PCOC

palliative care
outcomes collaboration

Victoria

Patient Outcomes in Palliative Care

July – December 2015

March 2016

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

www.pcoc.org.au

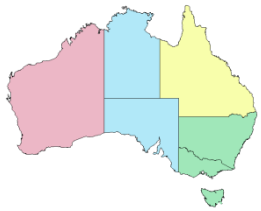
About the Palliative Care Outcomes Collaboration

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.

PCOC palliative care outcomes collaboration

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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.

Throughout this report, patient information for Victorian services is presented alongside the national figures for comparative purposes. 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.

The Victorian figures in this report are based on information submitted by 21 services. A list of these services is presented in Table 1 on the following page.
A full list of the services included in the national figures can be found at www.pcoc.org.au.

Interpretation hint:

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

Please use the following key when interpreting the tables:

na **The item is not applicable.**
u **The item was unavailable.**
s **The item was suppressed due to insufficient data as there was less than 10 observations.**

Table 1 List of Victorian services included in this report

Service name	Setting of care
Albury Wodonga Health, Palliative Care Consultancy Service	Community
Ballarat Hospice Care Victoria	Community
Banksia Palliative Care Service	Community
Cabrini Palliative Care, Prahran	Inpatient and community
Eastern Health Wantirna	Inpatient
Eastern Palliative Care	Community
Gandarra Palliative Care Unit - Ballarat	Inpatient
Goulburn Valley Hospice Inc.	Community
McCulloch House Supportive and Palliative Care Monash Health	Inpatient
Melbourne Citymission Palliative Care	Community
Mercy Palliative Care - Sunshine	Community
Northern Health Broadmeadows - McKenna House Palliative Care	Inpatient
Northern Health Palliative Care Consult Team	Inpatient
Peninsula Home Hospice	Community
Royal Melbourne Hospital Consult	Inpatient
Royal Melbourne Hospital Palliative Care Unit	Inpatient
South East Palliative Care	Community
St Vincent's Caritas Christi Hospice – Inpatient Unit, Kew	Inpatient
St Vincent's Hospital, Melbourne- Inpatient Unit, Fitzroy	Inpatient
Sunshine Hospital Palliative Care Unit	Inpatient
Werribee Mercy Hospital	Inpatient

Section 1 Benchmark summary

1.1 Victorian Services at a glance

Table 2 Summary of outcome measures by setting

Outcome measure	Description	Benchmark	Inpatient		Community	
			VIC Score	Benchmark Met?	VIC 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%	98.2	Yes	76.3	No
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	91.0	Yes	69.3	No
3. Change in pain	Benchmark 3.1: PCPSS Patients with absent or mild pain at phase start, remaining absent or mild at phase end	90%	91.3	Yes	84.8	No
	Benchmark 3.2: PCPSS Patients with moderate or severe pain at phase start, with absent or mild pain at phase end	60%	59.7	No	44.4	No
	Benchmark 3.3: SAS Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end	90%	89.7	No	81.0	No
	Benchmark 3.4: SAS Patients with moderate or severe distress from pain at phase start, with absent or mild at phase end	60%	55.5	No	46.3	No
4. Average improvement on the 2014 baseline national average (X-CAS)	Benchmark 4.1: Pain (PCPSS)	0.0	0.12	Yes	-0.14	No
	Benchmark 4.2: Other symptoms (PCPSS)	0.0	0.19	Yes	-0.15	No
	Benchmark 4.3: Family / carer (PCPSS)	0.0	0.21	Yes	-0.15	No
	Benchmark 4.4: Psychological / spiritual (PCPSS)	0.0	0.16	Yes	-0.09	No
	Benchmark 4.5: Pain (SAS)	0.0	0.33	Yes	-0.42	No
	Benchmark 4.6: Nausea (SAS)	0.0	0.22	Yes	-0.23	No
	Benchmark 4.7: Breathing problems (SAS)	0.0	0.26	Yes	-0.14	No
	Benchmark 4.8: Bowel problems (SAS)	0.0	0.31	Yes	-0.06	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:

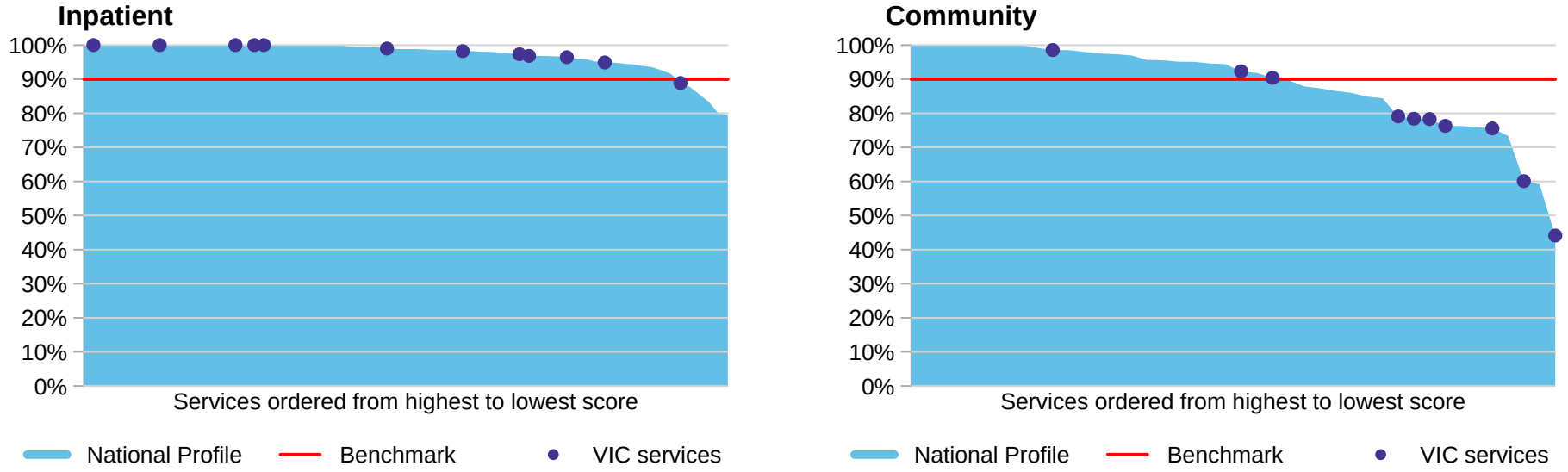
The national profile graphs on the following pages present Victorian services in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. Victorian services are highlighted as dots on the graph.

If no dot is present on a particular graph, this means that a service has not met the criteria for inclusion in this measure. This may be caused by insufficient data item completion, or a service having less than ten observations falling into a particular category, for example, fewer than 10 phases starting with moderate or severe SAS pain.

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

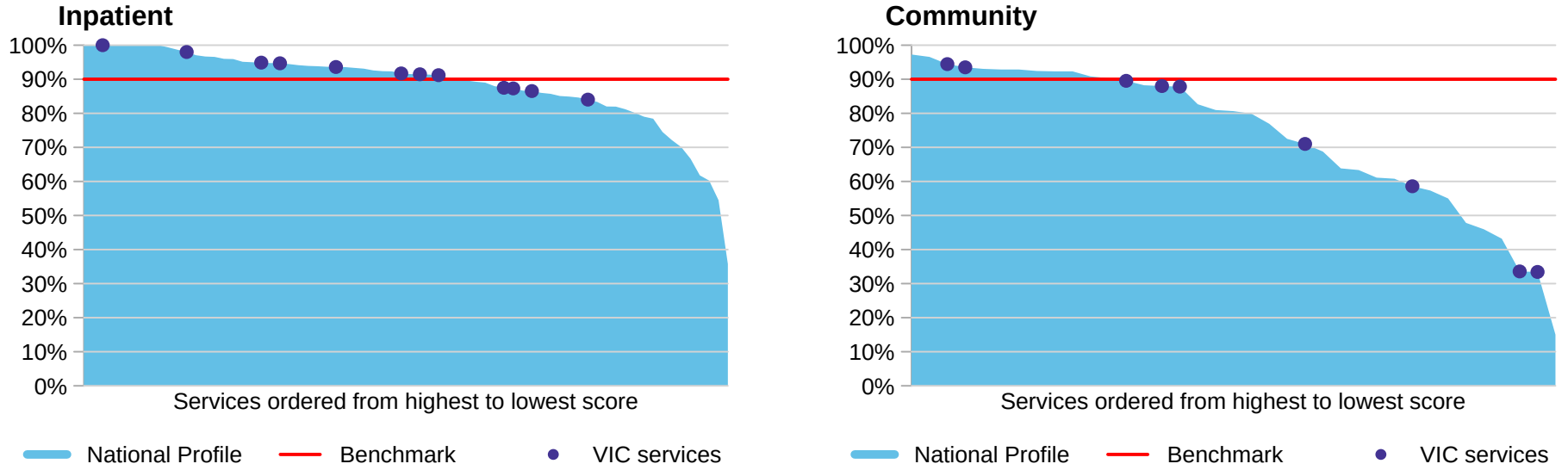
Outcome measure 1 – Time from date ready for care to episode start

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



Outcome measure 2 – Time in unstable phase

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



Outcome measure 3 – Change in pain

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

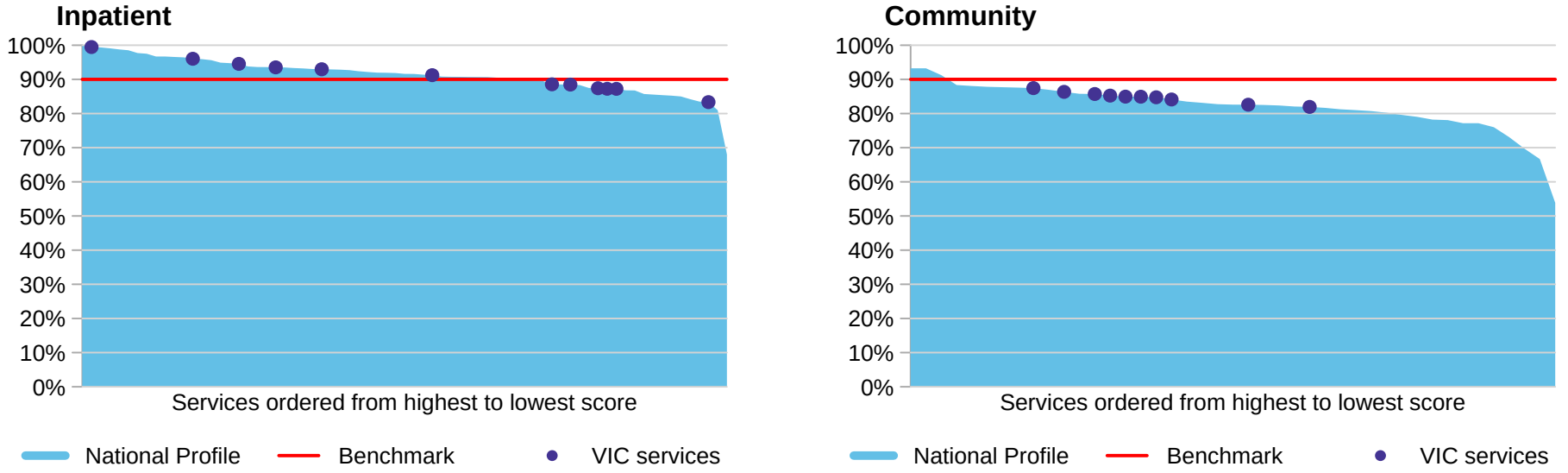


Figure 4 PCPSS: Percentage of patients with moderate or severe pain at phase start, with absent or mild pain at phase end

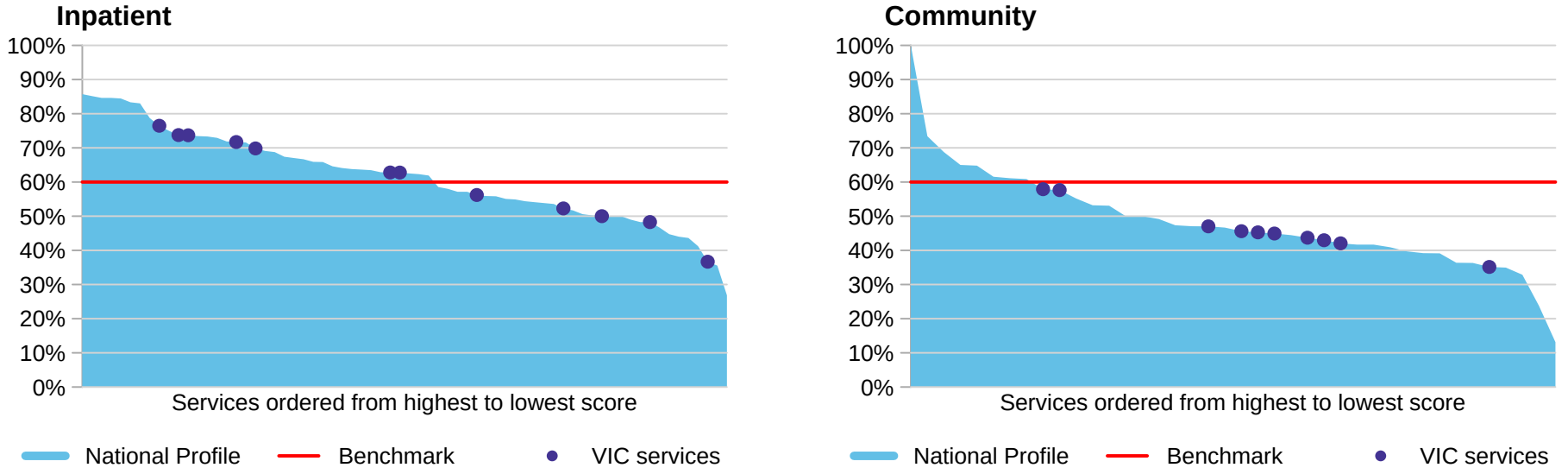


Figure 5 SAS: Percentage of patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end

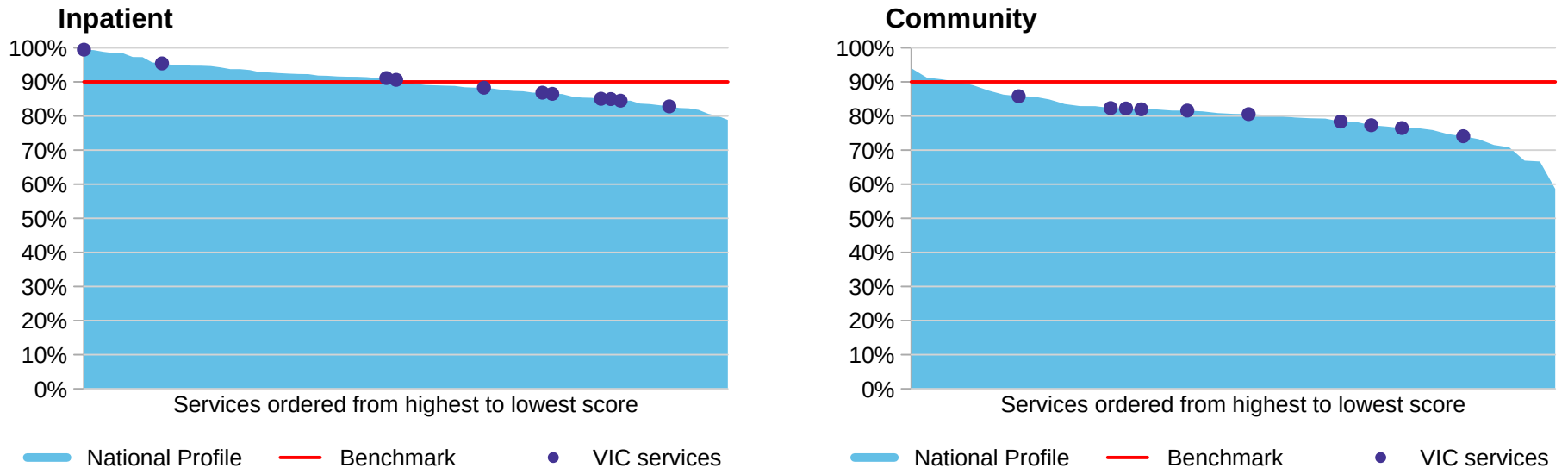
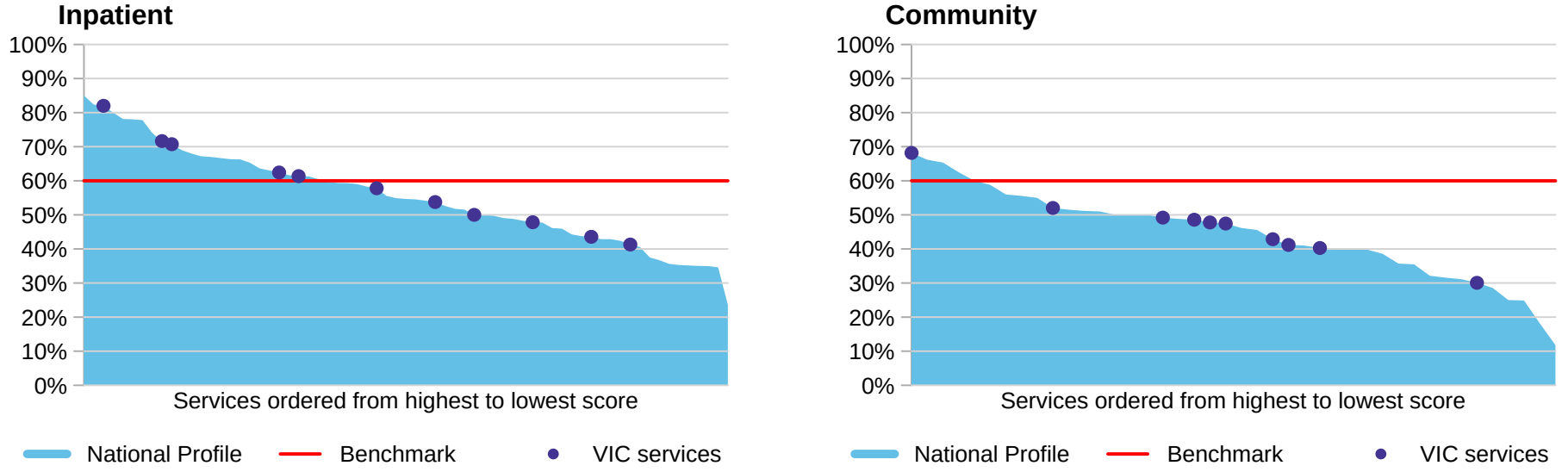


Figure 6 SAS: Percentage of patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end



Section 2 Outcome measures in detail

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

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

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

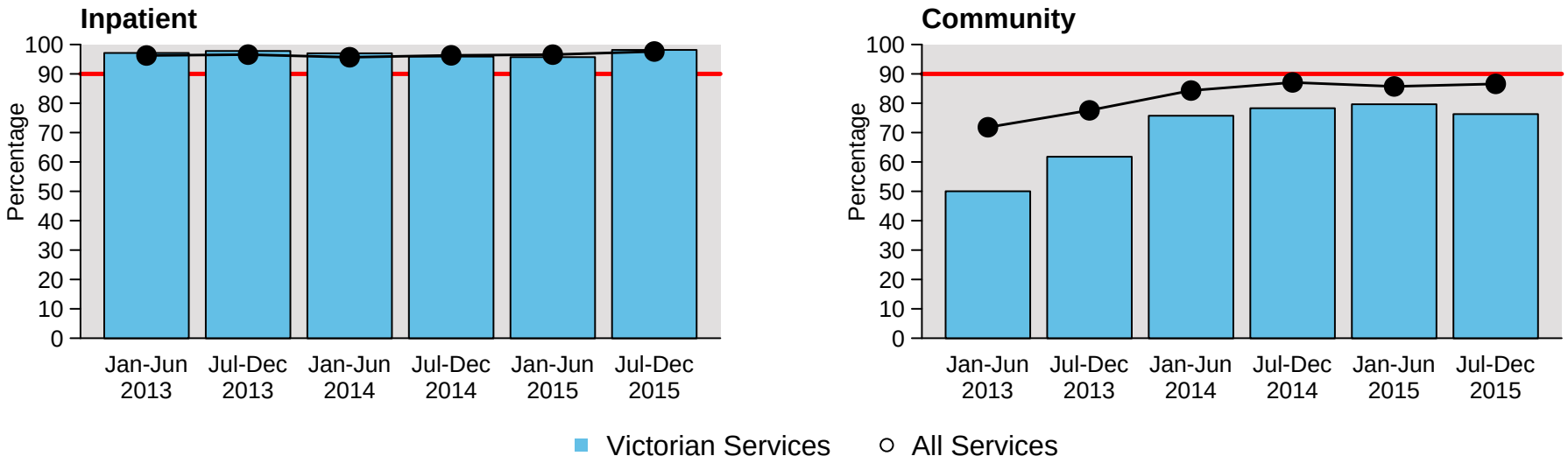
Table 3 Time from date ready for care to episode start by setting

Time (in days)	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Same day	2,736	93.6	11,313	92.8	2,777	68.6	8,656	81.7
Following day	132	4.5	584	4.8	314	7.8	519	4.9
2-7 days	48	1.6	258	2.1	749	18.5	1,064	10.0
8-14 days	4	0.1	24	0.2	138	3.4	223	2.1
Greater than 14 days	2	0.1	9	0.1	73	1.8	135	1.3
Average	1.1	na	1.1	na	2.5	na	1.9	na
Median	1	na	1	na	1	na	1	na

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

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

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



2.2 Outcome measure 2 – Time in unstable phase

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

An unstable phase is triggered if:

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

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

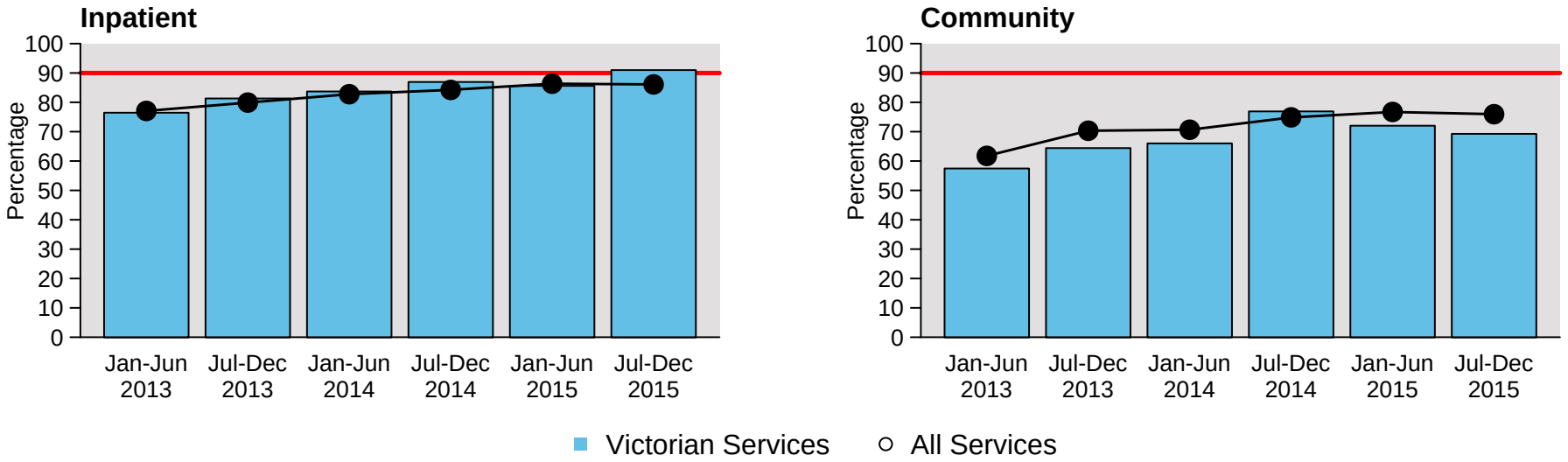
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom / crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the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

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

Table 4 Time in unstable phase by setting

Time in unstable phase	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Same day	121	8.4	279	4.0	362	21.7	899	23.9
1 day	666	46.5	3,292	47.5	488	29.3	1,255	33.3
2 days	353	24.7	1,647	23.8	202	12.1	444	11.8
3 days	163	11.4	750	10.8	102	6.1	261	6.9
4-5 days	97	6.8	572	8.3	121	7.3	237	6.3
6-7 days	15	1.0	192	2.8	103	6.2	211	5.6
8-14 days	14	1.0	148	2.1	130	7.8	213	5.7
Greater than 14 days	3	0.2	52	0.8	158	9.5	244	6.5
Total	*1,432*	*100.0*	*6,932*	*100.0*	*1,666*	*100.0*	*3,764*	*100.0*

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



2.3 Outcome measure 3 – Change in pain

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

Scores for PCPSS
0 absent
1 mild
2 moderate
3 severe

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

Interpretation hint:
This outcome measure should be viewed in conjunction with Table 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 5 Summary of outcome measure 3

Benchmarks: change in pain	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N*	%	N*	%	N*	%	N*	%
Benchmark 3.1: PCPSS (severity)	4,263	91.3	17,454	91.7	4,632	84.8	16,664	85.0
Benchmark 3.2: PCPSS (severity)	908	59.7	5,276	59.2	1,340	44.4	4,172	51.7
Benchmark 3.3: SAS (distress)	3,691	89.7	14,607	89.9	4,812	81.0	15,766	82.0
Benchmark 3.4: SAS (distress)	1,164	55.5	6,460	54.1	1,707	46.3	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

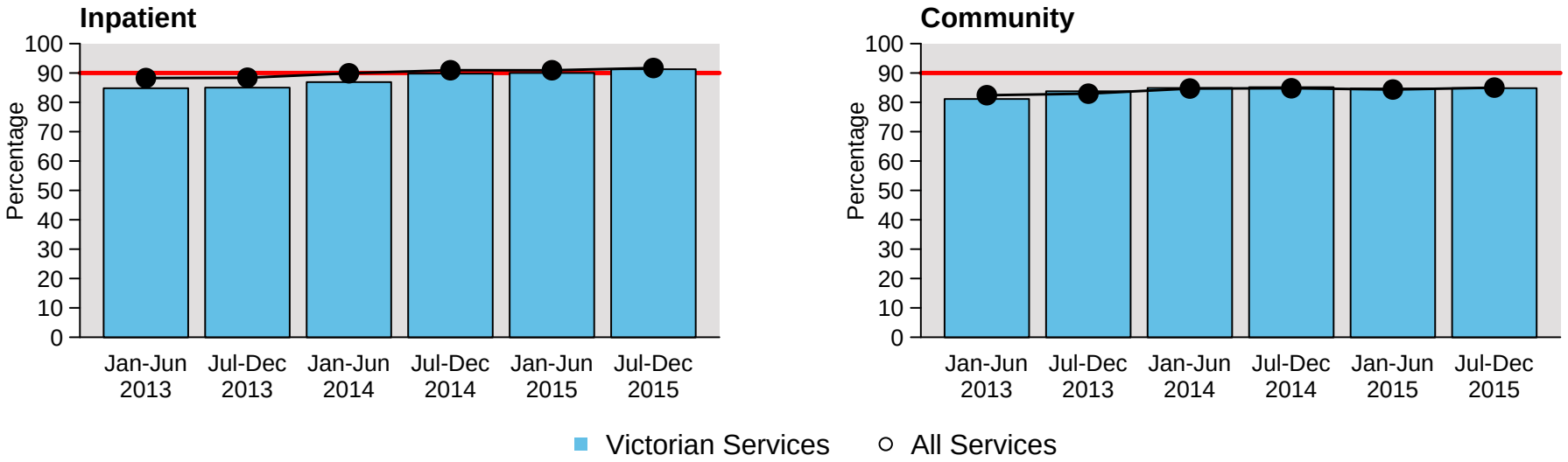


Figure 10 Trends in benchmark 3.2: Patients with moderate or severe pain at phase start, with absent or mild at phase end by setting

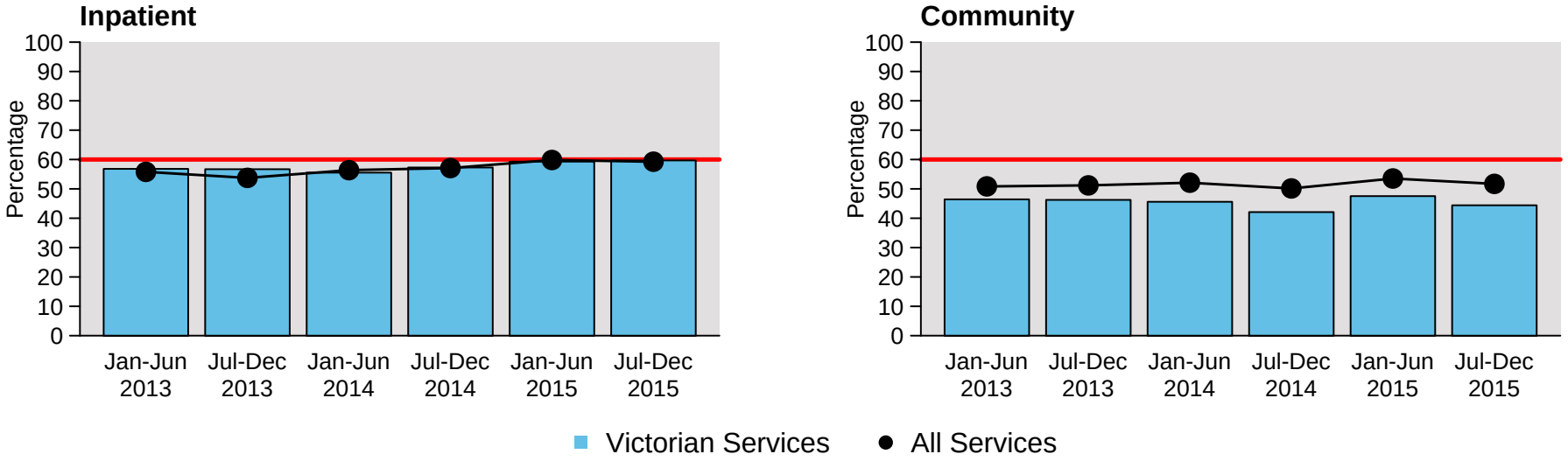


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Figure 11 Trends in benchmark 3.3: Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end by setting

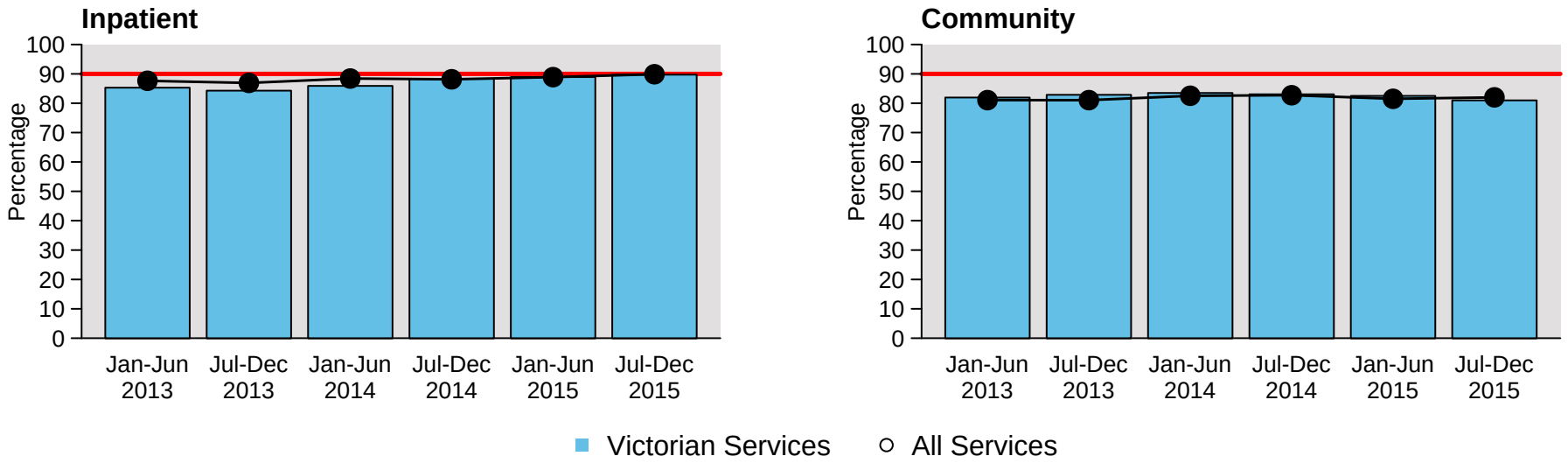
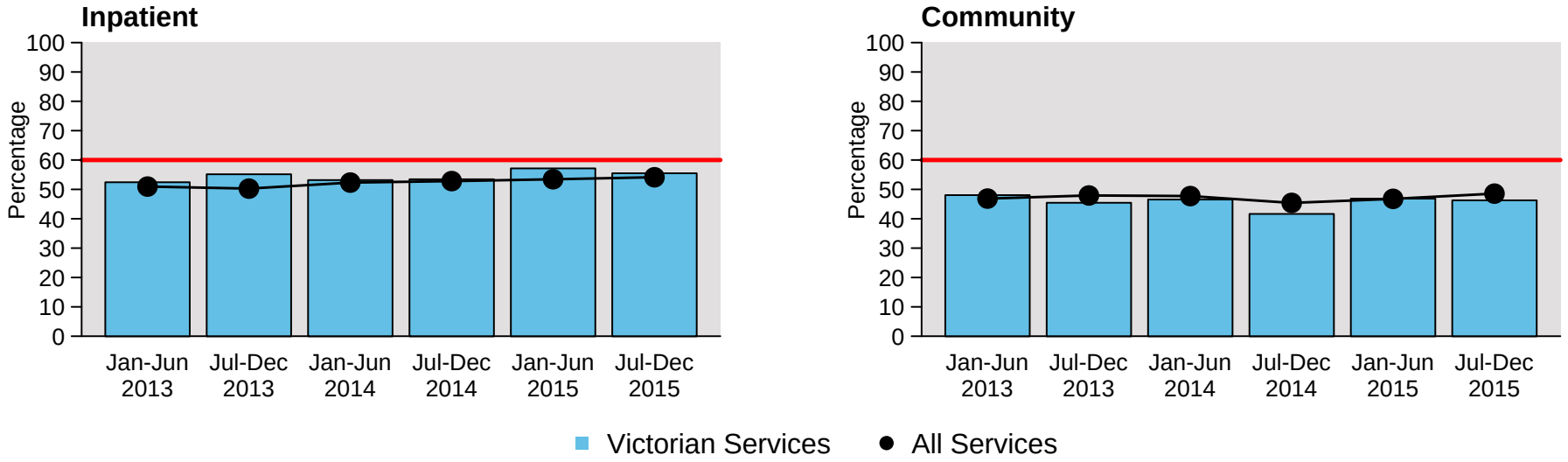


Figure 12 Trends in benchmark 3.4: Patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end by setting



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 6 Summary of outcome measure 4 – inpatient setting

Clinical Tool	Benchmark: Symptom	Victorian Services				All Services			
		X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline
PCPSS (severity)	4.1: Pain	0.12	5,171	3,483	67.4	0.11	22,730	14,587	64.2
	4.2: Other symptoms	0.19	5,164	3,776	73.1	0.21	22,356	16,327	73.0
	4.3: Family / carer	0.21	5,173	3,821	73.9	0.14	22,230	15,037	67.6
	4.4: Psychological / spiritual	0.16	5,175	3,224	62.3	0.16	22,710	13,893	61.2
SAS (distress)	4.5: Pain	0.33	4,855	3,452	71.1	0.33	21,067	14,494	68.8
	4.6: Nausea	0.22	4,854	4,439	91.5	0.19	20,941	18,379	87.8
	4.7: Breathing problems	0.26	4,857	3,936	81.0	0.29	21,007	16,467	78.4
	4.8: Bowel problems	0.31	4,854	3,990	82.2	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, patients' change in symptom was better than similar patients in the baseline reference period.
If X-CAS is equal to 0 then on average, patients' change in symptom was about the same as similar patients in the baseline reference period.
If X-CAS is less than 0 then on average, patients' change in symptom was worse than similar patients in the baseline reference period.

Table 7 Summary of outcome measure 4 – community setting

Clinical Tool	Benchmark: Symptom	Victorian Services				All Services			
		X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline
PCPSS (severity)	4.1: Pain	-0.14	5,972	2,795	46.8	-0.09	20,836	10,840	52.0
	4.2: Other symptoms	-0.15	5,589	3,178	56.9	-0.09	20,268	11,894	58.7
	4.3: Family / carer	-0.15	5,781	3,089	53.4	-0.06	20,202	11,851	58.7
	4.4: Psychological / spiritual	-0.09	5,773	2,359	40.9	-0.05	20,507	9,682	47.2
SAS (distress)	4.5: Pain	-0.42	6,519	3,381	51.9	-0.26	21,073	11,854	56.3
	4.6: Nausea	-0.23	6,013	4,433	73.7	-0.11	20,477	16,131	78.8
	4.7: Breathing problems	-0.14	5,737	3,480	60.7	-0.12	20,211	12,886	63.8
	4.8: Bowel problems	-0.06	5,655	3,732	66.0	-0.04	20,029	14,198	70.9

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

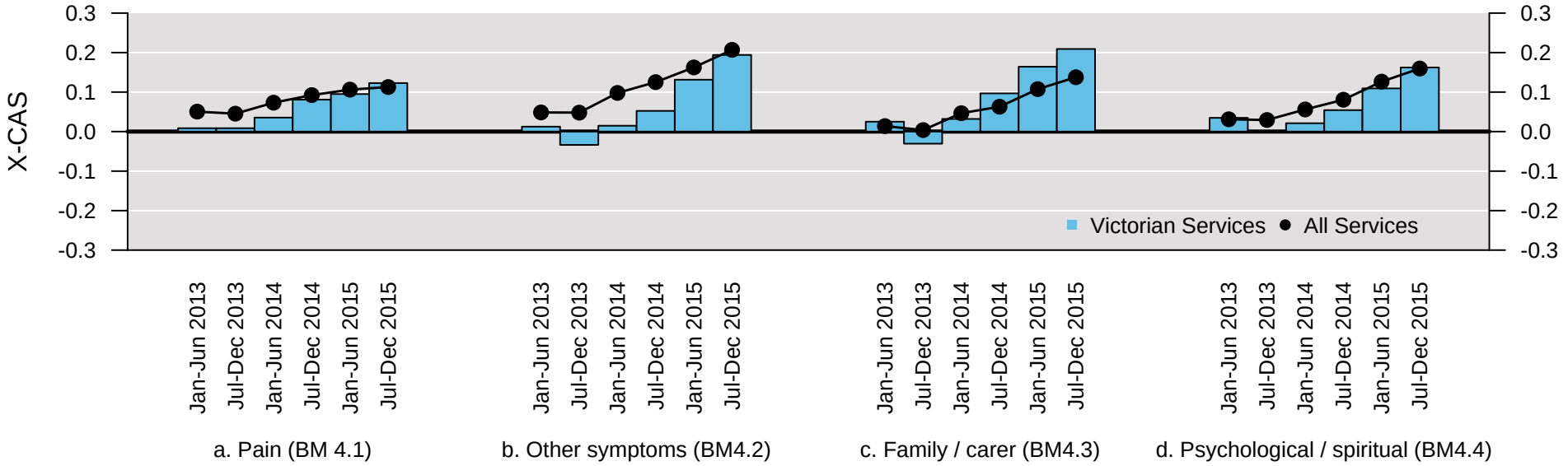


Figure 14 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – community setting

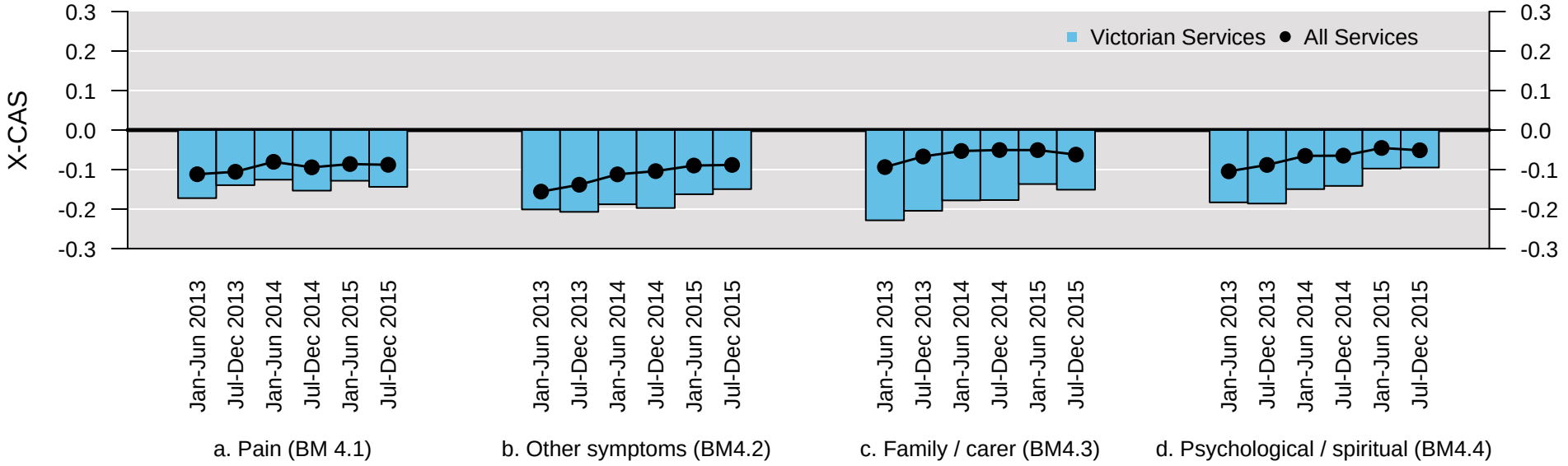


Figure 15 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – inpatient setting

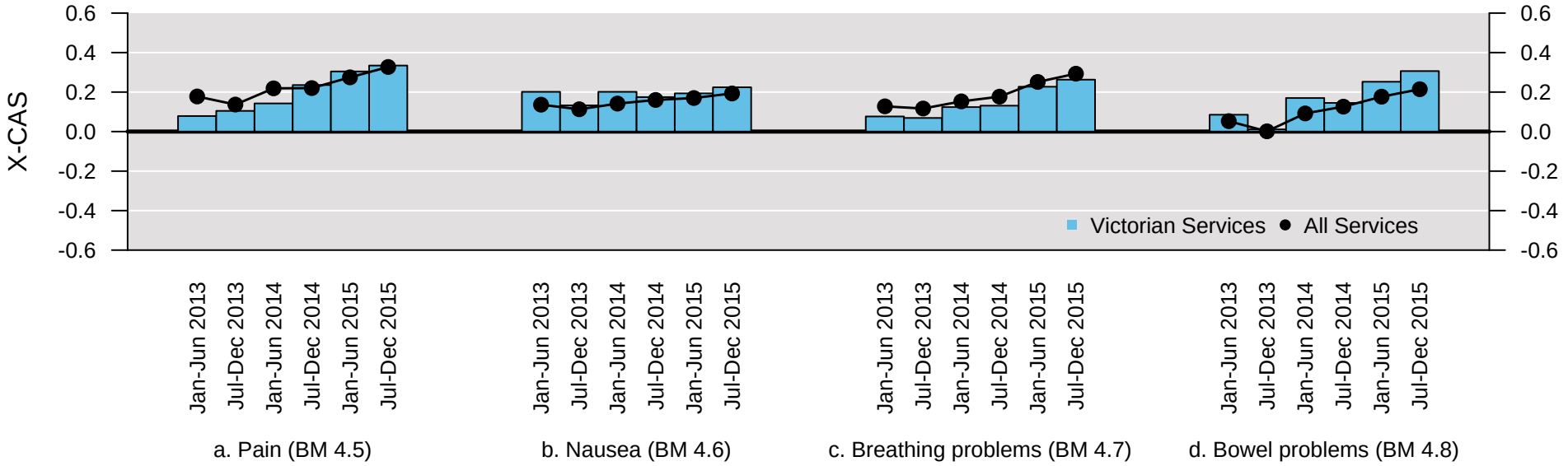
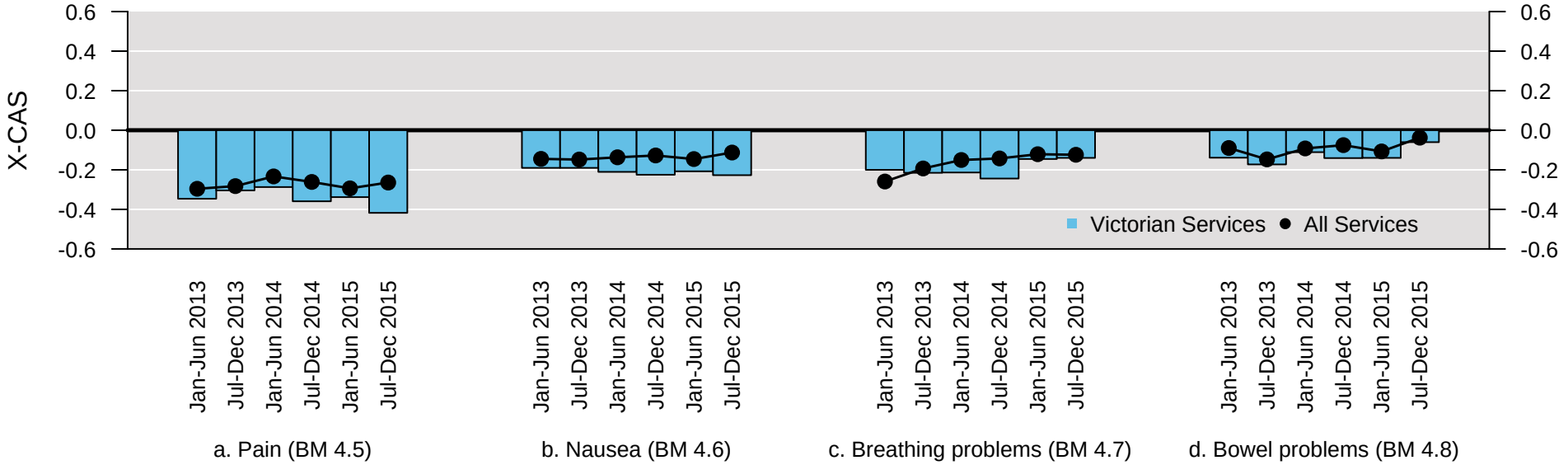


Figure 16 Trends in outcome measure 4: Symptom Assessment Scale (SAS) – community setting



Section 3 Descriptive analysis

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

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

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

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

Summaries of the national data are included for comparative purposes.

3.1 Profile of palliative care patients

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

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

Table 8 Indigenous status

Indigenous status	Victorian Services		All Services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	34	0.6	234	1.2
Torres Strait Islander but not Aboriginal origin	2	0.0	17	0.1
Both Aboriginal and Torres Strait Islander origin	2	0.0	9	0.0
Neither Aboriginal nor Torres Strait Islander origin	5,792	98.3	19,150	96.6
Not stated / inadequately described	65	1.1	419	2.1
Total	*5,895*	*100.0*	*19,829*	*100.0*

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

Table 9 Place of death

Place of death	Victorian Services		All Services	
	N	%	N	%
Private residence	645	25.8	2,200	22.4
Residential aged care facility	273	10.9	694	7.1
Hospital	1,569	62.8	6,882	70.1
Not stated / inadequately described	10	0.4	43	0.4
Total	*2,497*	*100.0*	*9,819*	*100.0*

The following two tables show the country of birth and the preferred language respectively for the patients in Victorian services and nationally. To allow for comparison with the broader Australian community the list of country of birth in Table 10 is in descending order of the most frequent country of birth according to the 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 11 (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 Country of birth

Country of birth	Victorian Services		All Services	
	N	%	N	%
Australia	3,135	53.2	12,434	62.7
England	275	4.7	1,458	7.4
New Zealand	54	0.9	306	1.5
China (excludes SARs and Taiwan)	85	1.4	219	1.1
India	36	0.6	137	0.7
Italy	444	7.5	820	4.1
Vietnam	80	1.4	163	0.8
Philippines	33	0.6	88	0.4
South Africa	21	0.4	109	0.5
Scotland	63	1.1	275	1.4
Malaysia	22	0.4	58	0.3
Germany	64	1.1	245	1.2
Greece	245	4.2	380	1.9
Sri Lanka	38	0.6	58	0.3
United States of America	13	0.2	53	0.3
All other countries	1,206	20.5	2,753	13.9
Not stated / inadequately described	81	1.4	273	1.4
Total	*5,895*	*100.0*	*19,829*	*100.0*

Table 11 Preferred language

Preferred language	Victorian Services		All Services	
	N	%	N	%
English	4,901	83.1	17,797	89.8
Chinese[(a)]	68	1.2	209	1.1
Hindi[(b)]	13	0.2	31	0.2
Arabic[(c)]	69	1.2	132	0.7
Italian	238	4.0	412	2.1
Vietnamese[(d)]	28	0.5	88	0.4
Greek	179	3.0	258	1.3
Filipino / Indonesian[(e)]	9	0.2	21	0.1
Macedonian / Croatian[(f)]	56	0.9	120	0.6
Spanish[(g)]	10	0.2	46	0.2
Tamil / Malayalam[(h)]	1	0.0	5	0.0
German[(i)]	10	0.2	31	0.2
Korean	2	0.0	21	0.1
Samoan / Tongan[(j)]	4	0.1	15	0.1
African languages[(k)]	4	0.1	8	0.0
All other languages	294	5.0	462	2.3
Not stated / inadequately described	9	0.2	173	0.9
Total	*5,895*	*100.0*	*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, Iiokano, 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 12 and Table 13 present a breakdown of malignant and non-malignant diagnosis for the patients in Victoria and at the national level. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 6 (0.1%) patients in Victorian services and was not stated for 55 (0.3%) patients nationally.

Table 12 Primary diagnosis - malignant

Primary diagnosis	Victorian Services			All Services		
	N	% malignant diagnosis	% all diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	73	1.7	1.2	226	1.5	1.1
Breast	356	8.1	6.0	1,166	7.7	5.9
CNS	95	2.2	1.6	332	2.2	1.7
Colorectal	490	11.1	8.3	1,717	11.3	8.7
Other GIT	418	9.5	7.1	1,398	9.2	7.1
Haematological	257	5.8	4.4	902	6.0	4.5
Head and neck	207	4.7	3.5	770	5.1	3.9
Lung	963	21.9	16.3	3,376	22.3	17.0
Pancreas	309	7.0	5.2	1,057	7.0	5.3
Prostate	289	6.6	4.9	1,037	6.8	5.2
Other urological	147	3.3	2.5	633	4.2	3.2
Gynaecological	213	4.8	3.6	733	4.8	3.7
Skin	100	2.3	1.7	553	3.6	2.8
Unknown primary	87	2.0	1.5	369	2.4	1.9
Other primary malignancy	161	3.7	2.7	563	3.7	2.8
Malignant – not further defined	242	5.5	4.1	321	2.1	1.6
All malignant	*4,407*	*100.0*	*74.8*	*15,153*	*100.0*	*76.4*

Table 13 Primary diagnosis - non-malignant

Primary diagnosis	Victorian Services			All Services		
	N	% non-malignant diagnosis	% all diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	254	17.1	4.3	799	17.3	4.0
HIV / AIDS	1	0.1	0.0	7	0.2	0.0
End stage kidney disease	120	8.1	2.0	409	8.9	2.1
Stroke	128	8.6	2.2	338	7.3	1.7
Motor neurone disease	59	4.0	1.0	198	4.3	1.0
Alzheimer's dementia	50	3.4	0.8	169	3.7	0.9
Other dementia	82	5.5	1.4	271	5.9	1.4
Other neurological disease	86	5.8	1.5	257	5.6	1.3
Respiratory failure	247	16.7	4.2	792	17.1	4.0
End stage liver disease	43	2.9	0.7	211	4.6	1.1
Diabetes and its complications	7	0.5	0.1	22	0.5	0.1
Sepsis	50	3.4	0.8	151	3.3	0.8
Multiple organ failure	27	1.8	0.5	136	2.9	0.7
Other non-malignancy	216	14.6	3.7	682	14.8	3.4
Non-malignant – not further defined	112	7.6	1.9	179	3.9	0.9
All non-malignant	*1,482*	*100.0*	*25.1*	*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 14 below presents the number and percentage of episodes by age group and sex for the patients seen by Victorian services and at the national level. Age has been calculated as at the beginning of each episode.

Table 14 Age group by sex

Age group	Victorian Services				All Services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	24	0.6	25	0.7	42	0.3	39	0.3
15 - 24	18	0.5	4	0.1	61	0.5	24	0.2
25 - 34	31	0.8	33	0.9	109	0.8	100	0.8
35 - 44	106	2.7	115	3.1	329	2.4	383	3.2
45 - 54	193	4.9	363	9.9	813	6.0	1,061	9.0
55 - 64	546	13.8	554	15.1	2,202	16.3	1,853	15.7
65 - 74	996	25.1	768	21.0	3,528	26.1	2,689	22.8
75 - 84	1,220	30.7	953	26.0	3,940	29.1	3,066	26.0
85+	836	21.1	850	23.2	2,504	18.5	2,587	21.9
Not stated / inadequately described	0	0.0	0	0.0	0	0.0	0	0.0
Total	*3,970*	*100.0*	*3,665*	*100.0*	*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 15 presents referral source by setting.

Table 15 Referral source by setting

Referral source	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Public hospital	1,962	65.2	7,655	59.1	2,733	59.1	6,632	53.6
Private hospital	293	9.7	1,082	8.4	343	7.4	1,275	10.3
Outpatient clinic	15	0.5	83	0.6	91	2.0	129	1.0
General medical practitioner	6	0.2	287	2.2	364	7.9	1,929	15.6
Specialist medical practitioner	14	0.5	574	4.4	288	6.2	761	6.1
Community-based palliative care agency	627	20.8	2,732	21.1	19	0.4	100	0.8
Community-based service	6	0.2	71	0.5	53	1.1	139	1.1
Residential aged care facility	24	0.8	59	0.5	420	9.1	772	6.2
Self, carer(s), family or friends	19	0.6	176	1.4	178	3.8	362	2.9
Other	24	0.8	153	1.2	119	2.6	248	2.0
Not stated / inadequately described	21	0.7	82	0.6	17	0.4	30	0.2
Total	*3,011*	*100.0*	*12,954*	*100.0*	*4,625*	*100.0*	*12,377*	*100.0*

Table 16 provides a summary of the time between referral to first contact by setting of care. The time from referral to first contact is calculated as the time from the date of referral received to either the date of first contact (if provided) or the episode start date.

Table 16 Referral to first contact by setting

Time (in days)	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Same day or following day	2,863	95.1	12,146	93.8	1,937	41.9	6,325	51.2
2-7 days	133	4.4	668	5.2	1,649	35.7	4,290	34.7
8-14 days	8	0.3	77	0.6	588	12.7	994	8.0
Greater than 14 days	6	0.2	57	0.4	446	9.7	756	6.1
Average	1.1	na	1.2	na	3.5	na	2.9	na
Median	1	na	1	na	3	na	1	na

Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

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

Length of episode	Inpatient		Community	
	Victorian Services	All Services	Victorian Services	All Services
Average length of episode	9.8	10.3	38.3	37.8
Median length of episode	5.0	6.0	26.0	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 18 Length of episode (in days) by setting

Length of episode	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Same day	345	11.6	837	6.5	112	2.7	259	2.3
1-2 days	589	19.9	2,527	19.7	281	6.7	723	6.5
3-4 days	421	14.2	1,911	14.9	225	5.4	593	5.4
5-7 days	426	14.4	2,140	16.7	354	8.5	952	8.6
8-14 days	589	19.9	2,596	20.3	546	13.0	1,471	13.3
15-21 days	240	8.1	1,217	9.5	385	9.2	1,006	9.1
22-30 days	160	5.4	717	5.6	359	8.6	978	8.9
31-60 days	161	5.4	723	5.6	728	17.4	1,960	17.7
61-90 days	26	0.9	99	0.8	382	9.1	982	8.9
Greater than 90 days	8	0.3	43	0.3	813	19.4	2,119	19.2
Total	*2,965*	*100.0*	*12,810*	*100.0*	*4,185*	*100.0*	*11,043*	*100.0*

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

Table 19 How episodes start – inpatient setting

Episode start mode	Victorian Services		All Services	
	N	%	N	%
Admitted from community*	1,803	59.9	7,565	58.4
Admitted from another hospital	675	22.4	3,001	23.2
Admitted from acute care in another ward	500	16.6	2,088	16.1
Change from acute care to palliative care – same ward	9	0.3	207	1.6
Other**	21	0.7	89	0.7
Not stated / inadequately described	3	0.1	4	0.0
Total	*3,011*	*100.0*	*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 20 How episodes end – inpatient setting

Episode end mode	Victorian Services		All Services	
	N	%	N	%
Discharged to community*	910	30.7	4,589	35.8
Discharged to another hospital	217	7.3	755	5.9
Death	1,569	52.9	6,882	53.7
Change from palliative care to acute care**	15	0.5	50	0.4
Change in sub-acute care type	17	0.6	49	0.4
End of consultative episode – inpatient episode ongoing	226	7.6	367	2.9
Other	2	0.1	109	0.9
Not stated / inadequately described	9	0.3	9	0.1
Total	*2,965*	*100.0*	*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 21 How episodes start – community setting

Episode start mode	Victorian Services		All Services	
	N	%	N	%
Admitted from inpatient palliative care	1,573	34.0	4,589	37.1
Other*	3,052	66.0	7,728	62.4
Not stated / inadequately described	0	0.0	60	0.5
Total	*4,625*	*100.0*	*12,377*	*100.0*

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

Table 22 How episodes end – community setting

Episode end mode	Victorian Services		All Services	
	N	%	N	%
Admitted for inpatient palliative care	1,789	42.7	3,478	31.5
Admitted for inpatient acute care	1,043	24.9	3,093	28.0
Admitted to another palliative care service	21	0.5	61	0.6
Admitted to primary health care	50	1.2	234	2.1
Discharged / case closure	344	8.2	1,136	10.3
Death	928	22.2	2,937	26.6
Other	10	0.2	86	0.8
Not stated / inadequately described	0	0.0	18	0.2
Total	*4,185*	*100.0*	*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 23 Number of phases by phase type and setting

Phase type	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Stable	1,731	24.8	7,783	25.8	3,126	33.7	10,579	37.3
Unstable	1,432	20.5	6,932	22.9	1,666	18.0	3,764	13.3
Deteriorating	2,311	33.1	9,433	31.2	3,734	40.3	11,609	41.0
Terminal	1,508	21.6	6,069	20.1	747	8.1	2,378	8.4
Total	*6,982*	*100.0*	*30,217*	*100.0*	*9,273*	*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 24 Average phase length (in days) by phase type and setting

Phase type	Inpatient		Community	
	Victorian Services	All Services	Victorian Services	All Services
Stable	7.2	7.3	24.7	20.9
Unstable	1.9	2.2	5.3	4.2
Deteriorating	4.8	5.0	16.0	12.9
Terminal	2.0	2.0	2.7	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 25 presents information relating to the manner in which stable phases ended, both for Victorian services and nationally. 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 26, Figure 18), deteriorating (Table 27, Figure 19) and terminal (Table 28, Figure 20) phases on the following pages.

Table 25 How stable phases end – by setting

How stable phases end	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	831	48.0	3,830	49.2	1,846	59.1	7,018	66.3
Discharge / case closure	883	51.0	3,873	49.8	1,199	38.4	3,268	30.9
Died	15	0.9	75	1.0	78	2.5	261	2.5
Not stated / inadequately described	2	0.1	5	0.1	3	0.1	32	0.3
Total	*1,731*	*100.0*	*7,783*	*100.0*	*3,126*	*100.0*	*10,579*	*100.0*

Figure 17 Stable phase progression

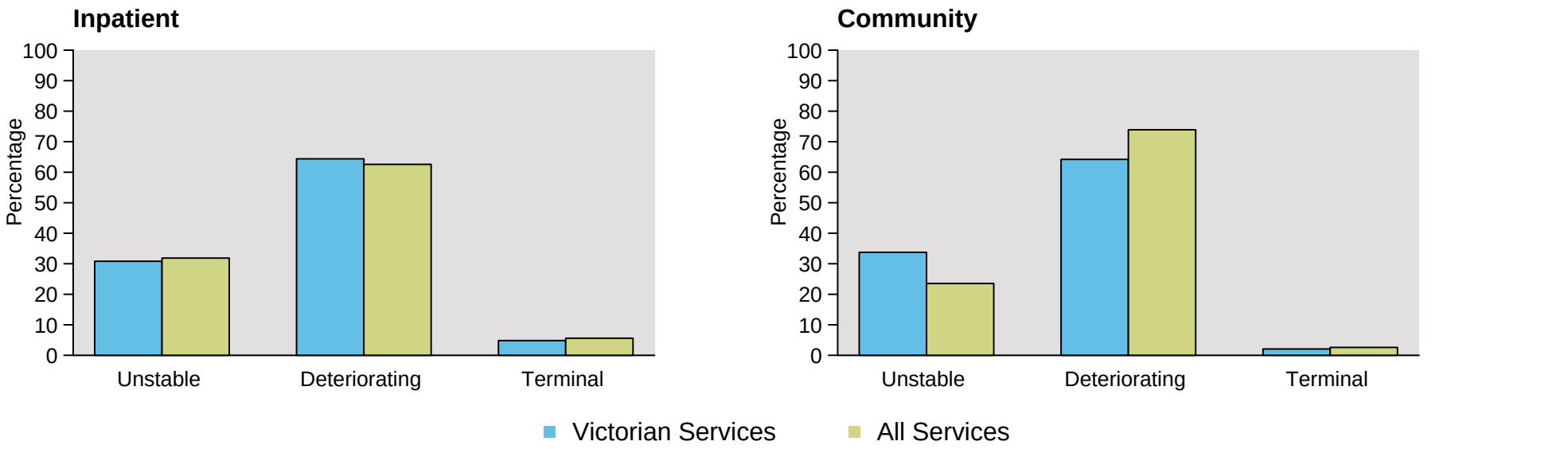


Table 26 How unstable phases end – by setting

How unstable phases end	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	1,345	93.9	6,324	91.2	1,049	63.0	2,442	64.9
Discharge / case closure	68	4.7	479	6.9	594	35.7	1,249	33.2
Died	18	1.3	126	1.8	22	1.3	67	1.8
Not stated / inadequately described	1	0.1	3	0.0	1	0.1	6	0.2
Total	*1,432*	*100.0*	*6,932*	*100.0*	*1,666*	*100.0*	*3,764*	*100.0*

Figure 18 Unstable phase progression

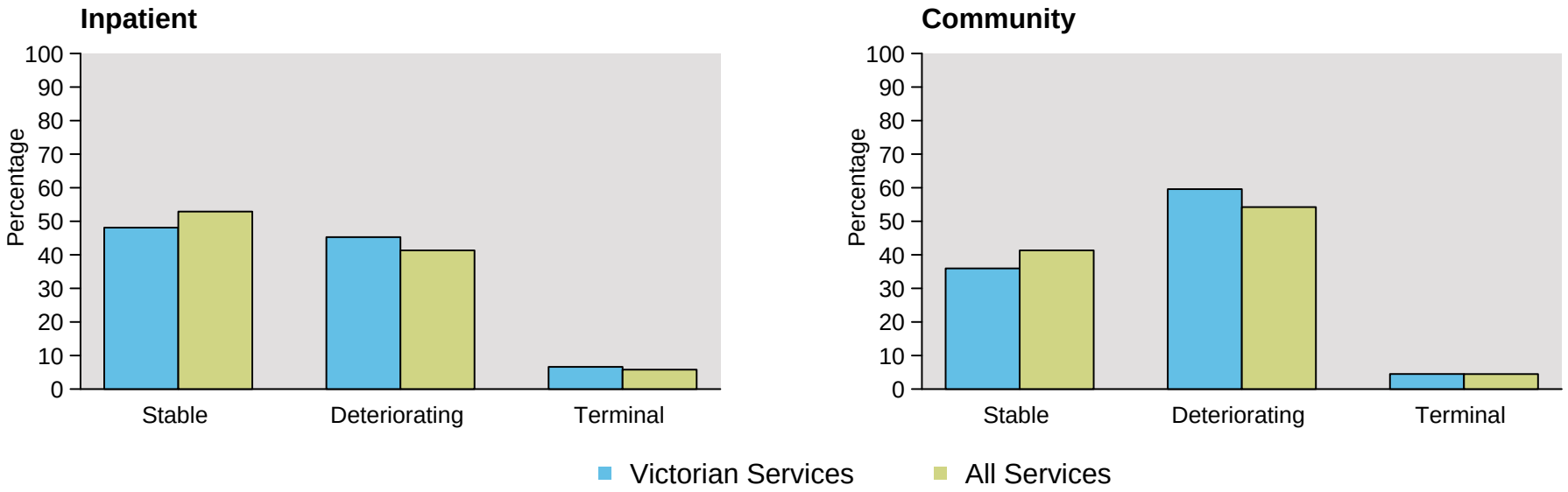


Table 27 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	1,770	76.6	7,004	74.2	2,108	56.5	7,447	64.1
Discharge / case closure	380	16.4	1,441	15.3	1,371	36.7	3,321	28.6
Died	159	6.9	983	10.4	254	6.8	821	7.1
Not stated / inadequately described	2	0.1	5	0.1	1	0.0	20	0.2
Total	*2,311*	*100.0*	*9,433*	*100.0*	*3,734*	*100.0*	*11,609*	*100.0*

Figure 19 Deteriorating phase progression

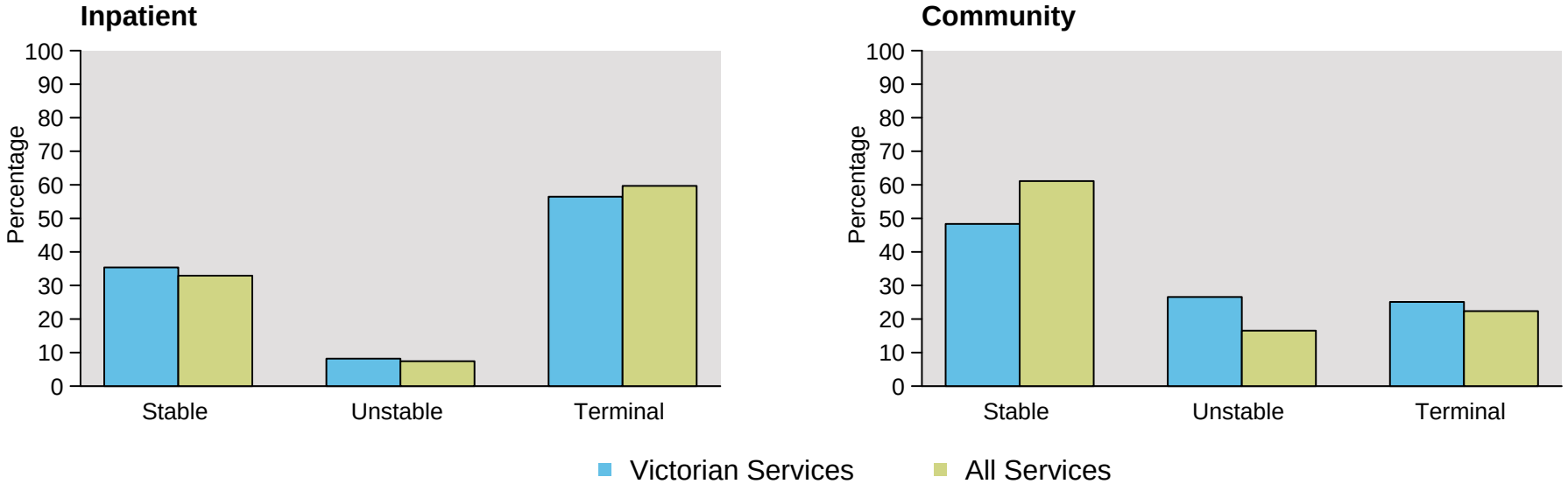
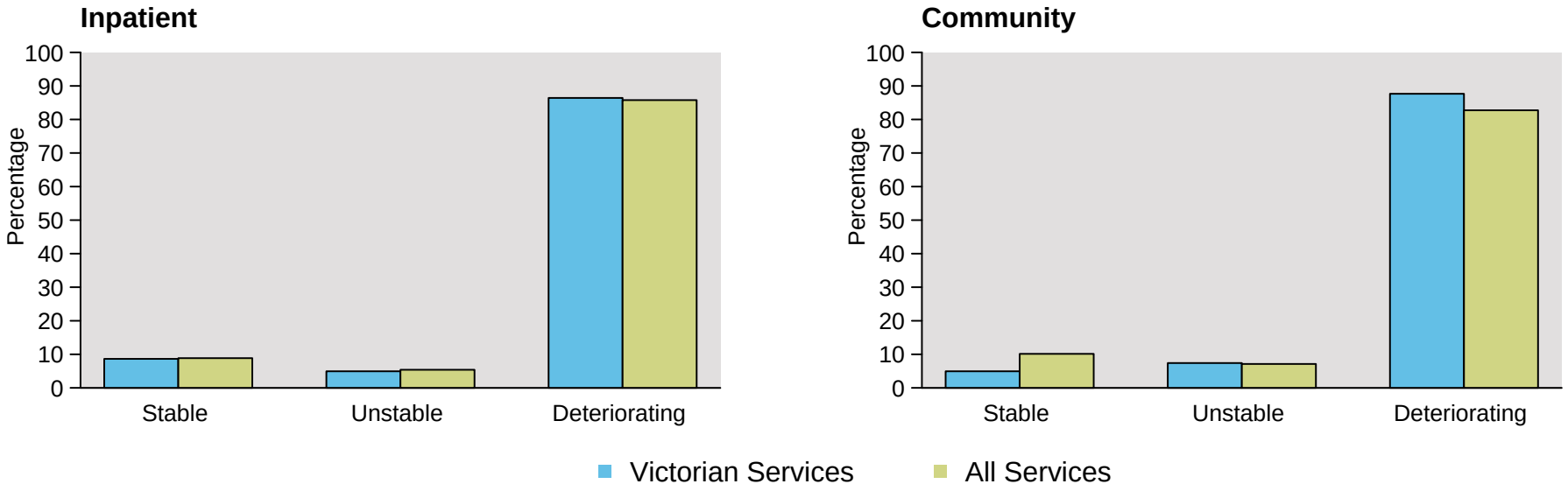


Table 28 How terminal phases end – by setting

How terminal phases end	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	81	5.4	260	4.3	81	10.8	365	15.3
Discharge / case closure	58	3.8	122	2.0	92	12.3	218	9.2
Died	1,369	90.8	5,686	93.7	574	76.8	1,793	75.4
Not stated / inadequately described	0	0.0	1	0.0	0	0.0	2	0.1
Total	*1,508*	*100.0*	*6,069*	*100.0*	*747*	*100.0*	*2,378*	*100.0*

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

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

Phase type		Victorian Services				All Services			
	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	64.3	26.5	8.5	0.7	47.7	38.9	11.6	1.8
	Other symptoms	37.9	50.5	10.5	1.0	30.2	51.5	16.2	2.1
	Psychological / spiritual	50.4	43.0	5.5	1.0	41.2	47.9	9.5	1.4
	Family / carer	64.9	30.3	4.2	0.5	46.4	41.6	9.9	2.0
Unstable	Pain	42.3	26.6	22.2	8.9	31.2	32.3	25.5	10.9
	Other symptoms	21.8	42.2	28.8	7.2	17.4	38.0	32.9	11.7
	Psychological / spiritual	36.0	44.9	14.9	4.3	30.2	45.3	19.6	4.9
	Family / carer	47.3	35.6	13.2	3.8	34.1	40.8	19.4	5.7
Deteriorating	Pain	52.7	31.9	12.4	3.0	40.3	37.8	17.1	4.8
	Other symptoms	25.6	49.1	21.6	3.7	21.3	44.0	28.2	6.5
	Psychological / spiritual	41.6	45.0	11.7	1.7	33.6	47.4	15.9	3.0
	Family / carer	45.8	40.5	11.5	2.2	32.4	43.1	19.7	4.9
Terminal	Pain	54.0	30.4	12.3	3.2	51.8	32.8	12.3	3.1
	Other symptoms	38.6	35.8	20.0	5.6	40.3	35.5	17.9	6.4
	Psychological / spiritual	58.8	28.1	10.1	3.0	57.2	31.3	8.9	2.6
	Family / carer	34.1	38.2	21.5	6.2	27.4	39.1	25.2	8.2

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

Phase type		Victorian Services				All Services			
	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	37.5	55.4	6.9	0.2	41.0	51.6	6.9	0.5
	Other symptoms	12.1	73.6	13.8	0.5	16.4	67.5	15.1	1.0
	Psychological / spiritual	21.8	67.5	10.2	0.5	30.2	59.7	9.4	0.7
	Family / carer	15.5	66.3	17.4	0.8	28.9	56.0	13.6	1.5
Unstable	Pain	14.4	34.5	37.7	13.4	18.4	30.4	34.7	16.5
	Other symptoms	3.4	32.3	51.6	12.6	4.7	29.7	50.6	15.0
	Psychological / spiritual	9.3	56.0	31.7	3.0	13.4	49.3	32.0	5.3
	Family / carer	7.7	37.0	47.3	8.0	11.8	36.1	42.0	10.1
Deteriorating	Pain	24.9	55.4	18.0	1.7	28.8	50.5	18.7	2.1
	Other symptoms	3.9	59.0	34.3	2.8	7.4	52.4	36.7	3.6
	Psychological / spiritual	12.6	67.7	18.8	0.9	17.8	60.2	20.2	1.8
	Family / carer	8.6	57.5	31.0	2.8	17.1	52.2	26.6	4.0
Terminal	Pain	30.3	51.7	15.6	2.4	38.0	43.1	15.6	3.3
	Other symptoms	15.2	48.9	31.4	4.5	23.6	43.1	27.1	6.2
	Psychological / spiritual	34.3	50.7	14.2	0.7	42.3	42.1	13.3	2.3
	Family / carer	4.5	40.5	44.8	10.2	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 31 and Table 32 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Alternative graphical representations of the SAS profile by phase type can be found in Appendix B.

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

Phase type		Victorian Services				All Services			
	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	84.8	7.8	6.0	1.4	72.1	15.8	10.2	1.9
	Appetite problems	74.4	15.4	9.1	1.0	60.7	22.7	14.4	2.2
	Nausea	90.8	5.2	3.6	0.3	82.1	11.1	6.0	0.9
	Bowel problems	76.7	15.3	6.9	1.0	66.0	20.1	11.5	2.5
	Breathing problems	75.2	13.7	9.9	1.2	67.6	17.9	12.0	2.5
	Fatigue	44.9	25.4	26.0	3.7	35.1	26.3	33.1	5.5
	Pain	64.5	20.9	13.3	1.4	48.2	30.4	18.8	2.7
Unstable	Difficulty sleeping	70.1	12.2	13.3	4.4	61.4	16.0	17.2	5.4
	Appetite problems	59.0	20.6	16.5	3.9	46.1	22.3	24.0	7.6
	Nausea	78.2	9.8	8.5	3.4	69.4	13.8	12.1	4.6
	Bowel problems	64.7	19.1	12.5	3.6	54.3	21.4	18.1	6.2
	Breathing problems	64.1	15.0	16.2	4.7	57.7	17.6	17.4	7.3
	Fatigue	33.3	23.6	32.8	10.2	25.6	19.9	40.3	14.3
	Pain	41.4	21.6	27.5	9.5	31.7	25.8	30.2	12.3
Deteriorating	Difficulty sleeping	84.5	7.3	7.0	1.2	73.8	12.3	11.4	2.6
	Appetite problems	68.4	16.3	12.3	3.0	56.7	20.0	18.3	5.0
	Nausea	83.8	8.9	6.1	1.3	78.9	10.4	8.5	2.2
	Bowel problems	73.9	14.2	9.9	2.0	63.9	18.5	14.1	3.4
	Breathing problems	67.4	15.4	13.4	3.8	59.6	17.6	17.1	5.7
	Fatigue	39.9	22.1	29.4	8.7	33.1	18.3	36.5	12.2
	Pain	52.3	24.4	20.3	3.0	41.1	29.3	24.1	5.5
Terminal	Difficulty sleeping	95.0	2.5	2.0	0.5	93.0	3.8	2.4	0.8
	Appetite problems	94.2	2.6	2.2	1.0	91.6	3.6	2.9	1.9
	Nausea	95.5	2.6	1.7	0.2	94.9	2.8	1.8	0.5
	Bowel problems	89.0	6.3	3.8	0.9	88.6	6.2	4.1	1.2
	Breathing problems	72.9	11.9	10.6	4.6	73.0	11.7	10.5	4.8
	Fatigue	77.7	5.6	11.3	5.4	79.3	5.5	9.6	5.6
	Pain	63.4	20.4	14.4	1.8	62.0	22.1	13.7	2.2

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

Phase type		Victorian Services				All Services			
	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	58.3	35.0	6.3	0.3	65.6	25.7	7.9	0.8
	Appetite problems	35.5	47.6	15.6	1.3	50.2	34.0	14.2	1.5
	Nausea	79.5	18.8	1.7	0.0	81.3	15.6	2.9	0.3
	Bowel problems	66.9	28.7	4.2	0.2	67.3	25.1	6.7	0.8
	Breathing problems	51.1	38.7	9.6	0.6	55.5	30.2	12.9	1.4
	Fatigue	9.3	48.1	39.4	3.2	17.1	37.3	41.2	4.4
	Pain	42.0	47.9	9.7	0.5	44.8	42.8	11.6	0.9
Unstable	Difficulty sleeping	43.1	35.2	19.1	2.6	45.8	27.5	21.8	4.9
	Appetite problems	23.0	36.6	33.8	6.6	34.8	29.2	29.4	6.7
	Nausea	58.3	19.8	17.2	4.8	61.5	17.5	15.7	5.4
	Bowel problems	56.8	25.7	14.5	2.9	57.1	23.0	15.7	4.2
	Breathing problems	42.8	33.0	20.0	4.1	45.0	27.7	21.3	6.0
	Fatigue	5.6	26.4	57.4	10.6	11.6	21.6	52.4	14.4
	Pain	18.1	26.8	40.1	15.0	20.0	24.3	38.1	17.6
Deteriorating	Difficulty sleeping	49.6	38.8	10.8	0.7	58.2	27.2	13.1	1.4
	Appetite problems	26.9	43.8	25.7	3.7	41.7	31.7	22.7	3.9
	Nausea	70.7	22.7	6.1	0.5	73.3	18.5	7.2	1.0
	Bowel problems	58.5	33.3	7.5	0.7	60.8	26.9	10.9	1.4
	Breathing problems	41.5	42.7	14.4	1.4	46.6	31.9	18.8	2.7
	Fatigue	6.7	35.2	49.0	9.1	12.4	25.8	51.8	10.0
	Pain	29.2	48.9	19.5	2.5	32.8	41.3	22.9	3.1
Terminal	Difficulty sleeping	77.0	14.7	7.8	0.5	78.2	11.3	9.1	1.5
	Appetite problems	71.2	13.3	6.8	8.7	81.7	7.8	5.5	5.1
	Nausea	83.0	11.4	5.1	0.4	86.0	8.7	4.5	0.7
	Bowel problems	63.7	26.5	8.7	1.1	75.8	15.9	7.2	1.1
	Breathing problems	54.7	29.4	13.0	2.9	59.3	21.8	14.5	4.4
	Fatigue	50.4	11.3	15.6	22.7	61.9	6.9	16.0	15.2
	Pain	35.2	44.1	17.6	3.1	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 33 shows the data for the AKPS at phase start.

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

AKPS assessment at phase start	Inpatient				Community			
	Victorian Services		All Services		Victorian Services		All Services	
	N	%	N	%	N	%	N	%
10 - Comatose or barely rousable	766	11.0	3,278	10.8	299	3.2	983	3.5
20 - Totally bedfast and requiring extensive nursing care	1,832	26.2	6,813	22.5	830	9.0	2,763	9.8
30 - Almost completely bedfast	983	14.1	3,944	13.1	630	6.8	2,019	7.1
40 - In bed more than 50% of the time	1,384	19.8	5,713	18.9	1,334	14.4	3,750	13.2
50 - Requires considerable assistance	1,211	17.3	4,978	16.5	2,450	26.4	7,092	25.0
60 - Requires occasional assistance	640	9.2	3,199	10.6	2,191	23.6	6,892	24.3
70 - Cares for self	123	1.8	654	2.2	777	8.4	3,263	11.5
80 - Normal activity with effort	24	0.3	213	0.7	146	1.6	722	2.5
90 - Able to carry on normal activity; minor signs or symptoms	10	0.1	82	0.3	19	0.2	119	0.4
100 - Normal; no complaints; no evidence of disease	1	0.0	5	0.0	1	0.0	12	0.0
Not stated/inadequately described	8	0.1	1,338	4.4	596	6.4	715	2.5
Total	*6,982*	*100.0*	*30,217*	*100.0*	*9,273*	*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/respite requirements.

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

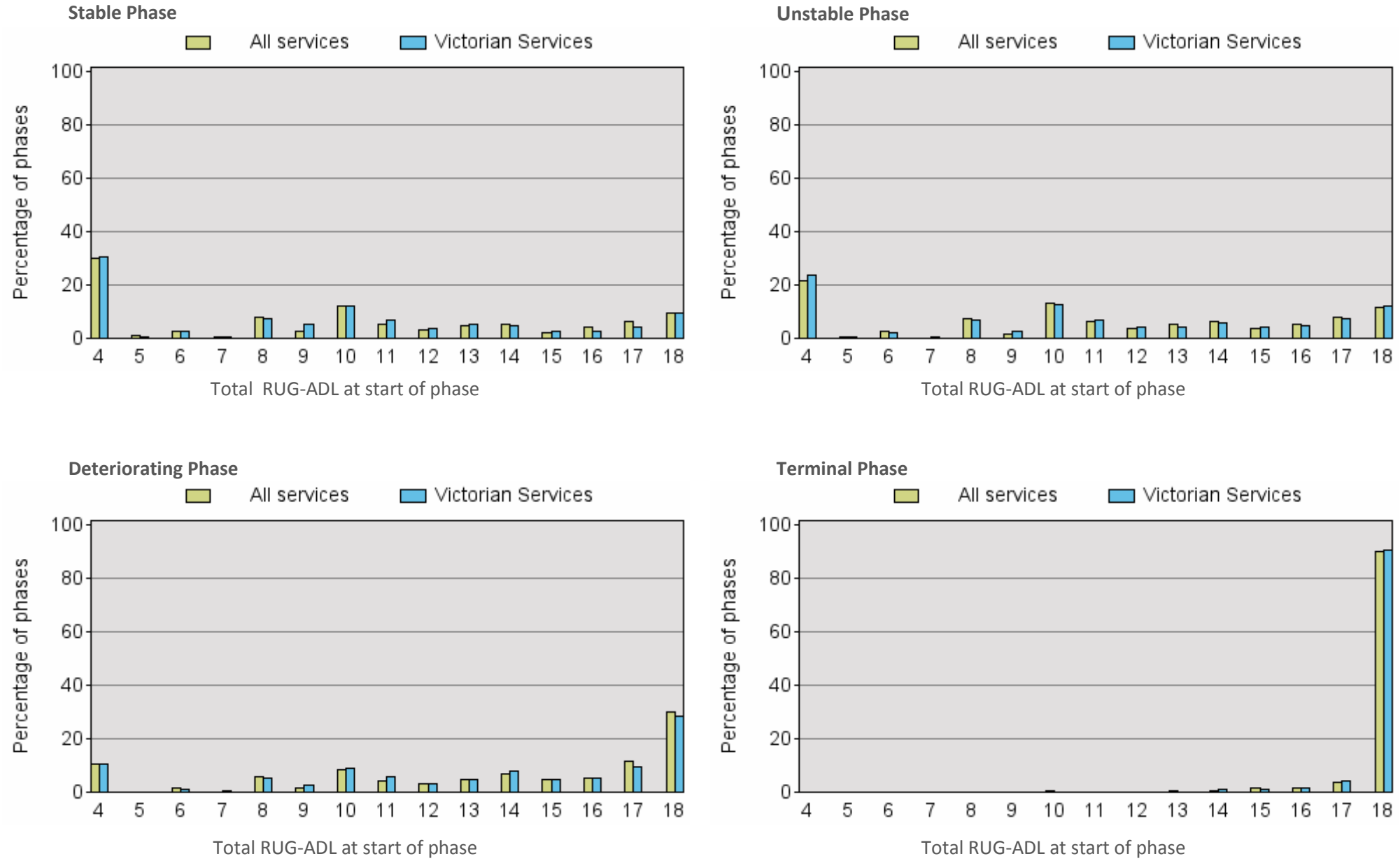
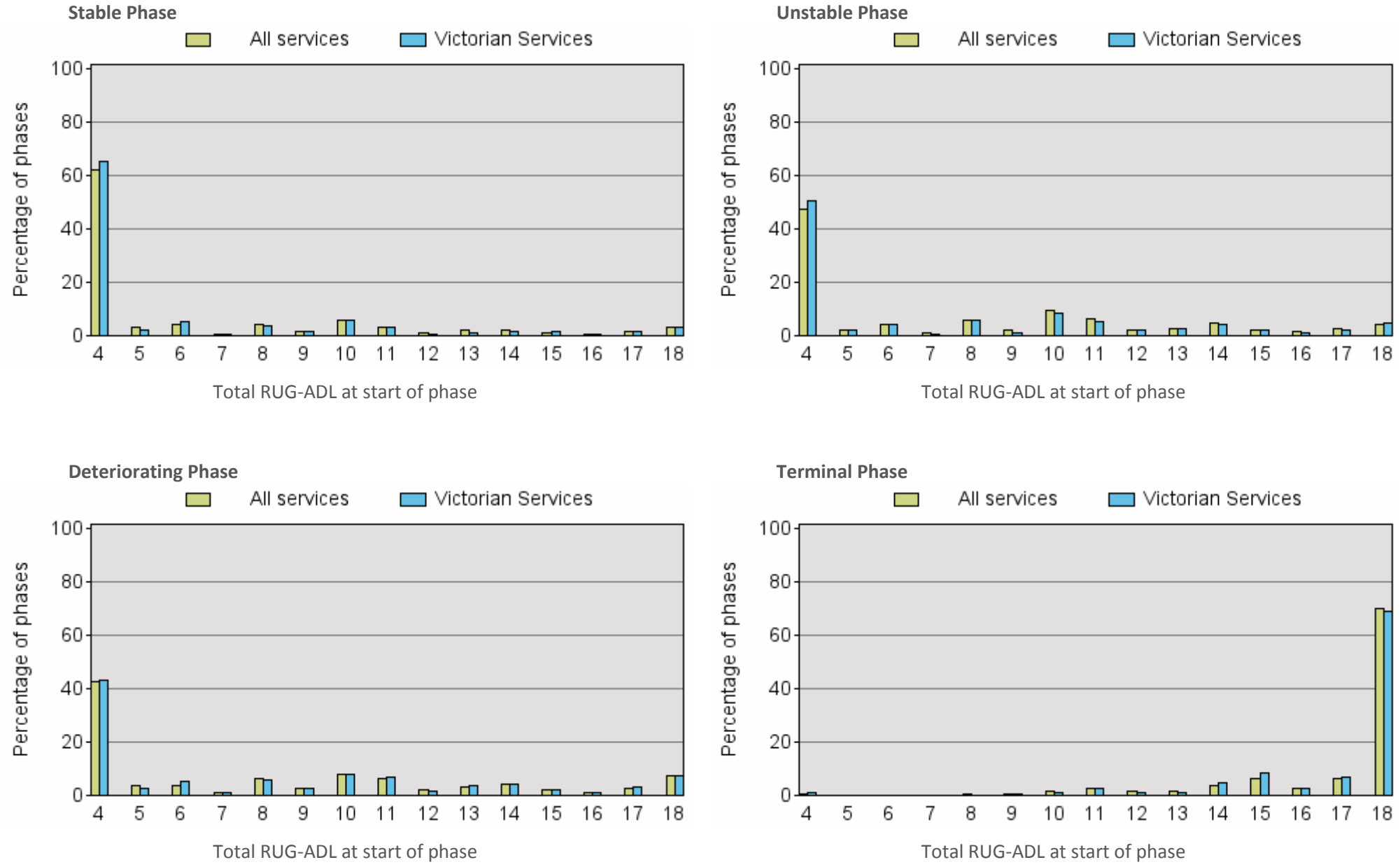


Figure 22 Total RUG-ADL at beginning of phase by phase type – community setting



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 34 shows the number of patients, episodes and phases included in this report – both for Victorian services and nationally.

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

	Inpatient		Community		Total	
	Victorian Services	All Services	Victorian Services	All Services	Victorian Services	All Services
Number of patients*	2,489	10,868	3,522	9,817	5,895	19,829
Number of episodes	3,011	12,954	4,625	12,377	7,636	25,331
Number of phases**	6,982	30,217	9,273	28,330	16,255	58,547
Percentage of patients*	42.2	54.8	59.7	49.5	100	100
Percentage of episodes	39.4	51.1	60.6	48.9	100	100
Percentage of phases	43.0	51.6	57.0	48.4	100	100
Average number of phases per episode***	2.3	2.3	1.9	2.2	2.1	2.3

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

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

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

Setting		Jul	Aug	Sep	Oct	Nov	Dec
Inpatient	No. of completed episodes	496	531	482	537	430	489
	No. of completed phases	1,205	1,243	1,116	1,249	1,080	1,089
Community	No. of completed episodes	781	707	664	690	684	659
	No. of completed phases	1,791	1,629	1,469	1,520	1,443	1,421

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

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

	Inpatient						Community					
	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*	2,337	2,067	2,177	2,228	2,556	2,489	2,803	2,983	2,881	3,110	3,496	3,522
Number of episodes	2,777	2,543	2,606	2,738	2,979	3,011	3,590	3,810	3,672	3,970	4,497	4,625
Number of phases**	6,523	6,353	5,841	6,128	6,975	6,982	6,021	6,815	6,444	7,414	9,082	9,273
Average number of phases per episode***	2.4	2.5	2.2	2.2	2.3	2.3	1.6	1.7	1.7	1.8	1.9	1.9

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

** Bereavement phases are excluded from this count.

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

A2 Data item completion

As shown in Table 37, Table 38 and Table 39 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

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

Table 37 Item completion (per cent complete) - patient level

Data item	Victorian Services	All Services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	98.9	97.9
Country of birth	98.5	98.6
Preferred language	99.8	99.1
Primary diagnosis	99.9	99.7

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

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

Data item	Inpatient		Community		Total	
	Victorian Services	All Services	Victorian Services	All Services	Victorian Services	All Services
Date of first contact	100.0	100.0	100.0	99.9	100.0	99.9
Referral date	100.0	100.0	99.9	99.9	99.9	99.9
Referral source	99.3	99.4	99.6	99.8	99.5	99.6
Date ready for care	100.0	97.2	99.9	96.9	99.9	97.0
Mode of episode start	99.9	100.0	100.0	99.5	100.0	99.7
Accommodation at episode start	99.8	99.9	89.7	95.5	92.5	97.2
Episode end date*	99.7	99.9	93.3	92.5	95.8	96.2
Mode of episode end	99.7	99.9	100.0	99.8	99.9	99.9
Accommodation at episode end	95.9	97.8	78.6	92.9	90.3	96.6
Place of death	na	na	98.9	98.5	98.9	98.5

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

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

Data item	Sub-Category	At phase start						At discharge					
		Inpatient		Community		Total		Inpatient		Community		Total	
	(where applicable)	Victorian Services	All Services	Victorian Services	All Services	Victorian Services	All Services	Victorian Services	All Services	Victorian Services	All Services	Victorian Services	All Services
RUG-ADL	Bed mobility	100.0	99.8	93.2	97.3	96.1	98.6	84.5	93.3	52.8	56.6	62.3	72.2
	Toileting	100.0	99.8	93.2	97.2	96.1	98.6	84.5	93.3	52.8	56.6	62.3	72.1
	Transfers	100.0	99.8	93.1	97.1	96.1	98.5	84.5	93.3	52.8	56.6	62.3	72.1
	Eating	99.9	99.7	92.8	96.5	95.8	98.1	84.5	93.3	52.5	56.4	62.1	72.0
PCPSS	Pain	99.9	99.4	92.8	97.1	95.8	98.3	84.5	93.2	52.8	56.2	62.3	71.9
	Other symptom	99.8	97.7	88.1	94.8	93.1	96.3	84.5	92.0	51.4	55.1	61.3	70.7
	Psychological / spiritual	100.0	99.3	91.1	96.2	94.9	97.8	84.5	93.1	51.8	55.5	61.6	71.4
	Family / carer	99.9	97.8	90.7	94.9	94.7	96.4	84.5	89.8	52.4	54.8	62.0	69.6
SAS	Difficulty sleeping	91.6	90.4	85.6	91.4	88.2	90.9	76.2	79.7	48.3	51.4	56.6	63.4
	Appetite problems	91.6	92.2	90.5	94.9	91.0	93.5	76.0	80.8	50.9	54.2	58.4	65.4
	Nausea	91.6	92.2	92.9	96.0	92.3	94.1	76.2	79.5	53.0	55.1	59.9	65.4
	Bowel problems	91.6	92.1	90.1	94.9	90.7	93.5	76.2	80.2	50.6	54.1	58.3	65.2
	Breathing problems	91.7	92.3	91.0	95.5	91.3	93.8	76.2	80.3	51.6	54.7	58.9	65.5
	Fatigue	91.6	92.2	92.7	95.9	92.2	94.0	76.2	81.8	52.7	55.1	59.7	66.4
	Pain	91.6	92.3	96.5	97.5	94.4	94.8	76.1	81.3	55.9	56.6	61.9	67.1
AKPS	-	99.9	95.6	93.6	97.5	96.3	96.5	84.2	91.7	53.5	58.8	62.7	72.7

Data item	Inpatient		Community		Total	
	Victorian Services	All Services	Victorian Services	All Services	Victorian Services	All Services
Phase End Reason	99.9	99.9	99.9	99.8	99.9	99.9

Appendix B Additional information on profile of SAS and PCPSS

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

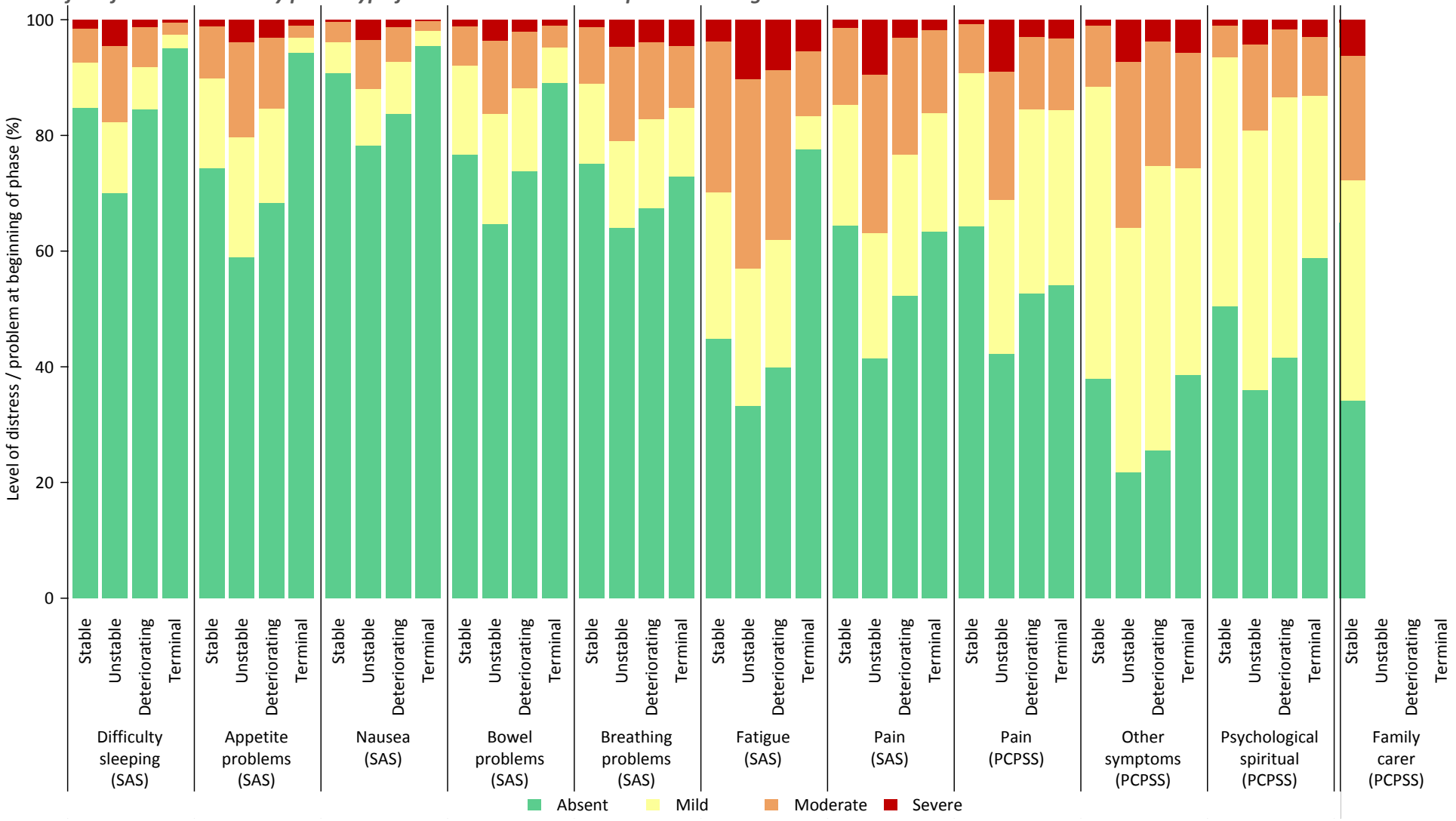
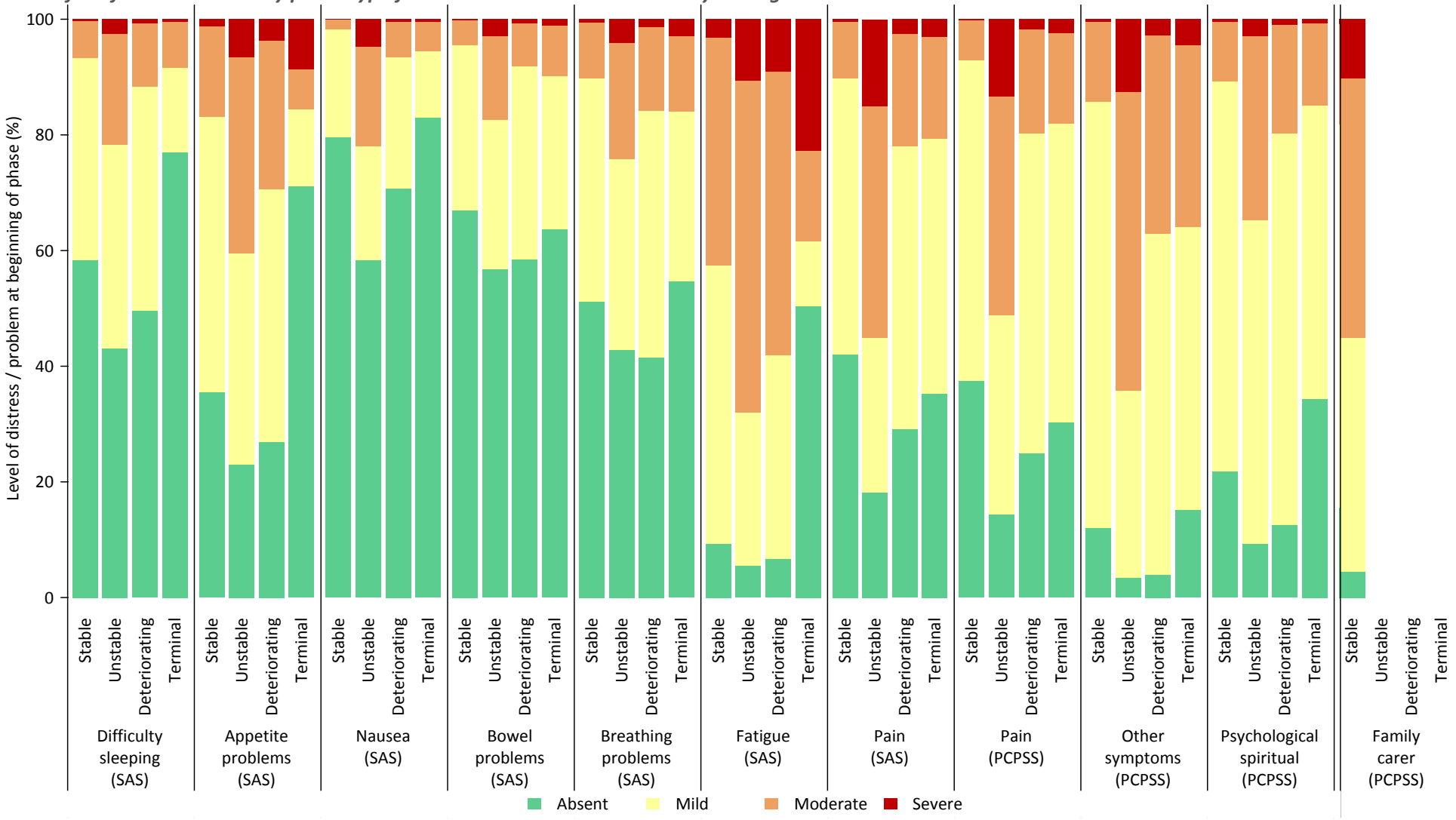


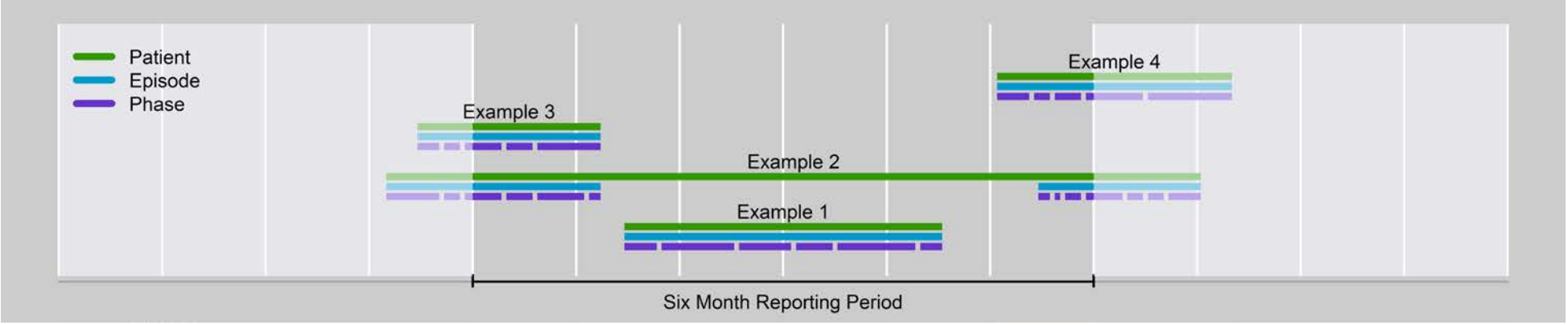
Figure 24 Profile of SAS and PCPSS by phase type for Victorian services – community setting



Appendix C Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 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	
Patient problems and symptoms are adequately controlled by established plan of care **and** ▪ Further interventions to maintain symptom control and quality of life have been planned **and** ▪ Family / carer situation is relatively stable and no new issues are apparent.	The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care.
Unstable	
An urgent change in the plan of care or emergency treatment is required **because** ▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and / or** ▪ Patient experiences a rapid increase in the severity of a current problem; **and / or** ▪ Family / carers circumstances change suddenly impacting on patient care.	▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom / crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and / or** ▪ Death is likely within days (i.e. patient is now terminal).
Deteriorating	
The care plan is addressing anticipated needs but requires periodic review **because** ▪ Patients overall functional status is declining **and** ▪ Patient experiences a gradual worsening of existing problem **and / or** ▪ Patient experiences a new but anticipated problem **and / or** ▪ Family / carers experience gradual worsening distress that impacts on the patient care.	▪ Patient condition plateaus (i.e. patient is now stable) **or** ▪ An urgent change in the care plan or emergency treatment **and / or** ▪ Family / carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** ▪ Death is likely within days (i.e. patient is now terminal).
Terminal	
Death is likely within days.	▪ Patient dies **or** ▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).
Bereavement – post death support	
▪ The patient has died ▪ Bereavement support provided to family / carers is documented in the deceased patient's clinical record.	▪ Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

Acknowledgements

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

Disclaimer PCOC has made every effort to ensure that the data used in this report are accurate. Data submitted to PCOC are checked for anomalies and services are asked to re-submit data prior to the production of the PCOC report. We would advise readers to use their professional judgement in considering all information contained in this report.

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