	10.3	38.9	29.4
	Pain	30.6	27.5	30.8	11.1	37.1	26.8	28.1	7.9
Terminal	Insomnia	87.0	7.4	4.5	1.1	87.1	6.3	5.2	1.4
	Appetite problems	84.6	6.5	4.2	4.7	82.6	4.3	5.4	7.8
	Nausea	89.1	6.2	4.3	0.4	91.1	4.5	3.2	1.1
	Bowel problems	79.7	9.2	8.3	2.8	78.2	9.3	8.8	3.7
	Breathing problems	62.4	14.5	14.3	8.8	61.4	13.3	15.0	10.3
	Fatigue	73.2	6.6	8.8	11.4	64.6	4.5	10.3	20.6
	Pain	55.1	22.2	17.9	4.8	54.3	20.2	20.3	5.2

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

Phase type		QLD				All Services			
	Symptom severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Insomnia	62.9	21.5	12.9	2.7	51.1	34.0	13.3	1.6
	Appetite problems	47.7	29.4	20.0	2.9	32.8	37.9	25.7	3.6
	Nausea	72.0	19.8	7.4	0.8	74.2	20.3	5.1	0.5
	Bowel problems	58.8	27.7	11.4	2.1	56.3	31.7	10.7	1.3
	Breathing problems	58.3	25.4	14.6	1.8	50.8	33.9	13.2	2.0
	Fatigue	20.8	25.7	42.9	10.5	10.0	33.0	48.0	9.0
	Pain	40.3	36.9	20.2	2.6	38.9	44.7	14.9	1.5
Unstable	Insomnia	28.0	32.7	28.9	10.4	34.8	33.1	25.7	6.4
	Appetite problems	21.7	28.9	39.6	9.8	20.0	26.4	41.5	12.2
	Nausea	53.0	21.4	18.5	7.1	54.8	23.2	16.0	6.0
	Bowel problems	39.9	29.8	24.4	6.0	40.5	33.8	20.1	5.6
	Breathing problems	47.9	22.6	22.9	6.5	43.2	29.6	22.2	5.0
	Fatigue	9.8	9.8	51.5	28.9	5.8	12.8	59.3	22.1
	Pain	15.5	23.5	38.7	22.3	17.2	30.4	36.7	15.7
Deteriorating	Insomnia	43.5	29.9	21.1	5.5	48.5	30.3	18.5	2.7
	Appetite problems	28.9	29.8	33.0	8.2	25.9	28.6	34.5	11.1
	Nausea	56.3	29.2	12.3	2.2	66.9	22.2	9.4	1.6
	Bowel problems	39.0	33.4	22.6	5.1	50.9	30.3	16.0	2.8
	Breathing problems	34.3	28.7	29.2	7.9	40.7	31.8	22.9	4.7
	Fatigue	10.3	10.7	52.4	26.6	7.3	14.6	55.0	23.0
	Pain	22.1	37.2	34.9	5.8	30.5	39.4	26.4	3.7
Terminal	Insomnia	76.4	13.6	7.3	2.7	75.9	12.3	8.9	2.8
	Appetite problems	67.3	13.6	7.3	11.8	60.2	5.6	10.8	23.4
	Nausea	80.9	10.0	5.5	3.6	86.1	9.7	3.3	0.8
	Bowel problems	73.6	16.4	8.2	1.8	69.9	18.6	9.0	2.4
	Breathing problems	49.1	16.4	26.4	8.2	49.4	22.9	20.5	7.2
	Fatigue	51.8	1.8	10.9	35.5	38.0	2.7	13.1	46.3
	Pain	49.1	30.0	17.3	3.6	43.0	35.5	18.2	3.3

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 Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status. The AKPS is often used in assessment of prognosis and is applicable to both inpatient and community palliative care. Table 32 shows the data for the AKPS at phase start.

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

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

AKPS assessment	Inpatient				Ambulatory & community			
	QLD	%	All Services	%	QLD	%	All Services	%
10 - Comatose or barely rousable	818	12.3	2,635	10.1	56	2.8	654	4.7
20 - Totally bedfast and requiring extensive nursing care	1,348	20.2	5,324	20.4	157	7.8	1,350	9.7
30 - Almost completely bedfast	979	14.7	3,236	12.4	128	6.3	884	6.4
40 - In bed more than 50% of the time	1,147	17.2	4,486	17.2	177	8.8	1,620	11.7
50 - Requires considerable assistance	1,048	15.7	4,669	17.9	480	23.8	3,399	24.4
60 - Requires occasional assistance	939	14.1	3,251	12.4	551	27.3	3,130	22.5
70 - Cares for self	305	4.6	882	3.4	329	16.3	1,801	13.0
80 - Normal activity with effort	54	0.8	252	1.0	113	5.6	579	4.2
90 - Able to carry on normal activity; minor signs or symptoms	12	0.2	64	0.2	17	0.8	166	1.2
100 - Normal; no complaints; no evidence of disease	1	0.0	4	0.0	1	0.0	6	0.0
Not stated/inadequately described	15	0.2	1,328	5.1	7	0.3	316	2.3
Total	6,666	100.0	26,131	100.0	2,016	100.0	13,905	100.0

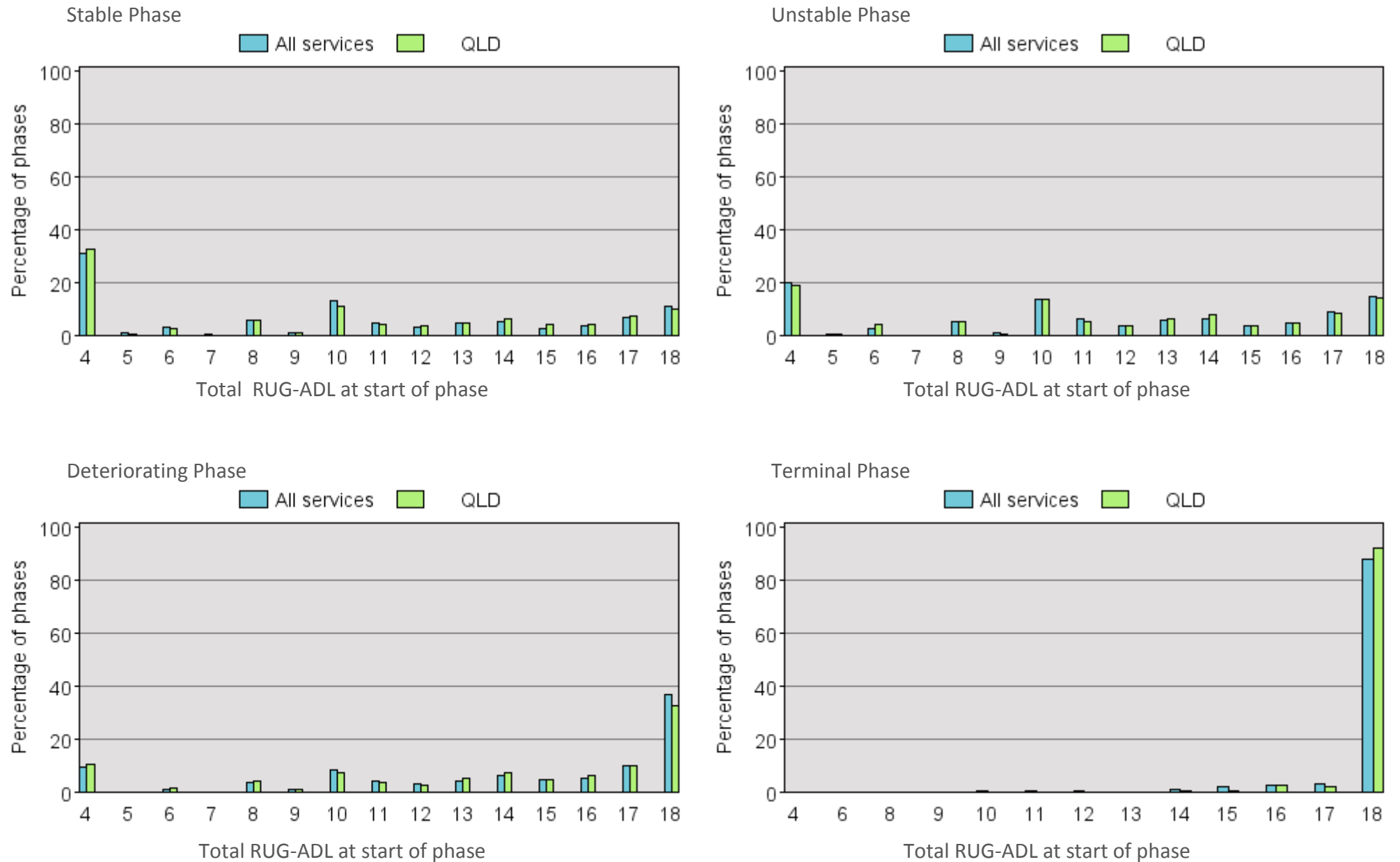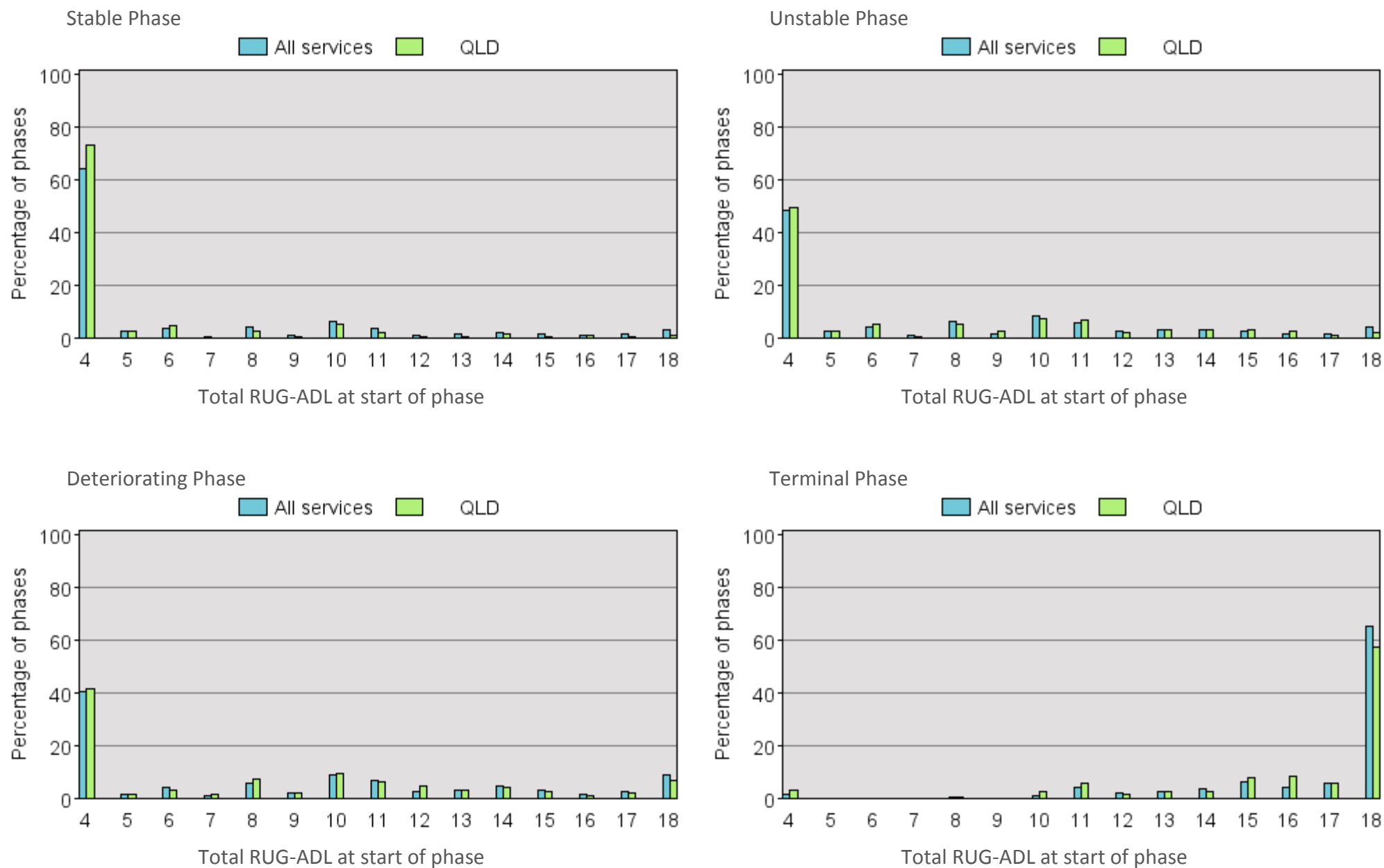Figure 23 Total RUG-ADL at beginning of phase by phase type – inpatient setting

Figure 24 Total RUG-ADL at beginning of phase by phase type – ambulatory & community settings

Stable Phase

Unstable Phase

Deteriorating Phase

Terminal Phase

Appendix A – Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that <u>end</u> 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 25 below displays four examples to help visualize this process.

Figure 25 Diagram of the PCOC data scoping method
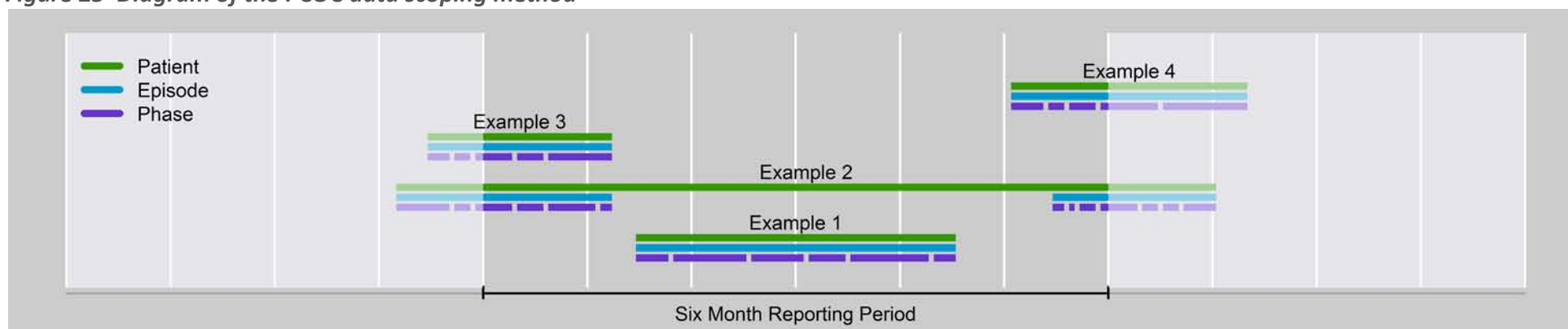
In <u>Example 1</u>, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

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

In <u>Example 3</u>, the patient has one episode and five phases. Only the last three phases will be included in the report as they are the only ones ending within the reporting period (the first two phases would have been included in the previous report). The episode and patient records would be included in the report.

In <u>Example 4</u>, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.

Appendix B – X-CAS technical notes

The procedure for calculating X-CAS is as follows:

Step 1. Using the baseline data, calculate the average change in symptom for <u>all patients</u> 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 <u>change in symptom score</u> (calculated in step 2) and the relevant expected change (calculated in step 1).

Step 4. Average all of the values calculated in step 3 to produce the service's Symptom Casemix-Adjusted Score (e.g. PCAS).

Example:

Phase	PCPSS Pain at start	PCPSS Pain at end	Step 1: Expected PCPSS Pain change (from Report 6 National Database)	Step2: PCPSS Pain change (start score minus end score)	Step 3: Difference (Step 2 minus Step 1)	Step 4: Average of values in step 3
Stable	0	1	-0.8	-1	-0.2	
Stable	1	1	-0.9	0	0.9	$\frac{-0.2+0.9+0.4-0.4}{4}$
Unstable	3	1	1.6	2	0.4	
Deteriorating	2	1	1.4	1	-0.4	= 0.175

Acknowledgements

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.