

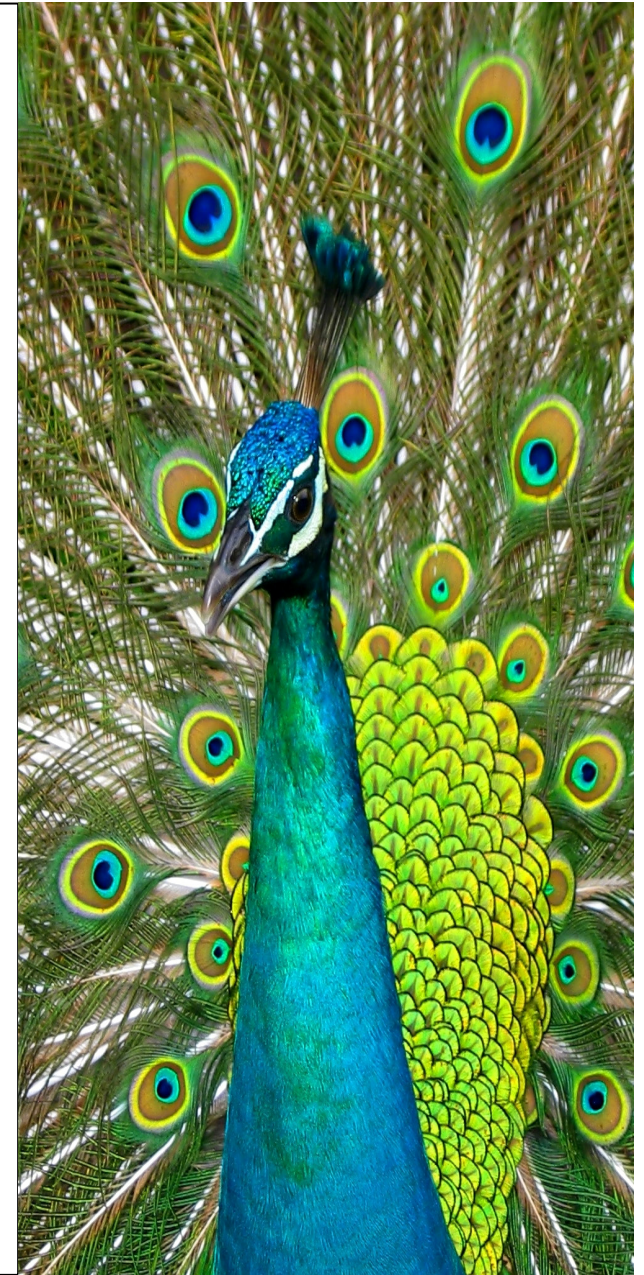
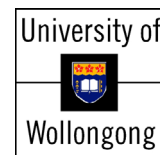


PCOC Report 8

New South Wales

July to December 2009

March 2010



PCOC REPORT 8

July to December 2009

Palliative Care Outcomes Collaboration (PCOC)

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Introduction

The Palliative Care Outcomes Collaboration (PCOC) was formed in mid-2005 and is funded by the Australian Government. It is a voluntary, quality initiative which aims to assist palliative care services to measure the standard and quality of care which is a stated goal of the *National Palliative Care Strategy*.

The development of the PCOC dataset has evolved after broad consultation with services and representatives of peak organisations and approval by PCOC's Scientific and Clinical Advisory Committee (SCAC). The clinical assessment tools - Phase of Care, PC Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australian-modified Karnofsky and RUG-ADL - provide measures of quality and outcomes. PCOC provides analysis of each service's data and also compares this to the national data.

For this PCOC Report 8, 91 palliative care services submitted data and the reporting period is July to December 2009.

Four benchmark measures, progressively introduced over time and formally adopted by the PCOC Management Advisory Board in December 2009, are also included in this report. See section 1 for an overview of these measures.

Please note

Data reported for services identifying as consultancy are included in the overnight admitted data analysis, with the exception of data reported for services identifying as outpatient or community consultancy which are included in the not admitted overnight data analysis.

In addition, interpret all figures carefully as results may appear distorted due to low frequencies being represented as percentages.

Some tables throughout the report may be incomplete. This is because some items may not be applicable to a particular service 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 or unable to be calculated due to missing or invalid data.

Section 1 - Summary

Data Summary

This report presents data from a total of 91 services. During the reporting period data were provided for a total of 10743 patients, with 13376 episodes and 28669 phases. For the purposes of reporting episode types, Ambulatory, Community and Consultation services have been grouped together to form the not admitted overnight episode type group.

Table 1 *Number and percentage of patients, episodes and phases - by episode type*

Episode type	Overnight admitted		Not admitted overnight		Total	
	NSW	All Services	NSW	All Services	NSW	All Services
Number of patients*	2443	7349	330	4078	2671	10743
Number of episodes	2860	8650	373	4726	3233	13376
Number of phases	6553	19065	752	9604	7305	28669
Percentage of patients*	91.5	68.4	12.4	38.0	100	100
Percentage of episodes	88.5	64.7	11.5	35.3	100	100
Percentage of phases	89.7	66.5	10.3	33.5	100	100
Average number of episodes per patient	1.2	1.2	1.3	1.3	1.2	1.3
Average number of phases per episode	2.3	2.2	2.0	2.0	2.3	2.2

* Patients seen in both an overnight admitted and not admitted overnight setting are only counted once in the Total column and hence numbers/percentages may not add to the total.

Summary of Benchmark Measures and Targets

PCOC has been progressively introducing benchmark measures into the routine PCOC reports. After extensive consultation at National Benchmarking Workshops, four benchmark measures were included in PCOC report 7. These benchmarks have been formally adopted by the PCOC Management Advisory Board.

Measure	Benchmark
1. Time from referral to first contact	90% contacted within 48 hours
2. Time in unstable phase	85% in their first phase remain unstable for less than 7 days 90% in a subsequent phase remain unstable for less than 7 days The median time in unstable phase is 2 days or less
3. Change in pain (both PCPSS and SAS)	90% with absent/mild pain at phase start remaining with absent/mild pain at phase end 60% with moderate/severe pain at phase start with absent/mild pain at phase end
4. Change in symptoms relative to the national average (8 symptoms are included)	0 or above

In addition, targets for services performing below the benchmark were also agreed. Targets of 10% improvement have been agreed to apply to all services not meeting the current benchmarks. Both the benchmarks and targets apply to all services as of the current reporting period July-Dec 09 (Report 8). For example if your service does not meet the 90% benchmark for Measure 1 then your target is to achieve an improvement of 10% over the next reporting period Jan-June 10 (for Report 9). Therefore, if you score 75% for Measure 1 in this report, your target is to score at least 82.5% for this measure in the next report (Report 9) which is a 10% improvement.

The following two tables provide a summary of the performance of NSW services in relation to the four benchmark measures for the period July to December 2009.

Table 2 Summary of benchmark measures 1-3

Measure	Description	Benchmark	Benchmark met (NSW score)			
			Overnight admitted		Not admitted overnight	
1. Time from referral to contact	Patients contacted within 48 hours of referral	90%	No	(85.3%)	No	(63.5%)
2. Time in unstable phase	Patients unstable less than 7 days - first phase	85%	No	(62.3%)	No	(34.1%)
	Patients unstable less than 7 days - subsequent phase	90%	No	(75.9%)	No	(43.8%)
	Median time in unstable phase	2 days or less	No	(4 days)	No	(8 days)
3. Change in pain						
PC Problem Severity Score (PCPSS)	Patients with absent/mild pain at phase start remaining absent/mild at phase end	90%	No	(72.6%)	No	(74.6%)
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	No	(25.4%)	No	(39.4%)
Symptom Assessment Score (SAS)	Patients with absent/mild pain at phase start remaining absent/mild at phase end	90%	No	(75.9%)	No	(76.3%)
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	No	(33.1%)	No	(42.4%)

Table 3 Summary of benchmark measure 4: Change in symptoms relative to the national average

Symptom		Benchmark	Benchmark met	NSW score
PC PSS	Pain	0 or above	No	(-0.13)
	Other symptoms	0 or above	No	(-0.17)
	Family/carer	0 or above	No	(-0.08)
	Psychological/spiritual	0 or above	No	(-0.23)
SAS	Pain	0 or above	No	(-0.33)
	Nausea	0 or above	No	(-0.26)
	Breathing	0 or above	No	(-0.05)
	Bowels	0 or above	No	(-0.60)

Section 2 - Descriptive analysis

Profile of palliative care patients

Table 4 *Indigenous Status - all patients*

Indigenous Status	NSW	All Services
Aboriginal but not Torres Strait Islander origin	20	101
Torres Strait Islander but not Aboriginal origin	5	21
Both Aboriginal and Torres Strait Islander origin	3	19
Neither Aboriginal nor Torres Strait Islander origin	2594	10300
Not stated/Inadequately described	49	302
Total	2671	10743

Table 5 *Sex - all patients*

Sex	NSW	%	All Services	%
Male	1462	54.7	5790	53.9
Female	1209	45.3	4939	46.0
Not stated/inadequately described	0	0.0	14	0.1
Total	2671	100.0	10743	100.0

Table 6 *Main language spoken at home - all patients*

Main language spoken at home	NSW	%	All Services	%
English	2291	85.8	9376	87.3
Italian	34	1.3	218	2.0
Greek	26	1.0	125	1.2
Cantonese	34	1.3	54	0.5
Vietnamese	14	0.5	53	0.5
Croatian	12	0.4	45	0.4
Macedonian	19	0.7	45	0.4
Arabic (including Lebanese)	16	0.6	39	0.4
Serbian	7	0.3	29	0.3
Spanish	18	0.7	27	0.3
Maltese	9	0.3	26	0.2
Mandarin	10	0.4	24	0.2
Polish	7	0.3	21	0.2
Turkish	8	0.3	16	0.1
German	4	0.1	15	0.1
All other languages	57	2.1	203	1.9
Not stated/inadequately described	105	3.9	427	4.0
Total	2671	100.0	10743	100.0

Note: The most common 15 languages from all services are reported separately, all other languages have been grouped together to form the category *All other languages*.

Table 7 Country of birth - all patients

Country of birth	NSW	%	All Services	%
Australia	1794	67.2	6728	62.6
England	134	5.0	754	7.0
Italy	67	2.5	416	3.9
Scotland	33	1.2	220	2.0
Greece	40	1.5	170	1.6
New Zealand	37	1.4	147	1.4
Germany	29	1.1	109	1.0
Netherlands	19	0.7	108	1.0
Croatia	27	1.0	101	0.9
Poland	15	0.6	75	0.7
Malta	25	0.9	74	0.7
India	16	0.6	72	0.7
Vietnam	17	0.6	69	0.6
China	42	1.6	68	0.6
Ireland	19	0.7	63	0.6
All other countries	327	12.2	968	9.0
Not stated/inadequately described	30	1.1	601	5.6
Total	2671	100.0	10743	100.0

Note: The most common 15 countries from all services are reported separately, all other countries have been grouped together to form the category *All other countries*.

Table 8 Primary diagnosis

Primary diagnosis		NSW	%	All services	%
Malignant	Bone and soft tissue	40	2.2	194	2.5
	Breast	54	2.9	488	6.2
	CNS	26	1.4	159	2.0
	Colorectal	72	3.9	724	9.3
	Gynaecological	42	2.3	349	4.5
	Haematological	32	1.7	318	4.1
	Head and neck	36	1.9	386	4.9
	Lung	115	6.2	1247	16.0
	Pancreas	40	2.2	345	4.4
	Prostate	30	1.6	420	5.4
	Skin	24	1.3	219	2.8
	Other GIT	44	2.4	439	5.6
	Other urological	23	1.2	289	3.7
	Other malignancy	52	2.8	310	4.0
	Unknown primary	13	0.7	152	1.9
	Malignant - not further defined	1212	65.3	1778	22.7
	<i>All malignant</i>	<i>1855</i>	<i>100.0</i>	<i>7817</i>	<i>100.0</i>
Non-malignant	Cardiovascular	23	10.7	317	18.4
	HIV/AIDS	4	1.9	7	0.4
	Kidney failure	15	7.0	157	9.1
	Neurological disease	15	7.0	272	15.8
	Respiratory failure	18	8.4	219	12.7
	Other non-malignancy	26	12.1	329	19.1
	Non-malignant - not further defined	113	52.8	424	24.6
	<i>All non-malignant</i>	<i>214</i>	<i>100.0</i>	<i>1725</i>	<i>100.0</i>

Note: All patients where diagnosis was Not stated/inadequately described are excluded from the table.

Profile of palliative care episodes

The 10743 patients from all services seen in the six month period had a total of 13376 episodes of palliative care. These episodes included inpatient, community and consultative episodes. For example, a patient who received both inpatient and community (home-based) palliative care during the period is generally counted as two episodes.

Episode level activity is presented below by 10 year age groups. The average age for all patients in NSW during this period was 71 years and for all services was 70 years.

Table 9 *Number of episodes by age group - all episodes*

Age group	NSW	%	All Services	%
< 15	8	0.2	82	0.6
15-24	5	0.2	43	0.3
25-34	17	0.5	120	0.9
35-44	94	2.9	436	3.3
45-54	291	9.0	1244	9.3
55-64	584	18.1	2338	17.5
65-74	812	25.1	3256	24.3
75-84	956	29.6	3916	29.3
85+	466	14.4	1941	14.5
Not stated/inadequately described	0	0.0	0	0.0
Total	3233	100.0	13376	100.0

Referral source refers to the service or organisation from which the patient was referred to for each individual episode of care. The following table presents referral source by episode type and shows that for all services, a higher proportion of overnight admitted patients were referred by a public hospital or a community-based palliative care agency. The table also shows that for all services, a higher proportion of patients not admitted overnight were referred by a public hospital or General Medical Practitioner rooms.

Table 10 Referral source by episode type

Referral source	Overnight admitted				Not admitted overnight			
	NSW	%	All Services	%	NSW	%	All Services	%
Public hospital - other than inpatient palliative care unit	833	29.1	3646	42.2	197	52.8	2027	42.9
Self, carer(s), family or friends	15	0.5	162	1.9	13	3.5	112	2.4
Private hospital - other than inpatient palliative care unit	57	2.0	568	6.6	11	2.9	372	7.9
Public palliative care inpatient unit/hospice	35	1.2	131	1.5	24	6.4	253	5.4
Private palliative care inpatient unit/hospice	5	0.2	59	0.7	1	0.3	59	1.2
General Medical Practitioner rooms	182	6.4	751	8.7	44	11.8	1045	22.1
Specialist Medical Practitioner rooms	173	6.0	273	3.2	30	8.0	314	6.6
Community-based palliative care agency	624	21.8	1682	19.4	13	3.5	77	1.6
Community-based service	190	6.6	290	3.4	28	7.5	92	1.9
Residential aged care facility	15	0.5	59	0.7	2	0.5	93	2.0
Other	59	2.1	186	2.2	5	1.3	218	4.6
Not stated/inadequately described	672	23.5	843	9.7	5	1.3	64	1.4
Total	2860	100.0	8650	100.0	373	100.0	4726	100.0

Table 11 *How episodes start and end - overnight admitted patients for NSW*

Mode of episode start	Mode of episode end					Total
	Discharged to usual accommodation	Discharged to interim accommodation	Discharged to another hospital	Death	All other reasons**	
Admitted from usual accommodation	539	50	61	804	31	1485
Admitted from other than usual accommodation	9	2	2	34	0	47
Admitted (transferred) from another hospital	198	28	54	742	10	1032
Admitted (transferred) from acute care in other ward	46	3	14	161	6	230
All other reasons*	6	0	2	34	0	42
Total	798	83	133	1775	47	2836
As a percentage of each start mode						
Admitted from usual accommodation	36.3	3.4	4.1	54.1	2.1	100.0
Admitted from other than usual accommodation	19.1	4.3	4.3	72.3	0.0	100.0
Admitted (transferred) from another hospital	19.2	2.7	5.2	71.9	1.0	100.0
Admitted (transferred) from acute care in other ward	20.0	1.3	6.1	70.0	2.6	100.0
All other reasons*	14.3	0.0	4.8	81.0	0.0	100.0
Total	28.1	2.9	4.7	62.6	1.7	100.0

Note: All episodes where episode start mode or episode end mode was Not stated/inadequately described are excluded from the table. Episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

* Includes: Change from acute care to palliative care while remaining on same ward; Change of sub-acute/non-acute care type; Statistical admission from leave.

** Includes: Change from palliative care to acute care - different ward; Change from palliative care to acute care - same ward; Discharged at own risk.

Table 12 *How episodes start and end - overnight admitted patients for all services*

Mode of episode start	Mode of episode end					Total
	Discharged to usual accommodation	Discharged to interim accommodation	Discharged to another hospital	Death	All other reasons**	
Admitted from usual accommodation	2329	183	243	2397	291	5443
Admitted from other than usual accommodation	29	12	8	78	8	135
Admitted (transferred) from another hospital	339	56	106	1419	44	1964
Admitted (transferred) from acute care in other ward	134	8	25	497	14	678
All other reasons*	70	6	12	107	27	222
Total	2901	265	394	4498	384	8442
As a percentage of each start mode						
Admitted from usual accommodation	42.8	3.4	4.5	44.0	5.3	100.0
Admitted from other than usual accommodation	21.5	8.9	5.9	57.8	5.9	100.0
Admitted (transferred) from another hospital	17.3	2.9	5.4	72.3	2.2	100.0
Admitted (transferred) from acute care in other ward	19.8	1.2	3.7	73.3	2.1	100.0
All other reasons*	31.5	2.7	5.4	48.2	12.2	100.0
Total	34.4	3.1	4.7	53.3	4.5	100.0

Note: All episodes where episode start mode or episode end mode was Not stated/inadequately described are excluded from the table. Episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

* Includes: Change from acute care to palliative care while remaining on same ward; Change of sub-acute/non-acute care type; Statistical admission from leave.

** Includes: Change from palliative care to acute care - different ward; Change from palliative care to acute care - same ward; Discharged at own risk.

Table 13 *How episodes start and end - patients not admitted overnight*

Mode of episode start	Mode of episode end					Total
	Discharged/ case closure	Admitted for inpatient palliative care	Admitted for inpatient acute care	Transfer for primary care	Death	
NSW						
New referral	49	44	6	14	120	233
Transfer from being an o/n PC patient	15	5	1	0	22	43
Total	64	49	7	14	142	276
As a percentage of each start mode						
New referral	21.0	18.9	2.6	6.0	51.5	100.0
Transfer from being an o/n PC patient	34.9	11.6	2.3	0.0	51.2	100.0
Total	23.2	17.8	2.5	5.1	51.4	100.0
All services						
New referral	692	543	518	52	1072	2877
Transfer from being an o/n PC patient	174	216	129	17	220	756
Total	866	759	647	69	1292	3633
As a percentage of each start mode						
New referral	24.1	18.9	18.0	1.8	37.3	100.0
Transfer from being an o/n PC patient	23.0	28.6	17.1	2.2	29.1	100.0
Total	23.8	20.9	17.8	1.9	35.6	100.0

Note: All episodes where episode start mode or episode end mode was Not stated/inadequately described are excluded from the table. Episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 14 Accommodation at episode start and end - all discharged patients

Accommodation at episode start	Accommodation at episode end				
	Private residence	Low level care	High level care	All other*	Total
NSW					
Private residence	547	9	26	81	663
Residential aged care (low level care)	0	6	3	2	11
Residential aged care (high level care)	2	0	12	2	16
All other	50	1	8	36	95
Total	599	16	49	121	785
As a percentage of each start accommodation					
Private residence	82.5	1.4	3.9	12.2	100.0
Residential aged care (low level care)	0.0	54.5	27.3	18.2	100.0
Residential aged care (high level care)	12.5	0.0	75.0	12.5	100.0
All other	52.6	1.1	8.4	37.9	100.0
Total	76.3	2.0	6.2	15.4	100.0
All services					
Private residence	2520	21	115	201	2857
Residential aged care (low level care)	9	23	16	4	52
Residential aged care (high level care)	11	1	99	3	114
All other	90	2	19	54	165
Total	2630	47	249	262	3188
As a percentage of each start accommodation					
Private residence	88.2	0.7	4.0	7.0	100.0
Residential aged care (low level care)	17.3	44.2	30.8	7.7	100.0
Residential aged care (high level care)	9.6	0.9	86.8	2.6	100.0
All other	54.5	1.2	11.5	32.7	100.0
Total	82.5	1.5	7.8	8.2	100.0

Note: All episodes where accommodation at episode start or end was Not stated/inadequately described are excluded from the table. Episodes that ended in death and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded. The all other category includes: Community group home; Boarding house; Transitional living unit.

Table 15 Level of support at episode start and end - all patients admitted from and discharged to private residence (home)

Level of support at episode start	Level of support at episode end				Total
	Without support (lives alone)	Without support (lives with others)	With support (lives alone or with others)	Other arrangements	
NSW					
Without support (lives alone)	3	1	17	1	22
Without support (lives with others)	0	8	11	0	19
With support (lives alone or with others)	0	0	464	0	464
Other arrangements	0	0	0	0	0
Total	3	9	492	1	505
As a percentage of each start support					
Without support (lives alone)	13.6	4.5	77.3	4.5	100.0
Without support (lives with others)	0.0	42.1	57.9	0.0	100.0
With support (lives alone or with others)	0.0	0.0	100.0	0.0	100.0
Other arrangements	na	na	na	na	na
Total	0.6	1.8	97.4	0.2	100.0
All services					
Without support (lives alone)	42	4	128	1	175
Without support (lives with others)	1	48	133	0	182
With support (lives alone or with others)	12	22	1942	1	1977
Other arrangements	0	0	1	0	1
Total	55	74	2204	2	2335
As a percentage of each start support					
Without support (lives alone)	24.0	2.3	73.1	0.6	100.0
Without support (lives with others)	0.5	26.4	73.1	0.0	100.0
With support (lives alone or with others)	0.6	1.1	98.2	0.1	100.0
Other arrangements	0.0	0.0	100.0	0.0	100.0
Total	2.4	3.2	94.4	0.1	100.0

Note: All episodes where level of support at episode start or end was Not stated/inadequately described are excluded from the table. Episodes that ended in death and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 16 Length of Stay (LOS) summary - overnight admitted patients

Length of stay	NSW	All services
Average length of episode	13.4	11.4
Median length of episode	9	7
Average number of phases per episode	2.3	2.2

Note: Bereavement phase records are excluded and episodes that remain open at the end of the reporting period (and hence do not have an episode end date), are also excluded. In addition, any records where LOS was greater than 90 days were considered to be outliers and are excluded from the average calculations.

Table 17 Length of Stay (LOS) - overnight admitted patients

Length of stay	NSW	%	All Services	%
Same day	75	2.6	351	4.2
1-2 days	403	14.2	1551	18.6
3-4 days	348	12.3	1100	13.2
5-7 days	448	15.8	1367	16.4
8-14 days	646	22.8	1773	21.3
15-21 days	357	12.6	894	10.7
22-30 days	243	8.6	568	6.8
31-60 days	236	8.3	542	6.5
61-90 days	54	1.9	118	1.4
Greater than 90 days	25	0.9	58	0.7
Total	2835	100.0	8322	100.0

Note: Bereavement phase records are excluded 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 18 Place of death - patients not admitted overnight

Place of death	NSW	%	All Services	%
Private residence	55	31.6	851	48.0
Residential aged care setting	13	7.5	205	11.6
Other location*	96	55.2	569	32.1
Not stated/inadequately described	10	5.7	148	8.3
Total	174	100.0	1773	100.0

* Includes patients who have died in a hospital setting without the episode of non-admitted palliative care being ended. Patients whose community episode is ended when admitted to hospital are excluded from this table (see Tables 11 and 12).

Profile of palliative care phases

Table 19 *Number of phases by phase type and episode type*

Phase	Overnight admitted				Not admitted overnight			
	NSW	%	All services	%	NSW	%	All services	%
Stable	1272	19.4	4244	22.3	156	20.7	2983	31.1
Unstable	2385	36.4	5858	30.7	268	35.6	2040	21.2
Deteriorating	1707	26.0	4960	26.0	199	26.5	3300	34.4
Terminal	1133	17.3	3145	16.5	59	7.8	929	9.7
Bereaved	56	0.9	858	4.5	70	9.3	352	3.7
All phases	6553	100.0	19065	100.0	752	100.0	9604	100.0

Table 20 *Average phase length (in days) by phase and episode type*

Phase	Overnight admitted		Not admitted overnight	
	NSW	All services	NSW	All services
Stable	8.4	7.5	27.4	21.4
Unstable	7.2	5.6	16.1	11.6
Deteriorating	5.3	5.9	21.5	15.9
Terminal	2.1	2.2	3.9	3.4
Bereaved	2.1	1.3	1.0	2.2

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

Figure 1 Total RUG-ADL at beginning of phase – overnight admitted patients

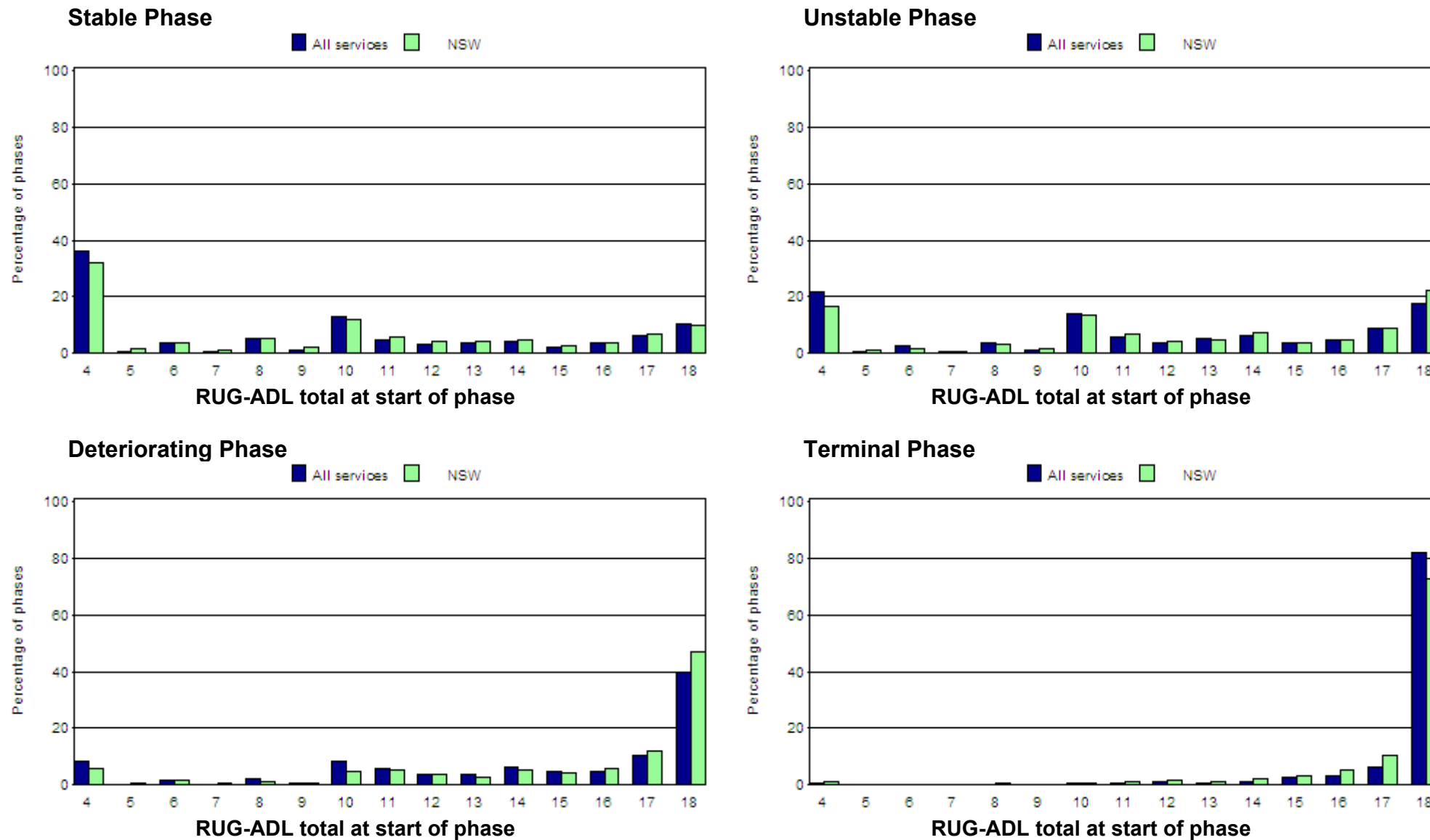


Figure 2 Total RUG-ADL at beginning of phase – patients not admitted overnight

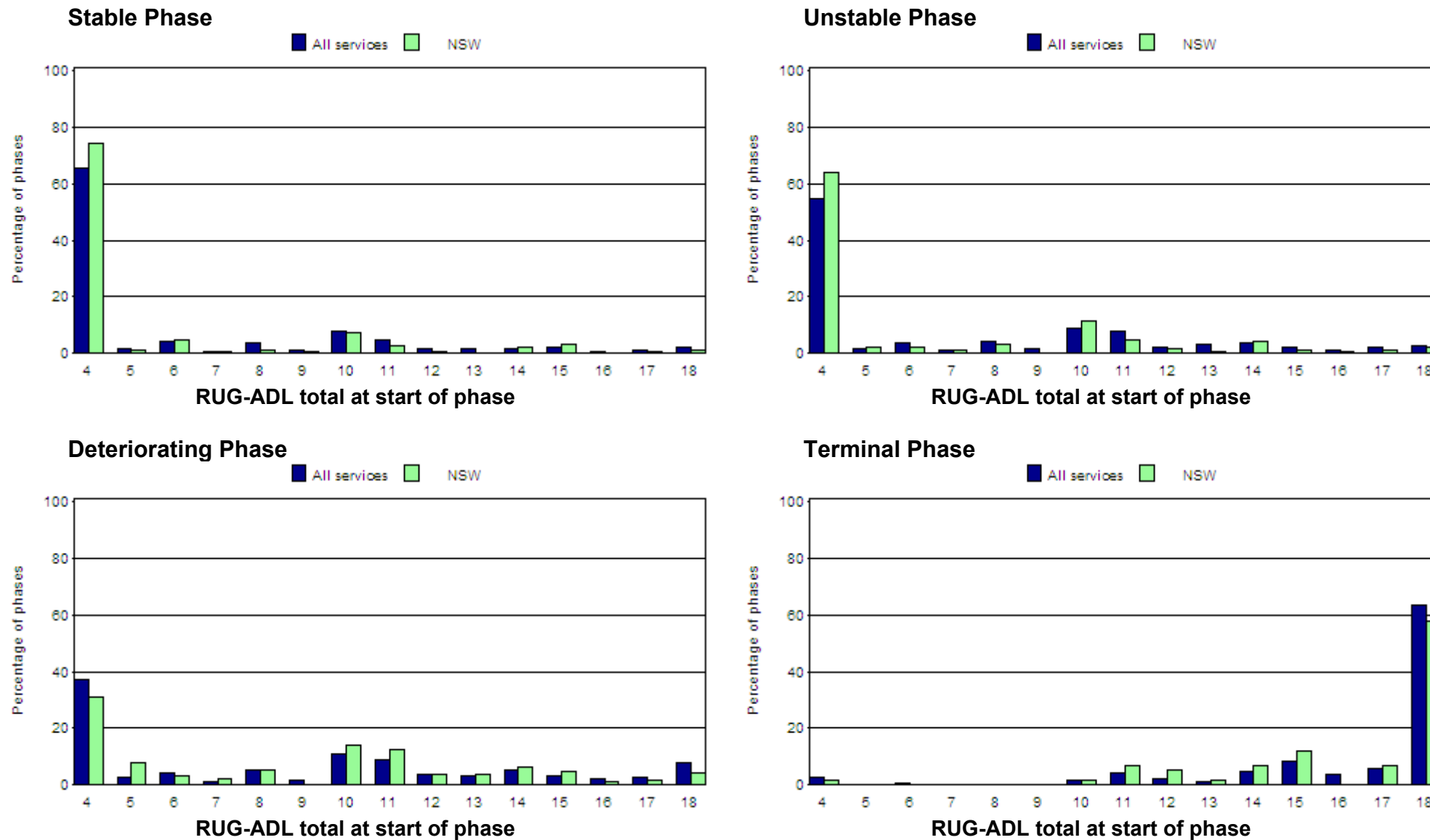


Table 21 *Profile of PC Problem Severity Scores (percentages) at beginning of phase by phase type - overnight admitted patients*

Phase	Problem severity	NSW				All services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	21.9	36.0	33.1	9.0	36.4	37.9	20.9	4.8
	Other Symptom	6.3	22.9	43.2	27.7	15.6	36.8	32.7	14.9
	Psychological/Spiritual	9.0	35.0	33.7	22.3	19.0	44.8	25.3	10.9
	Family/Carer	11.9	35.9	28.3	23.8	24.7	38.5	24.0	12.7
Unstable	Pain	12.0	24.6	38.3	25.1	18.2	26.1	34.6	21.1
	Other Symptom	4.3	11.6	42.2	41.9	7.1	18.5	42.6	31.9
	Psychological/Spiritual	8.7	26.3	34.0	31.1	11.0	32.7	34.4	21.9
	Family/Carer	7.2	25.0	33.6	34.2	14.5	28.7	32.5	24.3
Deteriorating	Pain	10.9	28.5	37.7	22.9	23.9	31.1	30.0	15.0
	Other Symptom	3.1	12.0	39.1	45.8	6.0	20.2	40.4	33.4
	Psychological/Spiritual	6.4	22.5	35.2	35.8	12.2	31.3	33.0	23.6
	Family/Carer	5.6	21.8	34.7	37.8	12.9	26.7	33.6	26.8
Terminal	Pain	13.0	24.0	34.6	28.5	29.5	28.5	24.9	17.1
	Other Symptom	5.5	7.6	31.2	55.7	13.6	19.1	29.3	37.9
	Psychological/Spiritual	10.6	18.4	28.7	42.3	25.5	25.2	23.6	25.7
	Family/Carer	4.1	15.0	29.4	51.5	9.4	21.4	31.5	37.7

Table 22 *Profile of PC Problem Severity Scores (percentages) at beginning of phase by phase type - patients not admitted overnight*

Phase	Problem severity	NSW				All services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	28.8	58.3	11.5	1.3	39.0	45.6	14.2	1.2
	Other Symptom	9.7	63.6	23.4	3.2	20.5	50.8	25.3	3.5
	Psychological/Spiritual	34.0	44.2	17.3	4.5	27.6	48.6	20.8	2.9
	Family/Carer	27.6	42.9	23.7	5.8	25.4	44.7	25.6	4.3
Unstable	Pain	14.6	35.4	32.8	17.2	21.4	32.4	30.9	15.3
	Other Symptom	3.4	23.2	50.9	22.5	9.3	23.4	46.9	20.4
	Psychological/Spiritual	11.2	26.9	44.4	17.5	13.0	36.6	37.3	13.1
	Family/Carer	10.4	23.9	50.7	14.9	14.1	29.9	42.0	14.0
Deteriorating	Pain	23.2	37.4	28.3	11.1	28.7	40.3	23.8	7.2
	Other Symptom	2.5	26.4	44.2	26.9	9.8	27.3	45.6	17.3
	Psychological/Spiritual	8.1	30.8	37.9	23.2	14.1	40.0	37.5	8.5
	Family/Carer	7.6	23.2	39.4	29.8	8.5	33.9	42.6	15.0
Terminal	Pain	27.6	34.5	20.7	17.2	36.3	35.5	19.5	8.6
	Other Symptom	3.4	25.4	35.6	35.6	20.0	25.7	31.4	23.0
	Psychological/Spiritual	18.6	30.5	27.1	23.7	28.1	36.2	25.8	10.0
	Family/Carer	3.4	20.3	33.9	42.4	6.2	22.2	49.5	22.0

Table 23 *Average Symptom Assessment Scores (SAS) at beginning of phase by phase and episode type*

Phase	Symptom Assessment Score	Overnight admitted		Not admitted overnight	
		NSW	All services	NSW	All services
Stable	Insomnia	2.2	1.7	1.8	1.5
	Appetite	3.4	2.7	2.4	2.5
	Nausea	1.4	0.9	0.8	0.7
	Bowels	2.7	2.1	1.7	1.3
	Breathing	2.4	1.8	1.5	1.7
	Fatigue	5.0	4.6	4.2	4.4
	Pain	3.0	2.3	1.8	1.8
Unstable	Insomnia	2.4	2.5	2.9	2.6
	Appetite	4.0	4.0	3.6	4.0
	Nausea	1.8	1.9	1.6	1.8
	Bowels	3.3	3.0	2.5	2.1
	Breathing	3.0	2.8	2.7	2.4
	Fatigue	5.4	5.6	5.6	5.6
	Pain	3.7	3.9	3.7	3.7
Deteriorating	Insomnia	2.4	2.1	2.9	2.0
	Appetite	4.8	4.0	4.3	3.7
	Nausea	1.8	1.5	1.5	1.2
	Bowels	3.5	2.9	2.9	1.7
	Breathing	3.2	3.0	3.4	2.4
	Fatigue	6.2	6.0	7.2	5.9
	Pain	3.8	3.4	3.2	2.5

Continued...

Phase	Symptom Assessment Score	Overnight admitted		Not admitted overnight	
		NSW	All services	NSW	All services
Terminal	Insomnia	2.7	1.3	2.4	1.5
	Appetite	4.1	2.6	5.3	4.9
	Nausea	1.7	0.9	2.0	0.7
	Bowels	3.2	2.1	3.2	1.6
	Breathing	3.8	3.4	2.4	2.8
	Fatigue	5.7	4.6	6.7	7.1
	Pain	3.6	2.9	3.0	2.4

Table 24 Karnofsky score at phase start by episode type

Karnofsky score	Overnight admitted				Not admitted overnight			
	NSW	%	All Services	%	NSW	%	All Services	%
Dead	74	1.1	96	0.5	0	0.0	53	0.6
Comatose or barely rousable	496	7.6	1680	9.2	13	1.9	263	2.8
Totally bedfast and requiring extensive nursing care	829	12.8	3119	17.1	37	5.4	703	7.6
Almost completely bedfast	438	6.7	1592	8.7	38	5.6	486	5.3
In bed more than 50% of the time	560	8.6	2371	13.0	48	7.0	815	8.8
Requires considerable assistance	794	12.2	2820	15.5	147	21.6	1802	19.5
Requires occasional assistance	503	7.7	2146	11.8	135	19.8	1648	17.8
Cares for self	178	2.7	672	3.7	144	21.1	1081	11.7
Normal activity with effort	94	1.4	316	1.7	55	8.1	570	6.2
Able to carry on normal activity; minor signs or symptoms	38	0.6	97	0.5	20	2.9	206	2.2
Normal; no complaints; no evidence of disease	1	0.0	5	0.0	0	0.0	33	0.4
Not stated/inadequately described	2492	38.4	3293	18.1	45	6.6	1592	17.2
Total	6497	100.0	18207	100.0	682	100.0	9252	100.0

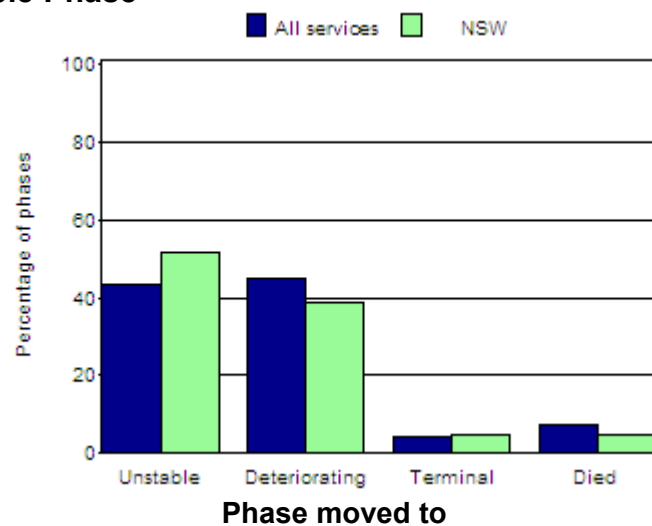
Note: Bereavement phase records are excluded from the table.

Table 25 Reason for phase end by phase and episode type

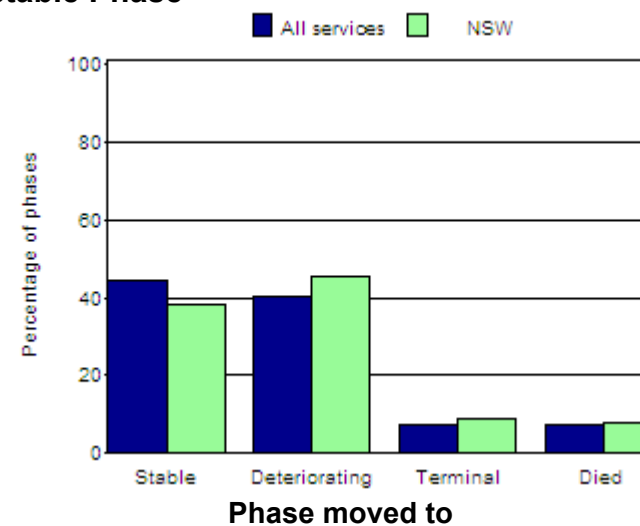
Phase	Reason for phase end	Overnight admitted				Not admitted overnight			
		NSW	%	All services	%	NSW	%	All services	%
Stable	Phase change	647	50.9	2119	49.9	100	64.1	1484	49.7
	Discharge/case closure	600	47.2	2024	47.7	40	25.6	679	22.8
	Died	20	1.6	89	2.1	11	7.1	155	5.2
	Bereavement phase end	1	0.1	2	0.0	0	0.0	0	0.0
	Not stated/Inadequately described	4	0.3	10	0.2	5	3.2	665	22.3
	<i>Total</i>	<i>1272</i>	<i>100.0</i>	<i>4244</i>	<i>100.0</i>	<i>156</i>	<i>100.0</i>	<i>2983</i>	<i>100.0</i>
Unstable	Phase change	1841	77.2	4648	79.3	210	78.4	1194	58.5
	Discharge/case closure	340	14.3	807	13.8	35	13.1	443	21.7
	Died	120	5.0	313	5.3	21	7.8	78	3.8
	Bereavement phase end	1	0.0	1	0.0	0	0.0	1	0.0
	Not stated/Inadequately described	83	3.5	89	1.5	2	0.7	324	15.9
	<i>Total</i>	<i>2385</i>	<i>100.0</i>	<i>5858</i>	<i>100.0</i>	<i>268</i>	<i>100.0</i>	<i>2040</i>	<i>100.0</i>
Deteriorating	Phase change	1139	66.7	3108	62.7	122	61.3	1692	51.3
	Discharge/case closure	90	5.3	745	15.0	46	23.1	921	27.9
	Died	473	27.7	1090	22.0	28	14.1	359	10.9
	Bereavement phase end	1	0.1	5	0.1	0	0.0	1	0.0
	Not stated/Inadequately described	4	0.2	12	0.2	3	1.5	327	9.9
	<i>Total</i>	<i>1707</i>	<i>100.0</i>	<i>4960</i>	<i>100.0</i>	<i>199</i>	<i>100.0</i>	<i>3300</i>	<i>100.0</i>
Terminal	Phase change	88	7.8	360	11.4	44	74.6	227	24.4
	Discharge/case closure	10	0.9	85	2.7	4	6.8	45	4.8
	Died	1024	90.4	2678	85.2	10	16.9	528	56.8
	Bereavement phase end	6	0.5	13	0.4	0	0.0	1	0.1
	Not stated/Inadequately described	5	0.4	9	0.3	1	1.7	128	13.8
	<i>Total</i>	<i>1133</i>	<i>100.0</i>	<i>3145</i>	<i>100.0</i>	<i>59</i>	<i>100.0</i>	<i>929</i>	<i>100.0</i>

Figure 3 Phase outcomes by phase - all phases

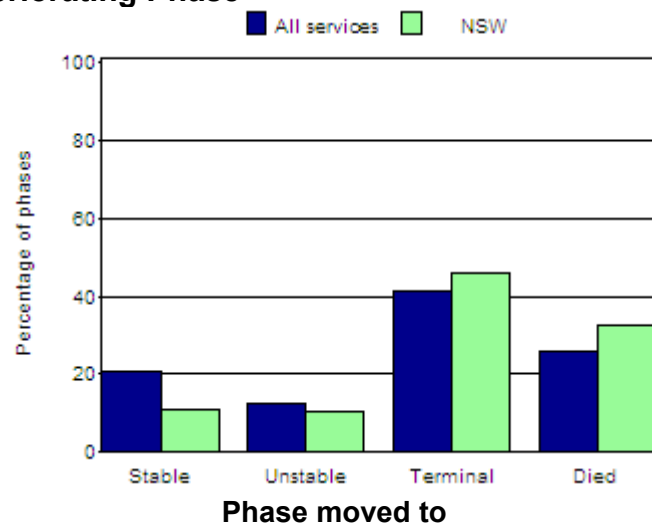
Stable Phase



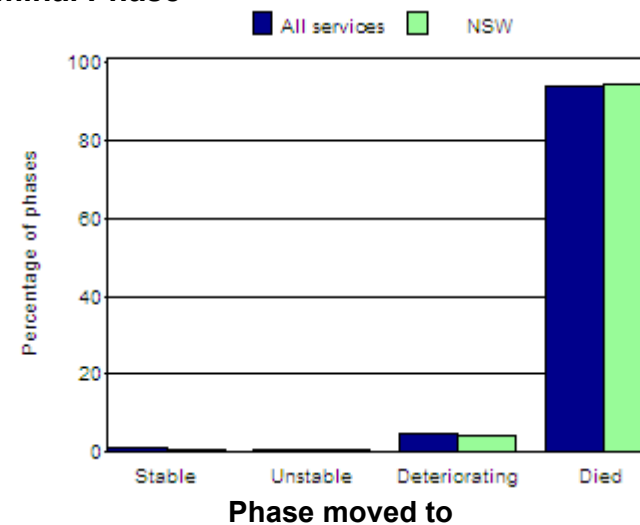
Unstable Phase



Deteriorating Phase



Terminal Phase



Section 3 - Benchmark analysis

Benchmark Measure 1 - Time from referral to first contact

Table 26 and Figures 4 and 5 below present descriptive data on the first benchmark measure. This measure is the percentage of patients seen within 48 hours of referral. The benchmark is **90%**.

The time from referral to first contact is calculated as the time from the date of referral to either the date of first contact (if provided) or the episode start date. Please note that the category *within 48 hours* represents those contacted on the same day as the referral or on the following day.

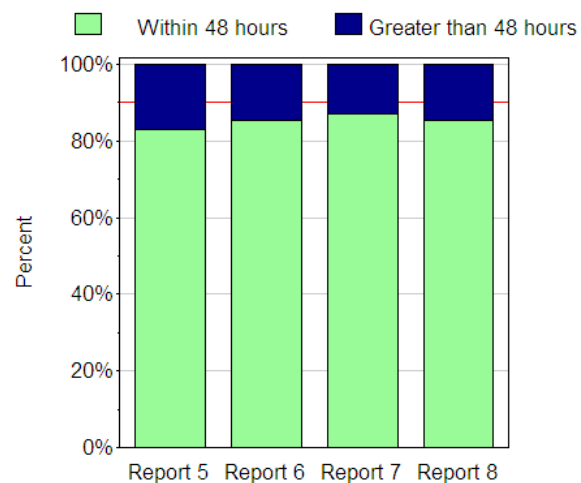
Table 26 *Time from referral to first contact by episode type*

Time (in days)	Overnight admitted patients				Patients not admitted overnight			
	NSW	%	All Services	%	NSW	%	All Services	%
Within 48 hours	2032	85.3	6945	86.7	231	63.5	2420	67.1
2-7 days	211	8.9	765	9.6	92	25.3	789	21.9
8-14 days	30	1.3	110	1.4	27	7.4	195	5.4
Greater than 14 days	108	4.5	190	2.4	14	3.8	204	5.7
Average	1.6	na	1.5	na	2.5	na	2.3	na
Median	1	na	1	na	1	na	1	na

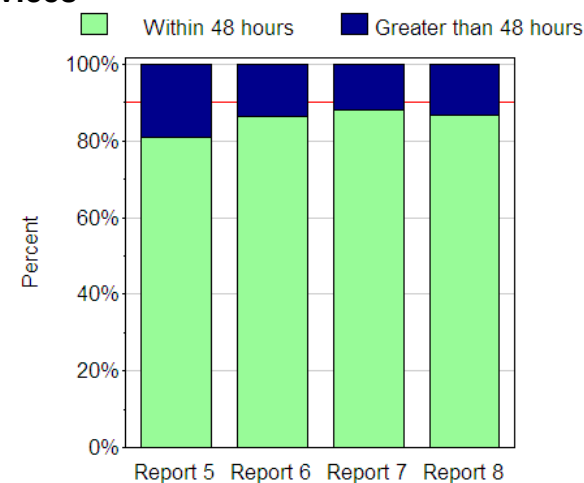
Note: Episodes where referral date, date of first contact, or episode start date were not recorded are excluded from the table. In addition, all records where time from referral to first contact or time from first contact to episode start was greater than 7 days were considered to be outliers and were assumed to equal 7 days for the purpose of calculating the average and median time.

Figure 4 Time from referral to first contact - overnight admitted patients

NSW

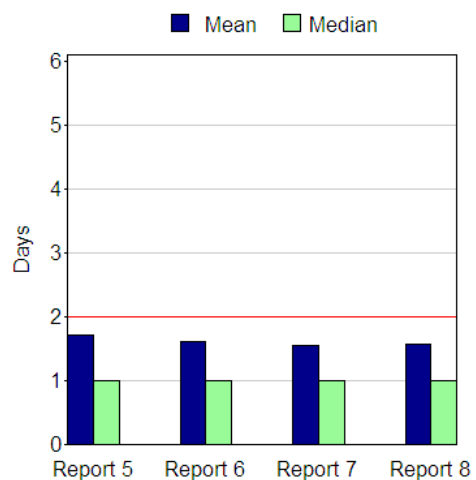


All services



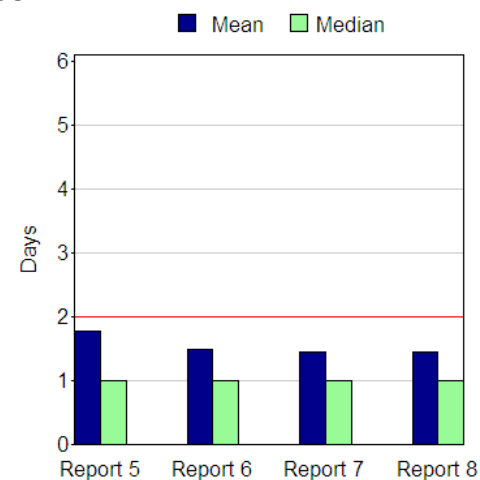
Time from referral to first contact

NSW



Time from referral to first contact

All services

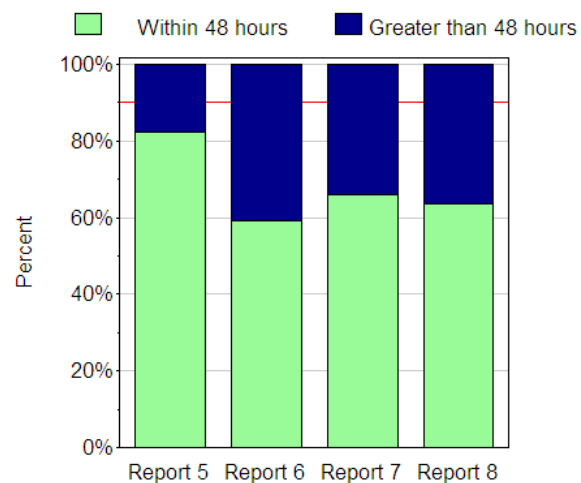


Mean and median time from referral to first contact

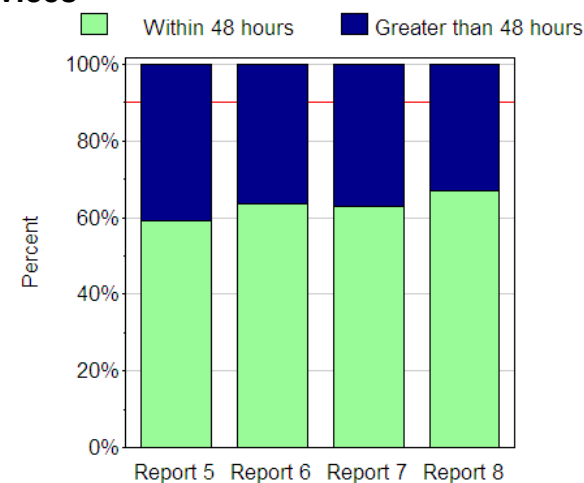
Mean and median time from referral to first contact

Figure 5 Time from referral to first contact - patients not admitted overnight

NSW

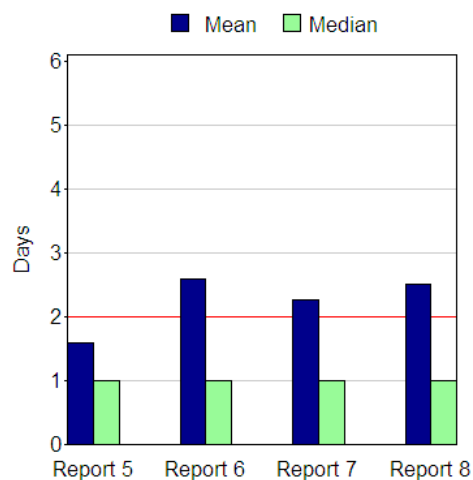


All services



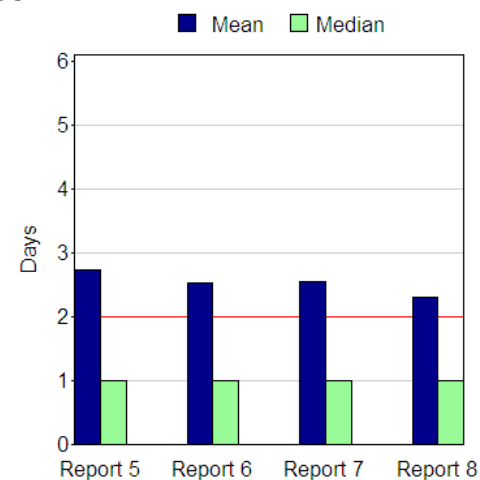
Time from referral to first contact

NSW



Time from referral to first contact

All services



Mean and median time from referral to first contact

Mean and median time from referral to first contact

Benchmark Measure 2 - Time in unstable phase

The following table presents descriptive data on the second benchmark measure. The first part of this measure is the percentage of patients remaining unstable for less than 7 days and is split by occurrence of unstable phase. The benchmark for patients in their first phase is **85%** and for patients in a subsequent phase is **90%**. The second part of this measure is the median time spent in the unstable phase and the benchmark is **2 days or less**.

Table 27 shows that for overnight admitted patients 4291 of the 5920 unstable phases occurred at the start of an episode (i.e. the patient was unstable on admission) and 1629 unstable phases occurred during the episode. In the first phase 71.4% of unstable phases were less than 7 days and for subsequent phases 80.1% of unstable phases were less than 7 days. In the first phase median time in the unstable phase was 4 days and in subsequent phases the median time in unstable phase was 2 days.

Similarly, for patients not admitted overnight, 932 of the 2041 unstable phases occurred at the start of an episode (i.e. the patient was unstable on admission) and 1109 unstable phases occurred during the episode. In the first phase 41.4% of unstable phases were less than 7 days and for subsequent phases 60.9% of unstable phases were less than 7 days. In the first phase the median time in the unstable phase was 9 days and in subsequent phases the median time in unstable phase was 4 days.

Table 27 *Time in unstable phase by episode type and occurrence of unstable phase*

Episode type	Occurrence of unstable phase	Number		Percent unstable for < 7 days		Median days in unstable phase	
		NSW	All Services	NSW	All Services	NSW	All Services
Overnight admitted	First phase	1879	4233	62.3	71.7	5	4
	Subsequent phase	506	1625	75.9	80.1	3	2
	Total	2385	5858	65.2	74.0	4	3
Not admitted overnight	First phase	138	931	34.1	41.4	9	9
	Subsequent phase	130	1109	43.8	60.9	8	4
	Total	268	2040	38.8	52.0	8	6

Benchmark Measure 3 - Change in pain

Change in pain PC Problem Severity Score (PCPSS)

The following two tables present data on the third benchmark measure in relation to pain PCPSS. The first measure is the percentage of patients with absent/mild pain at phase start remaining with absent/mild pain at phase end and the benchmark is **90%**. The second measure is the percentage of patients with moderate/severe pain at phase start with absent/mild pain at phase end and the benchmark is **60%**. Note that only phases with a valid pain score at both the start and the end of the phase are included in the following analysis.

Table 28 *Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase*

Episode type		NSW				All Services			
		Report 5	Report 6	Report 7	Report 8	Report 5	Report 6	Report 7	Report 8
Overnight admitted	Number	637	886	877	639	813	1650	2485	2896
	%	75.8	78.0	80.2	72.6	75.7	79.5	82.3	80.3
Not admitted overnight	Number	23	119	158	138	451	607	1201	1919
	%	74.2	87.5	81.0	74.6	90.7	82.4	79.1	82.0

Table 29 *Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase*

Episode type		NSW				All Services			
		Report 5	Report 6	Report 7	Report 8	Report 5	Report 6	Report 7	Report 8
Overnight admitted	Number	301	396	423	286	376	731	1024	1142
	%	34.2	32.2	34.1	25.4	31.4	36.7	38.1	40.2
Not admitted overnight	Number	12	22	30	37	45	122	270	403
	%	80.0	27.5	21.0	39.4	54.2	31.4	38.1	43.7

Change in pain Symptom Assessment Score (SAS)

The following two tables present data on the third benchmark measure in relation to pain SAS. The first measure is the percentage of patients with absent/mild pain at phase start remaining with absent/mild pain at phase end and the benchmark is **90%**. The second measure is the percentage of patients with moderate/severe pain at phase start with absent/mild pain at phase end and the benchmark is **60%**. Note that only phases with a valid pain score at both the start and the end of the phase are included in the following analysis.

Table 30 *Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase*

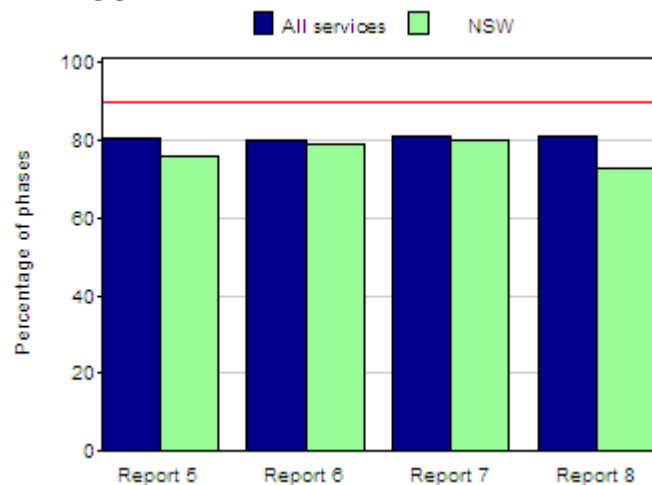
Episode type		NSW				All Services			
		Report 5	Report 6	Report 7	Report 8	Report 5	Report 6	Report 7	Report 8
Overnight admitted	Number	35	273	555	962	771	1771	3107	3896
	%	79.5	82.2	80.8	75.9	76.1	80.4	82.4	80.6
Not admitted overnight	Number	4	7	86	87	2710	3696	2624	2820
	%	100.0	53.8	77.5	76.3	82.5	83.3	81.6	80.7

Table 31 *Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase*

Episode type		NSW				All Services			
		Report 5	Report 6	Report 7	Report 8	Report 5	Report 6	Report 7	Report 8
Overnight admitted	Number	11	77	224	347	393	843	1235	1540
	%	16.4	25.8	35.2	33.1	37.8	38.9	41.2	40.3
Not admitted overnight	Number	1	5	12	25	570	625	552	642
	%	100.0	25.0	20.3	42.4	53.2	38.6	40.4	40.4

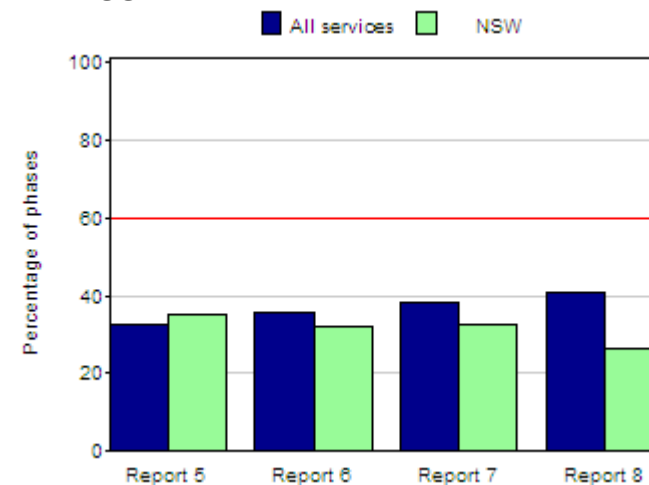
Figure 6 *Change in pain benchmark measures - all phases*

Pain PCPSS



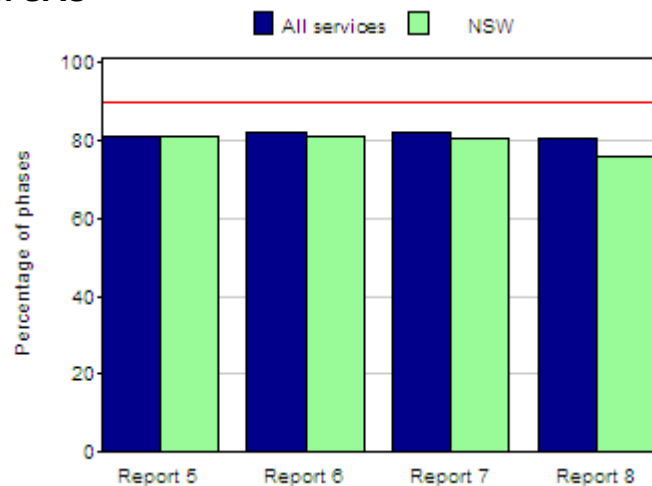
Absent/mild pain at both start and end of phase

Pain PCPSS



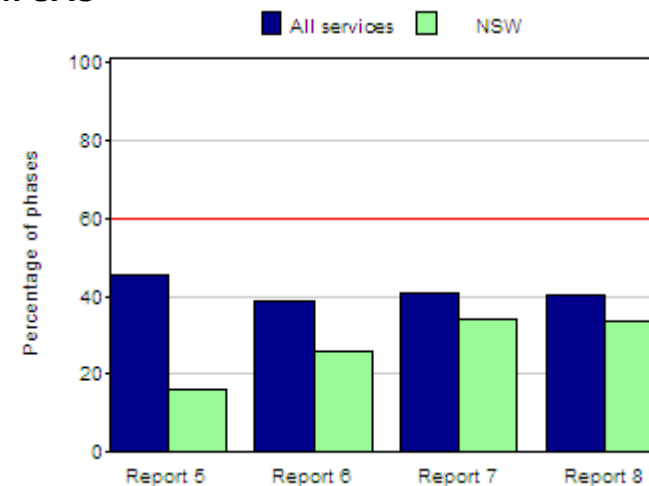
Mod/severe pain at start with absent/mild pain at end

Pain SAS



Absent/mild pain at both start and end of phase

Pain SAS

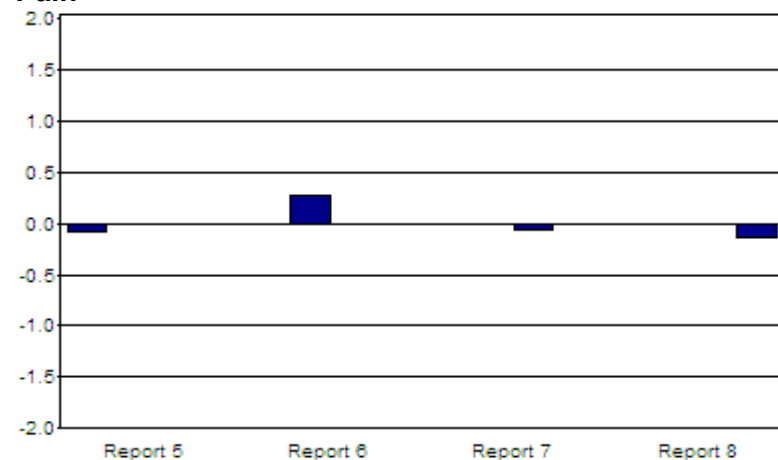


Mod/severe pain at start with absent/mild pain at end

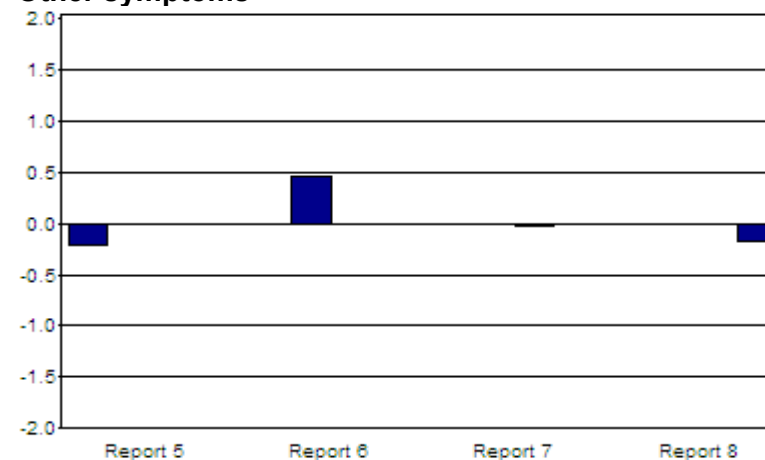
Benchmark Measure 4 - Change in symptoms relative to the national average

Figure 7 PCPSS mean change adjusted for phase and symptom score at start of phase for NSW

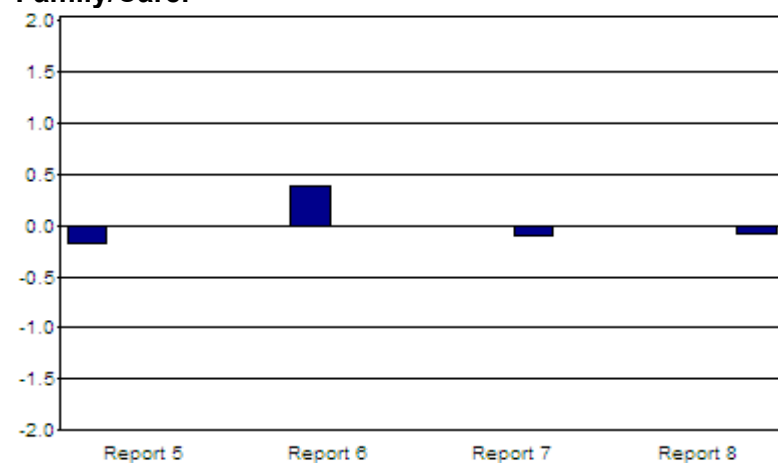
Pain



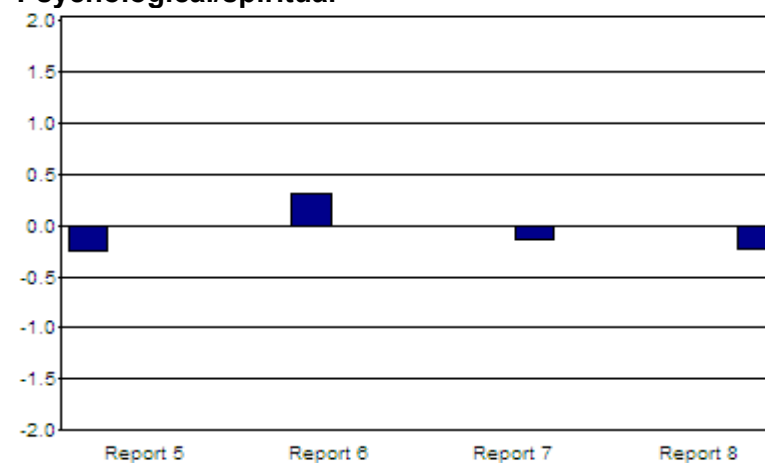
Other symptoms



Family/Carer



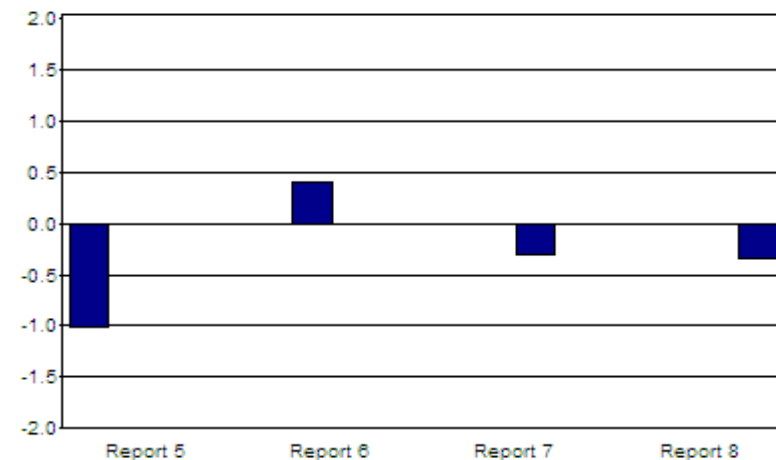
Psychological/spiritual



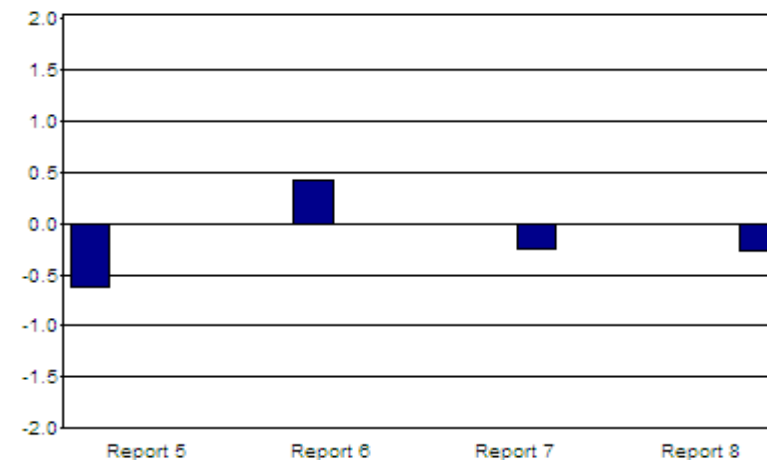
Note: Only services with 10 or more valid observations are included in the above graphs.

Figure 8 SAS mean change adjusted for phase and symptom score at start of phase for NSW

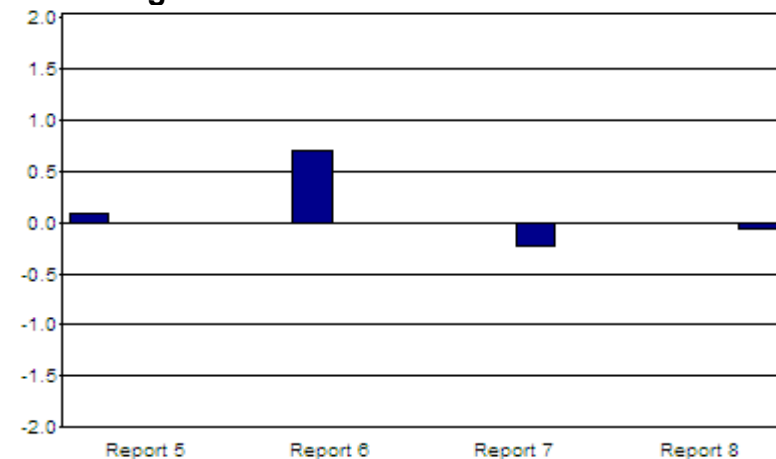
Pain



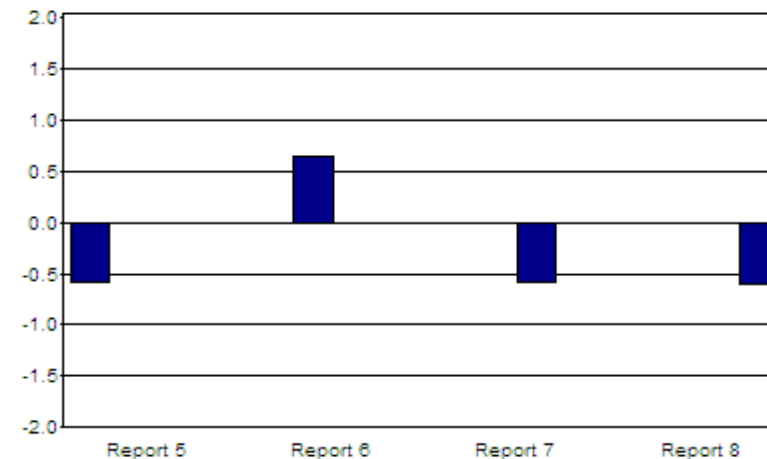
Nausea



Breathing



Bowels



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

Appendix 1 - Services included in this report

This report presents data from the following 91 services:

Table 32 *Services providing data*

Palliative Care Service	State	Begin date	End date	Months
Baringa Private Hospital	NSW	July 2009	October 2009	4
Calvary Health Care Sydney	NSW	July 2009	December 2009	6
Calvary Health Care Riverina	NSW	August 2009	November 2009	4
Calvary Mater Newcastle	NSW	July 2009	December 2009	6
Camden Hospital	NSW	July 2009	December 2009	6
Coffs Harbour Palliative Care Service	NSW	July 2009	December 2009	6
David Berry Hospital	NSW	July 2009	December 2009	6
Grafton Community Health - Palliative Care Service	NSW	July 2009	December 2009	6
Hope Healthcare - Braeside Hospital	NSW	July 2009	December 2009	6
Hope Healthcare - Greenwich Hospital	NSW	July 2009	December 2009	6
Hope Healthcare - Neringah Hospital	NSW	July 2009	December 2009	6
Lourdes Hospital	NSW	July 2009	December 2009	6
Manning Rural Referral Hospital	NSW	August 2009	December 2009	5
Mercy Care Centre - Young	NSW	July 2009	December 2009	6
Mercy Health Service Albury	NSW	July 2009	December 2009	6
Mt Druitt Hospital	NSW	July 2009	December 2009	6
Port Kembla Hospital	NSW	July 2009	December 2009	6
Sacred Heart Palliative Care Service	NSW	July 2009	December 2009	6
St Joseph's Hospital	NSW	July 2009	December 2009	6
St Vincent's Hospital Lismore	NSW	July 2009	December 2009	6
Tamworth Base Hospital	NSW	July 2009	December 2009	6
Tweed, Byron, Murwillumbah Community Health Service	NSW	July 2009	December 2009	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Westmead Hospital	NSW	July 2009	December 2009	6
Banksia Palliative Care Services	Vic	September 2009	December 2009	4
Broadmeadows Palliative Care	Vic	July 2009	December 2009	6
Caritas Christi - Fitzroy	Vic	July 2009	December 2009	6
Caritas Christi - Kew	Vic	July 2009	December 2009	6
Gandarra Palliative Care Unit - Ballarat	Vic	July 2009	December 2009	6
Goulburn Valley Hospice Inc.	Vic	July 2009	December 2009	6
Lower Hume Palliative Care	Vic	July 2009	December 2009	6
Melbourne Citymission Palliative Care	Vic	July 2009	December 2009	6
Mercy Palliative Care - Sunshine	Vic	July 2009	November 2009	5
South East Palliative Care	Vic	August 2009	December 2009	5
St John of God - Geelong	Vic	July 2009	November 2009	5
Sunraysia Community Palliative Care Service Clinic	Vic	August 2009	December 2009	5
Werribee Mercy Hospital	Vic	July 2009	December 2009	6
Western Health - Community	Vic	July 2009	December 2009	6
Western Health - Footscray	Vic	July 2009	December 2009	6
Western Health - Sunshine	Vic	August 2009	December 2009	5
Bundaberg Palliative Access	Qld	July 2009	December 2009	6
Cairns and Gordonvale Hospital	Qld	July 2009	December 2009	6
Canossa Private Hospital	Qld	July 2009	December 2009	6
Gladstone Hospital	Qld	July 2009	December 2009	6
Hervey Bay & Fraser Coast Palliative Care Service	Qld	July 2009	December 2009	6
Hopewell Hospice	Qld	July 2009	December 2009	6
Ipswich Hospice	Qld	July 2009	December 2009	6
Ipswich Hospital	Qld	July 2009	December 2009	6
Karuna Hospice Services	Qld	July 2009	December 2009	6
Logan - Beaudesert Hospital	Qld	September 2009	December 2009	4
Mater Adult's Hospital Brisbane	Qld	July 2009	December 2009	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Mater Private Brisbane	Qld	July 2009	December 2009	6
Mater Private Bundaberg	Qld	July 2009	November 2009	5
Mater Private Mackay	Qld	July 2009	December 2009	6
Mater Private Rockhampton	Qld	July 2009	December 2009	6
Mater Private Yeppoon	Qld	September 2009	October 2009	2
Mt Isa and Surrounds Palliative Care	Qld	July 2009	December 2009	6
Redcliffe Hospital Palliative Care Unit	Qld	July 2009	December 2009	6
Rockhampton Base Hospital	Qld	July 2009	December 2009	6
Royal Brisbane and Women's Hospital	Qld	July 2009	December 2009	6
St Vincent's Hospital Brisbane	Qld	July 2009	December 2009	6
Sunshine Coast and Cooloola Palliative Care Service	Qld	July 2009	December 2009	6
The Prince Charles Hospital	Qld	July 2009	December 2009	6
Toowoomba Hospital	Qld	July 2009	December 2009	6
Townsville Palliative Care Centre	Qld	July 2009	December 2009	6
Wesley Private	Qld	July 2009	December 2009	6
Adelaide Hills Community Health Service	SA	July 2009	November 2009	5
Calvary Health Care Adelaide (Mary Potter Hospice)	SA	July 2009	December 2009	6
Lyell McEwin Palliative Care Service	SA	July 2009	December 2009	6
Modbury Hospice SA	SA	July 2009	December 2009	6
Port Lincoln Health Service	SA	July 2009	December 2009	6
Port Pirie Regional Health Service	SA	July 2009	December 2009	6
Riverland Palliative Care Service	SA	August 2009	December 2009	5
Royal Adelaide Hospital	SA	July 2009	December 2009	6
South East Regional Community Health Service	SA	July 2009	December 2009	6
Southern Adelaide Palliative Services	SA	July 2009	December 2009	6
Stirling District Hospital	SA	November 2009	December 2009	2
Yorke Peninsula Palliative Care	SA	July 2009	December 2009	6
Albany Palliative Care Service	WA	July 2009	December 2009	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Bethesda Hospital	WA	July 2009	December 2009	6
Geraldton Palliative Care Community Service	WA	July 2009	December 2009	6
Northam Palliative Care	WA	July 2009	December 2009	6
Peel Community Palliative Care Service	WA	July 2009	December 2009	6
Royal Perth Hospital	WA	July 2009	December 2009	6
Silver Chain Hospice Care Service	WA	July 2009	December 2009	6
Sir Charles Gairdner Hospital	WA	July 2009	October 2009	4
St John of God Hospital - Bunbury	WA	August 2009	December 2009	5
St John of God Hospital - Geraldton	WA	July 2009	December 2009	6
St John of God Murdoch Community Hospice	WA	July 2009	December 2009	6
Calvary Health Care Tasmania - St John's	Tas	July 2009	December 2009	6
JW Whittle Palliative Care Unit	Tas	July 2009	December 2009	6
Calvary Health Care Canberra (Clare Holland House)	ACT	July 2009	December 2009	6

Appendix 2 - Data consistency

Consistency with PCOC version 2 data standards is summarised below. Over this 6 month period consistency with patient, episode and phase level data items for NSW and for all services has been calculated. Consistency refers to completion of data items used within this report with valid entries based on the PCOC version 2 item codes.

In addition, some data items are not required to be completed. For example, place of death is only required for not admitted overnight patients who died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was required to be completed.

Table 33 *Data consistency - patient level items*

	NSW	All Services
Data Item	% Complete	% Complete
Date of birth	100.0	100.0
Sex	100.0	99.9
Indigenous status	98.2	97.2
Country of birth	98.9	94.4
Main language	96.1	96.0
Primary diagnosis	77.5	89.2

Table 34 *Data consistency - episode level items*

Data Item	NSW	All Services
	% Complete	% Complete
Date of first contact/assessment	81.6	94.3
Referral date	85.1	87.7
Referral source	79.1	93.2
Episode start date	100.0	100.0
Mode of episode start	99.9	99.6
Accommodation at episode start	80.9	85.9
Episode end date	100.0	100.0
Level of support at episode start	52.8	77.3
Mode of episode end	98.8	97.1
Accommodation at episode end	72.6	74.5
Level of support at episode end	94.0	93.8
Place of death	93.2	88.7

Table 35 *Data consistency - phase level items*

Data item	Sub-Category (where applicable)	NSW %Complete	All Services %Complete
Phase start date		100.0	99.6
Phase		100.0	99.6
RUG-ADL at phase start	Bed Mobility	99.9	94.4
	Toileting	99.9	94.3
	Transfers	99.9	94.2
	Eating	99.9	94.0
PC Problem Severity at phase start	Pain	57.8	62.4
	Other Symptom	73.6	65.8
	Psychological/Spiritual	89.7	82.4
	Family/Carer	89.7	81.5
Symptom Assessment Score at phase start	Insomnia	59.1	83.3
	Appetite	59.1	83.2
	Nausea	59.1	83.5
	Bowels	59.1	83.3
	Breathing	59.1	83.7
	Fatigue	59.1	83.9
	Pain	59.1	84.3
Phase end reason		98.5	93.7
Karnofsky at phase start		65.3	82.6

Appendix 3 – Glossary

Overnight admitted and not admitted overnight groups

Where appropriate, the analysis in this report has been reported by episode type. The PCOC definition of episode type is “The location of the patient for this episode”. The options are as follows:

- 0 Overnight admitted patient in a non-designated inpatient palliative care bed/unit
- 1 Overnight admitted patient in a designated inpatient palliative care bed/unit.
- 3 Ambulatory
- 4 Community
- 5 Consultation service

These 5 options have been grouped into 2 for the purpose of reporting. The 2 groups are as follows:

- | | |
|------------------------|-----------------------------------|
| Overnight admitted | Includes episode types 0 and 1 |
| Not admitted overnight | Includes episode types 3, 4 and 5 |

However, consultation services have been difficult to categorise into the above groups. Consultation services have been included in the overnight admitted group, with the exception of services identifying as outpatient or community consultancy which have been included in the not admitted overnight group. Consultation services that treat patients in a hospital bed have been instructed to tick “0” or “1” for the episode type field. Consultation services that treat patients in an outpatient setting or in the community have been instructed to tick “5” for the episode type field.

Episode of care

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting (either overnight admitted patient or not admitted overnight patient). When a patient moves from their home to a residential aged care facility (RACF) it is considered their home and the episode continues. An episode of care refers to the care received between admission and separation within one setting. An episode of palliative care begins:

- on the day the patient is assessed face to face by the palliative care provider and there is agreement between the patient and the service.

An episode of palliative care ends when:

- the principal clinical intent of the care changes and the patient is no longer receiving palliative care or
- when the patient is formally separated from the hospital/hospice/community.

Phase of care

The palliative care phase is the stage of the patient's illness. Palliative care phases are not sequential and a patient may move back and forth between phases. Palliative care phases provide a clinical indication of the level of care required and have been shown to correlate strongly with survival within longitudinal, prospective studies. There are 5 palliative care phases; stable, unstable, deteriorating, terminal and bereaved. The definitions are as follows:

Phase 1: Stable

All clients not classified as unstable, deteriorating, or terminal.

- The person's symptoms are adequately controlled by established management. Further interventions to maintain symptom control and quality of life have been planned.
- The situation of the family/carers is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.

Phase 2: Unstable

- The person experiences the development of a new unexpected problem or a rapid increase in the severity of existing problems, either of which require an urgent change in management or emergency treatment
- The family/carers experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team.

Phase 3: Deteriorating

- The person experiences a gradual worsening of existing symptoms or the development of new but expected problems. These require the application of specific plans of care and regular review but not urgent or emergency treatment.
- The family/carers experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person. This requires a planned support program and counselling as necessary.

Phase 4: Terminal

Death is likely in a matter of days and no acute intervention is planned or required. The use of frequent, usually daily, interventions aimed at physical, emotional and spiritual issues is required.

The typical features of a person in this phase may include the following:

- Profoundly weak
- Essentially bed bound
- Drowsy for extended periods
- Disoriented and has a severely limited attention span
- Increasingly disinterested in food and drink
- Finding it difficult to swallow medication
- The family/carers recognise that death is imminent and care is focused on emotional and spiritual issues as a prelude to bereavement.

Phase 5: Bereaved

Death of the patient has occurred and the carers are grieving. A planned bereavement support program is available including referral for counseling as necessary. Record only one bereavement phase per patient - not one for each carer/family member.

Resource Utilisation Groups- Activities of Daily Living Definitions (RUG-ADL)

RUG-ADL consists of 4 items (bed mobility, toileting, transfers and eating) and should be assessed on admission, at phase change and at episode end. The item score definitions are as follows:

RUG –ADL Item	Score	Definition
BED MOBILITY		Ability to move in bed after the transfer into bed has been completed.
Independent or supervision only	1	Able to readjust position in bed, and perform own pressure area relief, through spontaneous movement around bed or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Able to readjust position in bed, and perform own pressure area relief, with the assistance of one person.
Other than two persons physical assist	4	Requires the use of a hoist or other assistive device to readjust position in bed and provide pressure relief. Still requires the assistance of one person for task.
Two or more persons physical assist	5	Requires 2 or more assistants to readjust position in bed, and perform pressure area relief.
TOILETING		Includes mobilising to the toilet, adjustment of clothing before and after toileting and maintaining perineal hygiene without the incidence of incontinence or soiling of clothes. If level of assistance differs between voiding and bowel movement, record the lower performance.
Independent or supervision only	1	Able to mobilise to toilet, adjusts clothing, cleans self, has no incontinence or soiling of clothing. All tasks are performed independently or with prompting from carer. No hands-on assistance required. May be independent with the use of a device. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of one person for one or more of the tasks.
Other than two persons physical assist	4	Requires the use of a catheter/uridome/urinal and/or colostomy/bedpan/commode chair and/or insertion of enema/ suppository. Requires assistance of one person for management of the device.
Two or more persons physical assist	5	Requires two or more assistants to perform any step of the task.
TRANSFER		Includes the transfer in and out of bed, bed to chair, in and out of shower/tub. Record the lowest performance of the day/night.
Independent or supervision only	1	Able to perform all transfers independently or with prompting of carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of one person to perform any transfer of the day/night.
Other than two persons physical assist	4	Requires use of a device for any of the transfers performed in the day/night. Requires only one person plus a device to perform the task.
Two or more persons physical assist	5	Requires 2 or more assistants to perform any transfer of the day/night.
EATING		Includes the tasks of cutting food, bringing food to mouth and chewing and swallowing food. Does not include preparation of the meal.
Independent or supervision only	1	Able to cut, chew and swallow food, independently or with supervision, once meal has been presented in the customary fashion. No hands-on assistance required. If individual relies on parenteral or gastrostomy feeding that he/she administers him/herself then Score 1.
Limited assistance	2	Requires hands on assistance of one person to set up or assist in bringing food to the mouth and/or requires food to be modified (soft or staged diet).
Extensive assistance/dependence/ tube fed	3	Person needs to be fed meal by assistant, or the individual does not eat or drink full meals by mouth but relies on parenteral/ gastrostomy feeding and does not administer feeds by him/herself.

PC Problem Severity Score (PCPSS)

The problem severity is an overall score of the patient/client and family and contains 4 items. The 4 items are:

1. Pain
2. Other symptoms
3. Psychological/spiritual
4. Family/carer

Each item is given a score from 0-3:

0 = Absent

1 = Mild

2 = Moderate

3 = Severe

Karnofsky (Australian) Performance Scale

The Karnofsky used in PCOC is the Australian (modified) version which is applicable to both inpatient and community palliative care. The Karnofsky Performance Scale assesses patient/client functioning and performance and can be used to indicate prognosis. The Karnofsky is often used in determining prognosis / survival times. The Karnofsky Performance Scale Definition Criteria is as follows:

100	Normal; no complaints; no evidence of disease
90	Able to carry on normal activity; minor signs of symptoms of disease
80	Normal activity with effort; some signs or symptoms of disease
70	Cares for self. Unable to carry on normal activity or to do active work
60	Able to care for most needs, but requires occasional assistance.
50	Requires considerable assistance and frequent medical care required.
40	In bed more than 50% of the time.
30	Almost completely bedfast.
20	Totally bedfast and requiring extensive nursing care by professionals and/or family.
10	Comatose or barely rousable.
0	Dead

Symptom Assessment Scale (SAS)

There are 7 items (symptoms) in total and each one is given a score between 0-10 (not at all to worst possible). The 7 symptoms are insomnia, appetite, nausea, bowels, breathing, fatigue and pain. Symptoms are rated by the patient/client except where they are unable due to language barrier, hearing impairment or physical condition such as terminal phase or delirium, in which case a proxy is used. Use the most appropriate proxy. This may be the nurse or the family member. Highly rated or problematic symptoms may trigger other assessments or clinical interventions.

Change in symptoms relative to the national average

These are measures of the mean change in symptoms on the PCPSS/SAS that are adjusted for both phase and for the symptom score at the start of each phase (note bereavement phases are excluded from the analysis). Therefore it is only able to be calculated on patients who either had a subsequent phase within the reporting period or were discharged. In other words it is a case mix adjusted score where we compare the change in symptom score for 'like' patients i.e. patients in the same phase who started with the same level of symptom.

This measure has been abbreviated to XCAS where X represents the symptom analysed. For example PCAS represents the Pain Case Mix Adjusted Score. Eight symptoms have been included in this report:

1. PCPSS Pain
2. PCPSS Other symptoms
3. PCPSS Psychological/spiritual
4. PCPSS Family/carer
5. SAS Pain
6. SAS Nausea
7. SAS Bowels
8. SAS Breathing

Your service is then able to see if you are doing the same, better or worse than the national average for similar patients. The baseline period for calculating the national averages is July-December 2008 (report 6 period) and this will remain as such for the next 2 years (until January 2011). On a national basis this means the change in symptoms relative to the national average for the report 6 period will be zero.

- If X-CAS for your service > 0
on average, your patients' change in symptom was better than similar patients in the national database.
- If X-CAS for your service = 0

On average, your patients' change in symptom was about the same as similar patients in the national database.

- If X-CAS for your service < 0

On average, your patients' change in symptom was worse than similar patients in the national database

The mathematical algorithm and calculations are demonstrated below:

- Calculate the average change for all patients in the same phase and with the same symptom start score (each symptom class). This is the **expected** change.
- For each patient's phase, calculate their change in symptom score
- For each patient's phase, calculate the difference between their symptom score change and the average change for all patients in the same phase and with the same symptom start score
- Average across the service to produce the service's Symptom Casemix-Adjusted Score (i.e. PCAS)

Example:

Phase	PCPSS Pain start	PCPSS Pain change	Expected PCPSS Pain change	Difference
Stable	0	-1	-0.8	-0.2
Stable	1	0	-0.9	0.9
Unstable	3	2	1.6	0.4
Deteriorating	2	1	1.4	-0.4
PCAS = 0.175 $[(-0.2+0.9+0.4-0.4)/4]$				

If you would like further clarification regarding any of the analysis throughout this report, please contact PCOC at pcoc@uow.edu.au.

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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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