



National Report on Patient Outcomes in Palliative Care in Australia

July – December 2015

March 2016

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

www.pcoc.org.au

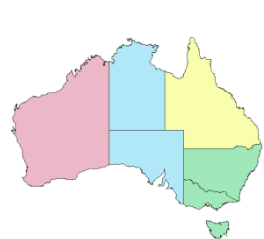
About the Palliative Care Outcomes Collaboration

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

Introduction.....	1
Section 1 Benchmark summary.....	2
1.1 Australian Outcomes at a glance.....	2
1.2 National benchmark profiles.....	3
Section 2 Outcome measures in detail.....	7
2.1 Outcome measure 1 – Time from date ready for care to episode start.....	7
2.2 Outcome measure 2 – Time in unstable phase.....	9
2.3 Outcome measure 3 – Change in pain.....	11
2.4 Outcome measure 4 – Change in symptoms relative to the baseline national average (X-CAS).....	14
Section 3 Descriptive analysis.....	18
3.1 Profile of palliative care patients.....	19
3.2 Profile of palliative care episodes.....	24
3.3 Profile of palliative care phases.....	30
Appendix A Summary of data included in this report.....	42
A1 Data summary.....	42
A2 Data item completion.....	44
Appendix B Additional information on profile of SAS and PCPSS.....	46
Appendix C Data scoping method.....	48
Appendix D Palliative Care Phase definitions.....	49
Acknowledgements.....	50

List of Tables

Table 1 Summary of outcome measures by setting	2
Table 2 Time from date ready for care to episode start by setting.....	7
Table 3 Time in unstable phase by setting	9
Table 4 Summary of outcome measure 3.....	11
Table 5 Summary of outcome measure 4 – inpatient setting	14
Table 6 Summary of outcome measure 4 – community setting	15
Table 7 Indigenous status.....	19
Table 8 Place of death	19
Table 9 Country of birth.....	20
Table 10 Preferred language	21
Table 11 Primary diagnosis - malignant.....	22
Table 12 Primary diagnosis - non-malignant	23
Table 13 Age group by sex.....	24
Table 14 Referral source by setting.....	25
Table 15 Referral to first contact by setting.....	26
Table 16 Length of episode (in days) summary by setting	27
Table 17 Length of episode (in days) by setting	27
Table 18 How episodes start – inpatient setting.....	28
Table 19 How episodes end – inpatient setting	28
Table 20 How episodes start – community setting	29
Table 21 How episodes end – community setting.....	29
Table 22 Number of phases by phase type and setting	30
Table 23 Average phase length (in days) by phase type and setting	30
Table 24 How stable phases end – by setting.....	31
Table 25 How unstable phases end – by setting	32
Table 26 How deteriorating phases end – by setting	33
Table 27 How terminal phases end – by setting.....	34
Table 28 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages).....	35
Table 29 Profile of PCPSS at beginning of phase by phase type –community setting (percentages)	36
Table 30 Profile of SAS scores at beginning of phase by phase type – inpatient setting (percentages).....	37
Table 31 Profile of SAS scores at beginning of phase by phase type –community setting (percentages).....	38

Table 32 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting	39
Table 33 Number and percentage of patients, episodes and phases by setting.....	42
Table 34 Number of completed episodes and phases by month and setting	43
Table 35 Number of patients, episodes and phases by setting and reporting period	43
Table 36 Item completion (per cent complete) - patient level.....	44
Table 37 Item completion by setting (per cent complete) - episode level.....	44
Table 38 Item completion by setting (per cent complete) - phase level.....	45

List of Figures

Figure 1 Percentage of patients with episodes that commenced on the day of, or the day after date ready for care.....	4
Figure 2 Percentage of patients in the unstable phase for 3 days or less.....	4
Figure 3 PCPSS: Percentage of patients with absent or mild pain at phase start, remaining absent or mild at phase end.....	5
Figure 4 PCPSS: Percentage of patients with moderate or severe pain at phase start, with absent or mild pain at phase end.....	5
Figure 5 SAS: Percentage of patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end.....	6
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.....	6
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.....	8
Figure 8 Trends in benchmark 2: Patients in the unstable phase for 3 days or less by setting.....	10
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.....	12
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.....	12
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.....	13
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.....	13
Figure 13 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – inpatient setting.....	16
Figure 14 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – community setting.....	16
Figure 15 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – inpatient setting.....	17
Figure 16 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – community setting.....	17
Figure 17 Stable phase progression.....	31
Figure 18 Unstable phase progression.....	32
Figure 19 Deteriorating phase progression.....	33
Figure 20 Terminal phase progression.....	34
Figure 21 Total RUG-ADL at beginning of phase by phase type – inpatient setting.....	40
Figure 22 Total RUG-ADL at beginning of phase by phase type – community setting.....	41
Figure 23 Profile of SAS and PCPSS by phase type – inpatient setting.....	46
Figure 24 Profile of SAS and PCPSS by phase type – community setting.....	47
Figure 25 Diagram of the PCOC data scoping method.....	48

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 July to December 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 19,829 patients, with 25,331 episodes of care and 58,547 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.

The national figures are based on information submitted by 102 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.
- 31 are community services. These services include primarily patients seen in the community as well as some patients with ambulatory/clinic episodes.
- 12 are services with both inpatient and community settings.

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. |

Section 1 Benchmark summary

1.1 Australian Outcomes at a glance

Table 1 Summary of outcome measures by setting

Outcome measure	Description	Benchmark	Inpatient		Community	
			Score (%)	Benchmark Met?	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%	97.6	Yes	86.6	No
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	86.1	No	76.0	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%	91.7	Yes	85.0	No
	Benchmark 3.2: PCPSS Patients with moderate or severe pain at phase start, with absent or mild pain at phase end	60%	59.2	No	51.7	No
	Benchmark 3.3: SAS Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end	90%	89.9	No	82.0	No
	Benchmark 3.4: SAS Patients with moderate or severe distress from pain at phase start, with absent or mild at phase end	60%	54.1	No	48.6	No
4. Average improvement on the 2014 baseline national average (X-CAS)	Benchmark 4.1: Pain (PCPSS)	0.0	0.11	Yes	-0.09	No
	Benchmark 4.2: Other symptoms (PCPSS)	0.0	0.21	Yes	-0.09	No
	Benchmark 4.3: Family / carer (PCPSS)	0.0	0.14	Yes	-0.06	No
	Benchmark 4.4: Psychological / spiritual (PCPSS)	0.0	0.16	Yes	-0.05	No
	Benchmark 4.5: Pain (SAS)	0.0	0.33	Yes	-0.26	No
	Benchmark 4.6: Nausea (SAS)	0.0	0.19	Yes	-0.11	No
	Benchmark 4.7: Breathing problems (SAS)	0.0	0.29	Yes	-0.12	No
	Benchmark 4.8: Bowel problems (SAS)	0.0	0.21	Yes	-0.04	No

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

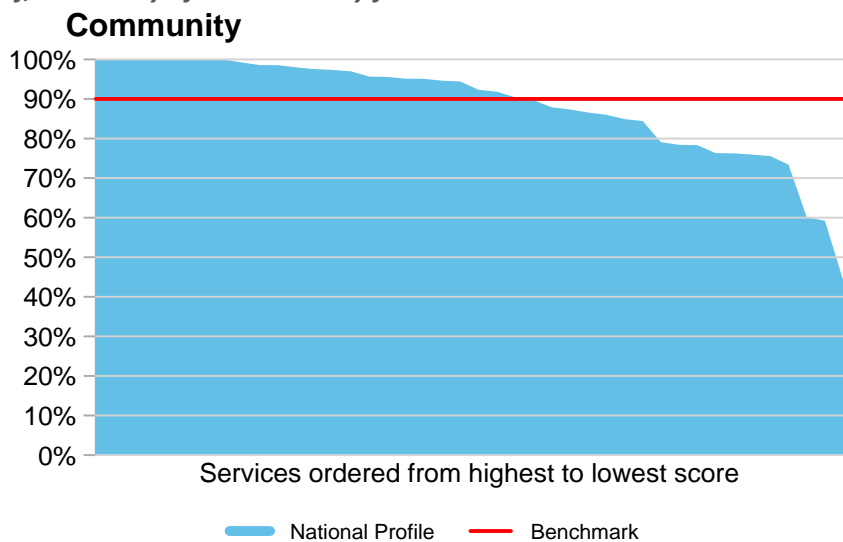
Interpretation hint:

The national profile graphs on the following pages allow services to see how they are performing in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure.

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

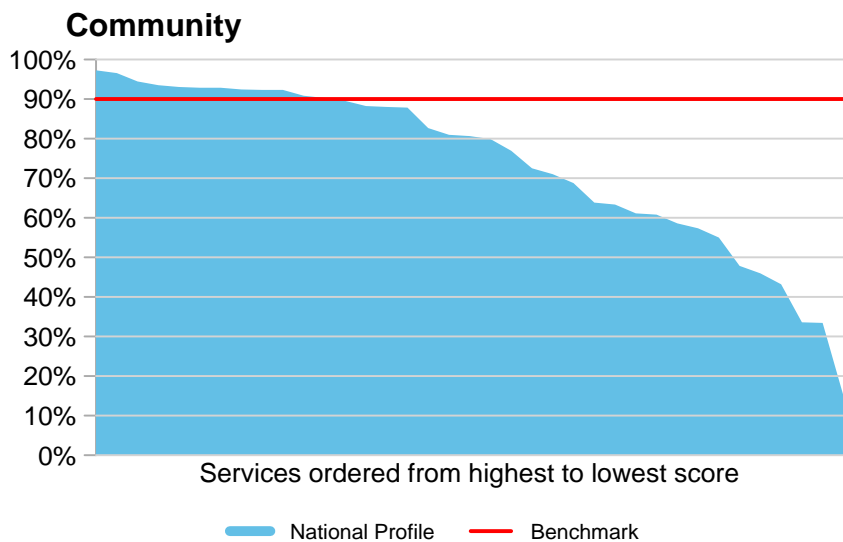
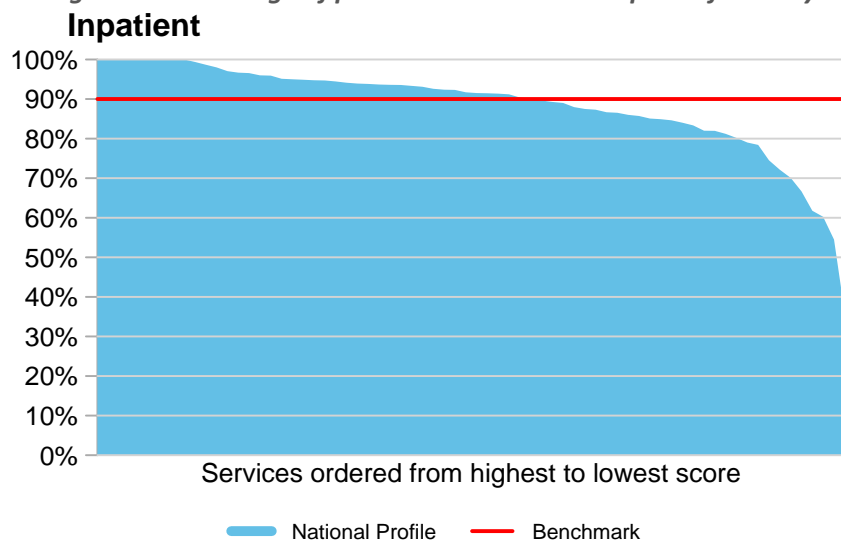
Outcome measure 1 – Time from date ready for care to episode start

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

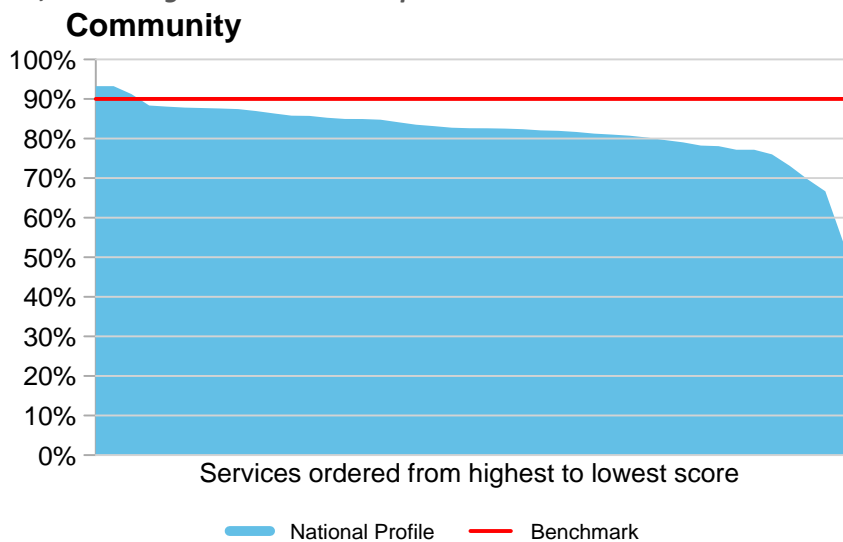
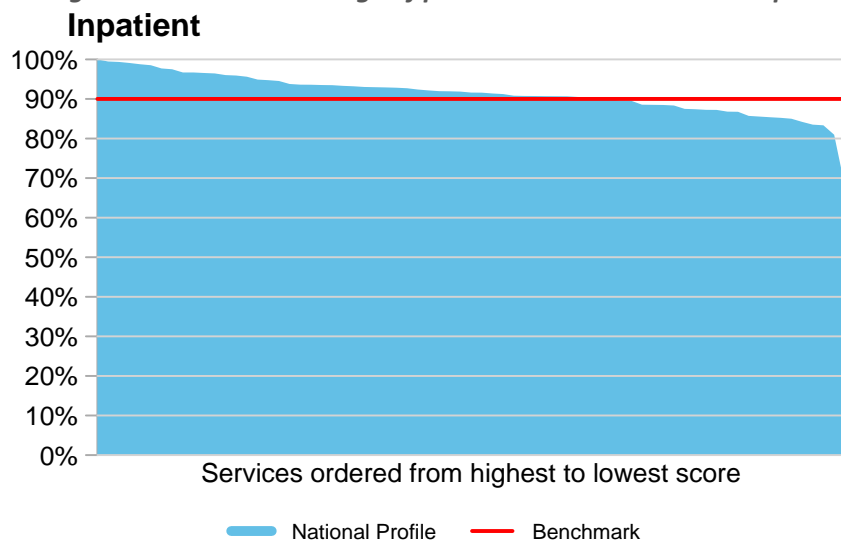


Figure 4 PCPSS: Percentage of patients with moderate or severe pain at phase start, with absent or mild pain at phase end

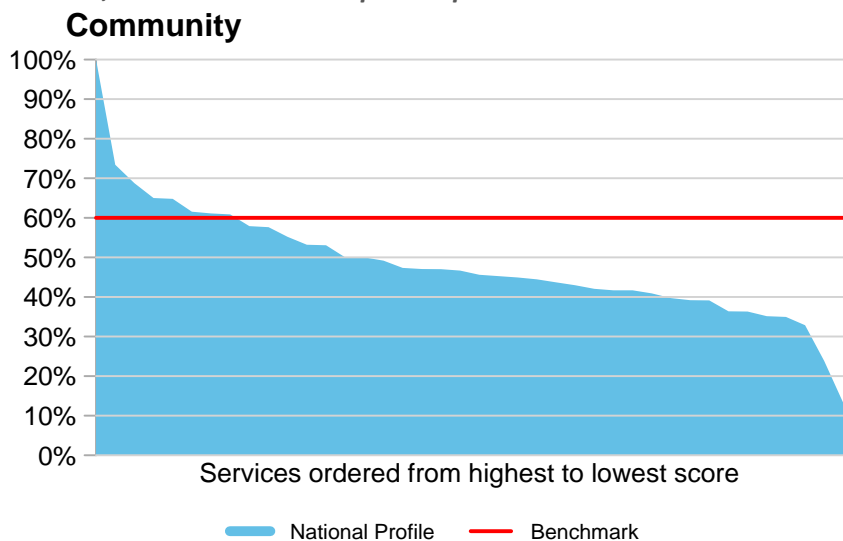
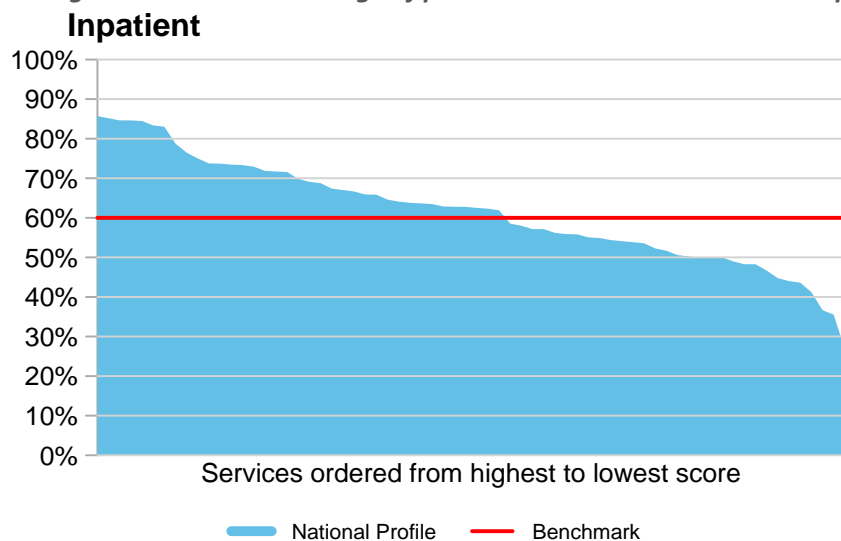


Figure 5 SAS: Percentage of patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end

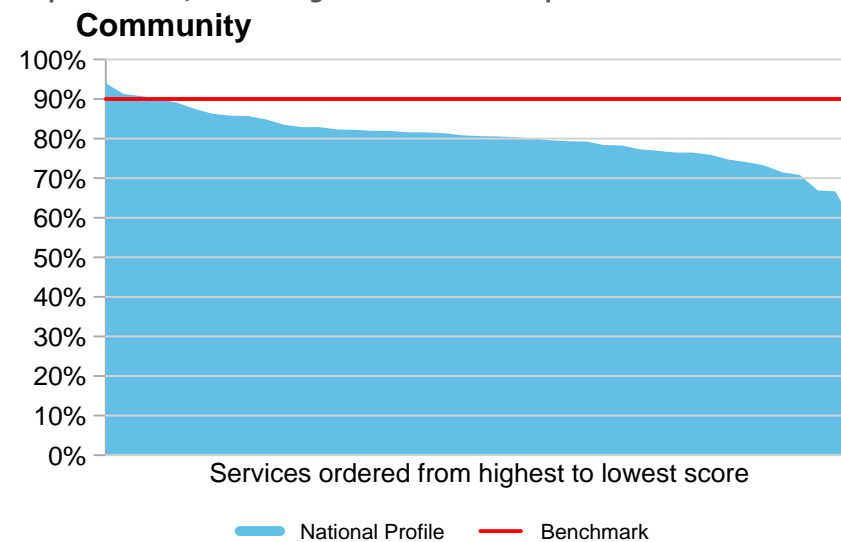
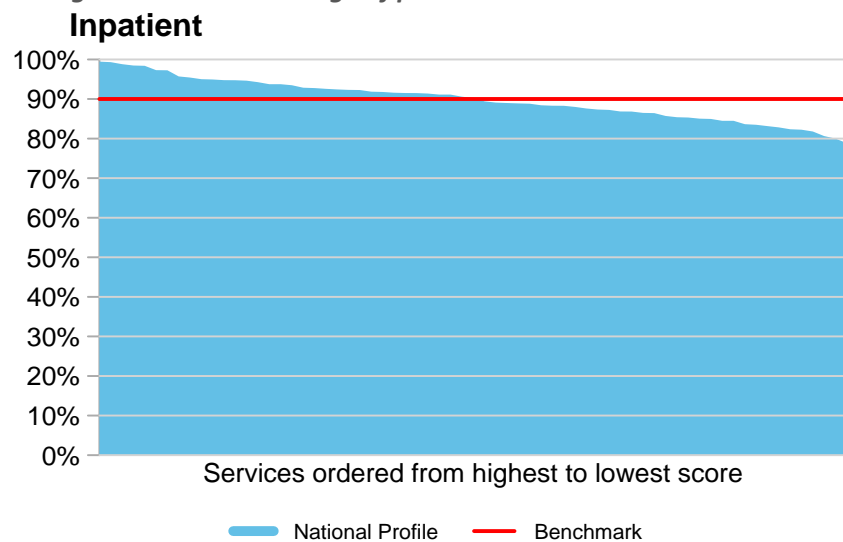
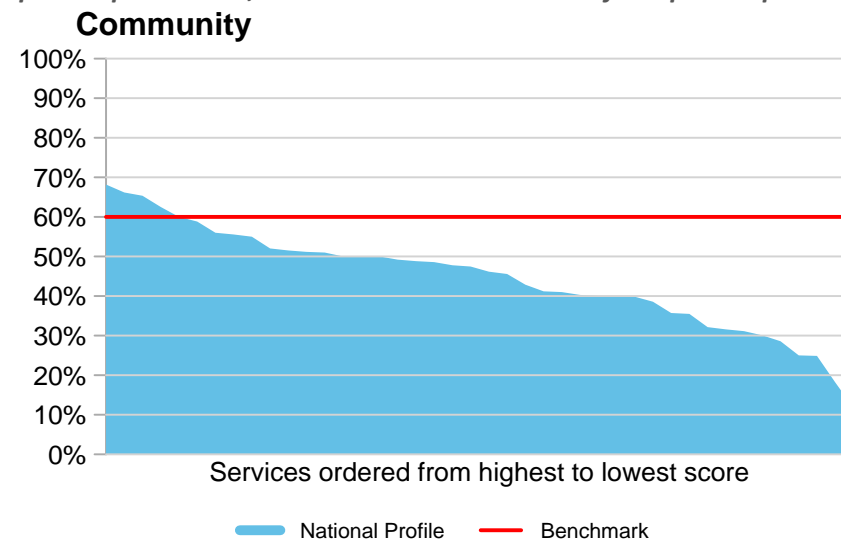
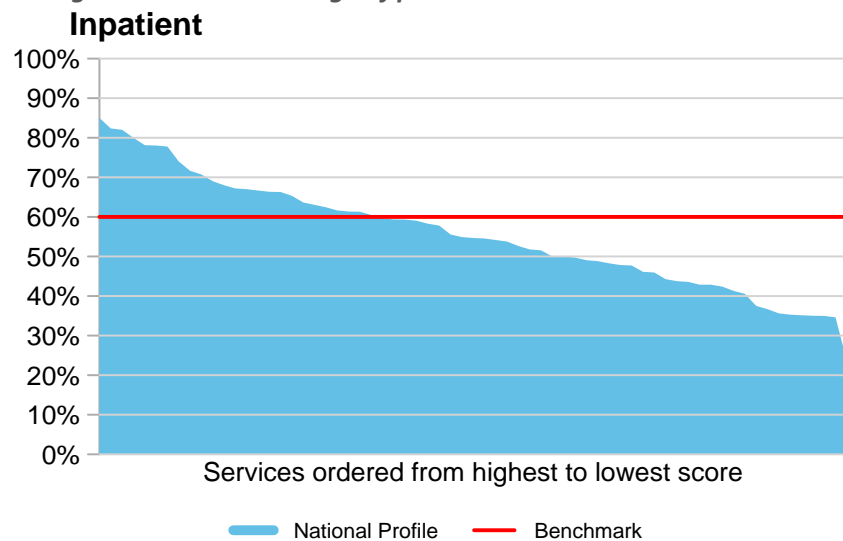


Figure 6 SAS: Percentage of patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end



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 2 Time from date ready for care to episode start by setting

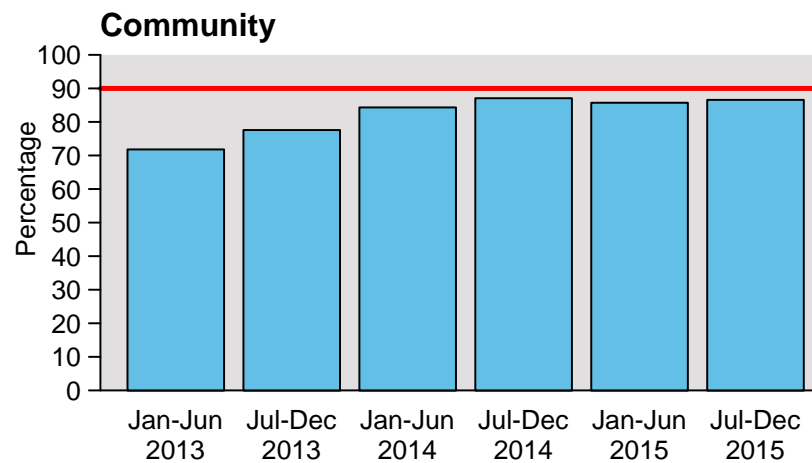
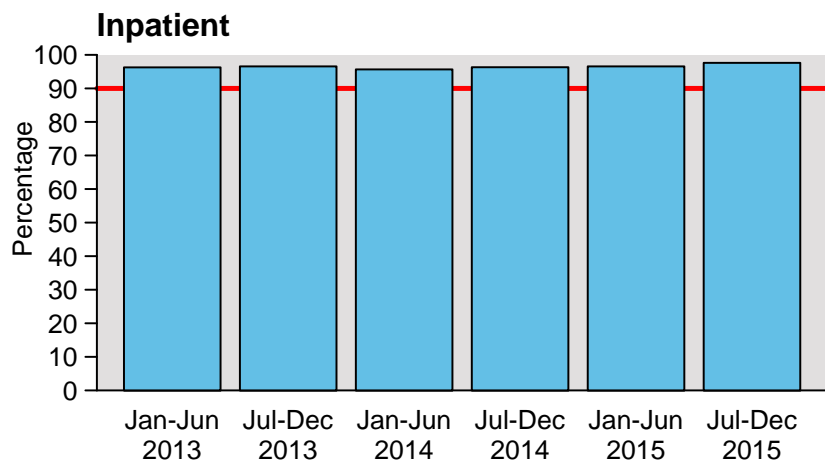
Time (in days)	Inpatient		Community	
	N	%	N	%
Same day	11,313	92.8	8,656	81.7
Following day	584	4.8	519	4.9
2-7 days	258	2.1	1,064	10.0
8-14 days	24	0.2	223	2.1
Greater than 14 days	9	0.1	135	1.3
Average	1.1	na	1.9	na
Median	1	na	1	na

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:

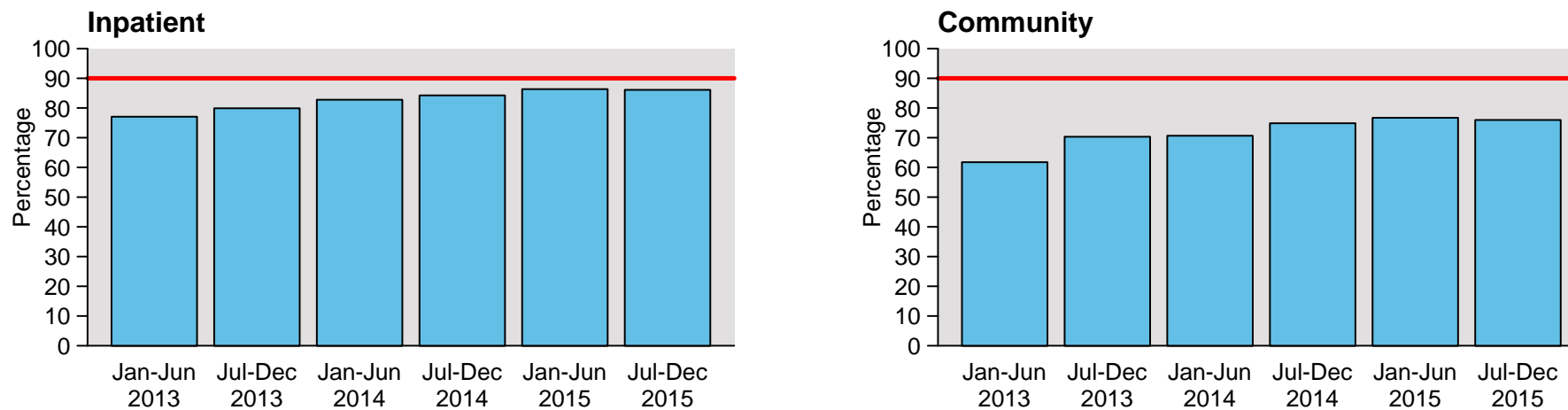
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom / crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient’s care. In this situation, the 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 3 Time in unstable phase by setting

Time in unstable phase	Inpatient		Community	
	N	%	N	%
Same day	279	4.0	899	23.9
1 day	3,292	47.5	1,255	33.3
2 days	1,647	23.8	444	11.8
3 days	750	10.8	261	6.9
4-5 days	572	8.3	237	6.3
6-7 days	192	2.8	211	5.6
8-14 days	148	2.1	213	5.7
Greater than 14 days	52	0.8	244	6.5
<i>Total</i>	<i>6,932</i>	<i>100.0</i>	<i>3,764</i>	<i>100.0</i>

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 28 to Table 31 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 4 Summary of outcome measure 3

Benchmarks: change in pain	Inpatient		Community	
	N*	%	N*	%
Benchmark 3.1: PCPSS (severity)	17,454	91.7	16,664	85.0
Benchmark 3.2: PCPSS (severity)	5,276	59.2	4,172	51.7
Benchmark 3.3: SAS (distress)	14,607	89.9	15,766	82.0
Benchmark 3.4: SAS (distress)	6,460	54.1	5,307	48.6

*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

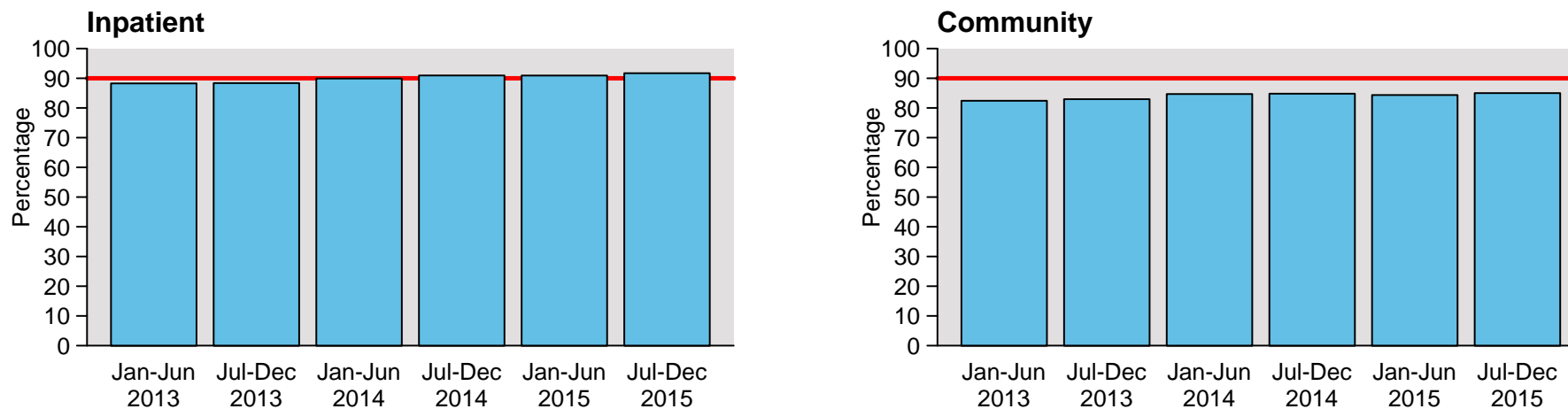


Figure 10 Trends in benchmark 3.2: Patients with moderate or severe pain at phase start, with absent or mild at phase end by setting

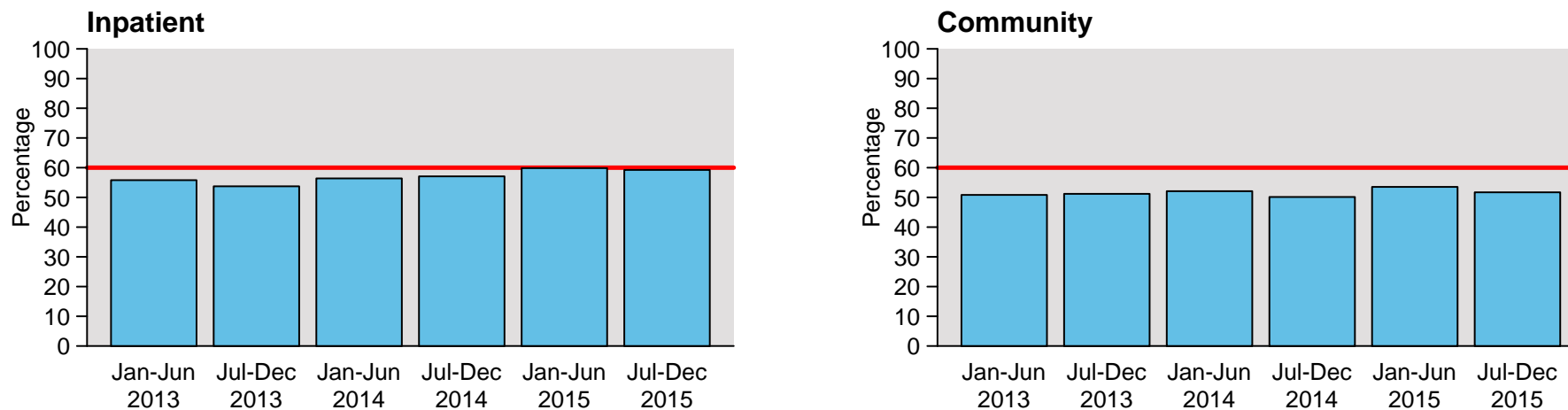


Figure 11 Trends in benchmark 3.3: Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end by setting

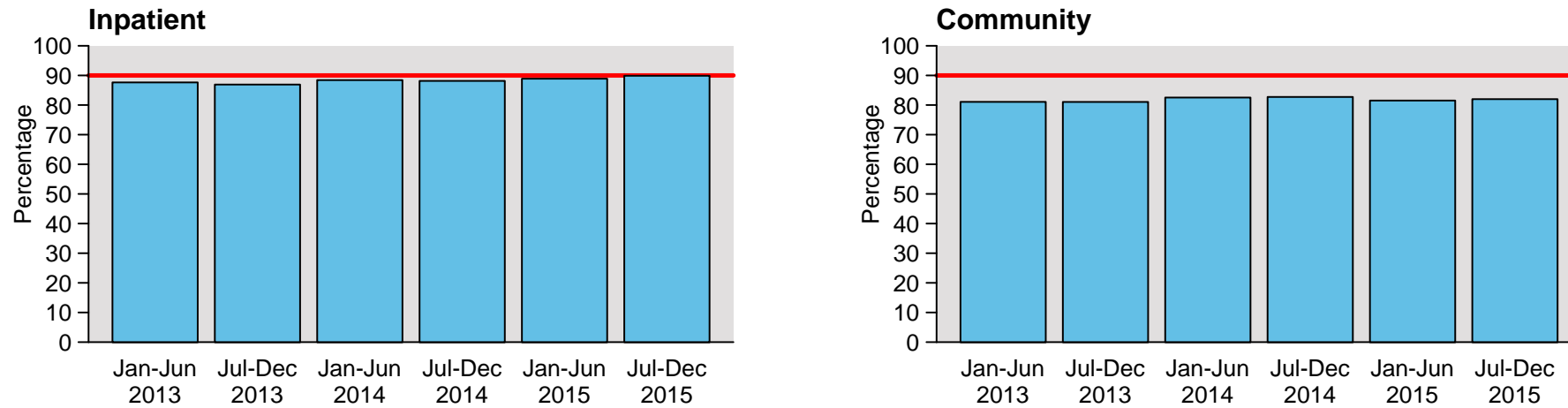
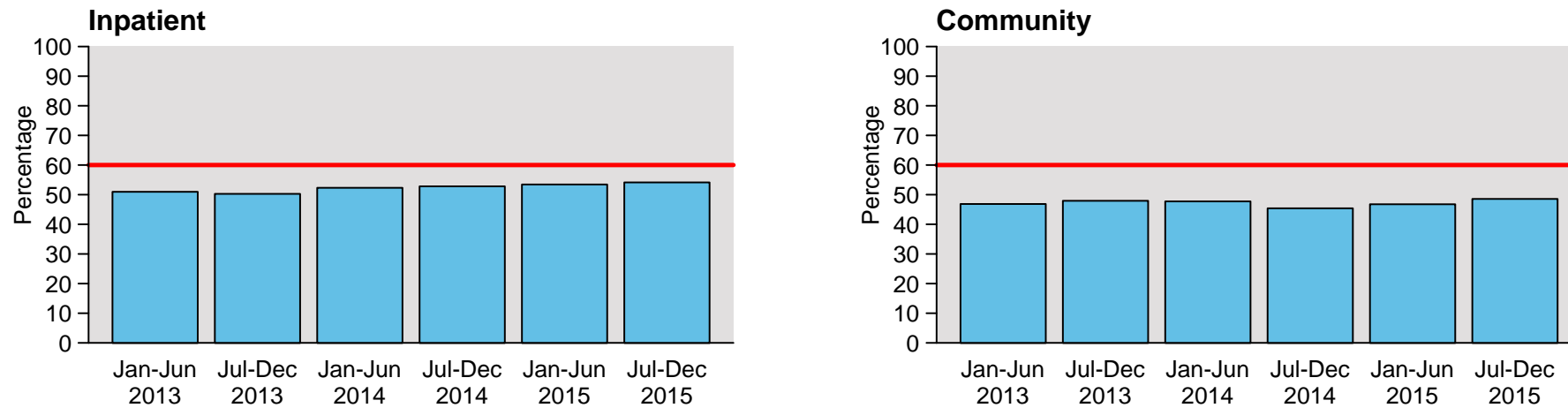


Figure 12 Trends in benchmark 3.4: Patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end by setting



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 5 Summary of outcome measure 4 – inpatient setting

Clinical Tool	Benchmark: Symptom	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	0.11	22,730	14,587	64.2
	4.2: Other symptoms	0.21	22,356	16,327	73.0
	4.3: Family / carer	0.14	22,230	15,037	67.6
	4.4: Psychological / spiritual	0.16	22,710	13,893	61.2
SAS (distress)	4.5: Pain	0.33	21,067	14,494	68.8
	4.6: Nausea	0.19	20,941	18,379	87.8
	4.7: Breathing problems	0.29	21,007	16,467	78.4
	4.8: Bowel problems	0.21	20,953	16,112	76.9

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, 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.

Table 6 Summary of outcome measure 4 – community setting

Clinical Tool	Benchmark: Symptom	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	-0.09	20,836	10,840	52.0
	4.2: Other symptoms	-0.09	20,268	11,894	58.7
	4.3: Family / carer	-0.06	20,202	11,851	58.7
	4.4: Psychological / spiritual	-0.05	20,507	9,682	47.2
SAS (distress)	4.5: Pain	-0.26	21,073	11,854	56.3
	4.6: Nausea	-0.11	20,477	16,131	78.8
	4.7: Breathing problems	-0.12	20,211	12,886	63.8
	4.8: Bowel problems	-0.04	20,029	14,198	70.9

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

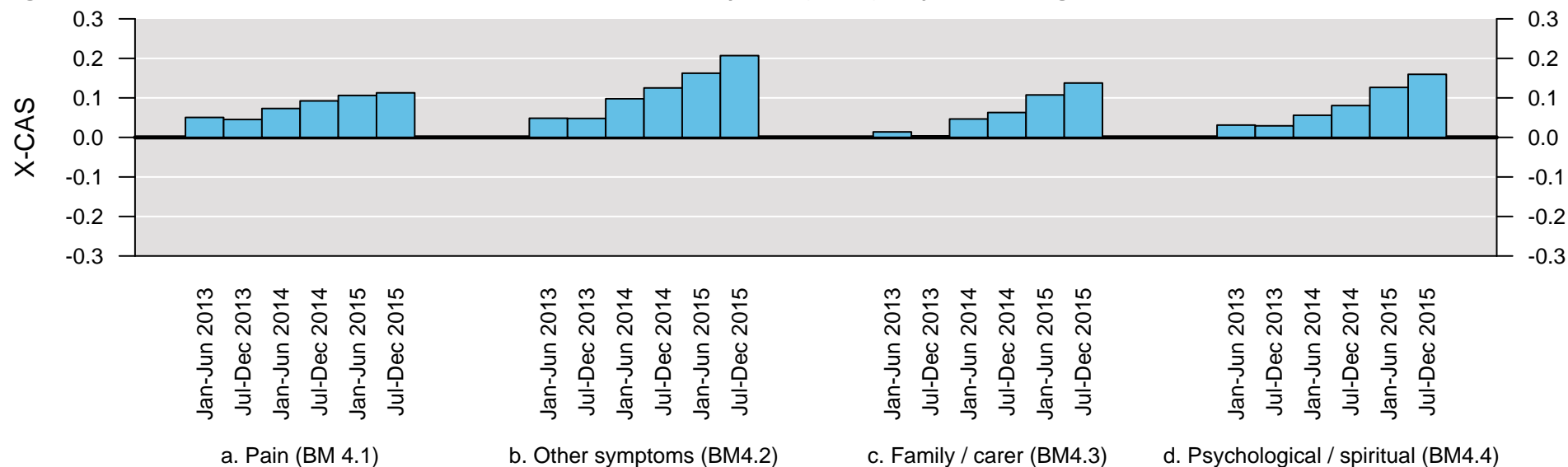


Figure 14 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – community setting

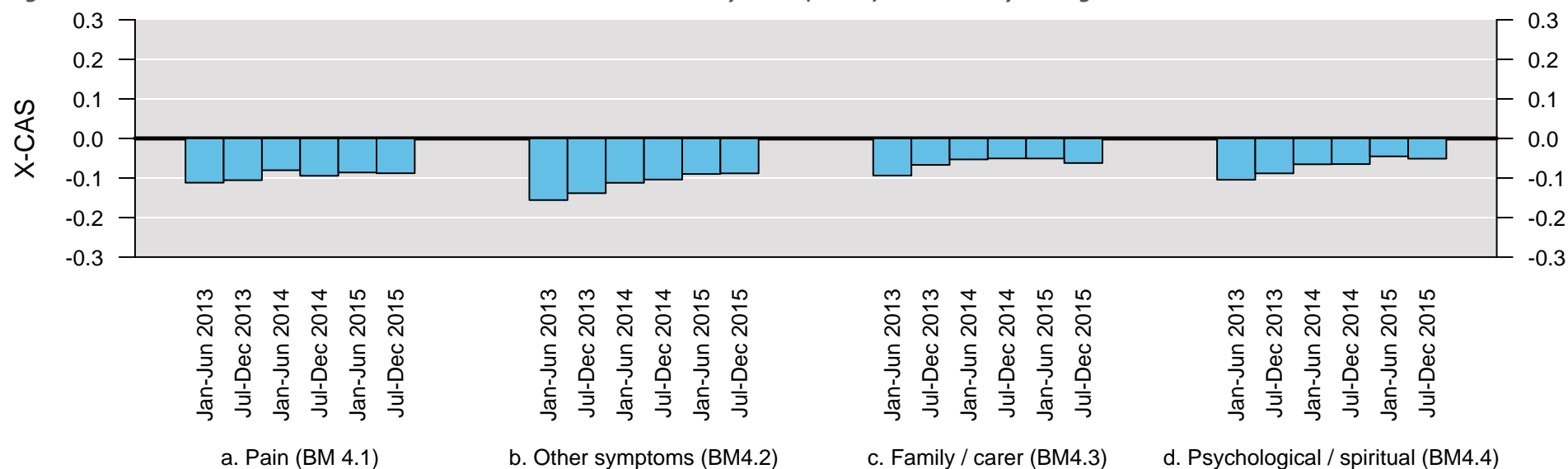


Figure 15 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – inpatient setting

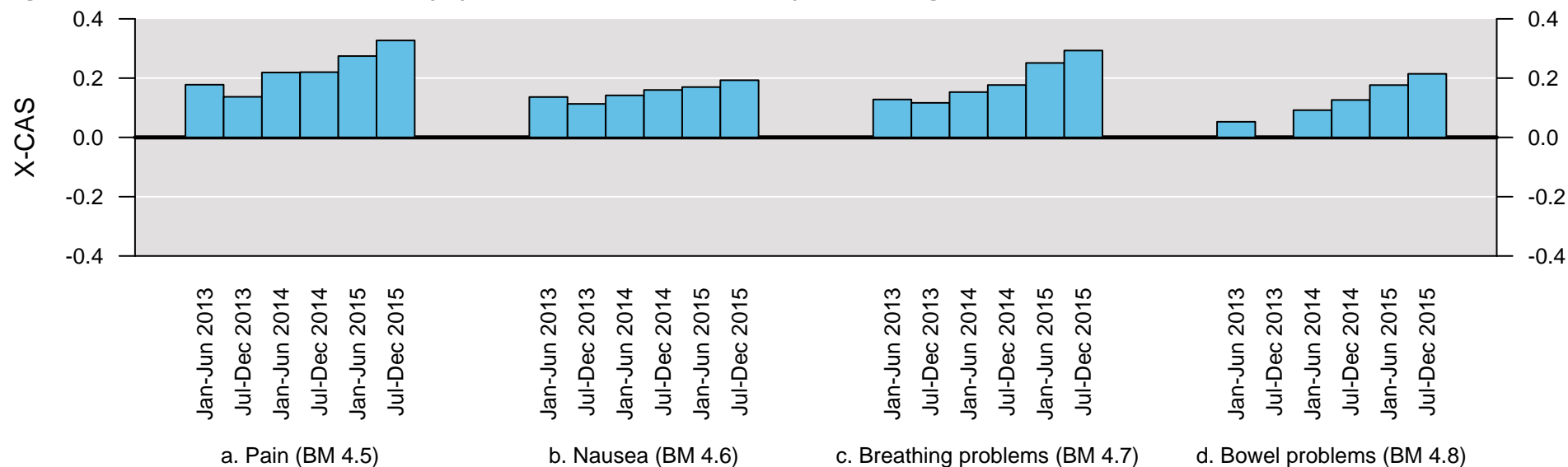
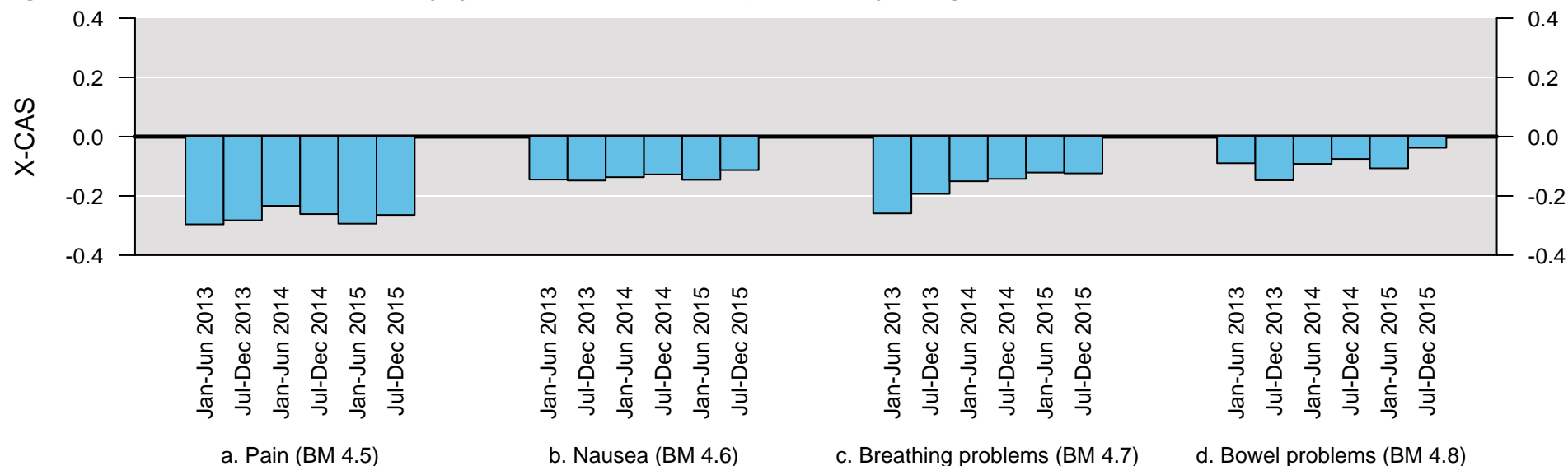


Figure 16 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – community setting



Section 3 Descriptive analysis

This section provides descriptive information of the data submitted 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.

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 7 below shows Indigenous status.

Table 7 Indigenous status

Indigenous status	N	%
Aboriginal but not Torres Strait Islander origin	234	1.2
Torres Strait Islander but not Aboriginal origin	17	0.1
Both Aboriginal and Torres Strait Islander origin	9	0.0
Neither Aboriginal nor Torres Strait Islander origin	19,150	96.6
Not stated / inadequately described	419	2.1
Total	19,829	100.0

Table 8 shows the breakdown of deaths by place of death. 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 8 Place of death

Place of death	N	%
Private residence	2,200	22.4
Residential aged care facility	694	7.1
Hospital	6,882	70.1
Not stated / inadequately described	43	0.4
Total	9,819	100.0

The following two tables show the country of birth and the preferred language respectively. To allow for comparison with the broader Australian community the list of country of birth in Table 9 is in descending order of the most frequent country of birth according to the 2011 Census (e.g. India was the fifth most common country of birth in the 2011 Census). The same approach has been taken with Table 10 (e.g. Italian was the fifth most frequently spoken language in the 2011 census). All other countries and languages have been grouped together to form the categories 'All other countries' and 'All other languages' respectively.

Table 9 Country of birth

Country of birth	N	%
Australia	12,434	62.7
England	1,458	7.4
New Zealand	306	1.5
China (excludes SARs and Taiwan)	219	1.1
India	137	0.7
Italy	820	4.1
Vietnam	163	0.8
Philippines	88	0.4
South Africa	109	0.5
Scotland	275	1.4
Malaysia	58	0.3
Germany	245	1.2
Greece	380	1.9
Sri Lanka	58	0.3
United States of America	53	0.3
All other countries	2,753	13.9
Not stated / inadequately described	273	1.4
Total	19,829	100.0

Table 10 Preferred language

Preferred language	N	%
English	17,797	89.8
Chinese ^(a)	209	1.1
Hindi ^(b)	31	0.2
Arabic ^(c)	132	0.7
Italian	412	2.1
Vietnamese ^(d)	88	0.4
Greek	258	1.3
Filipino / Indonesian ^(e)	21	0.1
Macedonian / Croatian ^(f)	120	0.6
Spanish ^(g)	46	0.2
Tamil / Malayalam ^(h)	5	0.0
German ⁽ⁱ⁾	31	0.2
Korean	21	0.1
Samoan / Tongan ^(j)	15	0.1
African languages ^(k)	8	0.0
All other languages	462	2.3
Not stated / inadequately described	173	0.9
Total	19,829	100.0

Also includes (a) Cantonese, Hakka, Mandarin, Wu and Min Nan

(b) Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, and Fijian Hindustani

(c) Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, and Mandaean (Mandaic)

(d) Khmer and Mon

(e) Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo, Javanese, and Pampangan

(f) Bosnian, Bulgarian, Serbian, and Slovene

(g) Catalan and Portuguese

(h) Kannada, Telugu, and Tulu

(i) Letzeburgish and Yiddish

(j) Fijian, Gilbertese, Maori, Nauruan, Niue, Rotuman, Tokelauan, Tuvaluan, and Yapese

(k) Acholi, Akan, Mauritian Creole, Oromo, Shona, Somali, Swahili, Yoruba, Zulu, Amharic, Bemba, Dinka, Ewe, Ga, Harari, Hausa, Igbo, Kikuyu, Krio, Luganda, Luo, Ndebele, Nuer, Nyanja (Chichewa), Shilluk, Tigré, Tigrinya, Tswana, Xhosa, Seychelles Creole, Anuak, Bari, Bassa, Dan (Gio-Dan), Fulfulde, Kinyarwanda (Rwanda), Kirundi (Rundi), Kpelle, Krahn, Liberian (Liberian English), Loma (Lorma), Lumun (Kuku Lumun), Madi, Mandinka, Mann, Moro (Nuba Moro) and Themne

Table 11 and Table 12 present a breakdown of malignant and non-malignant diagnosis. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 55 (0.3%) patients nationally.

Table 11 Primary diagnosis - malignant

Primary diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	226	1.5	1.1
Breast	1,166	7.7	5.9
CNS	332	2.2	1.7
Colorectal	1,717	11.3	8.7
Other GIT	1,398	9.2	7.1
Haematological	902	6.0	4.5
Head and neck	770	5.1	3.9
Lung	3,376	22.3	17.0
Pancreas	1,057	7.0	5.3
Prostate	1,037	6.8	5.2
Other urological	633	4.2	3.2
Gynaecological	733	4.8	3.7
Skin	553	3.6	2.8
Unknown primary	369	2.4	1.9
Other primary malignancy	563	3.7	2.8
Malignant – not further defined	321	2.1	1.6
<i>All malignant</i>	<i>15,153</i>	<i>100.0</i>	<i>76.4</i>

Table 12 Primary diagnosis - non-malignant

Primary diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	799	17.3	4.0
HIV / AIDS	7	0.2	0.0
End stage kidney disease	409	8.9	2.1
Stroke	338	7.3	1.7
Motor neurone disease	198	4.3	1.0
Alzheimer's dementia	169	3.7	0.9
Other dementia	271	5.9	1.4
Other neurological disease	257	5.6	1.3
Respiratory failure	792	17.1	4.0
End stage liver disease	211	4.6	1.1
Diabetes and its complications	22	0.5	0.1
Sepsis	151	3.3	0.8
Multiple organ failure	136	2.9	0.7
Other non-malignancy	682	14.8	3.4
Non-malignant – not further defined	179	3.9	0.9
All non-malignant	4,621	100.0	23.3

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 13 below presents the number and percentage of episodes by age group and sex. Age has been calculated as at the beginning of each episode.

Table 13 Age group by sex

Age group	Male		Female	
	N	%	N	%
< 15	42	0.3	39	0.3
15 - 24	61	0.5	24	0.2
25 - 34	109	0.8	100	0.8
35 - 44	329	2.4	383	3.2
45 - 54	813	6.0	1,061	9.0
55 - 64	2,202	16.3	1,853	15.7
65 - 74	3,528	26.1	2,689	22.8
75 - 84	3,940	29.1	3,066	26.0
85+	2,504	18.5	2,587	21.9
Not stated / inadequately described	0	0.0	0	0.0
Total	13,528	100.0	11,802	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 14 presents referral source by setting.

Table 14 Referral source by setting

Referral source	Inpatient		Community	
	N	%	N	%
Public hospital	7,655	59.1	6,632	53.6
Private hospital	1,082	8.4	1,275	10.3
Outpatient clinic	83	0.6	129	1.0
General medical practitioner	287	2.2	1,929	15.6
Specialist medical practitioner	574	4.4	761	6.1
Community-based palliative care agency	2,732	21.1	100	0.8
Community-based service	71	0.5	139	1.1
Residential aged care facility	59	0.5	772	6.2
Self, carer(s), family or friends	176	1.4	362	2.9
Other	153	1.2	248	2.0
Not stated / inadequately described	82	0.6	30	0.2
Total	12,954	100.0	12,377	100.0

Table 15 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 15 Referral to first contact by setting

Time (in days)	Inpatient		Community	
	N	%	N	%
Same day or following day	12,146	93.8	6,325	51.2
2-7 days	668	5.2	4,290	34.7
8-14 days	77	0.6	994	8.0
Greater than 14 days	57	0.4	756	6.1
Average	1.2	na	2.9	na
Median	1	na	1	na

Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact 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 16 gives a summary of the length of episode by setting. Table 17 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 16 Length of episode (in days) summary by setting

Length of episode	Inpatient	Community
Average length of episode	10.3	37.8
Median length of episode	6.0	26.0

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 17 Length of episode (in days) by setting

Length of episode	Inpatient		Community	
	N	%	N	%
Same day	837	6.5	259	2.3
1-2 days	2,527	19.7	723	6.5
3-4 days	1,911	14.9	593	5.4
5-7 days	2,140	16.7	952	8.6
8-14 days	2,596	20.3	1,471	13.3
15-21 days	1,217	9.5	1,006	9.1
22-30 days	717	5.6	978	8.9
31-60 days	723	5.6	1,960	17.7
61-90 days	99	0.8	982	8.9
Greater than 90 days	43	0.3	2,119	19.2
Total	12,810	100.0	11,043	100.0

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

Table 18 How episodes start – inpatient setting

Episode start mode	N	%
Admitted from community*	7,565	58.4
Admitted from another hospital	3,001	23.2
Admitted from acute care in another ward	2,088	16.1
Change from acute care to palliative care – same ward	207	1.6
Other**	89	0.7
Not stated / inadequately described	4	0.0
Total	12,954	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 19 How episodes end – inpatient setting

Episode end mode	N	%
Discharged to community*	4,589	35.8
Discharged to another hospital	755	5.9
Death	6,882	53.7
Change from palliative care to acute care**	50	0.4
Change in sub-acute care type	49	0.4
End of consultative episode – inpatient episode ongoing	367	2.9
Other	109	0.9
Not stated / inadequately described	9	0.1
Total	12,810	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 20 How episodes start – community setting

Episode start mode	N	%
Admitted from inpatient palliative care	4,589	37.1
Other*	7,728	62.4
Not stated / inadequately described	60	0.5
Total	12,377	100.0

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

Table 21 How episodes end – community setting

Episode end mode	N	%
Admitted for inpatient palliative care	3,478	31.5
Admitted for inpatient acute care	3,093	28.0
Admitted to another palliative care service	61	0.6
Admitted to primary health care	234	2.1
Discharged / case closure	1,136	10.3
Death	2,937	26.6
Other	86	0.8
Not stated / inadequately described	18	0.2
Total	11,043	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 22 Number of phases by phase type and setting

Phase type	Inpatient		Community	
	N	%	N	%
Stable	7,783	25.8	10,579	37.3
Unstable	6,932	22.9	3,764	13.3
Deteriorating	9,433	31.2	11,609	41.0
Terminal	6,069	20.1	2,378	8.4
Total	30,217	100.0	28,330	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 23 Average phase length (in days) by phase type and setting

Phase type	Inpatient	Community
Stable	7.3	20.9
Unstable	2.2	4.2
Deteriorating	5.0	12.9
Terminal	2.0	2.8

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

Table 24 presents information relating to the manner in which stable phases ended. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 17 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 25, Figure 18), deteriorating (Table 26, Figure 19) and terminal (Table 27, Figure 20) phases on the following pages.

Table 24 How stable phases end – by setting

How stable phases end	Inpatient		Community	
	N	%	N	%
Patient moved into another phase	3,830	49.2	7,018	66.3
Discharge / case closure	3,873	49.8	3,268	30.9
Died	75	1.0	261	2.5
Not stated / inadequately described	5	0.1	32	0.3
Total	7,783	100.0	10,579	100.0

Figure 17 Stable phase progression

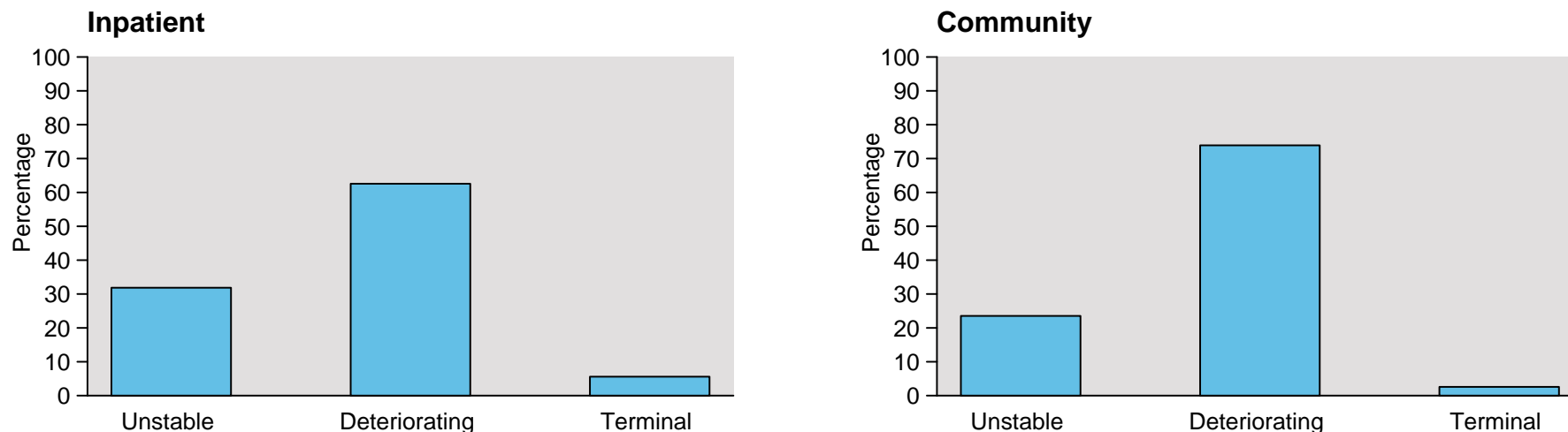


Table 25 How unstable phases end – by setting

How unstable phases end	Inpatient		Community	
	N	%	N	%
Patient moved into another phase	6,324	91.2	2,442	64.9
Discharge / case closure	479	6.9	1,249	33.2
Died	126	1.8	67	1.8
Not stated / inadequately described	3	0.0	6	0.2
<i>Total</i>	<i>6,932</i>	<i>100.0</i>	<i>3,764</i>	<i>100.0</i>

Figure 18 Unstable phase progression

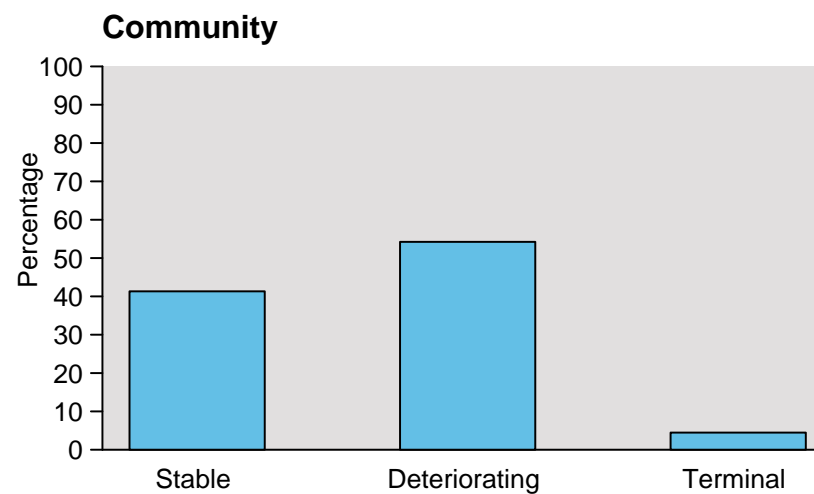
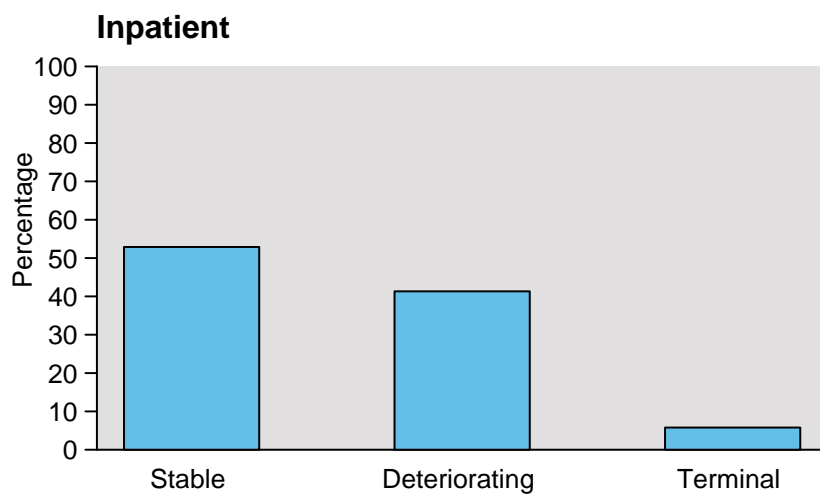


Table 26 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient		Community	
	N	%	N	%
Patient moved into another phase	7,004	74.2	7,447	64.1
Discharge / case closure	1,441	15.3	3,321	28.6
Died	983	10.4	821	7.1
Not stated / inadequately described	5	0.1	20	0.2
<i>Total</i>	<i>9,433</i>	<i>100.0</i>	<i>11,609</i>	<i>100.0</i>

Figure 19 Deteriorating phase progression

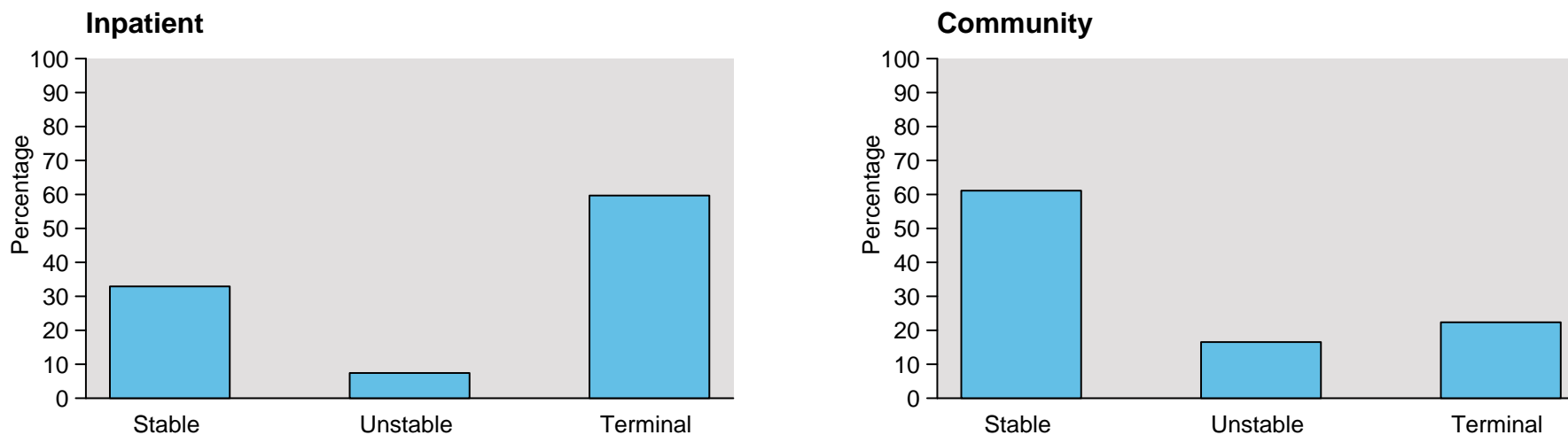
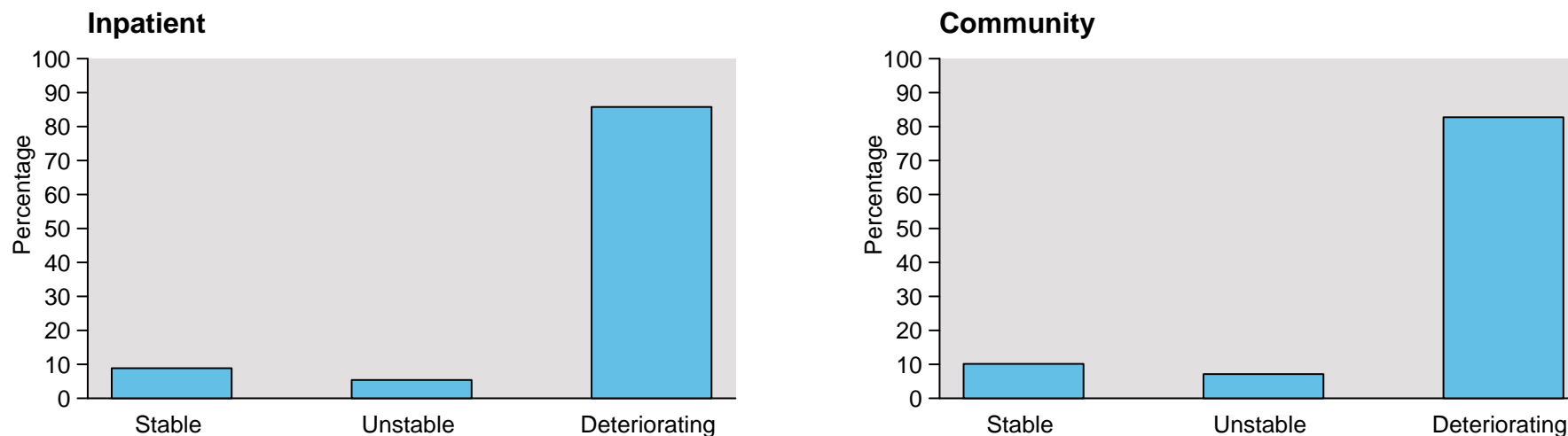


Table 27 How terminal phases end – by setting

How terminal phases end	Inpatient		Community	
	N	%	N	%
Patient moved into another phase	260	4.3	365	15.3
Discharge / case closure	122	2.0	218	9.2
Died	5,686	93.7	1,793	75.4
Not stated / inadequately described	1	0.0	2	0.1
<i>Total</i>	<i>6,069</i>	<i>100.0</i>	<i>2,378</i>	<i>100.0</i>

Figure 20 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 28 and Table 29 show the percentage scores for the inpatient and community settings respectively. Alternative graphical representations of PCPSS profile by phase type can be found in Appendix B.

Table 28 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	47.7	38.9	11.6	1.8
	Other symptoms	30.2	51.5	16.2	2.1
	Psychological / spiritual	41.2	47.9	9.5	1.4
	Family / carer	46.4	41.6	9.9	2.0
Unstable	Pain	31.2	32.3	25.5	10.9
	Other symptoms	17.4	38.0	32.9	11.7
	Psychological / spiritual	30.2	45.3	19.6	4.9
	Family / carer	34.1	40.8	19.4	5.7
Deteriorating	Pain	40.3	37.8	17.1	4.8
	Other symptoms	21.3	44.0	28.2	6.5
	Psychological / spiritual	33.6	47.4	15.9	3.0
	Family / carer	32.4	43.1	19.7	4.9
Terminal	Pain	51.8	32.8	12.3	3.1
	Other symptoms	40.3	35.5	17.9	6.4
	Psychological / spiritual	57.2	31.3	8.9	2.6
	Family / carer	27.4	39.1	25.2	8.2

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

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	41.0	51.6	6.9	0.5
	Other symptoms	16.4	67.5	15.1	1.0
	Psychological / spiritual	30.2	59.7	9.4	0.7
	Family / carer	28.9	56.0	13.6	1.5
Unstable	Pain	18.4	30.4	34.7	16.5
	Other symptoms	4.7	29.7	50.6	15.0
	Psychological / spiritual	13.4	49.3	32.0	5.3
	Family / carer	11.8	36.1	42.0	10.1
Deteriorating	Pain	28.8	50.5	18.7	2.1
	Other symptoms	7.4	52.4	36.7	3.6
	Psychological / spiritual	17.8	60.2	20.2	1.8
	Family / carer	17.1	52.2	26.6	4.0
Terminal	Pain	38.0	43.1	15.6	3.3
	Other symptoms	23.6	43.1	27.1	6.2
	Psychological / spiritual	42.3	42.1	13.3	2.3
	Family / carer	11.3	42.2	37.4	9.2

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 30 and Table 31 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Alternative graphical representations of the SAS profile by phase type can be found in Appendix B.

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

Phase type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	72.1	15.8	10.2	1.9
	Appetite problems	60.7	22.7	14.4	2.2
	Nausea	82.1	11.1	6.0	0.9
	Bowel problems	66.0	20.1	11.5	2.5
	Breathing problems	67.6	17.9	12.0	2.5
	Fatigue	35.1	26.3	33.1	5.5
	Pain	48.2	30.4	18.8	2.7
Unstable	Difficulty sleeping	61.4	16.0	17.2	5.4
	Appetite problems	46.1	22.3	24.0	7.6
	Nausea	69.4	13.8	12.1	4.6
	Bowel problems	54.3	21.4	18.1	6.2
	Breathing problems	57.7	17.6	17.4	7.3
	Fatigue	25.6	19.9	40.3	14.3
	Pain	31.7	25.8	30.2	12.3
Deteriorating	Difficulty sleeping	73.8	12.3	11.4	2.6
	Appetite problems	56.7	20.0	18.3	5.0
	Nausea	78.9	10.4	8.5	2.2
	Bowel problems	63.9	18.5	14.1	3.4
	Breathing problems	59.6	17.6	17.1	5.7
	Fatigue	33.1	18.3	36.5	12.2
	Pain	41.1	29.3	24.1	5.5
Terminal	Difficulty sleeping	93.0	3.8	2.4	0.8
	Appetite problems	91.6	3.6	2.9	1.9
	Nausea	94.9	2.8	1.8	0.5
	Bowel problems	88.6	6.2	4.1	1.2
	Breathing problems	73.0	11.7	10.5	4.8
	Fatigue	79.3	5.5	9.6	5.6
	Pain	62.0	22.1	13.7	2.2

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

Phase type	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	65.6	25.7	7.9	0.8
	Appetite problems	50.2	34.0	14.2	1.5
	Nausea	81.3	15.6	2.9	0.3
	Bowel problems	67.3	25.1	6.7	0.8
	Breathing problems	55.5	30.2	12.9	1.4
	Fatigue	17.1	37.3	41.2	4.4
	Pain	44.8	42.8	11.6	0.9
Unstable	Difficulty sleeping	45.8	27.5	21.8	4.9
	Appetite problems	34.8	29.2	29.4	6.7
	Nausea	61.5	17.5	15.7	5.4
	Bowel problems	57.1	23.0	15.7	4.2
	Breathing problems	45.0	27.7	21.3	6.0
	Fatigue	11.6	21.6	52.4	14.4
	Pain	20.0	24.3	38.1	17.6
Deteriorating	Difficulty sleeping	58.2	27.2	13.1	1.4
	Appetite problems	41.7	31.7	22.7	3.9
	Nausea	73.3	18.5	7.2	1.0
	Bowel problems	60.8	26.9	10.9	1.4
	Breathing problems	46.6	31.9	18.8	2.7
	Fatigue	12.4	25.8	51.8	10.0
	Pain	32.8	41.3	22.9	3.1
Terminal	Difficulty sleeping	78.2	11.3	9.1	1.5
	Appetite problems	81.7	7.8	5.5	5.1
	Nausea	86.0	8.7	4.5	0.7
	Bowel problems	75.8	15.9	7.2	1.1
	Breathing problems	59.3	21.8	14.5	4.4
	Fatigue	61.9	6.9	16.0	15.2
	Pain	42.9	35.5	18.2	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 32 shows the data for the AKPS at phase start.

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

AKPS assessment at phase start	Inpatient		Community	
	N	%	N	%
10 - Comatose or barely rousable	3,278	10.8	983	3.5
20 - Totally bedfast and requiring extensive nursing care	6,813	22.5	2,763	9.8
30 - Almost completely bedfast	3,944	13.1	2,019	7.1
40 - In bed more than 50% of the time	5,713	18.9	3,750	13.2
50 - Requires considerable assistance	4,978	16.5	7,092	25.0
60 - Requires occasional assistance	3,199	10.6	6,892	24.3
70 - Cares for self	654	2.2	3,263	11.5
80 - Normal activity with effort	213	0.7	722	2.5
90 - Able to carry on normal activity; minor signs or symptoms	82	0.3	119	0.4
100 - Normal; no complaints; no evidence of disease	5	0.0	12	0.0
Not stated/inadequately described	1,338	4.4	715	2.5
Total	30,217	100.0	28,330	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 21 and Figure 22 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/respice requirements.

Figure 21 Total RUG-ADL at beginning of phase by phase type – inpatient setting

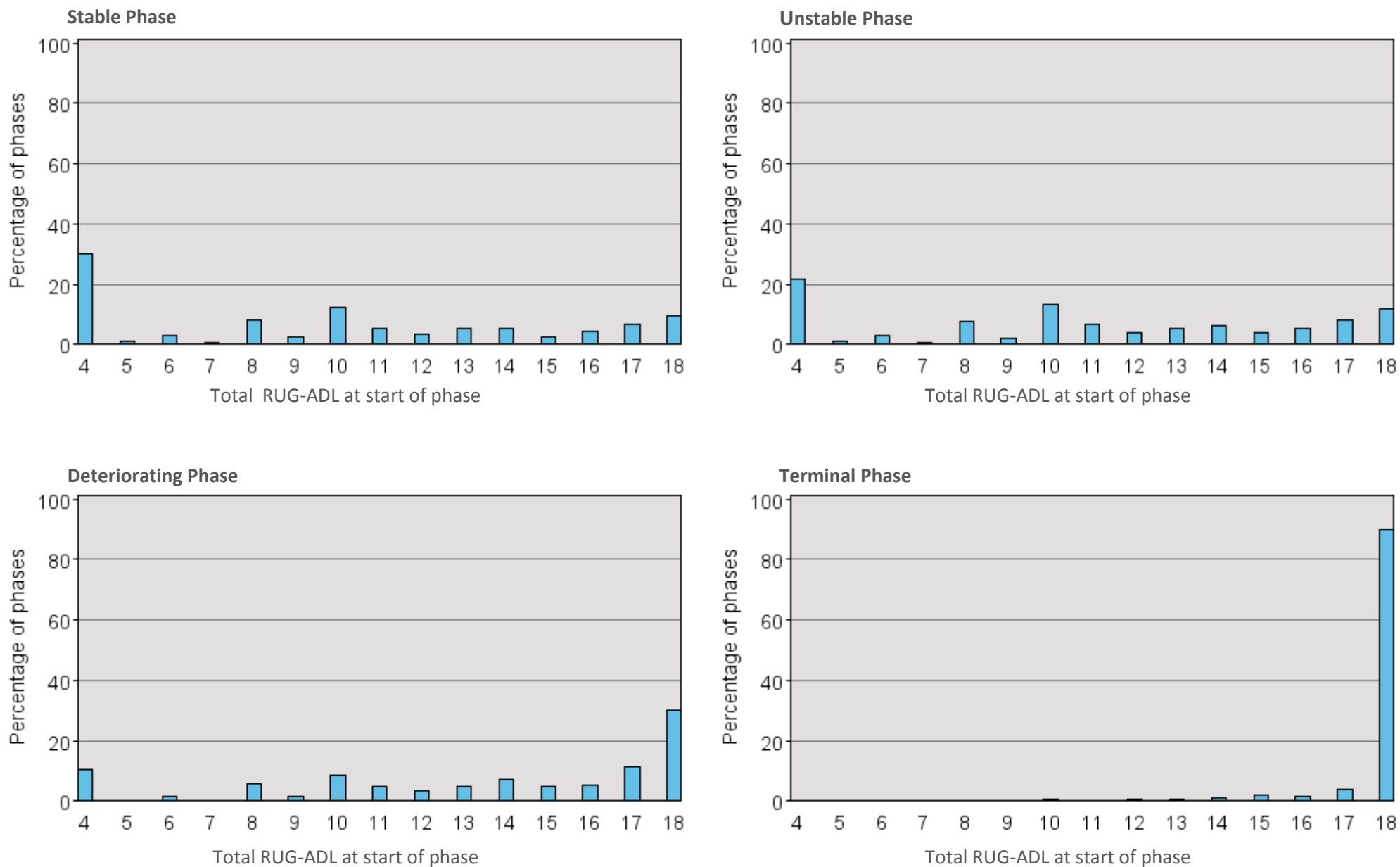
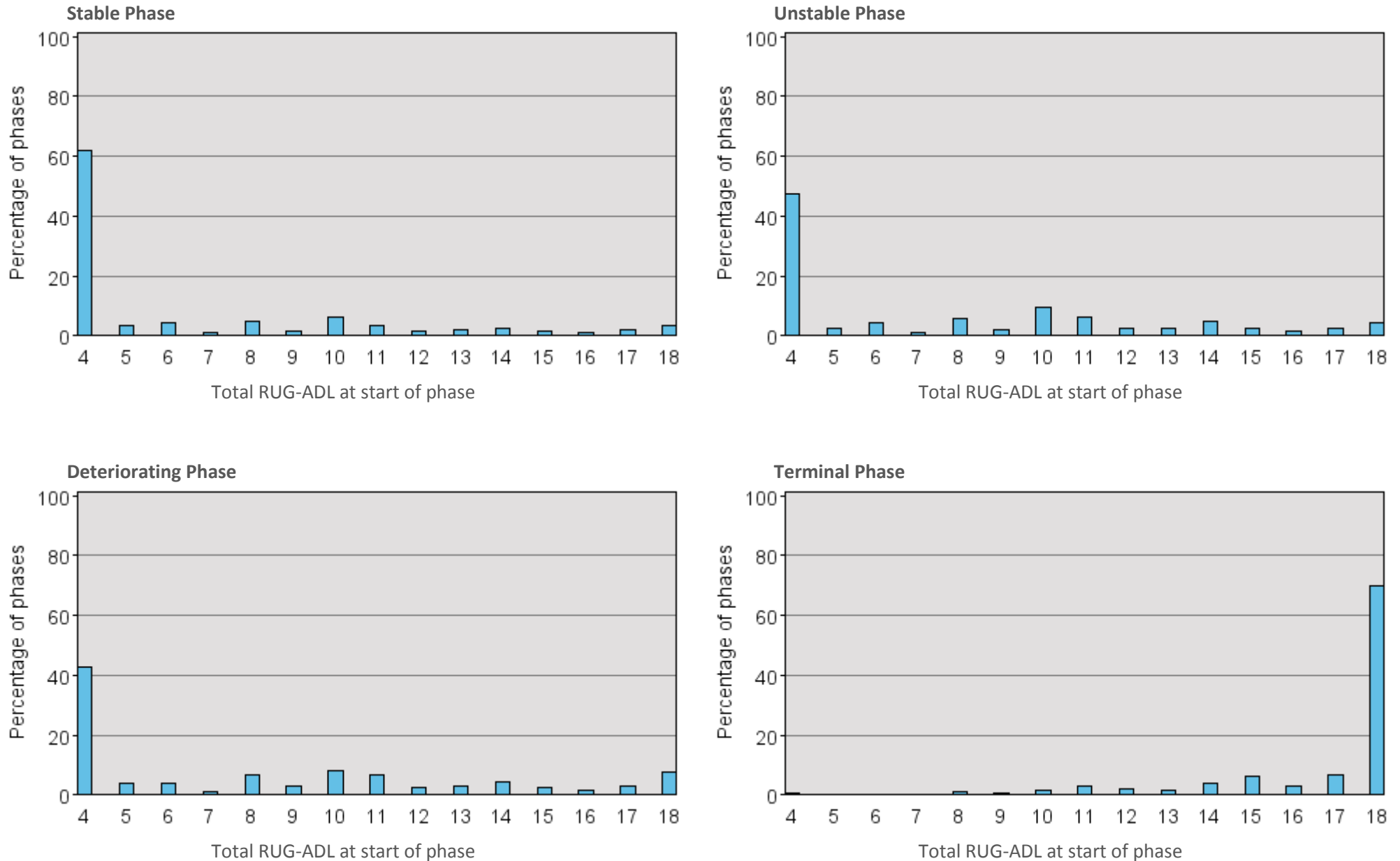


Figure 22 Total RUG-ADL at beginning of phase by phase type – community setting



Appendix A Summary of data included in this report

A1 Data summary

During the reporting period, data were provided for a total of 19,829 patients who between them had 25,331 episodes of care and 58,547 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 33 shows the number of patients, episodes and phases included in this report.

Table 33 Number and percentage of patients, episodes and phases by setting

	Inpatient	Community	Total
Number of patients*	10,868	9,817	19,829
Number of episodes	12,954	12,377	25,331
Number of phases**	30,217	28,330	58,547
Percentage of patients*	54.8	49.5	100
Percentage of episodes	51.1	48.9	100
Percentage of phases	51.6	48.4	100
Average number of phases per episode***	2.3	2.2	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 34 shows the number of completed episodes and phases by setting for each month in the current reporting period.

Table 34 Number of completed episodes and phases by month and setting

Setting		Jul	Aug	Sep	Oct	Nov	Dec
Inpatient	No. of completed episodes	2,201	2,191	2,093	2,184	2,019	2,122
	No. of completed phases	5,246	5,280	4,990	5,141	4,977	4,583
Community	No. of completed episodes	2,028	1,871	1,734	1,802	1,825	1,783
	No. of completed phases	5,168	4,851	4,481	4,610	4,568	4,652

Table 35 shows the number of patients, episodes and phases nationally over time and is reported by setting of care.

Table 35 Number of patients, episodes and phases by setting and reporting period

	Inpatient						Community					
	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2014	Jan-Jun 2015	Jul-Dec 2015	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2014	Jan-Jun 2015	Jul-Dec 2015
Number of patients*	9,737	9,646	9,502	10,311	10,692	10,868	7,546	8,541	8,206	8,963	9,391	9,817
Number of episodes	11,423	11,407	11,279	12,224	12,464	12,954	9,280	10,579	10,204	11,225	11,716	12,377
Number of phases**	26,875	28,359	26,013	28,409	29,459	30,217	19,500	22,961	22,567	25,058	26,532	28,330
Average number of phases per episode***	2.4	2.5	2.3	2.3	2.3	2.3	2.0	2.0	2.1	2.0	2.1	2.2

* 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 36, Table 37 and Table 38 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 36 Item completion (per cent complete) - patient level

Data item	Total
Date of birth	100.0
Sex	100.0
Indigenous status	97.9
Country of birth	98.6
Preferred language	99.1
Primary diagnosis	99.7

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

Table 37 Item completion by setting (per cent complete) - episode level

Data item	Inpatient	Community	Total
Date of first contact	100.0	99.9	99.9
Referral date	100.0	99.9	99.9
Referral source	99.4	99.8	99.6
Date ready for care	97.2	96.9	97.0
Mode of episode start	100.0	99.5	99.7
Accommodation at episode start	99.9	95.5	97.2
Episode end date*	99.9	92.5	96.2
Mode of episode end	99.9	99.8	99.9
Accommodation at episode end	97.8	92.9	96.6
Place of death	na	98.5	98.5

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

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

Data item	Sub-Category (where applicable)	At phase start			At discharge		
		Inpatient	Community	Total	Inpatient	Community	Total
RUG-ADL	Bed mobility	99.8	97.3	98.6	93.3	56.6	72.2
	Toileting	99.8	97.2	98.6	93.3	56.6	72.1
	Transfers	99.8	97.1	98.5	93.3	56.6	72.1
	Eating	99.7	96.5	98.1	93.3	56.4	72.0
PCPSS	Pain	99.4	97.1	98.3	93.2	56.2	71.9
	Other symptom	97.7	94.8	96.3	92.0	55.1	70.7
	Psychological / spiritual	99.3	96.2	97.8	93.1	55.5	71.4
	Family / carer	97.8	94.9	96.4	89.8	54.8	69.6
SAS	Difficulty sleeping	90.4	91.4	90.9	79.7	51.4	63.4
	Appetite problems	92.2	94.9	93.5	80.8	54.2	65.4
	Nausea	92.2	96.0	94.1	79.5	55.1	65.4
	Bowel problems	92.1	94.9	93.5	80.2	54.1	65.2
	Breathing problems	92.3	95.5	93.8	80.3	54.7	65.5
	Fatigue	92.2	95.9	94.0	81.8	55.1	66.4
	Pain	92.3	97.5	94.8	81.3	56.6	67.1
AKPS	-	95.6	97.5	96.5	91.7	58.8	72.7

Data item	Inpatient	Community	Total
Phase End Reason	99.9	99.8	99.9

Appendix B Additional information on profile of SAS and PCPSS

Figure 23 Profile of SAS and PCPSS by phase type – inpatient setting

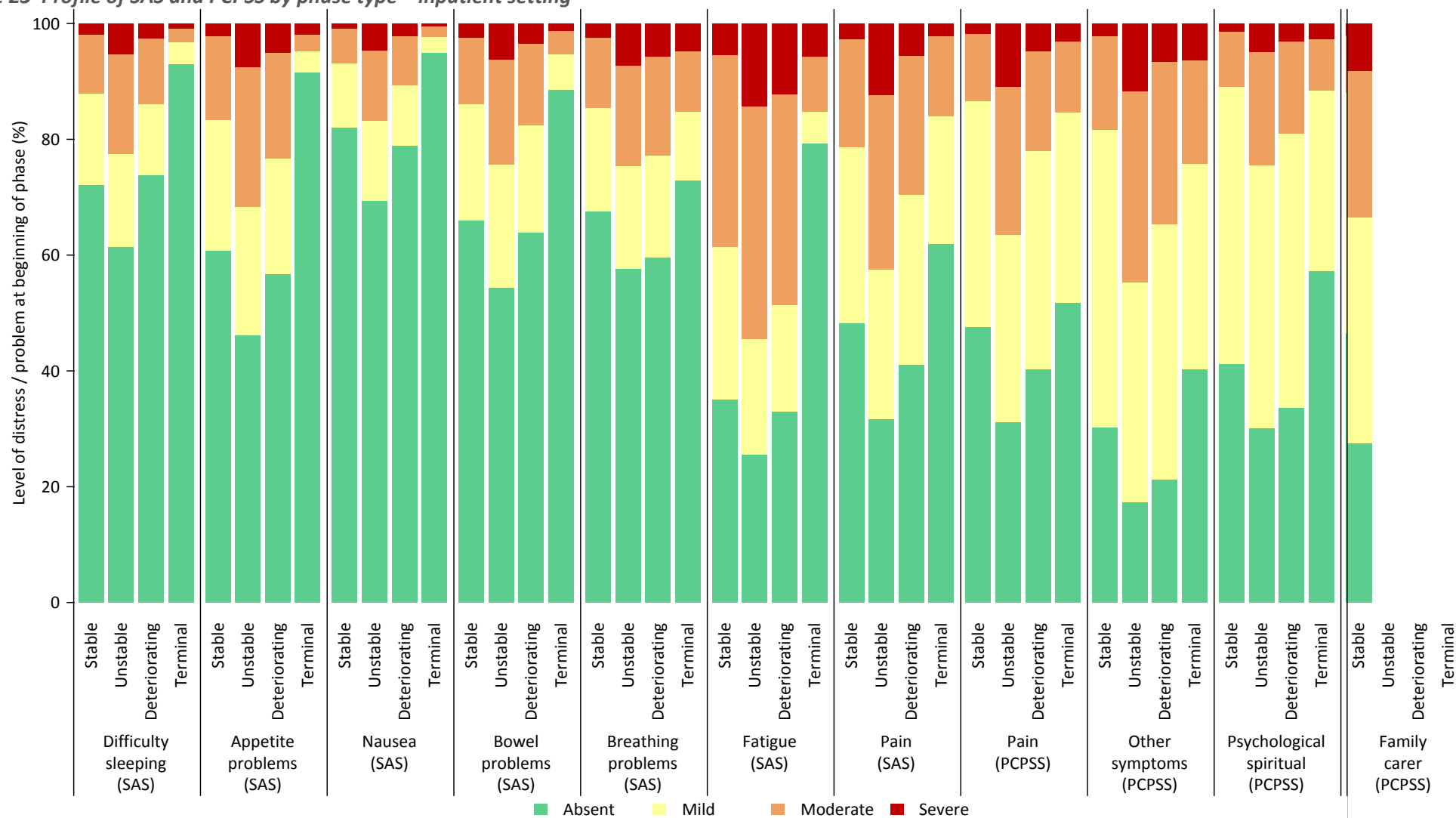
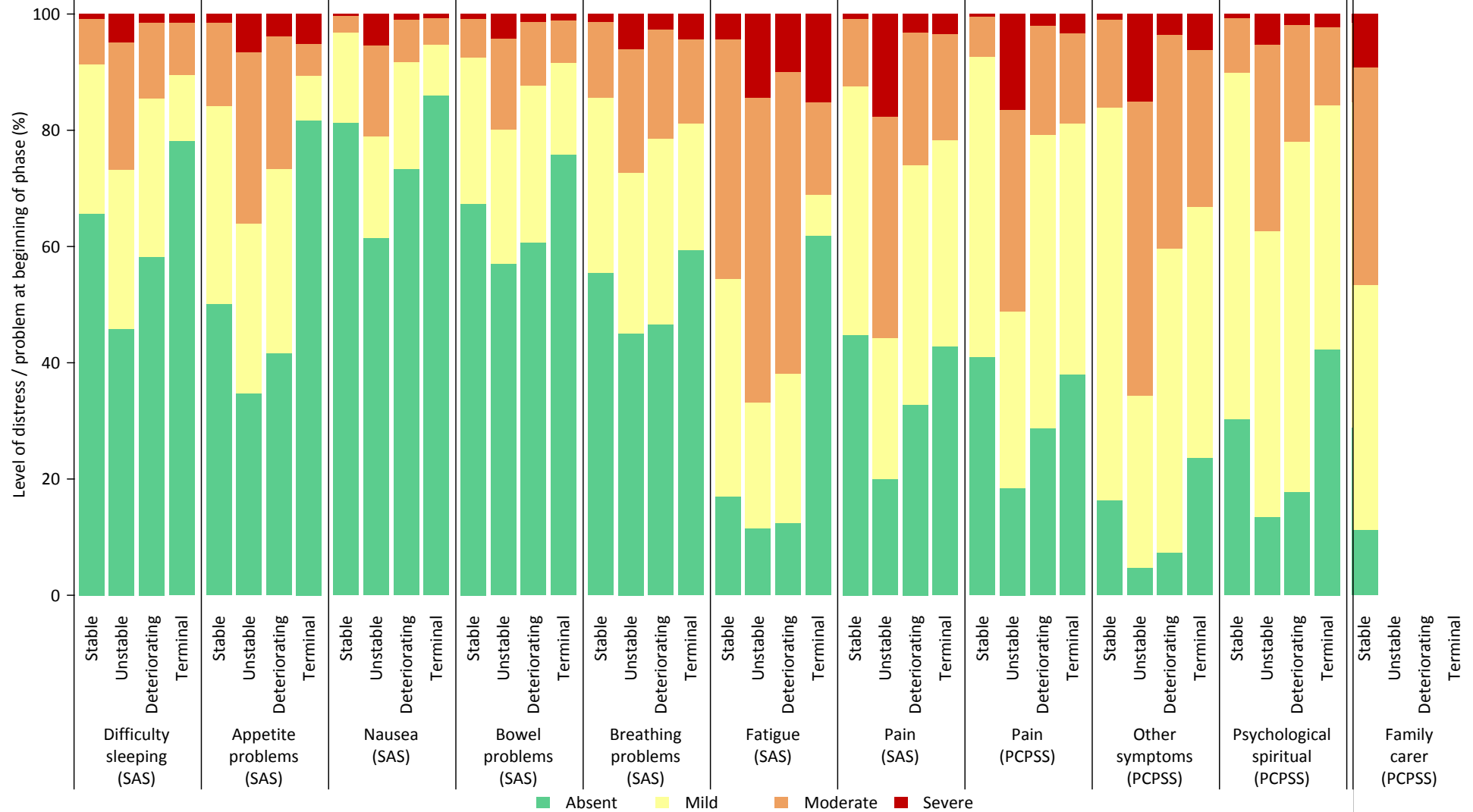


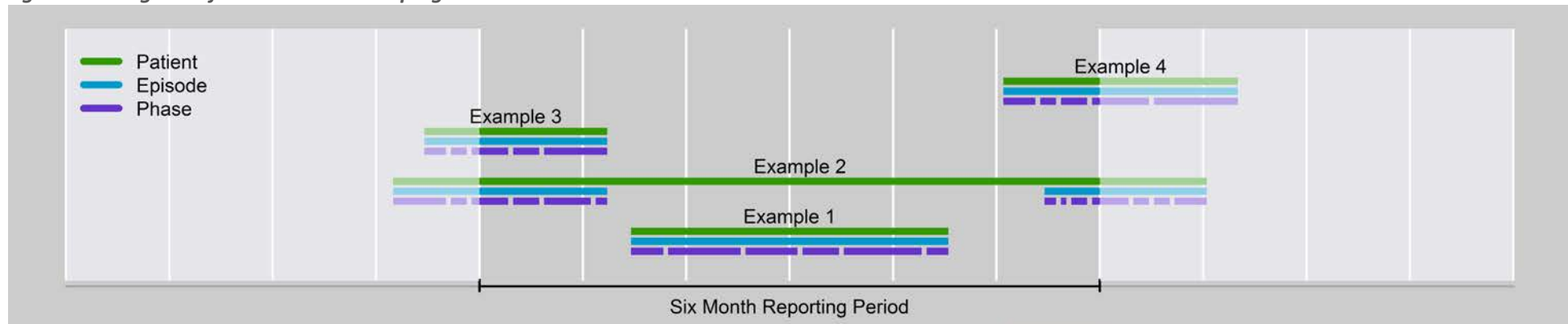
Figure 24 Profile of SAS and PCPSS by phase type – community setting



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 25 below displays four examples to help visualize this process.

Figure 25 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
Stable	
<p>Patient problems and symptoms are adequately controlled by established plan of care and</p> <ul style="list-style-type: none"> 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. 	<p>The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care.</p>
Unstable	
<p>An urgent change in the plan of care or emergency treatment is required because</p> <ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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).
Deteriorating	
<p>The care plan is addressing anticipated needs but requires periodic review because</p> <ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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).
Terminal	
<p>Death is likely within days.</p>	<ul style="list-style-type: none"> Patient dies or Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).
Bereavement – post death support	
<ul style="list-style-type: none"> The patient has died Bereavement support provided to family / carers is documented in the deceased patient's clinical record. 	<ul style="list-style-type: none"> Case closure <p>Note: If counselling is provided to a family member or carer, they become a client in their own right.</p>

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, Allingham S, Bird S, Clapham S, Quinsey K and Foskett L (2016) *National Report on Patient Outcomes in Palliative Care in Australia, July – December 2015*. Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong