

New South Wales

Patient Outcomes in Palliative Care

January – June 2015

September 2015

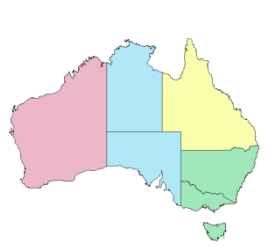




About the Palliative Care Outcomes Collaboration

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.***

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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 January to June 2015 period are summarised and patient outcomes benchmarked. The purpose of benchmarking is to drive palliative care service innovation and provide participating services with the opportunity to compare their service nationally.

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

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

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

A list of the NSW services is presented in Table 1 on the following page. Throughout the report, only information relating to care provided in hospitals (inpatient setting) in New South Wales is shown for NSW, as only two services provided information on palliative care provided in the community. 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 NSW services included in this report

Service name	Setting of care
Calvary Health Care Sydney	Inpatient
Calvary Mater Newcastle	Inpatient
Camden Hospital	Inpatient
David Berry Hospital	Inpatient
HammondCare - Braeside Hospital	Inpatient
HammondCare - Greenwich Hospital	Inpatient
HammondCare - Neringah Hospital	Inpatient
Hastings Macleay Community Palliative Care Service	Community*
Lourdes Hospital	Inpatient
Manning Rural Referral Hospital	Inpatient
Mercy Care Centre - Young	Inpatient
Mercy Health Service Albury	Inpatient and community*
Mt Druitt Hospital Supportive and Palliative Care Service	Inpatient
Nepean Hospital	Inpatient
Port Kembla Hospital	Inpatient
Prince of Wales Hospital Palliative Care	Inpatient
St Joseph's Hospital	Inpatient
St Vincent's Hospital Lismore	Inpatient
St Vincent's Hospital, Sydney	Inpatient
St Vincent's Hospital, Sydney - Palliative Care Consult Service	Inpatient
Tamworth Base Hospital	Inpatient
The Concord Centre for Palliative Care	Inpatient
Wauchope District Memorial Hospital	Inpatient
Westmead Hospital	Inpatient
Wollongong Hospital	Inpatient

* Community information is not included in this report, due to the small number of services providing data

Section 1 Benchmark summary

1.1 NSW services at a glance

Table 2 Summary of outcome measures 1 to 3 by setting

Outcome measure	Description	Benchmark	Inpatient		Community	
			NSW Score	Benchmark Met?	NSW 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%	95.9	Yes	na	na
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	89.0	No	na	na
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%	91.1	Yes	na	na
	Benchmark 3.2: PCPSS Patients with moderate or severe pain at phase start, with absent or mild pain at phase end	60%	59.0	No	na	na
	Benchmark 3.3: SAS Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end	90%	88.8	No	na	na
	Benchmark 3.4: SAS Patients with moderate or severe distress from pain at phase start, with absent or mild at phase end	60%	53.0	No	na	na

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

Clinical Tool	Description	Average improvement on baseline	Benchmark met?
PCPSS	Benchmark 4.1: Pain	0.11	Yes
	Benchmark 4.2: Other symptoms	0.14	Yes
	Benchmark 4.3: Family / carer	0.09	Yes
	Benchmark 4.4: Psychological / spiritual	0.13	Yes
SAS	Benchmark 4.5: Pain	0.29	Yes
	Benchmark 4.6: Nausea	0.14	Yes
	Benchmark 4.7: Breathing problems	0.25	Yes
	Benchmark 4.8: Bowel problems	0.20	Yes

The benchmark for
outcome measure 4 is zero.

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

1.2 National benchmark profiles

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

The selected benchmarks included are:

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

Interpretation hint:

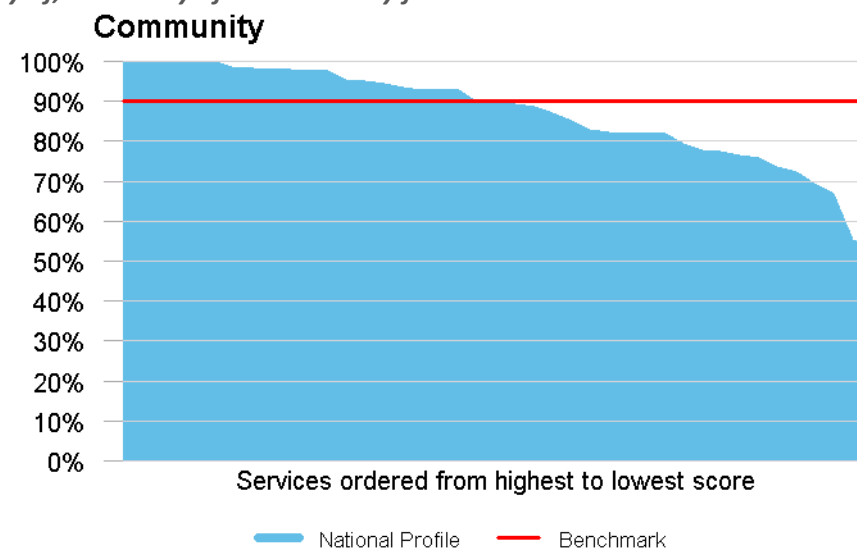
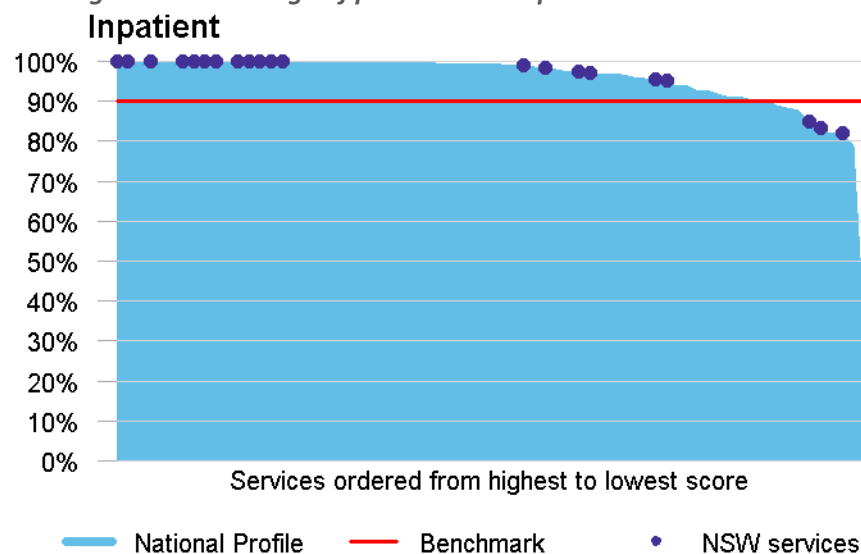
The national profile graphs on the following pages present NSW services in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. New South Wales services are highlighted as dots on the graph.

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

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

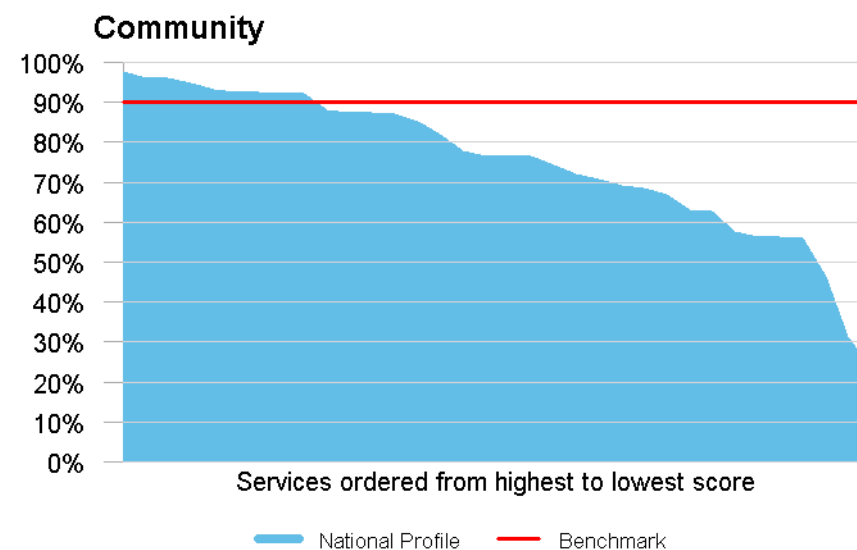
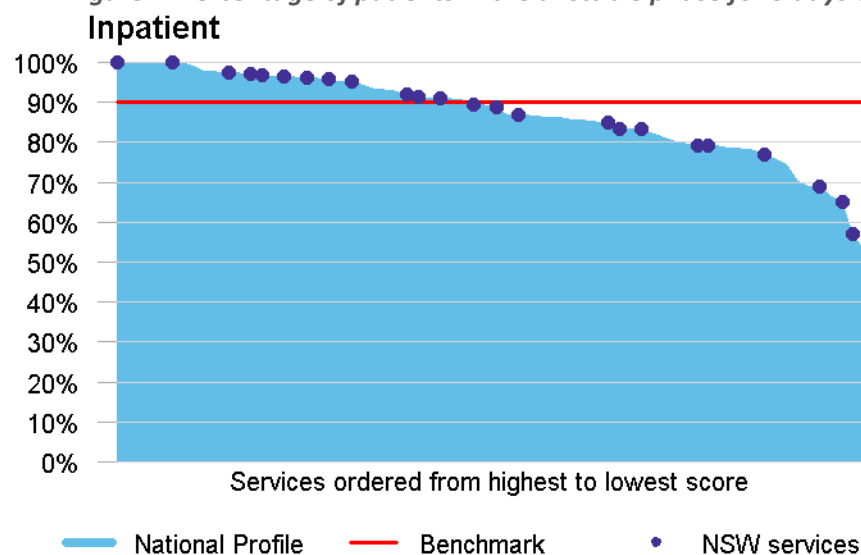
Outcome measure 1 – Time from date ready for care to episode start

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



Outcome measure 2 – Time in unstable phase

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



Outcome measure 3 – Change in pain

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

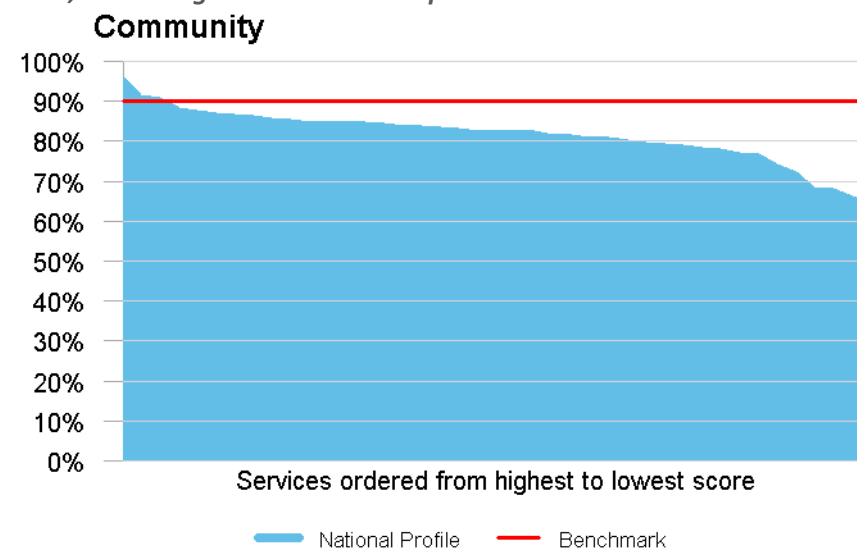
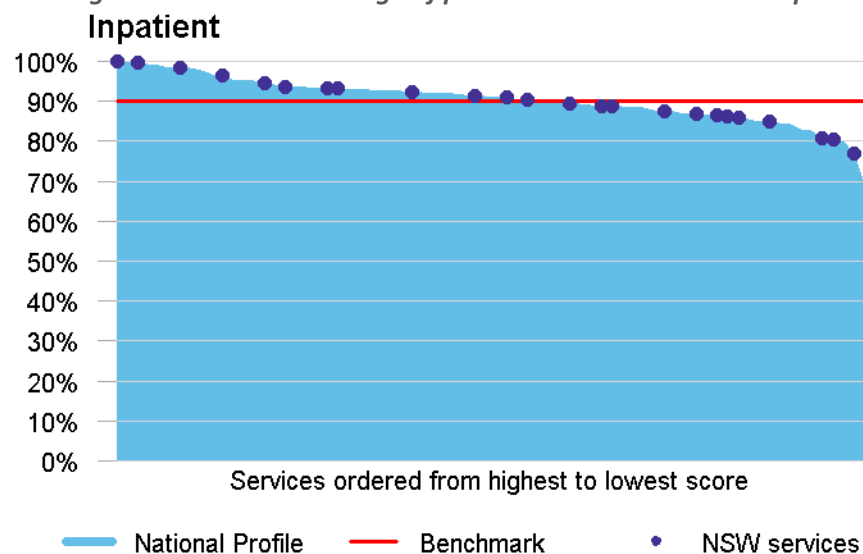


Figure 4 PCPSS: Percentage of patients with moderate or severe pain at phase start, with absent or mild pain at phase end

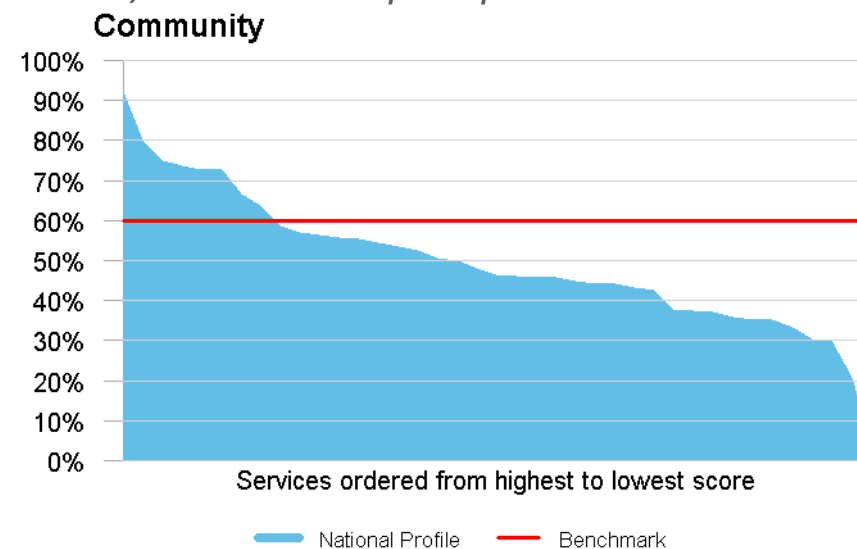
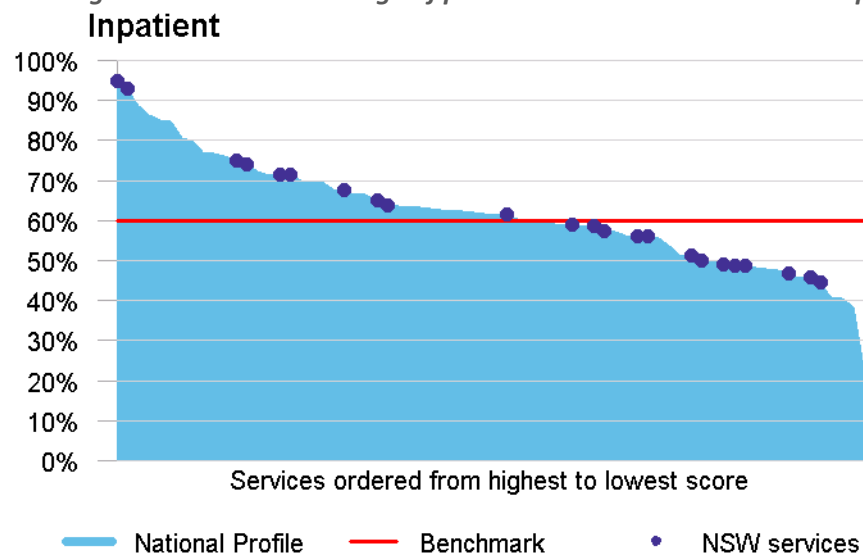


Figure 5 SAS: Percentage of patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end

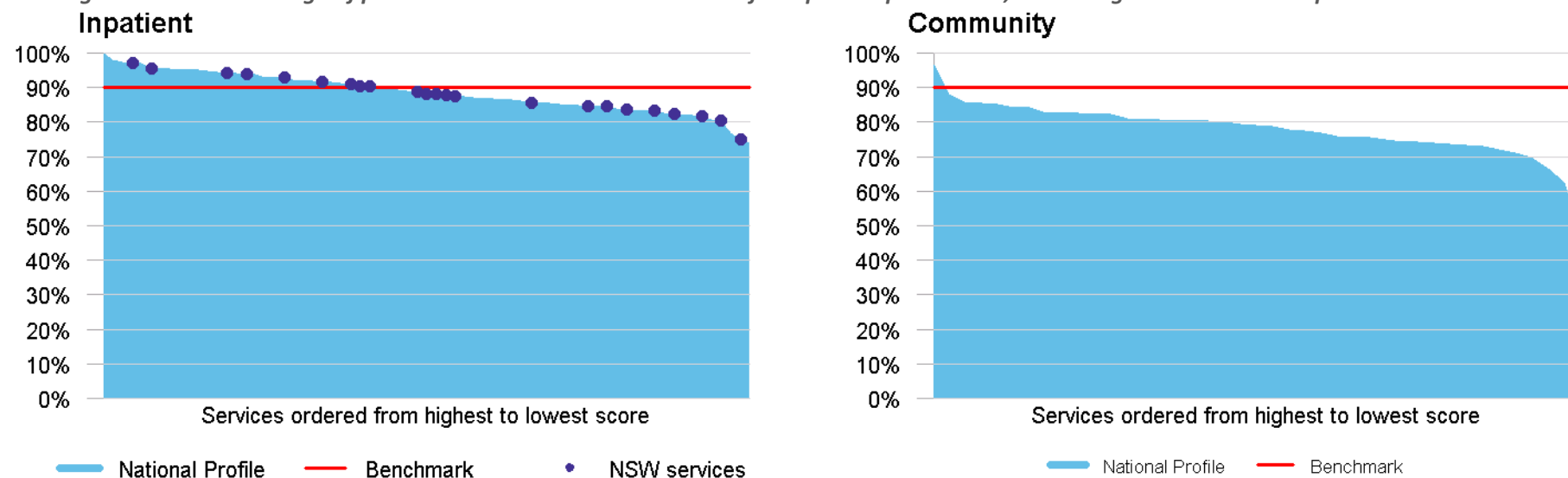
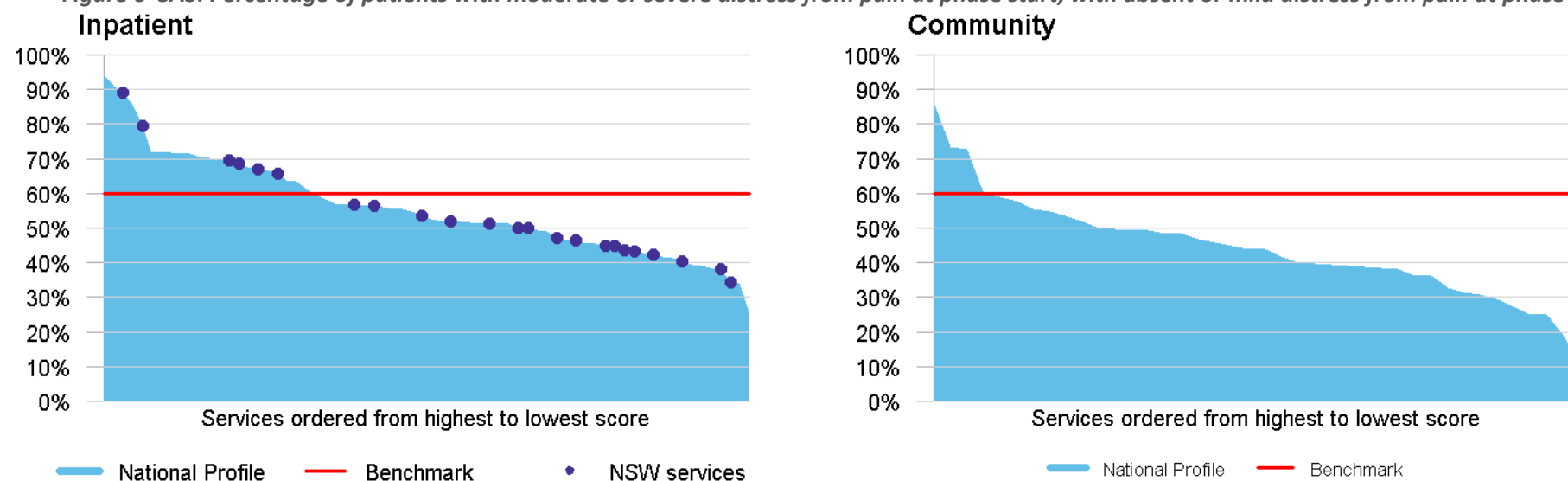


Figure 6 SAS: Percentage of patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end



Section 2 Outcome measures in detail

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

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

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

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

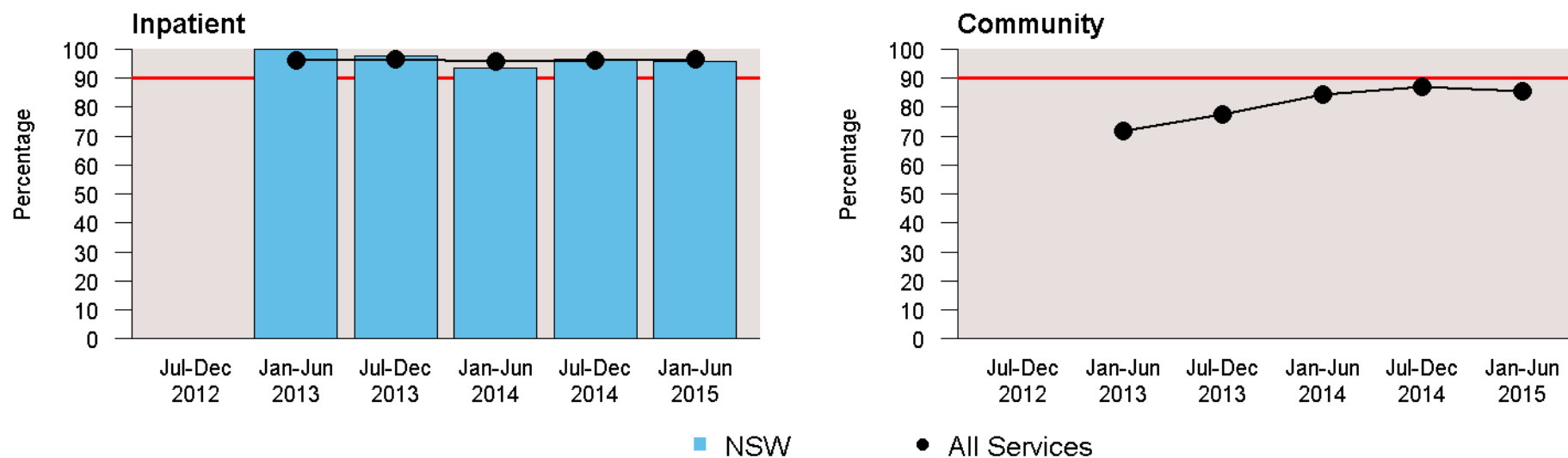
Time (in days)	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Same day	2,729	92.3	10,597	91.8	na	na	8,248	80.3
Following day	107	3.6	545	4.7	na	na	553	5.4
2-7 days	108	3.7	351	3.0	na	na	1,087	10.6
8-14 days	14	0.5	38	0.3	na	na	224	2.2
Greater than 14 days	0	0	9	0.1	na	na	156	1.5
Average	1.1	na	1.1	na	na	na	2.1	na
Median	1	na	1	na	na	na	1	na

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

Interpretation hint:

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

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



2.2 Outcome measure 2 – Time in unstable phase

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

An unstable phase is triggered if:

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

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

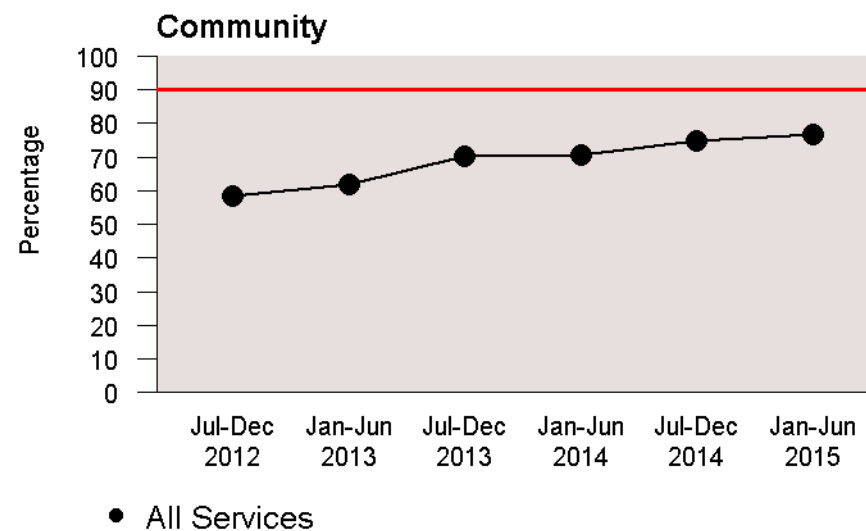
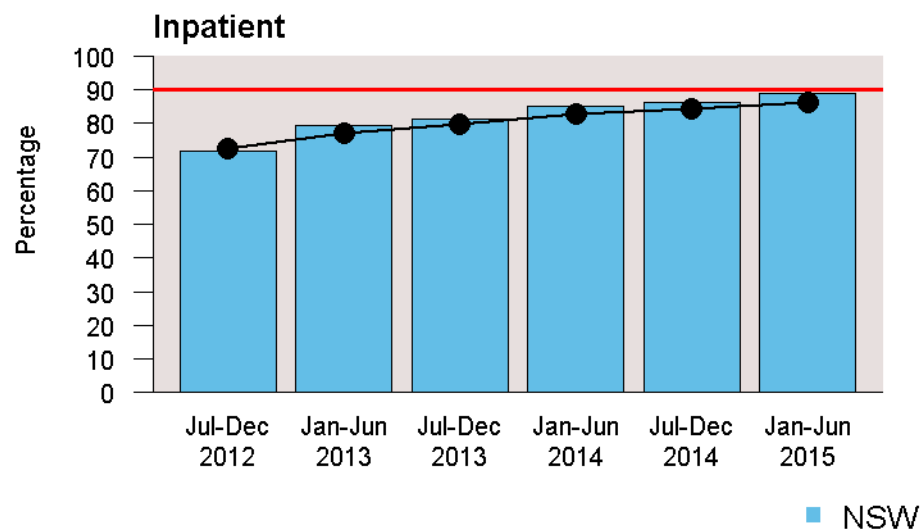
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom / crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the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

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

Table 5 Time in unstable phase by setting

Time in unstable phase	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Same day	48	1.7	233	3.4	na	na	849	23.4
1 day	1,421	50.6	3,277	47.2	na	na	1,239	34.2
2 days	747	26.6	1,724	24.8	na	na	441	12.2
3 days	284	10.1	763	11.0	na	na	252	7.0
4-5 days	209	7.4	595	8.6	na	na	236	6.5
6-7 days	61	2.2	196	2.8	na	na	187	5.2
8-14 days	28	1.0	129	1.9	na	na	203	5.6
Greater than 14 days	10	0.4	28	0.4	na	na	218	6.0
Total	2,808	100.0	6,945	100.0	na	na	3,625	100.0

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



2.3 Outcome measure 3 – Change in pain

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

Scores for PCPSS
0 absent
1 mild
2 moderate
3 severe

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

Interpretation hint:

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

- Benchmark 3.1:** This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild pain.
- Benchmark 3.2:** This benchmark relates to patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 60% of these phases must end with the patient's pain reduced to being absent or mild.
- Benchmark 3.3:** This benchmark relates to patients who have absent or mild distress from pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild distress from pain.
- Benchmark 3.4:** This benchmark relates to patients who have moderate or severe distress from pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 60% of these phases must end with the patient's distress from pain reduced to absent or mild.

Table 6 Summary of outcome measure 3

Benchmarks: change in pain	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N*	%	N*	%	N*	%	N*	%
Benchmark 3.1: PCPSS (severity)	5,966	91.1	16,578	90.9	na	na	15,665	84.4
Benchmark 3.2: PCPSS (severity)	1,865	59.0	5,399	59.8	na	na	3,992	53.5
Benchmark 3.3: SAS (distress)	5,361	88.8	14,451	88.9	na	na	14,633	81.5
Benchmark 3.4: SAS (distress)	2,356	53.0	6,419	53.5	na	na	5,255	46.8

*Total number of phases included in this benchmark.

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

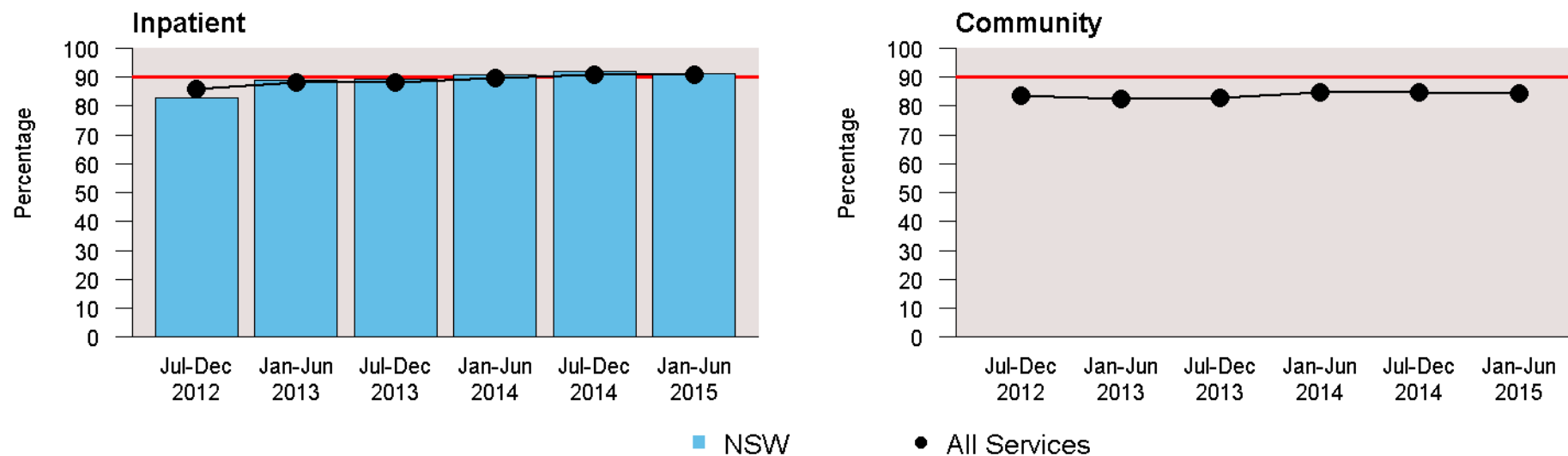


Figure 10 Trends in benchmark 3.2: Patients with moderate or severe pain at phase start, with absent or mild at phase end by setting

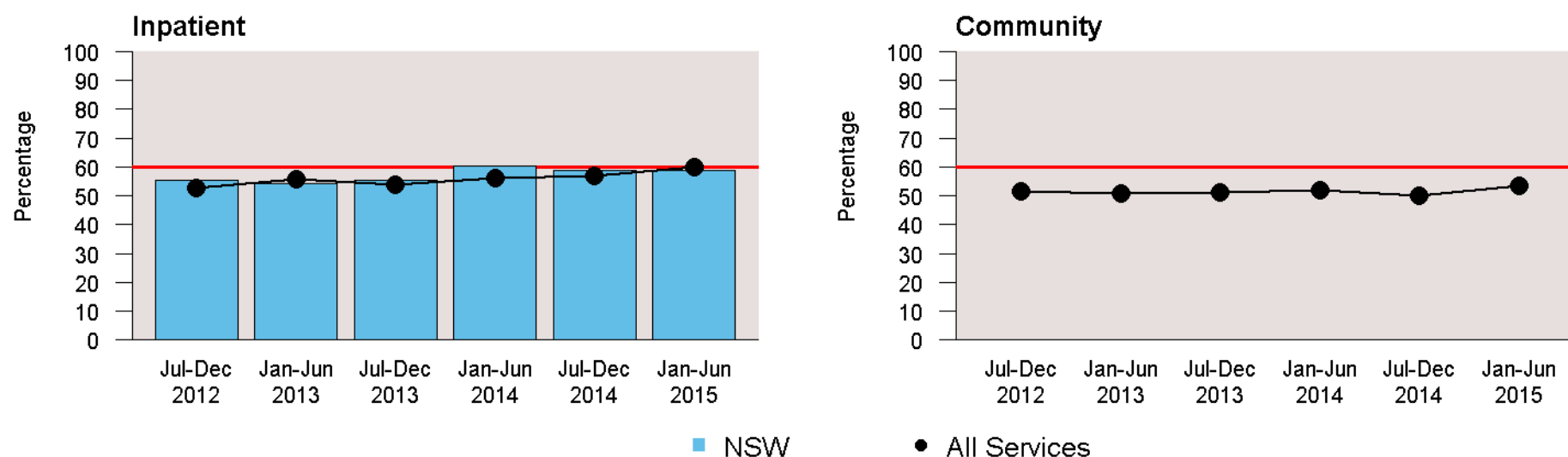


Figure 11 Trends in benchmark 3.3: Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end by setting

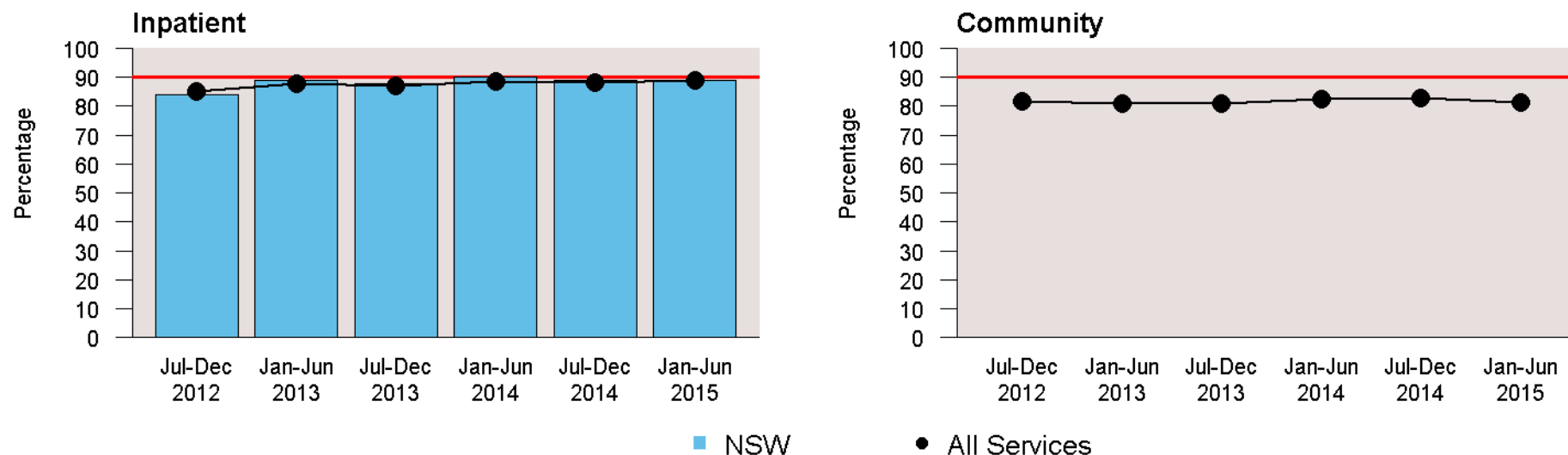
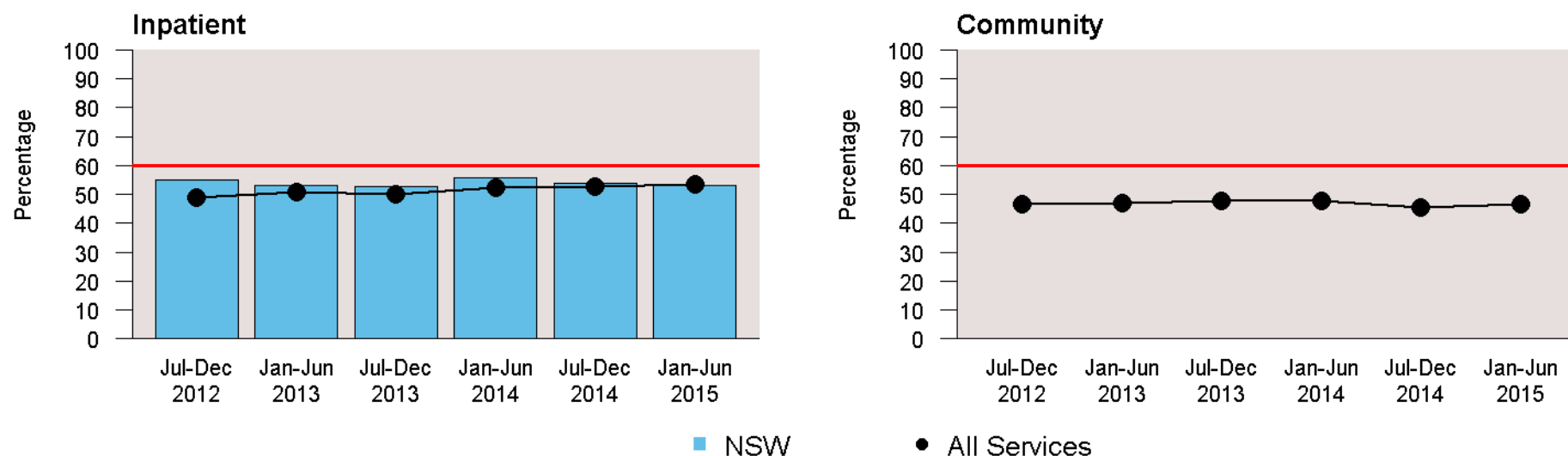


Figure 12 Trends in benchmark 3.4: Patients with moderate or severe distress from pain at phase start, with absent or mild distress from pain at phase end by setting



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

Outcome measure 4 includes a suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included in this report and the baseline reference period is January to June 2014. The suite of benchmarks included in outcome measure 4 are generally referred to as X-CAS – CAS standing for *Case-mix Adjusted Score*, and the X to represent that multiple symptoms are included. As X-CAS looks at change in symptom, they are only able to be calculated on phases which ended in phase change or discharge (as the phase end scores are required to determine the change).

Table 7 Summary of outcome measure 4

Clinical Tool	Benchmark: Symptom	NSW 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	0.11	7,831	5,037	64.3	0.02	41,634	24,461	58.8
	4.2: Other symptoms	0.14	7,830	5,411	69.1	0.04	40,844	26,307	64.4
	4.3: Family / carer	0.09	7,831	4,907	62.7	0.03	40,854	25,423	62.2
	4.4: Psychological / spiritual	0.13	7,831	4,579	58.5	0.05	41,465	22,401	54.0
SAS (distress)	4.5: Pain	0.29	7,717	5,235	67.8	0.00	40,758	25,154	61.7
	4.6: Nausea	0.14	7,717	6,669	86.4	0.02	40,240	33,123	82.3
	4.7: Breathing Problems	0.25	7,717	6,143	79.6	0.07	40,013	28,503	71.2
	4.8: Bowel Problems	0.20	7,717	5,871	76.1	0.04	39,831	28,751	72.2

Interpretation hint:

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

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

If X-CAS is equal to 0 then on average, patients' change in symptom was about the same as similar patients in the baseline reference period.

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

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

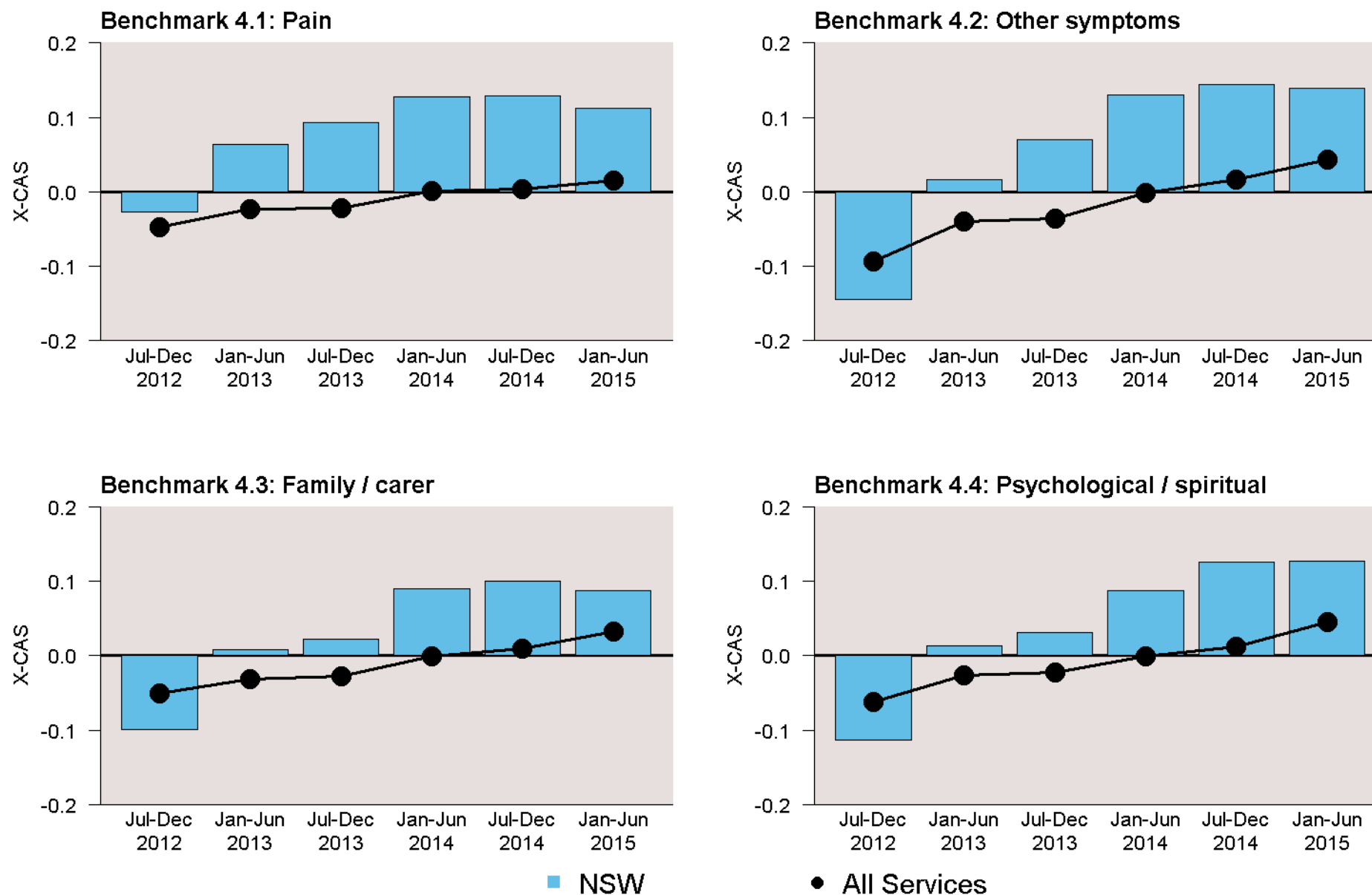
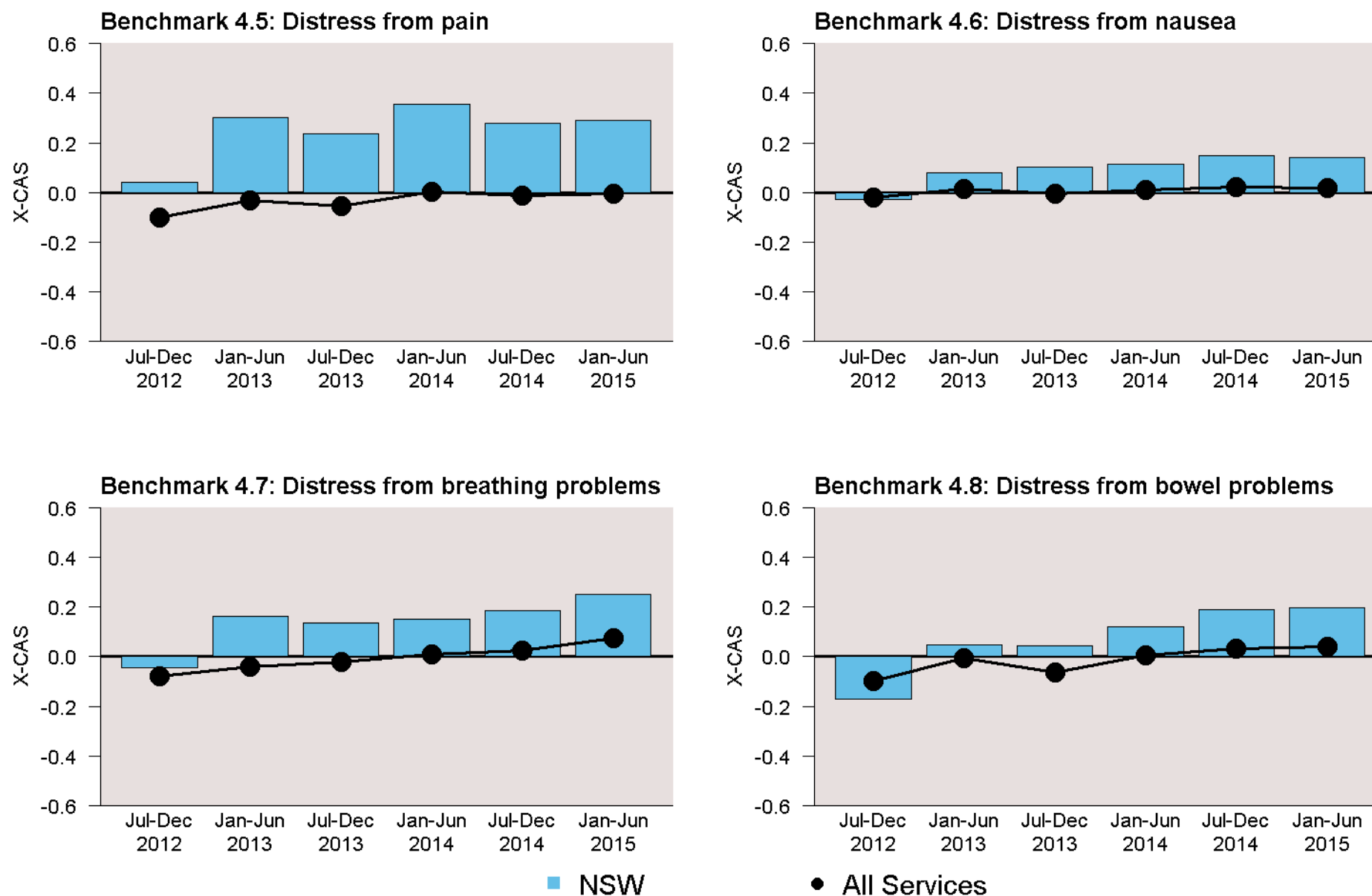


Figure 14 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)



Section 3 Descriptive analysis

This section provides descriptive information of the data submitted by NSW 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 NSW and nationally.

Table 8 Indigenous status

Indigenous status	NSW Services		All Services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	40	1.3	205	1.1
Torres Strait Islander but not Aboriginal origin	3	0.1	17	0.1
Both Aboriginal and Torres Strait Islander origin	1	0.0	13	0.1
Neither Aboriginal nor Torres Strait Islander origin	3,130	98.4	18,587	96.7
Not stated / inadequately described	6	0.2	398	2.1
Total	3,180	100.0	19,220	100.0

Table 9 shows the breakdown of deaths for the patients in NSW 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	NSW Services		All Services	
	N	%	N	%
Private residence	0	0.0	1,870	19.8
Residential aged care facility	0	0.0	695	7.4
Hospital	2,259	100.0	6,720	71.2
Not stated / inadequately described	0	0.0	150	1.6
Total	2,259	100.0	9,435	100.0

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

Table 10 Country of birth

Country of birth	NSW Services		All Services	
	N	%	N	%
Australia	1,965	61.8	11,998	62.4
England	178	5.6	1,367	7.1
New Zealand	51	1.6	357	1.9
China	94	3.0	240	1.2
Italy	107	3.4	757	3.9
Vietnam	24	0.8	152	0.8
India	22	0.7	143	0.7
Scotland	40	1.3	261	1.4
Philippines	27	0.8	84	0.4
Greece	58	1.8	398	2.1
Germany	38	1.2	233	1.2
South Africa	11	0.3	83	0.4
Malaysia	7	0.2	66	0.3
Netherlands	27	0.8	194	1.0
Lebanon	41	1.3	107	0.6
All other countries	471	14.8	2,500	13.0
Not stated / inadequately described	19	0.6	280	1.5
Total	3,180	100.0	19,220	100.0

Table 11 Preferred language

Preferred language	NSW Services		All Services	
	N	%	N	%
English	2,741	86.2	17,250	89.8
Italian	57	1.8	366	1.9
Greek	43	1.4	267	1.4
Chinese ^(a)	99	3.1	216	1.1
Arabic ^(b)	37	1.2	130	0.7
Vietnamese ^(c)	19	0.6	71	0.4
Spanish / Portuguese ^(d)	32	1.0	46	0.2
Filipino / Indonesian ^(e)	2	0.1	17	0.1
German ^(f)	4	0.1	30	0.2
Hindi ^(g)	12	0.4	29	0.2
Croatian / Macedonian ^(h)	48	1.5	126	0.7
Korean	11	0.3	15	0.1
Turkish ⁽ⁱ⁾	5	0.2	35	0.2
Polish ^(j)	6	0.2	25	0.1
Maltese	4	0.1	18	0.1
All other languages	37	1.2	416	2.2
Not stated / inadequately described	23	0.7	163	0.8
Total	3,180	100.0	19,220	100.0

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

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

The primary diagnosis was not stated for 15 (0.5%) patients in NSW and was not stated for 80 (0.4%) patients nationally.

Table 12 Primary diagnosis - malignant

Primary diagnosis	NSW Services			All Services		
	N	% malignant diagnosis	% all diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	30	1.1	0.9	238	1.6	1.2
Breast	214	8.1	6.7	1,176	7.9	6.1
CNS	62	2.3	1.9	344	2.3	1.8
Colorectal	265	10.0	8.3	1,644	11.0	8.6
Other GIT	236	8.9	7.4	1,401	9.4	7.3
Haematological	165	6.2	5.2	963	6.4	5.0
Head and neck	155	5.9	4.9	826	5.5	4.3
Lung	583	22.0	18.3	3,340	22.3	17.4
Pancreas	181	6.8	5.7	938	6.3	4.9
Prostate	174	6.6	5.5	1,003	6.7	5.2
Other urological	115	4.3	3.6	593	4.0	3.1
Gynaecological	142	5.4	4.5	740	4.9	3.9
Skin	127	4.8	4.0	589	3.9	3.1
Unknown primary	68	2.6	2.1	372	2.5	1.9
Other primary malignancy	97	3.7	3.1	526	3.5	2.7
Malignant – not further defined	32	1.2	1.0	259	1.7	1.3
All malignant	2,646	100.0	83.2	14,952	100.0	77.8

Table 13 Primary diagnosis - non-malignant

Primary diagnosis	NSW Services			All Services		
	N	% non-malignant diagnosis	% all diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	90	17.3	2.8	733	17.5	3.8
HIV / AIDS	1	0.2	0.0	6	0.1	0.0
End stage kidney disease	61	11.8	1.9	392	9.4	2.0
Stroke	33	6.4	1.0	282	6.7	1.5
Motor neurone disease	25	4.8	0.8	207	4.9	1.1
Alzheimer's dementia	13	2.5	0.4	148	3.5	0.8
Other dementia	22	4.2	0.7	237	5.7	1.2
Other neurological disease	32	6.2	1.0	335	8.0	1.7
Respiratory failure	89	17.1	2.8	674	16.1	3.5
End stage liver disease	30	5.8	0.9	171	4.1	0.9
Diabetes and its complications	4	0.8	0.1	16	0.4	0.1
Sepsis	15	2.9	0.5	116	2.8	0.6
Multiple organ failure	9	1.7	0.3	91	2.2	0.5
Other non-malignancy	80	15.4	2.5	646	15.4	3.4
Non-malignant – not further defined	15	2.9	0.5	134	3.2	0.7
All non-malignant	519	100.0	16.3	4,188	100.0	21.8

3.2 Profile of palliative care episodes

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as an inpatient or community patient.

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

An episode of palliative care ends when:

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

Table 14 below presents the number and percentage of episodes by age group and sex for the patients seen by NSW 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	NSW Services				All Services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	0	0.0	0	0.0	36	0.3	26	0.2
15 - 24	3	0.2	4	0.2	31	0.2	26	0.2
25 - 34	7	0.4	8	0.5	106	0.8	90	0.8
35 - 44	38	2.0	41	2.4	278	2.2	390	3.4
45 - 54	112	5.9	134	7.7	725	5.7	926	8.1
55 - 64	290	15.3	260	15.0	2,009	15.8	1,786	15.5
65 - 74	484	25.5	409	23.6	3,313	26.1	2,669	23.2
75 - 84	600	31.6	486	28.1	3,750	29.6	3,008	26.2
85+	367	19.3	389	22.5	2,440	19.2	2,566	22.3
Not stated / inadequately described	0	0.0	0	0.0	0	0.0	0	0.0
Total	1,901	100.0	1,731	100.0	12,688	100.0	11,487	100.0

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

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

Table 15 Referral source by setting

Referral source	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Public hospital	1,785	49.1	7,216	57.9	na	na	6,559	56.0
Private hospital	87	2.4	1,015	8.1	na	na	1,157	9.9
Outpatient clinic	33	0.9	98	0.8	na	na	66	0.6
General medical practitioner	270	7.4	418	3.4	na	na	1,714	14.6
Specialist medical practitioner	418	11.5	567	4.5	na	na	467	4.0
Community-based palliative care agency	949	26.1	2,767	22.2	na	na	105	0.9
Community-based service	11	0.3	49	0.4	na	na	210	1.8
Residential aged care facility	13	0.4	54	0.4	na	na	788	6.7
Self, carer(s), family or friends	49	1.3	148	1.2	na	na	423	3.6
Other	14	0.4	115	0.9	na	na	193	1.6
Not stated / inadequately described	4	0.1	17	0.1	na	na	34	0.3
Total	3,633	100.0	12,464	100.0	na	na	11,716	100.0

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

Table 16 Referral to first contact by setting

Time (in days)	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Same day or following day	3,211	91.6	11,587	94.0	na	na	6,201	52.9
2-7 days	239	6.8	607	4.9	na	na	3,930	33.5
8-14 days	36	1.0	69	0.6	na	na	912	7.8
Greater than 14 days	21	0.6	66	0.5	na	na	671	5.7
Average	1.3	na	1.2	na	na	na	2.8	na
Median	1	na	1	na	na	na	1	na

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

Table 17 gives a summary of the length of episodes for patients in NSW and nationally. Table 18 details the length of episodes by setting. The length of an 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	
	NSW Services	All Services	NSW Services	All Services
Average length of episode	12.5	10.9	na	38.3
Median length of episode	8.0	6.0	na	27.0

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

Table 18 Length of episode (in days) by setting

Length of episode	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Same day	103	2.9	757	6.2	na	na	416	4.0
1-2 days	583	16.2	2,322	19.0	na	na	740	7.1
3-4 days	484	13.5	1,837	15.0	na	na	573	5.5
5-7 days	602	16.7	1,998	16.3	na	na	803	7.7
8-14 days	813	22.6	2,544	20.8	na	na	1,260	12.0
15-21 days	404	11.2	1,151	9.4	na	na	950	9.1
22-30 days	298	8.3	741	6.1	na	na	918	8.8
31-60 days	248	6.9	683	5.6	na	na	1,812	17.3
61-90 days	38	1.1	139	1.1	na	na	926	8.8
Greater than 90 days	23	0.6	68	0.6	na	na	2,077	19.8
Total	3,596	100.0	12,240	100.0	na	na	10,475	100.0

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

Table 19 How episodes start – inpatient setting

Episode start mode	NSW Services		All Services	
	N	%	N	%
Admitted from community*	1,888	52.0	7,274	58.4
Admitted from another hospital	1,133	31.2	3,156	25.3
Admitted from acute care in another ward	479	13.2	1,721	13.8
Change from acute care to palliative care – same ward	119	3.3	206	1.7
Other**	14	0.4	100	0.8
Not stated / inadequately described	0	0.0	7	0.1
Total	3,633	100.0	12,464	100.0

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

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

Table 20 How episodes end – inpatient setting

Episode end mode	NSW Services		All Services	
	N	%	N	%
Discharged to community*	1,057	29.4	4,285	35.0
Discharged to another hospital	219	6.1	749	6.1
Death	2,259	62.8	6,720	54.9
Change from palliative care to acute care**	17	0.5	59	0.5
Change in sub-acute care type	14	0.4	57	0.5
End of consultative episode – inpatient episode ongoing	0	0.0	260	2.1
Other	27	0.8	100	0.8
Not stated / inadequately described	3	0.1	10	0.1
Total	3,596	100.0	12,240	100.0

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

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

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

Table 21 How episodes start – community setting

Episode start mode	NSW Services		All Services	
	N	%	N	%
Admitted from inpatient palliative care	na	na	4,150	35.4
Other*	na	na	7,505	64.1
Not stated / inadequately described	na	na	61	0.5
Total	na	na	11,716	100.0

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

Table 22 How episodes end – community setting

Episode end mode	NSW Services		All Services	
	N	%	N	%
Admitted for inpatient palliative care	na	na	3,166	30.2
Admitted for inpatient acute care	na	na	2,902	27.7
Admitted to another palliative care service	na	na	180	1.7
Admitted to primary health care	na	na	252	2.4
Discharged / case closure	na	na	1,079	10.3
Death	na	na	2,715	25.9
Other	na	na	164	1.6
Not stated / inadequately described	na	na	17	0.2
Total	na	na	10,475	100.0

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

3.3 Profile of palliative care phases

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

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

Table 23 *Number of phases by phase type and setting*

Phase type	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Stable	2,721	26.8	7,474	25.4	na	na	9,994	37.7
Unstable	2,808	27.7	6,945	23.6	na	na	3,625	13.7
Deteriorating	2,632	25.9	9,150	31.1	na	na	10,802	40.7
Terminal	1,985	19.6	5,890	20.0	na	na	2,111	8.0
Total	10,146	100.0	29,459	100.0	na	na	26,532	100.0

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

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

Phase type	Inpatient		Community	
	NSW Services	All Services	NSW Services	All Services
Stable	8.0	7.3	na	20.9
Unstable	2.0	2.2	na	4.1
Deteriorating	4.8	5.4	na	12.9
Terminal	2.0	2.1	na	3.0

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

Table 25 presents information relating to the manner in which stable phases ended, both for NSW and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 15 summarises the movement of patients out of the stable phase for the inpatient and community settings. This movement from one phase to another is referred to as phase progression and is derived by PCOC.

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

Table 25 How stable phases end – by setting

How stable phases end	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	1,619	59.5	3,825	51.2	na	na	6,461	64.6
Discharge / case closure	1,063	39.1	3,559	47.6	na	na	3,194	32.0
Died	37	1.4	86	1.2	na	na	301	3.0
Not stated / inadequately described	2	0.1	4	0.1	na	na	38	0.4
Total	2,721	100.0	7,474	100.0	na	na	9,994	100.0

Figure 15 Stable phase progression

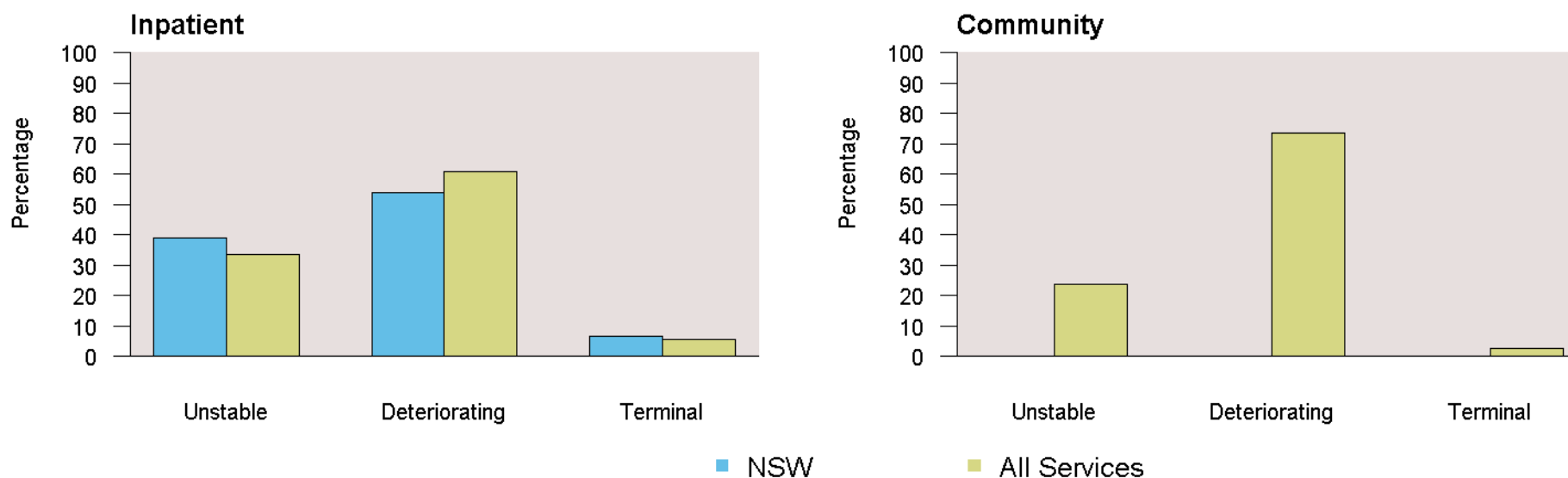


Table 26 How unstable phases end – by setting

How unstable phases end	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	2,673	95.2	6,296	90.7	na	na	2,400	66.2
Discharge / case closure	85	3.0	489	7.0	na	na	1,157	31.9
Died	50	1.8	156	2.2	na	na	65	1.8
Not stated / inadequately described	0	0.0	4	0.1	na	na	3	0.1
Total	2,808	100.0	6,945	100.0	na	na	3,625	100.0

Figure 16 Unstable phase progression

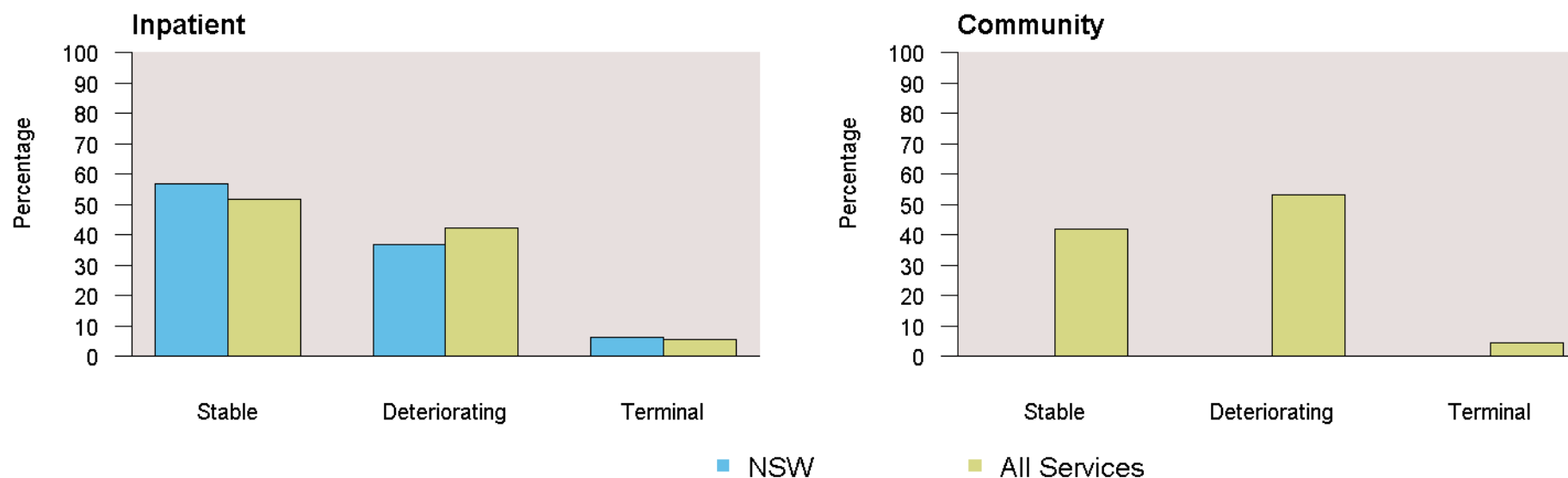


Table 27 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	2,187	83.1	6,834	74.7	na	na	6,853	63.4
Discharge / case closure	177	6.7	1,353	14.8	na	na	3,121	28.9
Died	268	10.2	958	10.5	na	na	794	7.4
Not stated / inadequately described	0	0.0	5	0.1	na	na	34	0.3
Total	2,632	100.0	9,150	100.0	na	na	10,802	100.0

Figure 17 Deteriorating phase progression

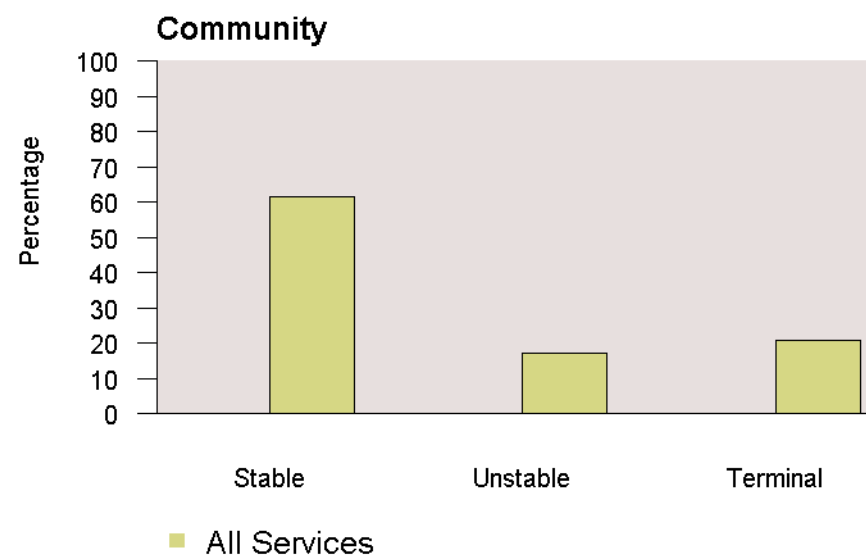
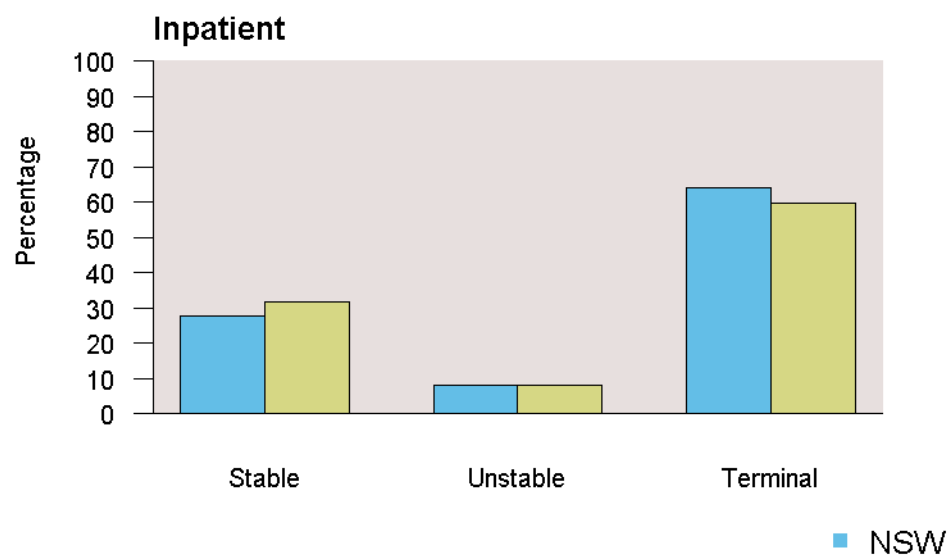
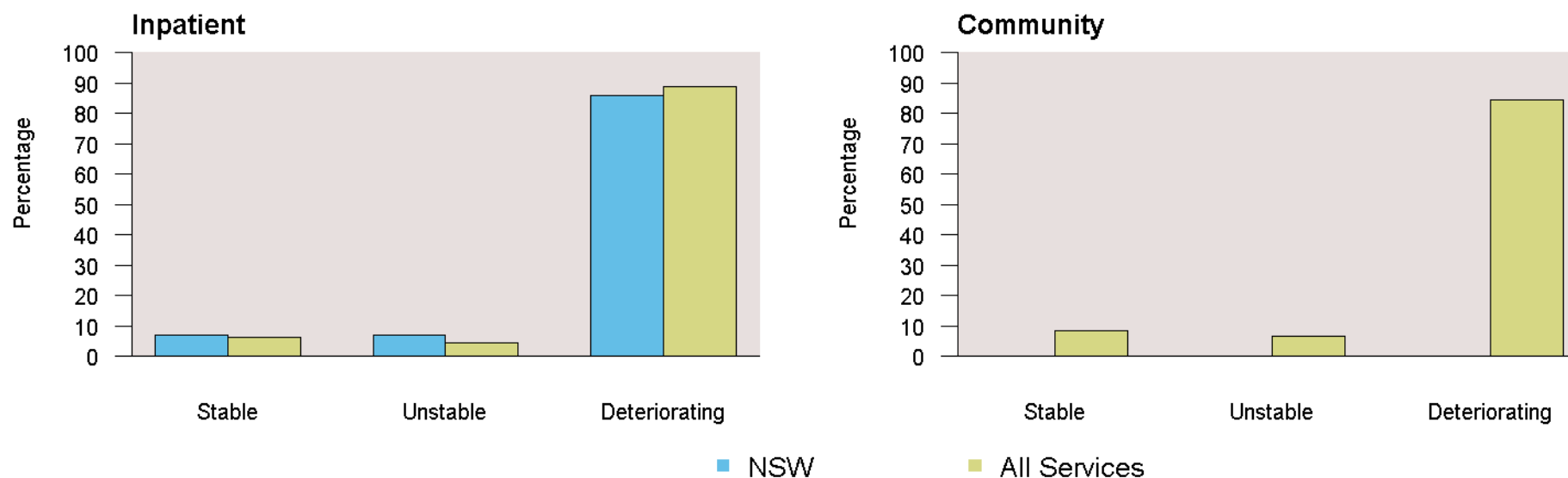


Table 28 How terminal phases end – by setting

How terminal phases end	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	71	3.6	265	4.5	na	na	340	16.1
Discharge / case closure	10	0.5	103	1.7	na	na	198	9.4
Died	1,904	95.9	5,516	93.7	na	na	1,567	74.2
Not stated / inadequately described	0	0.0	6	0.1	na	na	6	0.3
Total	1,985	100.0	5,890	100.0	na	na	2,111	100.0

Figure 18 Terminal phase progression



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

Table 29 and Table 30 show the percentage scores for the inpatient and community settings, respectively, for both NSW 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	Problem severity	NSW Services				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	47.0	37.7	12.7	2.5	48.6	37.6	11.6	2.2
	Other symptoms	26.4	51.8	18.5	3.2	29.1	51.2	16.9	2.8
	Psychological / spiritual	37.7	50.4	10.0	1.8	39.6	48.8	10.0	1.6
	Family / carer	39.1	47.6	11.3	2.1	43.0	44.3	10.5	2.3
Unstable	Pain	33.7	32.9	23.8	9.6	31.6	32.0	24.8	11.7
	Other symptoms	13.8	39.6	34.5	12.1	16.1	36.1	35.1	12.8
	Psychological / spiritual	29.1	48.0	18.2	4.8	27.5	45.4	21.3	5.8
	Family / carer	27.7	47.1	20.3	4.9	30.0	42.3	21.3	6.3
Deteriorating	Pain	37.2	40.0	18.6	4.3	39.0	36.6	19.0	5.4
	Other symptoms	14.9	45.1	33.4	6.5	18.4	41.9	31.8	7.9
	Psychological / spiritual	28.7	50.6	17.7	3.0	30.0	47.6	18.5	3.9
	Family / carer	24.8	49.3	21.4	4.5	29.4	42.9	21.9	5.8
Terminal	Pain	54.9	29.4	12.3	3.3	51.2	31.7	13.3	3.9
	Other symptoms	34.9	36.7	19.9	8.5	37.1	35.1	20.1	7.8
	Psychological / spiritual	52.2	34.9	10.1	2.8	53.4	32.6	10.8	3.2
	Family / carer	26.8	40.7	24.3	8.2	26.0	38.6	25.3	10.0

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

Phase type		NSW Services				All Services			
	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	na	na	na	na	40.8	51.4	7.3	0.6
	Other symptoms	na	na	na	na	16.1	66.5	16.1	1.3
	Psychological / spiritual	na	na	na	na	30.4	59.3	9.4	0.9
	Family / carer	na	na	na	na	30.6	54.0	13.7	1.6
Unstable	Pain	na	na	na	na	18.7	29.8	33.9	17.5
	Other symptoms	na	na	na	na	5.0	28.0	49.6	17.4
	Psychological / spiritual	na	na	na	na	12.4	46.5	34.0	7.1
	Family / carer	na	na	na	na	11.9	37.1	41.1	9.9
Deteriorating	Pain	na	na	na	na	29.2	49.3	19.0	2.4
	Other symptoms	na	na	na	na	8.3	50.7	37.1	4.0
	Psychological / spiritual	na	na	na	na	19.1	59.0	19.9	2.0
	Family / carer	na	na	na	na	17.4	51.3	27.3	3.9
Terminal	Pain	na	na	na	na	37.6	43.3	16.0	3.1
	Other symptoms	na	na	na	na	23.4	43.6	26.4	6.6
	Psychological / spiritual	na	na	na	na	43.6	40.8	13.0	2.6
	Family / carer	na	na	na	na	11.4	43.2	36.7	8.7

The Symptom Assessment Scale (SAS) is a patient rated (or proxy) assessment tool and reports a level of distress using a numerical rating scale from 0 - no distress to 10 - worst possible distress. The SAS reports on distress from seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient's perspective. The SAS scores are grouped in Table 31 and Table 32 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Alternative graphical representations of the SAS profile by phase type can be found in Appendix B.

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

Phase type	Symptom distress	NSW Services				All Services			
		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	70.8	16.9	10.2	2.2	69.4	17.1	11.1	2.5
	Appetite problems	55.8	22.5	18.3	3.3	58.0	22.3	16.6	3.1
	Nausea	79.3	12.2	7.2	1.3	80.3	12.4	6.2	1.1
	Bowel problems	64.2	19.1	14.1	2.6	63.6	20.6	12.9	2.9
	Breathing problems	70.0	15.6	11.3	3.1	66.4	17.6	12.6	3.4
	Fatigue	32.1	25.3	35.6	7.0	31.1	26.6	35.2	7.1
	Pain	46.1	31.1	20.0	2.9	46.6	31.3	19.4	2.8
Unstable	Difficulty sleeping	62.0	16.7	16.3	4.9	59.0	18.3	17.0	5.7
	Appetite problems	44.9	20.0	27.3	7.7	45.3	21.5	25.2	8.0
	Nausea	70.1	12.4	13.3	4.2	68.0	14.2	13.2	4.6
	Bowel problems	54.8	19.2	19.2	6.7	53.7	20.9	18.4	7.0
	Breathing problems	61.1	14.6	17.4	6.9	57.8	17.1	17.6	7.5
	Fatigue	25.1	18.1	42.2	14.6	23.7	19.9	41.3	15.1
	Pain	34.7	26.6	28.5	10.3	32.2	26.8	29.3	11.6
Deteriorating	Difficulty sleeping	75.9	11.9	10.0	2.1	72.4	13.9	11.3	2.4
	Appetite problems	56.0	16.5	21.2	6.2	55.0	19.4	19.5	6.1
	Nausea	79.5	9.2	8.6	2.7	77.7	10.8	8.8	2.7
	Bowel problems	64.1	18.9	13.9	3.2	62.1	19.8	14.2	3.9
	Breathing problems	62.5	16.5	15.4	5.6	59.1	17.7	16.9	6.3
	Fatigue	31.9	14.3	40.8	13.0	30.3	17.7	37.9	14.1
	Pain	40.4	30.3	24.3	5.0	39.9	30.0	24.3	5.8
Terminal	Difficulty sleeping	91.9	3.3	3.7	1.1	92.1	3.8	3.2	0.9
	Appetite problems	87.7	4.5	4.9	2.9	89.8	3.9	4.0	2.3
	Nausea	93.1	2.9	3.1	0.9	94.1	3.0	2.3	0.6
	Bowel problems	86.1	7.5	5.0	1.5	85.7	7.9	5.1	1.4
	Breathing problems	70.4	12.7	10.9	6.0	71.2	12.3	11.6	4.9
	Fatigue	73.3	7.5	10.7	8.5	75.8	5.9	10.4	7.8
	Pain	63.8	19.3	13.9	3.0	59.5	22.4	15.1	3.0

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

Phase type	Symptom distress	NSW Services				All Services			
		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	na	na	na	na	63.2	26.5	9.4	0.9
	Appetite problems	na	na	na	na	49.2	33.4	15.1	2.3
	Nausea	na	na	na	na	80.4	15.8	3.4	0.5
	Bowel problems	na	na	na	na	66.4	25.8	6.8	1.0
	Breathing problems	na	na	na	na	54.3	30.6	13.3	1.8
	Fatigue	na	na	na	na	15.1	35.7	43.9	5.3
	Pain	na	na	na	na	43.8	42.3	12.6	1.2
Unstable	Difficulty sleeping	na	na	na	na	43.0	26.7	24.2	6.1
	Appetite problems	na	na	na	na	32.2	26.8	30.9	10.0
	Nausea	na	na	na	na	60.3	18.7	15.2	5.8
	Bowel problems	na	na	na	na	51.2	26.8	16.8	5.3
	Breathing problems	na	na	na	na	44.9	28.1	20.7	6.3
	Fatigue	na	na	na	na	8.9	20.8	52.6	17.8
	Pain	na	na	na	na	20.2	23.9	37.7	18.2
Deteriorating	Difficulty sleeping	na	na	na	na	57.4	26.9	13.9	1.7
	Appetite problems	na	na	na	na	39.8	32.4	23.0	4.8
	Nausea	na	na	na	na	72.8	19.0	7.2	1.1
	Bowel problems	na	na	na	na	60.3	26.9	11.1	1.6
	Breathing problems	na	na	na	na	47.9	30.7	18.7	2.6
	Fatigue	na	na	na	na	12.2	23.0	52.3	12.4
	Pain	na	na	na	na	33.2	39.5	24.0	3.3
Terminal	Difficulty sleeping	na	na	na	na	75.8	13.3	9.0	1.9
	Appetite problems	na	na	na	na	79.0	7.5	6.2	7.3
	Nausea	na	na	na	na	83.9	10.8	4.6	0.7
	Bowel problems	na	na	na	na	73.2	18.0	7.8	1.0
	Breathing problems	na	na	na	na	55.7	24.0	16.1	4.2
	Fatigue	na	na	na	na	58.4	7.0	15.6	19.0
	Pain	na	na	na	na	40.2	35.0	21.3	3.5

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. Table 33 shows the data for the AKPS at phase start.

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

AKPS assessment at phase start	Inpatient				Community			
	NSW Services		All Services		NSW Services		All Services	
	N	%	N	%	N	%	N	%
10 - Comatose or barely rousable	927	9.1	3,099	10.5	na	na	915	3.4
20 - Totally bedfast and requiring extensive nursing care	2,272	22.4	6,617	22.5	na	na	2,569	9.7
30 - Almost completely bedfast	1,212	11.9	3,735	12.7	na	na	1,906	7.2
40 - In bed more than 50% of the time	1,941	19.1	5,608	19.0	na	na	3,438	13.0
50 - Requires considerable assistance	1,365	13.5	4,971	16.9	na	na	6,369	24.0
60 - Requires occasional assistance	852	8.4	3,053	10.4	na	na	6,553	24.7
70 - Cares for self	145	1.4	657	2.2	na	na	3,168	11.9
80 - Normal activity with effort	56	0.6	209	0.7	na	na	741	2.8
90 - Able to carry on normal activity; minor signs or symptoms	31	0.3	76	0.3	na	na	135	0.5
100 - Normal; no complaints; no evidence of disease	0	0.0	2	0.0	na	na	11	0.0
Not stated/inadequately described	1,345	13.3	1,432	4.9	na	na	727	2.7
Total	10,146	100.0	29,459	100.0	na	na	26,532	100.0

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. Figure 19 and Figure 20 on the following two pages summarise the total RUG-ADL at the beginning of each phase for inpatients and community patients. The total score on the RUG-ADL ranges from a minimum of 4 (lowest level of functional dependency) to a maximum of 18 (highest level of functional dependency).

AKPS & RUG-ADL can be used together to provide a profile of both patient dependency, equipment requirements, need for allied health referrals and carer burden/respite requirements.

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

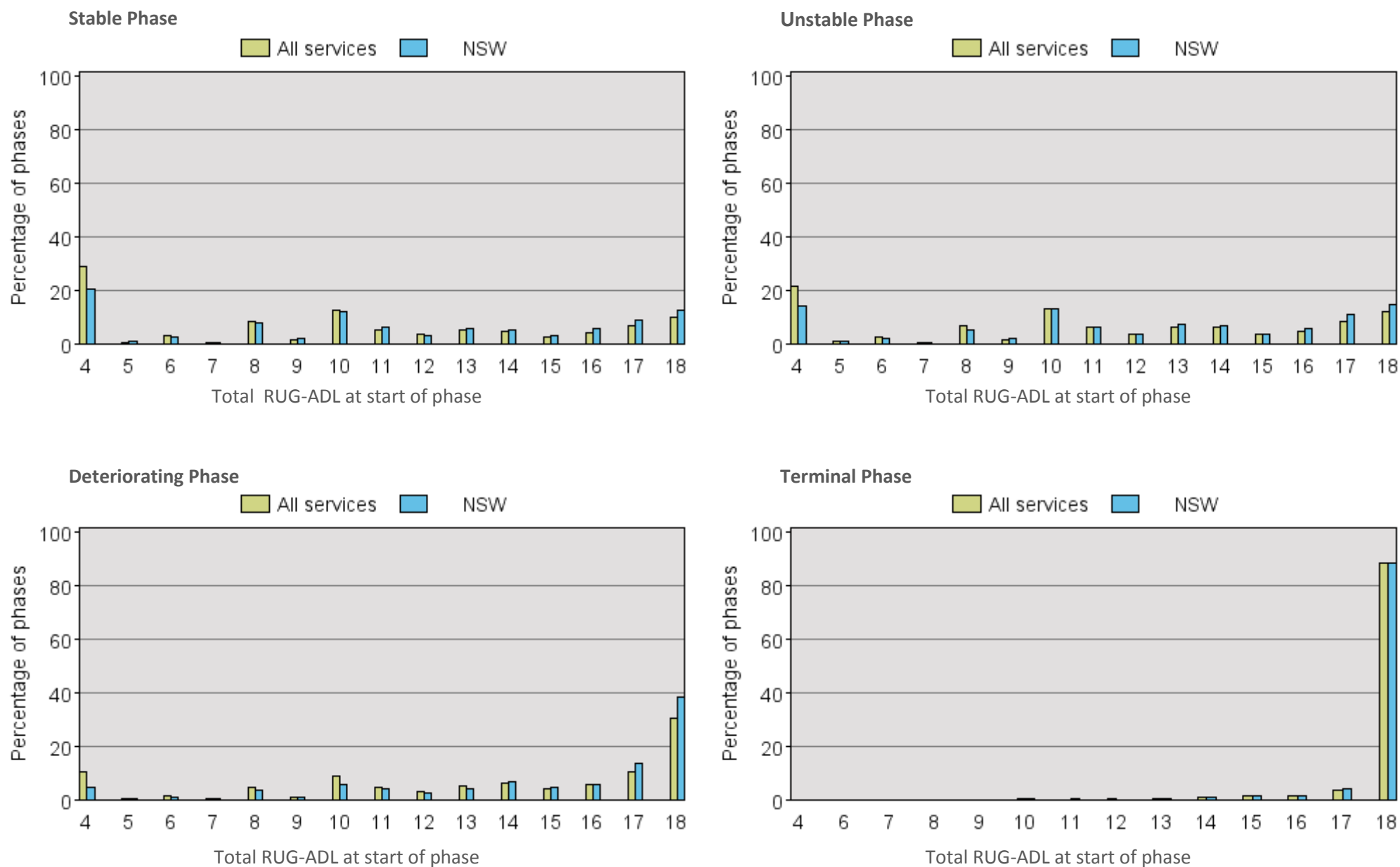
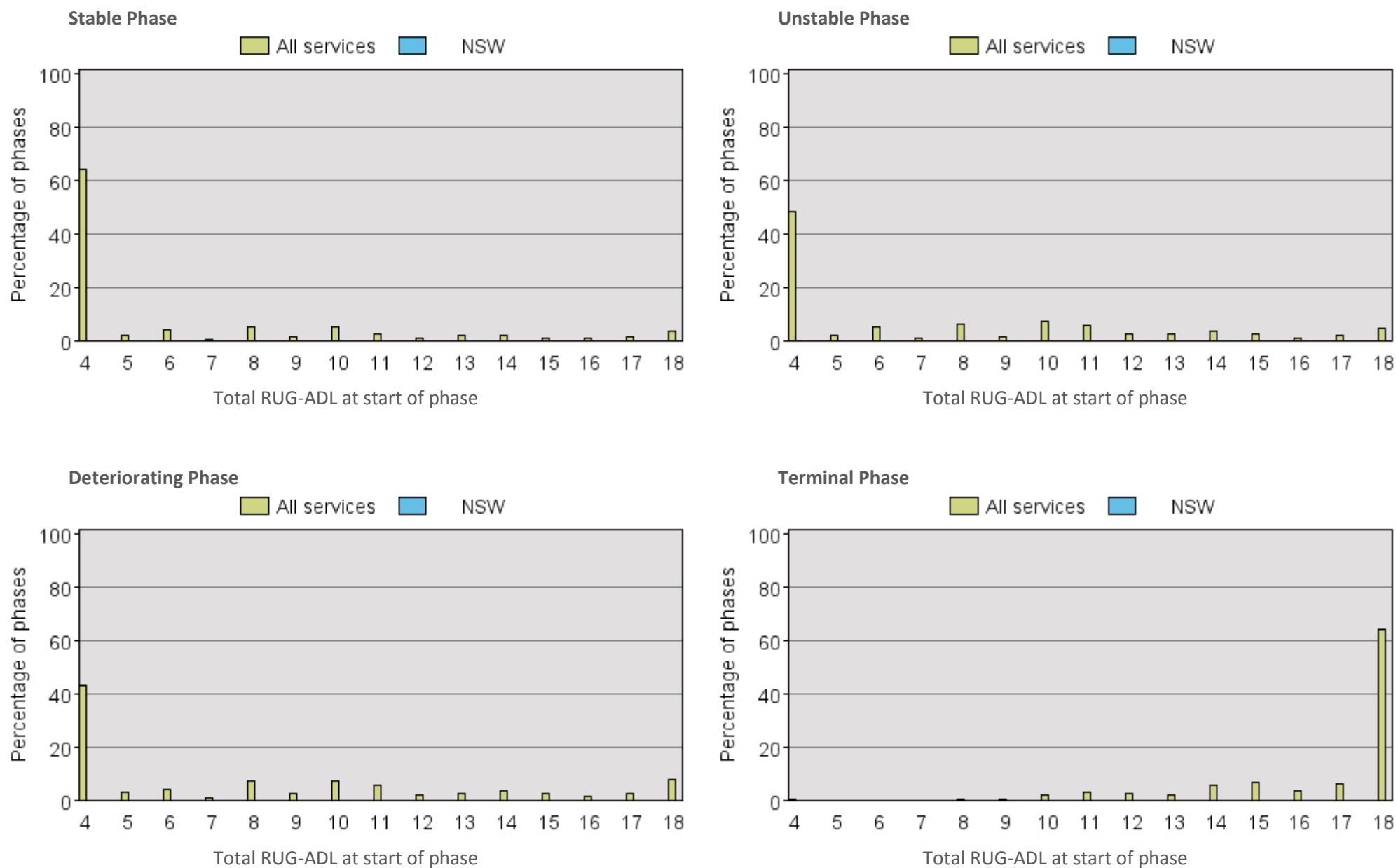


Figure 20 Total RUG-ADL at beginning of phase by phase type – community setting



Appendix A Summary of data included in this report

A1 Data summary

During the reporting period, data were provided for a total of 19,220 patients who between them had 24,180 episodes of care and 55,991 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Appendix C contains a more detailed explanation of this process). Table 34 shows the number of patients, episodes and phases included in this report – both for NSW and nationally.

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

	Inpatient		Community		Total	
	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services
Number of patients*	3,180	10,692	0	9,391	3,180	19,220
Number of episodes	3,633	12,464	0	11,716	3,633	24,180
Number of phases**	10,146	29,459	0	26,532	10,146	55,991
Percentage of patients*	100.0	55.6	0.0	48.9	100	100
Percentage of episodes	100.0	51.5	0.0	48.5	100	100
Percentage of phases	100.0	52.6	0.0	47.4	100	100
Average number of phases per episode***	2.8	2.3	na	2.1	2.8	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 NSW services.

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

		Jan	Feb	Mar	Apr	May	Jun
Inpatient	No. of completed episodes	588	582	633	561	640	592
	No. of completed phases	1,759	1,648	1,858	1,663	1,768	1,450
Community	No. of completed episodes	0	0	0	0	0	0
	No. of completed phases	0	0	0	0	0	0

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

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

	Inpatient						Community					
	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2014	Jan-Jun 2015	Jul-Dec 2012	Jan-Jun 2013	Jul-Dec 2013	Jan-Jun 2014	Jul-Dec 2014	Jan-Jun 2015
Number of patients*	2,921	2,856	3,006	2,721	2,855	3,180	0	0	0	0	0	0
Number of episodes	3,362	3,197	3,393	3,109	3,338	3,633	0	0	0	0	0	0
Number of phases**	9,197	9,182	10,141	8,869	9,537	10,146	0	0	0	0	0	0
Average number of phases per episode***	2.8	2.9	3.0	2.8	2.9	2.8	na	na	na	na	na	na

* 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	NSW Services	All Services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	99.8	97.9
Country of birth	99.4	98.5
Preferred language	99.3	99.2
Primary diagnosis	99.5	99.6

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

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

Data item	Inpatient		Community		Total	
	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services
Date of first contact	96.5	98.9	na	100.0	96.5	99.4
Referral date	96.5	98.9	na	100.0	96.5	99.4
Referral source	99.9	99.9	na	99.7	99.9	99.8
Date ready for care	85.2	95.6	na	99.9	85.2	97.7
Mode of episode start	100.0	99.9	na	99.5	100.0	99.7
Accommodation at episode start	100.0	99.9	na	96.6	100.0	97.9
Episode end date*	100.0	99.8	na	94.0	100.0	97.0
Mode of episode end	99.9	99.9	na	99.8	99.9	99.9
Accommodation at episode end	99.9	99.3	na	89.9	99.9	96.8
Place of death	na	na	na	94.4	na	94.4

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

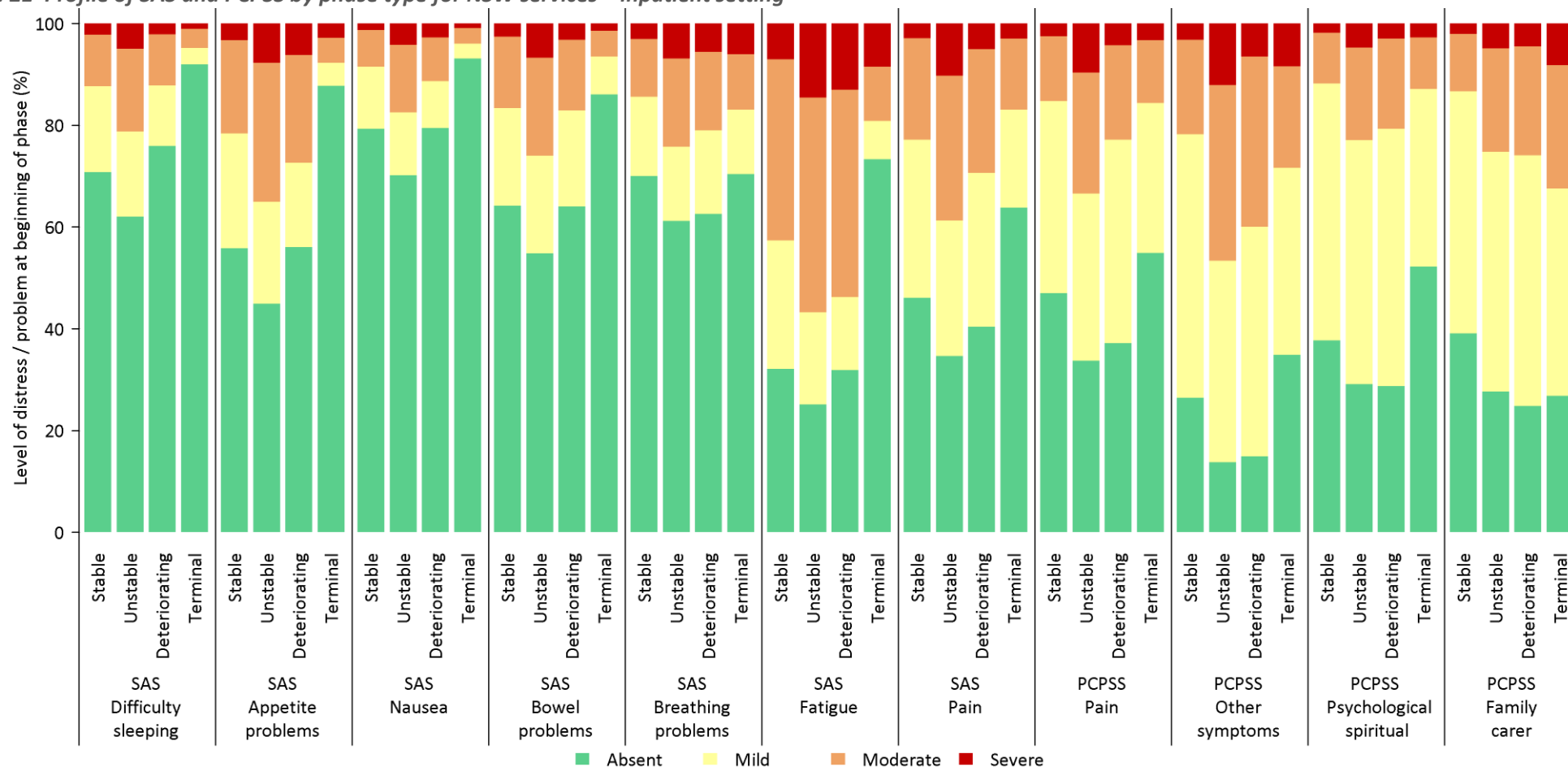
Table 39 Item completion by setting (per cent complete) - phase level

Data item	Sub-Category (where applicable)	At phase start						At discharge					
		Inpatient		Community		Total		Inpatient		Community		Total	
		NSW Services	All Services	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services
RUG-ADL	Bed mobility	100.0	99.7	na	96.9	100.0	98.3	96.9	91.4	na	60.9	96.9	73.6
	Toileting	100.0	99.7	na	96.7	100.0	98.3	96.9	91.3	na	60.9	96.9	73.6
	Transfers	100.0	99.7	na	96.5	100.0	98.2	96.9	91.3	na	60.8	96.9	73.6
	Eating	100.0	99.4	na	95.8	100.0	97.7	96.9	91.3	na	60.6	96.9	73.4
PCPSS	Pain	99.9	99.1	na	96.9	99.9	98.1	96.9	91.0	na	60.4	96.9	73.2
	Other symptom	99.9	97.4	na	95.0	99.9	96.2	96.8	90.0	na	59.7	96.8	72.3
	Psychological / spiritual	99.9	99.3	na	96.2	99.9	97.9	96.9	91.0	na	60.1	96.9	73.0
	Family / carer	99.9	98.0	na	95.3	99.9	96.7	96.9	87.7	na	59.9	96.9	71.5
SAS	Difficulty sleeping	98.5	93.9	na	92.9	98.5	93.4	90.9	79.6	na	57.2	90.9	66.6
	Appetite problems	98.5	94.1	na	95.1	98.5	94.6	90.9	80.2	na	59.3	90.9	68.0
	Nausea	98.5	94.1	na	96.2	98.5	95.1	90.9	79.6	na	60.0	90.9	68.2
	Bowel problems	98.5	94.0	na	95.2	98.5	94.5	90.9	80.1	na	58.9	90.9	67.8
	Breathing problems	98.5	94.2	na	95.6	98.5	94.8	90.9	79.9	na	59.5	90.9	68.0
	Fatigue	98.5	94.1	na	96.2	98.5	95.1	90.9	80.5	na	60.2	90.9	68.7
	Pain	98.5	94.2	na	97.4	98.5	95.7	90.9	80.5	na	61.0	90.9	69.1
AKPS	-	86.7	95.1	na	97.3	86.7	96.1	88.0	89.4	na	63.0	88.0	74.1

Data item	Inpatient		Community		Total	
	NSW Services	All Services	NSW Services	All Services	NSW Services	All Services
Phase End Reason	100.0	99.9	na	99.5	100.0	99.7

Appendix B Additional information on profile of SAS and PCPSS

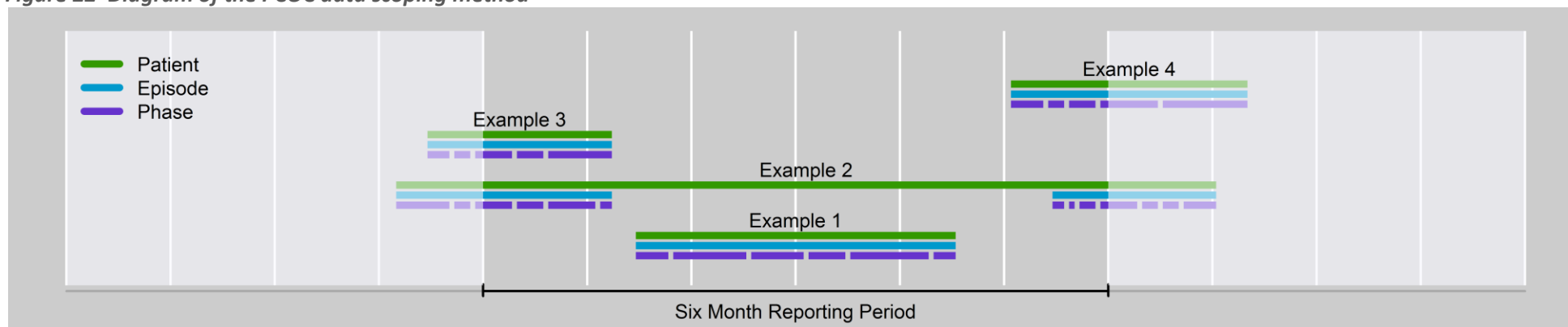
Figure 21 Profile of SAS and PCPSS by phase type for NSW services – inpatient setting



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 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.

Appendix D Palliative Care Phase definitions

START	END
1. Stable	
<p>Patient problems and symptoms are adequately controlled by established plan of care and</p> <ul style="list-style-type: none"> Further interventions to maintain symptom control and quality of life have been planned and Family / carer situation is relatively stable and no new issues are apparent. 	<p>The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care.</p>
2. 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).
3. Deteriorating	
<p>The care plan is addressing anticipated needs but requires periodic review because</p> <ul style="list-style-type: none"> Patients overall functional status is declining and Patient experiences a gradual worsening of existing problem and / or Patient experiences a new but anticipated problem and / or Family / carers experience gradual worsening distress that impacts on the patient care. 	<ul style="list-style-type: none"> Patient condition plateaus (i.e. patient is now stable) or An urgent change in the care plan or emergency treatment and / or Family / carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) or Death is likely within days (i.e. patient is now terminal).
4. 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).
5. Bereavement – post death support	
<ul style="list-style-type: none"> The patient has died Bereavement support provided to family / carers is documented in the deceased patient's clinical record. 	<ul style="list-style-type: none"> Case closure <p>Note: If counselling is provided to a family member or carer, they become a client in their own right.</p>

Acknowledgements

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<i>Disclaimer</i>	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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