



New South Wales and  
Australian Capital Territory

# 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](http://www.pcoc.org.au)

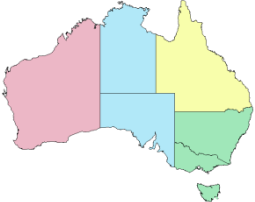




## About the Palliative Care Outcomes Collaboration

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		<b>Professor Kathy Eagar</b> , Australian Health Services Research Institute, University of Wollongong
	North Zone		<b>Professor Patsy Yates</b> , Institute of Health and Biomedical Innovation, Queensland University of Technology
	South Zone		<b>Professor David Currow</b> , Department of Palliative and Supportive Services, Flinders University
	West Zone		<b>Dr Claire Johnson</b> , 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](mailto: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 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 NSW and ACT 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 NSW and ACT figures in this report are based on information submitted by 27 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](http://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:

- |           |                                                                                                 |
|-----------|-------------------------------------------------------------------------------------------------|
| <b>na</b> | <b>The item is not applicable.</b>                                                              |
| <b>u</b>  | <b>The item was unavailable.</b>                                                                |
| <b>s</b>  | <b>The item was suppressed due to insufficient data as there was less than 10 observations.</b> |

**Table 1 List of NSW and ACT services included in this report**

Service name	Setting of care
Calvary Health Care Canberra (Clare Holland House)	Inpatient and community
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
Liverpool Hospital	Inpatient
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 and community
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



## Section 1 Benchmark summary

### 1.1 NSW and ACT services at a glance

*Table 2 Summary of outcome measures by setting*

Outcome measure	Description	Benchmark	Inpatient		Community	
			NSW/ACT Score	Benchmark Met?	NSW/ACT Score	Benchmark Met?
1. Time from date ready for care to episode start	Benchmark 1: Patients episode commences on the day of, or the day after date ready for care	90%	97.1	Yes	89.0	No*
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	83.2	No	82.5	No
3. Change in pain	Benchmark 3.1: PCPSS Patients with absent or mild pain at phase start, remaining absent or mild at phase end	90%	91.4	Yes	83.1	No
	Benchmark 3.2: PCPSS Patients with moderate or severe pain at phase start, with absent or mild pain at phase end	60%	57.2	No	43.7	No
	Benchmark 3.3: SAS Patients with absent or mild distress from pain at phase start, remaining absent or mild at phase end	90%	89.3	No	80.2	No
	Benchmark 3.4: SAS Patients with moderate or severe distress from pain at phase start, with absent or mild at phase end	60%	52.7	No	37.7	No
4. Average improvement on the 2014 baseline national average (X-CAS)	Benchmark 4.1: Pain (PCPSS)	0.0	0.10	Yes	-0.13	No
	Benchmark 4.2: Other symptoms (PCPSS)	0.0	0.19	Yes	-0.16	No
	Benchmark 4.3: Family / carer (PCPSS)	0.0	0.11	Yes	-0.19	No
	Benchmark 4.4: Psychological / spiritual (PCPSS)	0.0	0.15	Yes	-0.11	No
	Benchmark 4.5: Pain (SAS)	0.0	0.30	Yes	-0.54	No
	Benchmark 4.6: Nausea (SAS)	0.0	0.16	Yes	-0.19	No
	Benchmark 4.7: Breathing problems (SAS)	0.0	0.27	Yes	-0.32	No
	Benchmark 4.8: Bowel problems (SAS)	0.0	0.21	Yes	-0.25	No

\*The item completion for this benchmark was less than 80%. This result may not be reflective of NSW and ACT. See Appendix A for more details.

## 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:***

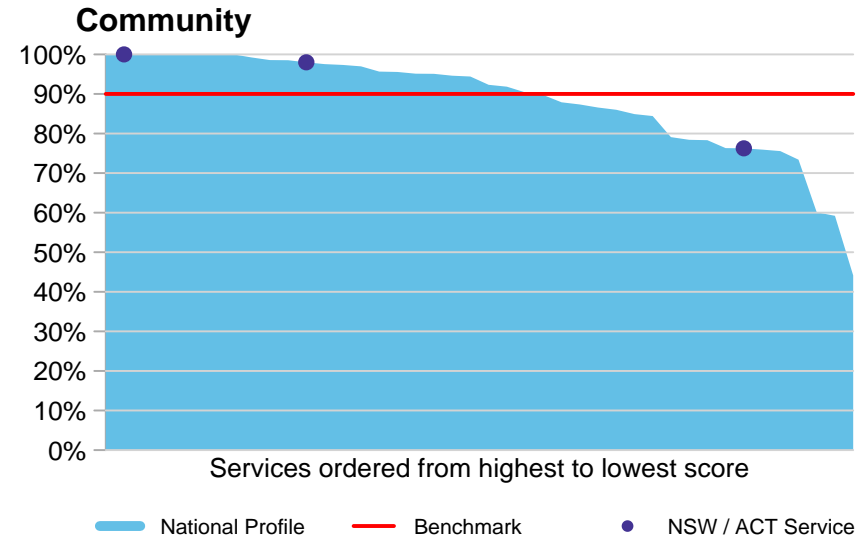
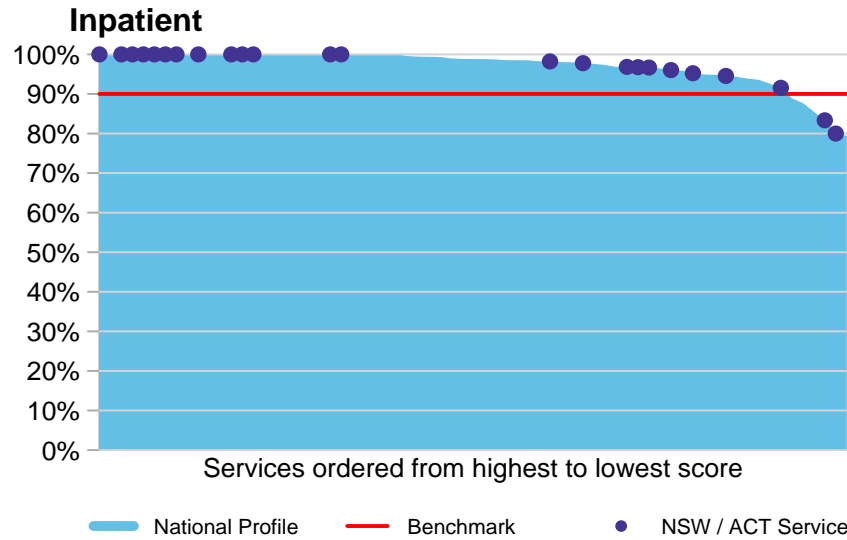
The national profile graphs on the following pages present NSW and ACT services in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. NSW and ACT services are highlighted as dots on the graph.

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.

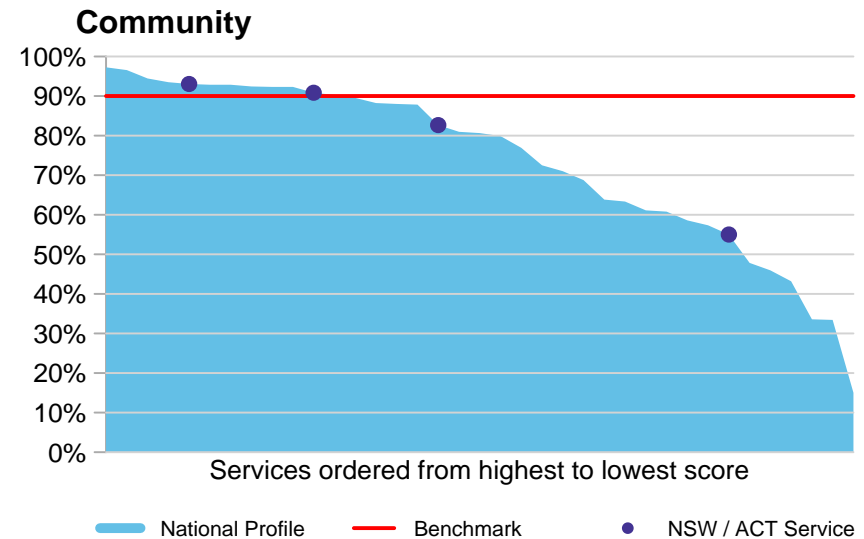
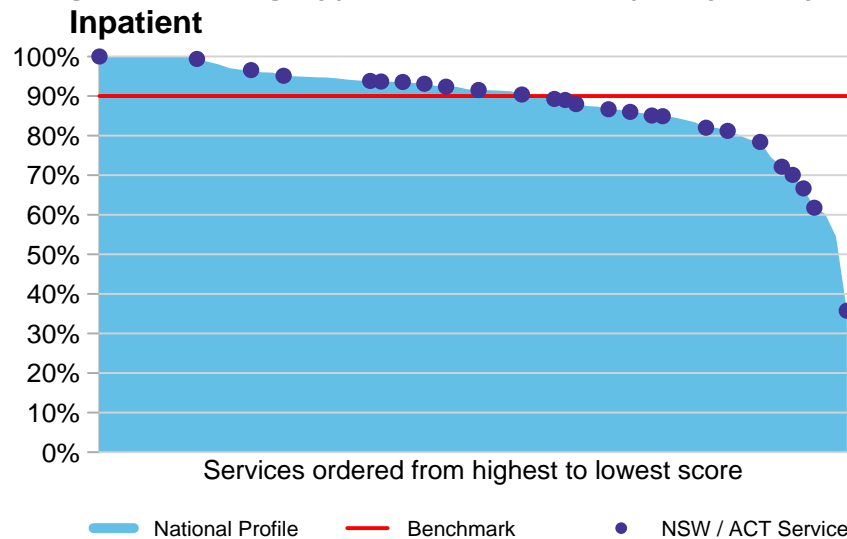
**Outcome measure 1 – Time from date ready for care to episode start**

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



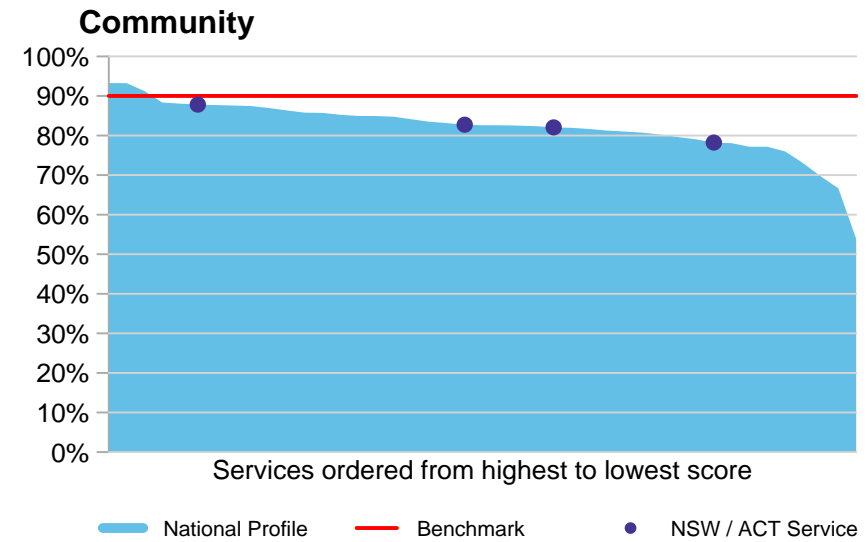
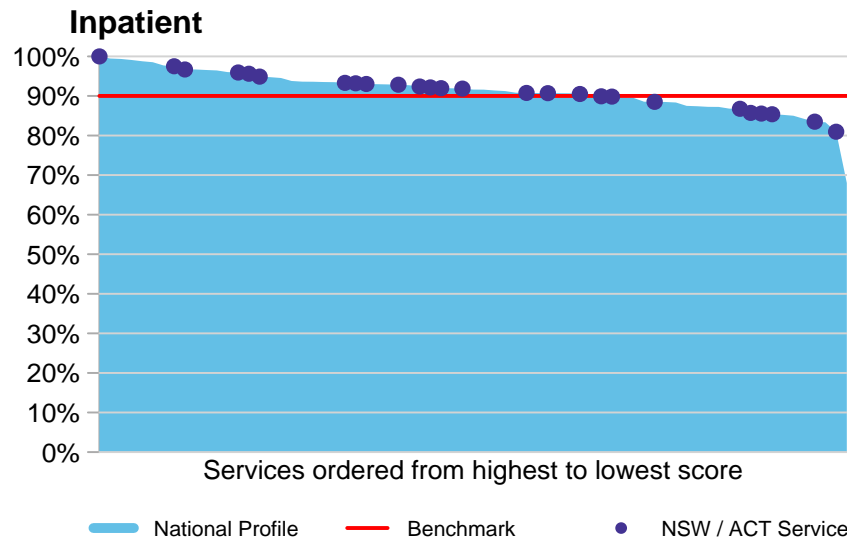
**Outcome measure 2 – Time in unstable phase**

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

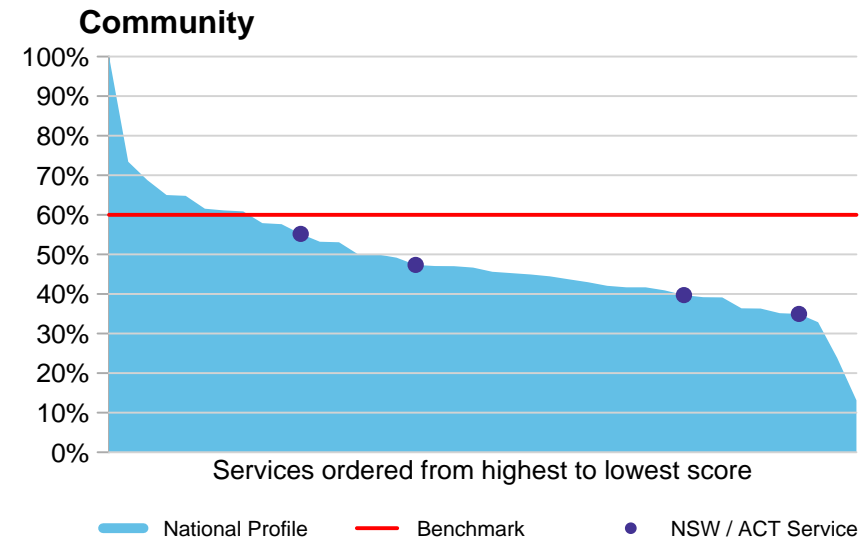
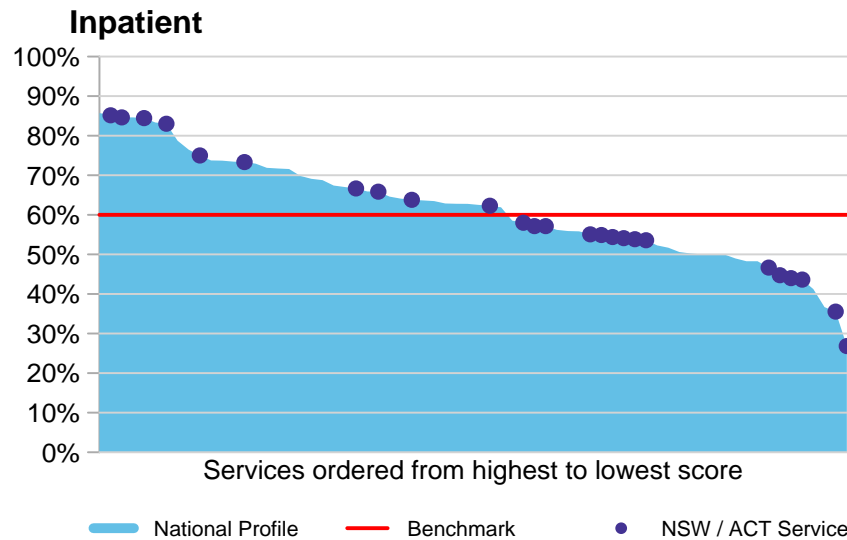


**Outcome measure 3 – Change in pain**

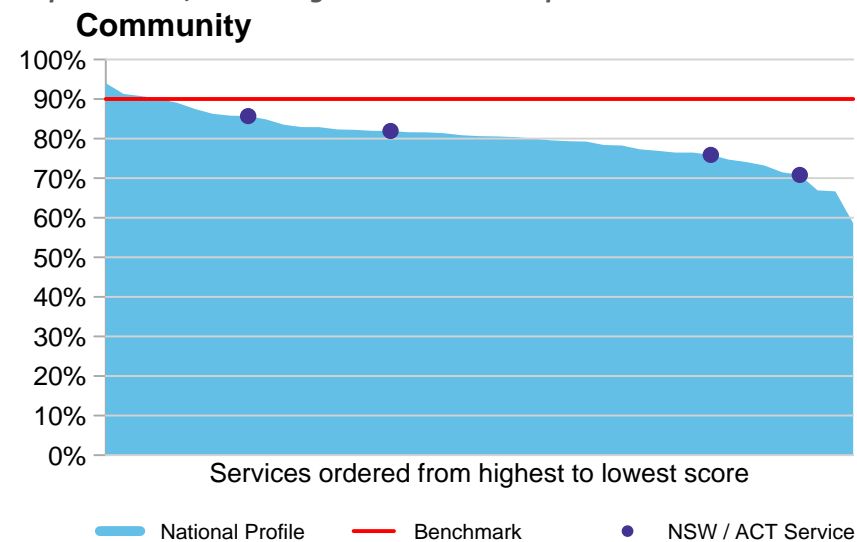
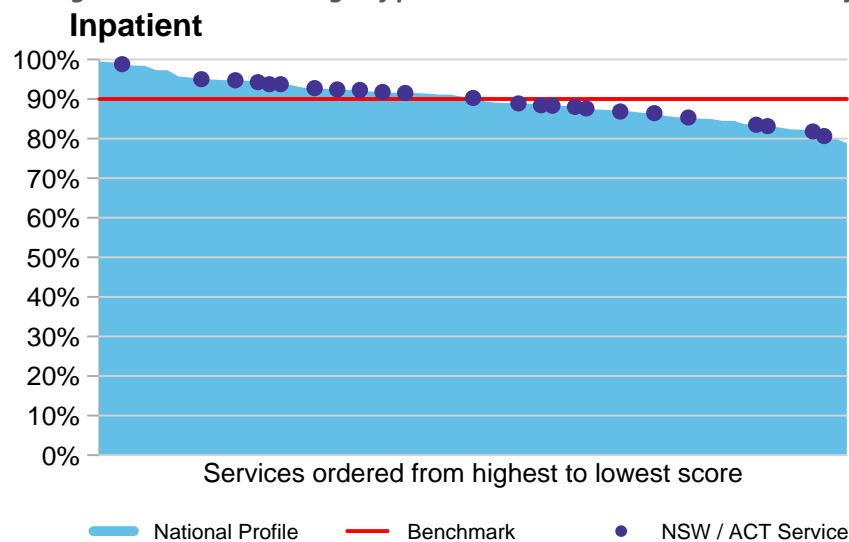
*Figure 3 PCPSS: Percentage of patients with absent or mild pain at phase start, remaining absent or mild at phase end*



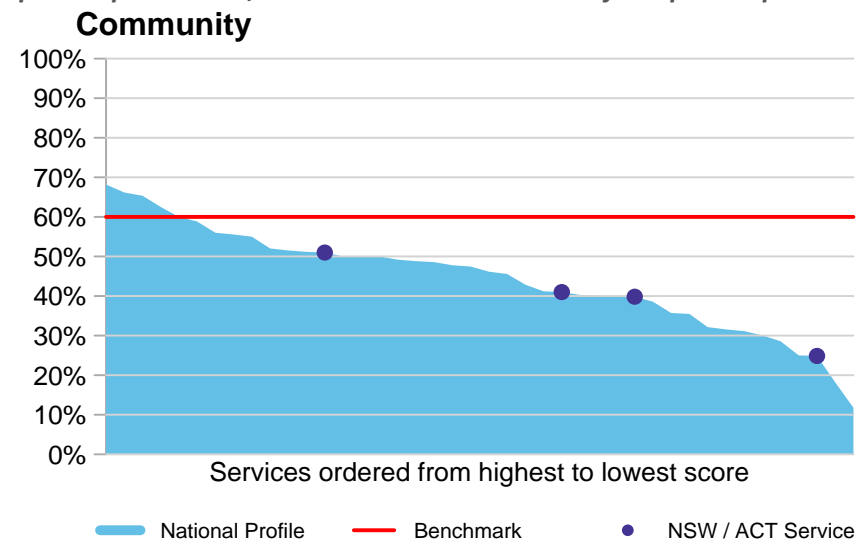
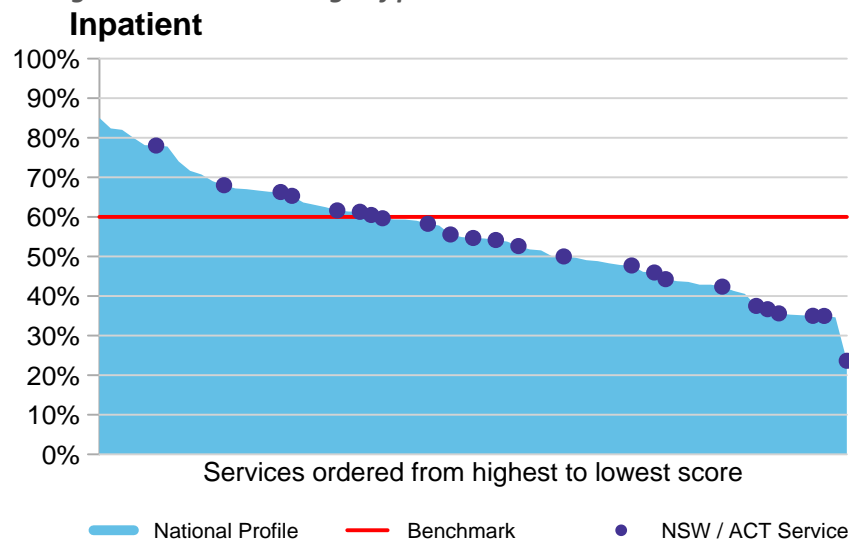
*Figure 4 PCPSS: Percentage of patients with moderate or severe pain at phase start, with absent or mild pain at phase end*



**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

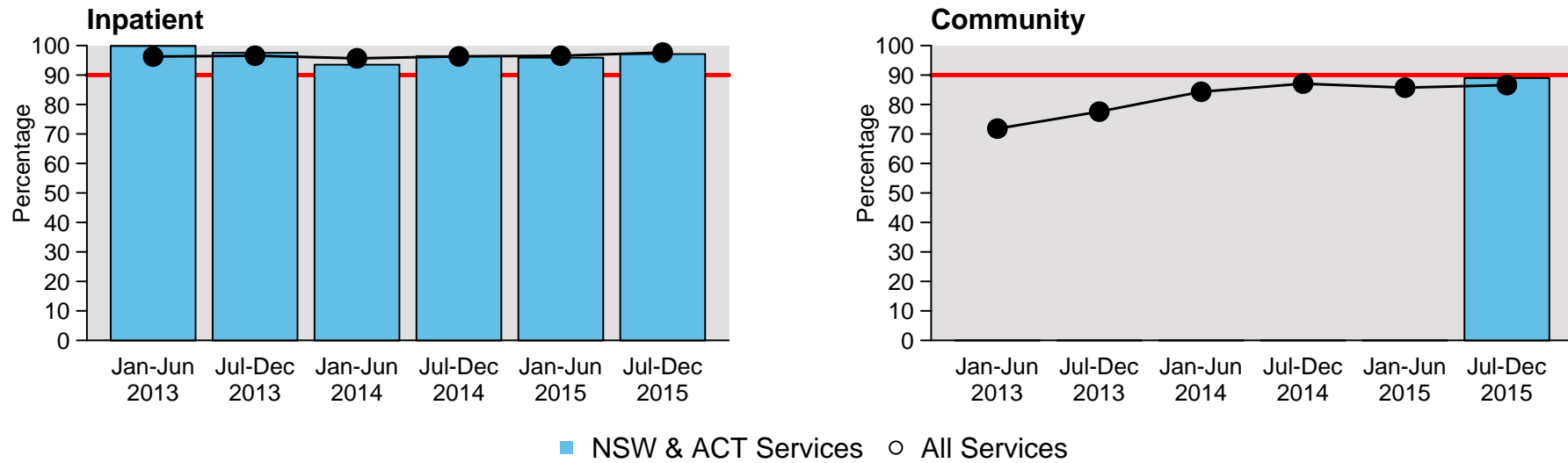
Time (in days)	Inpatient				Community			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Same day	3,267	93.3	11,313	92.8	589	85.4	8,656	81.7
Following day	132	3.8	584	4.8	25	3.6	519	4.9
2-7 days	85	2.4	258	2.1	40	5.8	1,064	10.0
8-14 days	14	0.4	24	0.2	21	3.0	223	2.1
Greater than 14 days	2	0.1	9	0.1	15	2.2	135	1.3
Average	1.1	na	1.1	na	2.4	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.

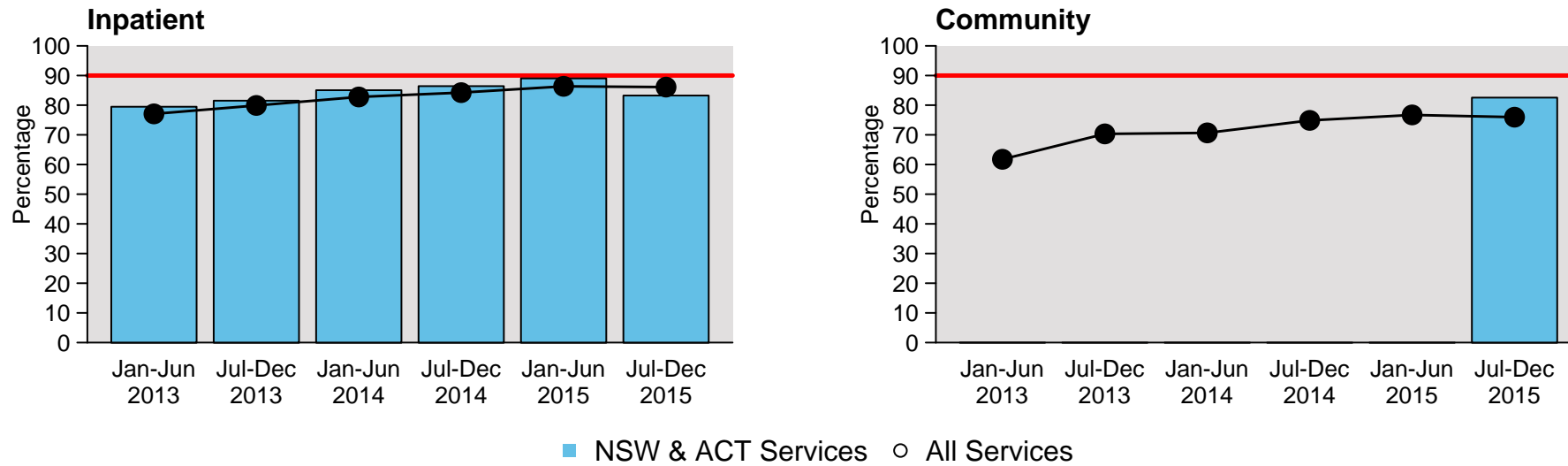
**Benchmark 2:** This benchmark relates to the time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for 3 days or less.

**Table 4 Time in unstable phase by setting**

Time in unstable phase	Inpatient				Community			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Same day	58	1.9	279	4.0	58	12.5	899	23.9
1 day	1,401	46.5	3,292	47.5	207	44.6	1,255	33.3
2 days	731	24.3	1,647	23.8	73	15.7	444	11.8
3 days	318	10.6	750	10.8	45	9.7	261	6.9
4-5 days	271	9.0	572	8.3	28	6.0	237	6.3
6-7 days	101	3.4	192	2.8	20	4.3	211	5.6
8-14 days	92	3.1	148	2.1	13	2.8	213	5.7
Greater than 14 days	41	1.4	52	0.8	20	4.3	244	6.5
<i>Total</i>	<i>3,013</i>	<i>100.0</i>	<i>6,932</i>	<i>100.0</i>	<i>464</i>	<i>100.0</i>	<i>3,764</i>	<i>100.0</i>



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



## 2.3 Outcome measure 3 – Change in pain

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

Scores for PCPSS  
0 absent  
1 mild  
2 moderate  
3 severe

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

### **Interpretation hint:**

This outcome measure should be viewed in conjunction with Table 28 to Table 31 and Appendix B.

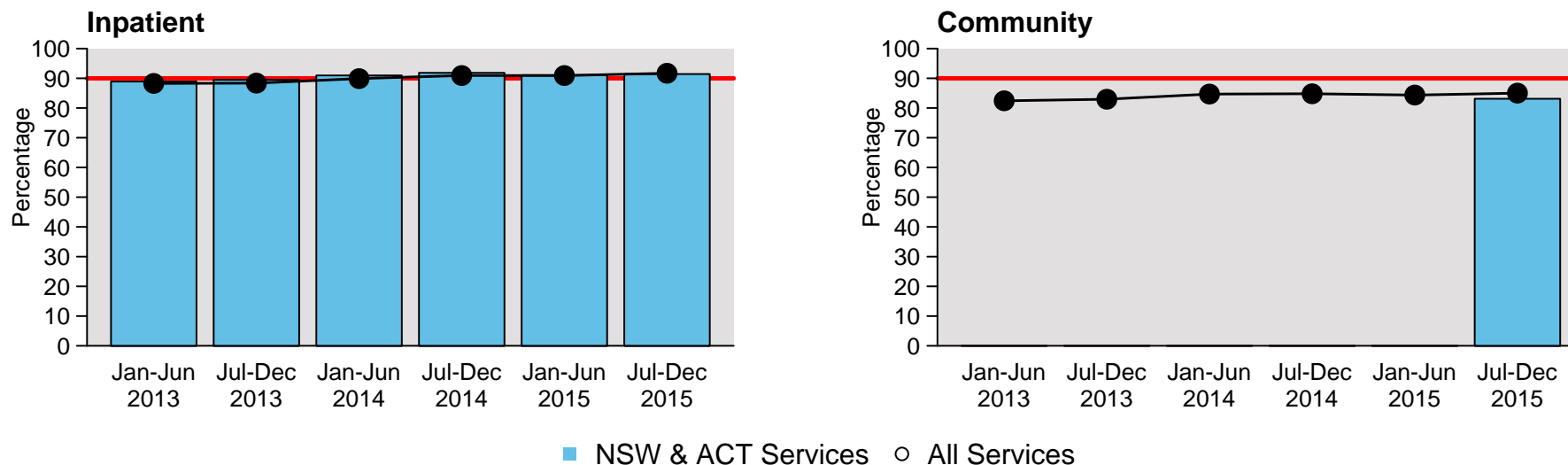
- Benchmark 3.1:** This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild pain.
- Benchmark 3.2:**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

**Table 5 Summary of outcome measure 3**

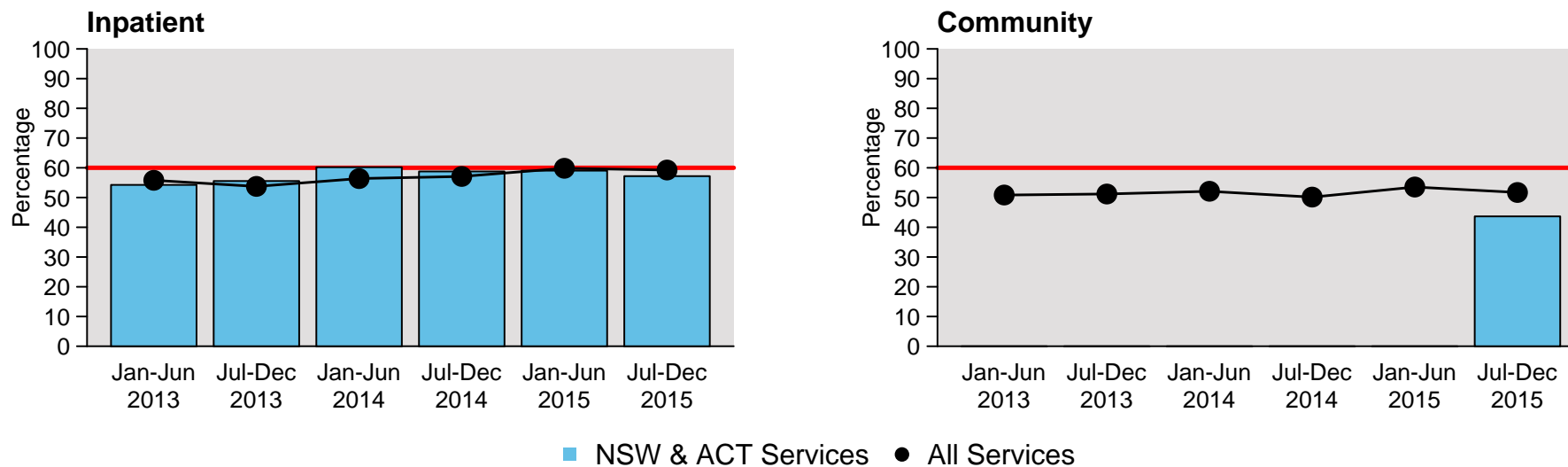
Benchmarks: change in pain	Inpatient				Community			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N*	%	N*	%	N*	%	N*	%
Benchmark 3.1: PCPSS (severity)	6,553	91.4	17,454	91.7	1,511	83.1	16,664	85.0
Benchmark 3.2: PCPSS (severity)	1,972	57.2	5,276	59.2	520	43.7	4,172	51.7
Benchmark 3.3: SAS (distress)	5,582	89.3	14,607	89.9	1,315	80.2	15,766	82.0
Benchmark 3.4: SAS (distress)	2,458	52.7	6,460	54.1	597	37.7	5,307	48.6

\*Total number of phases included in this benchmark.

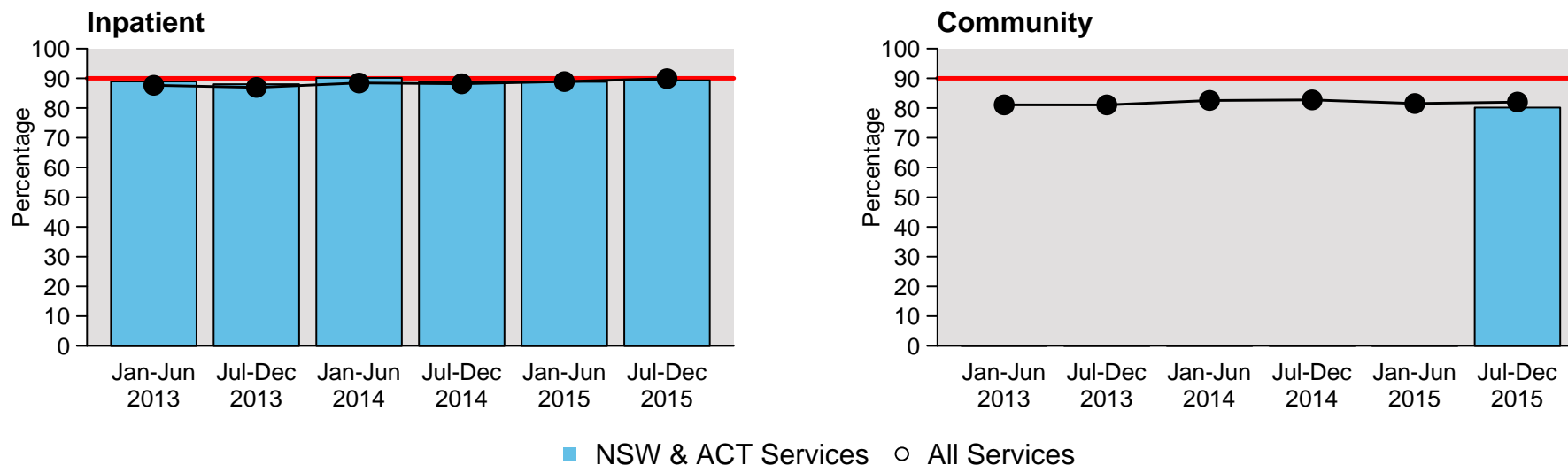
**Figure 9 Trends in benchmark 3.1: Patients with absent or mild pain at phase start, remaining absent or mild at phase end by setting**



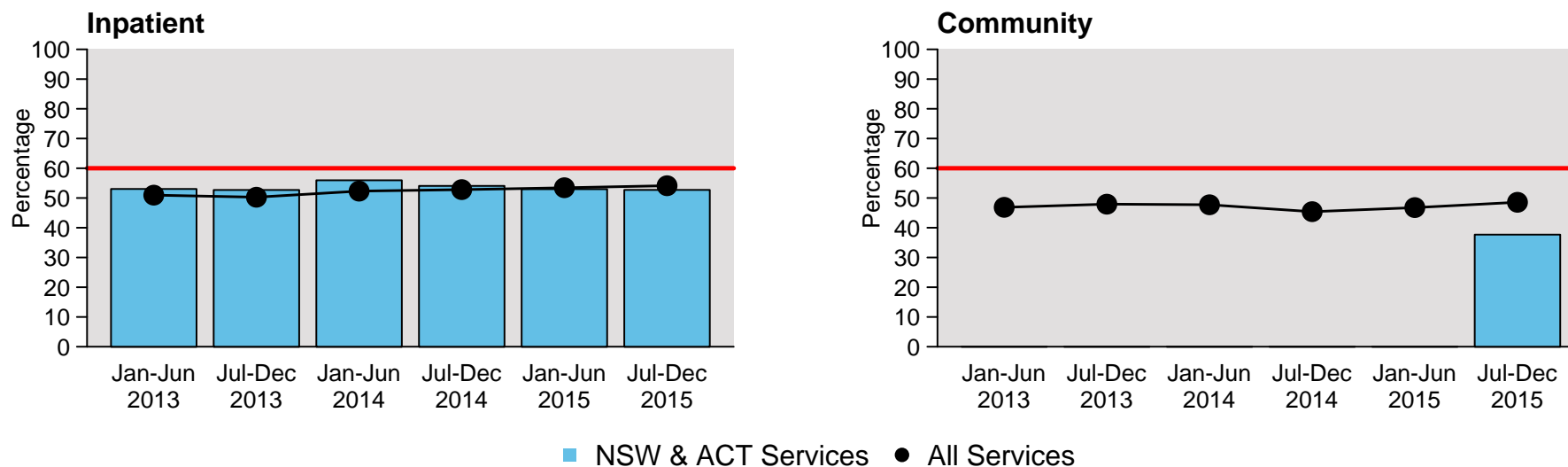
**Figure 10 Trends in benchmark 3.2: Patients with moderate or severe pain at phase start, with absent or mild at phase end by setting**



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



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



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

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

**Table 6 Summary of outcome measure 4 – inpatient setting**

Clinical Tool	Benchmark: Symptom	NSW & ACT 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	0.10	8,525	5,305	62.2	0.11	22,730	14,587	64.2
	4.2: Other symptoms	0.19	8,514	6,171	72.5	0.21	22,356	16,327	73.0
	4.3: Family / carer	0.11	8,514	5,524	64.9	0.14	22,230	15,037	67.6
	4.4: Psychological / spiritual	0.15	8,519	5,110	60.0	0.16	22,710	13,893	61.2
SAS (distress)	4.5: Pain	0.30	8,040	5,436	67.6	0.33	21,067	14,494	68.8
	4.6: Nausea	0.16	8,038	7,025	87.4	0.19	20,941	18,379	87.8
	4.7: Breathing problems	0.27	8,040	6,320	78.6	0.29	21,007	16,467	78.4
	4.8: Bowel problems	0.21	8,039	6,233	77.5	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.

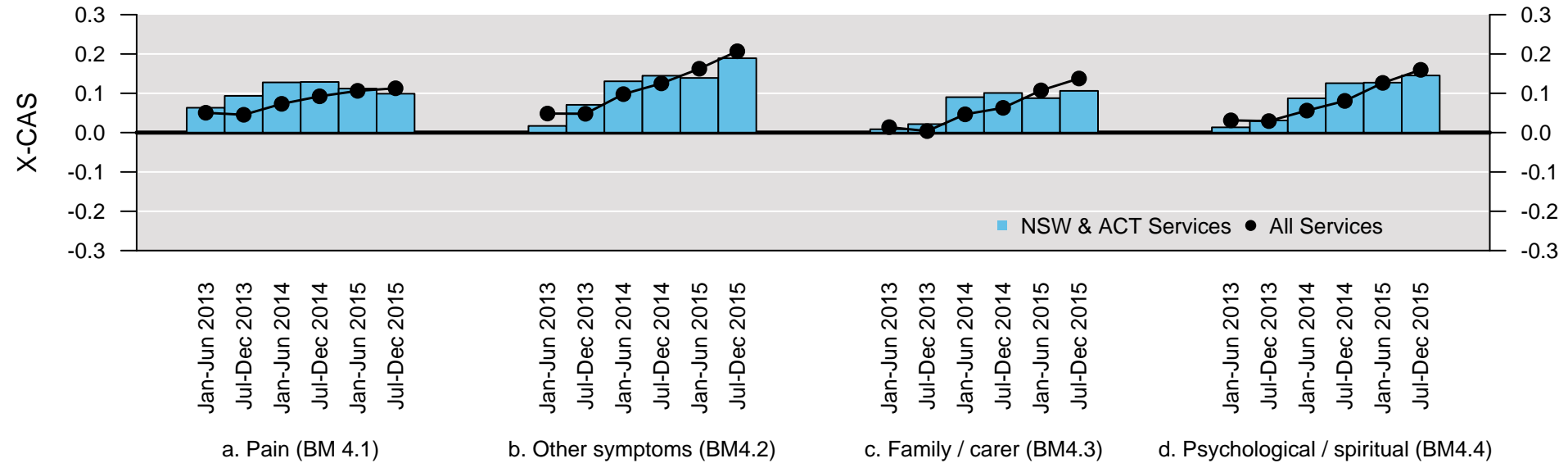
If X-CAS is equal to 0 then on average, patients' change in symptom was about the same as similar patients in the baseline reference period.

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

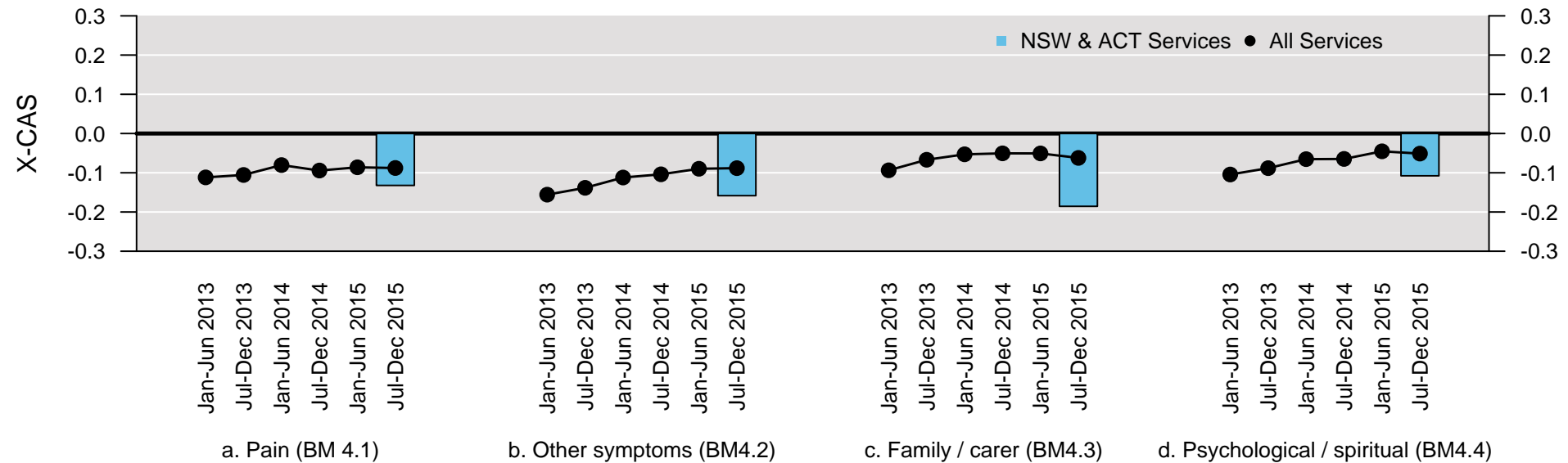
**Table 7 Summary of outcome measure 4 – community setting**

Clinical Tool	Benchmark: Symptom	NSW & ACT 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	-0.13	2,031	997	49.1	-0.09	20,836	10,840	52.0
	4.2: Other symptoms	-0.16	1,965	982	50.0	-0.09	20,268	11,894	58.7
	4.3: Family / carer	-0.19	1,799	851	47.3	-0.06	20,202	11,851	58.7
	4.4: Psychological / spiritual	-0.11	1,973	853	43.2	-0.05	20,507	9,682	47.2
SAS (distress)	4.5: Pain	-0.54	1,912	958	50.1	-0.26	21,073	11,854	56.3
	4.6: Nausea	-0.19	1,881	1,438	76.4	-0.11	20,477	16,131	78.8
	4.7: Breathing problems	-0.32	1,889	1,058	56.0	-0.12	20,211	12,886	63.8
	4.8: Bowel problems	-0.25	1,859	1,209	65.0	-0.04	20,029	14,198	70.9

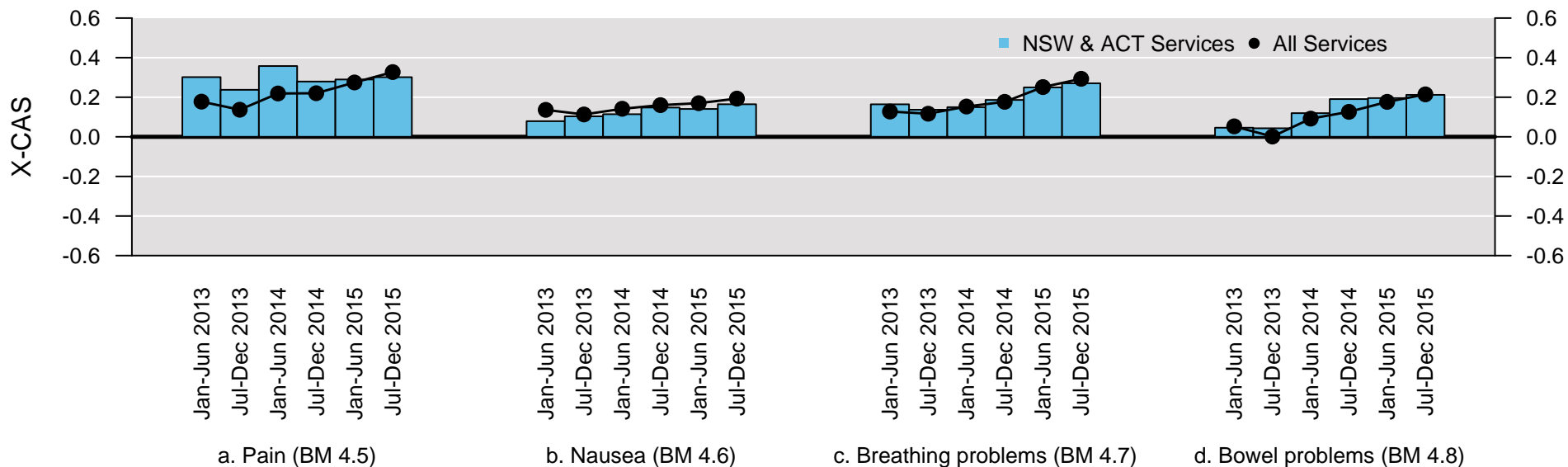
**Figure 13 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – inpatient setting**



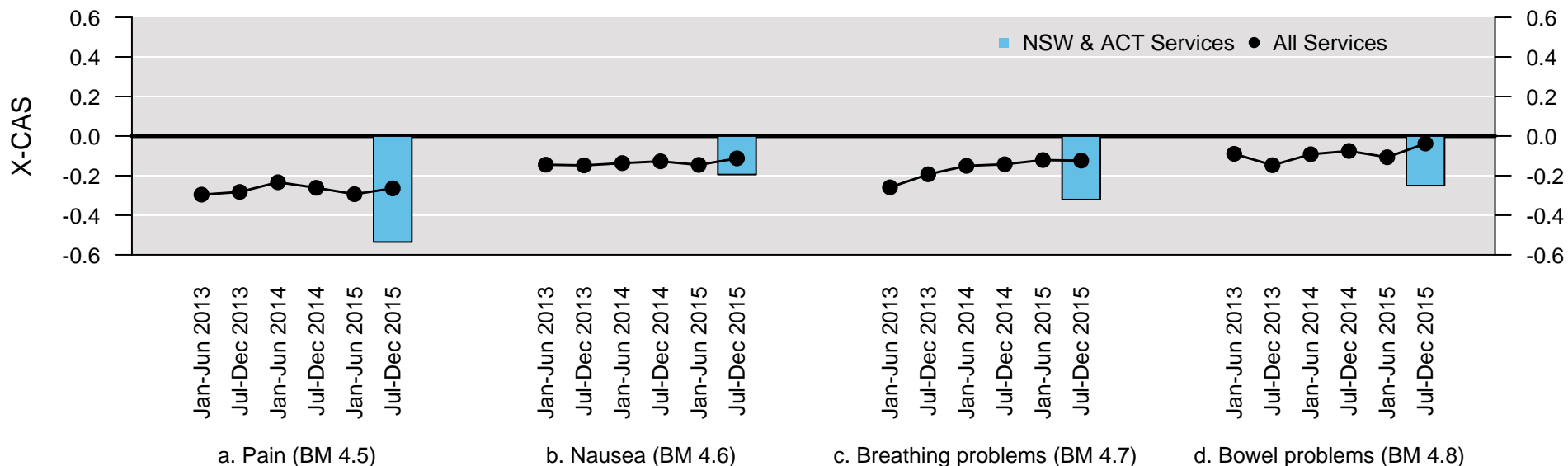
**Figure 14 Trends in outcome measure 4: Palliative Care Problem Severity Score (PCPSS) – community setting**



**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**





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## **Section 3      Descriptive analysis**

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

**Table 8 Indigenous status**

Indigenous status	NSW & ACT Services		All Services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	63	1.5	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	4,139	98.0	19,150	96.6
Not stated / inadequately described	19	0.4	419	2.1
<b>Total</b>	<b>4,225</b>	<b>100.0</b>	<b>19,829</b>	<b>100.0</b>

Table 9 shows the breakdown of deaths for the patients in NSW and ACT services and also 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 & ACT Services		All Services	
	N	%	N	%
Private residence	140	5.1	2,200	22.4
Residential aged care facility	90	3.3	694	7.1
Hospital	2,519	91.0	6,882	70.1
Not stated / inadequately described	20	0.7	43	0.4
<b>Total</b>	<b>2,769</b>	<b>100.0</b>	<b>9,819</b>	<b>100.0</b>

The following two tables show the country of birth and the preferred language respectively for the patients in NSW and ACT services and also 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	NSW & ACT Services		All Services	
	N	%	N	%
Australia	2,660	63.0	12,434	62.7
England	223	5.3	1,458	7.4
New Zealand	62	1.5	306	1.5
China (excludes SARs and Taiwan)	100	2.4	219	1.1
India	30	0.7	137	0.7
Italy	125	3.0	820	4.1
Vietnam	47	1.1	163	0.8
Philippines	27	0.6	88	0.4
South Africa	23	0.5	109	0.5
Scotland	54	1.3	275	1.4
Malaysia	13	0.3	58	0.3
Germany	61	1.4	245	1.2
Greece	67	1.6	380	1.9
Sri Lanka	12	0.3	58	0.3
United States of America	7	0.2	53	0.3
All other countries	703	16.6	2,753	13.9
Not stated / inadequately described	11	0.3	273	1.4
<b>Total</b>	<b>4,225</b>	<b>100.0</b>	<b>19,829</b>	<b>100.0</b>

**Table 11 Preferred language**

Preferred language	NSW & ACT Services		All Services	
	N	%	N	%
English	3,673	86.9	17,797	89.8
Chinese <sup>(a)</sup>	108	2.6	209	1.1
Hindi <sup>(b)</sup>	12	0.3	31	0.2
Arabic <sup>(c)</sup>	58	1.4	132	0.7
Italian	66	1.6	412	2.1
Vietnamese <sup>(d)</sup>	43	1.0	88	0.4
Greek	48	1.1	258	1.3
Filipino / Indonesian <sup>(e)</sup>	6	0.1	21	0.1
Macedonian / Croatian <sup>(f)</sup>	49	1.2	120	0.6
Spanish <sup>(g)</sup>	30	0.7	46	0.2
Tamil / Malayalam <sup>(h)</sup>	3	0.1	5	0.0
German <sup>(i)</sup>	5	0.1	31	0.2
Korean	18	0.4	21	0.1
Samoan / Tongan <sup>(j)</sup>	10	0.2	15	0.1
African languages <sup>(k)</sup>	0	0.0	8	0.0
All other languages	73	1.7	462	2.3
Not stated / inadequately described	23	0.5	173	0.9
<b>Total</b>	<b>4,225</b>	<b>100.0</b>	<b>19,829</b>	<b>100.0</b>

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

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

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

(d) Khmer and Mon

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

(f) Bosnian, Bulgarian, Serbian, and Slovene

(g) Catalan and Portuguese

(h) Kannada, Telugu, and Tulu

(i) Letzeburgish and Yiddish

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

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

Table 12 and Table 13 present a breakdown of malignant and non-malignant diagnosis for the patients in NSW and ACT services and also 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 16 (0.4%) patients in NSW and ACT services and was not stated for 55 (0.3%) patients nationally.

**Table 12 Primary diagnosis - malignant**

Primary diagnosis	NSW & ACT Services			All Services		
	N	% malignant diagnosis	% all diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	51	1.5	1.2	226	1.5	1.1
Breast	278	8.3	6.6	1,166	7.7	5.9
CNS	71	2.1	1.7	332	2.2	1.7
Colorectal	411	12.3	9.7	1,717	11.3	8.7
Other GIT	315	9.4	7.5	1,398	9.2	7.1
Haematological	177	5.3	4.2	902	6.0	4.5
Head and neck	188	5.6	4.4	770	5.1	3.9
Lung	724	21.6	17.1	3,376	22.3	17.0
Pancreas	242	7.2	5.7	1,057	7.0	5.3
Prostate	210	6.3	5.0	1,037	6.8	5.2
Other urological	147	4.4	3.5	633	4.2	3.2
Gynaecological	153	4.6	3.6	733	4.8	3.7
Skin	146	4.4	3.5	553	3.6	2.8
Unknown primary	63	1.9	1.5	369	2.4	1.9
Other primary malignancy	126	3.8	3.0	563	3.7	2.8
Malignant – not further defined	52	1.6	1.2	321	2.1	1.6
<b>All malignant</b>	<b>3,354</b>	<b>100.0</b>	<b>79.4</b>	<b>15,153</b>	<b>100.0</b>	<b>76.4</b>

**Table 13 Primary diagnosis - non-malignant**

Primary diagnosis	NSW & ACT Services			All Services		
	N	% non-malignant diagnosis	% all diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	147	17.2	3.5	799	17.3	4.0
HIV / AIDS	2	0.2	0.0	7	0.2	0.0
End stage kidney disease	85	9.9	2.0	409	8.9	2.1
Stroke	38	4.4	0.9	338	7.3	1.7
Motor neurone disease	35	4.1	0.8	198	4.3	1.0
Alzheimer's dementia	18	2.1	0.4	169	3.7	0.9
Other dementia	55	6.4	1.3	271	5.9	1.4
Other neurological disease	83	9.7	2.0	257	5.6	1.3
Respiratory failure	138	16.1	3.3	792	17.1	4.0
End stage liver disease	53	6.2	1.3	211	4.6	1.1
Diabetes and its complications	4	0.5	0.1	22	0.5	0.1
Sepsis	25	2.9	0.6	151	3.3	0.8
Multiple organ failure	32	3.7	0.8	136	2.9	0.7
Other non-malignancy	115	13.5	2.7	682	14.8	3.4
Non-malignant – not further defined	25	2.9	0.6	179	3.9	0.9
<i>All non-malignant</i>	<i>855</i>	<i>100.0</i>	<i>20.2</i>	<i>4,621</i>	<i>100.0</i>	<i>23.3</i>

### 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 and ACT services and also at the national level. Age has been calculated as at the beginning of each episode.

**Table 14 Age group by sex**

Age group	NSW & ACT Services				All Services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	3	0.1	8	0.3	42	0.3	39	0.3
15 - 24	5	0.2	5	0.2	61	0.5	24	0.2
25 - 34	14	0.5	8	0.3	109	0.8	100	0.8
35 - 44	56	2.0	92	3.7	329	2.4	383	3.2
45 - 54	206	7.5	205	8.3	813	6.0	1,061	9.0
55 - 64	498	18.1	407	16.5	2,202	16.3	1,853	15.7
65 - 74	656	23.8	528	21.4	3,528	26.1	2,689	22.8
75 - 84	834	30.3	666	27.0	3,940	29.1	3,066	26.0
85+	482	17.5	549	22.2	2,504	18.5	2,587	21.9
Not stated / inadequately described	0	0.0	0	0.0	0	0.0	0	0.0
<b>Total</b>	<b>2,754</b>	<b>100.0</b>	<b>2,468</b>	<b>100.0</b>	<b>13,528</b>	<b>100.0</b>	<b>11,802</b>	<b>100.0</b>

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 & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Public hospital	2,102	51.9	7,655	59.1	453	38.8	6,632	53.6
Private hospital	124	3.1	1,082	8.4	63	5.4	1,275	10.3
Outpatient clinic	36	0.9	83	0.6	4	0.3	129	1.0
General medical practitioner	199	4.9	287	2.2	196	16.8	1,929	15.6
Specialist medical practitioner	428	10.6	574	4.4	341	29.2	761	6.1
Community-based palliative care agency	914	22.6	2,732	21.1	7	0.6	100	0.8
Community-based service	26	0.6	71	0.5	13	1.1	139	1.1
Residential aged care facility	13	0.3	59	0.5	35	3.0	772	6.2
Self, carer(s), family or friends	65	1.6	176	1.4	34	2.9	362	2.9
Other	93	2.3	153	1.2	17	1.5	248	2.0
Not stated / inadequately described	53	1.3	82	0.6	6	0.5	30	0.2
<b>Total</b>	<b>4,053</b>	<b>100.0</b>	<b>12,954</b>	<b>100.0</b>	<b>1,169</b>	<b>100.0</b>	<b>12,377</b>	<b>100.0</b>



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 & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Same day or following day	3,701	91.4	12,146	93.8	737	63.0	6,325	51.2
2-7 days	280	6.9	668	5.2	251	21.5	4,290	34.7
8-14 days	47	1.2	77	0.6	63	5.4	994	8.0
Greater than 14 days	22	0.5	57	0.4	118	10.1	756	6.1
Average	1.3	na	1.2	na	2.6	na	2.9	na
Median	1	na	1	na	1	na	1	na

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

Table 17 gives a summary of the length of episode for patients in NSW and ACT services and also 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	
	NSW & ACT Services	All Services	NSW & ACT Services	All Services
Average length of episode	12.8	10.3	36.3	37.8
Median length of episode	8.0	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			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Same day	112	2.8	837	6.5	21	2.0	259	2.3
1-2 days	654	16.2	2,527	19.7	78	7.3	723	6.5
3-4 days	559	13.9	1,911	14.9	63	5.9	593	5.4
5-7 days	624	15.5	2,140	16.7	87	8.1	952	8.6
8-14 days	877	21.8	2,596	20.3	144	13.4	1,471	13.3
15-21 days	489	12.1	1,217	9.5	94	8.8	1,006	9.1
22-30 days	315	7.8	717	5.6	103	9.6	978	8.9
31-60 days	342	8.5	723	5.6	158	14.7	1,960	17.7
61-90 days	36	0.9	99	0.8	88	8.2	982	8.9
Greater than 90 days	23	0.6	43	0.3	237	22.1	2,119	19.2
<b>Total</b>	<b>4,031</b>	<b>100.0</b>	<b>12,810</b>	<b>100.0</b>	<b>1,073</b>	<b>100.0</b>	<b>11,043</b>	<b>100.0</b>

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

**Table 19 How episodes start – inpatient setting**

Episode start mode	NSW & ACT Services		All Services	
	N	%	N	%
Admitted from community*	1,993	49.2	7,565	58.4
Admitted from another hospital	1,116	27.5	3,001	23.2
Admitted from acute care in another ward	827	20.4	2,088	16.1
Change from acute care to palliative care – same ward	108	2.7	207	1.6
Other**	9	0.2	89	0.7
Not stated / inadequately described	0	0.0	4	0.0
<b>Total</b>	<b>4,053</b>	<b>100.0</b>	<b>12,954</b>	<b>100.0</b>

\* 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 & ACT Services		All Services	
	N	%	N	%
Discharged to community*	1,248	31.0	4,589	35.8
Discharged to another hospital	213	5.3	755	5.9
Death	2,519	62.5	6,882	53.7
Change from palliative care to acute care**	12	0.3	50	0.4
Change in sub-acute care type	15	0.4	49	0.4
End of consultative episode – inpatient episode ongoing	0	0.0	367	2.9
Other	24	0.6	109	0.9
Not stated / inadequately described	0	0.0	9	0.1
<b>Total</b>	<b>4,031</b>	<b>100.0</b>	<b>12,810</b>	<b>100.0</b>

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 & ACT Services		All Services	
	N	%	N	%
Admitted from inpatient palliative care	320	27.4	4,589	37.1
Other*	849	72.6	7,728	62.4
Not stated / inadequately described	0	0.0	60	0.5
<b>Total</b>	<b>1,169</b>	<b>100.0</b>	<b>12,377</b>	<b>100.0</b>

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

**Table 22 How episodes end – community setting**

Episode end mode	NSW & ACT Services		All Services	
	N	%	N	%
Admitted for inpatient palliative care	415	38.7	3,478	31.5
Admitted for inpatient acute care	190	17.7	3,093	28.0
Admitted to another palliative care service	0	0.0	61	0.6
Admitted to primary health care	35	3.3	234	2.1
Discharged / case closure	141	13.1	1,136	10.3
Death	250	23.3	2,937	26.6
Other	28	2.6	86	0.8
Not stated / inadequately described	14	1.3	18	0.2
<b>Total</b>	<b>1,073</b>	<b>100.0</b>	<b>11,043</b>	<b>100.0</b>

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 & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Stable	3,017	27.0	7,783	25.8	966	38.2	10,579	37.3
Unstable	3,013	26.9	6,932	22.9	464	18.3	3,764	13.3
Deteriorating	2,962	26.5	9,433	31.2	914	36.1	11,609	41.0
Terminal	2,191	19.6	6,069	20.1	186	7.4	2,378	8.4
<b>Total</b>	<b>11,183</b>	<b>100.0</b>	<b>30,217</b>	<b>100.0</b>	<b>2,530</b>	<b>100.0</b>	<b>28,330</b>	<b>100.0</b>

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 & ACT Services	All Services	NSW & ACT Services	All Services
Stable	8.3	7.3	21.8	20.9
Unstable	2.5	2.2	3.4	4.2
Deteriorating	4.7	5.0	13.9	12.9
Terminal	2.0	2.0	3.0	2.8

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

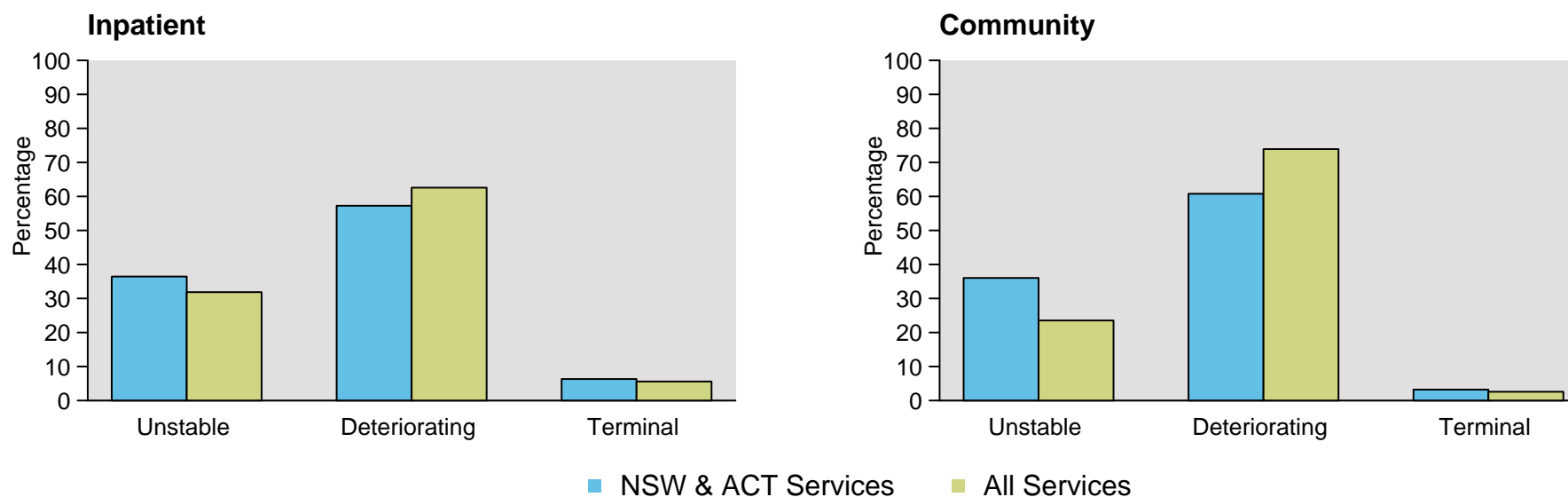
Table 25 presents information relating to the manner in which stable phases ended, both for NSW and ACT services and also nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 17 summarises the movement of patients out of the stable 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			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	1,787	59.2	3,830	49.2	594	61.5	7,018	66.3
Discharge / case closure	1,192	39.5	3,873	49.8	353	36.5	3,268	30.9
Died	36	1.2	75	1.0	19	2.0	261	2.5
Not stated / inadequately described	2	0.1	5	0.1	0	0.0	32	0.3
<b>Total</b>	<b>3,017</b>	<b>100.0</b>	<b>7,783</b>	<b>100.0</b>	<b>966</b>	<b>100.0</b>	<b>10,579</b>	<b>100.0</b>

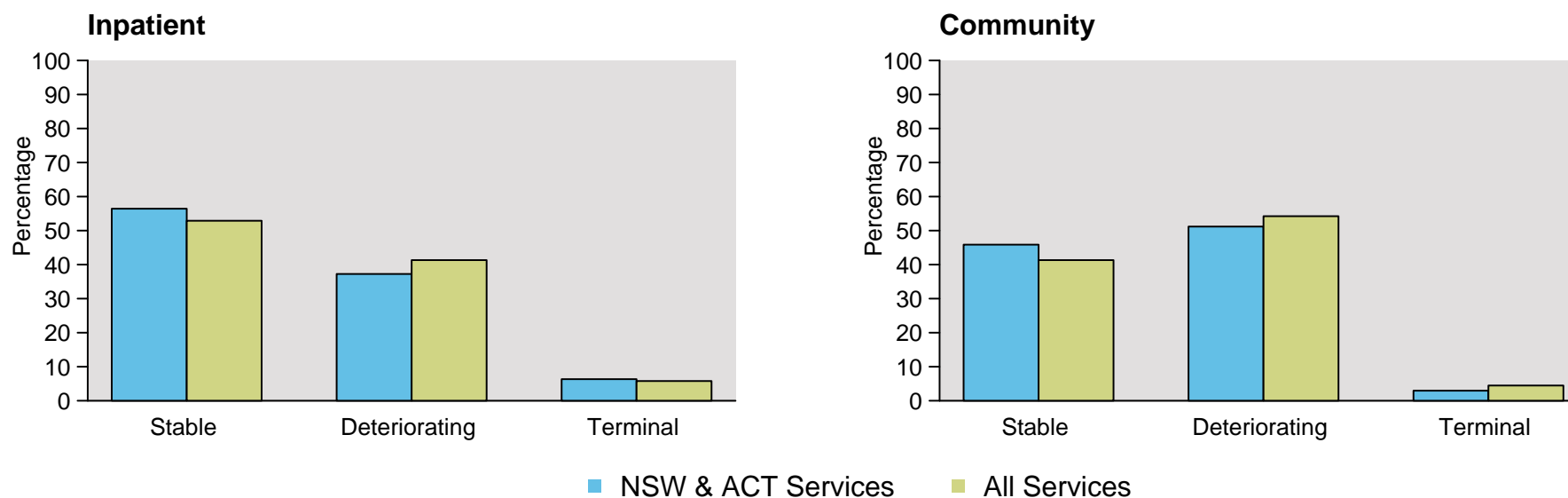
**Figure 17 Stable phase progression**



**Table 26** How unstable phases end – by setting

How unstable phases end	Inpatient				Community			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	2,809	93.2	6,324	91.2	338	72.8	2,442	64.9
Discharge / case closure	151	5.0	479	6.9	120	25.9	1,249	33.2
Died	52	1.7	126	1.8	6	1.3	67	1.8
Not stated / inadequately described	1	0.0	3	0.0	0	0.0	6	0.2
<b>Total</b>	<b>3,013</b>	<b>100.0</b>	<b>6,932</b>	<b>100.0</b>	<b>464</b>	<b>100.0</b>	<b>3,764</b>	<b>100.0</b>

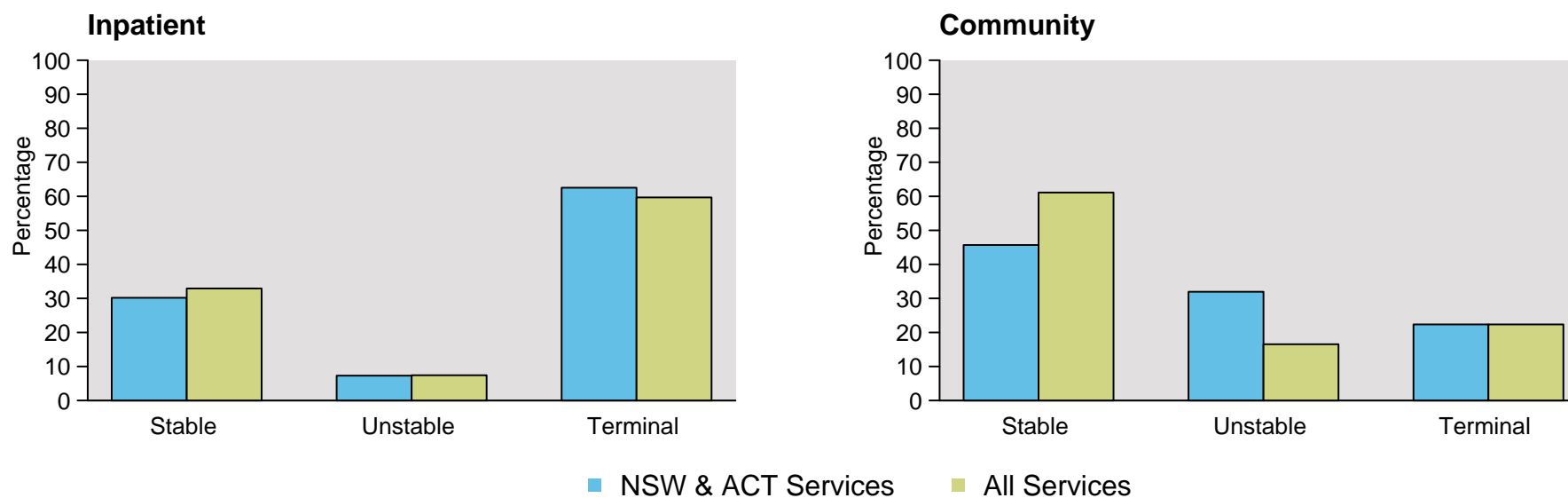
**Figure 18** Unstable phase progression



**Table 27** How deteriorating phases end – by setting

How deteriorating phases end	Inpatient				Community			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	2,469	83.4	7,004	74.2	510	55.8	7,447	64.1
Discharge / case closure	154	5.2	1,441	15.3	330	36.1	3,321	28.6
Died	337	11.4	983	10.4	74	8.1	821	7.1
Not stated / inadequately described	2	0.1	5	0.1	0	0.0	20	0.2
<b>Total</b>	<b>2,962</b>	<b>100.0</b>	<b>9,433</b>	<b>100.0</b>	<b>914</b>	<b>100.0</b>	<b>11,609</b>	<b>100.0</b>

**Figure 19** Deteriorating phase progression

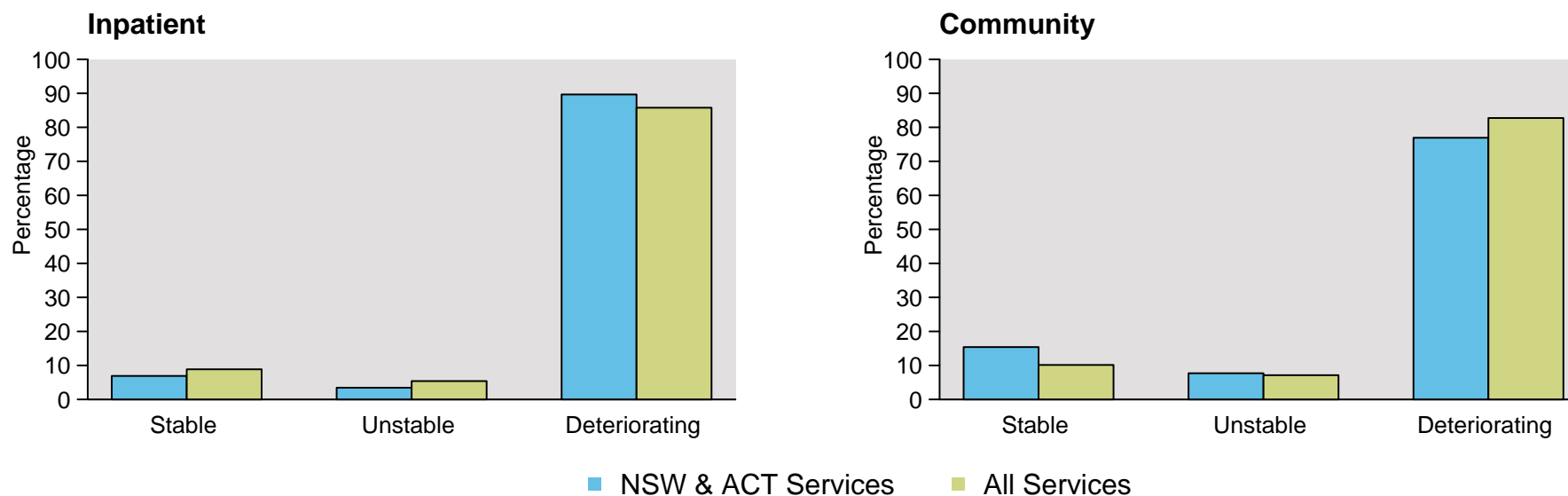




**Table 28** How terminal phases end – by setting

How terminal phases end	Inpatient				Community			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	87	4.0	260	4.3	13	7.0	365	15.3
Discharge / case closure	12	0.5	122	2.0	22	11.8	218	9.2
Died	2,091	95.4	5,686	93.7	151	81.2	1,793	75.4
Not stated / inadequately described	1	0.0	1	0.0	0	0.0	2	0.1
<b>Total</b>	<b>2,191</b>	<b>100.0</b>	<b>6,069</b>	<b>100.0</b>	<b>186</b>	<b>100.0</b>	<b>2,378</b>	<b>100.0</b>

**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 NSW and ACT and also 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 & ACT Services				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	43.2	41.9	12.9	2.0	47.7	38.9	11.6	1.8
	Other symptoms	27.4	53.5	17.1	2.0	30.2	51.5	16.2	2.1
	Psychological / spiritual	39.4	49.9	9.6	1.1	41.2	47.9	9.5	1.4
	Family / carer	41.7	46.3	10.0	1.9	46.4	41.6	9.9	2.0
Unstable	Pain	31.1	35.5	23.7	9.7	31.2	32.3	25.5	10.9
	Other symptoms	15.9	41.4	31.1	11.6	17.4	38.0	32.9	11.7
	Psychological / spiritual	31.5	46.7	18.3	3.5	30.2	45.3	19.6	4.9
	Family / carer	31.9	45.0	18.8	4.3	34.1	40.8	19.4	5.7
Deteriorating	Pain	37.4	40.8	18.1	3.7	40.3	37.8	17.1	4.8
	Other symptoms	20.3	45.2	28.9	5.7	21.3	44.0	28.2	6.5
	Psychological / spiritual	31.9	51.1	14.5	2.5	33.6	47.4	15.9	3.0
	Family / carer	27.7	48.9	19.3	4.2	32.4	43.1	19.7	4.9
Terminal	Pain	51.5	33.8	12.0	2.7	51.8	32.8	12.3	3.1
	Other symptoms	39.5	37.6	17.0	5.9	40.3	35.5	17.9	6.4
	Psychological / spiritual	55.5	33.9	8.1	2.5	57.2	31.3	8.9	2.6
	Family / carer	28.3	40.2	23.0	8.5	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	Problem severity	NSW & ACT Services				All Services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	42.2	46.5	10.5	0.7	41.0	51.6	6.9	0.5
	Other symptoms	14.2	57.2	26.2	2.4	16.4	67.5	15.1	1.0
	Psychological / spiritual	27.8	56.1	14.8	1.3	30.2	59.7	9.4	0.7
	Family / carer	18.6	54.7	22.7	4.0	28.9	56.0	13.6	1.5
Unstable	Pain	19.0	30.9	39.6	10.5	18.4	30.4	34.7	16.5
	Other symptoms	2.9	31.1	50.9	15.1	4.7	29.7	50.6	15.0
	Psychological / spiritual	9.2	46.0	38.6	6.3	13.4	49.3	32.0	5.3
	Family / carer	8.3	32.5	45.0	14.2	11.8	36.1	42.0	10.1
Deteriorating	Pain	22.9	49.4	24.3	3.4	28.8	50.5	18.7	2.1
	Other symptoms	5.4	40.6	46.0	8.0	7.4	52.4	36.7	3.6
	Psychological / spiritual	12.5	56.9	27.1	3.6	17.8	60.2	20.2	1.8
	Family / carer	7.3	42.8	41.6	8.4	17.1	52.2	26.6	4.0
Terminal	Pain	36.4	47.7	11.9	4.0	38.0	43.1	15.6	3.3
	Other symptoms	22.0	40.5	30.6	6.9	23.6	43.1	27.1	6.2
	Psychological / spiritual	47.6	36.5	12.4	3.5	42.3	42.1	13.3	2.3
	Family / carer	8.9	33.9	45.2	11.9	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	Symptom distress	NSW & ACT 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	73.0	14.2	10.7	2.1	72.1	15.8	10.2	1.9
	Appetite problems	61.7	21.5	14.5	2.3	60.7	22.7	14.4	2.2
	Nausea	82.1	10.7	6.5	0.7	82.1	11.1	6.0	0.9
	Bowel problems	67.0	18.8	12.0	2.2	66.0	20.1	11.5	2.5
	Breathing problems	68.3	17.1	11.8	2.8	67.6	17.9	12.0	2.5
	Fatigue	37.4	24.3	32.4	5.9	35.1	26.3	33.1	5.5
	Pain	46.4	30.8	19.8	3.1	48.2	30.4	18.8	2.7
Unstable	Difficulty sleeping	63.5	14.7	17.1	4.7	61.4	16.0	17.2	5.4
	Appetite problems	46.1	21.4	25.4	7.1	46.1	22.3	24.0	7.6
	Nausea	70.0	13.7	12.2	4.1	69.4	13.8	12.1	4.6
	Bowel problems	56.1	20.4	18.0	5.6	54.3	21.4	18.1	6.2
	Breathing problems	58.2	17.2	17.3	7.3	57.7	17.6	17.4	7.3
	Fatigue	26.7	19.1	39.9	14.3	25.6	19.9	40.3	14.3
	Pain	33.0	25.9	30.1	11.0	31.7	25.8	30.2	12.3
Deteriorating	Difficulty sleeping	76.0	11.0	10.2	2.7	73.8	12.3	11.4	2.6
	Appetite problems	58.6	19.2	18.6	3.7	56.7	20.0	18.3	5.0
	Nausea	80.2	9.5	8.3	2.0	78.9	10.4	8.5	2.2
	Bowel problems	66.2	17.4	13.4	3.0	63.9	18.5	14.1	3.4
	Breathing problems	63.0	16.9	15.2	4.9	59.6	17.6	17.1	5.7
	Fatigue	37.2	17.3	35.1	10.3	33.1	18.3	36.5	12.2
	Pain	42.3	29.8	23.0	5.0	41.1	29.3	24.1	5.5
Terminal	Difficulty sleeping	92.6	3.5	2.9	1.0	93.0	3.8	2.4	0.8
	Appetite problems	88.7	4.4	4.1	2.8	91.6	3.6	2.9	1.9
	Nausea	93.8	3.1	2.4	0.7	94.9	2.8	1.8	0.5
	Bowel problems	88.4	5.9	4.2	1.5	88.6	6.2	4.1	1.2
	Breathing problems	72.7	12.3	10.5	4.5	73.0	11.7	10.5	4.8
	Fatigue	76.7	7.4	10.1	5.8	79.3	5.5	9.6	5.6
	Pain	62.7	21.1	13.9	2.4	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	Symptom distress	NSW & ACT 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	61.1	27.0	10.5	1.4	65.6	25.7	7.9	0.8
	Appetite problems	48.5	32.7	17.0	1.8	50.2	34.0	14.2	1.5
	Nausea	80.3	15.4	4.1	0.2	81.3	15.6	2.9	0.3
	Bowel problems	60.2	27.4	10.7	1.7	67.3	25.1	6.7	0.8
	Breathing problems	49.9	30.7	17.3	2.1	55.5	30.2	12.9	1.4
	Fatigue	18.3	32.6	44.5	4.6	17.1	37.3	41.2	4.4
	Pain	42.1	42.0	14.8	1.1	44.8	42.8	11.6	0.9
Unstable	Difficulty sleeping	42.7	26.6	26.6	4.0	45.8	27.5	21.8	4.9
	Appetite problems	39.1	25.7	26.9	8.4	34.8	29.2	29.4	6.7
	Nausea	64.5	15.2	15.6	4.8	61.5	17.5	15.7	5.4
	Bowel problems	51.4	25.9	17.3	5.5	57.1	23.0	15.7	4.2
	Breathing problems	38.2	31.9	22.6	7.2	45.0	27.7	21.3	6.0
	Fatigue	8.9	23.6	53.0	14.5	11.6	21.6	52.4	14.4
	Pain	18.5	26.7	41.0	13.8	20.0	24.3	38.1	17.6
Deteriorating	Difficulty sleeping	55.5	26.6	15.9	2.1	58.2	27.2	13.1	1.4
	Appetite problems	35.2	31.6	25.1	8.1	41.7	31.7	22.7	3.9
	Nausea	68.3	18.5	10.8	2.3	73.3	18.5	7.2	1.0
	Bowel problems	49.4	29.0	18.6	3.1	60.8	26.9	10.9	1.4
	Breathing problems	37.0	29.9	27.3	5.8	46.6	31.9	18.8	2.7
	Fatigue	13.5	23.1	51.0	12.3	12.4	25.8	51.8	10.0
	Pain	22.3	43.1	29.2	5.4	32.8	41.3	22.9	3.1
Terminal	Difficulty sleeping	84.6	6.8	6.0	2.6	78.2	11.3	9.1	1.5
	Appetite problems	80.5	8.4	4.5	6.5	81.7	7.8	5.5	5.1
	Nausea	83.9	10.6	5.0	0.6	86.0	8.7	4.5	0.7
	Bowel problems	77.4	10.7	11.9	0.0	75.8	15.9	7.2	1.1
	Breathing problems	60.4	15.9	17.1	6.7	59.3	21.8	14.5	4.4
	Fatigue	67.1	9.3	14.3	9.3	61.9	6.9	16.0	15.2
	Pain	38.0	39.3	18.4	4.3	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			
	NSW & ACT Services		All Services		NSW & ACT Services		All Services	
	N	%	N	%	N	%	N	%
10 - Comatose or barely rousable	1,058	9.5	3,278	10.8	88	3.5	983	3.5
20 - Totally bedfast and requiring extensive nursing care	2,428	21.7	6,813	22.5	229	9.1	2,763	9.8
30 - Almost completely bedfast	1,469	13.1	3,944	13.1	210	8.3	2,019	7.1
40 - In bed more than 50% of the time	2,108	18.9	5,713	18.9	365	14.4	3,750	13.2
50 - Requires considerable assistance	1,598	14.3	4,978	16.5	687	27.2	7,092	25.0
60 - Requires occasional assistance	920	8.2	3,199	10.6	537	21.2	6,892	24.3
70 - Cares for self	186	1.7	654	2.2	292	11.5	3,263	11.5
80 - Normal activity with effort	91	0.8	213	0.7	75	3.0	722	2.5
90 - Able to carry on normal activity; minor signs or symptoms	37	0.3	82	0.3	18	0.7	119	0.4
100 - Normal; no complaints; no evidence of disease	0	0.0	5	0.0	0	0.0	12	0.0
Not stated/inadequately described	1,288	11.5	1,338	4.4	29	1.1	715	2.5
<b>Total</b>	<b>11,183</b>	<b>100.0</b>	<b>30,217</b>	<b>100.0</b>	<b>2,530</b>	<b>100.0</b>	<b>28,330</b>	<b>100.0</b>

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**

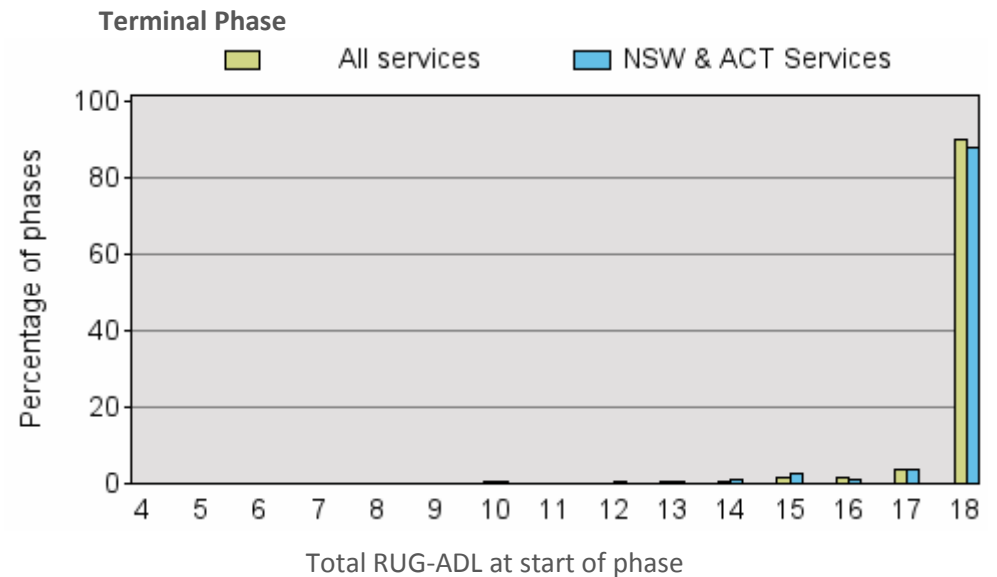
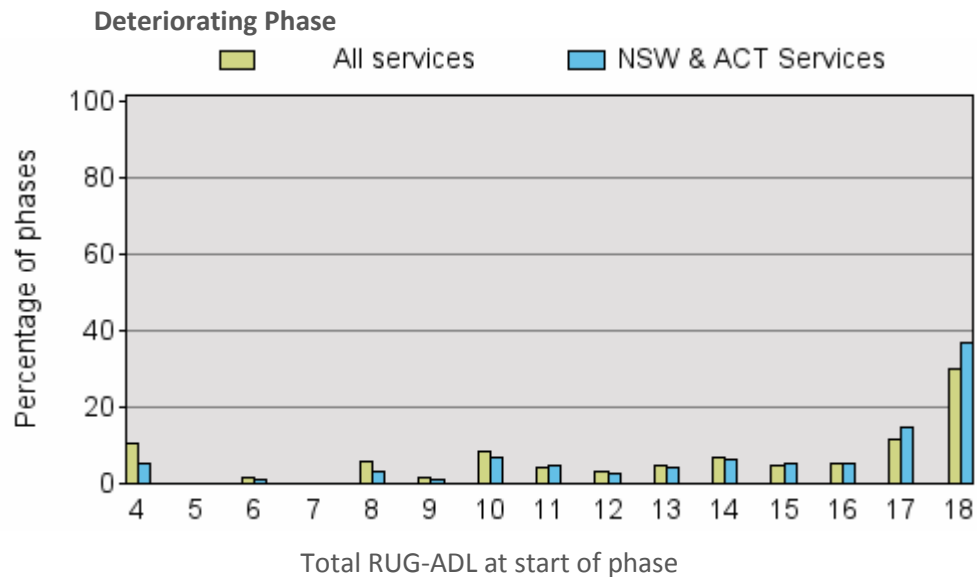
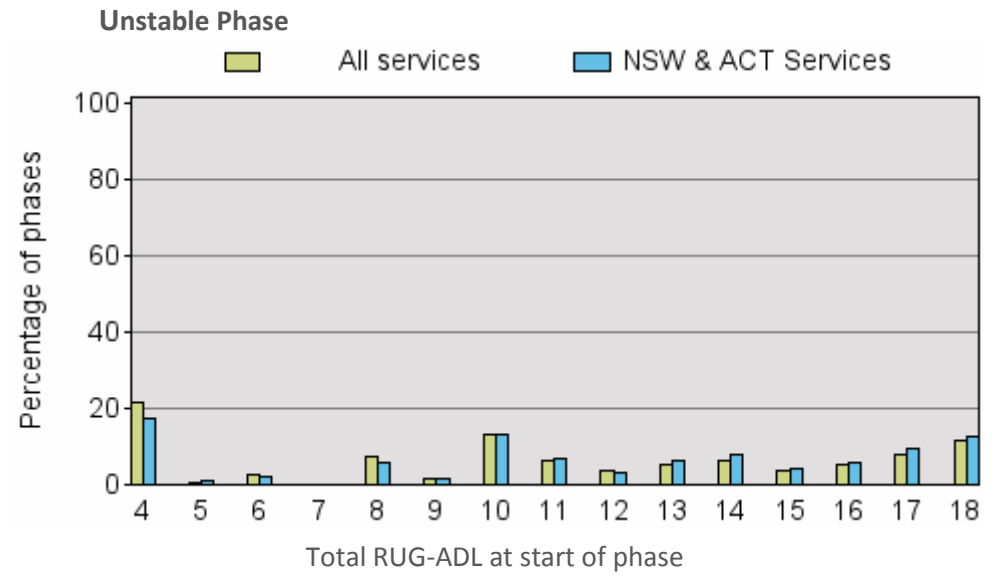
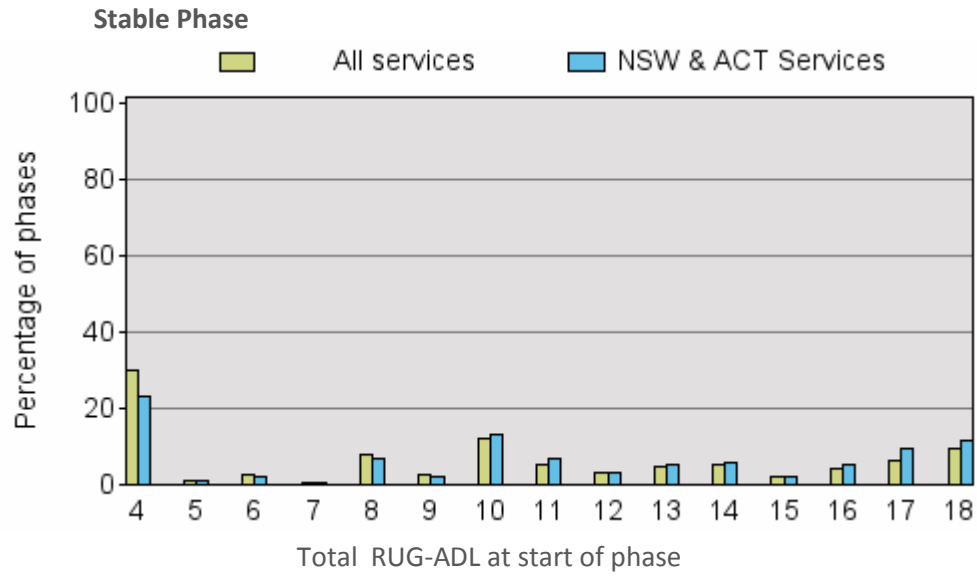
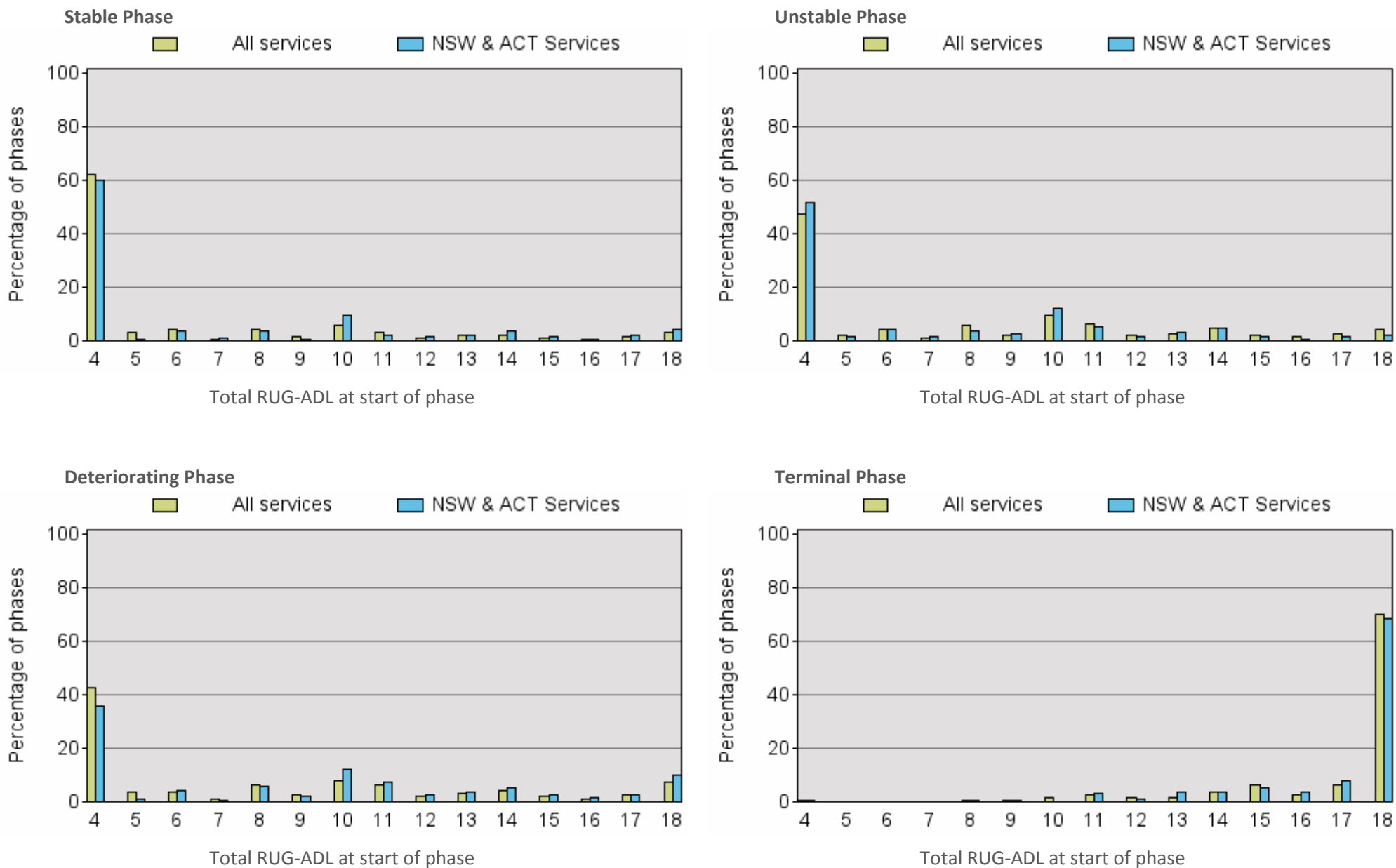


Figure 22 Total RUG-ADL at beginning of phase by phase type – community setting





## 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 NSW and ACT and also nationally.

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

	Inpatient		Community		Total	
	NSW & ACT Services	All Services	NSW & ACT Services	All Services	NSW & ACT Services	All Services
Number of patients*	3,527	10,868	938	9,817	4,225	19,829
Number of episodes	4,053	12,954	1,169	12,377	5,222	25,331
Number of phases**	11,183	30,217	2,530	28,330	13,713	58,547
Percentage of patients*	83.5	54.8	22.2	49.5	100	100
Percentage of episodes	77.6	51.1	22.4	48.9	100	100
Percentage of phases	81.6	51.6	18.4	48.4	100	100
Average number of phases per episode***	2.8	2.3	2.1	2.2	2.7	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 and ACT 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	708	707	668	644	636	668
	No. of completed phases	1,955	2,053	1,893	1,846	1,854	1,582
Community	No. of completed episodes	189	176	167	162	201	178
	No. of completed phases	453	437	431	388	466	355

Table 36 shows the number of patients, episodes and phases for NSW and ACT 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*	2,856	3,006	2,721	2,855	3,180	3,527	0	0	0	0	0	938
Number of episodes	3,197	3,393	3,109	3,338	3,633	4,053	0	0	0	0	0	1,169
Number of phases**	9,182	10,141	8,869	9,537	10,146	11,183	0	0	0	0	0	2,530
Average number of phases per episode***	2.9	3.0	2.8	2.9	2.8	2.8	na	na	na	na	na	2.1

\* 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 & ACT Services	All Services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	99.6	97.9
Country of birth	99.7	98.6
Preferred language	99.5	99.1
Primary diagnosis	99.6	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	
	NSW & ACT Services	All Services	NSW & ACT Services	All Services	NSW & ACT Services	All Services
Date of first contact	99.9	100.0	100.0	99.9	99.9	99.9
Referral date	99.9	100.0	100.0	99.9	99.9	99.9
Referral source	98.7	99.4	99.5	99.8	98.9	99.6
Date ready for care	91.0	97.2	68.5	96.9	86.0	97.0
Mode of episode start	100.0	100.0	100.0	99.5	100.0	99.7
Accommodation at episode start	99.9	99.9	99.6	95.5	99.8	97.2
Episode end date*	100.0	99.9	94.4	92.5	98.7	96.2
Mode of episode end	100.0	99.9	98.6	99.8	99.7	99.9
Accommodation at episode end	97.5	97.8	97.2	92.9	97.5	96.6
Place of death	na	na	91.9	98.5	91.9	98.5

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

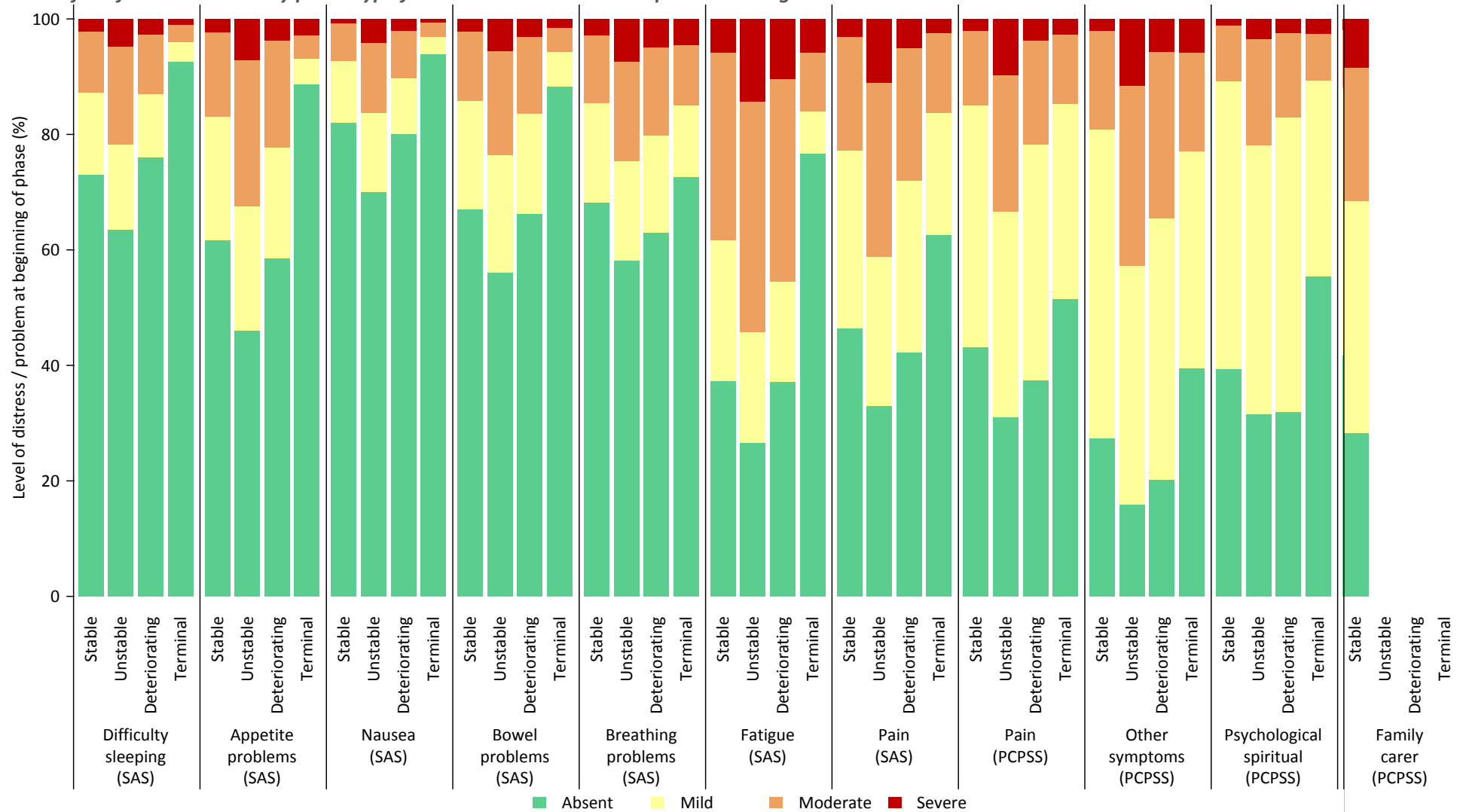
**Table 39 Item completion by setting (per cent complete) - phase level**

Data item	Sub-Category (where applicable)	At phase start						At discharge					
		Inpatient		Community		Total		Inpatient		Community		Total	
		NSW & ACT Services	All Services	NSW & ACT Services	All Services	NSW & ACT Services	All Services	NSW & ACT Services	All Services	NSW & ACT Services	All Services	NSW & ACT Services	All Services
RUG-ADL	Bed mobility	99.7	99.8	98.5	97.3	99.5	98.6	97.9	93.3	76.4	56.6	90.3	72.2
	Toileting	99.7	99.8	98.3	97.2	99.4	98.6	97.9	93.3	76.5	56.6	90.4	72.1
	Transfers	99.7	99.8	98.4	97.1	99.5	98.5	97.9	93.3	76.4	56.6	90.3	72.1
	Eating	99.6	99.7	96.9	96.5	99.1	98.1	97.9	93.3	75.9	56.4	90.1	72.0
PCPSS	Pain	99.0	99.4	97.5	97.1	98.7	98.3	98.6	93.2	76.1	56.2	90.7	71.9
	Other symptom	98.9	97.7	95.6	94.8	98.3	96.3	98.5	92.0	74.9	55.1	90.2	70.7
	Psychological / spiritual	99.0	99.3	95.6	96.2	98.3	97.8	98.6	93.1	74.9	55.5	90.2	71.4
	Family / carer	98.9	97.8	89.8	94.9	97.3	96.4	98.5	89.8	69.0	54.8	88.1	69.6
SAS	Difficulty sleeping	88.4	90.4	68.5	91.4	84.8	90.9	86.9	79.7	53.0	51.4	74.9	63.4
	Appetite problems	93.2	92.2	91.9	94.9	93.0	93.5	89.0	80.8	70.4	54.2	82.4	65.4
	Nausea	93.2	92.2	92.3	96.0	93.1	94.1	89.0	79.5	70.3	55.1	82.4	65.4
	Bowel problems	93.2	92.1	91.6	94.9	92.9	93.5	89.0	80.2	70.1	54.1	82.3	65.2
	Breathing problems	93.3	92.3	92.5	95.5	93.1	93.8	89.0	80.3	71.8	54.7	82.9	65.5
	Fatigue	93.2	92.2	92.1	95.9	93.0	94.0	89.0	81.8	70.9	55.1	82.6	66.4
	Pain	93.3	92.3	93.4	97.5	93.3	94.8	88.9	81.3	71.9	56.6	82.9	67.1
AKPS	-	88.5	95.6	98.9	97.5	90.4	96.5	92.6	91.7	88.4	58.8	91.1	72.7

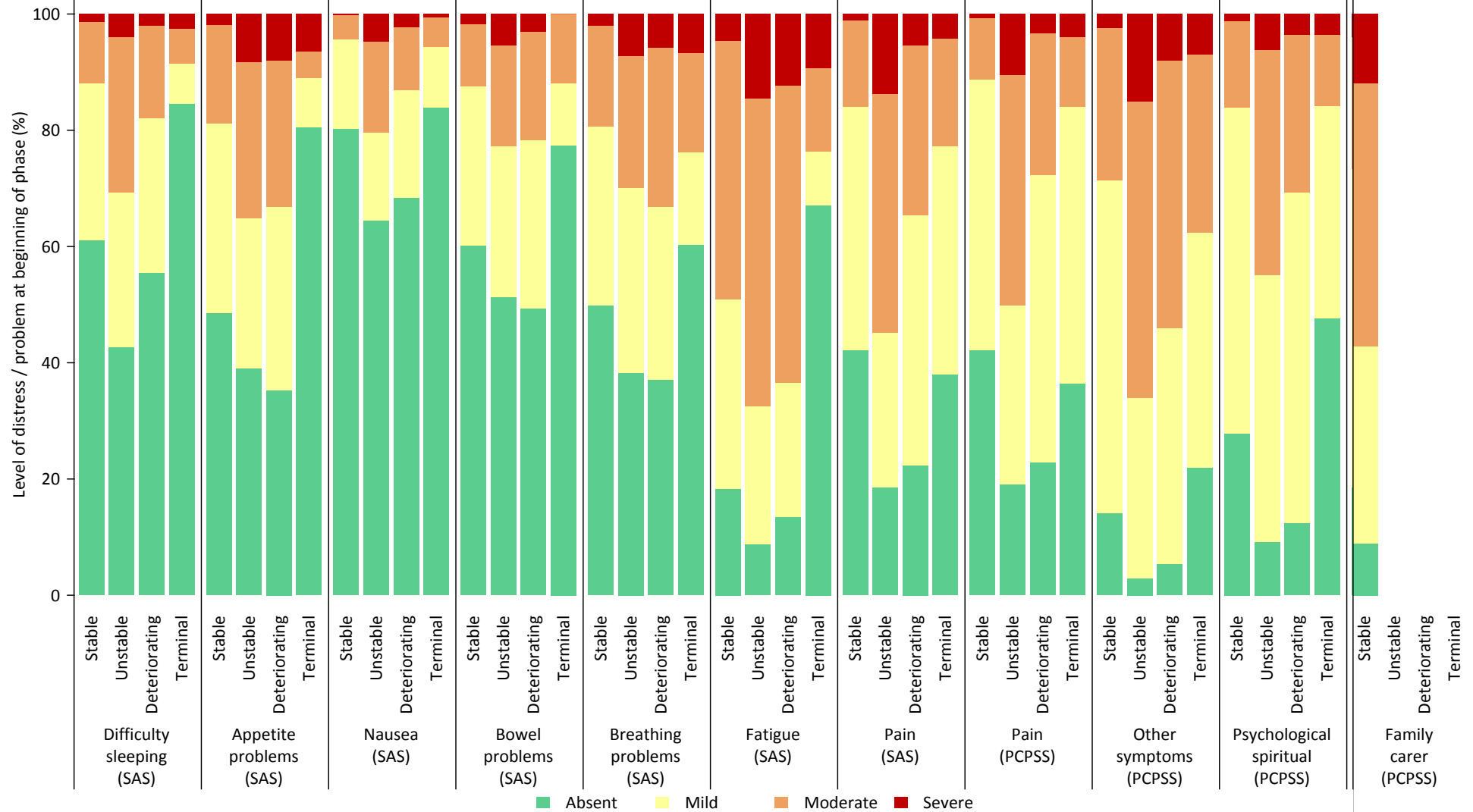
Data item	Inpatient		Community		Total	
	NSW & ACT Services	All Services	NSW & ACT Services	All Services	NSW & ACT Services	All Services
	Phase End Reason	99.9	99.9	100.0	99.8	100.0

## Appendix B Additional information on profile of SAS and PCPSS

Figure 23 Profile of SAS and PCPSS by phase type for NSW & ACT Services – inpatient setting



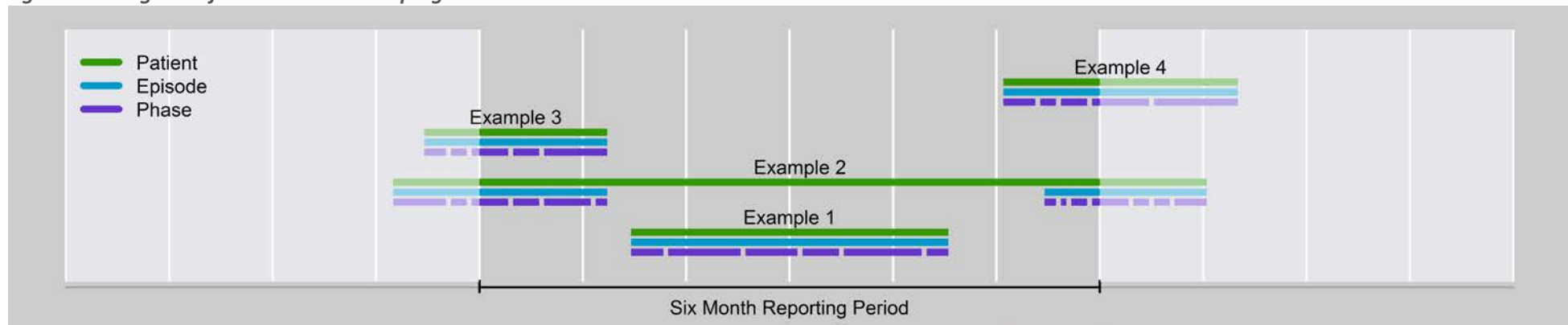
**Figure 24 Profile of SAS and PCPSS by phase type for NSW & ACT Services – community setting**



## 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
<b>Stable</b>	
<p>Patient problems and symptoms are adequately controlled by established plan of care <b>and</b></p> <ul style="list-style-type: none"> <li>Further interventions to maintain symptom control and quality of life have been planned <b>and</b></li> <li>Family / carer situation is relatively stable and no new issues are apparent.</li> </ul>	<p>The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care.</p>
<b>Unstable</b>	
<p>An urgent change in the plan of care or emergency treatment is required <b>because</b></p> <ul style="list-style-type: none"> <li>Patient experiences a new problem that was not anticipated in the existing plan of care, <b>and / or</b></li> <li>Patient experiences a rapid increase in the severity of a current problem; <b>and / or</b></li> <li>Family / carers circumstances change suddenly impacting on patient care.</li> </ul>	<ul style="list-style-type: none"> <li>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) <b>and / or</b></li> <li>Death is likely within days (i.e. patient is now terminal).</li> </ul>
<b>Deteriorating</b>	
<p>The care plan is addressing anticipated needs but requires periodic review <b>because</b></p> <ul style="list-style-type: none"> <li>Patients overall functional status is declining <b>and</b></li> <li>Patient experiences a gradual worsening of existing problem <b>and / or</b></li> <li>Patient experiences a new but anticipated problem <b>and / or</b></li> <li>Family / carers experience gradual worsening distress that impacts on the patient care.</li> </ul>	<ul style="list-style-type: none"> <li>Patient condition plateaus (i.e. patient is now stable) <b>or</b></li> <li>An urgent change in the care plan or emergency treatment <b>and / or</b></li> <li>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) <b>or</b></li> <li>Death is likely within days (i.e. patient is now terminal).</li> </ul>
<b>Terminal</b>	
<p>Death is likely within days.</p>	<ul style="list-style-type: none"> <li>Patient dies <b>or</b></li> <li>Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).</li> </ul>
<b>Bereavement – post death support</b>	
<ul style="list-style-type: none"> <li>The patient has died</li> <li>Bereavement support provided to family / carers is documented in the deceased patient's clinical record.</li> </ul>	<ul style="list-style-type: none"> <li>Case closure</li> </ul> <p>Note: If counselling is provided to a family member or carer, they become a client in their own right.</p>



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## 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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