

Patient outcomes in Palliative Care

National report
July to December 2018

April 2019

What is PCOC?

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national palliative care outcomes and benchmarking program. PCOC's primary objective is to systematically improve patient outcomes (including pain and symptom control).

Central to the program is a [framework and protocol for routine clinical assessment and response](#). This works in parallel with a routine point-of-care data collection, capturing clinically meaningful information. PCOC aims to drive improvement in patient outcomes through feedback to individual services and by facilitating service-to-service benchmarking.

The items in the PCOC data collection:

- provide clinicians with an approach to systematically assess individual patient experiences
- include routine Patient Reported Outcome Measures (PROMs) relating to symptom distress
- define a common clinical language to allow palliative care providers to communicate with each other
- facilitate the routine collection of nationally consistent palliative care data for the purpose of reporting and benchmarking to drive quality improvement at service, state, territory and national levels.

The assessment framework incorporates five validated 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).

If you would like more information or have any queries about this report please contact the PCOC national office at pcoc@uow.edu.au or on (02) 4221 4411



Contents

Introduction	1
1 Benchmark summary	2
2 Patient outcomes in more detail	3
2.1 Timely commencement of palliative care	3
2.2 Responsiveness in managing patients with urgent needs	5
2.3 Symptoms & problems in the absent to mild range at phase end	7
2.4 Casemix adjusted outcomes	14
3 Patient characteristics	17
4 Episodes of palliative care	20
5 Profile of palliative care phases	25
6 Symptoms and problems	30
7 Functional status and level of dependence	34
Appendices	40
A Summary of data included in this report	40
B Data item completion	42
C Data scoping method	44
D Interpreting benchmark profile graphs	45
E Palliative Care Phase definitions	46
Acknowledgements	47



Tables

Table 1	Summary of outcome measures by setting	2
Table 2	Time from date ready for care to episode start by setting.....	3
Table 3	Time in unstable phase by setting.....	5
Table 4	Achieving absent to mild symptoms/problems at phase end, when absent to mild at beginning.....	7
Table 5	Achieving absent to mild symptoms/problems at phase end, when moderate to severe at beginning	8
Table 6	Casemix adjusted outcomes – hospital / hospice setting.....	14
Table 7	Indigenous status	17
Table 8	Place of death.....	17
Table 9	Country of birth.....	18
Table 10	Preferred language.....	18
Table 11	Principal reason for palliative care - malignant diagnoses	19
Table 12	Principal reason for palliative care - non-malignant diagnosis	19
Table 13	Patient's age by sex	20
Table 14	Source of referral.....	21
Table 15	Length of episode (in days) summary by setting.....	22
Table 16	Length of episode by setting	22
Table 17	How hospital / hospice episodes start.....	23
Table 18	How hospital / hospice episodes end.....	23
Table 19	How community episodes start	24
Table 20	How community episodes end.....	24
Table 21	Number of phases by phase type and setting.....	25
Table 22	Average phase length (in days) by phase type and setting	25
Table 23	First phase of episode by setting.....	25
Table 24	How stable phases end by setting.....	26
Table 25	How unstable phases end by setting.....	27
Table 26	How deteriorating phases end by setting.....	28
Table 27	How terminal phases end by setting	29
Table 28	PCPSS at beginning of phase by phase type – hospital / hospice setting.....	30
Table 29	Symptom distress at the beginning of a phase by phase type.....	31
Table 30	Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting.....	34
Table 31	The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) at phase start by setting	37



Table 32	Summary of patients, episodes and phases by setting	40
Table 33	Number of completed episodes and phases by month and setting.....	41
Table 34	Number of patients, episodes and phases by setting and reporting period	41
Table 35	Item completion (%) - patient level.....	42
Table 36	Item completion (%) - episode level, by setting.....	42
Table 37	Item completion (%) - phase level, by setting.....	43



Figures

Figure 1	Time from date ready for care to episode start, all services (BM1).....	4
Figure 2	Time in unstable phase, all services (BM2).....	6
Figure 3	Pain, patients with absent to mild problem at phase end.....	9
Figure 4	Pain, patients experiencing absent to mild distress at phase end.....	10
Figure 5	Fatigue, patients experiencing absent to mild distress at phase end.....	11
Figure 6	Breathing problems, patients experiencing absent to mild distress at phase end.....	12
Figure 7	Family / carer problems, absent to mild at phase end.....	13
Figure 8	Trends in casemix adjusted outcomes - Palliative Care Problem Severity Score (PCPSS).....	15
Figure 9	Trends in casemix adjusted outcomes - Symptom Assessment Scale (SAS).....	16
Figure 10	Stable phase progression.....	26
Figure 11	Unstable phase progression.....	27
Figure 12	Deteriorating phase progression.....	28
Figure 13	Terminal phase progression.....	29
Figure 14	Profile of symptoms and problems by phase type – hospital / hospice setting.....	32
Figure 15	Profile of symptoms and problems by phase type – community setting.....	33
Figure 16	Distribution of AKPS at episode start.....	35
Figure 17	Distribution of AKPS at phase start by phase type.....	35
Figure 18	Percentage of phases beginning with an AKPS of 50 or less overtime.....	36
Figure 19	Distribution of Total RUG-ADL at episode start.....	38
Figure 20	Distribution of Total RUG-ADL at phase start by phase type.....	38
Figure 21	Percentage of phases beginning with a Total RUG-ADL of 10 or more overtime.....	39
Figure 22	Diagram of the PCOC data scoping method.....	44



Introduction

The Australian palliative care sector is a world leader in using routine clinical assessment information to guide patient centred care and measure patient and family outcomes. Providers of palliative care are commended for their commitment to excellence in delivering evidence-based, patient-centred care by using the routine Palliative Care Outcomes Collaboration (PCOC) assessment framework and contributing patient data toward national outcome measurement and benchmarking. PCOC acknowledges the dedication and willingness of clinicians to improve the care of patients, their families and caregivers. The information collected is not just data - it represents the real-life outcomes of over 40,000 Australians who die an expected death every year.

While the focus of this report is on the most recent information relating to July to December 2018, results over the last three years are also presented to highlight achievements and improvement in outcomes. The most recent information corresponds to 23,333 patients, having 29,931 episodes of care and 70,135 palliative care phases from 127 services who provide palliative care in hospital / hospice or in the person's home.

The purpose of benchmarking is to drive improvement and palliative care service innovation.

A full list of the services included in the national figures can be found at www.pcoc.org.au.

Please use the following key when interpreting the tables throughout this report

- **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**



1 Benchmark summary

Table 1 Summary of outcome measures by setting

Outcomes measure		Benchmark	Hospital / hospice % BM met?		Community % BM met?		Benchmark Reference No.
Timely commencement of palliative care							
Care commencing within two days of the person being ready		90%	97.2	Yes	86.7	No	1
Responsiveness in managing patients with urgent needs							
Patients unstable for three days or less		90%	89.3	No	85.1	No	2
Symptoms & problems in the absent to mild range at phase end							
Anticipatory care <i>when symptoms or problems are in the absent to mild range at phase start</i>	Pain (clinician reported)	90%	91.8	Yes	85.2	No	3.1
	Pain (patient reported)		90.8	Yes	84.2	No	3.3
	Fatigue (patient reported)		90.8	Yes	80.4	No	3.5
	Breathing problems (patient reported)		95.6	Yes	92.5	Yes	3.7
	Family / carer problems (clinician reported)		93.2	Yes	84.4	No	3.9
Responsive care <i>when symptoms or problems are in the moderate to severe range at phase start</i>	Pain (clinician reported)	60%	61.7	Yes	59.0	No	3.2
	Pain (patient reported)		58.1	No	53.3	No	3.4
	Fatigue (patient reported)		53.2	No	37.0	No	3.6
	Breathing problems (patient reported)		52.6	No	39.6	No	3.8
	Family / carer problems (clinician reported)		56.3	No	48.6	No	3.10
Casemix adjusted outcomes (change scores)			Score	BM met?	Score	BM met?	
Clinician reported problems (PCPSS)	Pain	0.0	0.09	Yes	-0.04	No	4.1
	Other symptoms		0.24	Yes	0.02	Yes	4.2
	Family / carer problems		0.19	Yes	0.02	Yes	4.3
	Psychological / spiritual problems		0.20	Yes	0.04	Yes	4.4
Patient reported symptom distress (SAS)	Pain	0.0	0.34	Yes	-0.11	No	4.5
	Nausea		0.21	Yes	-0.03	No	4.6
	Breathing problems		0.33	Yes	0.01	Yes	4.7
	Bowel problems		0.31	Yes	0.08	Yes	4.8

2 Patient outcomes in more detail

2.1 Timely commencement of palliative care

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

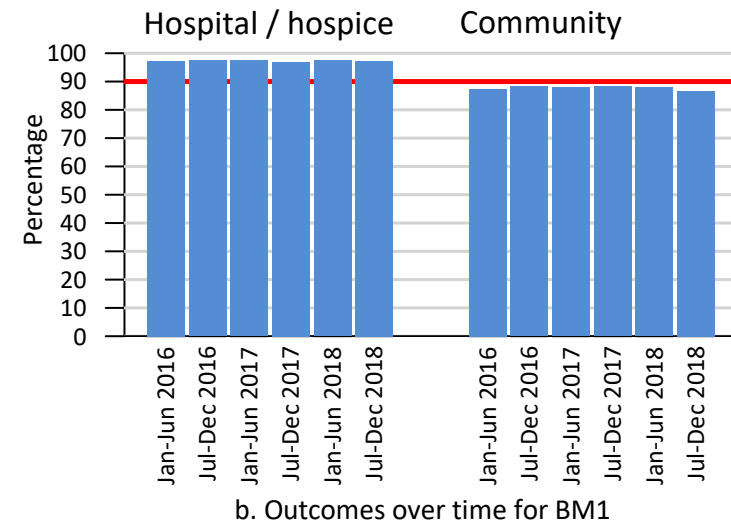
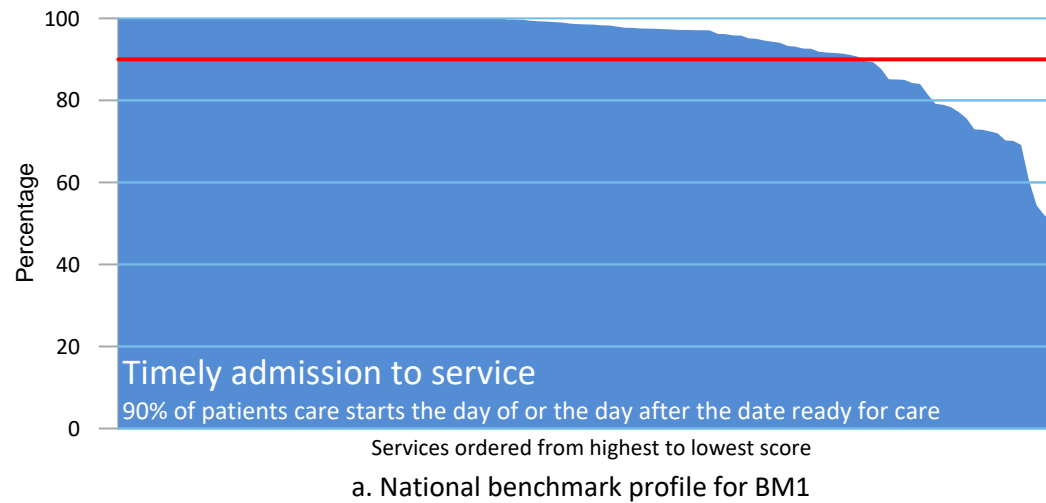
Time (in days)	Hospital / hospice		Community	
	N	%	N	%
Same day	12,822	92.5	10,483	82.0
Following day	643	4.6	597	4.7
2-7	357	2.6	1,198	9.4
8-14	23	0.2	296	2.3
15 +	10	0.1	211	1.7
Average	1.1	-	2.1	-
Median	1	-	1	-

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 1 Time from date ready for care to episode start, all services (BM1)



Key: National service profile Benchmark National results

Note: Only services with 10 or more valid assessments are included in the above graphs.

2.2 Responsiveness in managing patients with urgent needs

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:

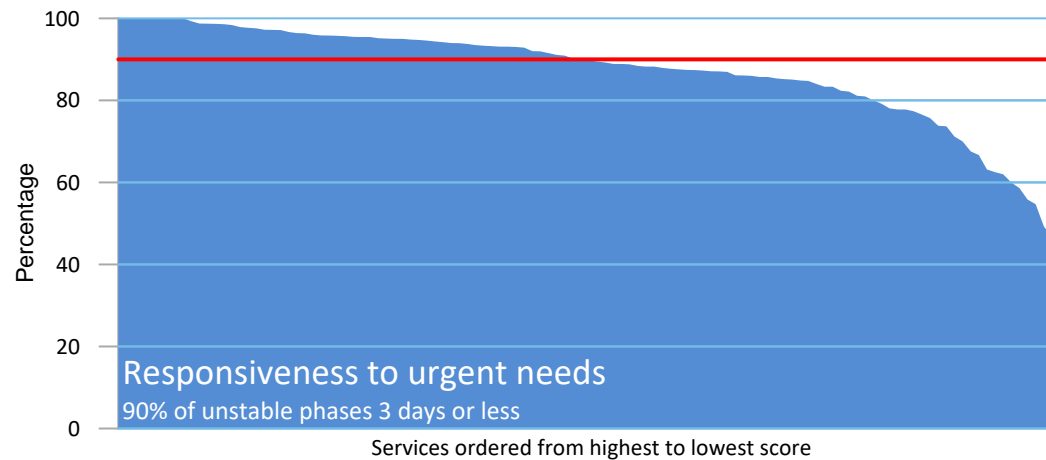
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom / crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the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

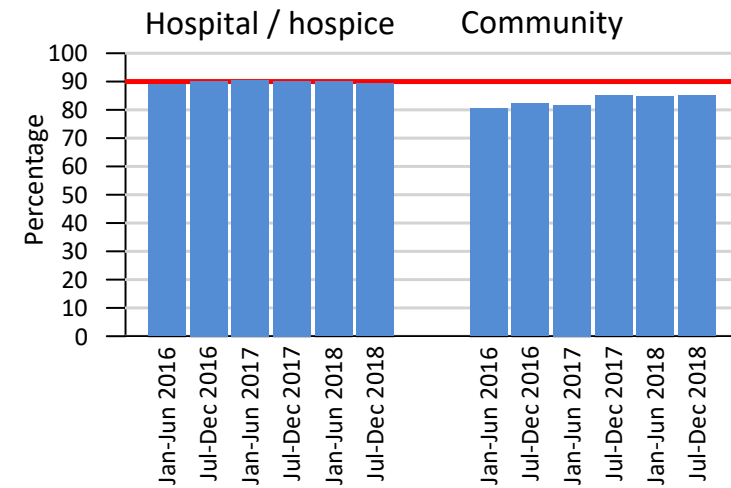
Table 3 Time in unstable phase by setting

Time in unstable phase	Hospital / hospice		Community	
	N	%	N	%
Same day	362	5.3	1,415	31.3
1 day	3,515	51.9	1,648	36.4
2 days	1,509	22.3	524	11.6
3 days	666	9.8	259	5.7
4 – 5 days	470	6.9	209	4.6
6 – 7 days	139	2.1	146	3.2
8 – 14 days	91	1.3	156	3.4
More than 14 days	25	0.4	165	3.6
Total	6,777	100.0	4,522	100.0

Figure 2 Time in unstable phase, all services (BM2)



a. National benchmark profile for BM2



b. Outcomes over time for BM2

Key: National service profile Benchmark National results

Note: Only services with 10 or more valid assessments are included in the above graphs.

2.3 Symptoms & problems in the absent to mild range at phase end

The outcome measures presented in this section focus on five symptom and problem areas:

1. Pain - clinician reported severity
2. Pain - patient reported distress
3. Fatigue - patient reported distress
4. Breathing problems - patient reported distress
5. Family / carer problems - clinician reported severity

A positive patient outcome is achieved if the patient, or family/carer, has an absent to mild symptom / problem at the end of a palliative care phase. However, the type of care delivered and the corresponding benchmarks achievement depends on the patient's (or family/carer) level of symptom or problem at start of the phase; scores in the absent to mild range trigger monitoring and review of care plans (anticipatory care), whilst scores in the moderate to severe range trigger interventions and actions to respond to needs (responsive care).

Anticipatory care

The anticipatory care outcome measures and benchmarks relate to patients who have absent or mild symptom / problem at the start of a phase of palliative care. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild symptom / problem. Table 4 summarises the number of phases starting with absent to mild symptom / problem, and the percentage of those ending in the absent to mild range.

Table 4 Achieving absent to mild symptoms/problems at phase end, when absent to mild at beginning

Symptom / problem ^a	Hospital / hospice		Community	
	N ^b	%	N ^b	%
Pain (clinician reported)	19,193	91.8	21,147	85.2
Pain (patient reported)	16,495	90.8	20,932	84.2
Fatigue (patient reported)	15,684	90.8	16,437	80.4
Breathing problems (patient reported)	18,817	95.6	21,325	92.5
Family / carer problems (clinician reported)	20,112	93.2	19,635	84.4

a. Phase records must have valid start and end scores for the PCPS and / or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with **absent to mild** symptom / problem.

Responsive care

The responsive care outcome measure and benchmarks relate to patients, or family/carer, who have a moderate or severe symptom / problem at the start of their phase of palliative care. Achieving an absent / mild symptom or problem outcome at phase end has been identified as more clinically challenging, so to meet this benchmark, 60% of these phases must end with the patient experiencing absent or mild symptom / problem.

Table 5 summarises the number of phases starting with moderate to severe symptom / problem and of those, the percentage ending in the absent to mild range.

Table 5 Achieving absent to mild symptoms/problems at phase end, when moderate to severe at beginning

Symptom / problem ^a	Hospital / hospice		Community	
	N ^b	%	N ^b	%
Pain (clinician reported)	4,993	61.7	4,621	59.0
Pain (patient reported)	5,690	58.1	5,583	53.3
Fatigue (patient reported)	6,473	53.2	8,740	37.0
Breathing problems (patient reported)	3,337	52.6	3,470	39.6
Family / carer problems (clinician reported)	3,253	56.3	4,520	48.6

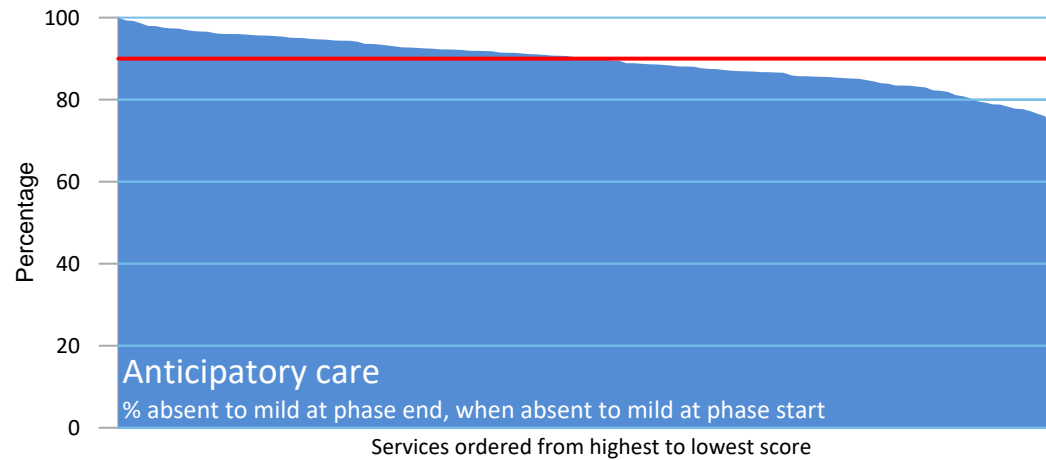
a. Phase records must have valid start and end scores for the PCPSS and / or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with the symptom or problem rated **moderate to severe**.

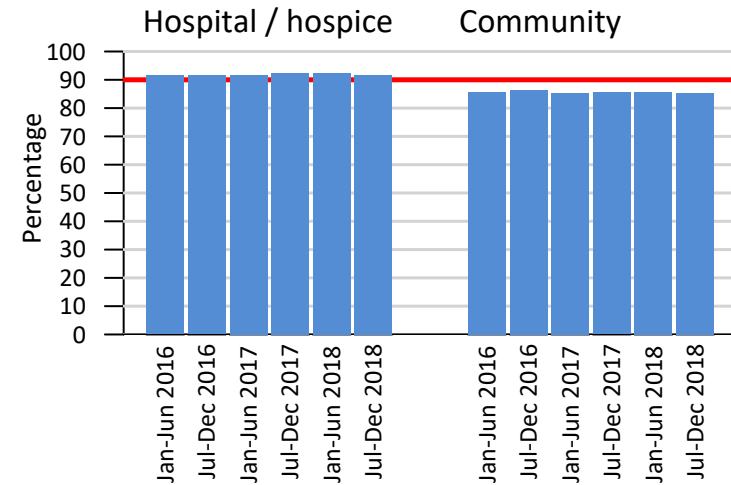
On the following pages, the results for the anticipatory and responsive care benchmarks are presented together for each of the five symptom and problem domains. The graphs included compare the outcomes achieved by your service to those of other individual services nationally, as well as showing any changes in outcomes over time.

Pain (clinician reported problem severity)

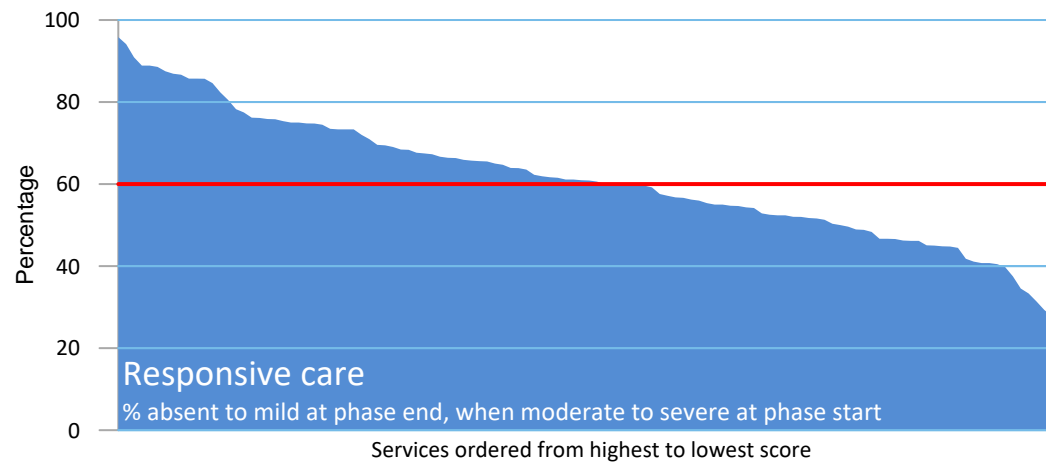
Figure 3 Pain, patients with absent to mild problem at phase end



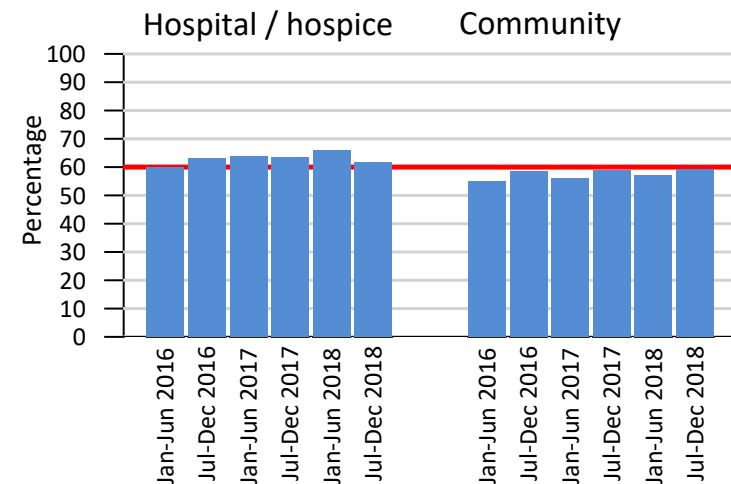
a. National service profile for BM3.1



b. Outcomes over time (BM3.1)



c. National service profile for BM3.2



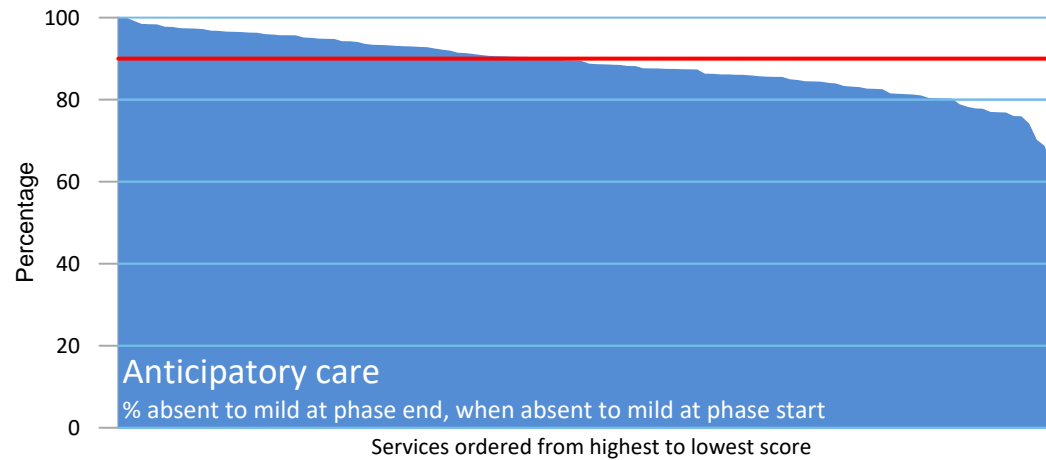
d. Outcomes over time (BM3.2)

Key: National service profile Benchmark National results

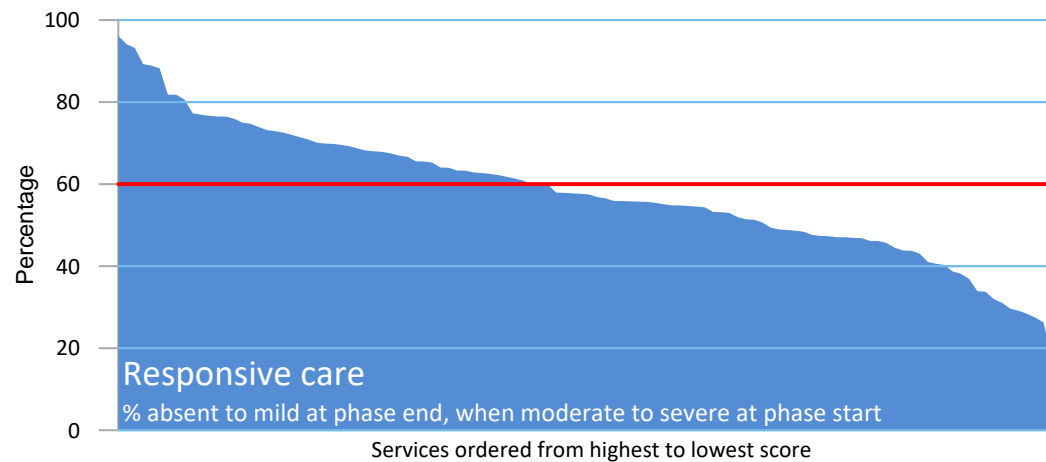
Note: Only services with 10 or more valid assessments are included in the above graphs.

Pain (patient reported distress)

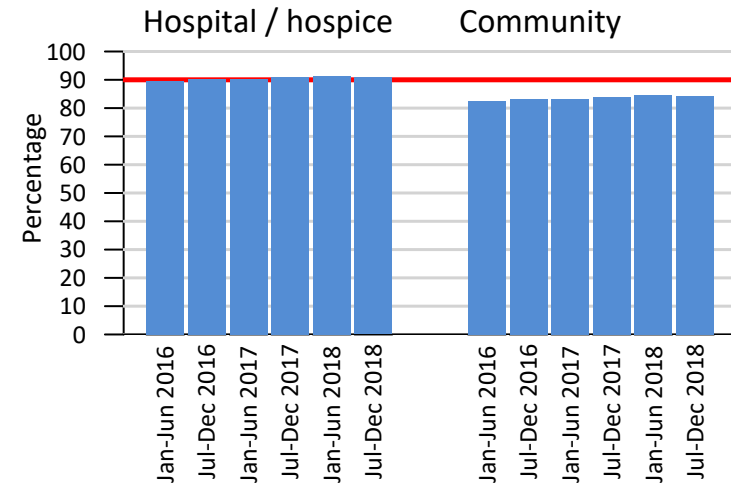
Figure 4 Pain, patients experiencing absent to mild distress at phase end



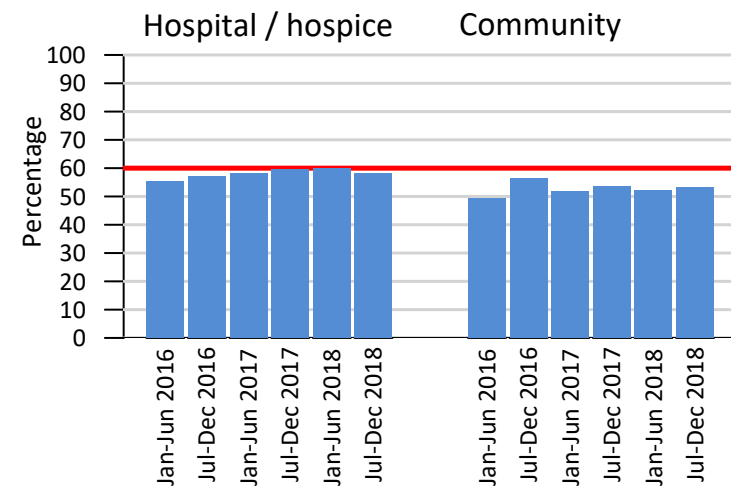
a. National benchmark profile for BM3.3



c. National benchmark profile for BM3.4



b. Outcomes over time BM3.3



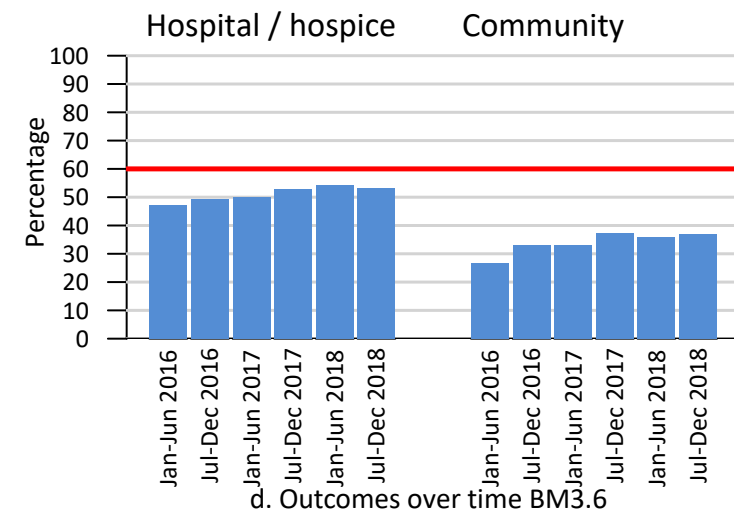
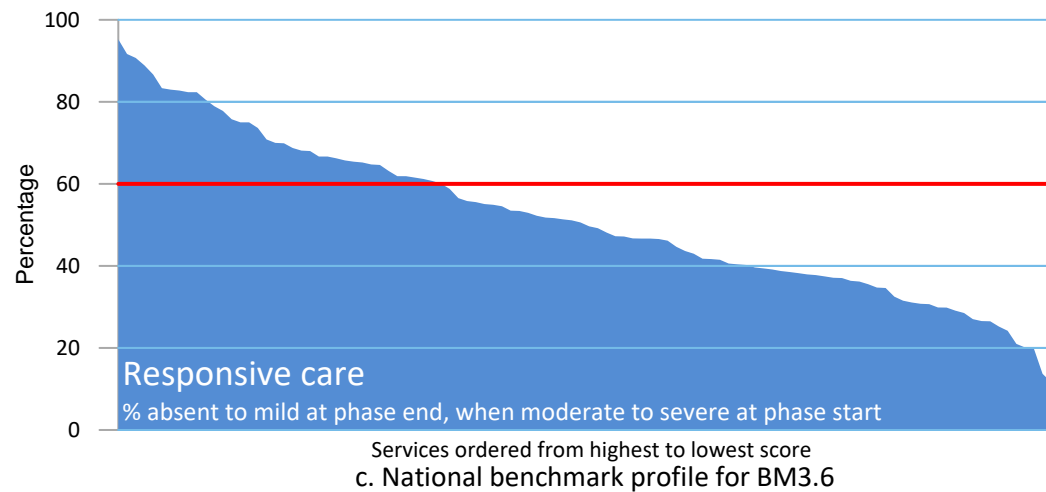
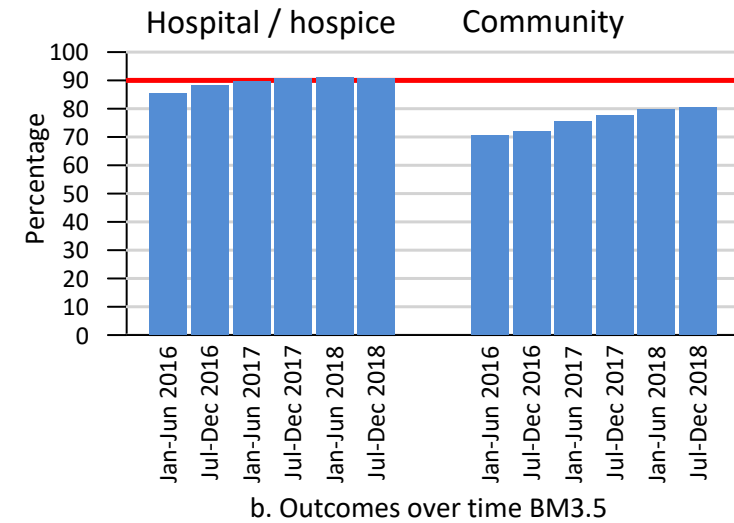
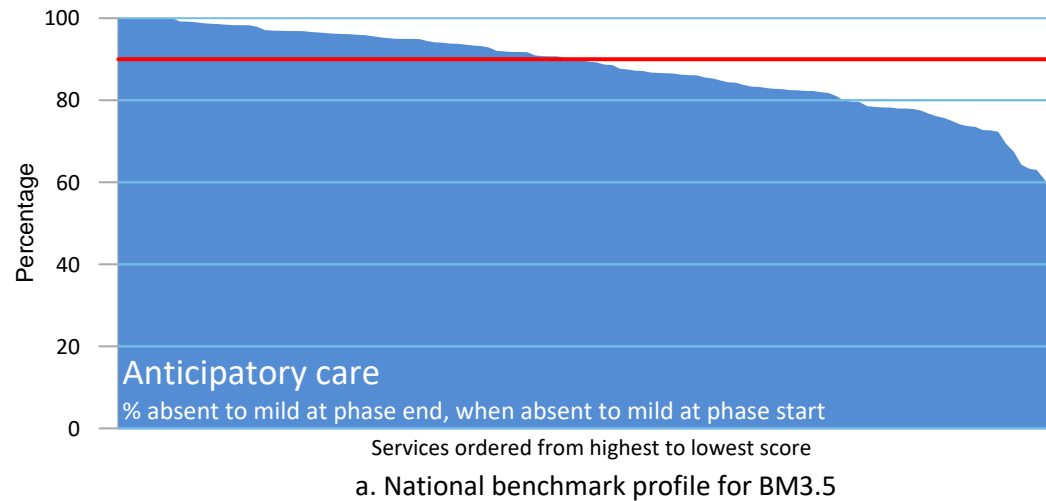
d. Outcomes over time BM3.4

Key: National service profile Benchmark National results

Note: Only services with 10 or more valid assessments are included in the above graphs.

Fatigue (patient reported distress)

Figure 5 Fatigue, patients experiencing absent to mild distress at phase end

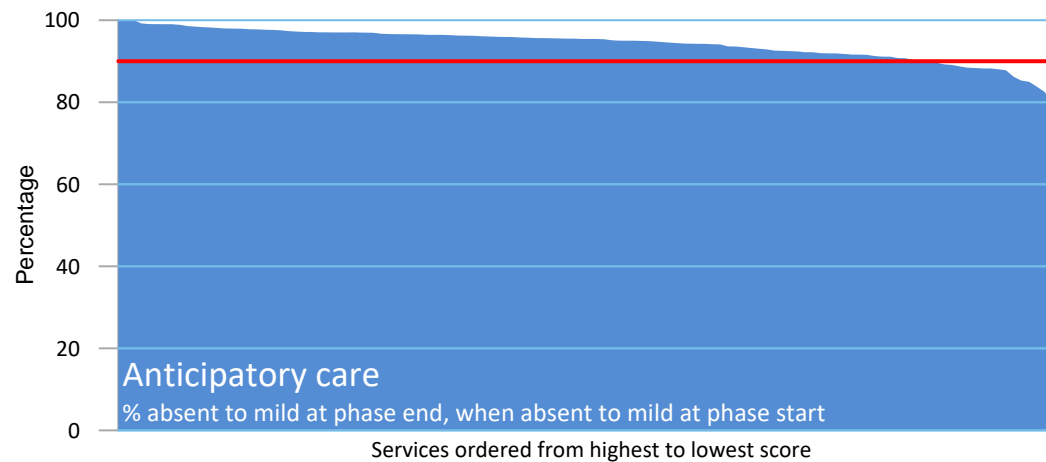


Key: National service profile Benchmark National results

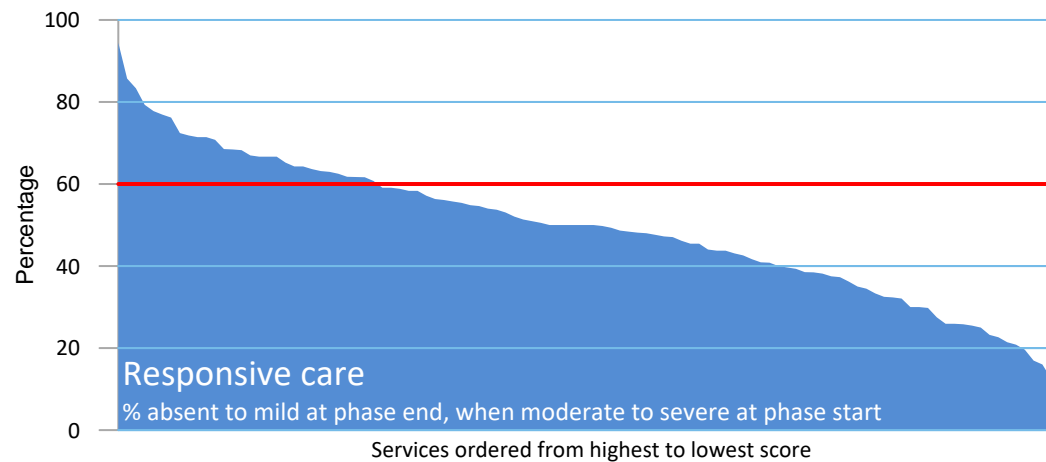
Note: Only services with 10 or more valid assessments are included in the above graphs.

Breathing problems (patient reported distress)

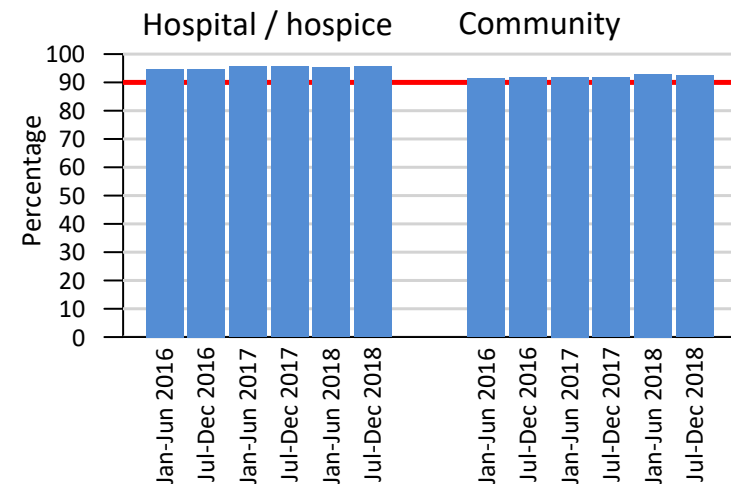
Figure 6 Breathing problems, patients experiencing absent to mild distress at phase end



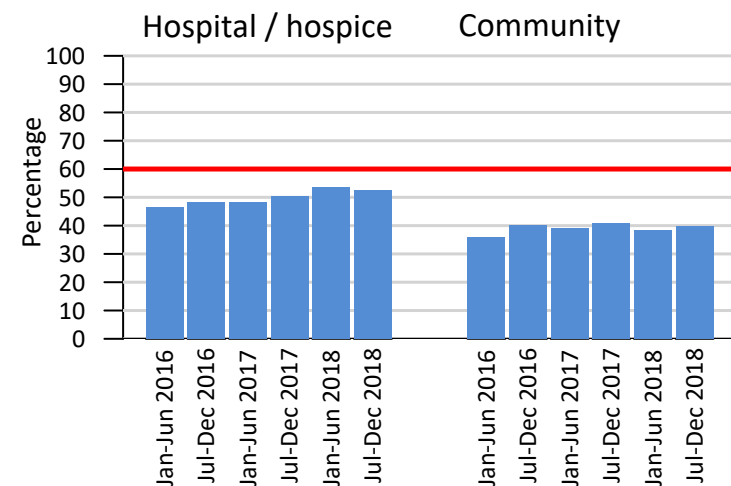
a. National benchmark profile for BM3.7



c. National benchmark profile for BM3.8



b. Outcomes over time BM3.7



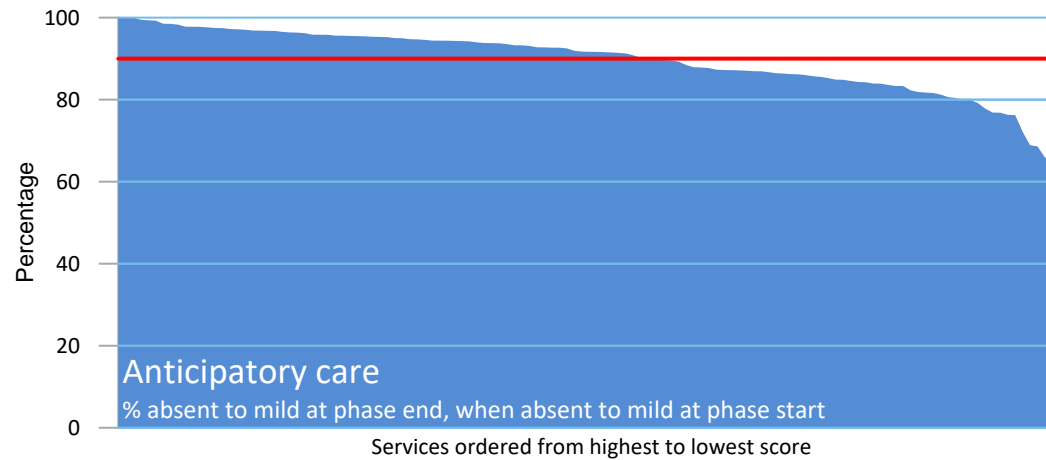
d. Outcomes over time BM3.8

Key: National service profile Benchmark National results

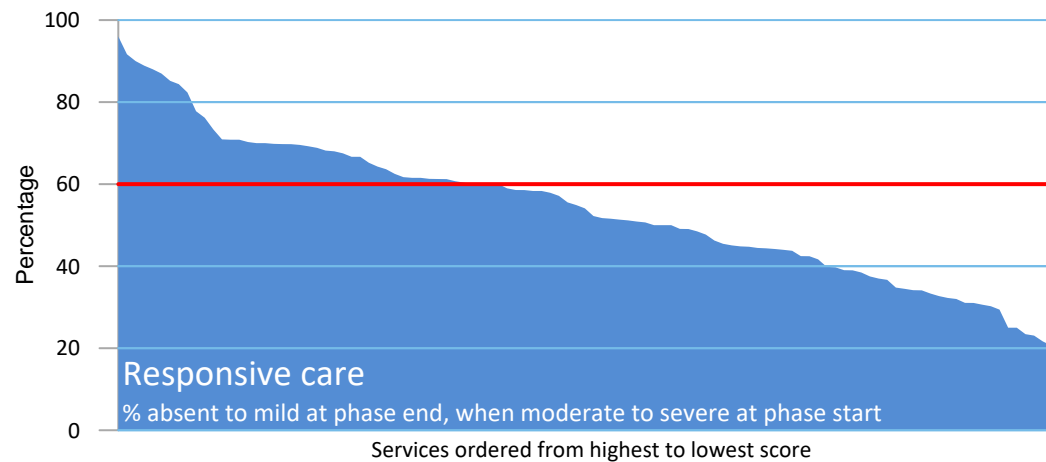
Note: Only services with 10 or more valid assessments are included in the above graphs.

Family / carer problems (clinician reported problem severity)

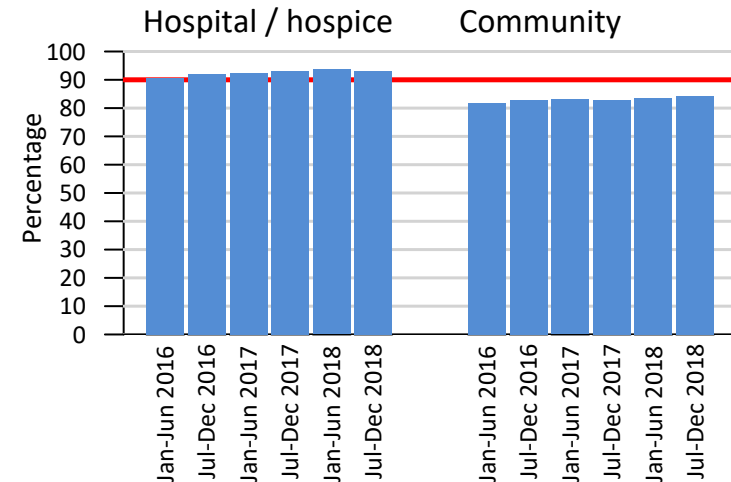
Figure 7 Family / carer problems, absent to mild at phase end



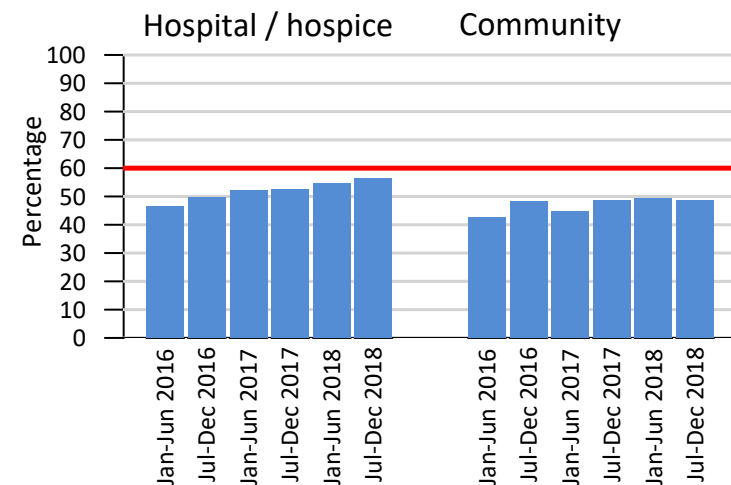
a. National benchmark profile for BM3.9



c. National benchmark profile for BM3.10



b. Outcomes over time BM3.9



d. Outcomes over time BM3.10

Key: National service profile Benchmark National results

Note: Only services with 10 or more valid assessments are included in the above graphs.

2.4 Casemix adjusted outcomes

Outcome measure 4 includes a suite of eight casemix adjusted scores used to compare the change in symptoms for similar patients. Patients in the same phase who started with the same level of symptom have their change in symptom compared to the reference period (January to June 2014).

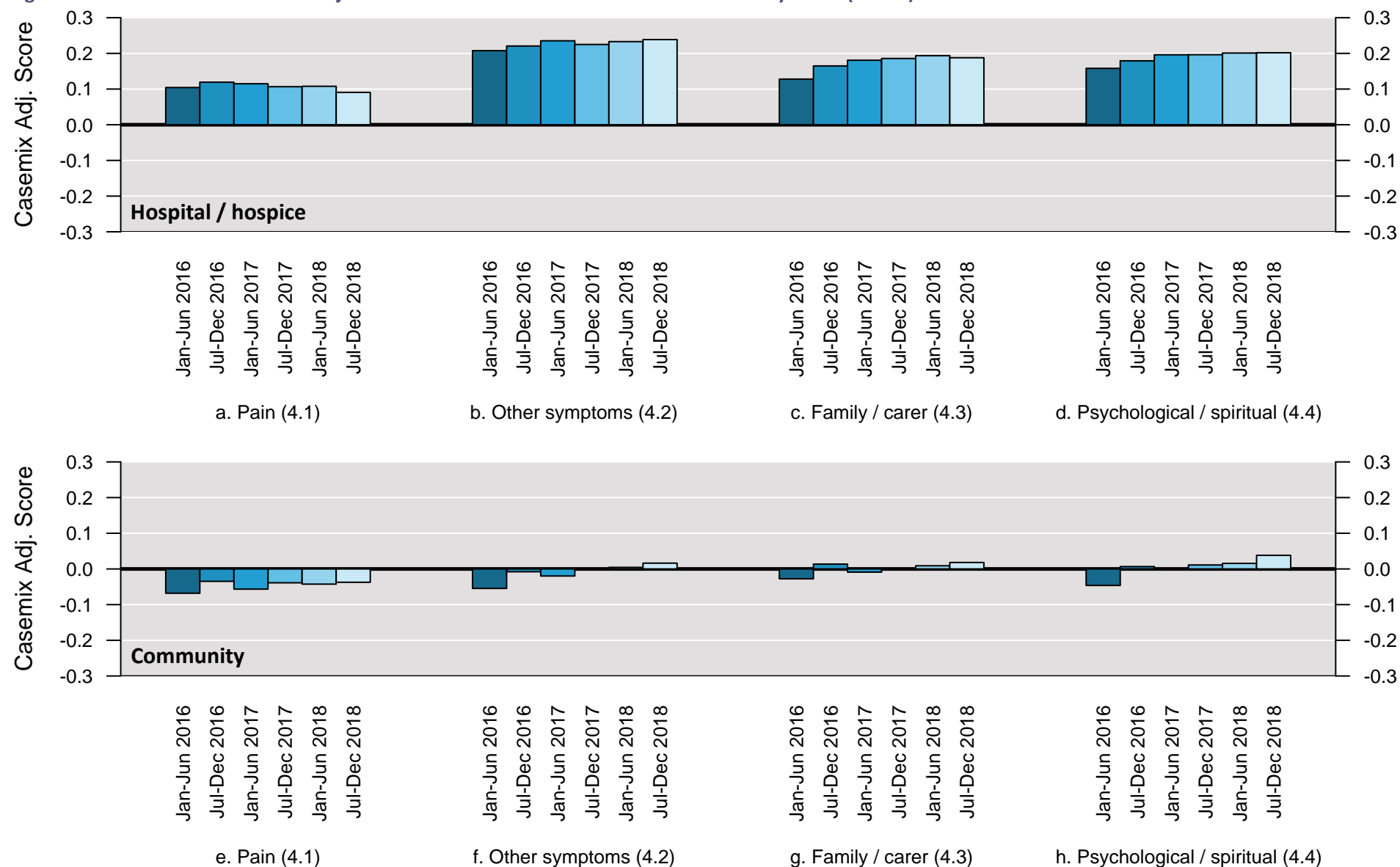
Table 6 Casemix adjusted outcomes – hospital / hospice setting

Clinical tool	Symptom / problem	Casemix adjusted score	Hospital / hospice			Casemix adjusted score	Community		
			Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)		Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)
PCPSS <i>Clinician reported severity</i>	Pain	0.09	24,186	14,946	61.8	-0.04	25,768	14,274	55.4
	Other symptoms	0.24	23,703	18,061	76.2	0.02	25,089	16,292	64.9
	Family / carer	0.19	23,365	16,913	72.4	0.02	24,155	15,749	65.2
	Psychological / spiritual	0.20	24,145	15,655	64.8	0.04	25,441	13,769	54.1
SAS <i>Patient reported distress</i>	Pain	0.34	22,185	15,241	68.7	-0.11	26,515	15,674	59.1
	Nausea	0.21	22,104	19,518	88.3	-0.03	25,013	20,258	81.0
	Breathing problems	0.33	22,154	17,730	80.0	0.01	24,795	17,084	68.9
	Bowel problems	0.31	22,114	17,853	80.7	0.08	24,553	18,379	74.9

The Casemix adjusted scores are calculated relative to a baseline reference period. A Casemix adjusted score:

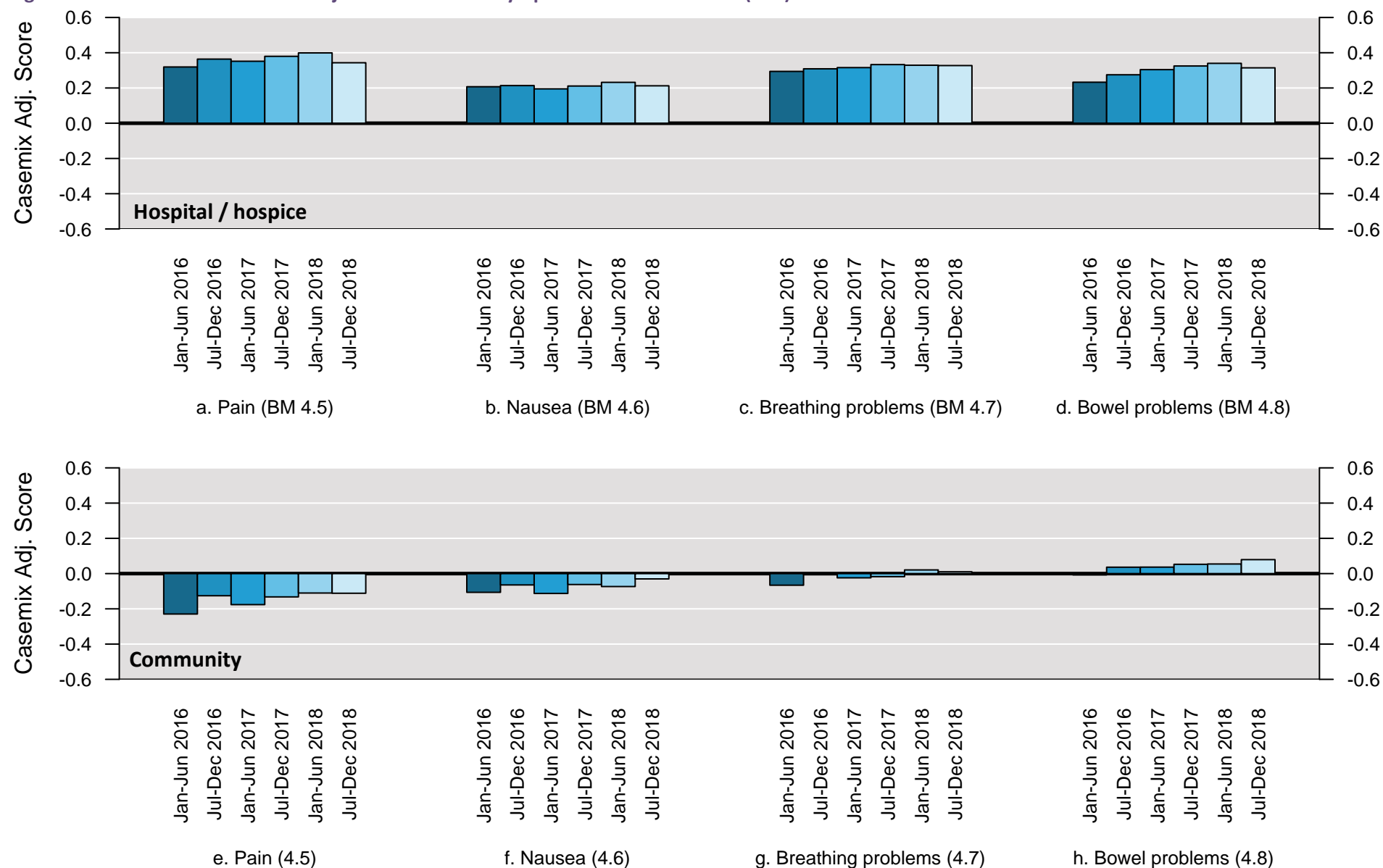
- **greater than 0** means that on average your patient's outcomes were **better than for similar patients** in the reference period
- **less than 0** means that on average, your patients' outcomes were **worse than to similar patients** in the reference period
- **equal to 0** means that on average, your patients' outcomes were **about the same as similar patients** in the reference period

Figure 8 Trends in casemix adjusted outcomes - Palliative Care Problem Severity Score (PCPSS)



Note: Only services with 10 or more valid assessments are included in the above graphs.

Figure 9 Trends in casemix adjusted outcomes - Symptom Assessment Scale (SAS)



Note: Only services with 10 or more valid assessments are included in the above graphs.

3 Patient characteristics

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 shows the Indigenous status for patients nationally.

Table 7 Indigenous status

Indigenous status	N	%
Aboriginal but not Torres Strait Islander origin	311	1.3
Torres Strait Islander but not Aboriginal origin	20	0.1
Both Aboriginal and Torres Strait Islander origin	30	0.1
Neither Aboriginal nor Torres Strait Islander origin	22,161	95.0
Not stated / inadequately described	811	3.5
Total	23,333	100.0

Table 8 shows the breakdown of deaths for the patients nationally for the reporting period. All inpatient deaths are reported in the hospital / hospice 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	2,346	20.9
Residential aged care facility	892	8.0
Hospital / hospice	7,938	70.8
Not stated / inadequately described	38	0.3
Total	11,214	100.0

Table 9 Country of birth

Country of birth	N	%
Australia	14,141	60.6
England	1,666	7.1
New Zealand	459	2.0
China	248	1.1
India	203	0.9
Italy	927	4.0
Vietnam	187	0.8
Philippines	117	0.5
South Africa	123	0.5
Scotland	282	1.2
Malaysia	97	0.4
Germany	253	1.1
Greece	518	2.2
Sri Lanka	85	0.4
United States of America	56	0.2
All other countries	3,257	14.0
Not stated	714	3.1
Total	23,333	100.0

The tables on this page 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 10 Preferred language

Language	N	%
English	20,626	88.4
Chinese ^(a)	284	1.2
Hindi ^(b)	44	0.2
Arabic ^(c)	220	0.9
Italian	436	1.9
Vietnamese ^(d)	123	0.5
Greek	345	1.5
Filipino / Indonesian ^(e)	42	0.2
Macedonian / Croatian ^(f)	198	0.8
Spanish ^(g)	83	0.4
Tamil / Malayalam ^(h)	7	0.0
German ⁽ⁱ⁾	20	0.1
Korean	30	0.1
Samoan / Tongan ^(j)	27	0.1
African languages	13	0.1
All other languages	412	1.8
Not stated	423	1.8
Total	23,333	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

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

Diagnosis was not stated for 170 (0.7%) patients nationally.

Table 11 Principal reason for palliative care - malignant diagnoses

Diagnosis	N	% of malignant diagnoses	% of all diagnoses
Bone and soft tissue	237	1.4	1.0
Breast	1,280	7.5	5.5
CNS	349	2.0	1.5
Colorectal	1,816	10.6	7.8
Other GIT	1,571	9.2	6.7
Haematological	1,104	6.5	4.7
Head and neck	864	5.1	3.7
Lung	3,677	21.5	15.8
Pancreas	1,287	7.5	5.5
Prostate	1,238	7.2	5.3
Other urological	765	4.5	3.3
Gynaecological	845	4.9	3.6
Skin	609	3.6	2.6
Unknown primary	475	2.8	2.0
Other primary malignancy	731	4.3	3.1
Malignant – nfd	234	1.4	1.0
All malignant diagnoses	17,082	100.0	73.2

Table 12 Principal reason for palliative care - non-malignant diagnosis

Diagnosis	N	% of non-malignant diagnosis	% of all diagnoses
Cardiovascular disease	1,022	16.8	4.4
HIV / AIDS	4	0.1	0.0
End stage kidney disease	532	8.7	2.3
Stroke	328	5.4	1.4
Motor neurone disease	284	4.7	1.2
Alzheimer's dementia	234	3.8	1.0
Other dementia	448	7.4	1.9
Other neurological disease	323	5.3	1.4
Respiratory failure	1,063	17.5	4.6
End stage liver disease	246	4.0	1.1
Diabetes & its complications	34	0.6	0.1
Sepsis	284	4.7	1.2
Multiple organ failure	146	2.4	0.6
Other non-malignancy	932	15.3	4.0
Non-malignant – nfd	201	3.3	0.9
All non-malignant	6,081	100.0	26.1

4 Episodes of palliative care

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 a hospital / hospice 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 hospital / hospice) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 13 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 Patient's age by sex

Age group	Male		Female	
	N	%	N	%
< 15	24	0.2	24	0.2
15 - 24	48	0.3	17	0.1
25 - 34	137	0.9	120	0.9
35 - 44	205	1.3	446	3.2
45 - 54	867	5.5	993	7.1
55 - 64	2,322	14.6	2,150	15.3
65 - 74	4,143	26.1	3,281	23.4
75 - 84	4,804	30.2	3,433	24.5
85 +	3,291	20.7	3,529	25.1
Unknown	47	0.0	45	0.0
Total	15,888	100.0	14,038	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 **Source of referral**

Referral source	Hospital / hospice		Community	
	N	%	N	%
Public hospital	9,002	61.3	8,219	53.9
Private hospital	1,368	9.3	1,698	11.1
Outpatient clinic	96	0.7	127	0.8
General medical practitioner	330	2.2	2,260	14.8
Specialist medical practitioner	509	3.5	857	5.6
Community-based palliative care agency	2,860	19.5	216	1.4
Community-based service	35	0.2	177	1.2
Residential aged care facility	69	0.5	785	5.1
Self, carer(s), family or friends	115	0.8	471	3.1
Other	156	1.1	382	2.5
Not stated / inadequately described	139	0.9	60	0.4
Total	14,679	100.0	15,252	100.0

Table 15 gives a summary of the length of palliative care episode. Table 16 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 15 Length of episode (in days) summary by setting

Length of episode	Hospital / hospice	Community
Average length of episode	10.1	37.4
Median length of episode	6.0	25.0

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 16 Length of episode by setting

Length of Episode (days)	Hospital / hospice		Community	
	N	%	N	%
Same day	1,022	7.1	352	2.7
1-2	2,933	20.2	831	6.3
3-4	2,163	14.9	813	6.1
5-7	2,469	17.0	1,094	8.3
8-14	2,866	19.8	1,792	13.5
15-21	1,291	8.9	1,236	9.3
22-30	832	5.7	1,215	9.2
31-60	741	5.1	2,235	16.9
61-90	124	0.9	1,117	8.4
90 +	48	0.3	2,570	19.4
Total	14,489	100.0	13,255	100.0

Note: Only episodes that end during the reporting period are included.

Table 17 How hospital / hospice episodes start

Episode start mode	N	%
Admitted from community ¹	8,754	59.6
Admitted from another hospital	3,199	21.8
Admitted from acute care in another ward	2,316	15.8
Change from acute care to palliative care – same ward	236	1.6
Other ²	96	0.7
Not stated / inadequately described	78	0.5
Total	14,679	100.0

¹ includes: admitted from usual accommodation, admitted from other than usual accommodation.

² includes: change of sub-acute/non-acute care type and other categories.

Table 18 How hospital / hospice episodes end

Episode end mode	N	%
Discharged to community ¹	4,887	33.7
Discharged to another hospital	735	5.1
Death	7,938	54.7
Change from palliative care to acute care ²	176	1.2
Change in sub-acute care type	174	1.2
End of consultative episode – inpatient episode ongoing	498	3.4
Other	68	0.5
Not stated / inadequately described	26	0.2
Total	14,502	100.0

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

¹ includes: discharged to usual accommodation, discharged to other than usual accommodation.

² includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.

Table 19 How community episodes start

Episode start mode	N	%
Admitted from inpatient palliative care	5,780	37.9
Other ¹	9,384	61.5
Not stated / inadequately described	88	0.6
Total	15,252	100.0

¹includes: patient was not transferred from being an overnight patient.

Table 20 How community episodes end

Episode end mode	N	%
Admitted for inpatient palliative care	4,024	30.3
Admitted for inpatient acute care	4,045	30.5
Admitted to another palliative care service	92	0.7
Admitted to primary health care	583	4.4
Discharged / case closure	1,020	7.7
Death	3,276	24.7
Other	184	1.4
Not stated / inadequately described	41	0.3
Total	13,265	100.0

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

5 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 E 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 21 Number of phases by phase type and setting

Phase type	Hospital / hospice		Community	
	N	%	N	%
Stable	8,383	24.9	13,627	37.3
Unstable	6,777	20.1	4,522	12.4
Deteriorating	11,264	33.5	15,490	42.4
Terminal	7,217	21.5	2,855	7.8
Total	33,641	100.0	36,494	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 22 Average phase length (in days) by phase type and setting

Phase type	Hospital / hospice	Community
Stable	7.0	20.4
Unstable	2.0	2.9
Deteriorating	5.2	11.9
Terminal	2.1	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 23 presents the first phase of the episode.

Table 23 First phase of episode by setting

First phase	Hospital / hospice		Community	
	N	%	N	%
Stable	2,086	14.7	5,688	42.7
Unstable	4,848	34.2	791	5.9
Deteriorating	5,595	39.5	6,335	47.5
Terminal	1,629	11.5	509	3.8
Total	14,158	100.0	13,323	100.0

Note: This table only includes the first phase if the episode has started in the reporting period.

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 10 summarises the movement of patients out of the stable phase by setting. 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 11), deteriorating (Table 26, Figure 12) and terminal (Table 27, Figure 13) phases on the following pages.

Table 24 How stable phases end by setting

How stable phases end	Hospital / hospice		Community	
	N	%	N	%
Patient moved into another phase	4,247	50.7	9,405	69.0
Discharge / case closure	4,011	47.8	3,907	28.7
Died	103	1.2	277	2.0
Not stated / inadequately described	22	0.3	38	0.3
Total	8,383	100.0	13,627	100.0

Figure 10 Stable phase progression

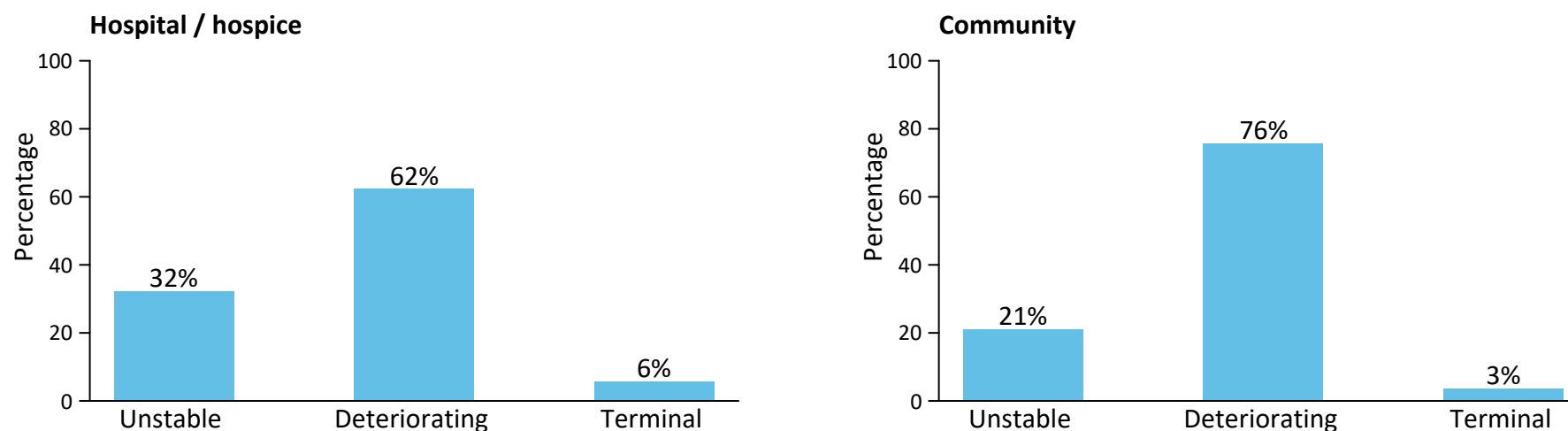


Table 25 How unstable phases end by setting

How unstable phases end	Hospital / hospice		Community	
	N	%	N	%
Patient moved into another phase	6,183	91.2	2,853	63.1
Discharge / case closure	473	7.0	1,595	35.3
Died	117	1.7	44	1.0
Not stated / inadequately described	4	0.1	30	0.7
Total	6,777	100.0	4,522	100.0

Figure 11 Unstable phase progression

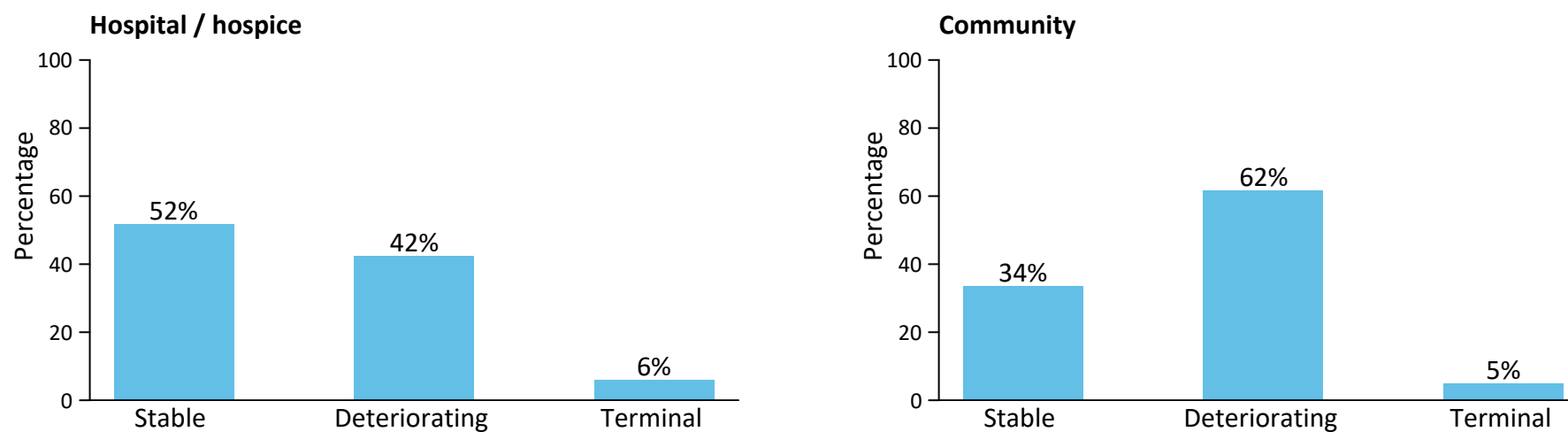


Table 26 How deteriorating phases end by setting

How deteriorating phases end	Hospital / hospice		Community	
	N	%	N	%
Patient moved into another phase	8,371	74.3	10,567	68.2
Discharge / case closure	1,907	16.9	4,022	26.0
Died	972	8.6	846	5.5
Not stated / inadequately described	14	0.1	55	0.4
Total	11,264	100.0	15,490	100.0

Figure 12 Deteriorating phase progression

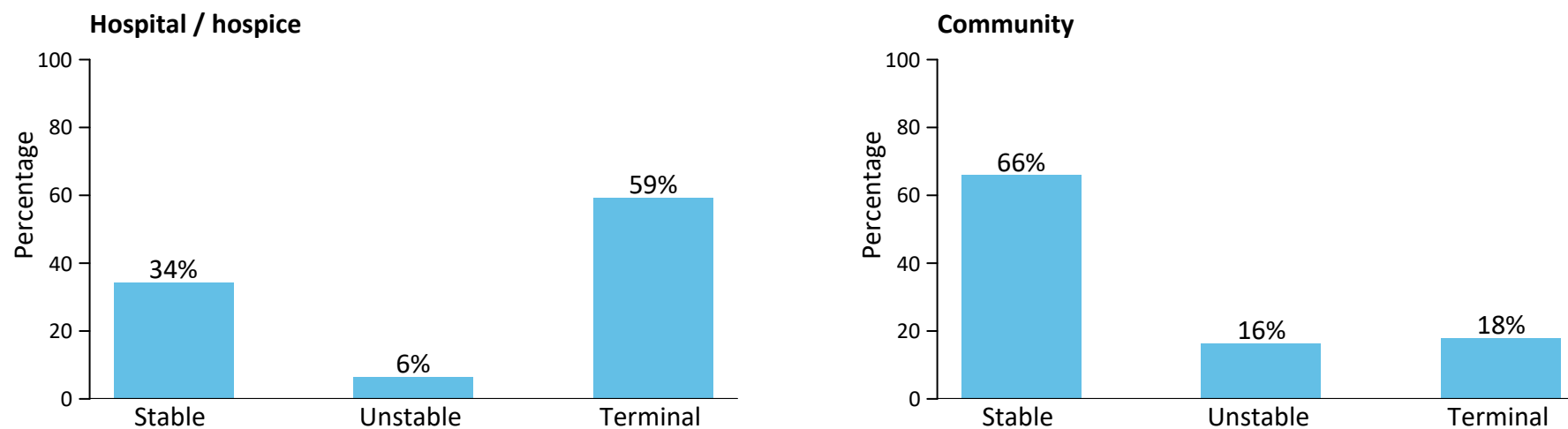
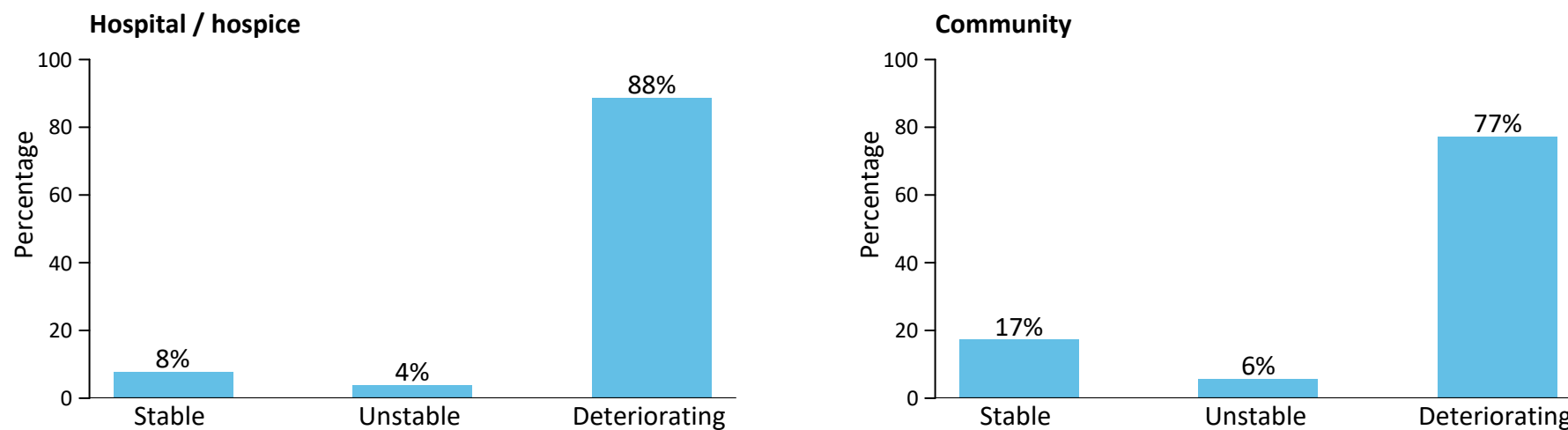


Table 27 How terminal phases end by setting

How terminal phases end	Hospital / hospice		Community	
	N	%	N	%
Patient moved into another phase	312	4.3	407	14.3
Discharge / case closure	170	2.4	339	11.9
Died	6,734	93.3	2,084	73.0
Not stated / inadequately described	1	0.0	25	0.9
Total	7,217	100.0	2,855	100.0

Figure 13 Terminal phase progression



6 Symptoms and problems

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 shows the percentage scores for the hospital / hospice and community settings.

Table 28 PCPSS at beginning of phase by phase type – hospital / hospice setting

Phase type	Problem	Hospital / hospice (%)				Community (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	47.6	43.0	8.1	1.3	47.7	47.7	4.4	0.3
	Other symptoms	37.9	51.3	9.7	1.1	25.7	65.7	8.1	0.5
	Psychological / spiritual	51.1	43.1	5.3	0.6	41.2	53.8	4.8	0.2
	Family / carer	53.0	40.3	5.9	0.8	39.1	53.9	6.7	0.3
Unstable	Pain	29.5	35.9	26.3	8.4	20.7	28.1	36.4	14.8
	Other symptoms	20.5	41.9	29.6	8.1	9.0	30.0	45.9	15.1
	Psychological / spiritual	35.8	44.7	16.2	3.3	21.1	46.6	26.3	5.9
	Family / carer	36.9	43.9	15.8	3.4	18.1	39.2	35.5	7.2
Deteriorating	Pain	37.2	42.8	17.2	2.9	32.8	47.8	18.2	1.2
	Other symptoms	24.2	48.1	23.6	4.1	12.0	56.1	30.2	1.7
	Psychological / spiritual	39.9	46.5	12.2	1.4	25.5	58.1	15.7	0.7
	Family / carer	37.8	45.7	14.0	2.6	21.7	56.6	20.2	1.5
Terminal	Pain	45.9	39.3	12.3	2.6	42.8	41.3	13.7	2.2
	Other symptoms	40.1	40.1	15.9	3.9	32.6	43.1	21.0	3.3
	Psychological / spiritual	61.0	31.6	6.2	1.3	52.1	36.1	10.6	1.2
	Family / carer	32.0	46.0	17.8	4.2	16.7	50.0	30.0	3.3

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 29 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 Figure 14 and Figure 15.

Table 29 Symptom distress at the beginning of a phase by phase type

Phase type	Symptom	Hospital / hospice (%)				Community (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Difficulty sleeping	79.1	14.6	5.5	0.8	73.5	21.0	5.0	0.5
	Appetite problems	73.7	18.9	6.5	0.9	63.1	30.5	5.9	0.6
	Nausea	84.6	11.3	3.5	0.6	84.0	13.8	2.0	0.1
	Bowel problems	72.5	20.1	6.4	1.1	73.1	22.1	4.4	0.4
	Breathing problems	70.7	19.4	8.4	1.5	59.9	31.3	8.0	0.8
	Fatigue	44.6	35.2	18.1	2.1	27.4	47.5	23.3	1.9
	Pain	49.2	35.7	13.5	1.7	47.4	44.2	7.7	0.7
Unstable	Difficulty sleeping	64.4	20.1	12.4	3.2	52.0	24.5	19.4	4.1
	Appetite problems	56.9	24.4	15.2	3.6	47.4	29.9	19.2	3.5
	Nausea	70.5	16.3	10.0	3.2	62.6	16.7	16.2	4.5
	Bowel problems	59.7	22.5	13.9	3.9	58.0	23.6	14.6	3.8
	Breathing problems	58.0	21.5	14.9	5.6	48.7	26.0	19.2	6.0
	Fatigue	32.1	30.8	29.7	7.3	20.0	29.4	41.2	9.4
	Pain	30.5	29.9	28.9	10.7	20.5	27.7	36.0	15.8
Deteriorating	Difficulty sleeping	75.4	15.2	8.0	1.4	66.0	24.9	8.1	1.0
	Appetite problems	66.4	21.8	10.2	1.7	52.6	35.3	11.0	1.2
	Nausea	78.9	13.8	6.0	1.3	76.4	17.8	5.2	0.6
	Bowel problems	68.0	20.7	9.5	1.8	65.6	25.3	8.1	0.9
	Breathing problems	61.7	21.4	13.7	3.3	53.2	31.3	14.2	1.3
	Fatigue	38.8	29.4	26.4	5.4	21.0	39.9	35.5	3.6
	Pain	39.3	36.0	21.3	3.4	34.0	44.4	19.5	2.2
Terminal	Difficulty sleeping	92.2	5.4	2.0	0.4	81.6	11.4	6.1	1.0
	Appetite problems	92.4	5.6	1.4	0.6	88.1	7.0	3.9	1.0
	Nausea	93.4	4.4	1.9	0.3	87.8	8.4	3.3	0.4
	Bowel problems	89.2	7.3	2.9	0.6	81.3	13.8	4.4	0.5
	Breathing problems	71.7	16.8	8.7	2.8	67.5	20.0	10.4	2.0
	Fatigue	78.1	11.2	8.3	2.4	73.3	12.5	10.2	4.0
	Pain	55.3	29.9	12.9	1.8	46.8	33.1	18.4	1.8

Figure 14 Profile of symptoms and problems by phase type – hospital / hospice setting

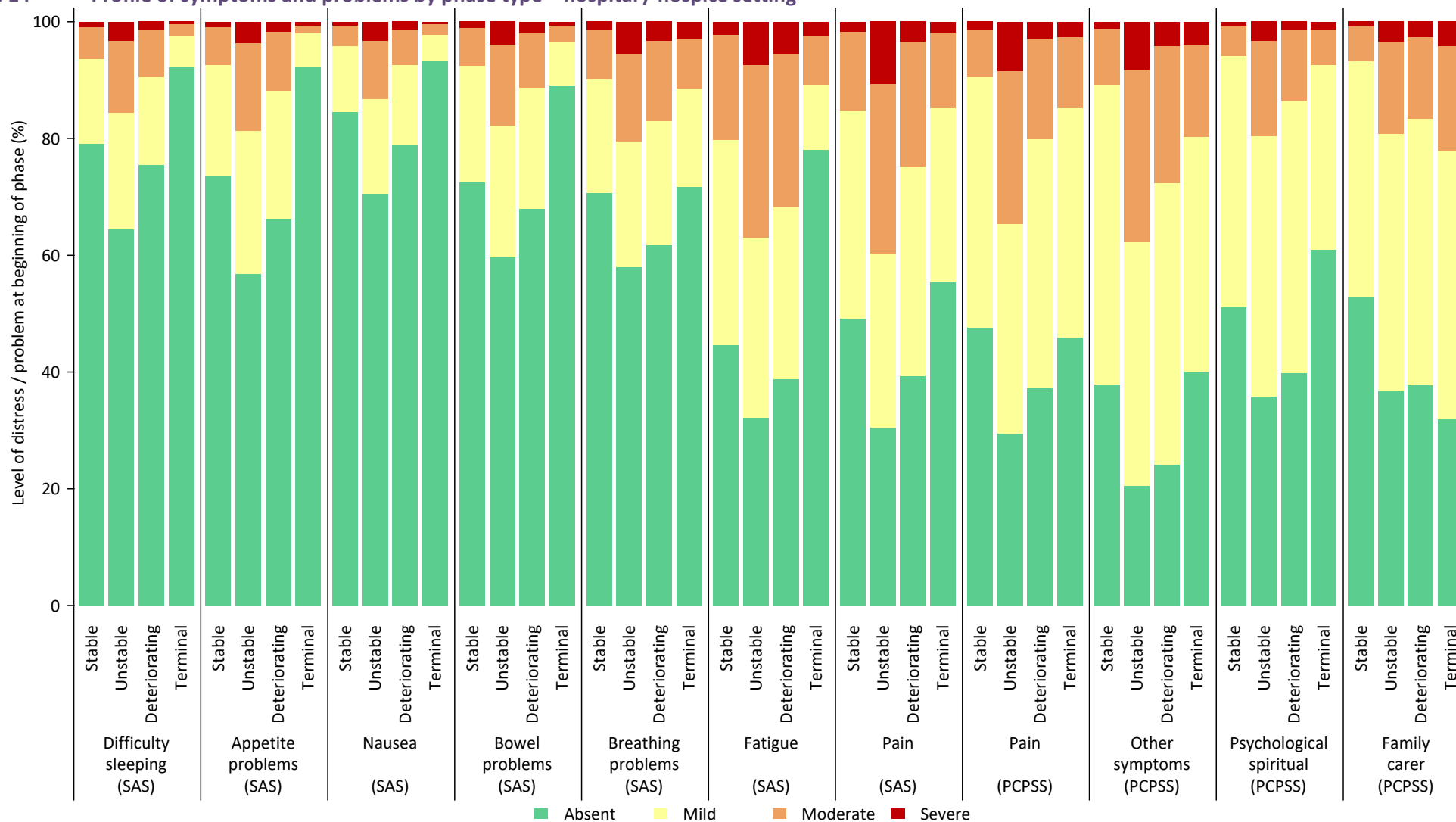
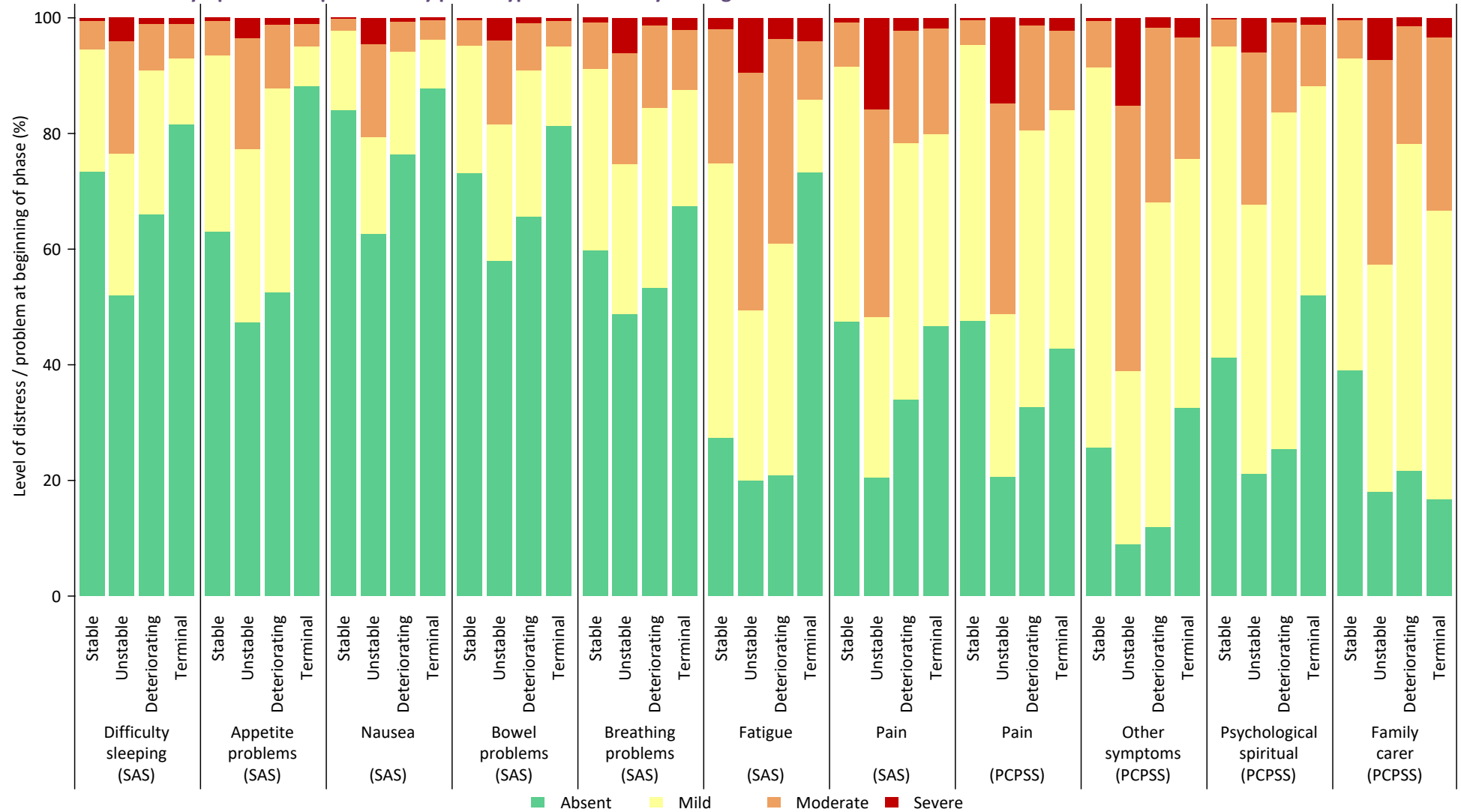


Figure 15 Profile of symptoms and problems by phase type – community setting



7 Functional status and level of dependence

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 30 shows the data for the AKPS at phase start.

Table 30 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting

AKPS assessment at phase start	Hospital / hospice		Community	
	N	%	N	%
Comatose or barely rousable (10)	3,463	10.3	1,089	3.0
Totally bedfast and requiring extensive nursing care (20)	8,221	24.4	3,725	10.2
Almost completely bedfast (30)	5,172	15.4	3,073	8.4
In bed more than 50% of the time (40)	6,839	20.3	5,503	15.1
Requires considerable assistance (50)	5,089	15.1	8,416	23.1
Requires occasional assistance (60)	3,192	9.5	8,039	22.0
Cares for self (70)	690	2.1	3,939	10.8
Normal activity with effort (80)	220	0.7	768	2.1
Able to carry on normal activity; minor signs or symptoms (90)	55	0.2	137	0.4
Normal; no complaints; no evidence of disease (100)	7	0.0	5	0.0
Not stated/inadequately described	693	2.1	1,800	4.9
Total	33,641	100.0	36,494	100.0

Figure 16 Distribution of AKPS at episode start

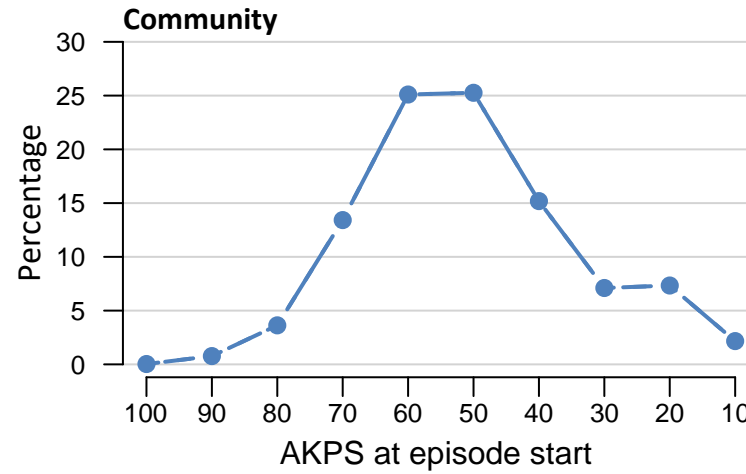
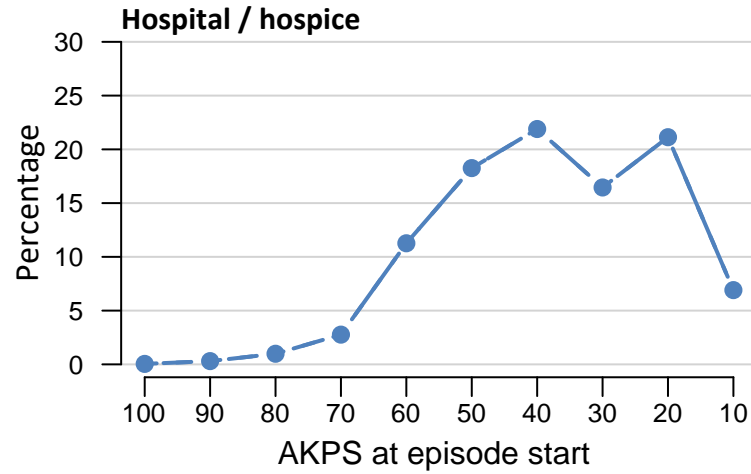
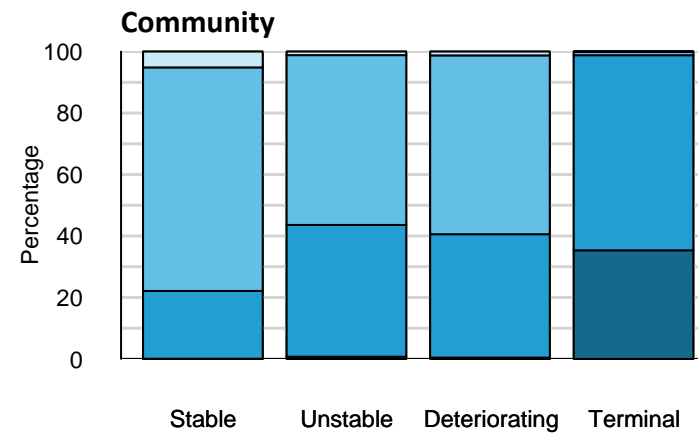
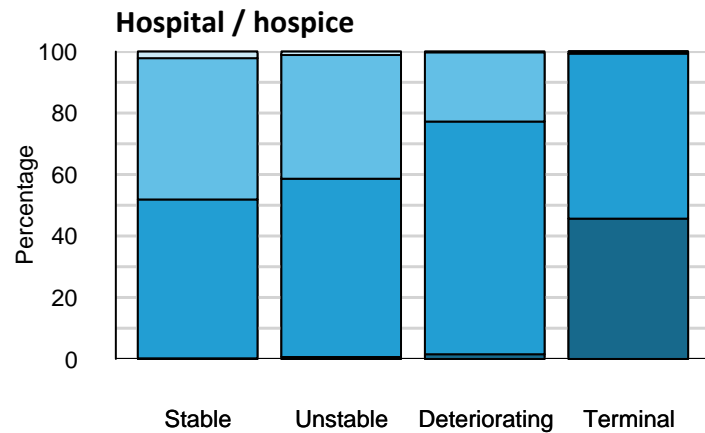
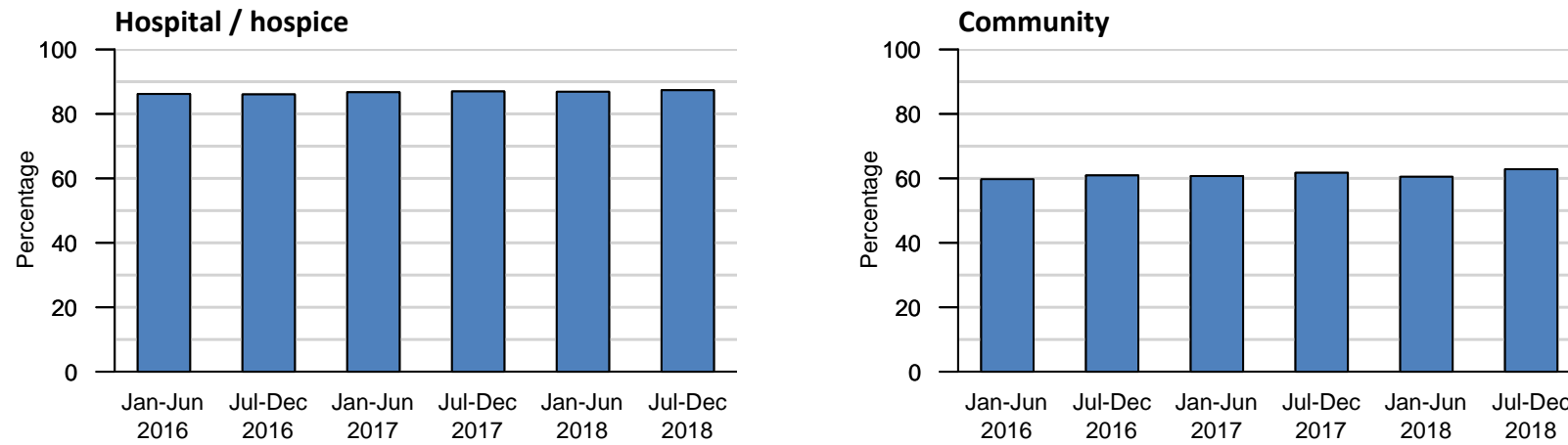


Figure 17 Distribution of AKPS at phase start by phase type



■ 10 ■ 20-40 ■ 50-70 ■ 80-100

Figure 18 Percentage of phases beginning with an AKPS of 50 or less overtime



The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) tool consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL items are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. **Error! Reference source not found.** summaries the RUG-ADL items at the beginning of each phase for hospital / hospice and community patients.

Table 31 The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) at phase start by setting

Item	RUG-ADL assessment at phase start	Hospital / hospice		Community	
		N	%	N	%
Bed mobility	Independent or supervision only (1)	9,380	28.0	20,941	61.7
	Limited physical assistance (3)	5,920	17.6	4,498	13.3
	Other than two person physical assist (4)	3,848	11.5	2,670	7.9
	Two or more person physical assist (5)	14,396	42.9	5,814	17.1
Toileting	Independent or supervision only (1)	6,162	18.4	17,630	52.0
	Limited physical assistance (3)	6,955	20.7	6,587	19.4
	Other than two person physical assist (4)	4,983	14.9	3,509	10.3
	Two or more person physical assist (5)	15,438	46.0	6,182	18.2
Transfers	Independent or supervision only (1)	6,169	18.4	17,494	51.7
	Limited physical assistance (3)	6,762	20.2	6,690	19.8
	Other than two person physical assist (4)	4,642	13.8	3,383	10.0
	Two or more person physical assist (5)	15,960	47.6	6,300	18.6
Eating	Independent or supervision only (1)	13,669	40.9	22,709	67.5
	Limited physical assistance (2)	7,325	21.9	5,397	16.0
	Extensive assistance/total dependence/tube fed (3)	12,444	37.2	5,547	16.5

Figure 19 Distribution of Total RUG-ADL at episode start

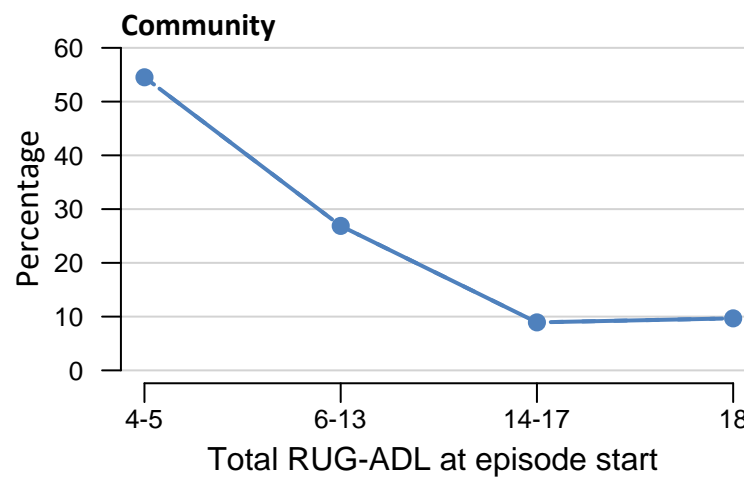
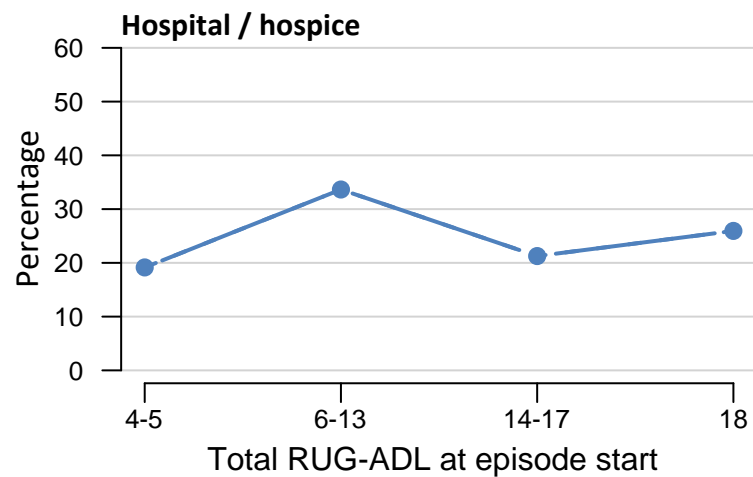
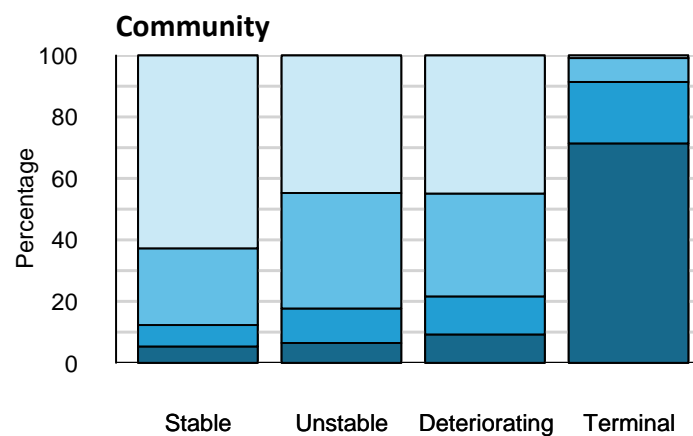
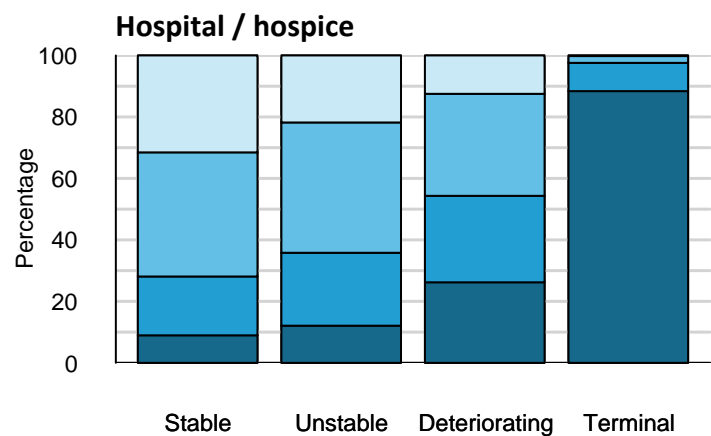
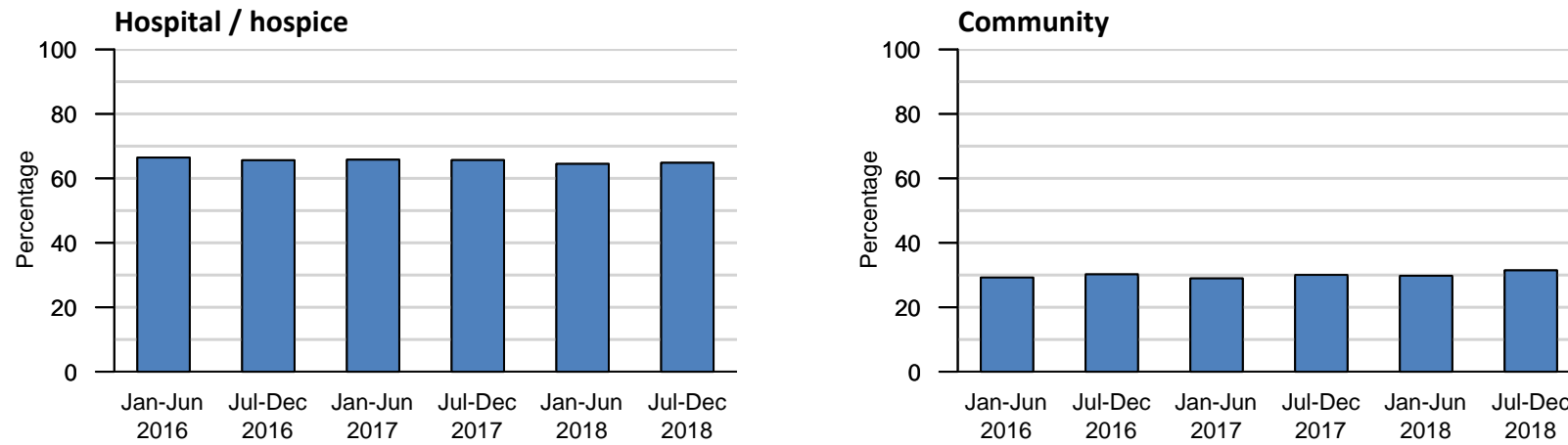


Figure 20 Distribution of Total RUG-ADL at phase start by phase type



■ 18 ■ 14-17 ■ 6-13 ■ 4-5

Figure 21 Percentage of phases beginning with a Total RUG-ADL of 10 or more overtime



Appendices

A Summary of data included in this report

During the reporting period, data were provided for a total of 23,333 patients who between them had 29,931 episodes of care and 70,135 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 32 shows the number of patients, episodes and phases included in this report.

Table 32 Summary of patients, episodes and phases by setting

	Hospital / hospice	Community	Total
Patients (N)	12,437	12,097	23,333
Episodes (N)	14,679	15,252	29,931
Phases (N)	33,641	36,494	70,135
Patients (%)	53.3	51.8	100
Episodes (%)	49.0	51.0	100
Phases (%)	48.0	52.0	100
Average number of phases per episode***	2.3	2.3	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 33 shows the number of completed episodes and phases by setting for each month in the current reporting period.

Table 33 Number of completed episodes and phases by month and setting

Setting		Jul	Aug	Sep	Oct	Nov	Dec
Hospital / hospice	Completed episodes (N)	2,478	2,582	2,279	2,448	2,308	2,398
	Completed phases (N)	5,909	5,970	5,447	5,743	5,427	5,125
Community	Completed episodes (N)	2,310	2,351	2,080	2,233	2,106	2,185
	Completed phases (N)	6,391	6,372	5,693	6,086	5,966	5,986

Table 34 shows the number of patients, episodes and phases over time and is reported by setting of care.

Table 34 Number of patients, episodes and phases by setting and reporting period

	Hospital / hospice						Community					
	Jan-Jun 2016	Jul-Dec 2016	Jan-Jun 2017	Jul-Dec 2017	Jan-Jun 2018	Jul-Dec 2018	Jan-Jun 2016	Jul-Dec 2016	Jan-Jun 2017	Jul-Dec 2017	Jan-Jun 2018	Jul-Dec 2018
Patients¹	10,784	12,173	11,885	12,360	12,091	12,437	9,219	8,733	10,038	10,504	11,562	12,097
Episodes	12,722	14,221	14,008	14,549	14,403	14,679	11,974	11,099	12,790	13,317	14,687	15,252
Phases²	30,255	33,798	33,044	33,577	33,023	33,641	26,721	26,238	30,285	31,209	35,241	36,494
Phases per episode³	2.4	2.4	2.4	2.3	2.3	2.3	2.1	2.2	2.2	2.2	2.3	2.3

¹ Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.

² Bereavement phases are excluded from this count.

³ Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

B Data item completion

As shown in Table 35, Table 36 and Table 37 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 35 Item completion (%) - patient level

Data item	% completion
Date of birth	100.0
Sex	100.0
Indigenous status	96.5
Country of birth	96.9
Preferred language	98.6
Diagnosis	99.3

Table 36 Item completion (%) - episode level, by setting

Data item	Hospital / hospice	Community	Total
Date of first contact	99.5	99.9	99.7
Referral date	99.7	99.9	99.8
Referral source	99.1	99.6	99.3
Date ready for care	97.8	96.2	97.0
Mode of episode start	99.5	99.4	99.4
Accommodation at episode start	99.5	97.9	98.5
Episode end date ¹	99.6	90.6	95.0
Mode of episode end	99.8	99.7	99.8
Accommodation at episode end	98.6	98.2	98.5
Place of death	-	98.8	98.8

¹ Episode end date item completion may be affected by open episodes.

Table 37 Item completion (%) - phase level, by setting

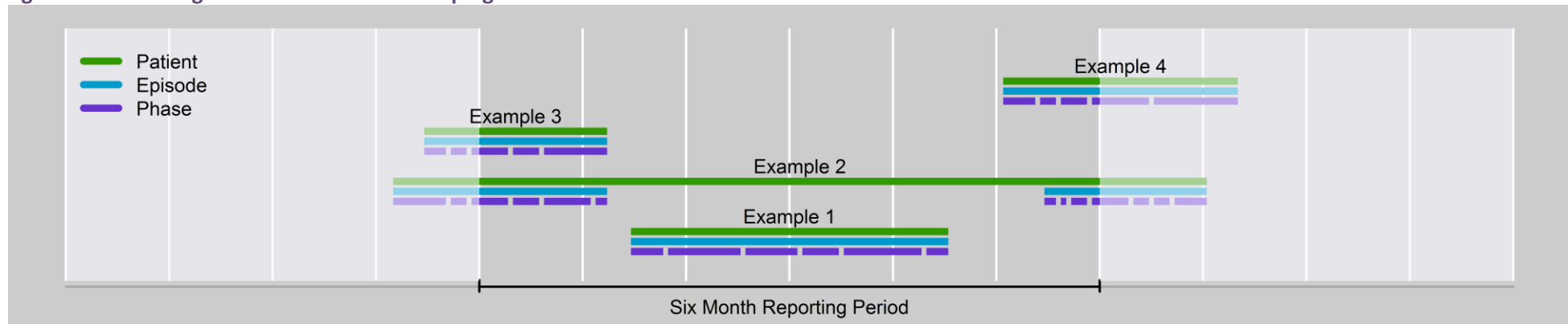
Data item	Sub-Category (where applicable)	At phase start			At discharge		
		Hospital / hospice	Community	Total	Hospital / hospice	Community	Total
RUG-ADL	Bed mobility	99.7	93.0	96.2	81.5	50.4	62.8
	Toileting	99.7	92.9	96.2	81.6	50.3	62.8
	Transfers	99.7	92.8	96.1	81.6	50.3	62.8
	Eating	99.4	92.2	95.7	81.5	49.7	62.4
PCPSS	Pain	99.2	94.2	96.6	81.1	50.6	62.8
	Other symptom	97.2	92.0	94.5	80.0	49.7	61.8
	Psychological / spiritual	99.1	93.4	96.1	81.1	50.1	62.5
	Family / carer	96.5	89.6	92.9	77.8	47.2	59.4
SAS	Difficulty sleeping	90.3	90.4	90.3	71.9	48.0	57.5
	Appetite problems	90.3	91.3	90.8	71.8	48.7	57.9
	Nausea	90.3	92.5	91.5	71.5	49.7	58.4
	Bowel problems	90.2	91.6	90.9	71.9	48.7	57.9
	Breathing problems	90.4	92.0	91.2	71.9	49.5	58.5
	Fatigue	90.3	92.9	91.7	72.3	50.0	58.9
	Pain	90.5	95.4	93.0	72.4	51.9	60.1
AKPS	-	97.9	95.1	96.4	80.2	52.5	63.6

Data item	Hospital / hospice	Community	Total
Phase End Reason	99.8	99.5	99.6

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 22 below displays four examples to help visualize this process.

Figure 22 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.

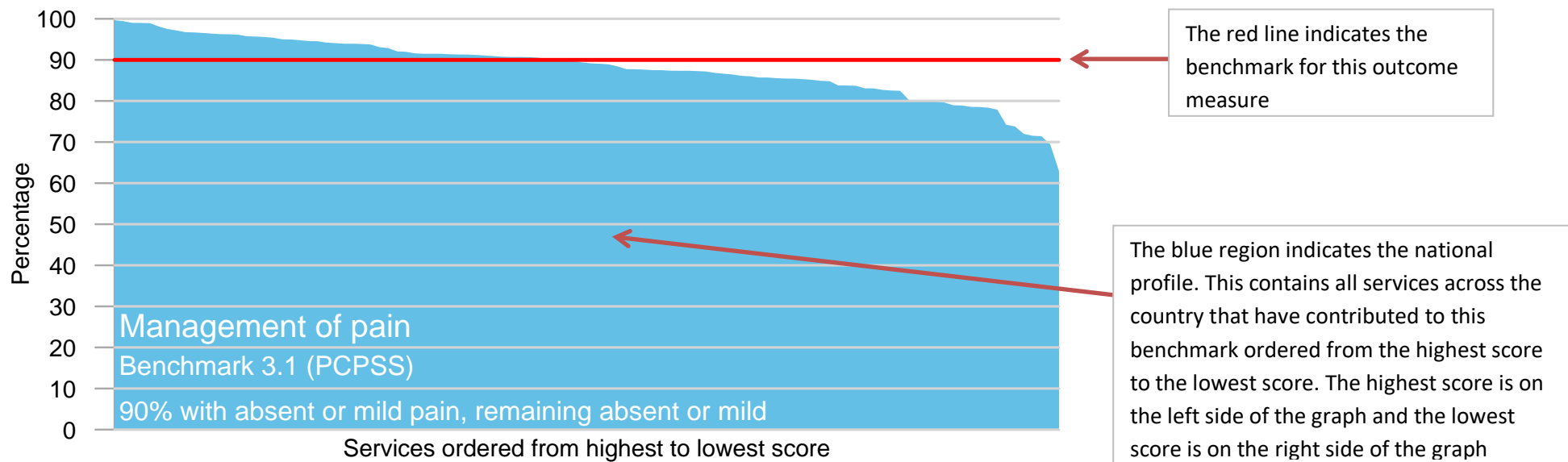
In Example 2, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in 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.

D Interpreting benchmark profile graphs

The national profile graphs present the comparison of all palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure.



E Palliative Care Phase definitions

Phase type	Start	End
Stable	<ul style="list-style-type: none"> ▪ 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. 	<ul style="list-style-type: none"> ▪ The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care.
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 / or ▪ 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).



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, Burns S, Allingham S, Foskett L and Clapham S (2019) <i>Patient Outcomes in Palliative Care in Australia: National report for July – December 2018</i> . Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong