PCOC National Report on Palliative Care in Australia

January to June 2009

October 2009

Funded by the Australian Government

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Palliative Care Outcomes Collaboration (PCOC)

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Introduction

Funding

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.* In part, this will be achieved by collecting and analysing data and reporting findings to services.

Dataset

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 PCOC database contains data from April 2006 to June 2009 on 41,135 patients with 51,075 episodes of care and 104,108 phases of care.

PCOC reports

PCOC provides analysis of each service's data and also compares this to the national data. The clinical assessment tools - Phase of Care, PC Problem Severity Score (PSS), Symptom Assessment Scale (SAS), Australian-modified Karnofsky and RUG-ADL - provide measures of quality and outcomes.

PCOC Report 7

86 palliative care services submitted data for this report and the reporting period is January to June 2009. PCOC is progressively introducing benchmark measures into the PCOC Reports. These measures are chosen based on discussions and outcomes from the annual PCOC Benchmarking Workshops. There are four benchmark measures included in Report 7 although no benchmarks have yet been set as these are still to be agreed. Agreement of benchmarks will occur later in the year after the next SCAC meeting when suggested benchmarks from the workshops held during May-June 2009 will be considered. The benchmark measures are:

Benchmark measure 1 - Time from referral to first contact (Table 24, Figure 4)
Benchmark measure 2 - Time in the unstable phase (Table 25)
Benchmark measure 3 - Change in pain (both PC PSS and SAS) (Tables 26 – 29, Figure 5)
Benchmark measure 4 - Change in symptoms relative to the national average (Figures 6 and 7)

Although the benchmark measures have been reported by setting of care (overnight admitted and not admitted overnight), services and PCOC suggested that actual benchmarks should be the same across all settings as it should be seen through the patient's eyes rather than the service provider's eyes.

Time from referral to first contact is calculated by the difference between the referral date and the date of first contact or episode start date (which ever occurs first or has been provided) and is calculated for all episodes of care and across all settings of care. Although definitional issues around this measure have been identified it was decided that it is still a useful measure of service responsiveness and that future changes incorporated into the Version 3 dataset will improve the collection, quality and understanding of the items required for this measure.

Time in the unstable phase is calculated by the difference between the phase start date and the phase end date and is analysed by episode type and then occurrence of the unstable phase during the episode.

Change in pain is calculated by the difference in pain score from the beginning of a phase to the end of phase and is calculated using both PSS pain and SAS pain measures. It is also reported by setting of care. The proposed benchmark measures are the proportion of patients with absent or mild pain at the beginning of a phase whose pain remained absent or mild at the end of the phase and the proportion of patients with moderate or severe pain at the beginning of a phase whose pain decreased to absent or mild at the end of the phase.

Change in symptoms relative to the national average measures 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. This measure allows services to compare the change in symptom score for 'like' patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms have been included in this report (PCPSS pain, other symptoms, psychological/spiritual, family/carer; SAS pain, nausea, bowels, breathing).

Once benchmark measures are adopted they can be reviewed and adjusted over time and other measures can be considered at future workshops.

Points to 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 - Data Summary

This report presents data from a total of 86 services. During the reporting period data were provided for a total of 9436 patients, with 11690 episodes and 24881 phases. For the purposes of reporting episode types Ambulatory, Community and Consultation service have been grouped together to for 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
Number of patients*	6861	3143	9436
Number of episodes	7923	3767	11690
Number of phases	17288	7593	24881
Percentage of patients**	72.7	33.3	100
Percentage of episodes	67.8	32.2	100
Percentage of phases	69.5	30.5	100

Notes:

* Patients who have been in both an overnight admitted and Not admitted overnight setting are only counted once in the Total column and hence numbers may not add to the total.

** Patients who have been in both an overnight admitted and Not admitted overnight setting are only counted once in the Total column and hence percentages may not add to 100.

Table 2 Patients with multiple episodes - overnight admitted patients

Patients with:	Number	%	Average age at first admission	Malignant %	Non-malignant %
1 episode	6037	88.0	71	71.5	13.7
2 episodes	652	9.5	68	83.3	6.4
3 episodes	124	1.8	65	89.5	4.0
4 episodes	33	0.5	67	78.8	12.1
5 or more episodes	15	0.2	62	86.7	6.7

Note: Records where diagnosis was not provided are excluded from the table and hence the percentage of malignant and non-malignant may not add to 100.

Section 2 - Descriptive analysis

Profile of palliative care patients

Table 3 Indigenous Status - all patients

Indigenous Status	Number	%
Aboriginal but not Torres Strait Islander origin	78	0.8
Torres Strait Islander but not Aboriginal origin	18	0.2
Both Aboriginal and Torres Strait Islander origin	12	0.1
Neither Aboriginal nor Torres Strait Islander origin	9117	96.6
Not stated/Inadequately described	211	2.2
Total	9436	100.0

Table 4 Sex - all patients

Sex	Number	%
Male	5111	54.2
Female	4304	45.6
Not stated/inadequately described	21	0.2
Total	9436	100.0

Table 5 Main language spoken at home - all patients

Main language spoken at home	Number	%
English	8000	84.8
Italian	131	1.4
Greek	76	0.8
Croatian	57	0.6
Cantonese	53	0.6
Vietnamese	28	0.3
Macedonian	24	0.3
Maltese	21	0.2
Spanish	21	0.2
Serbian	19	0.2
Mandarin	19	0.2
Polish	17	0.2
German	16	0.2
Arabic (including Lebanese)	12	0.1
French	11	0.1
All other languages	138	1.5
Not stated/inadequately described	793	8.4
Total	9436	100.0

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

Table 6 Country of birth - all patients

Country of birth	Number	%
Australia	6104	64.7
England	788	8.4
Italy	315	3.3
Scotland	159	1.7
New Zealand	147	1.6
Greece	127	1.3
Germany	113	1.2
Netherlands	96	1.0
Croatia	81	0.9
China	72	0.8
Poland	69	0.7
Malta	66	0.7
Ireland	59	0.6
Vietnam	54	0.6
Yugoslavia	44	0.5
All other countries	840	8.9
Not stated/inadequately described	302	3.2
Total	9436	100.0

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

Profile of palliative care episodes

The 9436 patients from Number seen in the six month period had a total of 11690 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 group. The average age for all patients at a national level was 70 years.

Table 7 Number of episodes by age group - all episodes

Age group	Number	%
< 15	56	0.5
15-24	48	0.4
25-34	131	1.1
35-44	350	3.0
45-54	1053	9.0
55-64	2146	18.4
65-74	2980	25.5
75-84	3327	28.5
85+	1599	13.7
Not stated/inadequately described	0	0.0
Total	11690	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 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 a higher proportion of patients not admitted overnight were referred by a public hospital or General Medical Practitioner rooms.

Table 8 Referral source by episode type

Referral source	Overnight admitted		Not admitted overnight	
	Number	%	Number	%
Public hospital - other than inpatient palliative care unit	3227	40.7	1580	41.9
Self, carer(s), family or friends	223	2.8	97	2.6
Private hospital - other than inpatient palliative care unit	562	7.1	316	8.4
Public palliative care inpatient unit/hospice	127	1.6	179	4.8
Private palliative care inpatient unit/hospice	38	0.5	51	1.4
General Medical Practitioner rooms	676	8.5	803	21.3
Specialist Medical Practitioner rooms	209	2.6	273	7.2
Community-based palliative care agency	1344	17.0	136	3.6
Community-based service	257	3.2	91	2.4
Residential aged care facility	44	0.6	96	2.5
Other	185	2.3	121	3.2
Not stated/inadequately described	1031	13.0	24	0.6
Total	7923	100.0	3767	100.0

Table 9 How episodes start and end - overnight admitted patients

Mode of episode start	Mode of episode end					
	Discharged to usual accommodation	Discharged to interim accommodation	Discharged to another hospital	Death	All other reasons**	Total
Admitted from usual accommodation	2102	121	226	2267	257	4973
Admitted from other than usual accommodation	24	17	25	67	7	140
Admitted (transferred) from another hospital	276	38	112	1330	35	1791
Admitted (transferred) from acute care in other ward	58	14	26	384	9	491
All other reasons*	126	5	3	122	72	328
Total	*2586*	*195*	*392*	*4170*	*380*	*7723*
As a percentage of each start mode						
Admitted from usual accommodation	42.3	2.4	4.5	45.6	5.2	100.0
Admitted from other than usual accommodation	17.1	12.1	17.9	47.9	5.0	100.0
Admitted (transferred) from another hospital	15.4	2.1	6.3	74.3	2.0	100.0
Admitted (transferred) from acute care in other ward	11.8	2.9	5.3	78.2	1.8	100.0
All other reasons*	38.4	1.5	0.9	37.2	22.0	100.0
Total	*33.5*	*2.5*	*5.1*	*54.0*	*4.9*	*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 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 10 How episodes start and end - patients not admitted overnight

Mode of episode start	Mode of episode end					
	Discharged/ case closure	Admitted for inpatient palliative care	Admitted for inpatient acute care	Transfer for primary care	Death	Total
New referral	550	512	482	55	874	2473
Transfer from being an o/n PC patient	147	151	127	22	190	637
Total	*697*	*663*	*609*	*77*	*1064*	*3110*
As a percentage of each start mode						
New referral	22.2	20.7	19.5	2.2	35.3	100.0
Transfer from being an o/n PC patient	23.1	23.7	19.9	3.5	29.8	100.0
Total	*22.4*	*21.3*	*19.6*	*2.5*	*34.2*	*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 are also excluded.

Table 11 Accommodation at episode start and end - all discharged patients

	Accommodation at episode end				
Accommodation at episode start	Private residence	Low level care	High level care	All other*	Total
Private residence	2208	17	97	175	2497
Residential aged care (low level care)	8	22	9	5	44
Residential aged care (high level care)	6	4	107	3	120
All other	111	5	10	44	170
Total	*2333*	*48*	*223*	*227*	*2831*
As a percentage of each start accommodation					
Private residence	88.4	0.7	3.9	7.0	100.0
Residential aged care (low level care)	18.2	50.0	20.5	11.4	100.0
Residential aged care (high level care)	5.0	3.3	89.2	2.5	100.0
All other	65.3	2.9	5.9	25.9	100.0
Total	*82.4*	*1.7*	*7.9*	*8.0*	*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 are also excluded. The all other category includes: Community group home; Boarding house; Transitional living unit.

Table 12 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				
	Without support (lives alone)	Without support (lives with others)	With support (lives alone or with others)	Other arrangements	Total
Without support (lives alone)	54	4	86	1	145
Without support (lives with others)	1	61	126	0	188
With support (lives alone or with others)	12	17	1661	0	1690
Other arrangements	0	0	0	0	0
Total	*67*	*82*	*1873*	*1*	*2023*
As a percentage of each start support					
Without support (lives alone)	37.2	2.8	59.3	0.7	100.0
Without support (lives with others)	0.5	32.4	67.0	0.0	100.0
With support (lives alone or with others)	0.7	1.0	98.3	0.0	100.0
Other arrangements	na	na	na	na	na
Total	*3.3*	*4.1*	*92.6*	*0.0*	*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 are also excluded.

Table 13 Primary diagnosis by episode type - summary

	Overnight admitted		Not admitted overnight	
Primary diagnosis	Number	%	Number	%
Malignant	5911	74.6	2985	79.2
Non-malignant	951	12.0	702	18.6
Not stated/inadequately described	1061	13.4	80	2.1
Total	7923	100.0	3767	100.0

Table 14 Primary diagnosis by episode type

Primary diagnosis		Overnight admitted		Not admitted overnight	
		Number	%	Number	%
Malignant	Bone and soft tissue	175	3.2	116	4.9
	Breast	478	8.8	189	8.0
	CNS	122	2.3	57	2.4
	Colorectal	616	11.4	221	9.3
	Gynaecological	276	5.1	133	5.6
	Haematological	319	5.9	132	5.6
	Head and neck	342	6.3	139	5.9
	Lung	1173	21.7	485	20.5
	Pancreas	261	4.8	133	5.6
	Prostate	432	8.0	203	8.6
	Skin	243	4.5	97	4.1
	Other GIT	434	8.0	227	9.6
	Other Urological	244	4.5	108	4.6
	Other Malignancy	300	5.5	131	5.5
	All malignant	*5415*	*100.0*	*2371*	*100.0*
Non-malignant	Cardiovascular	207	22.4	79	24.9
	HIV/AIDS	16	1.7	0	0.0
	Kidney failure	115	12.4	45	14.2
	Neurological disease	224	24.2	80	25.2
	Respiratory failure	114	12.3	58	18.3
	Other non-malignancy	248	26.8	55	17.4
	All non-malignant	*924*	*100.0*	*317*	*100.0*

Note: All episodes where diagnosis was Not stated/inadequately described or where the breakdown of malignant and non-malignant was not provided are excluded from the table.

Table 15 Length of Stay (LOS) summary - overnight admitted patients

Length of stay	All services
Average length of episode	12.0
Median length of episode	7
Average number of phases per episode	2.0

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 from the analysis. In addition, any records where LOS was greater than 90 days were considered to be outliers and are excluded from the average calculations.

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

Length of stay	Number	%
Same day	297	3.9
1-2 days	1469	19.1
3-4 days	1033	13.4
5-7 days	1183	15.4
8-14 days	1649	21.4
15-21 days	846	11.0
22-30 days	525	6.8
31-60 days	539	7.0
61-90 days	106	1.4
Greater than 90 days	48	0.6
Total	7695	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 from the table.

Table 17 Place of death - patients not admitted overnight

Place of death	Number	%
Private residence	619	57.7
Residential aged care setting	138	12.9
Other location*	211	19.7
Not stated/inadequately described	105	9.8
Total	1073	100.0

* Includes patients who have died in a hospital setting without the episode of a non-admitted palliative care being ended. Patients whose community episode is ended when admitted to hospital are excluded from this table (see Table 10).

Profile of palliative care phases

Table 18 Number of phases by phase type and episode type

Phase	Overnight admitted		Not admitted overnight	
	Number	%	Number	%
Stable	3566	20.6	1724	22.7
Unstable	5605	32.4	2189	28.8
Deteriorating	4351	25.2	2789	36.7
Terminal	2922	16.9	677	8.9
Bereaved	844	4.9	214	2.8
All phases	17288	100.0	7593	100.0

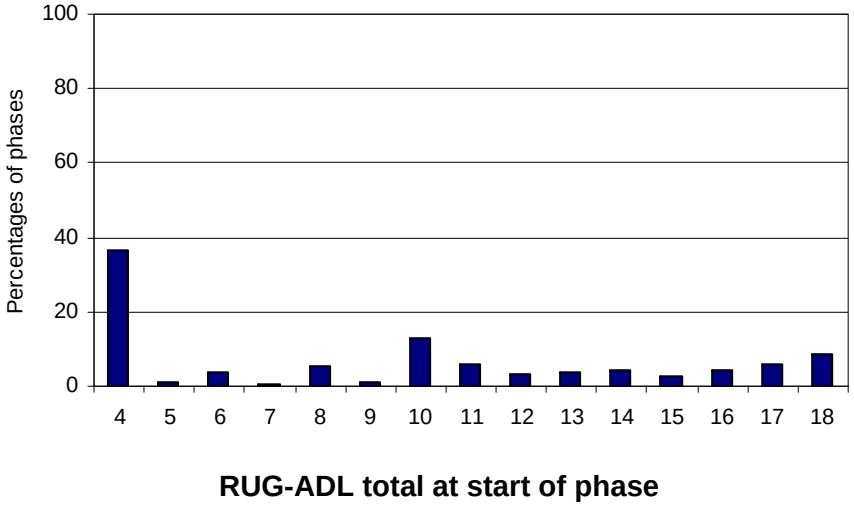
Table 19 Average phase length (in days) by phase and episode type

Phase	Overnight admitted	Not admitted overnight
Stable	7.0	20.3
Unstable	6.6	11.2
Deteriorating	5.7	13.8
Terminal	2.5	2.8
Bereaved	1.4	1.5

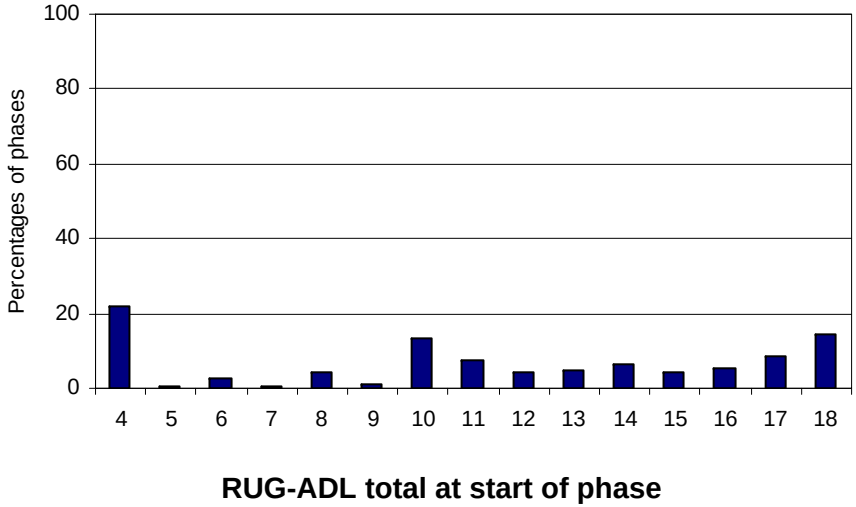
Note: Phase records where length of phase was greater than 90 days are excluded from the average calculations.

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

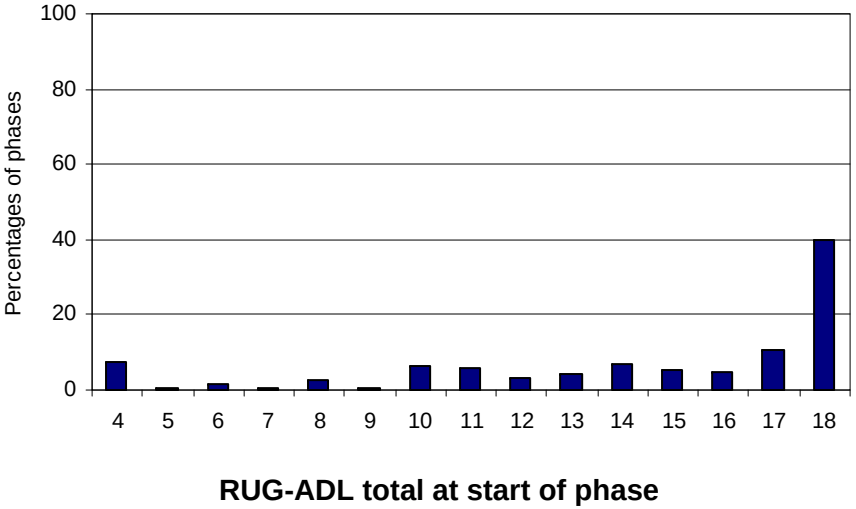
Stable Phase



Unstable Phase



Deteriorating Phase



Terminal Phase

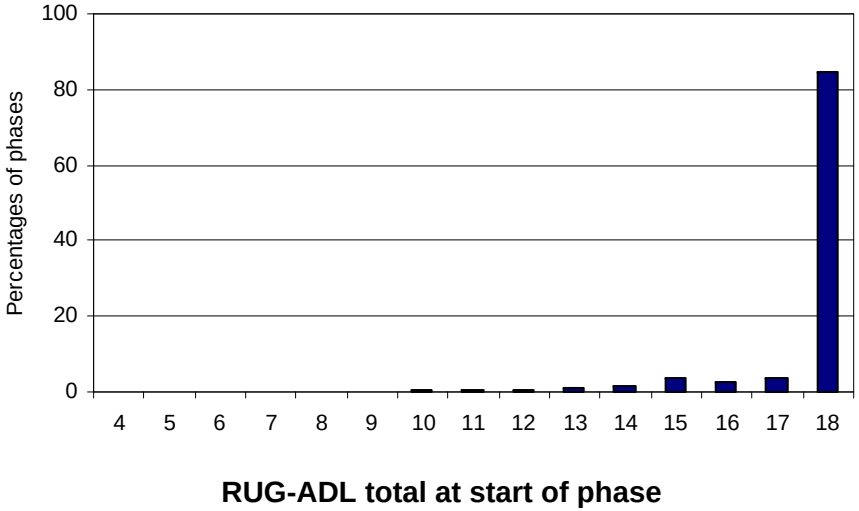
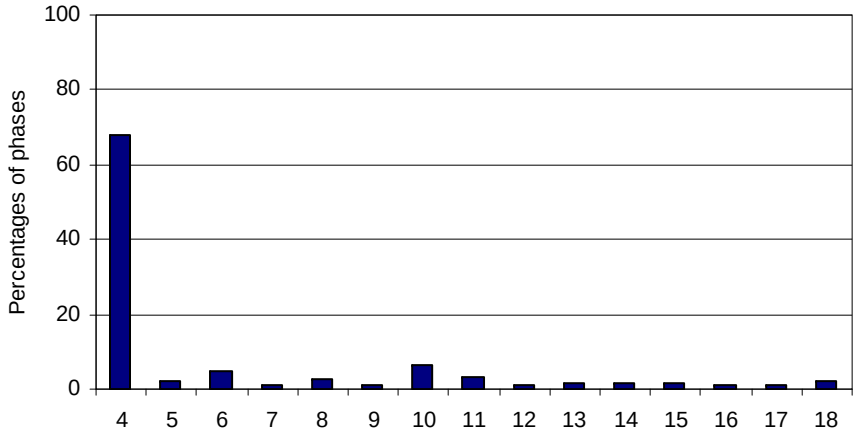
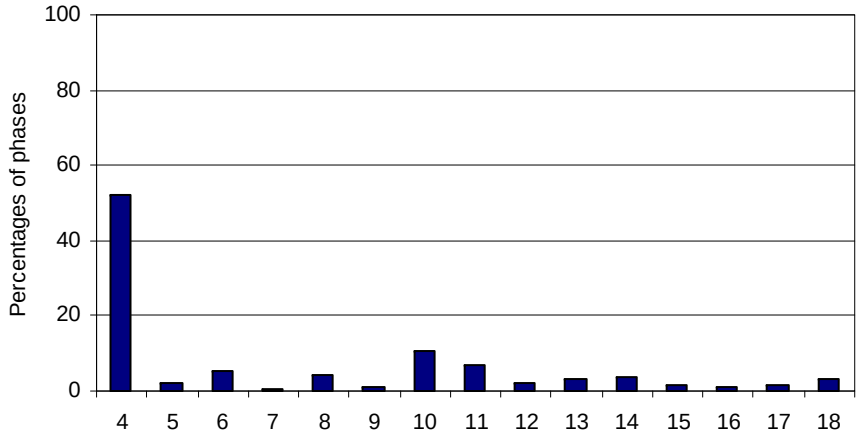


Figure 2 Total RUG-ADL at beginning of phase – patients not admitted overnight

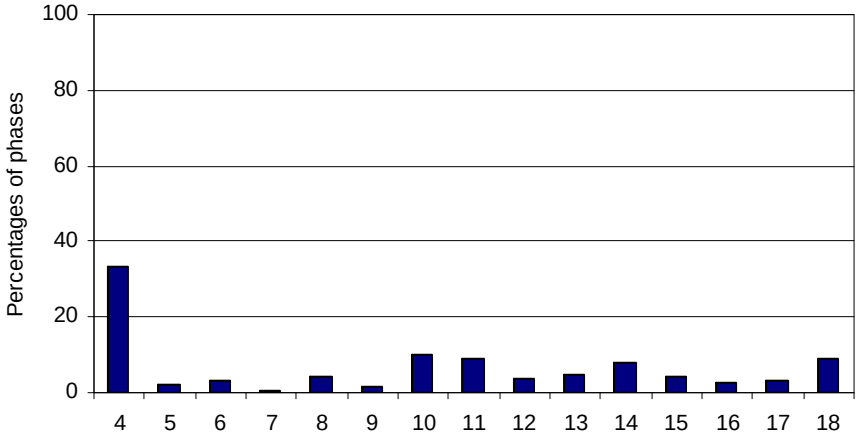
Stable Phase



Unstable Phase



Deteriorating Phase



Terminal Phase

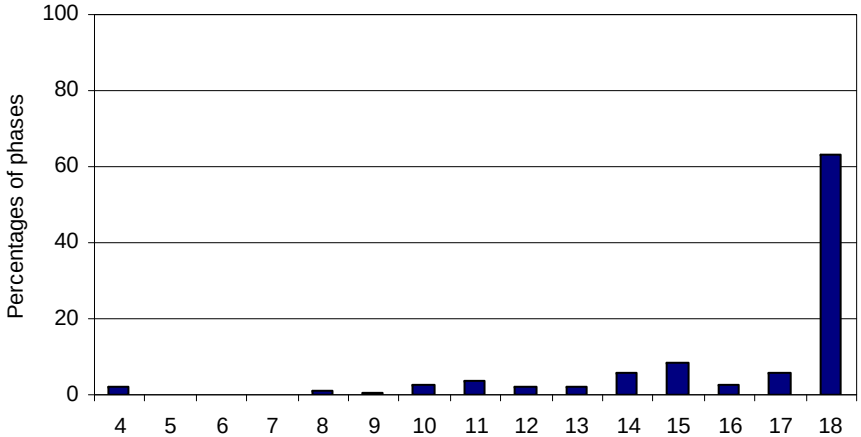


Table 20 Profile of PC Problem Severity Scores (percentages) at beginning of phase by phase and episode type

Phase	Problem severity	Overnight admitted				Not admitted overnight			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	29.7	43.9	21.5	4.9	46.4	40.0	12.2	1.5
	Other Symptom	12.8	43.4	33.3	10.4	24.3	50.3	22.0	3.3
	Psychological/Spiritual	20.7	45.1	25.4	8.8	38.3	45.4	14.0	2.4
	Family/Carer	27.9	38.0	23.4	10.8	37.0	41.6	18.2	3.3
Unstable	Pain	15.8	27.0	37.8	19.4	26.2	24.5	31.7	17.6
	Other Symptom	6.1	19.1	46.1	28.7	11.2	19.5	46.5	22.8
	Psychological/Spiritual	11.8	32.1	37.2	18.9	23.8	30.8	33.6	11.8
	Family/Carer	18.3	26.3	34.1	21.3	22.5	30.1	31.7	15.7
Deteriorating	Pain	17.1	32.6	34.1	16.2	28.2	35.7	25.5	10.6
	Other Symptom	5.6	19.9	41.9	32.6	9.5	26.5	45.4	18.6
	Psychological/Spiritual	12.3	29.6	36.1	22.1	20.7	35.5	32.8	11.0
	Family/Carer	13.7	23.4	36.8	26.2	16.8	29.8	36.9	16.5
Terminal	Pain	25.2	32.1	26.6	16.1	33.3	31.5	23.3	11.8
	Other Symptom	12.8	22.6	30.0	34.6	17.0	20.0	33.3	29.7
	Psychological/Spiritual	27.2	26.5	24.4	21.9	35.4	24.1	25.8	14.8
	Family/Carer	9.7	19.0	34.1	37.1	14.5	15.7	42.6	27.2

Table 21 Average Symptom Assessment Scores (SAS) at beginning of phase by phase and episode type

Phase	Symptom Assessment Score	Overnight admitted	Not admitted overnight
Stable	Insomnia	1.7	1.3
	Appetite	2.6	2.4
	Nausea	0.9	0.6
	Bowels	1.9	1.2
	Breathing	1.7	1.6
	Fatigue	4.3	4.4
	Pain	2.3	1.6
Unstable	Insomnia	2.7	2.4
	Appetite	3.9	3.8
	Nausea	2.0	1.6
	Bowels	3.0	1.9
	Breathing	2.7	2.2
	Fatigue	5.5	5.8
	Pain	4.0	3.4
Deteriorating	Insomnia	2.1	2.0
	Appetite	4.2	3.8
	Nausea	1.6	1.1
	Bowels	3.1	1.7
	Breathing	3.1	2.3
	Fatigue	6.1	6.0
	Pain	3.5	2.4

Continued...

Phase	Symptom Assessment Score	Overnight admitted	Not admitted overnight
Terminal	Insomnia	1.0	1.8
	Appetite	2.5	4.7
	Nausea	0.8	0.9
	Bowels	2.0	1.6
	Breathing	3.7	3.0
	Fatigue	4.6	7.4
	Pain	2.9	2.4

Table 22 Karnofsky score at phase start by episode type

Karnofsky score	Overnight admitted		Not admitted overnight	
	Number	%	Number	%
Dead	47	0.3	3	0.0
Comatose or barely rousable	1528	9.3	108	1.5
Totally bedfast and requiring extensive nursing care	2537	15.4	388	5.3
Almost completely bedfast	1528	9.3	286	3.9
In bed more than 50% of the time	1894	11.5	527	7.1
Requires considerable assistance	2511	15.3	1058	14.3
Requires occasional assistance	1847	11.2	968	13.1
Cares for self	612	3.7	622	8.4
Normal activity with effort	348	2.1	318	4.3
Able to carry on normal activity; minor signs or symptoms	113	0.7	90	1.2
Normal; no complaints; no evidence of disease	9	0.1	5	0.1
Not stated/inadequately described	3470	21.1	3006	40.7
Total	16444	100.0	7379	100.0

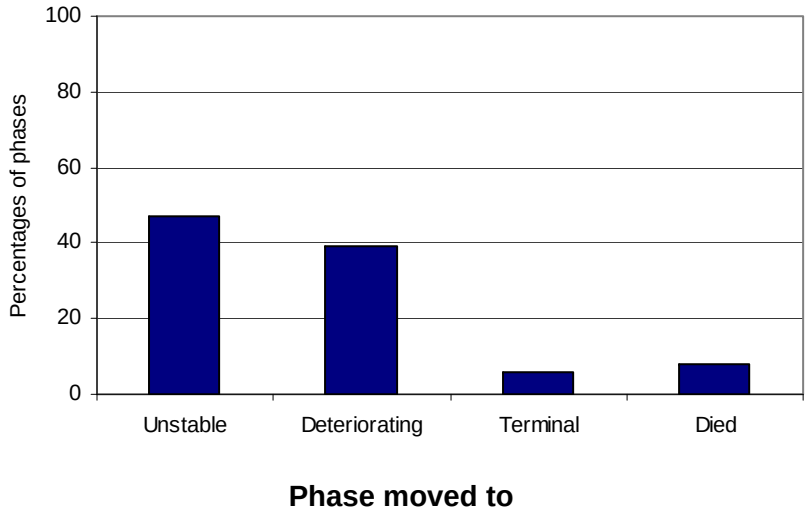
Note: Bereavement phase records are excluded from the table.

Table 23 Reason for phase end by phase and episode type

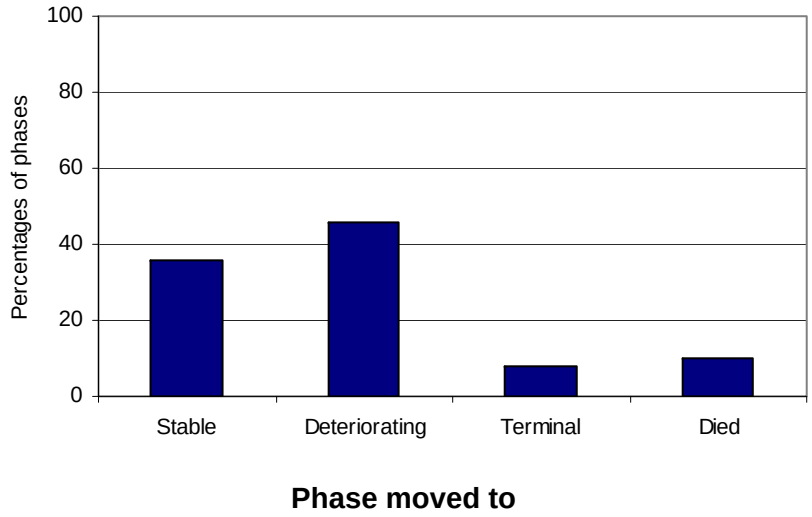
Phase	Reason for phase end	Overnight admitted		Not admitted overnight	
		Number	%	Number	%
Stable	Phase change	1725	48.4	1041	60.4
	Discharge/case closure	1733	48.6	594	34.5
	Died	80	2.2	74	4.3
	Bereavement phase end	3	0.1	0	0.0
	Not stated/Inadequately described	25	0.7	15	0.9
	Total	*3566*	*100.0*	*1724*	*100.0*
Unstable	Phase change	4253	75.9	1506	68.8
	Discharge/case closure	913	16.3	574	26.2
	Died	380	6.8	103	4.7
	Bereavement phase end	3	0.1	0	0.0
	Not stated/Inadequately described	56	1.0	6	0.3
	Total	*5605*	*100.0*	*2189*	*100.0*
Deteriorating	Phase change	2782	63.9	1628	58.4
	Discharge/case closure	656	15.1	897	32.2
	Died	876	20.1	258	9.3
	Bereavement phase end	16	0.4	0	0.0
	Not stated/Inadequately described	21	0.5	6	0.2
	Total	*4351*	*100.0*	*2789*	*100.0*
Terminal	Phase change	382	13.1	160	23.6
	Discharge/case closure	96	3.3	53	7.8
	Died	2417	82.7	462	68.2
	Bereavement phase end	20	0.7	2	0.3
	Not stated/Inadequately described	7	0.2	0	0.0
	Total	*2922*	*100.0*	*677*	*100.0*

Figure 3 Phase outcomes by phase - all phases

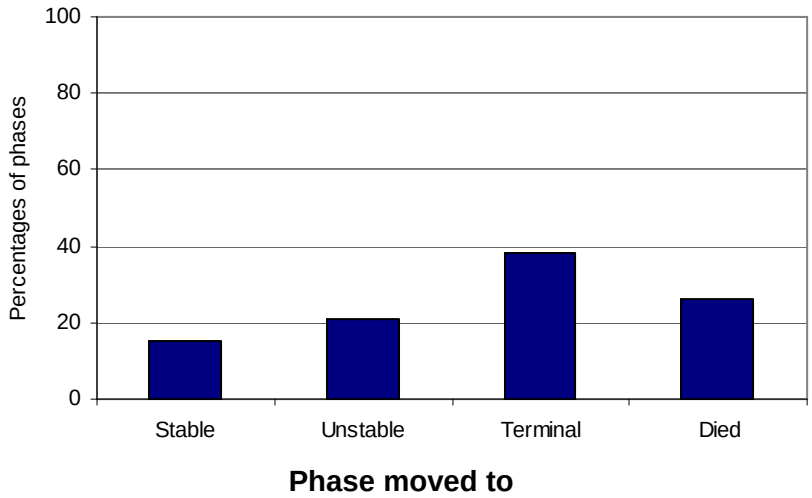
Stable Phase



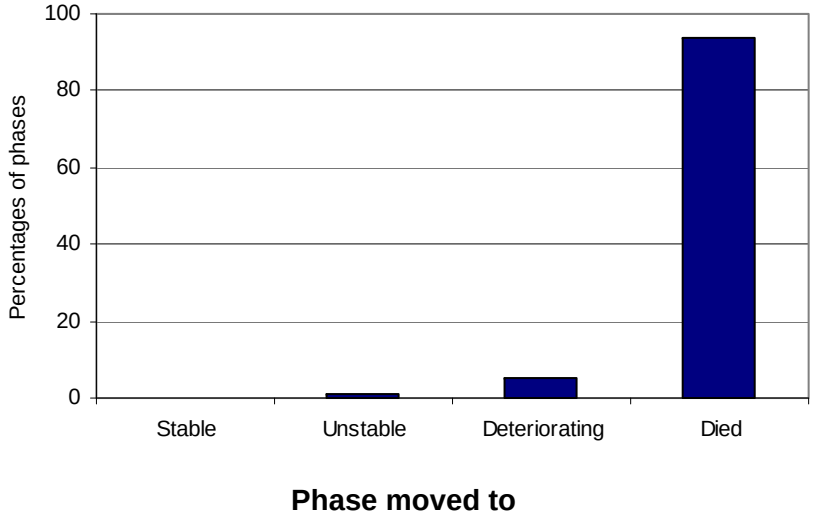
Unstable Phase



Deteriorating Phase



Terminal Phase



Benchmark Measure 1 - Time from referral to first contact

PCOC is progressively introducing benchmark measures into the PCOC reports. Table 24 and Figure 4 below present descriptive data on the first benchmark measure. Please note that no benchmarks have yet been set as these are still to be agreed at the next SCAC meeting to be held later in 2009. PCOC will present some recommendations to the SCAC based on outcomes from all 3 benchmarking workshops held during May-June 2009.

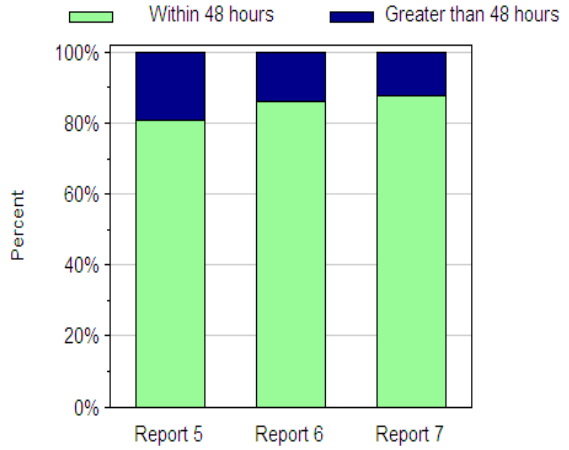
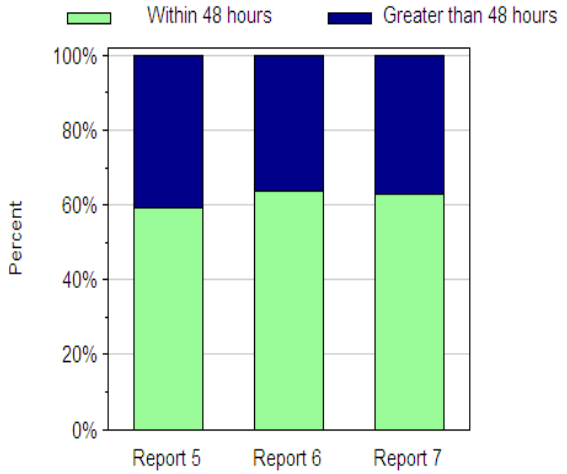
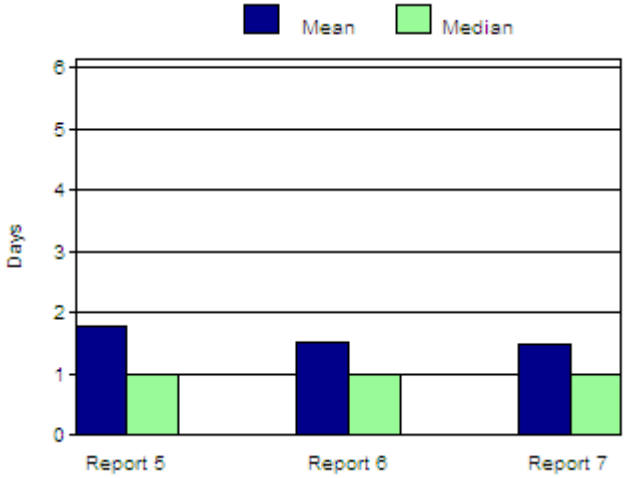
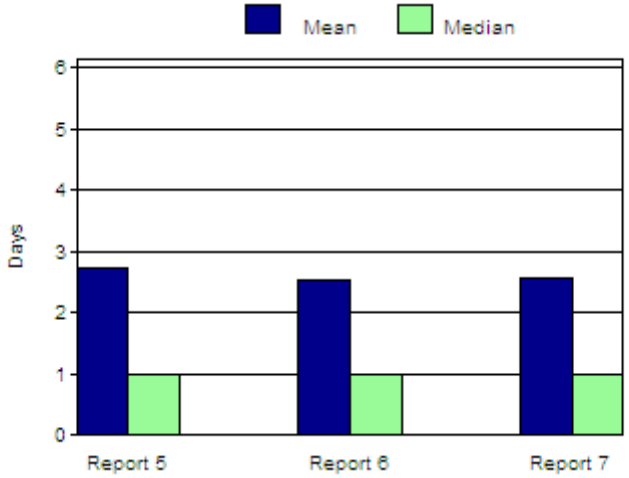
The time from referral to first contact is calculated as the time from the date of referral to either the date of first contact (if provided) or the episode start date. Please note that the category *within 48 hours* represents those contacted on the same day as the referral or on the following day.

Table 24 Time from referral to first contact by episode start

Time (in days)	Overnight admitted		Not admitted overnight	
	Number	%	Number	%
Within 48 hours	6216	87.9	1737	62.9
2-7 days	550	7.8	643	23.3
8-14 days	110	1.6	220	8.0
Greater than 14 days	194	2.7	162	5.9
Average	1.5	na	2.6	na
Median	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 by episode type

Overnight admitted	Not admitted overnight
	
Time from referral to first contact	**Time from referral to first contact**
	
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. Once again, please note that no benchmarks have yet been set as these are still to be agreed.

Table 25 shows that for overnight admitted patients 4240 of the 5605 unstable phases occurred at the start of an episode (i.e. the patient was unstable on admission) and 1365 unstable phases occurred during the episode. A total of 27.1% of unstable phases were longer than 7 days in length, with the average phase length being 6.6 days and the median 4 days.

Similarly, for patients not admitted overnight, 1046 of the 2189 unstable phases occurred as the first phase of an episode and 1143 unstable phases occurred in subsequent phases of the episode. A total of 38.4% of unstable phases for patients not admitted overnight were longer than 7 days in length, with the average unstable phase length being 15.3 days and the median 5 days.

Table 25 Time in unstable phase by episode type and occurrence of unstable phase

Episode type	Occurrence of unstable phase	Number	Percent unstable for > 7 days	Average days in unstable phase	Median days in unstable phase
Overnight admitted	First phase	4240	28.9	7	4
	Not first phase	1365	21.5	5.3	3
	Total	*5605*	*27.1*	*6.6*	*4*
Not admitted overnight	First phase	1046	51.1	22.1	8
	Not first phase	1143	26.8	9.1	3
	Total	*2189*	*38.4*	*15.3*	*5*

Benchmark Measure 3 - Change in pain

Change in pain PC Problem Severity Score (PSS)

The following two tables present data on the third benchmark measure in relation to pain PSS. The following measures have been introduced after consideration of discussions around pain at the 2009 benchmarking workshops but no benchmarks have yet been set as these are still to be agreed. 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 26 Measure 1: Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase

Episode type	Report 5	Report 6	Report 7
Overnight admitted			
Number	806	1651	2387
Percent	75.5	79.5	82.4
Not admitted overnight			
Number	150	608	1201
Percent	76.5	82.4	79.1

Table 27 Measure 2: Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase

Episode type	Report 5	Report 6	Report 7
Overnight admitted			
Number	374	731	1005
Percent	31.2	36.7	38.1
Not admitted overnight			
Number	45	123	270
Percent	54.2	31.7	38.1

Change in pain Symptom Assessment Score (SAS)

The following two tables present data on the third benchmark measure in relation to pain SAS. The following measures have been introduced after consideration of discussions around pain at the 2009 benchmarking workshops but no benchmarks have yet been set as these are still to be agreed. Please note that in the following analysis a pain SAS of 0-3 has been classified as absent or mild and a pain SAS of 4-10 has been classified as moderate or severe. 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 Measure 1: Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase

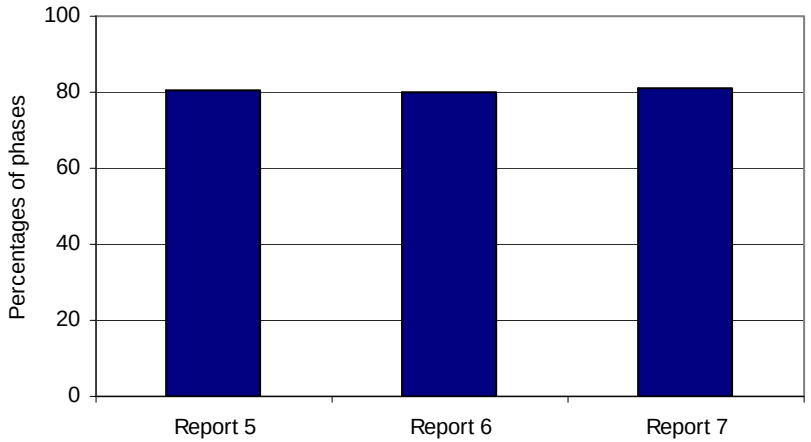
Episode type	Report 5	Report 6	Report 7
Overnight admitted			
Number	771	1772	3107
Percent	76.1	80.4	82.4
Not admitted overnight			
Number	2710	3697	2624
Percent	82.5	83.3	81.6

Table 29 Measure 2: Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase

Episode type	Report 5	Report 6	Report 7
Overnight admitted			
Number	393	843	1235
Percent	37.8	38.9	41.2
Not admitted overnight			
Number	570	626	552
Percent	53.2	38.6	40.4

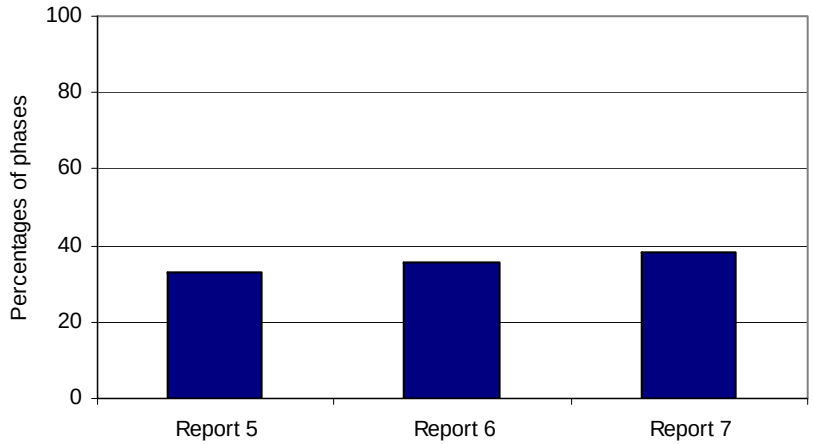
Figure 5 Change in pain benchmark measures - all phases

Pain PSS



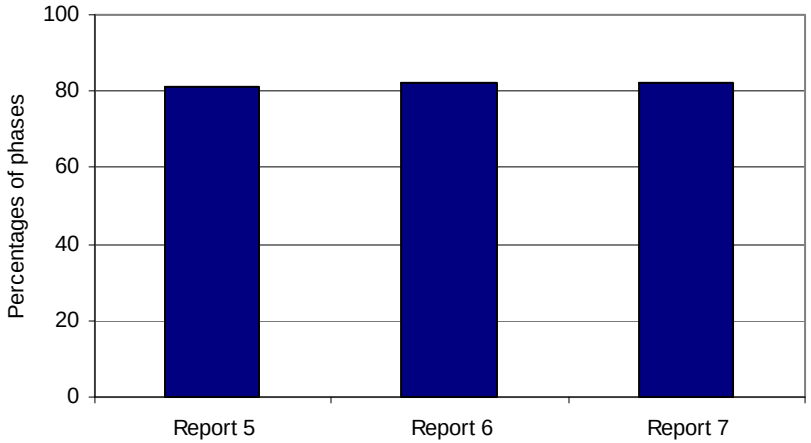
Measure 1: Absent/mild pain at both start and end of phase

Pain PSS



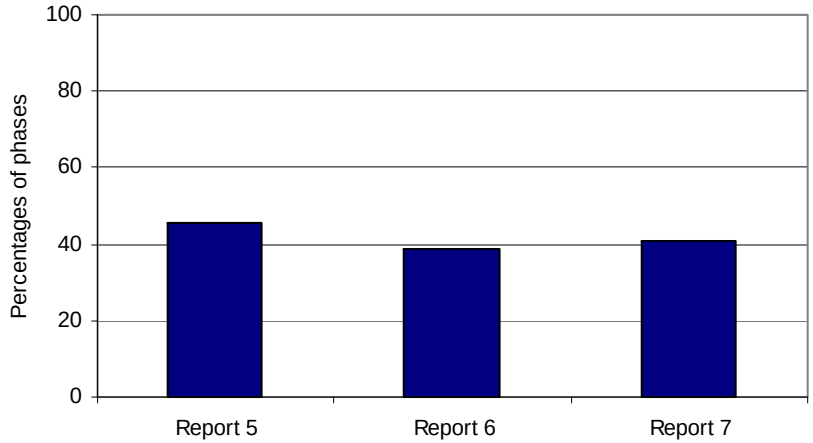
Measure 2: Mod/severe pain at start with absent/mild pain at end

Pain SAS



Measure 1: Absent/mild pain at both start and end of phase

Pain SAS



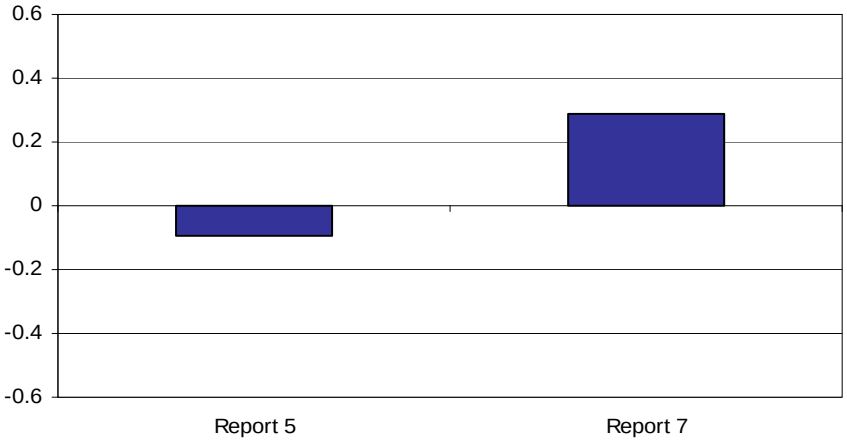
Measure 2: Mod/severe pain at start with absent/mild pain at end

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

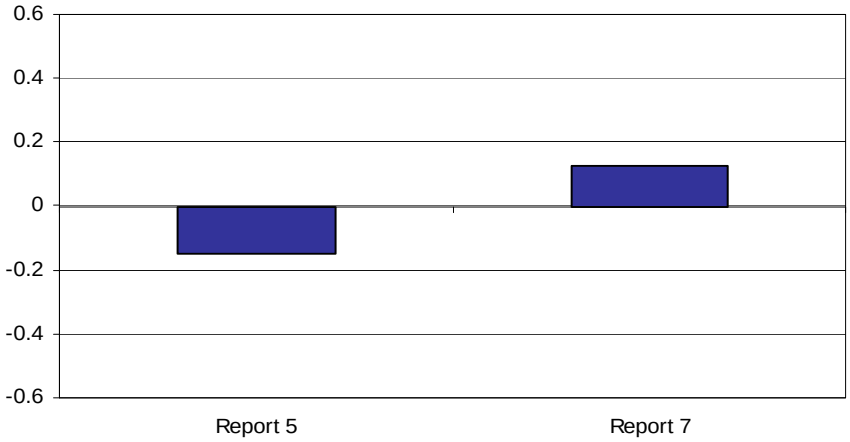
Please refer to the glossary section on page 44 for a detailed explanation of the following analysis.

Figure 6 PCPSS mean change adjusted for phase and symptom score at start of phase

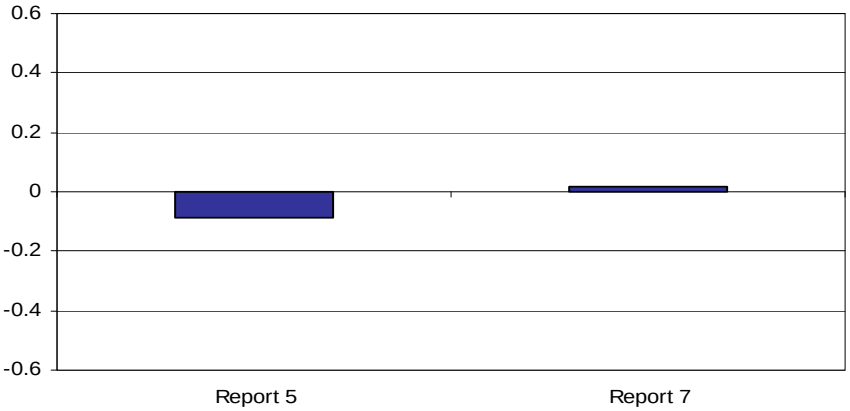
Pain



Other symptoms



Family/Carer



Psychological/spiritual

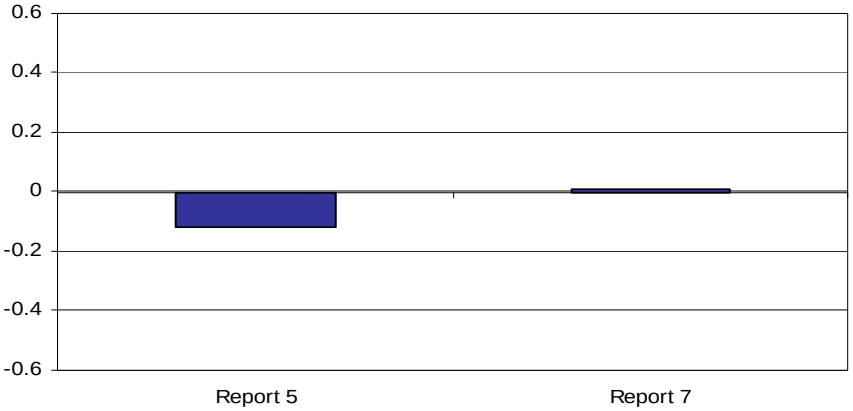
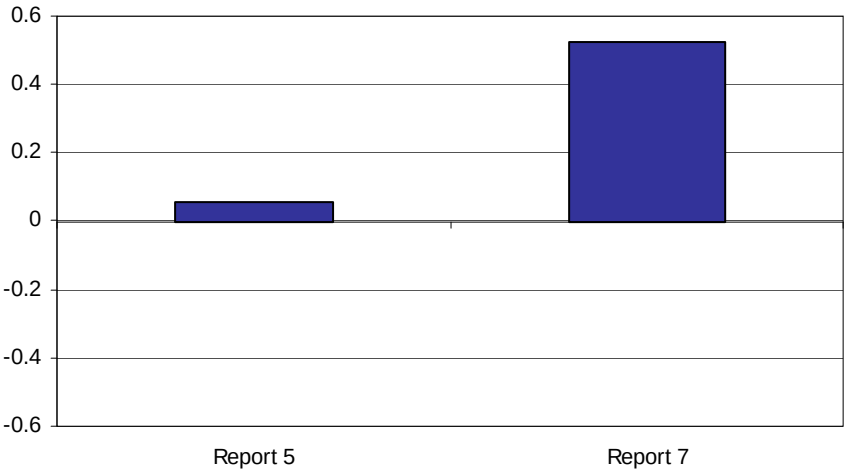
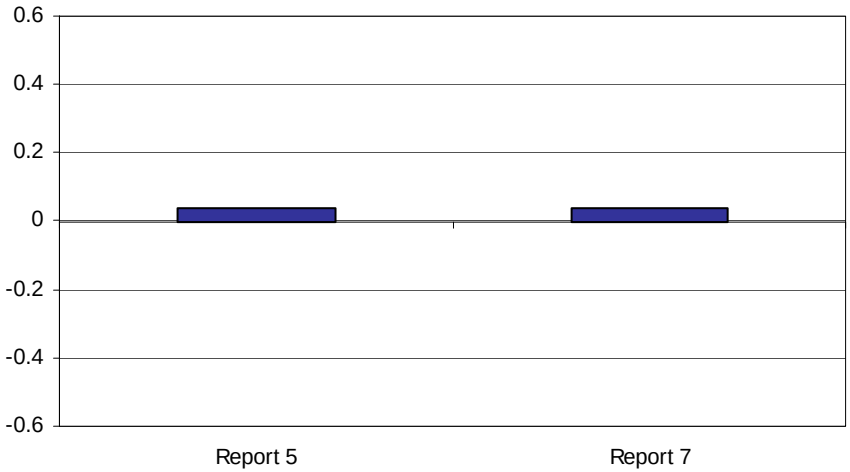


Figure 7 SAS mean change adjusted for phase and symptom score at start of phase

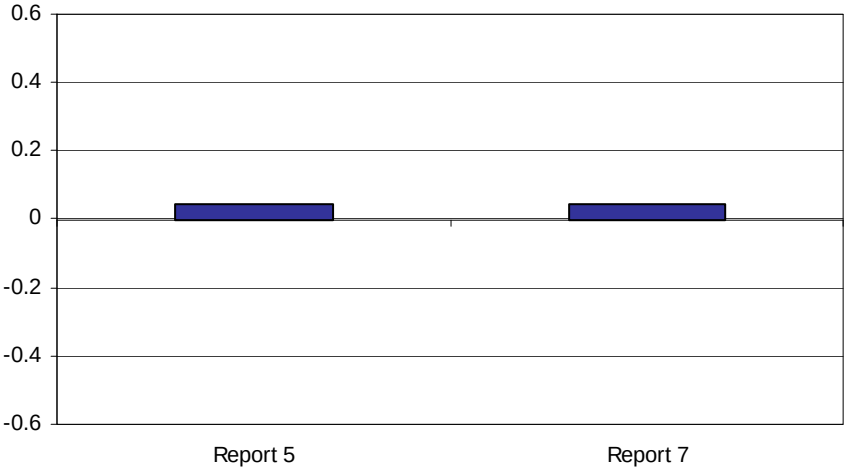
Pain



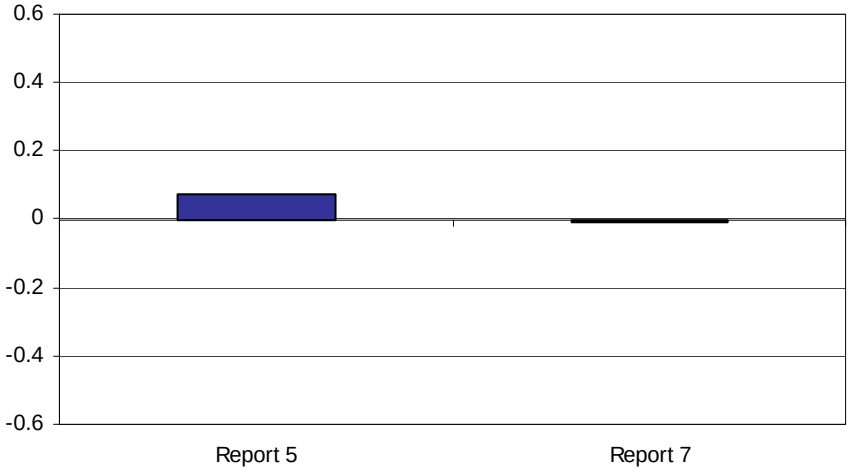
Nausea



Breathing



Bowels



Appendix 1 - Services included in this report

This report presents data from the following 86 services:

Table 30 Services providing data

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

Continued...

Palliative Care Service	State	Begin date	End date	Months
Broad Meadows Palliative Care	Vic	March 2009	June 2009	4
Caritas Christi - Fitzroy	Vic	January 2009	June 2009	6
Caritas Christi - Kew	Vic	January 2009	June 2009	6
Gandarra Palliative Care Unit - Ballarat	Vic	January 2009	June 2009	6
Lower Hume Palliative Care	Vic	April 2009	June 2009	3
Melbourne City Mission	Vic	June 2009	June 2009	1
Mercy Palliative Care	Vic	January 2009	June 2009	6
Mercy Palliative Care - Medical Consultant	Vic	January 2009	June 2009	6
Peter MacCallum Cancer Centre	Vic	January 2009	June 2009	6
Werribee Mercy Hospital	Vic	January 2009	June 2009	6
Western Health Footscray	Vic	January 2009	June 2009	6
Western Health Sunshine	Vic	February 2009	April 2009	3
Western Hospital Community	Vic	January 2009	June 2009	6
Bundaberg Palliative Access	Qld	January 2009	June 2009	6
Cairns and Gordonvale Hospital	Qld	January 2009	June 2009	6
Canossa Private Hospital	Qld	January 2009	June 2009	6
Gladstone Hospital	Qld	January 2009	June 2009	6
Hervey Bay & Fraser Coast Palliative Care Service	Qld	January 2009	June 2009	6
Hopewell Hospice	Qld	January 2009	June 2009	6
Ipswich Hospice	Qld	January 2009	June 2009	6
Ipswich Hospital	Qld	January 2009	June 2009	6
Karuna Hospice Services	Qld	January 2009	June 2009	6
Logan - Beaudesert Hospital	Qld	March 2009	June 2009	4
Mater Adult's Brisbane	Qld	January 2009	June 2009	6
Mater Private Brisbane	Qld	January 2009	June 2009	6
Mater Private Bundaberg	Qld	January 2009	June 2009	6
Mater Private Gladstone	Qld	January 2009	June 2009	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Mater Private Mackay	Qld	January 2009	June 2009	6
Mater Private Rockhampton	Qld	January 2009	June 2009	6
Mater Private Yeppoon	Qld	February 2009	May 2009	4
Mt Isa and Surrounds Palliative Care	Qld	January 2009	June 2009	6
Redcliffe Hospital Palliative Care Unit	Qld	January 2009	June 2009	6
Rockhampton Base Hospital	Qld	January 2009	June 2009	6
Royal Brisbane and Women's Hospital	Qld	January 2009	June 2009	6
St Vincent's Hospital Brisbane	Qld	January 2009	June 2009	6
Sunshine Coast and Cooloola Palliative Care Service	Qld	January 2009	June 2009	6
The Prince Charles Hospital	Qld	January 2009	June 2009	6
Toowoomba Hospital	Qld	April 2009	June 2009	3
Townsville Palliative Care Centre	Qld	January 2009	June 2009	6
Townsville Spiritus	Qld	January 2009	June 2009	6
Adelaide Hills Community Health Service	SA	January 2009	June 2009	6
Calvary Health Care Adelaide (Mary Potter Hospice)	SA	January 2009	June 2009	6
Lyell McEwin Palliative Care Service	SA	January 2009	June 2009	6
Modbury Hospice SA	SA	January 2009	June 2009	6
Port Pirie Regional Health Service	SA	January 2009	June 2009	6
Royal Adelaide Hospital	SA	January 2009	June 2009	6
South East Regional Community Health Service	SA	January 2009	June 2009	6
Southern Adelaide Palliative Care Service	SA	January 2009	June 2009	6
Yorke Peninsula Palliative Care	SA	January 2009	May 2009	5
Albany Palliative Care Service	WA	January 2009	June 2009	6
Bethesda Hospital	WA	January 2009	June 2009	6
Geraldton Palliative Care Community Service	WA	January 2009	June 2009	6
Kalgoorlie Regional Hospital - Restorative Care Unit	WA	January 2009	June 2009	6
Peel Community Palliative Care Service	WA	January 2009	June 2009	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Royal Perth Hospital	WA	January 2009	June 2009	6
SJOG Health Care - Geraldton	WA	January 2009	June 2009	6
Silver Chain Hospice Care Service	WA	January 2009	June 2009	6
Sir Charles Gairdner Hospital	WA	January 2009	June 2009	6
St John of God Murdoch Community Hospice	WA	January 2009	June 2009	6
St John of God Subiaco	WA	March 2009	June 2009	4
Calvary Health Care Tasmania - St John's	Tas	January 2009	June 2009	6
Calvary Health Care Tasmania - St Lukes	Tas	January 2009	March 2009	3
Whittle Ward Palliative Care	Tas	January 2009	June 2009	6
Calvary Health Care Canberra (Clare Holland House)	ACT	January 2009	June 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 have been calculated for all services. 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 31 Data consistency - patient level items

Data Item	% Complete
Date of Birth	100.0
Sex	99.8
Indigenous Status	97.8
Country of birth	96.8
Main language	91.6

Table 32 Data consistency - episode level items

Data Item	% Complete
Date of first contact/assessment	90.0
Referral date	84.6
Referral source	91.0
Episode start date	100.0
Mode of episode start	99.2
Accommodation at episode start	87.4
Diagnosis	90.2
Episode end date	100.0
Level of support at episode start	76.7
Mode of episode end	96.8
Accommodation at episode end	70.7
Level of support at episode end	93.8
Place of death	90.2

Table 33 Data consistency - phase level items

Data item	Sub-Category (where applicable)	Number %Complete
Phase start date		100.0
Phase		100.0
RUG-ADL at phase start	Bed Mobility	88.8
	Toileting	88.8
	Transfers	88.8
	Eating	88.8
PC Problem Severity at phase start	Pain	61.1
	Other Symptom	62.5
	Psychological/Spiritual	83.7
	Family/Carer	83.5
Symptom Assessment Score at phase start	Insomnia	80.0
	Appetite	79.7
	Nausea	80.6
	Bowels	80.2
	Breathing	80.5
	Fatigue	80.2
	Pain	80.7
Phase end reason		99.4
Karnofsky at phase start		74.0

Appendix 3 – Glossary

Overnight admitted and not overnight admitted 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 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 for time 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 counselling 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 (hence Figures 6 and 7 exclude report 6).

- 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 database.

- If X-CAS for your service < 0

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