UNIVERSITY
OF WOLLONGONG
AUSTRALIA

University of Wollongong
Research Online

2015

Queensland, patient outcomes in palliative care, January - June 2015

Alanna M. Connolly
University of Wollongong, alannah@uow.edu.au

Sonia Bird
University of Wollongong, marcolin@uow.edu.au

Sabina P. Clapham
University of Wollongong, sabinac@uow.edu.au

L Carnew

Claire Christiansen

See next page for additional authors

Publication Details

A. M. Connolly, S. Bird, S. P. Clapham, L. Carnew, C. Christiansen, K. Quinsey, L. M. Foskett & S. F. Allingham, Queensland, patient outcomes in palliative care, January - June 2015 (Australian Health Services Research Institute, University of Wollongong, 2015).
http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow205083.pdf

Research Online is the open access institutional repository for the University of Wollongong. For further information contact the UOW Library: research-pubs@uow.edu.au

Queensland, patient outcomes in palliative care, January - June 2015

Abstract

The Palliative Care Outcomes Collaboration (PCOC) is a 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. This is achieved via the PCOC patient outcome improvement framework which is designed to: * provide clinicians with the tools to systematically assess individual patient experiences using validated clinical assessment tools, * 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, * provide service-to-service benchmarking reports and opportunities to discuss sector results at benchmarking workshops, and * support research using the PCOC longitudinal database (2006-2015).

Keywords

care, queensland, january, june, 2015, patient, palliative, outcomes

Publication Details

A. M. Connolly, S. Bird, S. P. Clapham, L. Carnew, C. Christiansen, K. Quinsey, L. M. Foskett & S. F. Allingham, Queensland, patient outcomes in palliative care, January - June 2015 (Australian Health Services Research Institute, University of Wollongong, 2015). http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow205083.pdf

Authors

Alanna M. Connolly, Sonia Bird, Sabina P. Clapham, L Carnew, Claire Christiansen, Karen Quinsey, Linda M. Foskett, and Samuel F. Allingham

This report is available at Research Online: http://ro.uow.edu.au/ahsri/734

PCOC
palliative care
outcomes collaboration

Queensland

Patient Outcomes in Palliative Care

January – June 2015

September 2015

PCOC is a national palliative care project funded by the
Australian Government Department of Health

www.pcoc.org.au

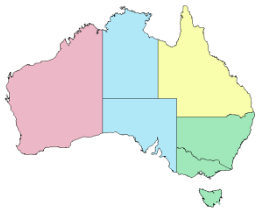
About the Palliative Care Outcomes Collaboration

The Palliative Care Outcomes Collaboration (PCOC) is a 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. This is achieved via the PCOC patient outcome improvement framework which is designed to:

- provide clinicians with the tools to systematically assess individual patient experiences using validated clinical assessment tools,
- 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,
- provide service-to-service benchmarking reports and opportunities to discuss sector results at benchmarking workshops, and
- support research using the PCOC longitudinal database (2006-2015).

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 (AKPS) scale and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

PCOC has divided Australia into four zones for the purpose of engaging with palliative care service providers. Each zone is represented by a chief investigator from one of the 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	🟥	**Dr 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 team, located within the Australian Health Services Research Institute at the University of Wollongong, coordinates the patient outcomes reporting, education program, and quality activities across the four zones.

If you would like more information or have any queries about this report please contact your local quality improvement facilitator or contact the national office at pcoc@uow.edu.au or phone (02) 4221 4411.

Table of Contents

List of Tables

List of Figures

Introduction

The Palliative Care Outcomes Collaboration (PCOC) assists services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this patient outcome report, data submitted for the January to June 2015 period are summarised and patient outcomes benchmarked. The purpose of benchmarking is to drive palliative care service innovation and provide participating services with the opportunity to compare their service nationally.

Patient outcomes are reported for a total of 19,220 patients, with 24,180 episodes of care and 55,991 palliative care phases. The information included in this report is determined by a data scoping method. See Appendix A for more information on the data included in this report.

Throughout this report, patient information for Queensland services is presented alongside the national figures for comparative purposes. The national figures are based on information submitted by 100 services, of which:

- 59 are inpatient services. Inpatient services include patients who have been seen in designated palliative care beds as well as non-designated bed consultations.
- 28 are community services. These services include primarily patients seen in the community as well as some patients with ambulatory/clinic episodes.
- 13 are services with both inpatient and community settings.

The Queensland figures in this report are based on information submitted by 26 services. A list of these services is presented in Table 1 on the following page.
A full list of the services included in the national figures can be found at www.pcoc.org.au.

Interpretation hint:

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.**
s	**The item was suppressed due to insufficient data as there was less than 10 observations.**

Table 1 List of Queensland services included in this report

Service name	Setting of care
Blue Care Metro North Cluster	Community
Blue Care Metro South Cluster	Community
Blue Care South Coast Cluster	Community
Blue Care Sunshine Coast Cluster	Community
Bundaberg Palliative Access	Community
Caloundra Hospital	Inpatient
Gordonvale Hospital	Community
Hervey Bay and Fraser Coast Palliative Care Service	Inpatient and community
Hopewell Hospice	Inpatient
Ipswich Hospice	Inpatient
Ipswich Hospital	Inpatient and community
Karuna Hospice Services	Community
Mater Adult's Hospital Brisbane	Inpatient
Mater Private Brisbane	Inpatient
Mater Private Mackay	Inpatient
Robina Hospital Supportive & Specialist Palliative Inpatient Unit	Inpatient
Rockhampton Base Hospital	Inpatient and community
Royal Brisbane and Women's Hospital, Palliative Care Consultation-Liaison Service	Inpatient
St Vincent's Hospital Brisbane	Inpatient and community
Sunshine Coast Palliative Care Service	Inpatient
Toowoomba Hospice	Inpatient
Toowoomba Hospital Oncology Unit	Inpatient
Townsville Hospital Consultation	Inpatient
Townsville Palliative Care Centre	Inpatient
Wesley Private	Inpatient
Wynnum Hospital	Inpatient

Section 1 Benchmark summary

1.1 Queensland services at a glance

Table 2 Summary of outcome measures 1 to 3 by setting

Outcome measure	Description	Benchmark	Inpatient		Community	
			QLD Score	Benchmark Met?	QLD Score	Benchmark Met?
1. Time from date ready for care to episode start	Benchmark 1: Patients episode commences on the day of, or the day after date ready for care	90%	97.3	Yes	90.2	Yes
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	79.3	No	76.3	No
3. Change in pain	Benchmark 3.1: PCPSS Patients with absent or mild pain at phase start, remaining absent or mild at phase end	90%	91.4	Yes	79.3	No
	Benchmark 3.2: PCPSS Patients with moderate or severe pain at phase start, with absent or mild pain at phase end	60%	62.8	Yes	35.4	No
	Benchmark 3.3: SAS Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end	90%	89.8	No	77.0	No
	Benchmark 3.4: SAS Patients with moderate or severe distress from pain at phase start, with absent or mild at phase end	60%	51.7	No	32.3	No

Table 3 Summary of outcome measure 4: Average improvement on the 2014 baseline national average (X-CAS)

Clinical Tool	Description	Average improvement on baseline	Benchmark met?
PCPSS	Benchmark 4.1: Pain	0.00	Yes
	Benchmark 4.2: Other symptoms	0.07	Yes
	Benchmark 4.3: Family / carer	0.00	Yes
	Benchmark 4.4: Psychological / spiritual	0.06	Yes
SAS	Benchmark 4.5: Pain	-0.10	No
	Benchmark 4.6: Nausea	-0.01	No
	Benchmark 4.7: Breathing problems	0.02	Yes
	Benchmark 4.8: Bowel problems	-0.11	No

The benchmark for
outcome measure 4 is zero.

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

1.2 National benchmark profiles

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

The selected benchmarks included are:

Benchmark 1	Patients episode commences on the day of or the day after date ready for care
Benchmark 2	Patients in the unstable phase for 3 days or less
Benchmark 3.1	PCPSS: Patients with absent or mild pain at phase start, remaining absent or mild at phase end
Benchmark 3.2	PCPSS: Patients with moderate or severe pain at phase start, with absent or mild pain at phase end
Benchmark 3.3	SAS: Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end
Benchmark 3.4	SAS: Patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end

Interpretation hint:

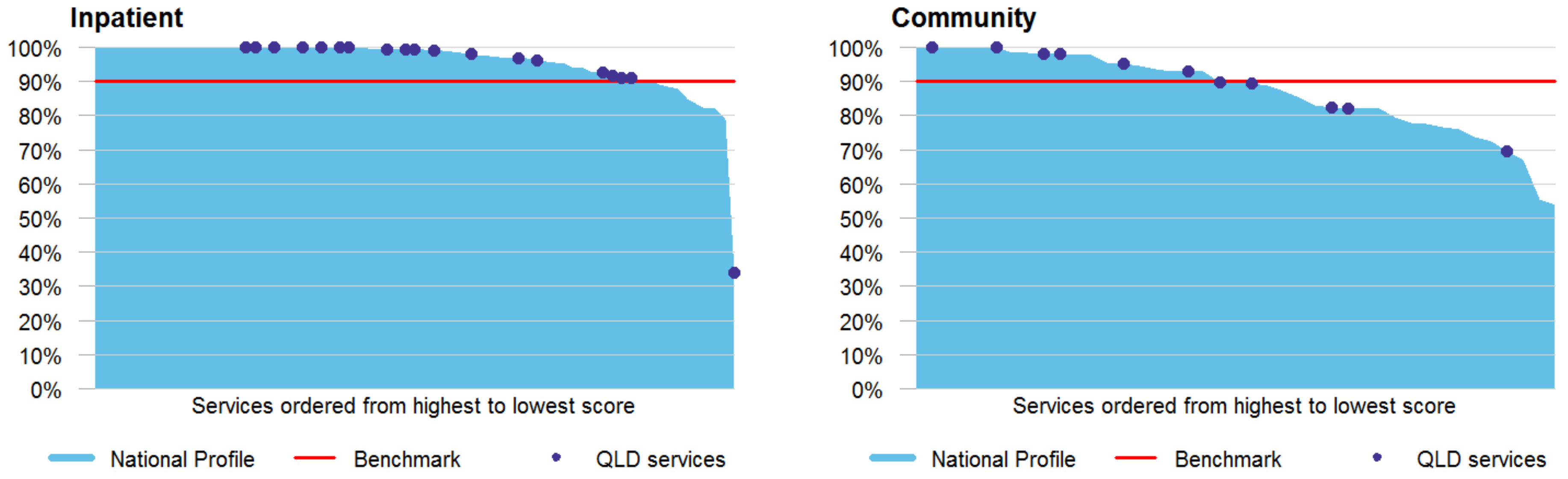
The national profile graphs on the following pages present Queensland services in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. Queensland services are highlighted as dots on the graph.

If a dot is missing on a particular graph, this means that a service has not met the criteria for inclusion in this measure. This may be caused by insufficient data item completion, or the service not having any data falling into a particular category, for example, no phases starting with moderate or severe pain.

The red line on the graph indicates the benchmark for that outcome measure.

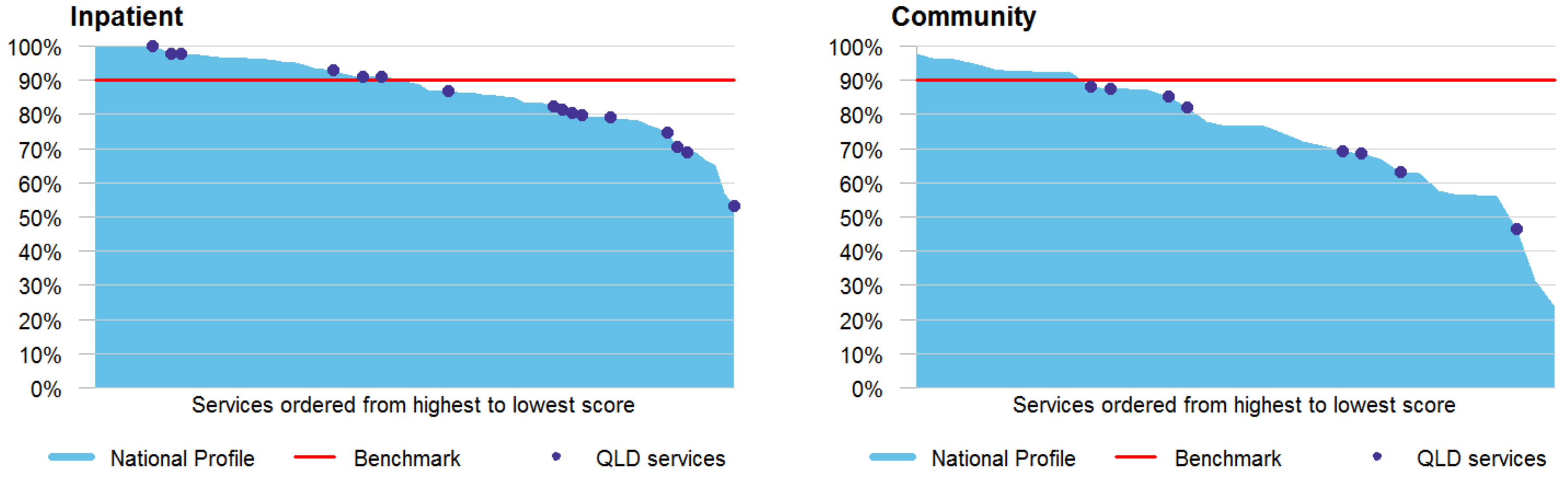
Outcome measure 1 – Time from date ready for care to episode start

Figure 1 Percentage of patients with episodes that commenced on the day of, or the day after date ready for care



Outcome measure 2 – Time in unstable phase

Figure 2 Percentage of patients in the unstable phase for 3 days or less



Outcome measure 3 – Change in pain

Figure 3 PCPSS: Percentage of patients with absent or mild pain at phase start, remaining absent or mild at phase end

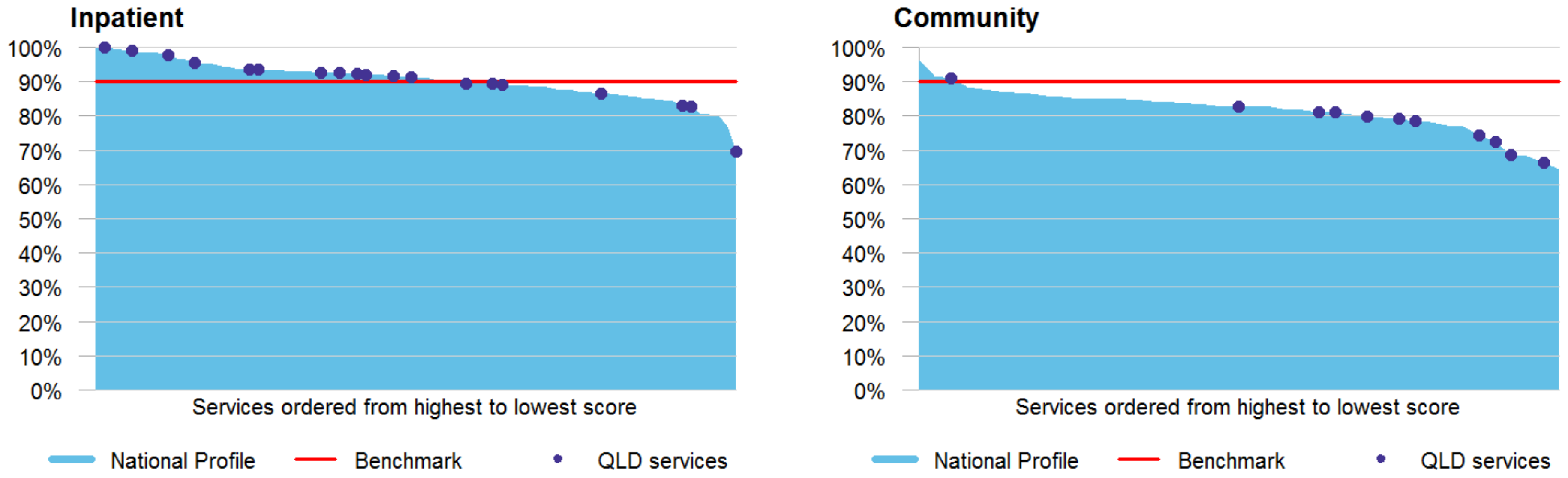


Figure 4 PCPSS: Percentage of patients with moderate or severe pain at phase start, with absent or mild pain at phase end

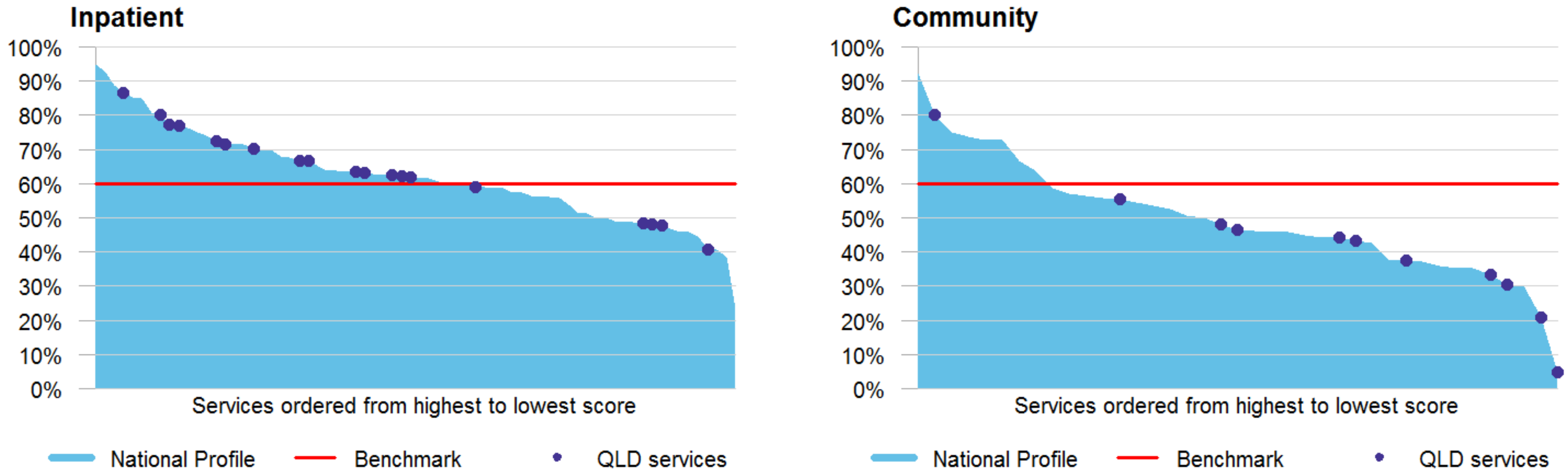


Figure 5 SAS: Percentage of patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end

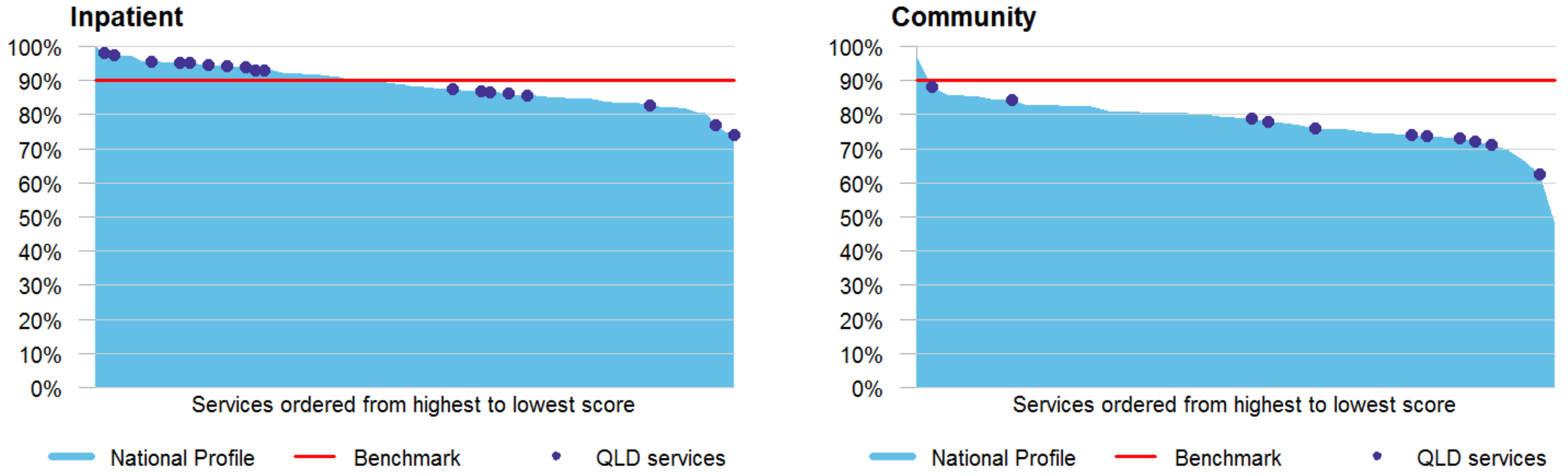
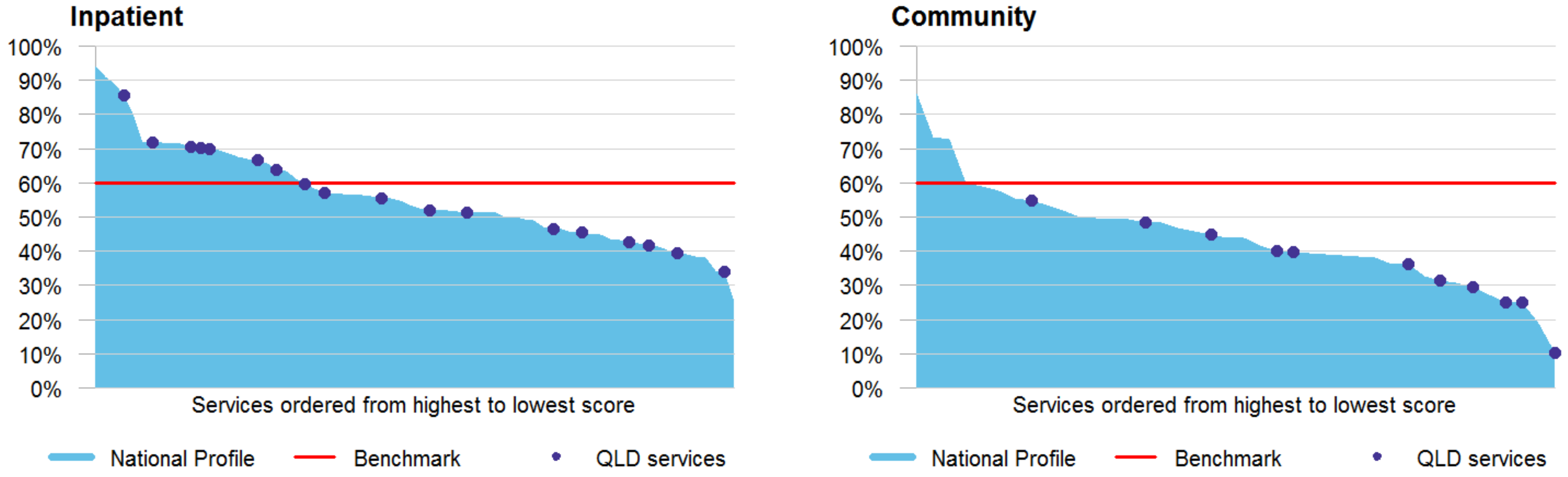


Figure 6 SAS: Percentage of patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end



Section 2 Outcome measures in detail

2.1 Outcome measure 1 – Time from date ready for care to episode start

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This benchmark was set following feedback and subsequent consultation with PCOC participants. Service providers acknowledge that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday to Friday) are not distinguished from services operating seven days a week (all services are being benchmarked together).

Benchmark 1: This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following date ready for care.

Table 4 Time from date ready for care to episode start by setting

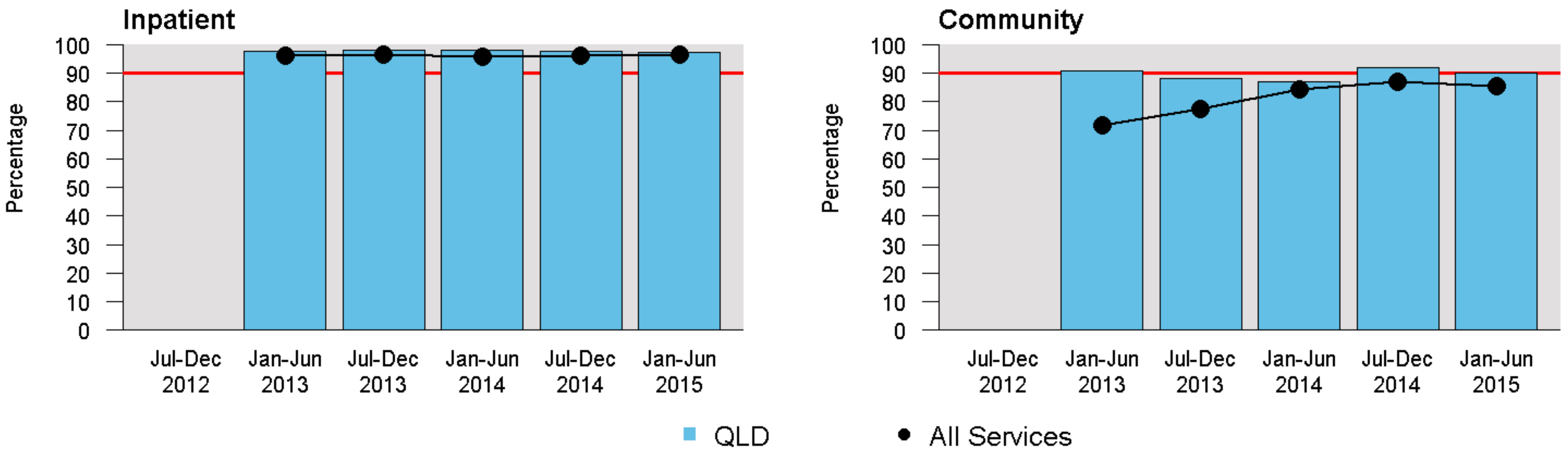
Time (in days)	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Same day	3,224	93.6	10,597	91.8	1,368	83.6	8,248	80.3
Following day	128	3.7	545	4.7	107	6.5	553	5.4
2-7 days	74	2.1	351	3.0	125	7.6	1,087	10.6
8-14 days	14	0.4	38	0.3	18	1.1	224	2.2
Greater than 14 days	5	0.1	9	0.1	18	1.1	156	1.5
Average	1.1	na	1.1	na	1.7	na	2.1	na
Median	1	na	1	na	1	na	1	na

Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Interpretation hint:

Outcome measure 1 only includes episodes that have commenced in the reporting period. As a result, the number of episodes included in the calculation of this benchmark may not match the number of episodes in Appendix A. For more information on data scoping methods, see Appendix C.

Figure 7 Trends in benchmark 1: Patients with episodes that commenced on the day of, or the day after date ready for care by setting



2.2 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 patient's care.

The patient moves out of the unstable phase in one of two ways:

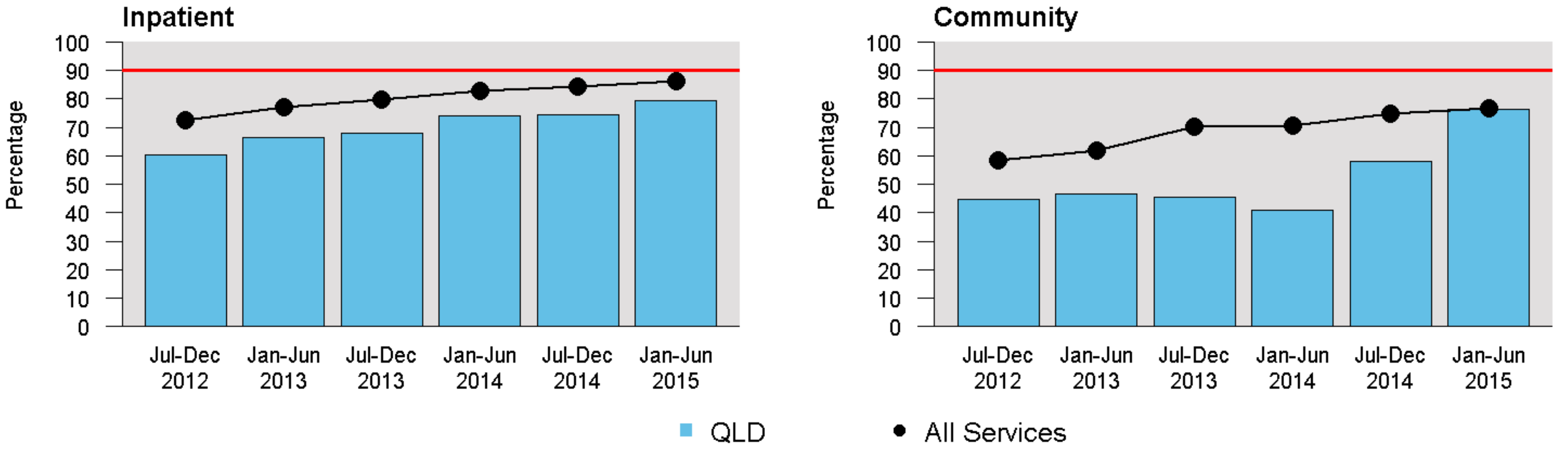
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom / crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the 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.

Benchmark 2: This benchmark relates to the time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for 3 days or less.

Table 5 Time in unstable phase by setting

Time in unstable phase	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Same day	43	2.5	233	3.4	163	27.3	849	23.4
1 day	690	40.4	3,277	47.2	148	24.7	1,239	34.2
2 days	384	22.5	1,724	24.8	79	13.2	441	12.2
3 days	236	13.8	763	11.0	66	11.0	252	7.0
4-5 days	191	11.2	595	8.6	39	6.5	236	6.5
6-7 days	83	4.9	196	2.8	33	5.5	187	5.2
8-14 days	69	4.0	129	1.9	32	5.4	203	5.6
Greater than 14 days	10	0.6	28	0.4	38	6.4	218	6.0
Total	***1,706***	***100.0***	***6,945***	***100.0***	***598***	***100.0***	***3,625***	***100.0***

Figure 8 Trends in benchmark 2: Patients in the unstable phase for 3 days or less by setting



2.3 Outcome measure 3 – Change in pain

The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS) provide two different perspectives of pain. The PCPSS is clinician rated and measures the severity of pain as a clinical problem while the SAS is patient rated and measures distress caused by pain. There are two benchmarks related to each tool: one relating to patients with an absent or mild score, and the other relating to patients with a moderate or severe score. Phase records must have valid start and end scores for the PCPSS and / or SAS clinical assessment tools to be included in the benchmarks.

Scores for PCPSS
0 absent
1 mild
2 moderate
3 severe

Scores for SAS
0 = absent distress
1-3 = mild distress
4-7 = moderate distress
8-10 = severe distress

Interpretation hint:
This outcome measure should be viewed in conjunction with Table 29 to Table 32 and Appendix B.

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.

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.

Benchmark 3.3: This benchmark relates to patients who have absent or mild distress from 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 distress from pain.

Benchmark 3.4: This benchmark relates to patients who have moderate or severe distress from 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 distress from pain reduced to absent or mild.

Table 6 Summary of outcome measure 3

Benchmarks: change in pain	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N*	%	N*	%	N*	%	N*	%
Benchmark 3.1: PCPSS (severity)	3,848	91.4	16,578	90.9	1,980	79.3	15,665	84.4
Benchmark 3.2: PCPSS (severity)	1,588	62.8	5,399	59.8	687	35.4	3,992	53.5
Benchmark 3.3: SAS (distress)	2,916	89.8	14,451	88.9	1,759	77.0	14,633	81.5
Benchmark 3.4: SAS (distress)	1,723	51.7	6,419	53.5	827	32.3	5,255	46.8

*Total number of phases included in this benchmark.

Figure 9 Trends in benchmark 3.1: Patients with absent or mild pain at phase start, remaining absent or mild at phase end by setting

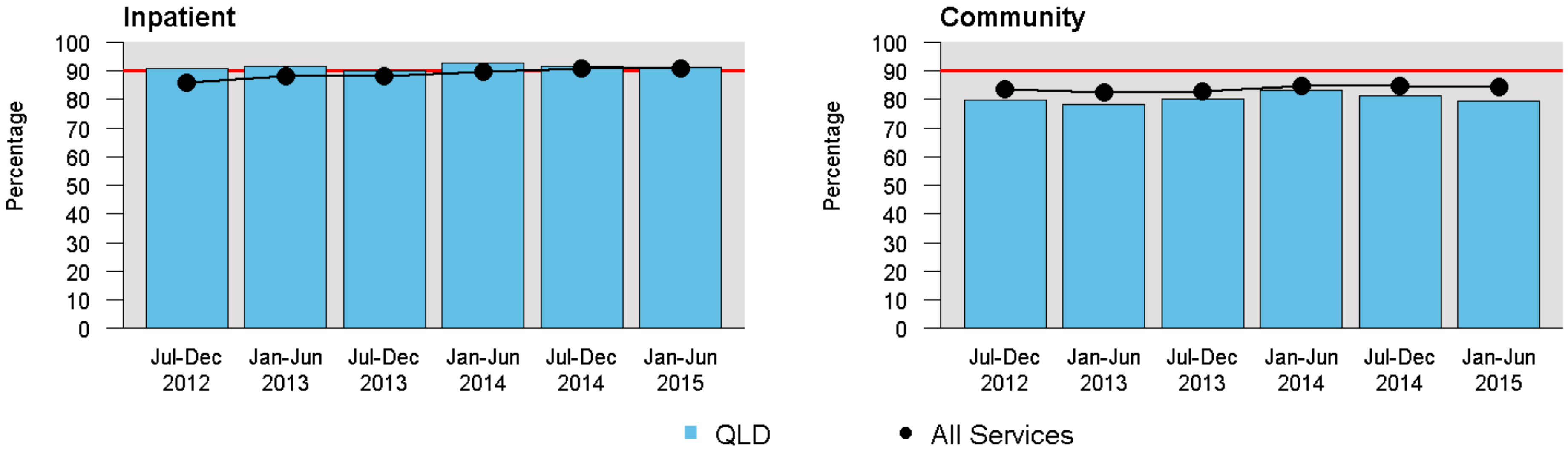


Figure 10 Trends in benchmark 3.2: Patients with moderate or severe pain at phase start, with absent or mild at phase end by setting

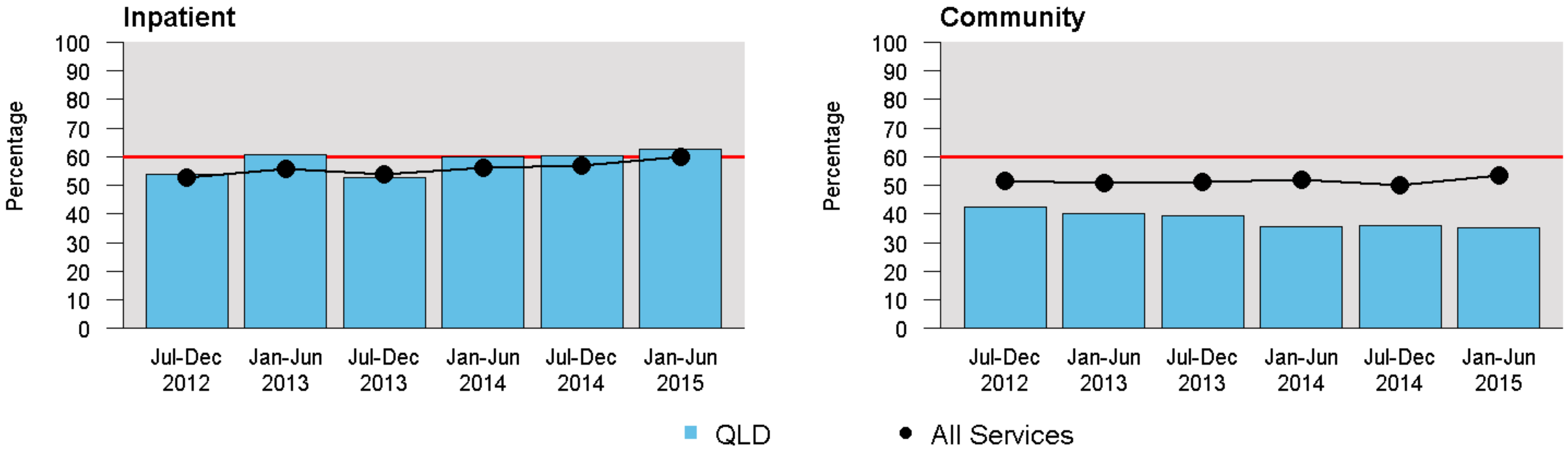


Figure 11 Trends in benchmark 3.3: Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end by setting

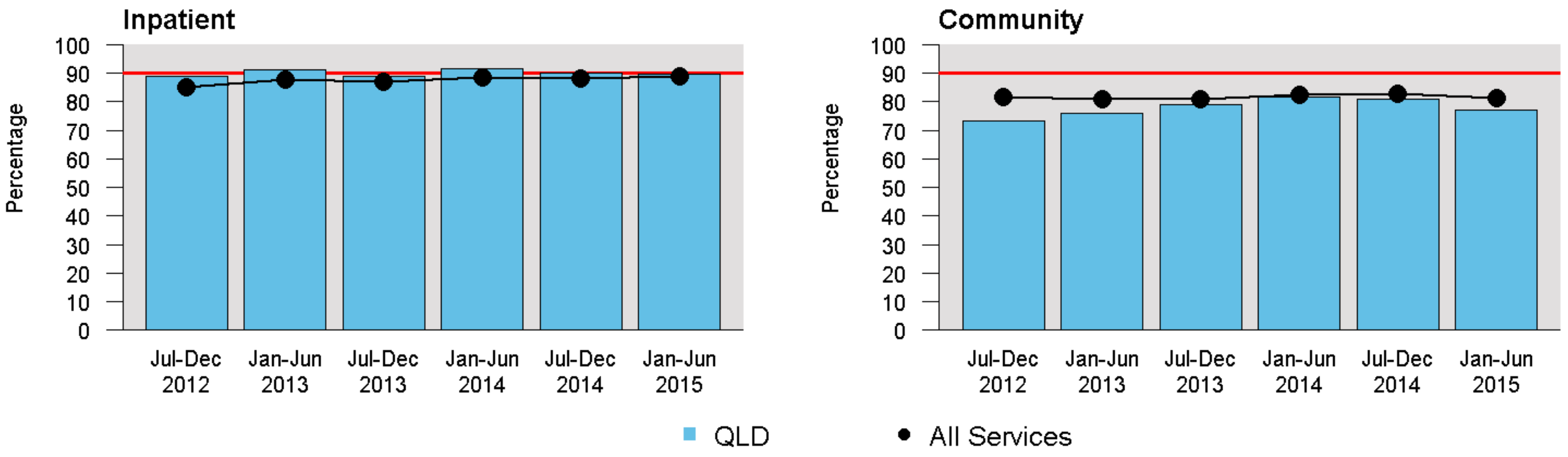
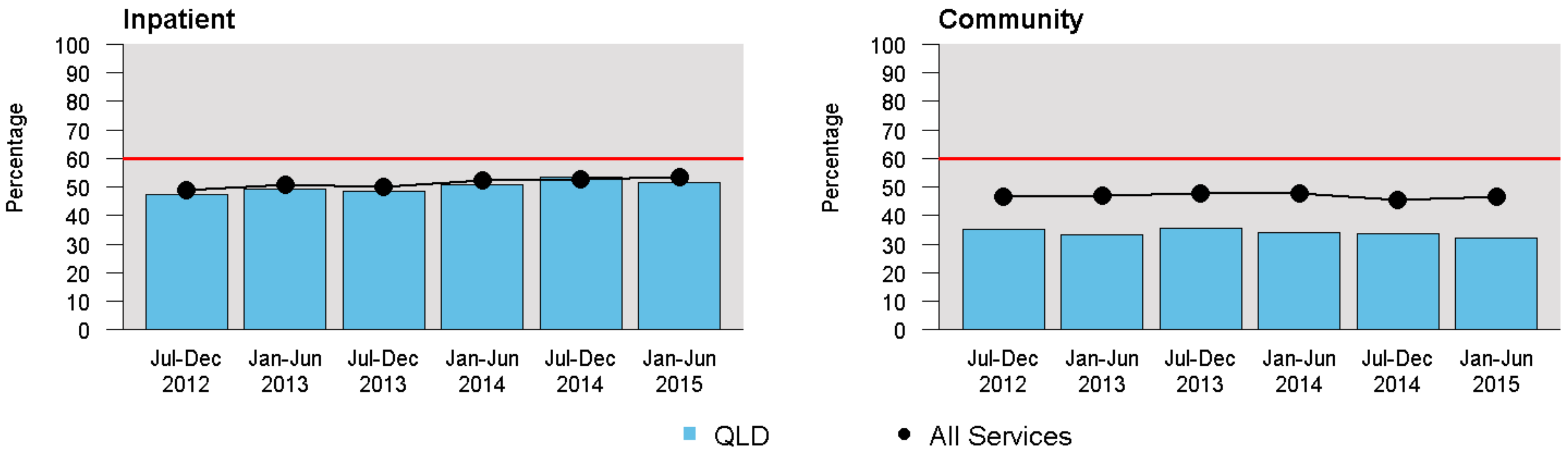


Figure 12 Trends in benchmark 3.4: Patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end by setting



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

Outcome 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 and the baseline reference period is January to June 2014. The suite of benchmarks included in outcome 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. As X-CAS looks 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).

Table 7 Summary of outcome measure 4

Clinical Tool	Benchmark: Symptom	Queensland Services				All Services			
		X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline
PCPSS (severity)	4.1: Pain	0.00	8,103	4,772	58.9	0.02	41,634	24,461	58.8
	4.2: Other symptoms	0.07	8,073	5,240	64.9	0.04	40,844	26,307	64.4
	4.3: Family / carer	0.00	7,944	4,842	61.0	0.03	40,854	25,423	62.2
	4.4: Psychological / spiritual	0.06	8,067	4,549	56.4	0.05	41,465	22,401	54.0
SAS (distress)	4.5: Pain	-0.10	7,225	4,275	59.2	0.00	40,758	25,154	61.7
	4.6: Nausea	-0.01	7,160	5,618	78.5	0.02	40,240	33,123	82.3
	4.7: Breathing Problems	0.02	7,183	4,968	69.2	0.07	40,013	28,503	71.2
	4.8: Bowel Problems	-0.11	7,190	4,778	66.5	0.04	39,831	28,751	72.2

Interpretation hint:

The X-CAS measures are calculated relative to a baseline reference period (currently January to June 2014). As a result:

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

Figure 13 Trends in outcome measure 4 – Palliative Care Problem Severity Score (PCPSS)

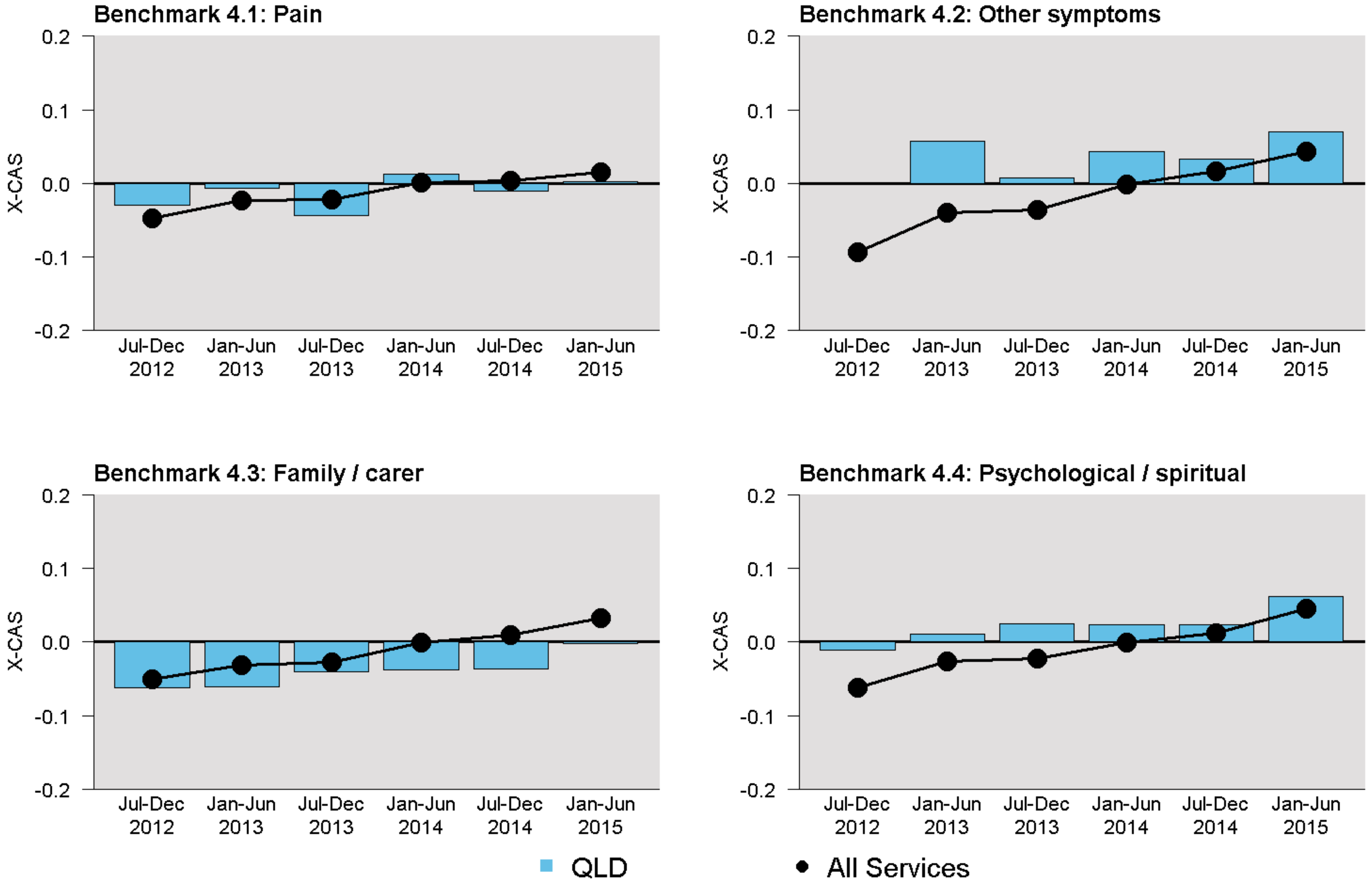
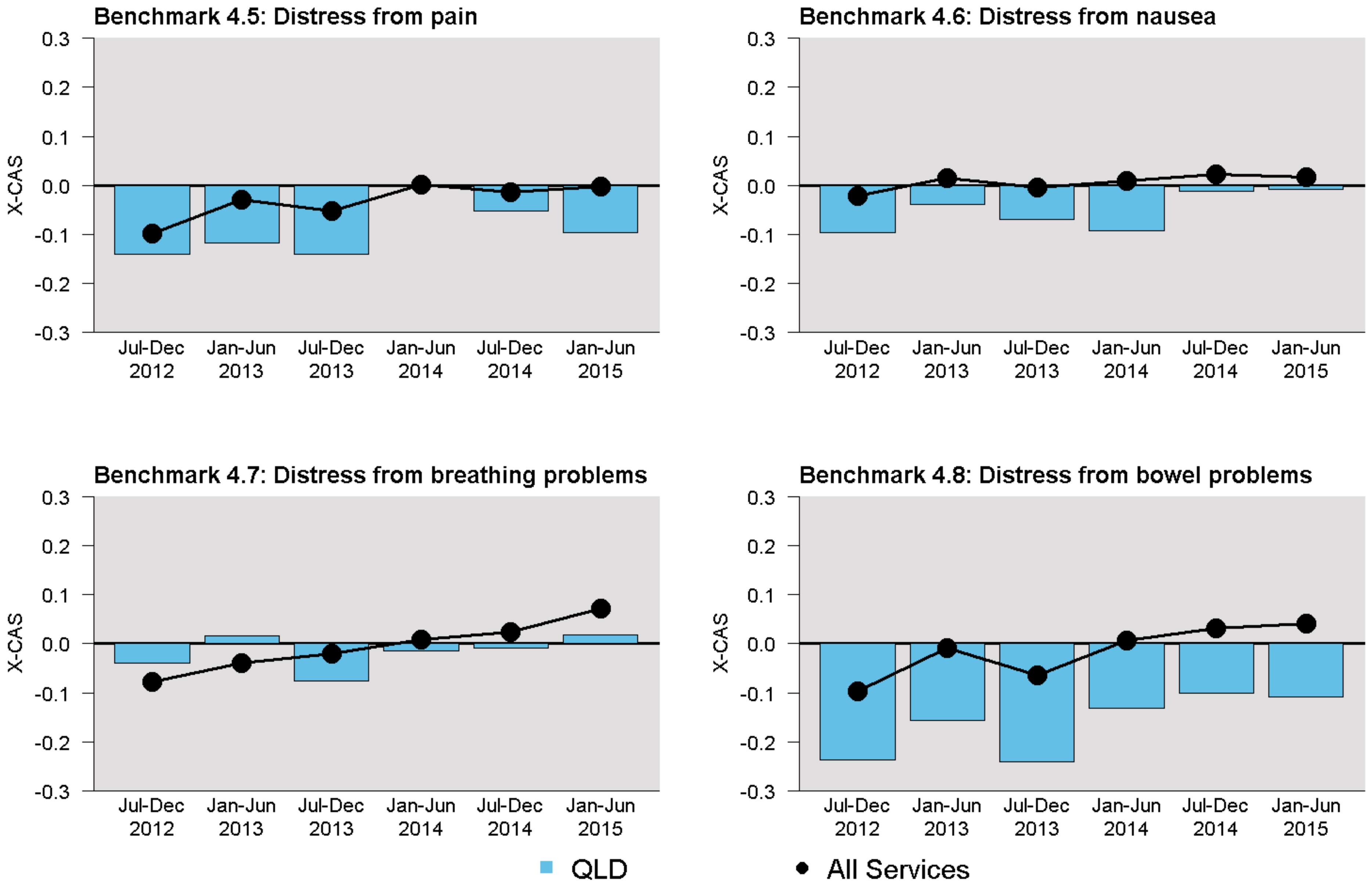


Figure 14 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)



Section 3 Descriptive analysis

This section provides descriptive information of the data submitted by Queensland services at each of the three levels – patient, episode and phase.

Patient level information describes demographics such as Indigenous status, sex, preferred language and country of birth. This information about the patient provides a context to the episode and phase level information and enhances the meaningfulness of patient outcomes.

Episode level information describes the setting of palliative care service provision. It also includes information relating to the facility or organisation that has referred the patient, how an episode starts and ends, and the setting in which the patient died.

Phase level information describes the clinical condition of the patient during the episode, using five clinical assessment tools. These are phase of illness, the patient's functional status and performance, pain and other common symptoms, the patient's psychological / spiritual and family / carer domain.

Summaries of the national data are included for comparative purposes.

3.1 Profile of palliative care patients

PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and / or treatment as evidenced by the existence of a medical record. Family and carers are included in this definition if interventions relating to them are recorded in the patient medical record.

Table 8 shows the Indigenous status for the patients in Queensland and nationally.

Table 8 Indigenous status

Indigenous status	Queensland Services		All Services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	55	1.4	205	1.1
Torres Strait Islander but not Aboriginal origin	6	0.1	17	0.1
Both Aboriginal and Torres Strait Islander origin	1	0.0	13	0.1
Neither Aboriginal nor Torres Strait Islander origin	3,929	96.9	18,587	96.7
Not stated / inadequately described	64	1.6	398	2.1
Total	***4,055***	***100.0***	***19,220***	***100.0***

Table 9 shows the breakdown of deaths for patients in Queensland and nationally for the reporting period. All inpatient deaths are reported in the hospital category while the community deaths are reported in the private residence and residential aged care facility categories.

Table 9 Place of death

Place of death	Queensland Services		All Services	
	N	%	N	%
Private residence	279	15.4	1,870	19.8
Residential aged care facility	30	1.7	695	7.4
Hospital	1,484	81.9	6,720	71.2
Not stated / inadequately described	20	1.1	150	1.6
Total	***1,813***	***100.0***	***9,435***	***100.0***

The following two tables show the country of birth and the preferred language respectively for patients in Queensland and nationally. To allow for comparison with the broader Australian community the list of country of birth in Table 10 is in descending order of the most frequent country of birth according to the 2006 Census (e.g. Italy was the fifth most common country of birth in the 2006 Census). The same approach has been taken with Table 11 (e.g. Greek was the third most frequently spoken language in the 2006 census). All other countries and languages have been grouped together to form the categories 'All other countries' and 'All other languages' respectively.

Table 10 Country of birth

Country of birth	Queensland Services		All Services	
	N	%	N	%
Australia	3,083	76.0	11,998	62.4
England	238	5.9	1,367	7.1
New Zealand	143	3.5	357	1.9
China	18	0.4	240	1.2
Italy	46	1.1	757	3.9
Vietnam	11	0.3	152	0.8
India	11	0.3	143	0.7
Scotland	48	1.2	261	1.4
Philippines	13	0.3	84	0.4
Greece	15	0.4	398	2.1
Germany	48	1.2	233	1.2
South Africa	16	0.4	83	0.4
Malaysia	5	0.1	66	0.3
Netherlands	32	0.8	194	1.0
Lebanon	0	0.0	107	0.6
All other countries	291	7.2	2,500	13.0
Not stated / inadequately described	37	0.9	280	1.5
Total	***4,055***	***100.0***	***19,220***	***100.0***

Table 11 Preferred language

Preferred language	Queensland Services		All Services	
	N	%	N	%
English	3,944	97.3	17,250	89.8
Italian	9	0.2	366	1.9
Greek	10	0.2	267	1.4
Chinese[a]	8	0.2	216	1.1
Arabic[b]	0	0.0	130	0.7
Vietnamese[c]	0	0.0	71	0.4
Spanish / Portuguese[d]	0	0.0	46	0.2
Filipino / Indonesian[e]	2	0.0	17	0.1
German[f]	5	0.1	30	0.2
Hindi[g]	1	0.0	29	0.2
Croatian / Macedonian[h]	0	0.0	126	0.7
Korean	0	0.0	15	0.1
Turkish[i]	0	0.0	35	0.2
Polish[j]	1	0.0	25	0.1
Maltese	0	0.0	18	0.1
All other languages	41	1.0	416	2.2
Not stated / inadequately described	34	0.8	163	0.8
Total	***4,055***	***100.0***	***19,220***	***100.0***

(a) Chinese includes: Cantonese, Hakka, Mandarin, Wu and Min Nan; **(b) Middle Eastern Semitic Languages includes:** Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, Mandaean (Mandaic); **(c) Mon-Khmer includes:** Khmer, Mon; **(d) Iberian Romance includes:** Catalan; **(e) Southeast Asian Austronesian Languages includes**: Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo (Hiligaynon), Javanese, Pampangan; **(f) German and Related Languages include:** Letzeburgish, Yiddish; **(g) Indo-Aryan includes:** Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, Fijian Hindustani; **(h) South Slavic includes:** Bosnian, Bulgarian, Serbian, Slovene; **(i) Turkic includes:** Azeri, Tatar, Turkmen, Uygur, Uzbek; **(j) West Slavic includes:** Czech, Slovak

Table 12 and Table 13 present a breakdown of malignant and non-malignant diagnosis for patients in Queensland and nationally. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 4 (0.1%) patients in Queensland and was not stated for 80 (0.4%) patients nationally.

Table 12 Primary diagnosis - malignant

Primary diagnosis	Queensland Services			All Services		
	N	% malignant diagnosis	% all diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	57	1.7	1.4	238	1.6	1.2
Breast	248	7.5	6.1	1,176	7.9	6.1
CNS	70	2.1	1.7	344	2.3	1.8
Colorectal	363	11.0	9.0	1,644	11.0	8.6
Other GIT	254	7.7	6.3	1,401	9.4	7.3
Haematological	235	7.1	5.8	963	6.4	5.0
Head and neck	198	6.0	4.9	826	5.5	4.3
Lung	729	22.0	18.0	3,340	22.3	17.4
Pancreas	188	5.7	4.6	938	6.3	4.9
Prostate	248	7.5	6.1	1,003	6.7	5.2
Other urological	117	3.5	2.9	593	4.0	3.1
Gynaecological	195	5.9	4.8	740	4.9	3.9
Skin	150	4.5	3.7	589	3.9	3.1
Unknown primary	94	2.8	2.3	372	2.5	1.9
Other primary malignancy	152	4.6	3.7	526	3.5	2.7
Malignant – not further defined	17	0.5	0.4	259	1.7	1.3
All malignant	***3,315***	***100.0***	***81.8***	***14,952***	***100.0***	***77.8***

Table 13 Primary diagnosis - non-malignant

Primary diagnosis	Queensland Services			All Services		
	N	% non-malignant diagnosis	% all diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	147	20.0	3.6	733	17.5	3.8
HIV / AIDS	3	0.4	0.1	6	0.1	0.0
End stage kidney disease	81	11.0	2.0	392	9.4	2.0
Stroke	55	7.5	1.4	282	6.7	1.5
Motor neurone disease	44	6.0	1.1	207	4.9	1.1
Alzheimer's dementia	15	2.0	0.4	148	3.5	0.8
Other dementia	39	5.3	1.0	237	5.7	1.2
Other neurological disease	40	5.4	1.0	335	8.0	1.7
Respiratory failure	102	13.9	2.5	674	16.1	3.5
End stage liver disease	58	7.9	1.4	171	4.1	0.9
Diabetes and its complications	4	0.5	0.1	16	0.4	0.1
Sepsis	18	2.4	0.4	116	2.8	0.6
Multiple organ failure	26	3.5	0.6	91	2.2	0.5
Other non-malignancy	90	12.2	2.2	646	15.4	3.4
Non-malignant – not further defined	14	1.9	0.3	134	3.2	0.7
All non-malignant	***736***	***100.0***	***18.2***	***4,188***	***100.0***	***21.8***

3.2 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 community patient.

An episode of palliative care starts on the date when the comprehensive palliative care assessment is undertaken and documented using the five clinical assessment tools.

An episode of palliative care ends when:

- the patient is formally separated from the current setting of care (e.g. from community to inpatient) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 14 below presents the number and percentage of episodes by age group and sex for the patients seen by Queensland services and at the national level. Age has been calculated as at the beginning of each episode.

Table 14 Age group by sex

Age group	Queensland Services				All Services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	2	0.1	7	0.3	36	0.3	26	0.2
15 - 24	7	0.2	6	0.2	31	0.2	26	0.2
25 - 34	24	0.8	36	1.5	106	0.8	90	0.8
35 - 44	75	2.6	110	4.5	278	2.2	390	3.4
45 - 54	168	5.8	217	8.9	725	5.7	926	8.1
55 - 64	523	18.1	430	17.7	2,009	15.8	1,786	15.5
65 - 74	845	29.3	618	25.5	3,313	26.1	2,669	23.2
75 - 84	827	28.7	598	24.6	3,750	29.6	3,008	26.2
85+	415	14.4	404	16.7	2,440	19.2	2,566	22.3
Not stated / inadequately described	0	0.0	0	0.0	0	0.0	0	0.0
Total	*2,886*	*100.0*	*2,426*	*100.0*	*12,688*	*100.0*	*11,487*	*100.0*

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

Referral source refers to the facility or organisation from which the patient was referred for each episode of care. Table 15 presents referral source by setting.

Table 15 Referral source by setting

Referral source	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Public hospital	2,268	64.6	7,216	57.9	1,262	70.1	6,559	56.0
Private hospital	467	13.3	1,015	8.1	201	11.2	1,157	9.9
Outpatient clinic	28	0.8	98	0.8	6	0.3	66	0.6
General medical practitioner	59	1.7	418	3.4	170	9.4	1,714	14.6
Specialist medical practitioner	44	1.3	567	4.5	20	1.1	467	4.0
Community-based palliative care agency	485	13.8	2,767	22.2	25	1.4	105	0.9
Community-based service	20	0.6	49	0.4	23	1.3	210	1.8
Residential aged care facility	16	0.5	54	0.4	15	0.8	788	6.7
Self, carer(s), family or friends	58	1.7	148	1.2	50	2.8	423	3.6
Other	65	1.9	115	0.9	23	1.3	193	1.6
Not stated / inadequately described	3	0.1	17	0.1	5	0.3	34	0.3
Total	***3,513***	***100.0***	***12,464***	***100.0***	***1,800***	***100.0***	***11,716***	***100.0***

Table 16 provides a summary of the time between referral to first contact by setting of care. 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 16 Referral to first contact by setting

Time (in days)	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Same day or following day	3,363	95.9	11,587	94.0	1,061	59.0	6,201	52.9
2-7 days	120	3.4	607	4.9	561	31.2	3,930	33.5
8-14 days	7	0.2	69	0.6	112	6.2	912	7.8
Greater than 14 days	18	0.5	66	0.5	65	3.6	671	5.7
Average	1.1	na	1.2	na	2.4	na	2.8	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 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Table 17 gives a summary of the length of episodes for patients in Queensland and nationally. Table 18 details the length of episodes 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 17 Length of episode (in days) summary by setting

Length of episode	Inpatient		Community	
	Queensland Services	All Services	Queensland Services	All Services
Average length of episode	8.6	10.9	35.4	38.3
Median length of episode	5.0	6.0	22.5	27.0

Note: Records where length of episode was greater than 180 days were considered to be atypical and are excluded from the average calculations. Only episodes ending during the reporting period are included.

Table 18 Length of episode (in days) by setting

Length of episode	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Same day	252	7.3	757	6.2	84	5.1	416	4.0
1-2 days	740	21.4	2,322	19.0	159	9.6	740	7.1
3-4 days	589	17.1	1,837	15.0	107	6.4	573	5.5
5-7 days	617	17.9	1,998	16.3	127	7.6	803	7.7
8-14 days	709	20.5	2,544	20.8	183	11.0	1,260	12.0
15-21 days	261	7.6	1,151	9.4	145	8.7	950	9.1
22-30 days	139	4.0	741	6.1	155	9.3	918	8.8
31-60 days	117	3.4	683	5.6	259	15.6	1,812	17.3
61-90 days	21	0.6	139	1.1	116	7.0	926	8.8
Greater than 90 days	7	0.2	68	0.6	327	19.7	2,077	19.8
Total	***3,452***	***100.0***	***12,240***	***100.0***	***1,662***	***100.0***	***10,475***	***100.0***

Note: Only episodes ending during the reporting period are included.

Table 19 How episodes start – inpatient setting

Episode start mode	Queensland Services		All Services	
	N	%	N	%
Admitted from community*	2,234	63.6	7,274	58.4
Admitted from another hospital	548	15.6	3,156	25.3
Admitted from acute care in another ward	600	17.1	1,721	13.8
Change from acute care to palliative care – same ward	76	2.2	206	1.7
Other**	55	1.6	100	0.8
Not stated / inadequately described	0	0.0	7	0.1
Total	***3,513***	***100.0***	***12,464***	***100.0***

* includes: admitted from usual accommodation, admitted from other than usual accommodation.

** includes: change of sub-acute/non-acute care type and other categories.

Table 20 How episodes end – inpatient setting

Episode end mode	Queensland Services		All Services	
	N	%	N	%
Discharged to community*	1,559	45.2	4,285	35.0
Discharged to another hospital	269	7.8	749	6.1
Death	1,484	43.0	6,720	54.9
Change from palliative care to acute care**	19	0.6	59	0.5
Change in sub-acute care type	23	0.7	57	0.5
End of consultative episode – inpatient episode ongoing	83	2.4	260	2.1
Other	14	0.4	100	0.8
Not stated / inadequately described	1	0.0	10	0.1
Total	***3,452***	***100.0***	***12,240***	***100.0***

Note: Only episodes ending during the reporting period are included.

* includes: discharged to usual accommodation, discharged to other than usual accommodation.

** includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.

Table 21 How episodes start – community setting

Episode start mode	Queensland Services		All Services	
	N	%	N	%
Admitted from inpatient palliative care	699	38.8	4,150	35.4
Other*	1,046	58.1	7,505	64.1
Not stated / inadequately described	55	3.1	61	0.5
Total	***1,800***	***100.0***	***11,716***	***100.0***

*includes: patient was not transferred from being an overnight patient.

Table 22 How episodes end – community setting

Episode end mode	Queensland Services		All Services	
	N	%	N	%
Admitted for inpatient palliative care	751	45.2	3,166	30.2
Admitted for inpatient acute care	282	17.0	2,902	27.7
Admitted to another palliative care service	131	7.9	180	1.7
Admitted to primary health care	48	2.9	252	2.4
Discharged / case closure	99	6.0	1,079	10.3
Death	329	19.8	2,715	25.9
Other	21	1.3	164	1.6
Not stated / inadequately described	1	0.1	17	0.2
Total	***1,662***	***100.0***	***10,475***	***100.0***

Note: Only episodes ending during the reporting period are included.

3.3 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. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence. See Appendix D for more information on the definition of palliative care phase.

The clinical assessments are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge.

Table 23 Number of phases by phase type and setting

Phase type	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Stable	1,781	25.4	7,474	25.4	1,506	44.9	9,994	37.7
Unstable	1,706	24.3	6,945	23.6	598	17.8	3,625	13.7
Deteriorating	2,289	32.6	9,150	31.1	1,022	30.5	10,802	40.7
Terminal	1,246	17.7	5,890	20.0	228	6.8	2,111	8.0
Total	***7,022***	***100.0***	***29,459***	***100.0***	***3,354***	***100.0***	***26,532***	***100.0***

Note: Bereavement phases have been excluded due to inconsistent data collection and bereavement practices. Bereavement phases are not included in the total phases count.

Table 24 Average phase length (in days) by phase type and setting

Phase type	Inpatient		Community	
	Queensland Services	All Services	Queensland Services	All Services
Stable	5.9	7.3	22.8	20.9
Unstable	2.6	2.2	4.3	4.1
Deteriorating	5.4	5.4	10.9	12.9
Terminal	2.2	2.1	2.5	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 25 presents information relating to the manner in which stable phases ended, both for Queensland and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 15 summarises the movement of patients out of the stable phase for the inpatient and community settings. This movement from one phase to another is referred to as phase progression and is derived by PCOC.

Similar information is presented for the unstable (Table 26, Figure 16), deteriorating (Table 27, Figure 17) and terminal (Table 28, Figure 18) phases on the following pages.

Table 25 How stable phases end – by setting

How stable phases end	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	671	37.7	3,825	51.2	878	58.3	6,461	64.6
Discharge / case closure	1,094	61.4	3,559	47.6	579	38.4	3,194	32.0
Died	16	0.9	86	1.2	46	3.1	301	3.0
Not stated / inadequately described	0	0.0	4	0.1	3	0.2	38	0.4
Total	***1,781***	***100.0***	***7,474***	***100.0***	***1,506***	***100.0***	***9,994***	***100.0***

Figure 15 Stable phase progression

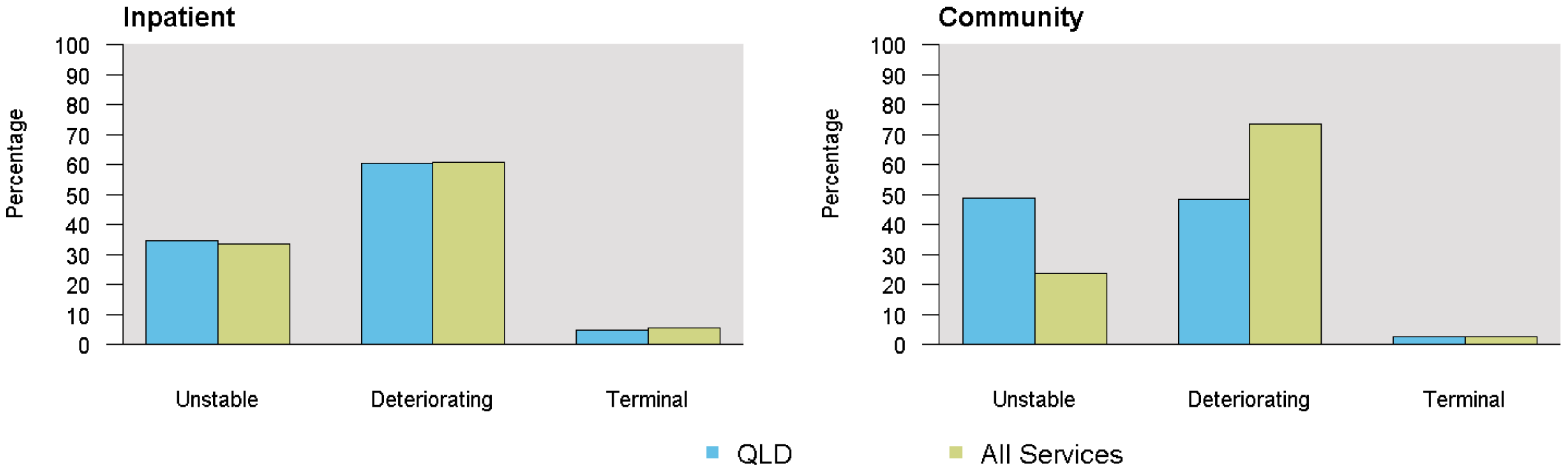


Table 26 How unstable phases end – by setting

How unstable phases end	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	1,408	82.5	6,296	90.7	350	58.5	2,400	66.2
Discharge / case closure	262	15.4	489	7.0	241	40.3	1,157	31.9
Died	35	2.1	156	2.2	6	1.0	65	1.8
Not stated / inadequately described	1	0.1	4	0.1	1	0.2	3	0.1
Total	***1,706***	***100.0***	***6,945***	***100.0***	***598***	***100.0***	***3,625***	***100.0***

Figure 16 Unstable phase progression

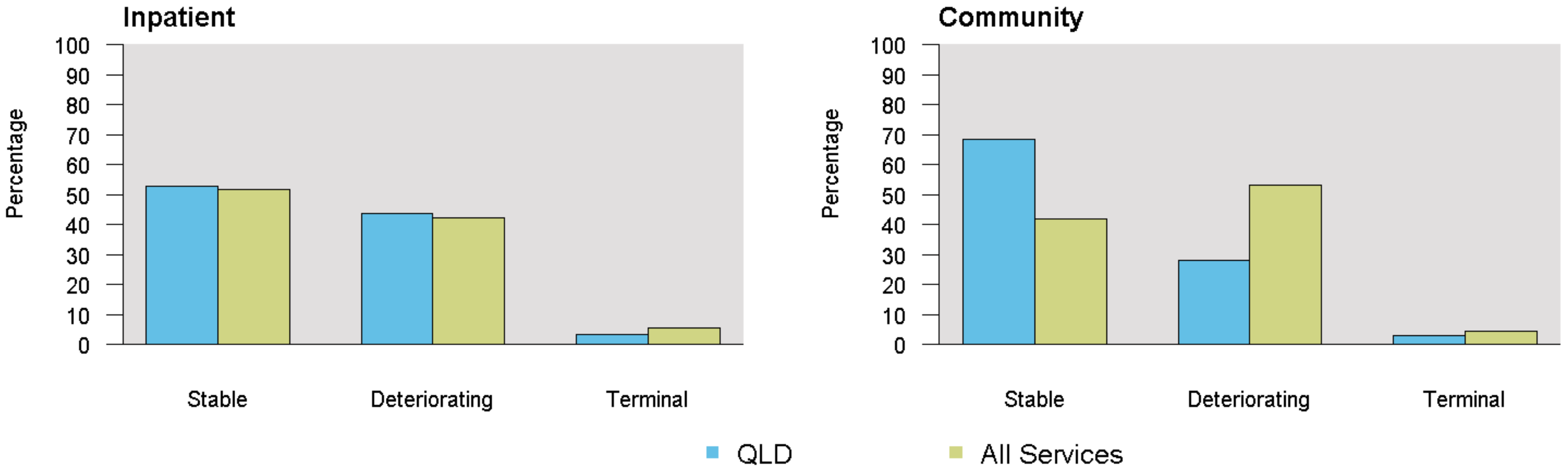


Table 27 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	1,454	63.5	6,834	74.7	447	43.7	6,853	63.4
Discharge / case closure	591	25.8	1,353	14.8	467	45.7	3,121	28.9
Died	243	10.6	958	10.5	106	10.4	794	7.4
Not stated / inadequately described	1	0.0	5	0.1	2	0.2	34	0.3
Total	*2,289*	*100.0*	*9,150*	*100.0*	*1,022*	*100.0*	*10,802*	*100.0*

Figure 17 Deteriorating phase progression

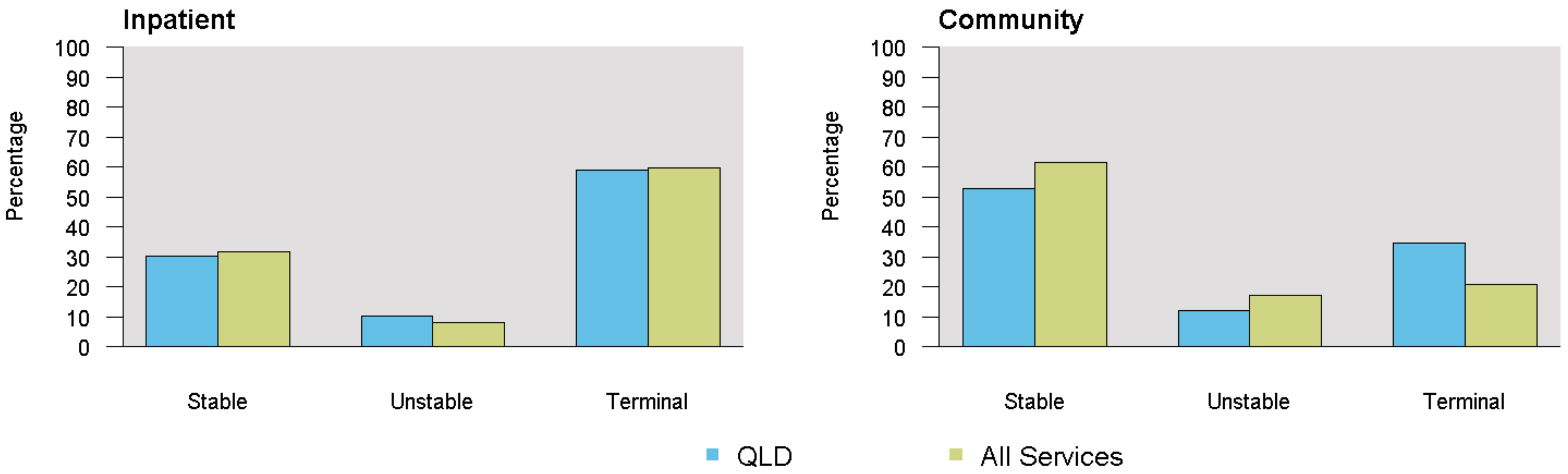
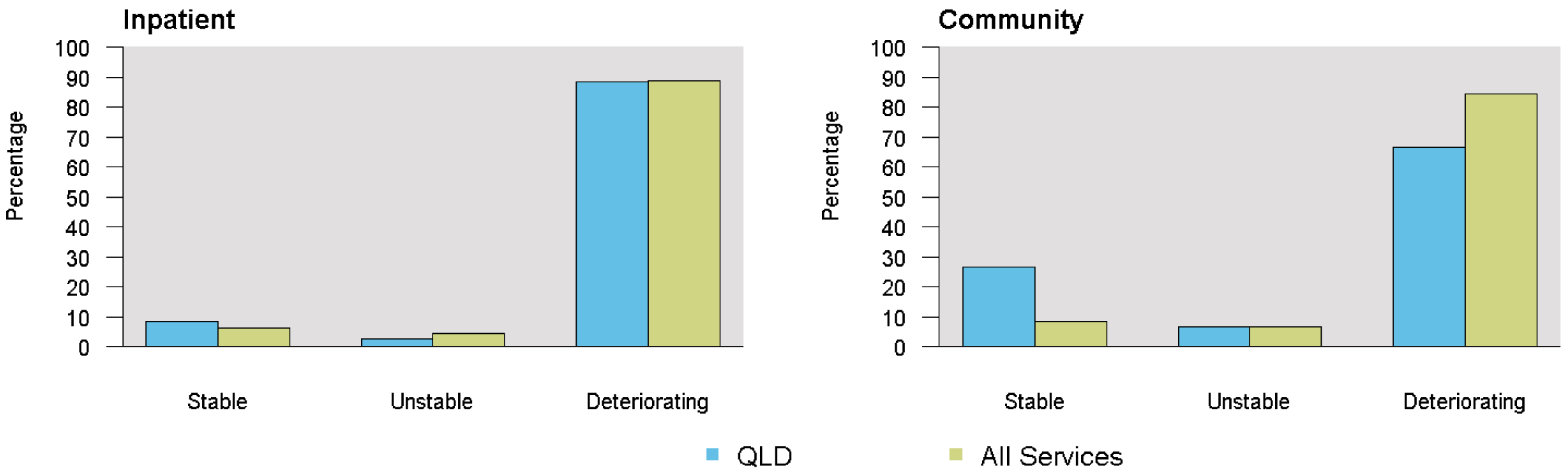


Table 28 How terminal phases end – by setting

How terminal phases end	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	35	2.8	265	4.5	15	6.6	340	16.1
Discharge / case closure	20	1.6	103	1.7	40	17.5	198	9.4
Died	1,187	95.3	5,516	93.7	171	75.0	1,567	74.2
Not stated / inadequately described	4	0.3	6	0.1	2	0.9	6	0.3
Total	***1,246***	***100.0***	***5,890***	***100.0***	***228***	***100.0***	***2,111***	***100.0***

Figure 18 Terminal phase progression



The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains (pain, other symptoms, psychological / spiritual and family / carer). The ratings are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe.

Table 29 and Table 30 show the percentage scores for the inpatient and community settings, respectively, for both Queensland and nationally. Alternative graphical representations of PCPSS profile by phase type can be found in Appendix B.

Table 29 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)

Phase type		Queensland Services				All Services			
	Problem severity	**Absent**	**Mild**	**Moderate**	**Severe**	**Absent**	**Mild**	**Moderate**	**Severe**
Stable	Pain	42.9	42.0	12.2	2.9	48.6	37.6	11.6	2.2
	Other symptoms	30.4	49.0	17.5	3.1	29.1	51.2	16.9	2.8
	Psychological / spiritual	41.0	46.8	10.5	1.8	39.6	48.8	10.0	1.6
	Family / carer	40.2	45.0	11.9	2.9	43.0	44.3	10.5	2.3
Unstable	Pain	22.4	32.9	28.3	16.3	31.6	32.0	24.8	11.7
	Other symptoms	15.8	29.5	39.6	15.1	16.1	36.1	35.1	12.8
	Psychological / spiritual	24.9	43.2	25.0	6.9	27.5	45.4	21.3	5.8
	Family / carer	30.5	37.3	24.5	7.7	30.0	42.3	21.3	6.3
Deteriorating	Pain	32.6	37.6	20.7	9.1	39.0	36.6	19.0	5.4
	Other symptoms	15.8	38.4	33.5	12.3	18.4	41.9	31.8	7.9
	Psychological / spiritual	28.1	47.4	18.7	5.8	30.0	47.6	18.5	3.9
	Family / carer	23.9	41.6	25.2	9.4	29.4	42.9	21.9	5.8
Terminal	Pain	46.3	35.6	13.7	4.3	51.2	31.7	13.3	3.9
	Other symptoms	42.0	33.4	17.8	6.8	37.1	35.1	20.1	7.8
	Psychological / spiritual	58.3	30.2	8.1	3.3	53.4	32.6	10.8	3.2
	Family / carer	19.7	38.2	28.1	14.0	26.0	38.6	25.3	10.0

Table 30 Profile of PCPSS at beginning of phase by phase type –community setting (percentages)

Phase type		Queensland Services				All Services			
	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	35.3	49.8	13.4	1.5	40.8	51.4	7.3	0.6
	Other symptoms	16.4	59.9	20.9	2.8	16.1	66.5	16.1	1.3
	Psychological / spiritual	28.7	58.3	11.1	1.9	30.4	59.3	9.4	0.9
	Family / carer	25.4	53.2	18.4	2.9	30.6	54.0	13.7	1.6
Unstable	Pain	18.4	31.1	31.8	18.7	18.7	29.8	33.9	17.5
	Other symptoms	6.7	27.5	43.8	21.9	5.0	28.0	49.6	17.4
	Psychological / spiritual	16.8	50.2	25.1	7.9	12.4	46.5	34.0	7.1
	Family / carer	14.3	40.9	32.3	12.4	11.9	37.1	41.1	9.9
Deteriorating	Pain	28.0	42.7	24.9	4.4	29.2	49.3	19.0	2.4
	Other symptoms	8.8	40.9	41.6	8.6	8.3	50.7	37.1	4.0
	Psychological / spiritual	20.6	55.8	20.2	3.5	19.1	59.0	19.9	2.0
	Family / carer	11.8	47.8	32.6	7.9	17.4	51.3	27.3	3.9
Terminal	Pain	36.7	38.5	19.5	5.4	37.6	43.3	16.0	3.1
	Other symptoms	20.7	35.6	27.9	15.8	23.4	43.6	26.4	6.6
	Psychological / spiritual	32.3	43.6	16.4	7.7	43.6	40.8	13.0	2.6
	Family / carer	5.4	37.9	38.8	17.9	11.4	43.2	36.7	8.7

The Symptom Assessment Scale (SAS) is a patient rated (or proxy) assessment tool and reports a level of distress using a numerical rating scale from 0 - no distress to 10 - worst possible distress. The SAS reports on distress from seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient’s perspective. The SAS scores are grouped in Table 31 and Table 32 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). Alternative graphical representations of the SAS profile by phase type can be found in Appendix B.

Table 31 Profile of SAS scores at beginning of phase by phase type – inpatient setting (percentages)

Phase type		Queensland Services				All Services			
	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	59.8	21.9	15.5	2.8	69.4	17.1	11.1	2.5
	Appetite problems	50.2	25.2	20.6	4.0	58.0	22.3	16.6	3.1
	Nausea	73.8	17.7	7.3	1.2	80.3	12.4	6.2	1.1
	Bowel problems	55.4	24.3	15.5	4.8	63.6	20.6	12.9	2.9
	Breathing problems	61.3	20.3	13.3	5.0	66.4	17.6	12.6	3.4
	Fatigue	24.0	27.5	38.4	10.1	31.1	26.6	35.2	7.1
	Pain	39.7	34.7	21.7	3.9	46.6	31.3	19.4	2.8
Unstable	Difficulty sleeping	47.4	26.5	18.9	7.1	59.0	18.3	17.0	5.7
	Appetite problems	34.6	25.7	28.7	11.0	45.3	21.5	25.2	8.0
	Nausea	59.0	19.1	16.0	5.8	68.0	14.2	13.2	4.6
	Bowel problems	42.1	25.9	22.5	9.6	53.7	20.9	18.4	7.0
	Breathing problems	51.0	20.1	19.3	9.7	57.8	17.1	17.6	7.5
	Fatigue	17.0	17.7	46.9	18.4	23.7	19.9	41.3	15.1
	Pain	21.6	28.8	35.1	14.6	32.2	26.8	29.3	11.6
Deteriorating	Difficulty sleeping	66.7	17.0	13.1	3.2	72.4	13.9	11.3	2.4
	Appetite problems	43.4	23.4	24.8	8.4	55.0	19.4	19.5	6.1
	Nausea	69.0	15.0	11.7	4.2	77.7	10.8	8.8	2.7
	Bowel problems	53.9	21.8	18.3	6.1	62.1	19.8	14.2	3.9
	Breathing problems	51.5	18.8	20.6	9.2	59.1	17.7	16.9	6.3
	Fatigue	22.8	15.3	41.0	20.9	30.3	17.7	37.9	14.1
	Pain	31.8	31.9	27.8	8.5	39.9	30.0	24.3	5.8
Terminal	Difficulty sleeping	92.6	4.0	2.7	0.7	92.1	3.8	3.2	0.9
	Appetite problems	91.0	3.4	3.0	2.7	89.8	3.9	4.0	2.3
	Nausea	93.9	3.2	2.0	1.0	94.1	3.0	2.3	0.6
	Bowel problems	86.6	7.4	4.5	1.6	85.7	7.9	5.1	1.4
	Breathing problems	71.8	11.8	10.8	5.7	71.2	12.3	11.6	4.9
	Fatigue	79.9	3.8	8.1	8.2	75.8	5.9	10.4	7.8
	Pain	56.9	24.8	14.3	4.0	59.5	22.4	15.1	3.0

Table 32 Profile of SAS scores at beginning of phase by phase type –community setting (percentages)

Phase type		Queensland Services				All Services			
	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	58.3	24.9	14.7	2.1	63.2	26.5	9.4	0.9
	Appetite problems	47.0	29.5	20.0	3.5	49.2	33.4	15.1	2.3
	Nausea	74.7	16.9	7.2	1.2	80.4	15.8	3.4	0.5
	Bowel problems	58.4	26.7	12.6	2.2	66.4	25.8	6.8	1.0
	Breathing problems	53.6	23.9	18.4	4.1	54.3	30.6	13.3	1.8
	Fatigue	16.4	28.0	44.3	11.4	15.1	35.7	43.9	5.3
	Pain	38.2	39.9	19.6	2.2	43.8	42.3	12.6	1.2
Unstable	Difficulty sleeping	44.2	23.5	24.6	7.7	43.0	26.7	24.2	6.1
	Appetite problems	42.5	22.6	26.6	8.2	32.2	26.8	30.9	10.0
	Nausea	63.4	15.6	14.9	6.2	60.3	18.7	15.2	5.8
	Bowel problems	48.5	24.5	19.7	7.2	51.2	26.8	16.8	5.3
	Breathing problems	47.1	23.1	20.0	9.8	44.9	28.1	20.7	6.3
	Fatigue	11.8	20.9	46.4	20.9	8.9	20.8	52.6	17.8
	Pain	18.5	25.6	36.9	19.0	20.2	23.9	37.7	18.2
Deteriorating	Difficulty sleeping	57.1	21.6	17.6	3.6	57.4	26.9	13.9	1.7
	Appetite problems	34.9	29.2	27.2	8.8	39.8	32.4	23.0	4.8
	Nausea	64.4	21.9	11.6	2.1	72.8	19.0	7.2	1.1
	Bowel problems	46.1	28.2	21.0	4.6	60.3	26.9	11.1	1.6
	Breathing problems	41.6	23.9	26.0	8.5	47.9	30.7	18.7	2.6
	Fatigue	10.2	12.9	49.1	27.8	12.2	23.0	52.3	12.4
	Pain	31.5	33.6	28.8	6.0	33.2	39.5	24.0	3.3
Terminal	Difficulty sleeping	69.5	12.3	12.8	5.4	75.8	13.3	9.0	1.9
	Appetite problems	64.0	11.0	12.5	12.5	79.0	7.5	6.2	7.3
	Nausea	82.8	12.3	4.4	0.5	83.9	10.8	4.6	0.7
	Bowel problems	65.5	20.7	11.3	2.5	73.2	18.0	7.8	1.0
	Breathing problems	51.2	24.6	14.3	9.9	55.7	24.0	16.1	4.2
	Fatigue	45.8	9.9	18.7	25.6	58.4	7.0	15.6	19.0
	Pain	43.3	32.0	19.2	5.4	40.2	35.0	21.3	3.5

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. Table 33 shows the data for the AKPS at phase start.

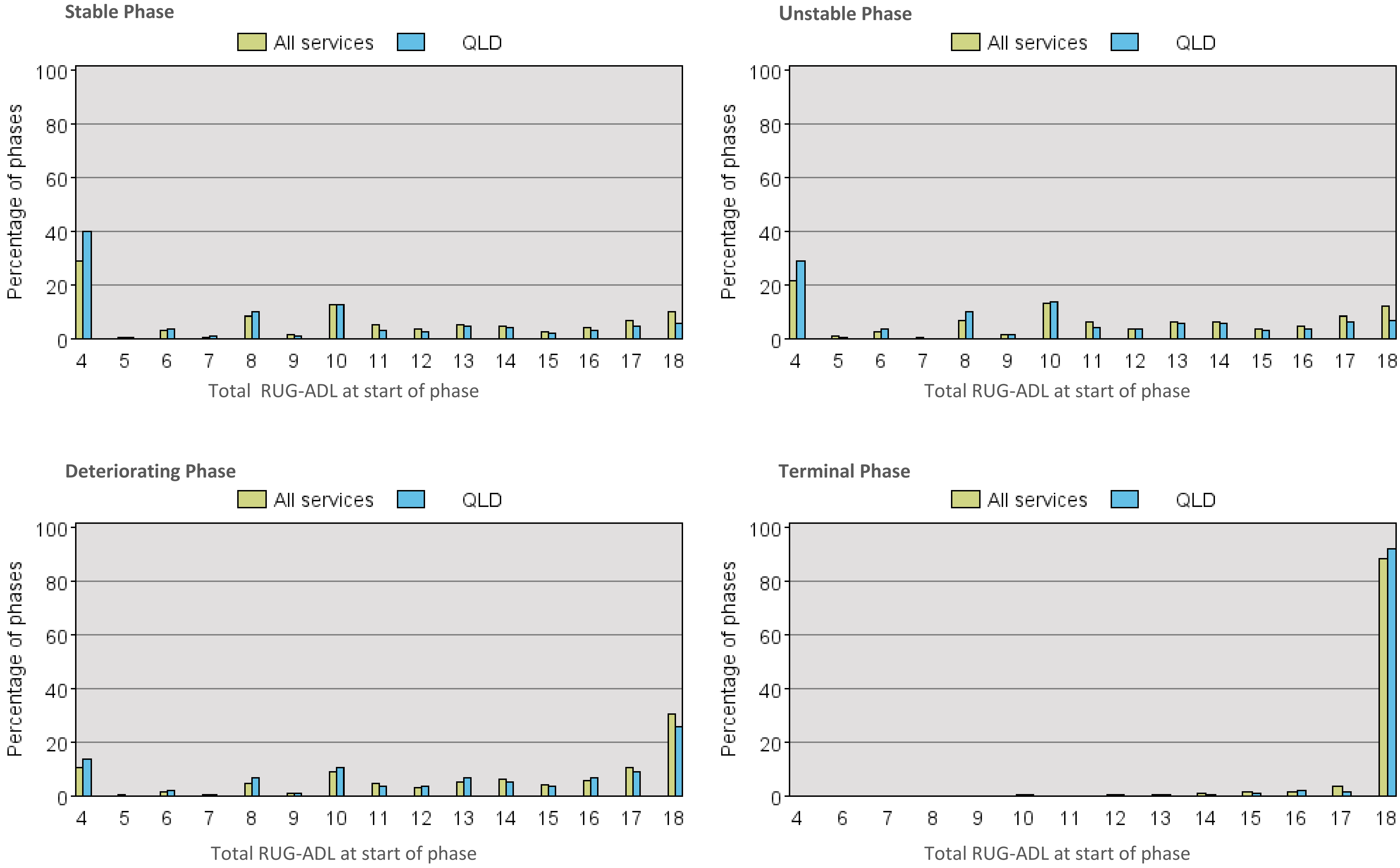
Table 33 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting

AKPS assessment at phase start	Inpatient				Community			
	Queensland Services		All Services		Queensland Services		All Services	
	N	%	N	%	N	%	N	%
10 - Comatose or barely rousable	770	11.0	3,099	10.5	72	2.1	915	3.4
20 - Totally bedfast and requiring extensive nursing care	1,305	18.6	6,617	22.5	254	7.6	2,569	9.7
30 - Almost completely bedfast	867	12.3	3,735	12.7	242	7.2	1,906	7.2
40 - In bed more than 50% of the time	1,343	19.1	5,608	19.0	438	13.1	3,438	13.0
50 - Requires considerable assistance	1,336	19.0	4,971	16.9	963	28.7	6,369	24.0
60 - Requires occasional assistance	985	14.0	3,053	10.4	851	25.4	6,553	24.7
70 - Cares for self	277	3.9	657	2.2	335	10.0	3,168	11.9
80 - Normal activity with effort	82	1.2	209	0.7	134	4.0	741	2.8
90 - Able to carry on normal activity; minor signs or symptoms	19	0.3	76	0.3	32	1.0	135	0.5
100 - Normal; no complaints; no evidence of disease	2	0.0	2	0.0	5	0.1	11	0.0
Not stated/inadequately described	36	0.5	1,432	4.9	28	0.8	727	2.7
Total	***7,022***	***100.0***	***29,459***	***100.0***	***3,354***	***100.0***	***26,532***	***100.0***

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. Figure 19 and Figure 20 on the following two pages summarise the total RUG-ADL at the beginning of each phase for inpatients 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).

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.

Figure 19 Total RUG-ADL at beginning of phase by phase type – inpatient setting



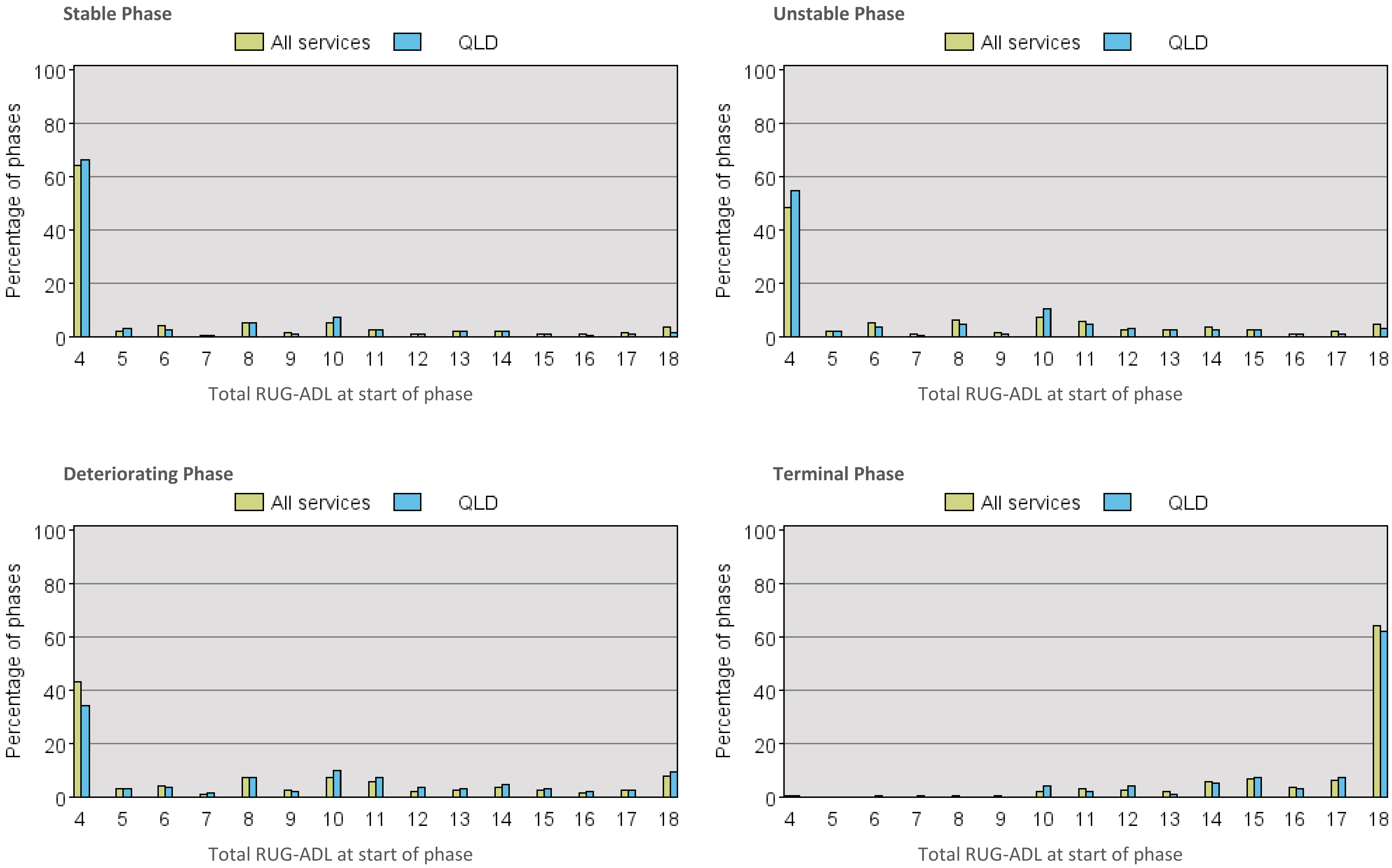
Stable Phase

Unstable Phase

Deteriorating Phase

Terminal Phase

Figure 20 Total RUG-ADL at beginning of phase by phase type – community setting



Appendix A Summary of data included in this report

A1 Data summary

During the reporting period, data were provided for a total of 19,220 patients who between them had 24,180 episodes of care and 55,991 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 (Appendix C contains a more detailed explanation of this process). Table 34 shows the number of patients, episodes and phases included in this report – both for Queensland and nationally.

Table 34 Number and percentage of patients, episodes and phases by setting

	Inpatient		Community		Total	
	Queensland Services	All Services	Queensland Services	All Services	Queensland Services	All Services
Number of patients*	2,885	10,692	1,455	9,391	4,055	19,220
Number of episodes	3,513	12,464	1,800	11,716	5,313	24,180
Number of phases**	7,022	29,459	3,354	26,532	10,376	55,991
Percentage of patients*	71.1	55.6	35.9	48.9	100	100
Percentage of episodes	66.1	51.5	33.9	48.5	100	100
Percentage of phases	67.7	52.6	32.3	47.4	100	100
Average number of phases per episode***	2.0	2.3	1.8	2.1	1.9	2.3

* Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.
** Bereavement phases are excluded from this count.
*** Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Table 35 shows the number of completed episodes and phases by setting for each month in the current reporting period for Queensland services.

Table 35 Number of completed episodes and phases by month and setting

		Jan	Feb	Mar	Apr	May	Jun
Inpatient	No. of completed episodes	514	560	638	544	597	599
	No. of completed phases	1,088	1,155	1,266	1,087	1,228	1,198
Community	No. of completed episodes	250	243	325	287	276	281
	No. of completed phases	543	535	624	546	550	556

Table 36 shows the number of patients, episodes and phases for Queensland services over time and is reported by setting of care.

Table 36 Number of patients, episodes and phases by setting and reporting period

	Inpatient						Community					
	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2014	Jan-Jun 2015	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2014	Jan-Jun 2015
Number of patients*	2,383	2,543	2,120	2,421	2,754	2,882	1,179	1,372	1,646	1,521	1,690	1,453
Number of episodes	2,852	3,090	2,589	2,967	3,311	3,513	1,366	1,576	1,918	1,820	2,113	1,800
Number of phases**	5,656	5,913	5,552	5,626	6,609	7,022	2,160	2,678	3,218	3,106	3,888	3,354
Average number of phases per episode***	2.0	1.9	2.2	1.9	2.0	2.0	1.5	1.7	1.6	1.6	1.7	1.8

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

** Bereavement phases are excluded from this count.

*** Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

A2 Data item completion

As shown in Table 37, Table 38 and Table 39 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 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 37 Item completion (per cent complete) - patient level

Data item	Queensland Services	All Services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	98.4	97.9
Country of birth	99.1	98.5
Preferred language	99.2	99.2
Primary diagnosis	99.9	99.6

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

Table 38 Item completion by setting (per cent complete) - episode level

Data item	Inpatient		Community		Total	
	Queensland Services	All Services	Queensland Services	All Services	Queensland Services	All Services
Date of first contact	99.9	98.9	99.9	100.0	99.9	99.4
Referral date	99.9	98.9	99.9	100.0	99.9	99.4
Referral source	99.9	99.9	99.7	99.7	99.8	99.8
Date ready for care	99.9	95.6	99.9	99.9	99.9	97.7
Mode of episode start	100.0	99.9	96.9	99.5	99.0	99.7
Accommodation at episode start	99.9	99.9	95.9	96.6	98.1	97.9
Episode end date*	99.8	99.8	95.9	94.0	98.5	97.0
Mode of episode end	100.0	99.9	99.9	99.8	100.0	99.9
Accommodation at episode end	99.1	99.3	97.5	89.9	98.9	96.8
Place of death	na	na	94.3	94.4	94.3	94.4

* Episode end date item completion may be affected by open episodes.

Table 39 Item completion by setting (per cent complete) - phase level

Data item	Sub-Category	At phase start						At discharge					
		Inpatient		Community		Total		Inpatient		Community		Total	
	(where applicable)	Queensland Services	All Services	Queensland Services	All Services	Queensland Services	All Services	Queensland Services	All Services	Queensland Services	All Services	Queensland Services	All Services
RUG-ADL	Bed mobility	99.6	99.7	99.4	96.9	99.5	98.3	97.8	91.4	76.3	60.9	89.1	73.6
	Toileting	99.6	99.7	99.4	96.7	99.5	98.3	97.8	91.3	76.3	60.9	89.1	73.6
	Transfers	99.6	99.7	99.3	96.5	99.5	98.2	97.8	91.3	76.3	60.8	89.1	73.6
	Eating	99.2	99.4	99.3	95.8	99.2	97.7	97.6	91.3	76.0	60.6	88.9	73.4
PCPSS	Pain	99.0	99.1	99.2	96.9	99.1	98.1	97.7	91.0	75.7	60.4	88.8	73.2
	Other symptom	98.7	97.4	98.7	95.0	98.7	96.2	97.7	90.0	75.6	59.7	88.8	72.3
	Psychological / spiritual	98.8	99.3	98.8	96.2	98.8	97.9	97.3	91.0	75.4	60.1	88.5	73.0
	Family / carer	98.1	98.0	96.8	95.3	97.7	96.7	95.7	87.7	74.5	59.9	87.2	71.5
SAS	Difficulty sleeping	86.1	93.9	96.7	92.9	89.5	93.4	75.4	79.6	72.9	57.2	74.4	66.6
	Appetite problems	86.2	94.1	97.2	95.1	89.8	94.6	76.6	80.2	73.5	59.3	75.3	68.0
	Nausea	86.2	94.1	97.3	96.2	89.8	95.1	75.0	79.6	73.5	60.0	74.4	68.2
	Bowel problems	86.0	94.0	97.3	95.2	89.7	94.5	76.6	80.1	73.7	58.9	75.4	67.8
	Breathing problems	86.3	94.2	97.3	95.6	89.8	94.8	75.7	79.9	73.8	59.5	75.0	68.0
	Fatigue	86.3	94.1	97.5	96.2	89.9	95.1	77.9	80.5	73.7	60.2	76.2	68.7
	Pain	86.3	94.2	97.5	97.4	89.9	95.7	77.4	80.5	73.9	61.0	76.0	69.1
AKPS	-	99.5	95.1	99.2	97.3	99.4	96.1	98.6	89.4	82.7	63.0	92.2	74.1

Data item	Inpatient		Community		Total	
	Queensland Services	All Services	Queensland Services	All Services	Queensland Services	All Services
Phase End Reason	99.9	99.9	99.7	99.5	99.8	99.7

Appendix B Additional information on profile of SAS and PCPSS

Figure 21 Profile of SAS and PCPSS by phase type for Queensland services – inpatient setting

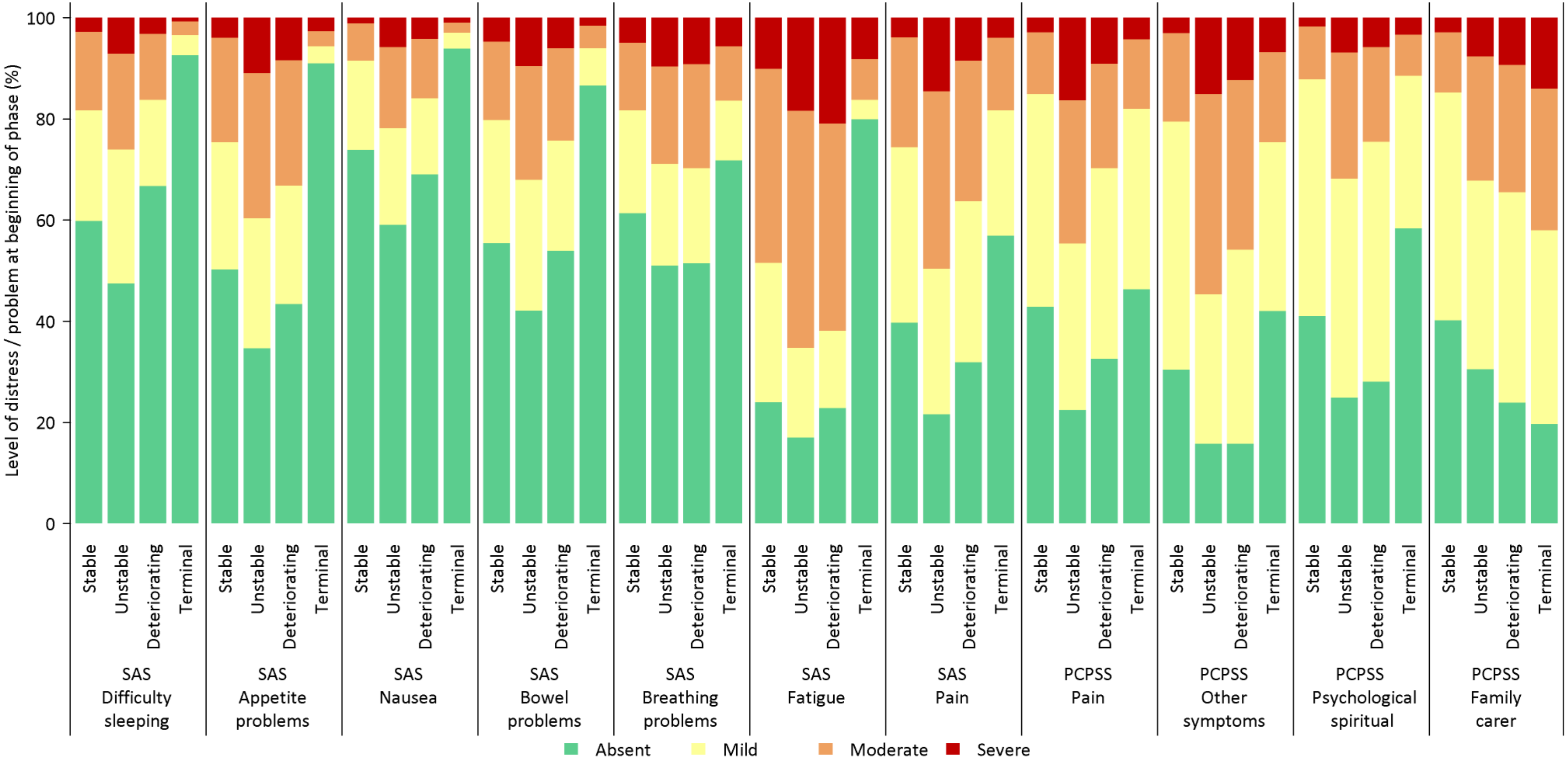
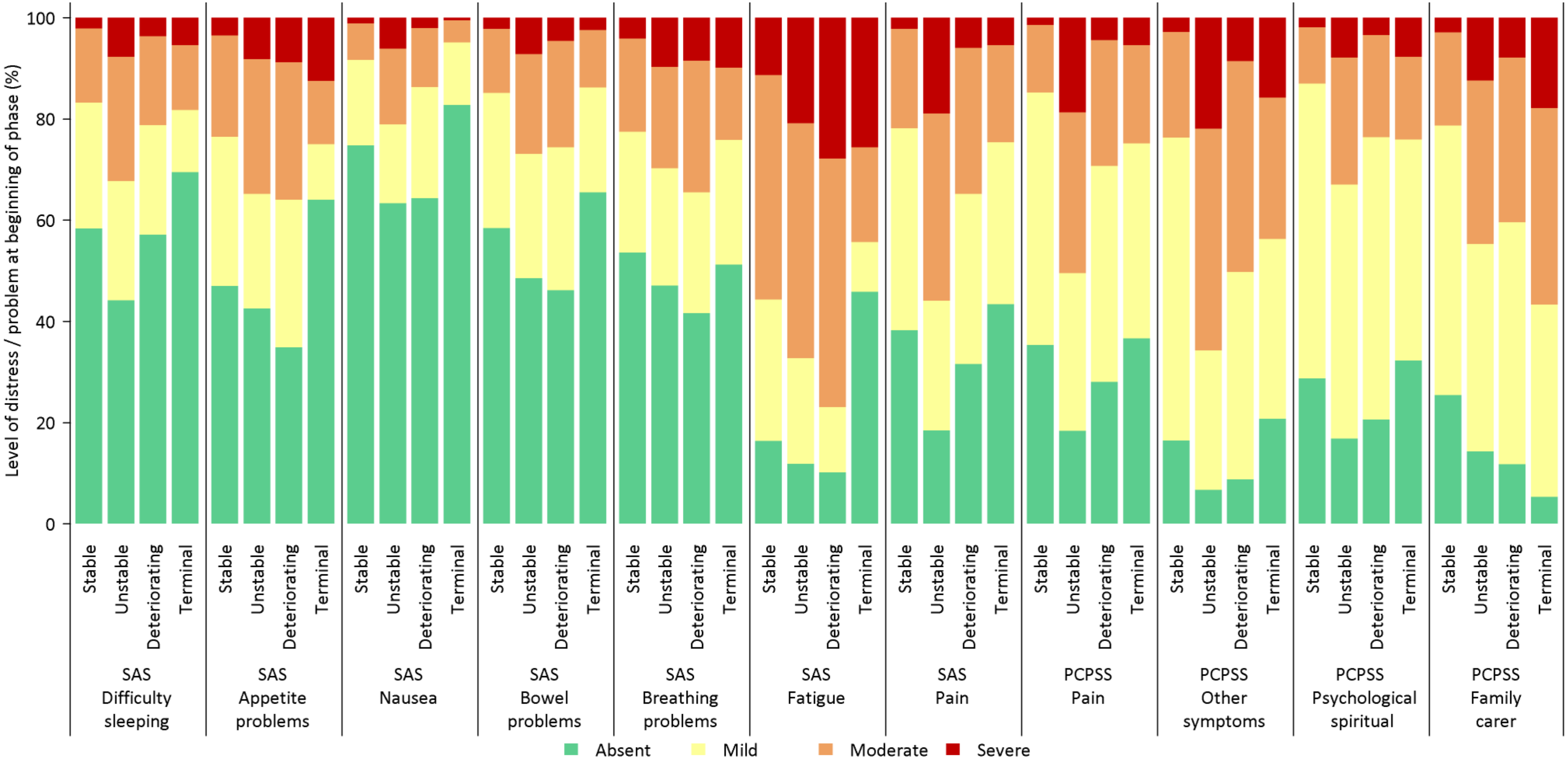


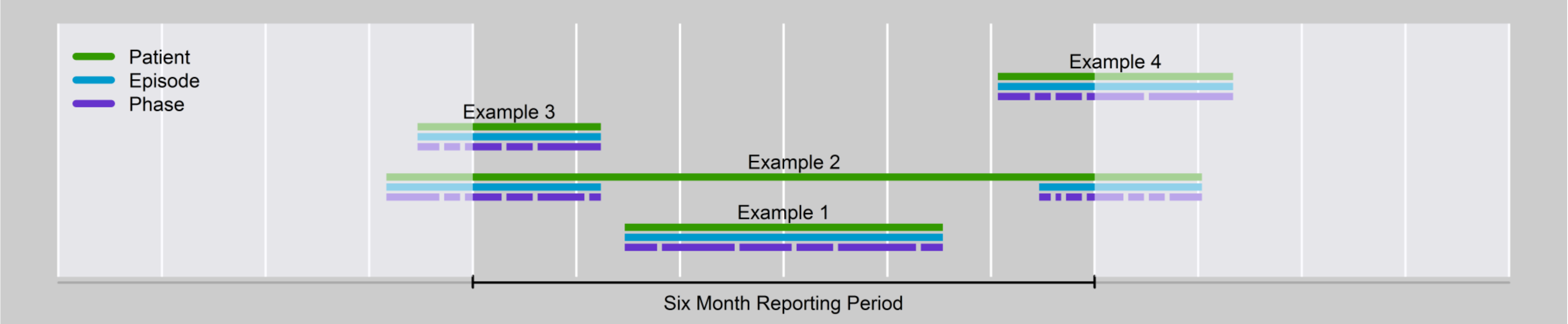
Figure 22 Profile of SAS and PCPSS by phase type for Queensland services – community setting



Appendix C Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 23 below displays four examples to help visualize this process.

Figure 23 Diagram of the PCOC data scoping method



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

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

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

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

Appendix D Palliative Care Phase definitions

START	END
1. Stable	
Patient problems and symptoms are adequately controlled by established plan of care **and** ▪ Further interventions to maintain symptom control and quality of life have been planned **and** ▪ Family / carer situation is relatively stable and no new issues are apparent.	The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care.
2. Unstable	
An urgent change in the plan of care or emergency treatment is required **because** ▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and / or** ▪ Patient experiences a rapid increase in the severity of a current problem; **and / or** ▪ Family / carers circumstances change suddenly impacting on patient care.	▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom / crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and / or** ▪ Death is likely within days (i.e. patient is now terminal).
3. Deteriorating	
The care plan is addressing anticipated needs but requires periodic review **because** ▪ Patients overall functional status is declining **and** ▪ Patient experiences a gradual worsening of existing problem **and / or** ▪ Patient experiences a new but anticipated problem **and / or** ▪ Family / carers experience gradual worsening distress that impacts on the patient care.	▪ Patient condition plateaus (i.e. patient is now stable) **or** ▪ An urgent change in the care plan or emergency treatment **and / or** ▪ Family / carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** ▪ Death is likely within days (i.e. patient is now terminal).
4. Terminal	
Death is likely within days.	▪ Patient dies **or** ▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).
5. Bereavement – post death support	
▪ The patient has died ▪ Bereavement support provided to family / carers is documented in the deceased patient's clinical record.	▪ Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

Acknowledgements

Contributions

PCOC wishes to acknowledge the valuable contribution made by the many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible.

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.

Copyright

This work is copyright. It may be produced in whole or in part for study or training purposes subject to the inclusion of an acknowledgement of the source. It is not for commercial usage or sale. Reproduction for purposes other than those above requires the written permission of PCOC.

Suggested Citation

Connolly A, Bird S, Clapham S, Carnew L, Christiansen C, Quinsey K, Foskett L and Allingham S (2015) *Patient Outcomes in Palliative Care – Queensland, January – June 2015.* Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong