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## **Outcomes in Palliative Care, Report 11 January - June 2011: Queensland**

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## Outcomes in Palliative Care, Report 11 January - June 2011: Queensland

### Abstract

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

In each of the three sections, data and analysis for 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 2011 period. A full list of these services can be found at [www.pcoc.org.au](http://www.pcoc.org.au)

### Keywords

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# Outcomes in Palliative Care

## Report 11 January – June 2011



Queensland

# 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)

## Contents

Introduction .....	4
Section 1 – Queensland at a Glance .....	5
Section 2 – Benchmark Analysis .....	11
Measure 1 - Time from referral to first contact .....	11
Measure 2 - Time in unstable phase .....	13
Measure 3 - Change in pain .....	14
Measure 4 – Change in symptoms relative to the baseline national average (X-CAS) .....	17
Section 3 - Descriptive analysis.....	20
Profile of palliative care patients .....	21
Profile of palliative care episodes.....	23
Profile of palliative care phases.....	26
Appendix A – Summary of data included in this report .....	36
A1 – Data Summary .....	36
A2 – Data Item Completion .....	37
A3 – Data scoping methodology.....	39
Appendix B – Benchmark Notes .....	40
B1 – Outline of Benchmark Measures and Targets .....	40
B2 – National profile graphs .....	41
B3 – X-CAS technical notes .....	41
Acknowledgements .....	42

## List of Tables

Table 1	Summary of benchmark measures 1-3 .....	5
Table 2	Summary of benchmark measure 4: Change in symptoms relative to the national average (X-CAS) .....	5
Table 3	Time from referral to first contact by episode type .....	11
Table 4	Time in unstable phase by episode type and occurrence of unstable phase .....	13
Table 5	Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase .....	14
Table 6	Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase .....	14
Table 7	Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase .....	15
Table 8	Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase .....	15
Table 9	Indigenous Status - all patients .....	21
Table 10	Primary diagnosis .....	22
Table 11	Referral source by episode type .....	24
Table 12	Place of death - patients not admitted overnight .....	24
Table 13	Length of episode summary .....	25
Table 14	Length of episode breakdown .....	25
Table 15	Number of phases by phase type and episode type .....	26
Table 16	Average phase length (in days) by phase and episode type .....	26
Table 17	Profile of PC Problem Severity Scores at beginning of phase by phase type - overnight admitted (percentages) .....	27
Table 18	Profile of PC Problem Severity Scores at beginning of phase by phase type - not admitted overnight (percentages) .....	28
Table 19	Karnofsky score at phase start by episode type .....	31
Table 20	How stable phases end .....	32
Table 21	How unstable phases end .....	33
Table 22	How deteriorating phases end .....	34
Table 23	How terminal phases end .....	35
Table 24	Number and percentage of patients, episodes and phases - by episode type .....	36
Table 25	Item completion- patient level .....	37
Table 26	Item completion- episode level .....	37
Table 27	Data completion - phase level .....	38

## List of Figures

Figure 1	Time from referral to first contact .....	12
Figure 2	Change in pain benchmark measures - all phases .....	16
Figure 3	PCPSS mean change adjusted for phase and symptom score at start of phase .....	18
Figure 4	SAS mean change adjusted for phase and symptom score at start of phase .....	19
Figure 5	Total RUG-ADL at beginning of phase – overnight admitted patients.....	29
Figure 6	Total RUG-ADL at beginning of phase – patients not admitted overnight .....	30
Figure 7	Stable phase progression - overnight admitted.....	32
Figure 8	Stable phase progression - not admitted overnight .....	32
Figure 9	Unstable phase progression - overnight admitted .....	33
Figure 10	Unstable phase progression - not admitted overnight.....	33
Figure 11	Deteriorating phase progression - overnight admitted .....	34
Figure 12	Deteriorating phase progression - not admitted overnight .....	34
Figure 13	Terminal phase progression - overnight admitted .....	35
Figure 14	Terminal phase progression - not admitted overnight.....	35
Figure 15	Diagram of the PCOC data scoping process.....	39

# 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:

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In each of the three sections, data and analysis for 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 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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Phone: (02) 4221 5093

*“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 – Queensland at a Glance

*Table 1 Summary of benchmark measures 1-3*

Measure	Description	Benchmark	Overnight admitted		Not admitted overnight	
			QLD Score	Benchmark Met?	QLD Score	Benchmark Met?
1. Time from referral to contact	Patients contacted on same or following day	90%	94.6	Yes	59.3	No
2. Time in unstable phase	Patients unstable less than 7 days - first phase	85%	75.9	No	70.6	No
	Patients unstable less than 7 days - Not first phase	90%	74.9	No	75.5	No
	Median time in unstable phase	2 days or less	3 days	No	2 days	Yes
3. Change in pain PC Problem Severity Score (PCPSS)  Symptom Assessment Score (SAS)	Patients with absent/mild pain at phase start remaining absent/mild at phase end	90%	88.0	No	76.3	No
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	57.6	No	53.2	No
	Patients with absent/mild pain at phase start remaining absent/mild at phase end	90%	87.5	No	77.2	No
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	45.1	No	46.8	No

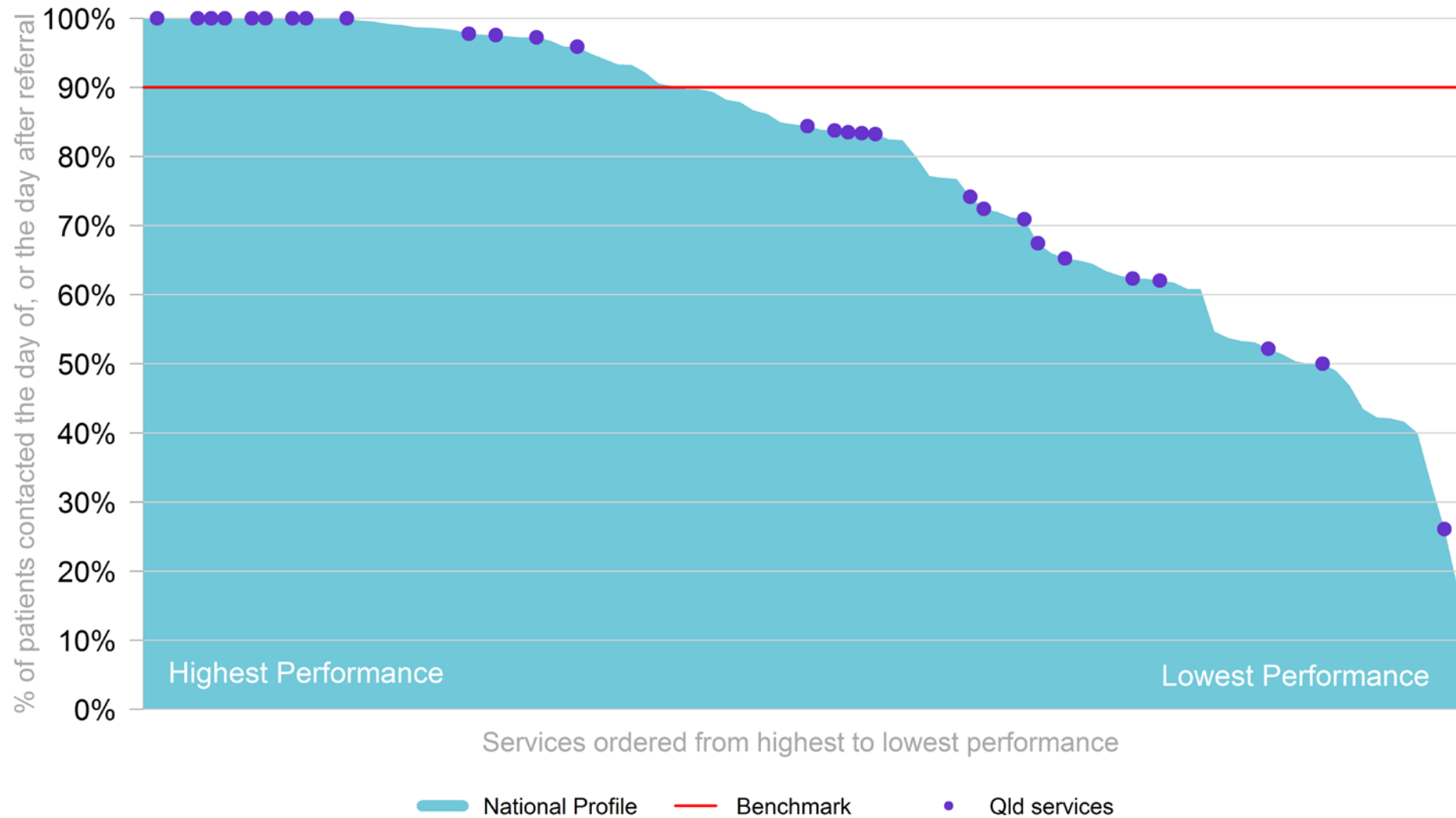
*Table 2 Summary of benchmark measure 4: Change in symptoms relative to the national average (X-CAS)*

Clinical Tool	Symptom	Benchmark	QLD score	Benchmark met?
PC PSS	Pain	0 or above	0.23	Yes
	Other symptoms	0 or above	0.42	Yes
	Family/carer	0 or above	0.17	Yes
	Psychological/spiritual	0 or above	0.23	Yes
SAS	Pain	0 or above	0.33	Yes
	Nausea	0 or above	0.18	Yes
	Breathing	0 or above	0.35	Yes
	Bowels	0 or above	0.31	Yes

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

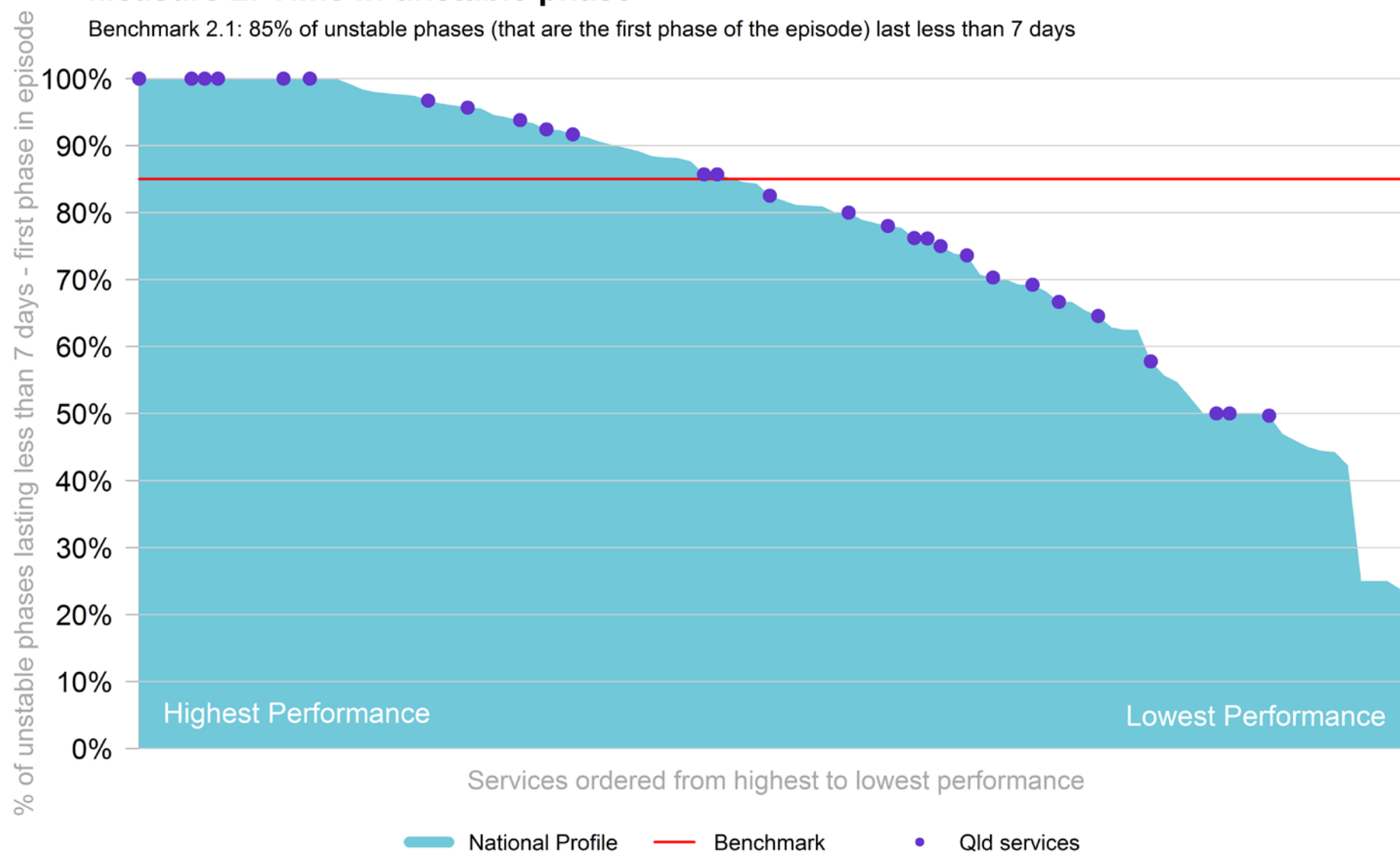
### Measure 1: Time from referral to first contact

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



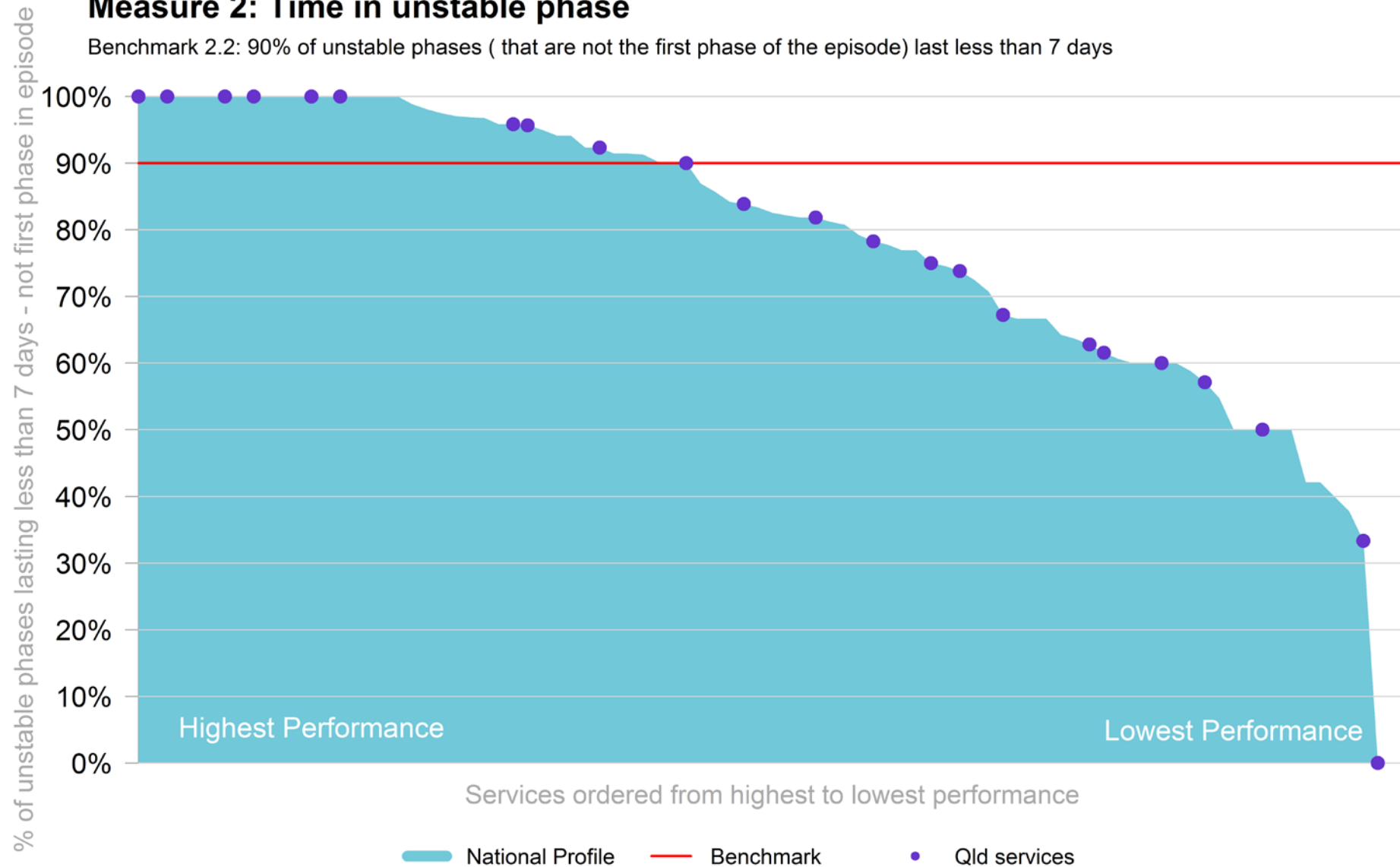
## Measure 2: Time in unstable phase

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



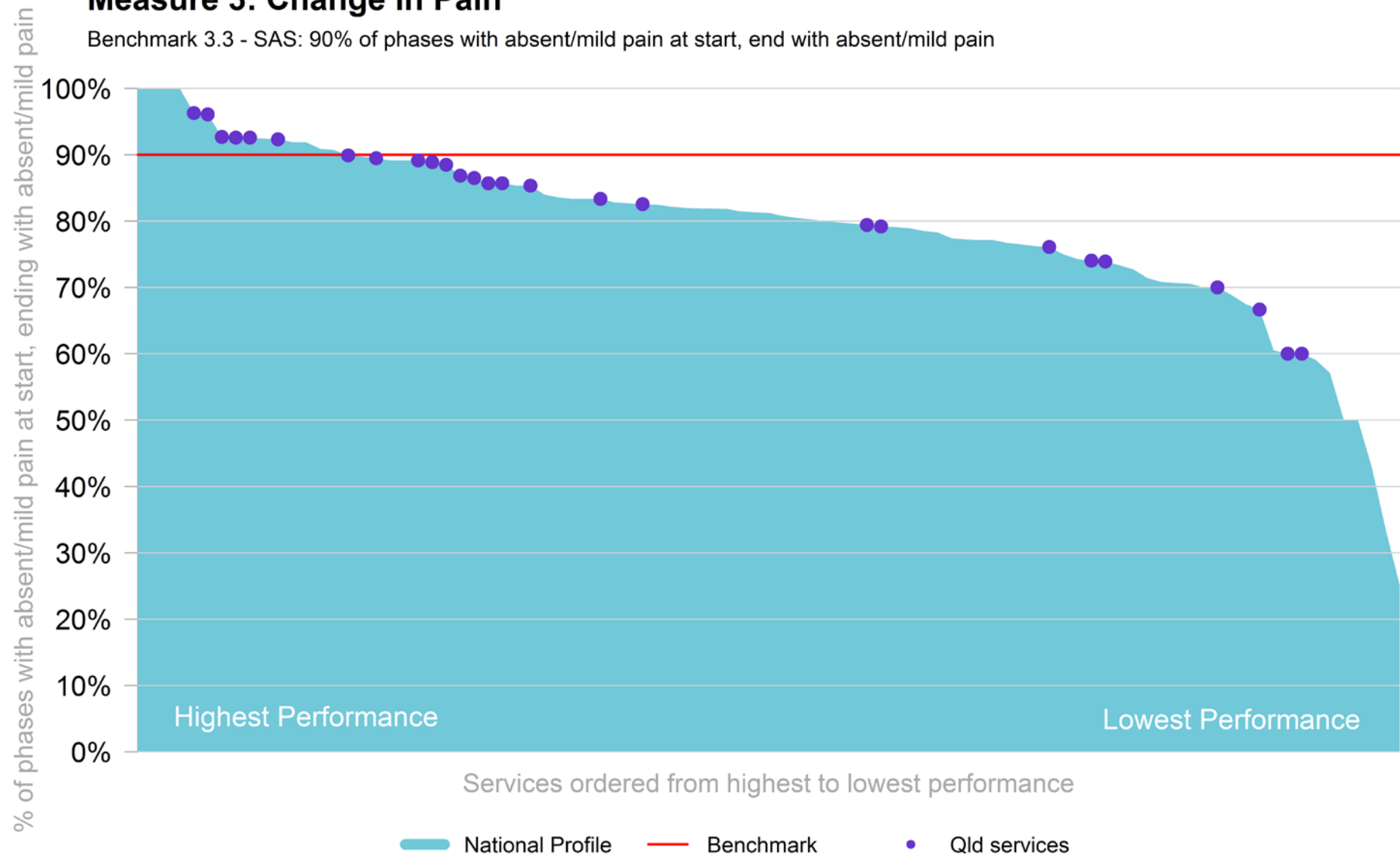
## Measure 2: Time in unstable phase

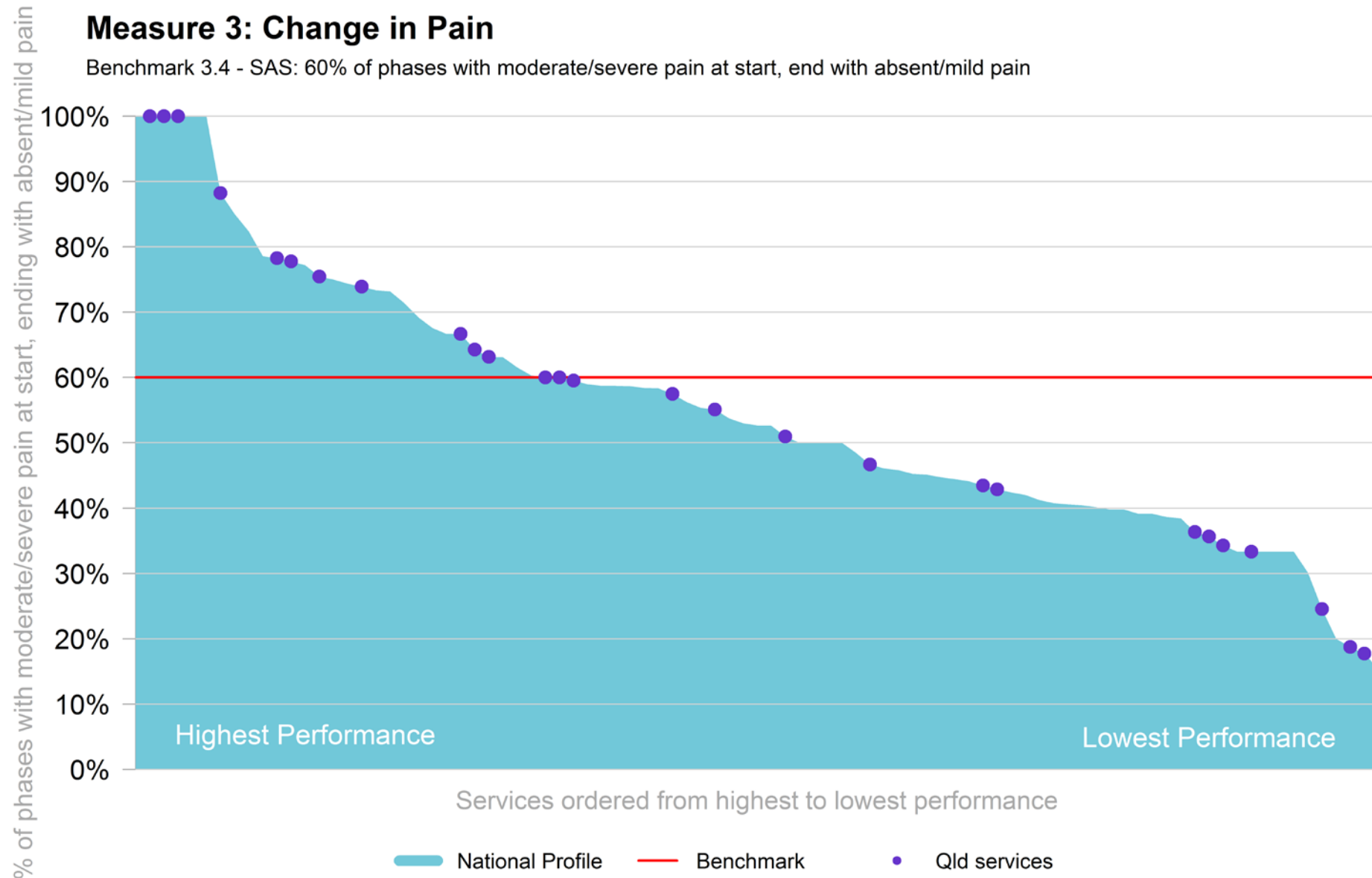
Benchmark 2.2: 90% of unstable phases ( that are not the first phase of the episode) last less than 7 days



### Measure 3: Change in Pain

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





## 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.

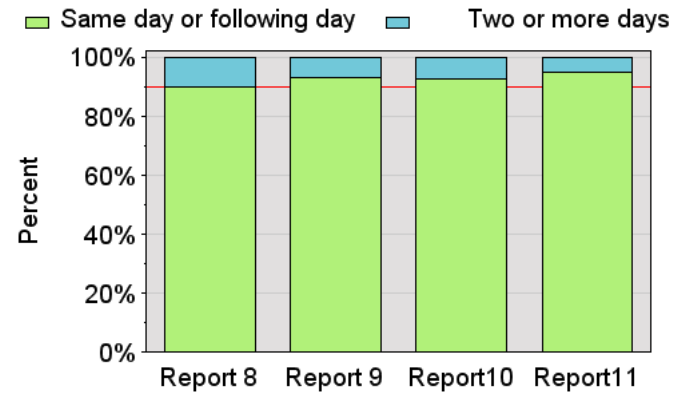
*Table 3 Time from referral to first contact by episode type*

Time (in days)	Overnight admitted				Not admitted overnight			
	QLD	%	All Services	%	QLD	%	All Services	%
Same day or following day	2788	94.6	9127	89.6	733	59.3	3058	52.1
2-7 days	139	4.7	878	8.6	384	31.0	1856	31.6
8-14 days	13	0.4	110	1.1	72	5.8	560	9.5
Greater than 14 days	7	0.2	74	0.7	48	3.9	395	6.7
Average	1.2	na	1.3	na	2.4	na	2.9	na
Median	1	na	1	na	1	na	1	na

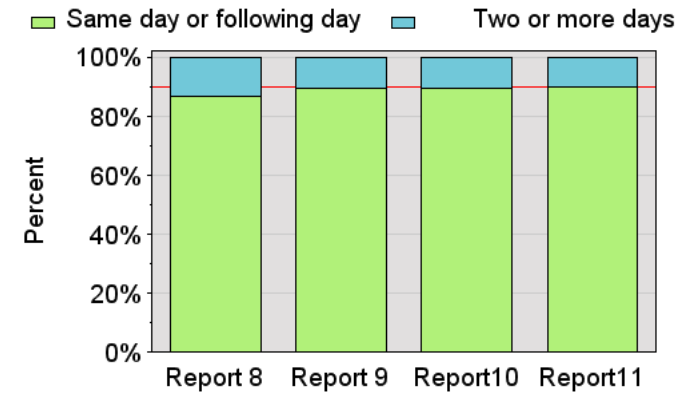
Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact or time from first contact to episode start was greater than 7 days were considered to be outliers and were assumed to equal 7 days for the purpose of calculating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

*Figure 1 Time from referral to first contact*

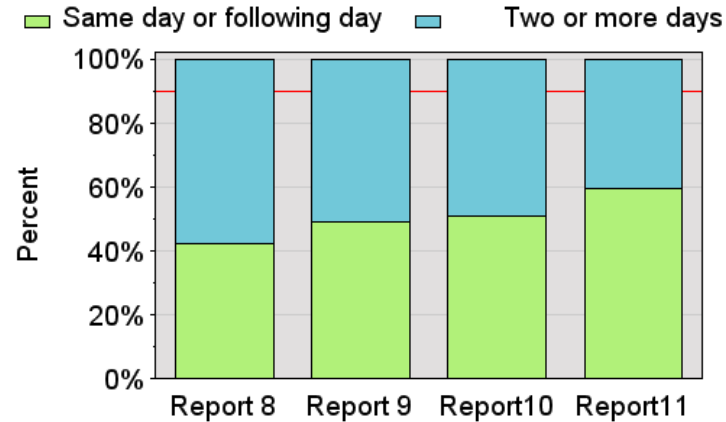
Overnight admitted episodes for QLD



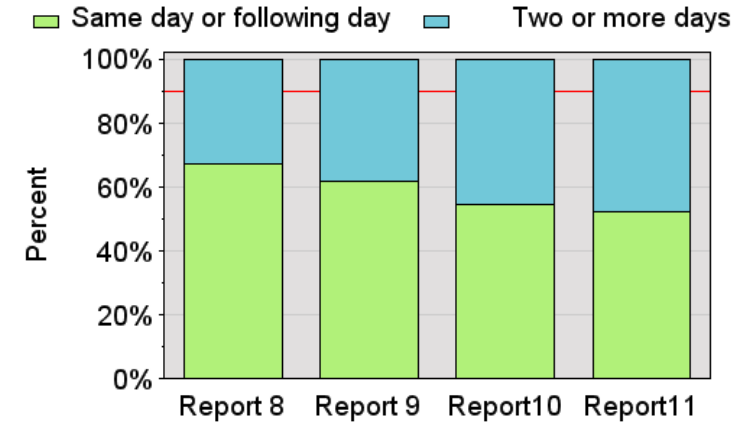
Overnight admitted episodes for all services



Not admitted overnight episodes for QLD



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	
		QLD	All Services	QLD	All Services	QLD	All Services
Overnight admitted	First phase	1497	5088	75.9	79.8	3	3
	Subsequent phase	367	2461	74.9	86.4	3	2
	<b>Total</b>	<b>1864</b>	<b>7549</b>	<b>75.7</b>	<b>82.0</b>	<b>3</b>	<b>3</b>
Not admitted overnight	First phase	109	847	70.6	59.6	2	4
	Subsequent phase	155	1146	75.5	67.8	3	3
	<b>Total</b>	<b>264</b>	<b>1993</b>	<b>73.5</b>	<b>64.3</b>	<b>2</b>	<b>3</b>

## 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		QLD				All Services			
		Report 8	Report 9	Report 10	Report 11	Report 8	Report 9	Report 10	Report 11
Overnight admitted	Number	302	507	898	1162	2166	2860	3969	5153
	%	80.5	83.8	83.1	88.0	75.9	79.0	79.0	82.1
Not admitted overnight	Number	265	344	406	312	1336	1441	2415	2176
	%	82.0	78.9	75.5	76.3	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		QLD				All Services			
		Report 8	Report 9	Report 10	Report 11	Report 8	Report 9	Report 10	Report 11
Overnight admitted	Number	235	334	510	562	1031	1257	1655	1858
	%	59.9	57.8	52.4	57.6	40.8	44.0	46.6	48.0
Not admitted overnight	Number	58	88	110	82	382	485	806	646
	%	47.5	44.4	53.9	53.2	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		QLD				All Services			
		Report 8	Report 9	Report 10	Report 11	Report 8	Report 9	Report 10	Report 11
Overnight admitted	Number	436	617	836	940	2950	3370	4672	5902
	%	80.3	82.3	84.6	87.5	76.7	79.8	78.8	81.8
Not admitted overnight	Number	187	314	356	287	2008	1978	2825	2566
	%	65.2	75.1	74.2	77.2	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		QLD				All Services			
		Report 8	Report 9	Report 10	Report 11	Report 8	Report 9	Report 10	Report 11
Overnight admitted	Number	346	379	512	523	1339	1453	1912	2159
	%	44.5	44.6	46.6	45.1	41.0	41.3	45.7	46.4
Not admitted overnight	Number	90	111	125	80	598	591	846	708
	%	42.1	45.5	48.1	46.8	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

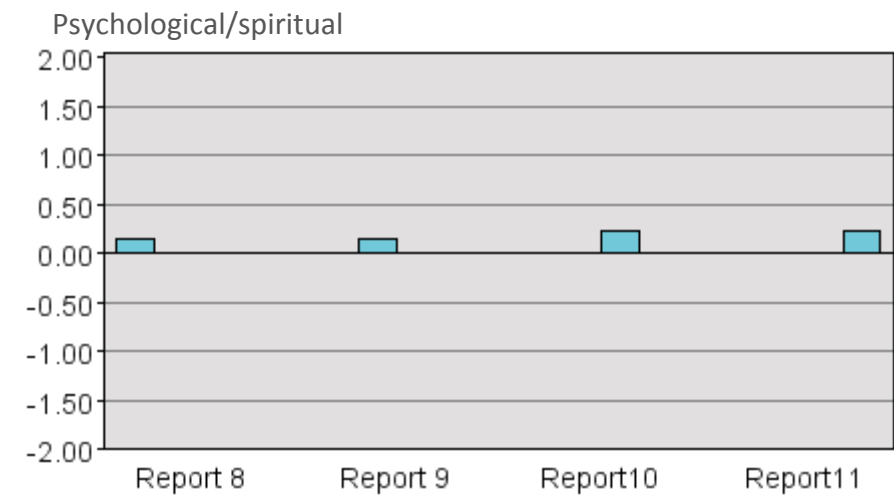
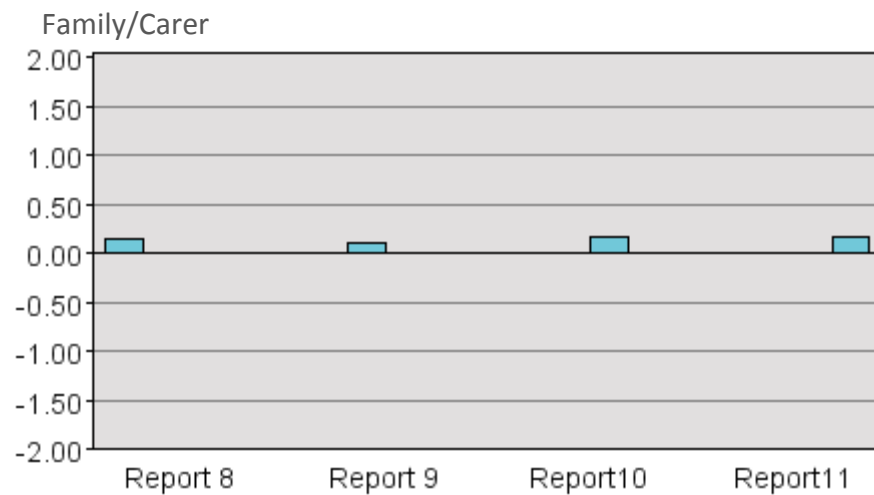
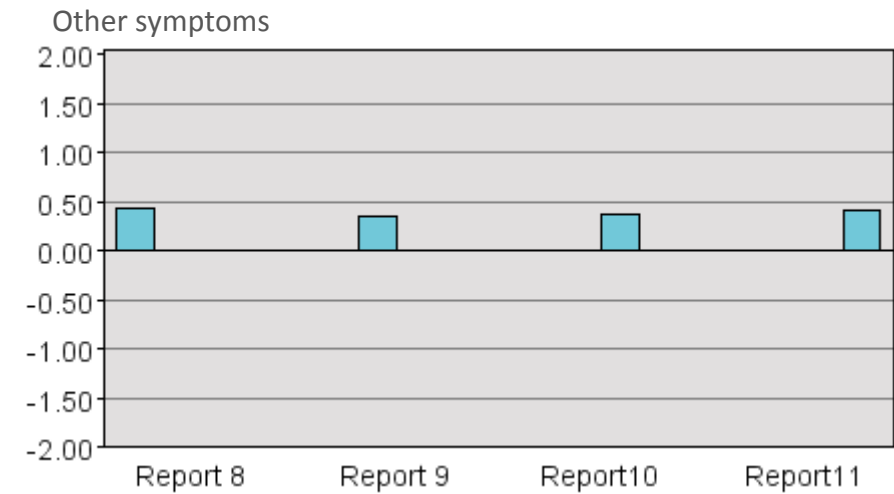
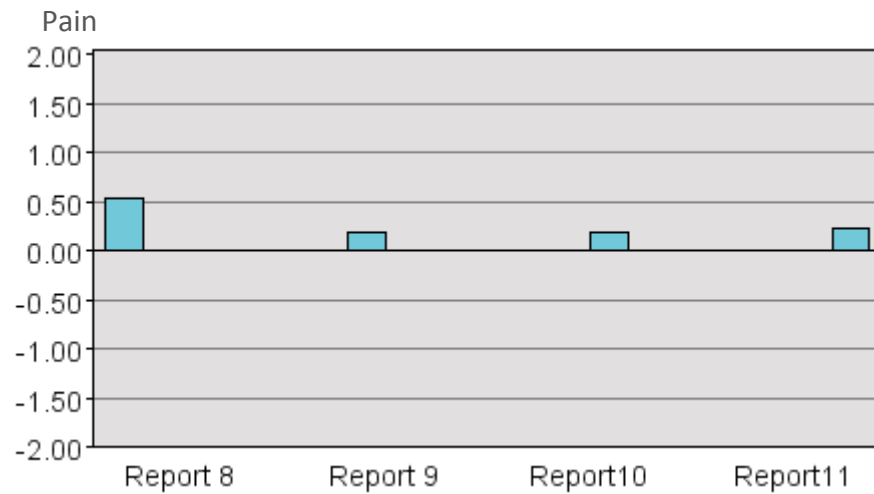
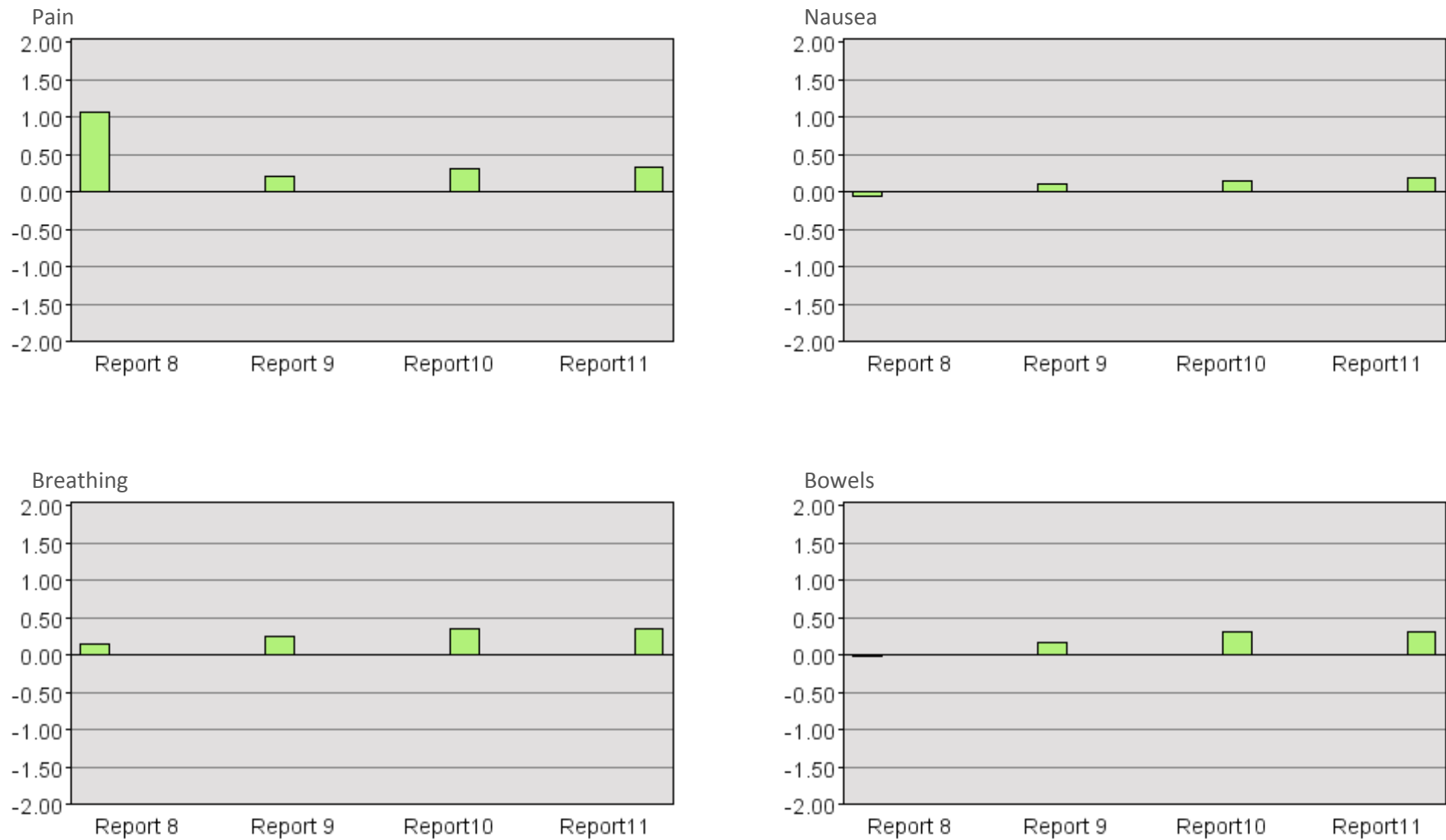


Figure 4 SAS mean change adjusted for phase and symptom score at start of phase



## 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 by QLD services at each level for the current reporting period. Summaries of the national data are included for comparative purposes.

Some tables throughout this section 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.

In addition, interpret all figures carefully as results may appear distorted due to low frequencies being represented as percentages.

## 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 for 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 9 Indigenous Status - all patients*

Indigenous Status	QLD	All Services
Aboriginal but not Torres Strait Islander origin	44	141
Torres Strait Islander but not Aboriginal origin	10	25
Both Aboriginal and Torres Strait Islander origin	1	17
Neither Aboriginal nor Torres Strait Islander origin	3036	12982
Not stated/inadequately described	54	720
<b>Total</b>	<b>3145</b>	<b>13885</b>

Table 10 shows a breakdown of malignant and non-malignant diagnosis for the patients for your service and at the national level. The development of Version 3 Data Set will include further opportunity to expand on diagnosis for both malignant and non-malignant categories. When a service is experiencing a higher than national average of patients under any category, there is opportunity to discuss the issues with your Quality Improvement Facilitator. Where possible your Quality Improvement Facilitator can connect services experiencing similar issues across Australia.

Table 10 Primary diagnosis

Primary diagnosis		QLD	%	All Services	%
Malignant	Bone and soft tissue	38	1.4	215	1.9
	Breast	218	8.2	883	7.7
	CNS	50	1.9	196	1.7
	Colorectal	317	11.9	1260	11.0
	Gynaecological	152	5.7	546	4.8
	Haematological	168	6.3	607	5.3
	Head and neck	145	5.5	656	5.7
	Lung	536	20.2	2245	19.6
	Pancreas	148	5.6	619	5.4
	Prostate	213	8.0	764	6.7
	Skin	136	5.1	429	3.8
	Other GIT	199	7.5	965	8.4
	Other urological	114	4.3	453	4.0
	Other malignancy	133	5.0	604	5.3
	Unknown primary	92	3.5	328	2.9
	Malignant - not further defined	0	0.0	662	5.8
	<b>All malignant</b>	<b>2659</b>	<b>100.0</b>	<b>11432</b>	<b>100.0</b>
Non-malignant	Cardiovascular	105	23.9	440	20.0
	HIV/AIDS	3	0.7	9	0.4
	Kidney failure	76	17.3	285	13.0
	Neurological disease	98	22.3	491	22.4
	Respiratory failure	52	11.8	322	14.7
	Other non-malignancy	106	24.1	567	25.8
	Non-malignant - not further defined	0	0.0	82	3.7
	<b>All non-malignant</b>	<b>440</b>	<b>100.0</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			
	QLD	%	All Services	%	QLD	%	All Services	%
Public hospital - other than inpatient palliative care unit	1522	50.4	4741	45.2	413	33.1	3305	47.9
Self, carer(s), family or friends	171	5.7	315	3.0	59	4.7	227	3.3
Private hospital - other than inpatient palliative care unit	295	9.8	714	6.8	92	7.4	862	12.5
Public palliative care inpatient unit/hospice	149	4.9	306	2.9	312	25.0	411	6.0
Private palliative care inpatient unit/hospice	16	0.5	48	0.5	14	1.1	39	0.6
General medical practitioner	219	7.3	620	5.9	170	13.6	847	12.3
Specialist medical practitioner	96	3.2	332	3.2	105	8.4	366	5.3
Community-based palliative care agency	388	12.9	2206	21.0	23	1.8	89	1.3
Community-based service	32	1.1	393	3.7	41	3.3	185	2.7
Residential aged care facility	29	1.0	83	0.8	4	0.3	184	2.7
Other	16	0.5	88	0.8	5	0.4	174	2.5
Not stated/inadequately described	84	2.8	654	6.2	10	0.8	205	3.0
<b>Total</b>	<b>3017</b>	<b>100.0</b>	<b>10500</b>	<b>100.0</b>	<b>1248</b>	<b>100.0</b>	<b>6894</b>	<b>100.0</b>

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

Place of death	QLD	%	All Services	%
Private residence	142	46.7	1055	56.9
Residential aged care setting	13	4.3	288	15.5
Other location*	84	27.6	345	18.6
Not stated/inadequately described	65	21.4	165	8.9
<b>Total</b>	<b>304</b>	<b>100.0</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 for QLD and nationally.

*Table 13 Length of episode summary*

Length of episode	Overnight admitted		Not admitted overnight	
	QLD	All Services	QLD	All Services
Average length of episode	10.4	11.6	22.0	23.3
Median length of episode	6.0	7.0	20.0	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			
	QLD	%	All Services	%	QLD	%	All Services	%
Same day	55	1.9	367	3.6	149	12.8	535	8.3
1-2 days	561	19.6	1902	18.5	109	9.3	506	7.9
3-4 days	448	15.7	1387	13.5	56	4.8	305	4.7
5-7 days	543	19.0	1730	16.8	68	5.8	459	7.1
8-14 days	601	21.0	2167	21.1	142	12.2	788	12.2
15-21 days	270	9.5	1079	10.5	87	7.5	610	9.5
22-30 days	168	5.9	704	6.8	106	9.1	553	8.6
31-60 days	159	5.6	718	7.0	162	13.9	1003	15.6
61-90 days	28	1.0	158	1.5	102	8.7	552	8.6
Greater than 90 days	23	0.8	74	0.7	185	15.9	1131	17.6
Total	2856	100.0	10286	100.0	1166	100.0	6442	100.0

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

## Profile of palliative care phases

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			
	QLD	%	All Services	%	QLD	%	All Services	%
Stable	1542	22.5	6914	26.1	737	38.6	4338	36.6
Unstable	1864	27.2	7549	28.5	264	13.8	1993	16.8
Deteriorating	1708	24.9	6595	24.9	737	38.6	4383	37.0
Terminal	1076	15.7	4084	15.4	121	6.3	1036	8.8
Bereaved	665	9.7	1381	5.2	52	2.7	90	0.8
All phases	6855	100.0	26523	100.0	1911	100.0	11840	100.0

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

Phase	Overnight admitted		Not admitted overnight	
	QLD	All Services	QLD	All Services
Stable	6.5	7.0	22.6	23.6
Unstable	5.1	4.3	7.1	8.6
Deteriorating	5.9	5.3	16.3	16.1
Terminal	2.2	2.2	4.2	2.9
Bereaved	1.0	1.1	2.0	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	QLD				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	44.2	41.6	11.4	2.8	43.0	37.5	15.5	4.0
	Other Symptom	29.1	48.7	17.8	4.5	20.2	42.7	27.3	9.8
	Psychological/Spiritual	38.5	41.8	14.6	5.1	24.7	45.9	21.8	7.6
	Family/Carer	42.1	36.1	15.5	6.3	33.4	37.9	19.9	8.9
Unstable	Pain	20.1	26.6	33.4	19.9	25.2	27.6	30.5	16.6
	Other Symptom	9.0	27.1	42.5	21.4	8.1	24.4	41.8	25.7
	Psychological/Spiritual	18.2	35.7	33.7	12.4	13.9	34.9	34.8	16.4
	Family/Carer	25.0	29.4	32.0	13.6	21.0	31.0	30.5	17.6
Deteriorating	Pain	32.0	35.7	22.8	9.6	30.7	32.4	26.3	10.6
	Other Symptom	10.0	34.7	39.0	16.3	9.2	26.2	40.0	24.6
	Psychological/Spiritual	24.0	40.9	26.0	9.1	17.3	35.9	30.5	16.2
	Family/Carer	22.1	33.8	30.0	14.1	21.1	30.2	30.1	18.6
Terminal	Pain	46.5	30.7	15.3	7.4	38.2	28.4	21.9	11.6
	Other Symptom	33.0	28.8	24.4	13.8	21.0	22.5	28.9	27.5
	Psychological/Spiritual	53.9	23.9	15.4	6.8	35.3	26.5	21.5	16.6
	Family/Carer	21.3	26.6	29.5	22.5	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	QLD				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	45.7	41.4	10.9	2.0	36.8	48.9	13.0	1.3
	Other Symptom	25.5	50.5	22.4	1.5	15.7	55.3	26.5	2.4
	Psychological/Spiritual	45.0	37.6	14.8	2.6	24.8	52.4	20.5	2.3
	Family/Carer	42.5	37.8	17.0	2.7	23.8	46.0	26.5	3.7
Unstable	Pain	18.2	29.9	36.4	15.5	17.3	27.5	35.4	19.8
	Other Symptom	9.5	28.4	43.6	18.6	6.4	27.0	45.4	21.2
	Psychological/Spiritual	18.9	45.1	27.7	8.3	13.4	39.9	34.4	12.2
	Family/Carer	25.0	38.6	26.5	9.8	15.0	29.7	38.0	17.4
Deteriorating	Pain	32.6	43.1	18.5	5.8	26.2	45.6	22.8	5.5
	Other Symptom	8.3	40.1	39.5	12.1	6.5	34.6	46.3	12.6
	Psychological/Spiritual	28.4	42.7	21.8	7.1	18.2	46.1	28.7	7.1
	Family/Carer	23.9	38.5	28.4	9.2	13.8	32.1	41.9	12.2
Terminal	Pain	49.6	25.6	17.4	7.4	36.4	38.9	17.3	7.4
	Other Symptom	33.9	28.9	24.8	12.4	21.2	33.1	30.1	15.6
	Psychological/Spiritual	46.3	38.0	13.2	2.5	42.7	34.8	15.2	7.2
	Family/Carer	16.5	43.0	28.1	12.4	12.7	29.6	37.1	20.5

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

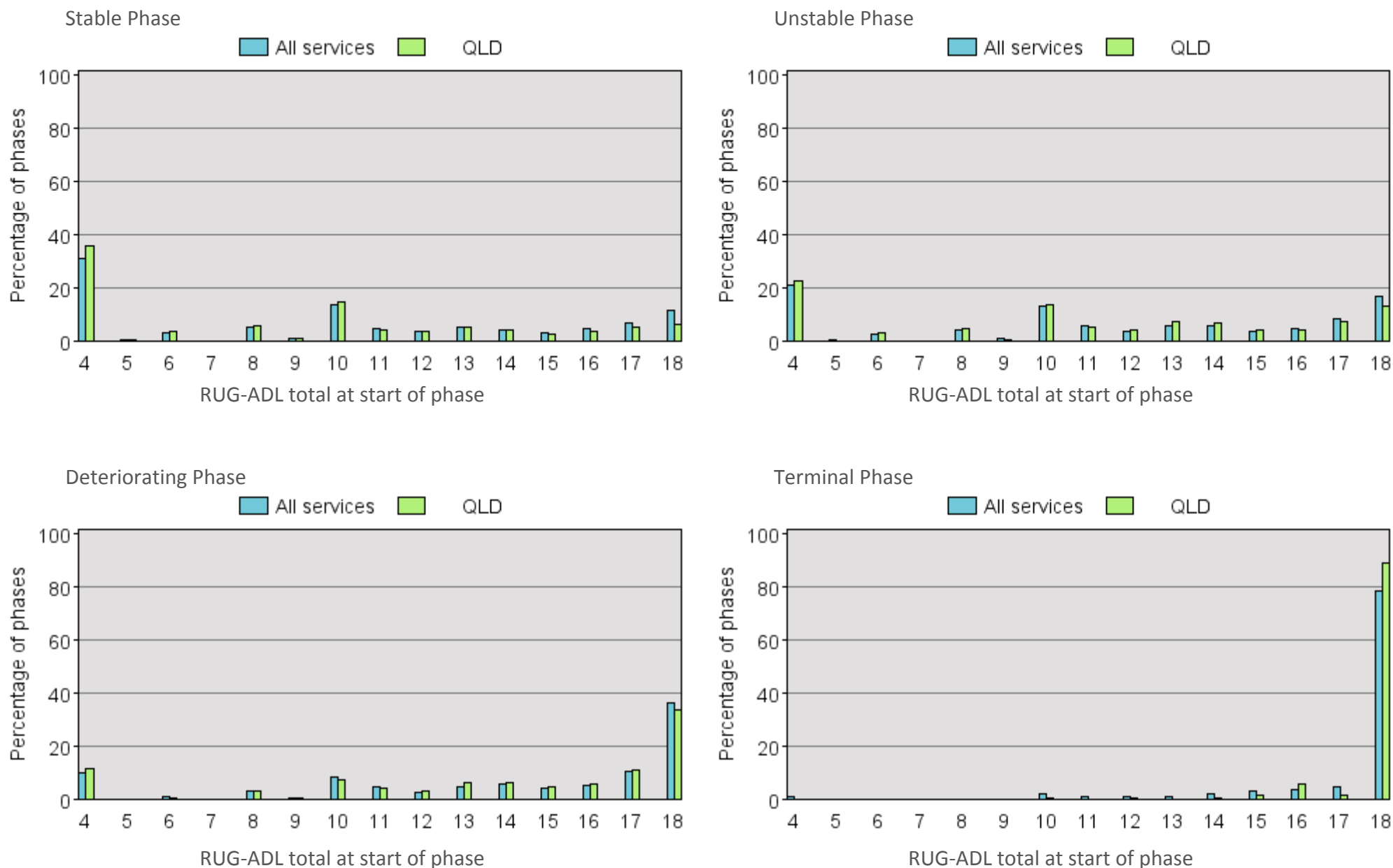
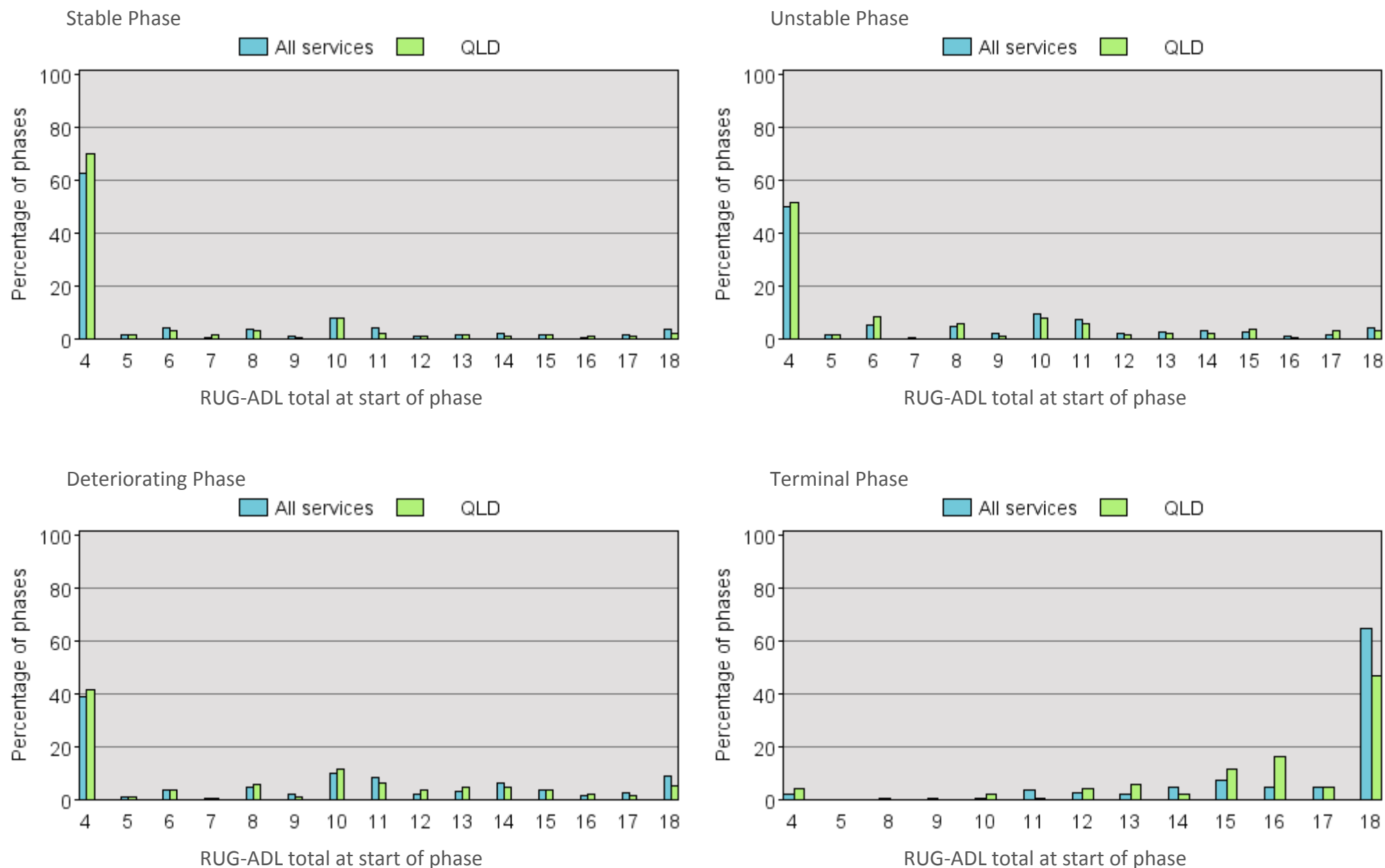


Figure 6 Total RUG-ADL at beginning of phase – patients not admitted overnight



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			
	QLD	%	All Services	%	QLD	%	All Services	%
Comatose or barely rousable	679	11.0	2298	9.2	40	2.2	453	3.9
Totally bedfast and requiring extensive nursing care	1194	19.3	5020	20.0	125	6.7	1049	9.0
Almost completely bedfast	770	12.5	2887	11.5	92	5.0	742	6.4
In bed more than 50% of the time	1102	17.8	4035	16.1	260	14.0	1473	12.6
Requires considerable assistance	1084	17.5	4837	19.3	439	23.7	2626	22.5
Requires occasional assistance	877	14.2	3311	13.2	553	29.8	2651	22.7
Cares for self	294	4.8	1003	4.0	236	12.7	1670	14.3
Normal activity with effort	106	1.7	377	1.5	67	3.6	588	5.0
Able to carry on normal activity; minor signs or symptoms	46	0.7	117	0.5	29	1.6	157	1.3
Normal; no complaints; no evidence of disease	2	0.0	7	0.0	5	0.3	8	0.1
Not stated/inadequately described	25	0.4	1165	4.6	9	0.5	265	2.3
Total	6179	100.0	25057	100.0	1855	100.0	11682	100.0

Table 20 How stable phases end

Phase end reason	Overnight admitted				Not admitted overnight			
	QLD	%	All Services	%	QLD	%	All Services	%
Phase change	601	39.0	3926	56.8	322	43.7	2843	65.5
Discharge/case closure	913	59.2	2841	41.1	319	43.3	1169	26.9
Died	25	1.6	117	1.7	52	7.1	266	6.1
Bereavement phase end	2	0.1	10	0.1	0	0.0	1	0.0
Not stated/inadequately described	1	0.1	20	0.3	44	6.0	59	1.4
<b>Total</b>	<b>1542</b>	<b>100.0</b>	<b>6914</b>	<b>100.0</b>	<b>737</b>	<b>100.0</b>	<b>4338</b>	<b>100.0</b>

Figure 7 Stable phase progression - overnight admitted

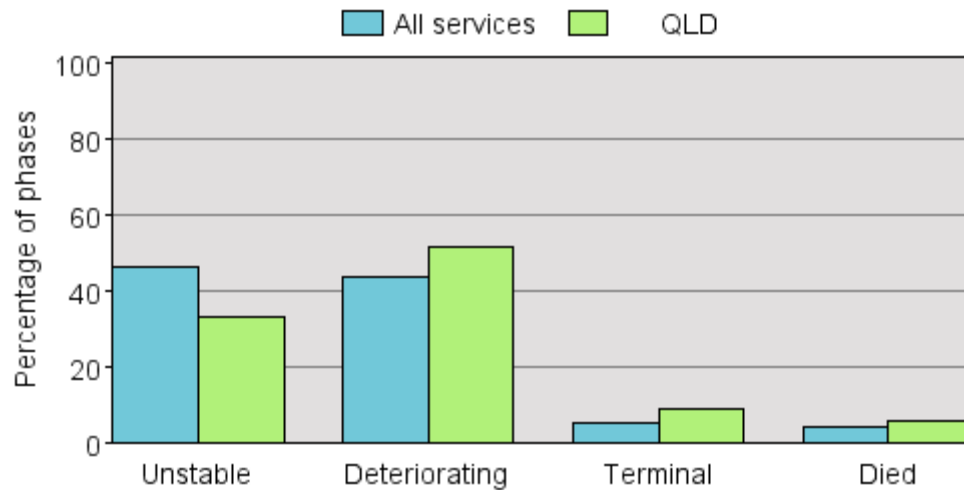


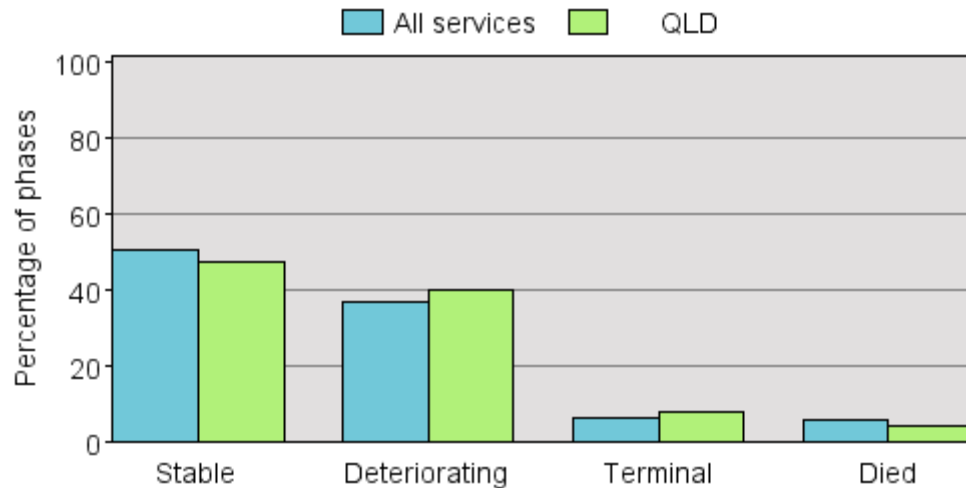
Figure 8 Stable phase progression - not admitted overnight



*Table 21 How unstable phases end*

Phase end reason	Overnight admitted				Not admitted overnight			
	QLD	%	All Services	%	QLD	%	All Services	%
Phase change	1532	82.2	6464	85.6	127	48.1	1406	70.5
Discharge/case closure	262	14.1	721	9.6	109	41.3	462	23.2
Died	69	3.7	345	4.6	7	2.7	89	4.5
Bereavement phase end	0	0.0	12	0.2	1	0.4	4	0.2
Not stated/inadequately described	1	0.1	7	0.1	20	7.6	32	1.6
<b>Total</b>	<b>1864</b>	<b>100.0</b>	<b>7549</b>	<b>100.0</b>	<b>264</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*

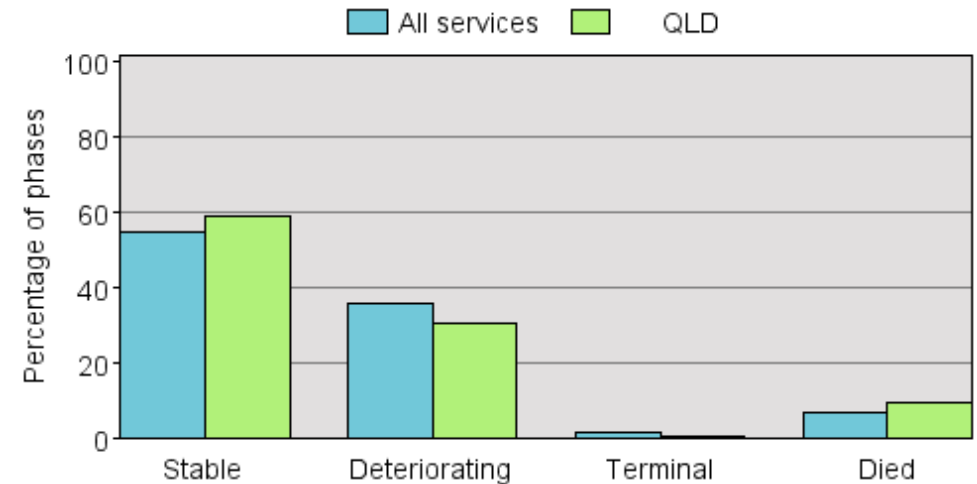


Table 22 How deteriorating phases end

Phase end reason	Overnight admitted				Not admitted overnight			
	QLD	%	All Services	%	QLD	%	All Services	%
Phase change	1036	60.7	4595	69.7	253	34.3	2304	52.6
Discharge/case closure	428	25.1	844	12.8	366	49.7	1366	31.2
Died	230	13.5	1110	16.8	100	13.6	679	15.5
Bereavement phase end	10	0.6	37	0.6	3	0.4	4	0.1
Not stated/inadequately described	4	0.2	9	0.1	15	2.0	30	0.7
<b>Total</b>	<b>1708</b>	<b>100.0</b>	<b>6595</b>	<b>100.0</b>	<b>737</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

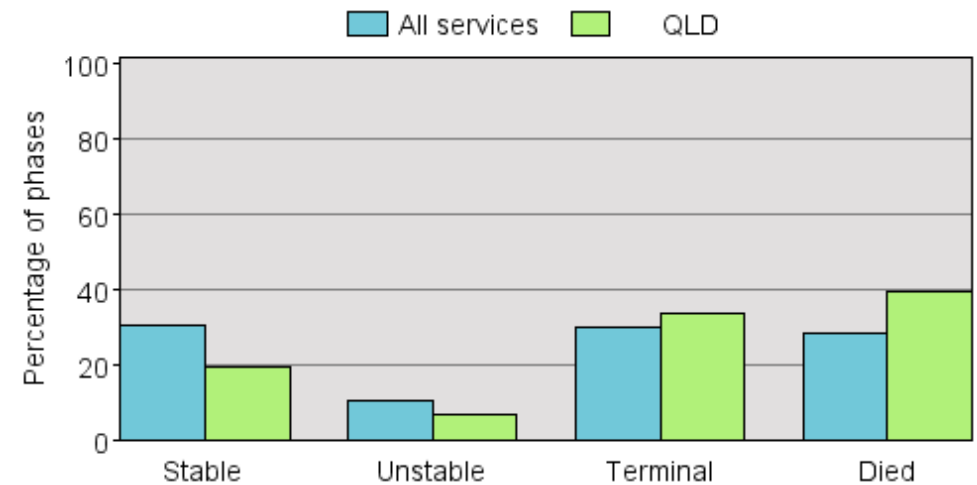


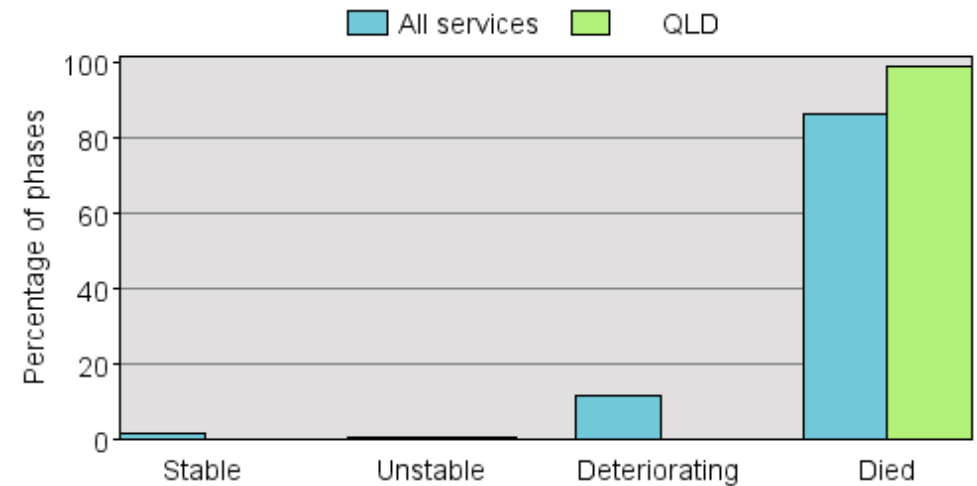
Table 23 How terminal phases end

Phase end reason	Overnight admitted				Not admitted overnight			
	QLD	%	All Services	%	QLD	%	All Services	%
Phase change	79	7.3	480	11.8	5	4.1	224	21.6
Discharge/case closure	12	1.1	75	1.8	8	6.6	75	7.2
Died	966	89.8	3416	83.6	104	86.0	724	69.9
Bereavement phase end	19	1.8	106	2.6	3	2.5	6	0.6
Not stated/inadequately described	0	0.0	7	0.2	1	0.8	7	0.7
<b>Total</b>	<b>1076</b>	<b>100.0</b>	<b>4084</b>	<b>100.0</b>	<b>121</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, 28 of which were from QLD. 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 – 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 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	
	QLD	All Services	QLD	All Services	QLD	All Services
Number of patients*	2484	8890	991	5750	3145	13885
Number of episodes	3017	10500	1248	6894	4265	17394
Number of phases	6855	26523	1911	11840	8766	38363
Percentage of patients*	79.0	64.0	31.5	41.4	100	100
Percentage of episodes	70.7	60.4	29.3	39.6	100	100
Percentage of phases	78.2	69.1	21.8	30.9	100	100
Average number of phases per episode**	2.1	2.4	1.5	1.7	1.9	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	
	QLD	All Services
Date of birth	100.0	100.0
Sex	99.9	99.9
Indigenous status	98.3	94.8
Country of birth	98.9	94.1
Main language	96.7	91.5
Primary diagnosis	98.5	98.6

*Table 26 Item completion- episode level*

Data item	% Complete	
	QLD	All Services
Date of first contact/assessment	97.8	96.2
Referral date	98.1	92.3
Referral source	97.8	95.1
Episode start date	100.0	100.0
Mode of episode start	96.7	99.0
Accommodation at episode start	98.9	97.4
Episode end date	99.5	99.9
Level of support at episode start	98.8	82.9
Mode of episode end	99.5	98.1
Accommodation at episode end	88.0	88.1
Level of support at episode end	99.7	97.1
Place of death	78.6	91.1

*Table 27 Item completion - phase level*

Data item	Sub-Category	% Complete	
		QLD	All Services
	(where applicable)		
Phase start date	-	100.0	100.0
Phase	-	100.0	100.0
RUG-ADL at phase start	Bed Mobility	91.4	95.2
	Toileting	91.4	95.1
	Transfers	91.4	95.0
	Eating	91.4	94.4
PC Problem Severity at phase start	Pain	89.0	79.1
	Other Symptom	85.4	83.1
	Psychological/Spiritual	96.8	92.8
	Family/Carer	96.7	91.6
Symptom Assessment Score at phase start	Insomnia	86.9	86.7
	Appetite	86.9	89.2
	Nausea	86.9	89.5
	Bowels	86.9	88.9
	Breathing	86.9	89.5
	Fatigue	86.9	89.7
	Pain	86.9	90.0
Phase end reason	-	98.9	99.5
Karnofsky at phase start	-	99.6	96.1

Some tables throughout this report may be incomplete. This is because some items may not be applicable or it may be due to data quality issues.

Please use the following key when interpreting the tables:

**na** The item is not applicable

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

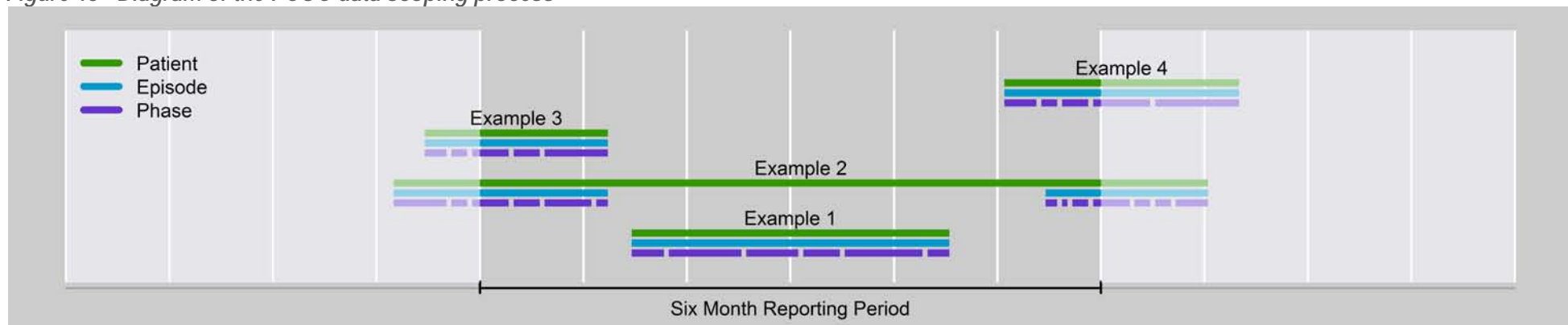
In addition, interpret all figures carefully as results may appear distorted due to low frequencies being represented as percentages.

### 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 PCPSS 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. The PCOC Quality Improvement Facilitators (QIFs) can assist services to identify areas where improvements can be made.

## B2 – National profile graphs

In each national profile graph, the shaded region describes the national profile for that benchmark. QLD services are highlighted as dots on the graph. Graphs may have differing numbers of dots, caused by services not qualifying for inclusion in a particular benchmark. This may be caused by insufficient data item completion, or services not having any records falling into a particular category, for example, no phases starting with moderate/severe SAS pain.

## 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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### *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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