2011

PCOC National Report on Palliative Care in Australia July to December 2010

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PCOC National Report on Palliative Care in Australia July to December 2010

Abstract
The Palliative Care Outcomes Collaboration (PCOC) was established in mid-2005 and is funded under the National Palliative Care Program and is supported by the Australian Government Department of Health and Ageing. 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 current PCOC dataset (Version 2) evolved after consultation with services and approval by PCOC's Scientific and Clinical Advisory Committee (SCAC) and went live on 1 July 2007. The dataset includes the clinical assessment tools - Phase of Care, PC Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status Scale (AKPS) and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) – which provide measures of quality and outcomes of care. PCOC provides analysis of each service's data and compares this to the national data. Four benchmark measures are routinely included in each report.

For this PCOC Report 10, 91 palliative care services submitted data and are included in this report. The reporting period is July to December 2010.

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palliative care outcomes collaboration

PCOC National Report on Palliative Care in Australia

July to December 2010

March 2011

PCOC is funded under the *National Palliative Care Program* and is supported by the Australian Government Department of Health and Ageing.

Palliative Care Outcomes Collaboration (PCOC)

PCOC is a voluntary quality initiative to assist palliative care service providers to improve practice and is funded under the *National Palliative Care Program* and is supported by the Australian Government Department of Health and Ageing.

The aim of PCOC is to develop and support a national benchmarking system that will contribute to improved palliative care outcomes.

PCOC is a collaboration between four centres and is divided into four zones for the purpose of engaging with palliative care service providers.

The four PCOC zones and partners are:

Centre for Health Service Development, University of Wollongong – PCOC Central
Cancer and Palliative Care Research and Evaluation Unit, University of Western Australia – PCOC West
Department of Palliative and Supportive Services, Flinders University of South Australia – PCOC South
Institute of Health and Biomedical Innovation, Queensland University of Technology - PCOC North

Contact details for PCOC are available at http://chsd.uow.edu.au/pcoc/

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Introduction

The Palliative Care Outcomes Collaboration (PCOC) was established in mid-2005 and is funded under the *National Palliative Care Program* and is supported by the Australian Government Department of Health and Ageing. 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*.

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For this PCOC Report 10, 91 palliative care services submitted data and are included in this report. The reporting period is July to December 2010.

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 includes data from a total of 91 services. During the reporting period data were provided for a total of 13193 patients, with 16767 episodes and 36804 phases.

These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined. As a consequence, it is possible that not all phases within any particular episode are included in this report, so the average number of phases per episode calculation may be an underestimate (for episodes that cross-over 2 or more reporting periods) as it only includes phases that ended within the current reporting period.

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

Episode type	Overnight Admitted	Not admitted overnight	Total
Number of patients*	8213	5891	13193
Number of episodes	9638	7129	16767
Number of phases	23781	13023	36804
Percentage of patients*	62.3	44.7	100
Percentage of episodes	57.5	42.5	100
Percentage of phases	64.6	35.4	100
Average number of episodes per patient	1.3	1.3	1.3
Average number of phases per episode**	2.4	1.8	2.1

* 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.

** Average number of phases per episode is only calculated for closed episodes and excludes bereavement phases.

Summary of Benchmark Measures and Targets

Beginning in the reporting period January to June 2009 (Report 7), PCOC introduced four benchmark measures into the routine PCOC reports.

Measure	Benchmark
1. Time from referral to first contact	90% contacted on the same day or the following day
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

Targets of 10% improvement have been agreed to apply to Number not meeting the current benchmarks. For example if a service does not meet the 90% benchmark for Measure 1 then their target is to achieve an improvement of 10% over the next reporting period. Therefore, if a service scored 75% for Measure 1 in this report, their target is to score at least 82.5% for this measure in the next report which is a 10% improvement.

The following two tables provide a summary of the national performance in relation to the four benchmark measures for the period July to December 2010.

Table 2 Summary of benchmark measures 1-3

Measure	Description	Benchmark	Benchmark met (national score)			
			Overnight admitted		Not admitted overnight	
1. Time from referral to contact	Patients contacted on same or following day	90%	No	(89.2)	No	(54.5)
2. Time in unstable phase	Patients unstable less than 7 days - first phase	85%	No	(77.5)	No	(48.5)
	Patients unstable less than 7 days - Not first phase	90%	No	(87.6)	No	(61.9)
	Median time in unstable phase	2 days or less	No	(3 days)	No	(5 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	(79.0)	No	(74.9)
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	No	(46.6)	No	(57.5)
Symptom Assessment Score (SAS)	Patients with absent/mild pain at phase start remaining absent/mild at phase end	90%	No	(78.8)	No	(76.4)
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	No	(45.7)	No	(55.3)

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

Symptom		Benchmark	Benchmark met	National score
PC PSS	Pain	0 or above	Yes	0.11
	Other symptoms	0 or above	Yes	0.21
	Family/carer	0 or above	Yes	0.11
	Psychological/spiritual	0 or above	Yes	0.90
SAS	Pain	0 or above	Yes	0.13
	Nausea	0 or above	Yes	0.10
	Breathing	0 or above	Yes	0.24
	Bowels	0 or above	Yes	0.13

Section 2 - Descriptive analysis

Profile of palliative care patients

Table 4 Indigenous Status - all patients

Indigenous Status	Number
Aboriginal but not Torres Strait Islander origin	144
Torres Strait Islander but not Aboriginal origin	19
Both Aboriginal and Torres Strait Islander origin	7
Neither Aboriginal nor Torres Strait Islander origin	12317
Not stated/inadequately described	706
Total	13193

Table 5 Sex - all patients

Sex	Number	%
Male	7142	54.1
Female	6033	45.7
Not stated/inadequately described	18	0.1
Total	13193	100.0

Table 6 Main language spoken at home - all patients

Main language spoken at home	Number	%
English	11248	85.3
Italian	256	1.9
Greek	145	1.1
Cantonese	87	0.7
Arabic (including Lebanese)	56	0.4
Croatian	47	0.4
Vietnamese	47	0.4
Mandarin	43	0.3
Polish	30	0.2
Macedonian	28	0.2
Serbian	27	0.2
German	27	0.2
Turkish	26	0.2
Spanish	22	0.2
Maltese	19	0.1
All other languages	247	1.9
Not stated/inadequately described	838	6.4
Total	13193	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 7 Country of birth - all patients

Country of birth	Number	%
Australia	8294	62.9
England	968	7.3
Italy	468	3.5
Greece	213	1.6
New Zealand	207	1.6
Scotland	180	1.4
Germany	160	1.2
Netherlands	141	1.1
China	123	0.9
Poland	94	0.7
Croatia	89	0.7
India	84	0.6
Ireland	76	0.6
Malta	76	0.6
Vietnam	74	0.6
All other countries	954	7.2
Not stated/inadequately described	992	7.5
Total	13193	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*.

Table 8 Primary diagnosis

Primary diagnosis		Number	%
Malignant	Bone and soft tissue	337	3.1
	Breast	823	7.6
	CNS	246	2.3
	Colorectal	1113	10.2
	Gynaecological	593	5.4
	Haematological	551	5.1
	Head and neck	636	5.8
	Lung	2033	18.7
	Pancreas	574	5.3
	Prostate	699	6.4
	Skin	417	3.8
	Other GIT	856	7.9
	Other urological	442	4.1
	Other malignancy	550	5.1
	Unknown primary	283	2.6
	Malignant - not further defined	735	6.8
	All malignant	*10888*	*100.0*
Non-malignant	Cardiovascular	446	21.4
	HIV/AIDS	10	0.5
	Kidney failure	231	11.1
	Neurological disease	444	21.3
	Respiratory failure	353	16.9
	Other non-malignancy	519	24.9
	Non-malignant - not further defined	81	3.9
	All non-malignant	*2084*	*100.0*

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

Profile of palliative care episodes

The 13193 patients from all services seen in the six month period had a total of 16767 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 was 70 years.

Table 9 Number of episodes by age group - all episodes

Age group	Number	%
< 15	94	0.6
15-24	80	0.5
25-34	153	0.9
35-44	577	3.4
45-54	1467	8.7
55-64	2948	17.6
65-74	4126	24.6
75-84	4771	28.5
85+	2542	15.2
Not stated/inadequately described	9	0.0
Total	16767	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.

Table 10 Referral source by episode type

Referral source	Overnight admitted		Not admitted overnight	
	Number	%	Number	%
Public hospital - other than inpatient palliative care unit	4188	43.5	3130	43.9
Self, carer(s), family or friends	287	3.0	217	3.0
Private hospital - other than inpatient palliative care unit	673	7.0	783	11.0
Public palliative care inpatient unit/hospice	219	2.3	337	4.7
Private palliative care inpatient unit/hospice	39	0.4	53	0.7
General Medical Practitioner rooms	642	6.7	1170	16.4
Specialist Medical Practitioner rooms	450	4.7	426	6.0
Community-based palliative care agency	1798	18.7	123	1.7
Community-based service	332	3.4	153	2.1
Residential aged care facility	59	0.6	125	1.8
Other	182	1.9	306	4.3
Not stated/inadequately described	769	8.0	306	4.3
Total	9638	100.0	7129	100.0

Table 11 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	2396	191	476	2605	277	5945
Admitted from other than usual accommodation	33	12	19	62	6	132
Admitted (transferred) from another hospital	425	62	153	1707	58	2405
Admitted (transferred) from acute care in other ward	163	14	48	617	22	864
All other reasons*	27	3	5	51	7	93
Total	*3044*	*282*	*701*	*5042*	*370*	*9439*
As a percentage of each start mode						
Admitted from usual accommodation	40.3	3.2	8.0	43.8	4.7	100.0
Admitted from other than usual accommodation	25.0	9.1	14.4	47.0	4.5	100.0
Admitted (transferred) from another hospital	17.7	2.6	6.4	71.0	2.4	100.0
Admitted (transferred) from acute care in other ward	18.9	1.6	5.6	71.4	2.5	100.0
All other reasons*	29.0	3.2	5.4	54.8	7.5	100.0
Total	*32.2*	*3.0*	*7.4*	*53.4*	*3.9*	*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 (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 - 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	880	1464	831	73	1773	5021
Transfer from being an o/n PC patient	155	727	211	20	296	1409
Total	*1035*	*2191*	*1042*	*93*	*2069*	*6430*
As a percentage of each start mode						
New referral	17.5	29.2	16.6	1.5	35.3	100.0
Transfer from being an o/n PC patient	11.0	51.6	15.0	1.4	21.0	100.0
Total	*16.1*	*34.1*	*16.2*	*1.4*	*32.2*	*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 (and hence do not have an episode end date) are also excluded.

Table 13 Accommodation at episode start and end

Accommodation at episode start	Accommodation at episode end				
	Private residence	Low level care	High level care	All other	Total
Private residence	3211	21	149	356	3737
Residential aged care (low level care)	7	31	17	9	64
Residential aged care (high level care)	10	9	143	18	180
All other	88	3	11	65	167
Total	*3316*	*64*	*320*	*448*	*4148*
As a percentage of each start accommodation					
Private residence	85.9	0.6	4.0	9.5	100.0
Residential aged care (low level care)	10.9	48.4	26.6	14.1	100.0
Residential aged care (high level care)	5.6	5.0	79.4	10.0	100.0
All other	52.7	1.8	6.6	38.9	100.0
Total	*79.9*	*1.5*	*7.7*	*10.8*	*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 14 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)	64	2	117	0	183
Without support (lives with others)	1	67	122	1	191
With support (lives alone or with others)	13	16	2573	6	2608
Other arrangements	0	0	3	2	5
Total	*78*	*85*	*2815*	*9*	*2987*
As a percentage of each start support					
Without support (lives alone)	35.0	1.1	63.9	0.0	100.0
Without support (lives with others)	0.5	35.1	63.9	0.5	100.0
With support (lives alone or with others)	0.5	0.6	98.7	0.2	100.0
Other arrangements	0.0	0.0	60.0	40.0	100.0
Total	*2.6*	*2.8*	*94.2*	*0.3*	*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 15 Length of Stay (LOS) summary - overnight admitted patients

Length of stay	National
Average length of episode	11.6
Median length of episode	7
Average number of phases per episode	2.5

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 16 Length of Stay (LOS) - overnight admitted patients

Length of stay	Number	%
Same day	346	3.7
1-2 days	1681	17.8
3-4 days	1308	13.9
5-7 days	1565	16.6
8-14 days	1997	21.2
15-21 days	976	10.4
22-30 days	696	7.4
31-60 days	670	7.1
61-90 days	122	1.3
Greater than 90 days	60	0.6
Total	9421	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 17 Place of death - patients not admitted overnight

Place of death	Number	%
Private residence	1198	57.5
Residential aged care setting	299	14.3
Other location*	474	22.7
Not stated/inadequately described	113	5.4
Total	2084	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 18 Number of phases by phase type and episode type

Phase	Overnight admitted		Not admitted overnight	
	Number	%	Number	%
Stable	6074	25.5	4649	35.7
Unstable	6863	28.9	2527	19.4
Deteriorating	5891	24.8	4358	33.5
Terminal	3739	15.7	1165	8.9
Bereaved	1214	5.1	324	2.5
All phases	23781	100.0	13023	100.0

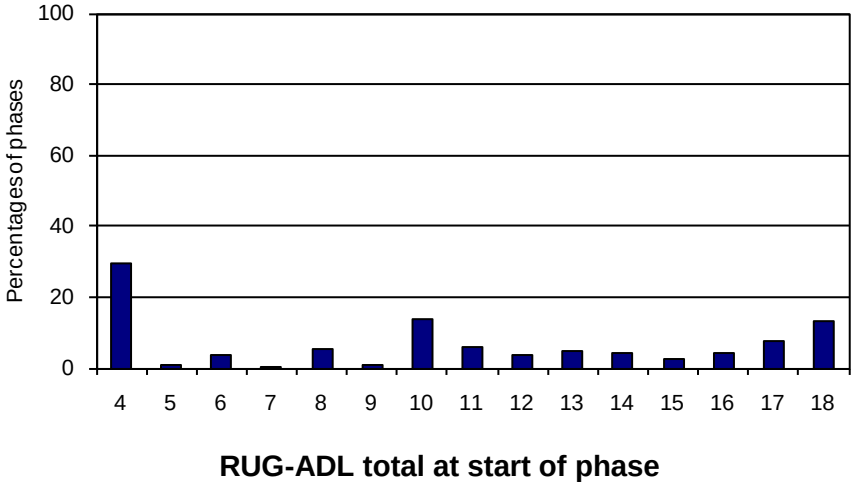
Table 19 Average phase length (in days) by phase and episode type

Phase	Overnight admitted	Not admitted overnight
Stable	7.5	23.4
Unstable	4.4	10.1
Deteriorating	5.5	16.4
Terminal	2.2	3.0
Bereaved	1.1	1.3

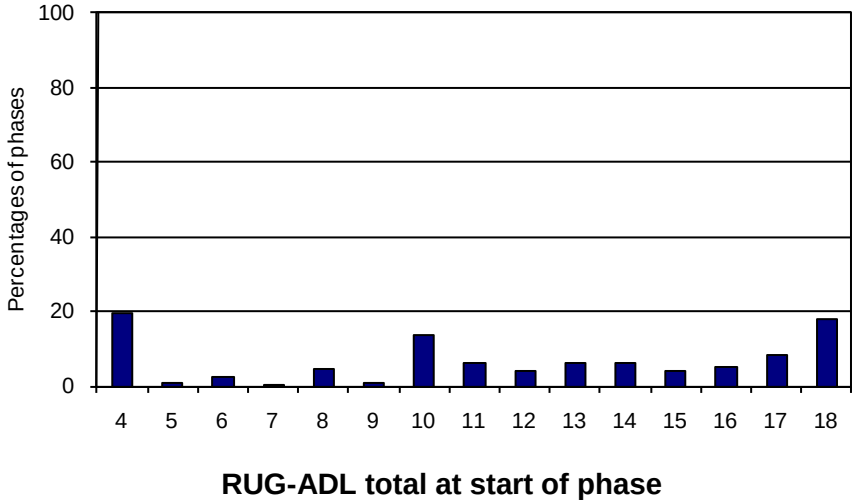
Note: Phase records where length of phase was greater than 90 days were considered to be outliers and are excluded from the average calculations.

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

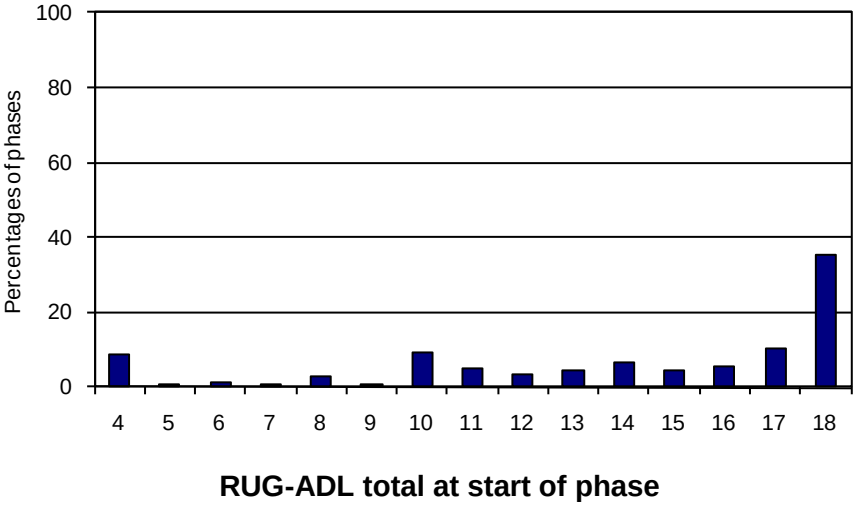
Stable Phase



Unstable Phase



Deteriorating Phase



Terminal Phase

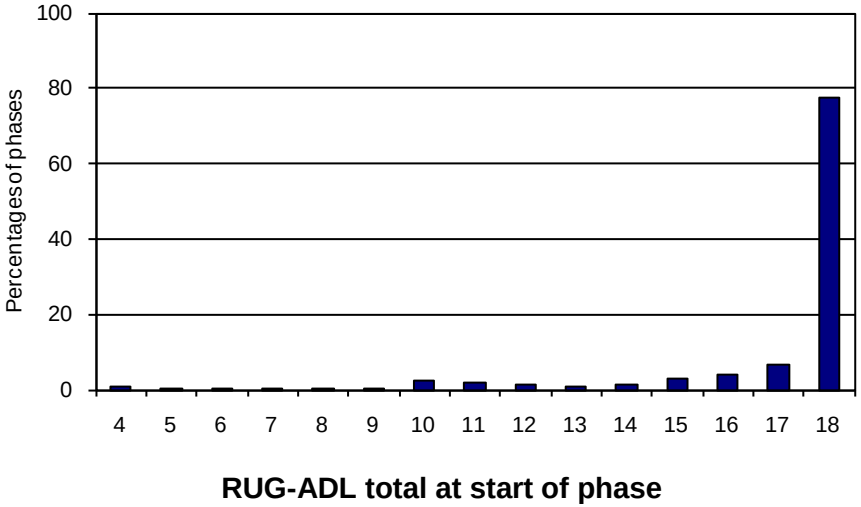
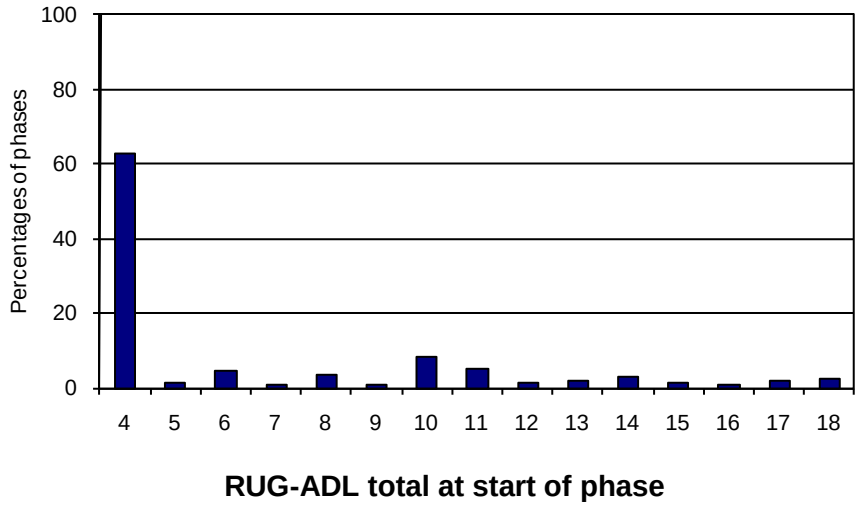
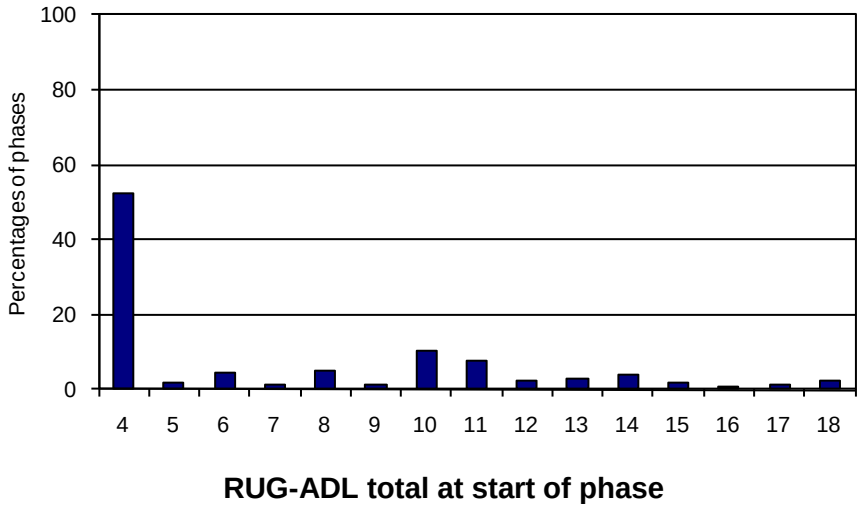


Figure 2 Total RUG-ADL at beginning of phase – patients not admitted overnight

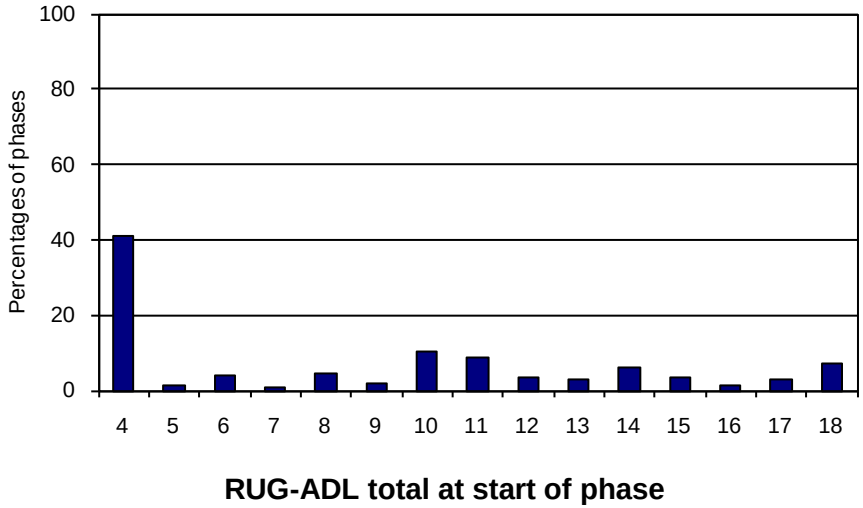
Stable Phase



Unstable Phase



Deteriorating Phase



Terminal Phase

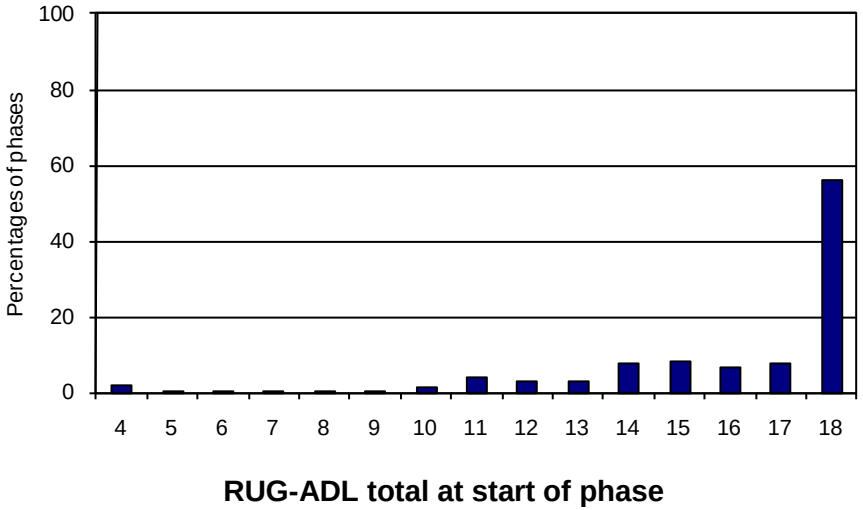


Table 20 Profile of PC Problem Severity Scores (percentages) at beginning of phase by phase type - overnight admitted patients

Phase	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	38.6	40.4	16.3	4.8
	Other Symptom	15.4	41.7	32.4	10.6
	Psychological/Spiritual	22.0	45.4	22.6	10.0
	Family/Carer	30.5	38.3	20.5	10.7
Unstable	Pain	22.3	27.2	31.8	18.6
	Other Symptom	6.7	22.8	40.8	29.7
	Psychological/Spiritual	12.3	34.5	33.6	19.6
	Family/Carer	20.1	31.4	29.4	19.1
Deteriorating	Pain	26.5	31.8	28.1	13.7
	Other Symptom	7.1	20.8	38.6	33.5
	Psychological/Spiritual	15.4	33.3	31.5	19.8
	Family/Carer	16.9	29.0	30.6	23.4
Terminal	Pain	35.8	27.2	21.8	15.2
	Other Symptom	20.4	22.0	28.8	28.8
	Psychological/Spiritual	34.4	28.0	20.2	17.3
	Family/Carer	13.3	25.8	31.1	29.8

Table 21 Profile of PC Problem Severity Scores (percentages) at beginning of phase by phase type - patients not admitted overnight

Phase	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	35.0	49.8	14.0	1.2
	Other Symptom	16.0	55.0	26.1	2.8
	Psychological/Spiritual	23.6	54.1	19.6	2.7
	Family/Carer	21.8	47.0	26.7	4.5
Unstable	Pain	16.9	27.9	37.5	17.7
	Other Symptom	5.2	28.7	47.9	18.2
	Psychological/Spiritual	11.2	41.9	37.5	9.3
	Family/Carer	12.4	31.5	42.8	13.3
Deteriorating	Pain	26.7	44.1	24.3	4.8
	Other Symptom	5.3	34.1	49.2	11.4
	Psychological/Spiritual	15.6	46.2	31.7	6.5
	Family/Carer	10.6	34.1	43.2	12.1
Terminal	Pain	34.5	38.6	21.1	5.8
	Other Symptom	20.6	29.3	31.1	19.1
	Psychological/Spiritual	37.0	31.4	22.6	9.0
	Family/Carer	7.2	22.8	46.7	23.3

Table 22 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	1.5	1.4
	Appetite	2.5	2.6
	Nausea	0.9	0.6
	Bowels	1.9	1.1
	Breathing	1.7	1.5
	Fatigue	4.4	4.1
	Pain	2.2	1.7
Unstable	Insomnia	2.3	2.5
	Appetite	3.8	3.9
	Nausea	1.6	1.7
	Bowels	2.7	1.9
	Breathing	2.5	2.2
	Fatigue	5.4	5.5
	Pain	3.6	3.8
Deteriorating	Insomnia	1.9	1.9
	Appetite	3.7	3.7
	Nausea	1.3	1.0
	Bowels	2.6	1.6
	Breathing	2.8	2.3
	Fatigue	5.6	5.7
	Pain	3.3	2.4

Continued...

Phase	Symptom Assessment Score	Overnight admitted	Not admitted overnight
Terminal	Insomnia	0.9	1.2
	Appetite	2.1	3.4
	Nausea	0.7	0.6
	Bowels	1.8	1.2
	Breathing	2.8	2.3
	Fatigue	3.8	5.9
	Pain	2.6	2.0

Table 23 Karnofsky score at phase start by episode type

Karnofsky score	Overnight admitted		Not admitted overnight	
	Number	%	Number	%
Comatose or barely rousable	2049	9.1	448	3.6
Totally bedfast and requiring extensive nursing care	4582	20.5	1065	8.4
Almost completely bedfast	2471	11.0	741	5.9
In bed more than 50% of the time	3518	15.7	1361	10.8
Requires considerable assistance	4304	19.2	2766	21.9
Requires occasional assistance	2904	13.0	2901	23.0
Cares for self	870	3.9	1791	14.2
Normal activity with effort	309	1.4	826	6.5
Able to carry on normal activity; minor signs or symptoms	109	0.5	252	2.0
Normal; no complaints; no evidence of disease	8	0.0	12	0.1
Not stated/inadequately described	1280	5.7	456	3.6
Total	22404	100.0	12619	100.0

Note: Bereavement phase and records where Karnofsky was 0 (dead) are excluded from the table.

Table 24 Reason for phase end by phase and episode type

Phase	Phase end reason	Overnight admitted		Not admitted overnight	
		Number	%	Number	%
Stable	Phase change	3104	51.1	3260	70.1
	Discharge/case closure	2810	46.3	1088	23.4
	Died	143	2.4	223	4.8
	Bereavement phase end	6	0.1	1	0.0
	Not stated/inadequately described	11	0.2	77	1.7
	Total	*6074*	*100.0*	*4649*	*100.0*
Unstable	Phase change	5915	86.2	2007	79.4
	Discharge/case closure	628	9.2	424	16.8
	Died	300	4.4	67	2.7
	Bereavement phase end	11	0.2	1	0.0
	Not stated/inadequately described	9	0.1	28	1.1
	Total	*6863*	*100.0*	*2527*	*100.0*
Deteriorating	Phase change	4005	68.0	2660	61.0
	Discharge/case closure	777	13.2	1266	29.1
	Died	1075	18.2	399	9.2
	Bereavement phase end	26	0.4	5	0.1
	Not stated/inadequately described	8	0.1	28	0.6
	Total	*5891*	*100.0*	*4358*	*100.0*
Terminal	Phase change	403	10.8	445	38.2
	Discharge/case closure	93	2.5	65	5.6
	Died	3215	86.0	642	55.1
	Bereavement phase end	23	0.6	3	0.3
	Not stated/inadequately described	5	0.1	10	0.9
	Total	*3739*	*100.0*	*1165*	*100.0*

Benchmark Measure 1 - Time from referral to first contact

Table 25 and Figures 3 and 4 below present descriptive data on the first benchmark measure. This measure is the percentage of patients seen either on the day of, or the day following the referral. The benchmark is 90%.

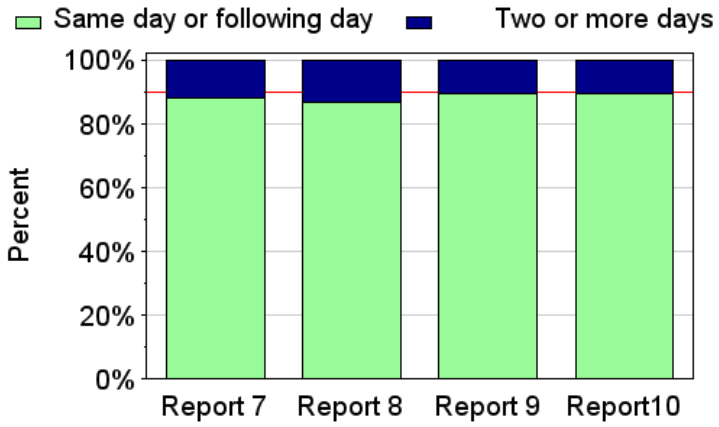
The time from referral to first contact is calculated as the time from the date of referral to either the date of first contact (if provided) or the episode start date.

Table 25 Time from referral to first contact by episode type

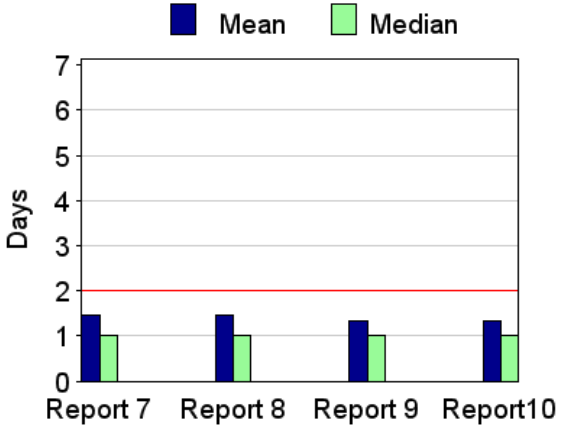
Time (in days)	Overnight admitted		Not admitted overnight	
	Number	%	Number	%
Same day or following day	8270	89.2	3299	54.5
2-7 days	818	8.8	1746	28.8
8-14 days	104	1.1	562	9.3
Greater than 14 days	80	0.9	449	7.4
Average	1.3	na	2.9	na
Median	1	na	1	na

Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact 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 3 Time from referral to first contact - overnight admitted patients

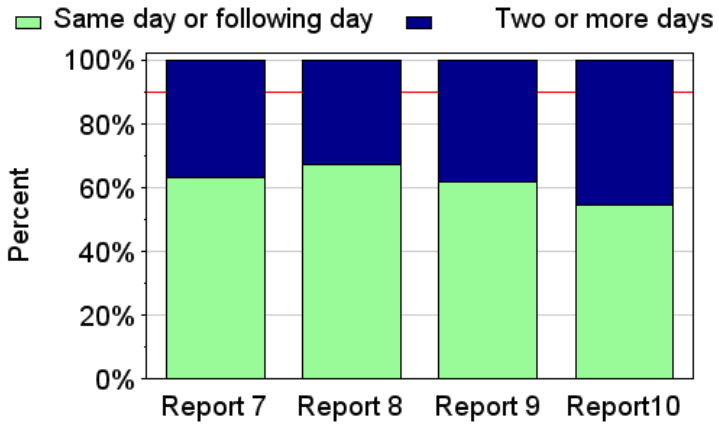


Time from referral to first contact

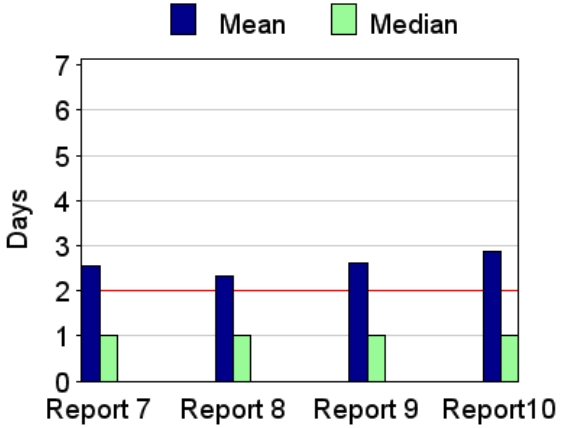


Mean and median time from referral to first contact

Figure 4 Time from referral to first contact - patients not admitted overnight



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 based on whether the patient is in the unstable phase at the start of the episode (i.e. first phase of episode) or is assessed in the unstable phase during the episode (i.e. not the first phase of episode). The benchmark is 85% for patients when the first phase is the unstable phase and 90% for patients in the unstable phase during an episode when it is not the first phase. The second part of this measure is the median time spent in the unstable phase and the benchmark is 2 days or less.

Table 26 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
Overnight admitted	First phase	4553	77.5	3
	Not first phase	2310	87.6	2
	Total	*6863*	*80.9*	*3*
Not admitted overnight	First phase	1075	48.5	7
	Not first phase	1452	61.9	4
	Total	*2527*	*56.2*	*5*

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 27 Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase

Episode type		Report 7	Report 8	Report 9	Report 10
Overnight admitted	Number	2485	2166	2860	3969
	%	82.3	75.9	79.0	79.0
Not admitted overnight	Number	1201	1336	1441	2415
	%	79.1	77.1	75.8	74.9

Table 28 Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase

Episode type		Report 7	Report 8	Report 9	Report 10
Overnight admitted	Number	1024	1031	1257	1655
	%	38.1	40.8	44.0	46.6
Not admitted overnight	Number	270	382	485	806
	%	38.1	54.0	55.7	57.5

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.

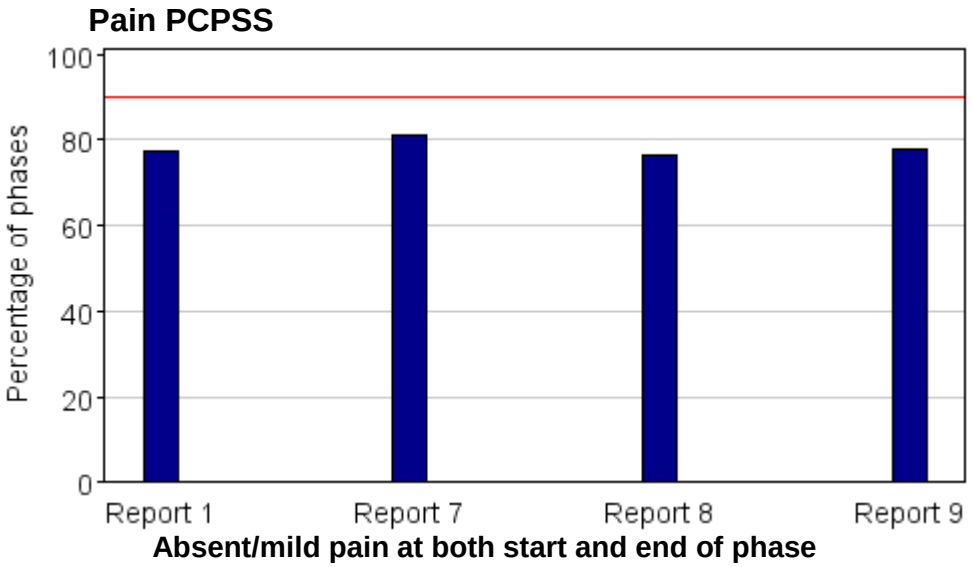
Table 29 Patients with absent or mild pain at beginning of phase whose pain remained absent or mild at end of phase

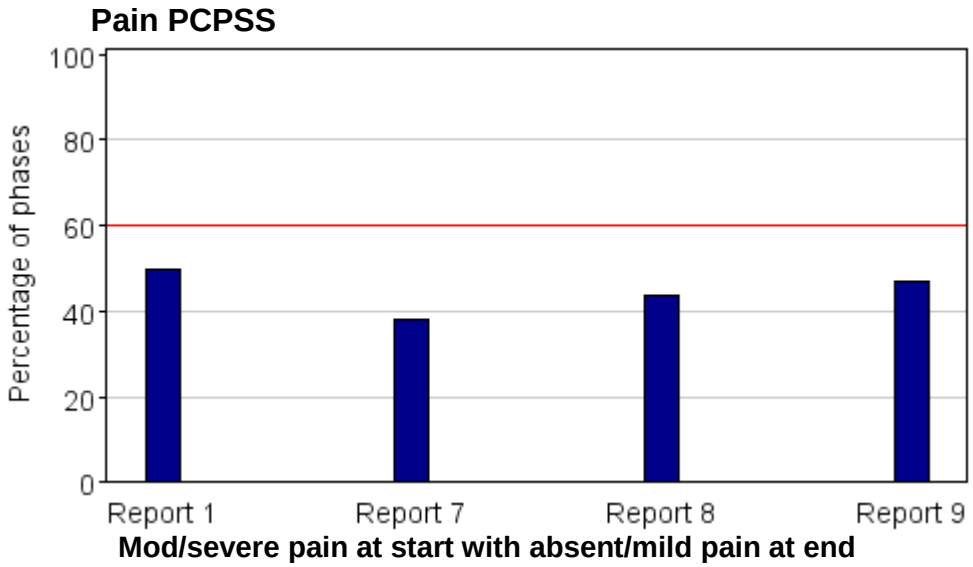
Episode type		Report 7	Report 8	Report 9	Report 10
Overnight admitted	Number	3107	2950	3370	4672
	%	82.4	76.7	79.8	78.8
Not admitted overnight	Number	2624	2008	1978	2825
	%	81.6	76.8	78.2	76.4

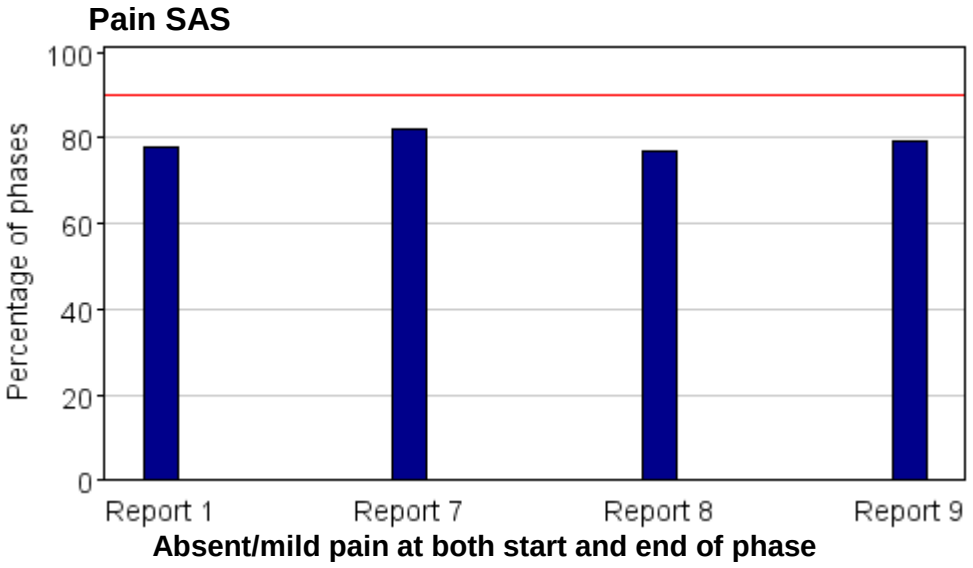
Table 30 Patients with moderate or severe pain at beginning of phase whose pain decreased to absent or mild at end of phase

Episode type		Report 7	Report 8	Report 9	Report 10
Overnight admitted	Number	1235	1339	1453	1912
	%	41.2	41.0	41.3	45.7
Not admitted overnight	Number	552	598	591	846
	%	40.4	50.1	53.1	55.3

Figure 5 Change in pain benchmark measures - all phases







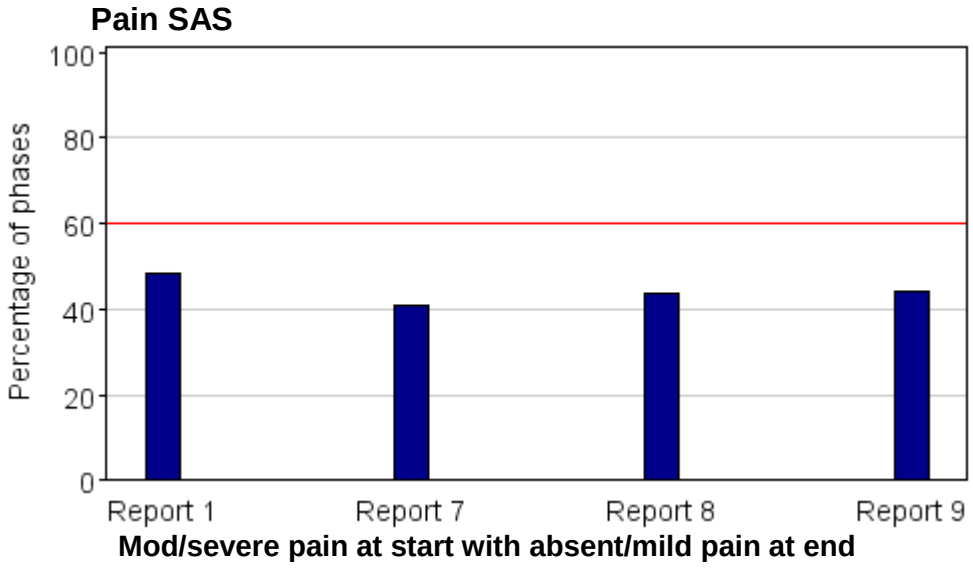
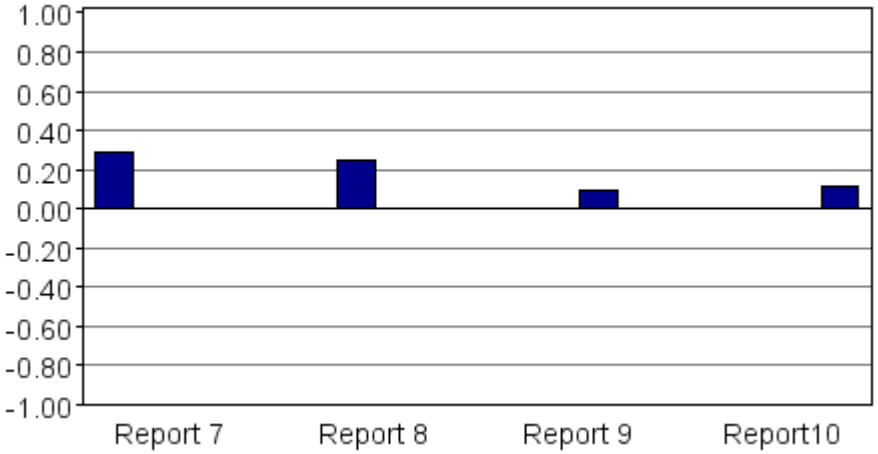
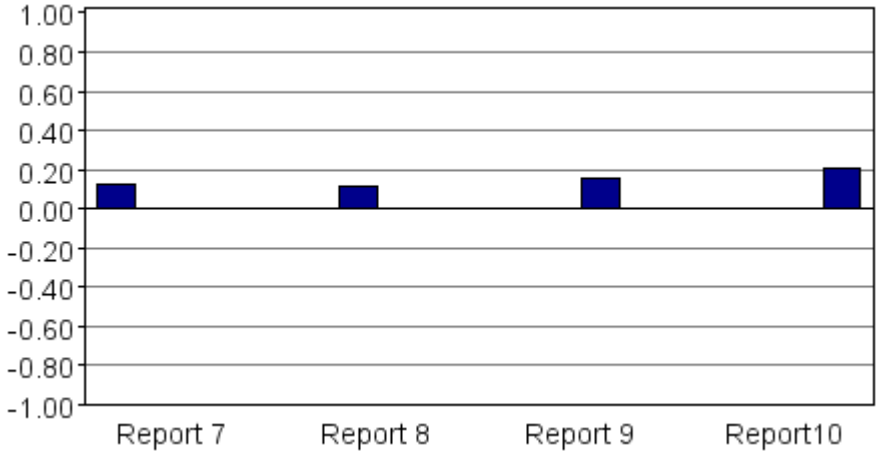


Figure 6 PCPSS mean change adjusted for phase and symptom score at start of phase

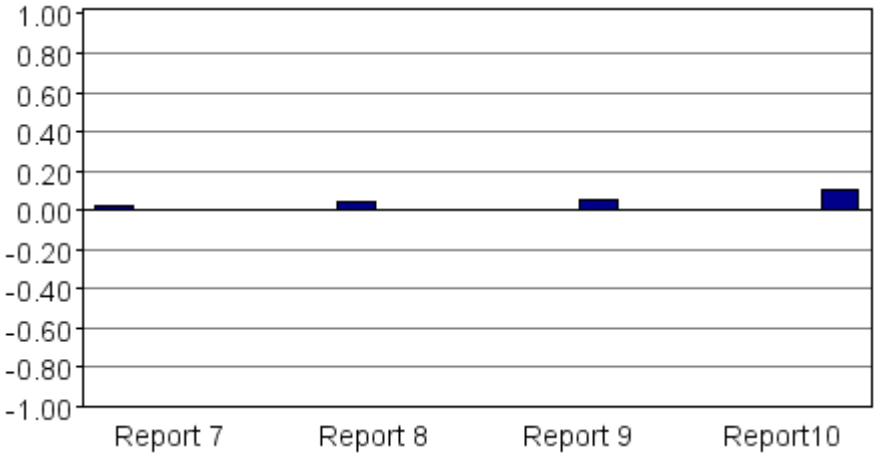
Pain



Other symptoms



Family/Carer



Psychological/spiritual

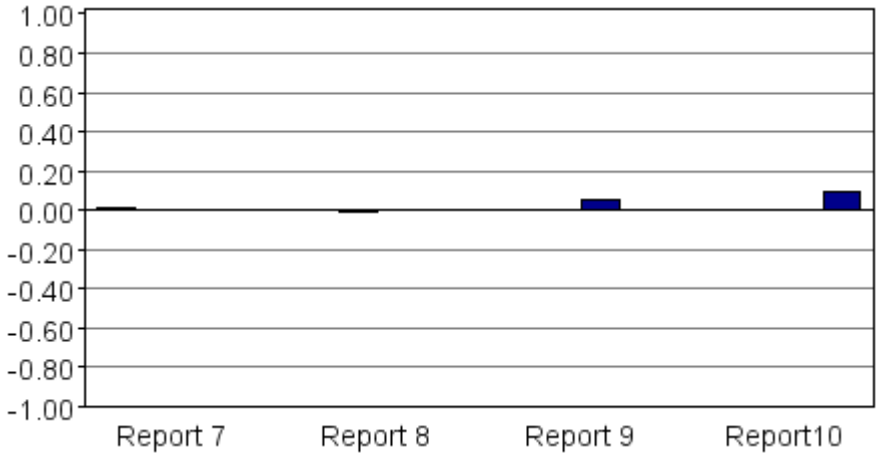
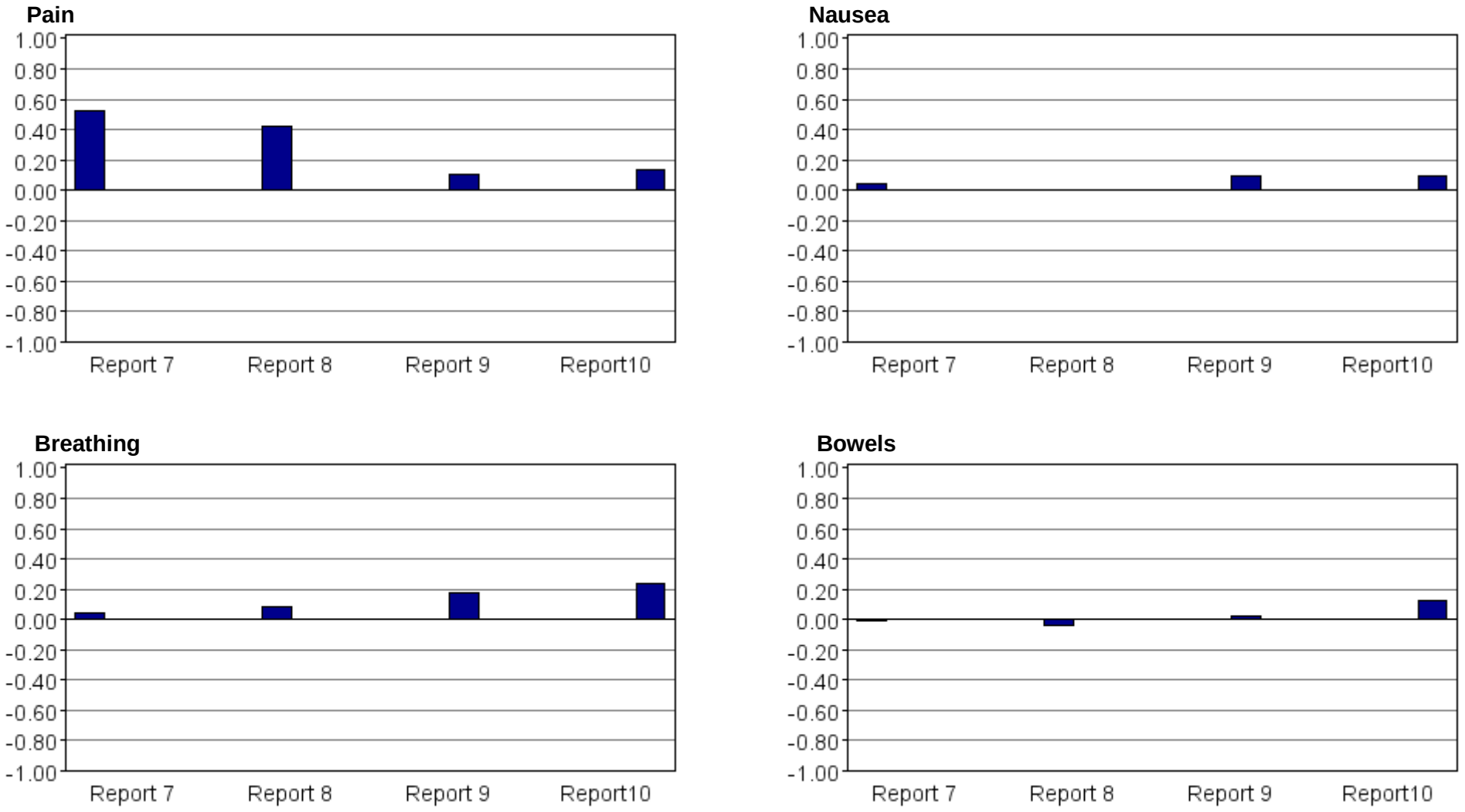


Figure 7 SAS mean change adjusted for phase and symptom score at start of phase



Appendix 1 - Services included in this report

This report includes data from the following 91 services:

Table 11 Services providing data

Palliative Care Service	State	Begin date	End date	Months
Baringa Private Hospital	NSW	July 2010	November 2010	5
Calvary Health Care Sydney	NSW	July 2010	December 2010	6
Calvary Health Care Riverina	NSW	July 2010	November 2010	5
Calvary Mater Newcastle	NSW	July 2010	December 2010	6
Camden Hospital	NSW	July 2010	August 2010	2
Canterbury Hospital	NSW	July 2010	December 2010	6
Coffs Harbour Palliative Care Service	NSW	July 2010	December 2010	6
David Berry Hospital	NSW	July 2010	December 2010	6
HammondCare - Braeside Hospital	NSW	July 2010	December 2010	6
HammondCare - Greenwich Hospital	NSW	July 2010	December 2010	6
HammondCare - Neringah Hospital	NSW	July 2010	December 2010	6
Lourdes Hospital	NSW	July 2010	December 2010	6
Manning Rural Referral Hospital	NSW	July 2010	December 2010	6
Mercy Care Centre - Young	NSW	July 2010	December 2010	6
Mercy Health Service Albury	NSW	July 2010	December 2010	6
Mt Druitt Hospital	NSW	July 2010	December 2010	6
Port Kembla Hospital	NSW	July 2010	December 2010	6
Sacred Heart Palliative Care Service	NSW	July 2010	December 2010	6
St Joseph's Hospital	NSW	July 2010	December 2010	6
St Vincent's Hospital Lismore	NSW	July 2010	December 2010	6
St Vincent's Hospital, Sydney - Palliative Care Consult Service	NSW	July 2010	December 2010	6
Tamworth Base Hospital	NSW	July 2010	December 2010	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Tweed Heads Community Health	NSW	July 2010	December 2010	6
Westmead Hospital	NSW	July 2010	December 2010	6
Banksia Palliative Care Services	VIC	July 2010	December 2010	6
Caritas Christi - Fitzroy	VIC	July 2010	December 2010	6
Caritas Christi - Kew	VIC	July 2010	December 2010	6
Eastern Palliative Care	VIC	July 2010	December 2010	6
Gandarra Palliative Care Unit - Ballarat	VIC	July 2010	December 2010	6
Goulburn Valley Hospice Inc.	VIC	July 2010	December 2010	6
Lower Hume Palliative Care	VIC	July 2010	December 2010	6
McCulloch House - inpatient unit	VIC	December 2010	December 2010	1
Melbourne Citymission Palliative Care	VIC	July 2010	December 2010	6
Mercy Palliative Care - Medical Consultant	VIC	July 2010	December 2010	6
Mercy Palliative Care - Sunshine	VIC	July 2010	December 2010	6
Northern Health Broadmeadows Palliative Care Unit	VIC	July 2010	December 2010	6
Northern Health Palliative Care Consult Team	VIC	July 2010	August 2010	2
Peter MacCallum Cancer Centre	VIC	July 2010	December 2010	6
Royal Melbourne Hospital Palliative Care Unit	VIC	July 2010	December 2010	6
South East Palliative Care	VIC	July 2010	December 2010	6
Sunraysia Community Palliative Care Service Clinic	VIC	July 2010	December 2010	6
Werribee Mercy Hospital	VIC	July 2010	December 2010	6
Western Health - Community	VIC	August 2010	December 2010	5
Bundaberg Palliative Access	QLD	July 2010	December 2010	6
Cairns and Gordonvale Hospital	QLD	July 2010	December 2010	6
Caloundra Hospital	QLD	July 2010	December 2010	6
Canossa Private Hospital	QLD	July 2010	December 2010	6
Gladstone Hospital	QLD	July 2010	December 2010	6
Gympie Hospital	QLD	July 2010	November 2010	5
Hervey Bay & Fraser Coast Palliative Care Service	QLD	July 2010	December 2010	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Hopewell Hospice	QLD	July 2010	December 2010	6
Ipswich Hospice	QLD	July 2010	December 2010	6
Ipswich Hospital	QLD	July 2010	December 2010	6
Karuna Hospice Services	QLD	July 2010	December 2010	6
Mater Adult's Hospital Brisbane	QLD	July 2010	December 2010	6
Mater Private Brisbane	QLD	July 2010	December 2010	6
Mater Private Bundaberg	QLD	July 2010	December 2010	6
Mater Private Mackay	QLD	July 2010	December 2010	6
Mater Private Rockhampton	QLD	July 2010	December 2010	6
Nambour Hospital	QLD	July 2010	December 2010	6
Redcliffe Hospital Palliative Care Unit	QLD	July 2010	December 2010	6
Rockhampton Base Hospital	QLD	July 2010	December 2010	6
Royal Brisbane and Women's Hospital	QLD	July 2010	December 2010	6
St Vincent's Hospital Brisbane	QLD	July 2010	December 2010	6
Sunshine Coast and Cooloola Community Palliative Care Service	QLD	July 2010	December 2010	6
The Prince Charles Hospital	QLD	July 2010	December 2010	6
Townsville Palliative Care Centre	QLD	July 2010	December 2010	6
Wesley Private	QLD	July 2010	December 2010	6
Adelaide Hills Community Health Service	SA	July 2010	December 2010	6
Calvary Health Care Adelaide (Mary Potter Hospice)	SA	July 2010	December 2010	6
Lyell McEwin Palliative Care Service	SA	July 2010	December 2010	6
Modbury Hospice SA	SA	July 2010	December 2010	6
Port Lincoln Health Service	SA	July 2010	December 2010	6
Port Pirie Regional Health Service	SA	July 2010	December 2010	6
Royal Adelaide Hospital	SA	July 2010	December 2010	6
South East Regional Community Health Service	SA	July 2010	December 2010	6
Southern Adelaide Palliative Services	SA	July 2010	December 2010	6
Stirling District Hospital	SA	July 2010	December 2010	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Yorke Peninsula Palliative Care	SA	July 2010	December 2010	6
Albany Palliative Care Service	WA	July 2010	December 2010	6
Bethesda Hospital	WA	July 2010	December 2010	6
Geraldton Palliative Care Community Service	WA	July 2010	December 2010	6
Northam Palliative Care	WA	July 2010	December 2010	6
Peel Community Palliative Care Service	WA	July 2010	December 2010	6
Royal Perth Hospital	WA	July 2010	December 2010	6
Silver Chain Hospice Care Service	WA	July 2010	December 2010	6
St John of God Hospital - Geraldton	WA	July 2010	December 2010	6
St John of God Murdoch Community Hospice	WA	July 2010	December 2010	6
Calvary Health Care Tasmania - St John's	TAS	July 2010	December 2010	6
JW Whittle Palliative Care Unit	TAS	July 2010	December 2010	6
Calvary Health Care Canberra (Clare Holland House)	ACT	July 2010	December 2010	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 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 12 Data consistency - patient level items

Data item	% Complete
Date of birth	100.0
Sex	99.9
Indigenous status	94.6
Country of birth	92.5
Main language	93.6
Primary diagnosis	98.3

Table 13 Data consistency - episode level items

Data item	% Complete
Date of first contact/assessment	95.3
Referral date	91.4
Referral source	93.6
Episode start date	100.0
Mode of episode start	99.4
Accommodation at episode start	92.7
Episode end date	99.9
Level of support at episode start	81.6
Mode of episode end	98.3
Accommodation at episode end	82.2
Level of support at episode end	93.6
Place of death	94.6

Table 14 Data consistency - phase level items

Data item	Sub-Category (where applicable)	%Complete
Phase start date		100.0
Phase		100.0
RUG-ADL at phase start	Bed Mobility	94.2
	Toileting	94.2
	Transfers	94.0
	Eating	93.4
PC Problem Severity at phase start	Pain	75.8
	Other Symptom	81.9
	Psychological/Spiritual	90.6
	Family/Carer	89.0
Symptom Assessment Score at phase start	Insomnia	83.5
	Appetite	86.6
	Nausea	86.9
	Bowels	86.2
	Breathing	86.9
	Fatigue	87.5
	Pain	87.9
Phase end reason		99.5
Karnofsky at phase start		95.1

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

Australia-modified Karnofsky Performance Status Scale (AKPS)

The Karnofsky used in PCOC is the Australia-modified version which is applicable to both inpatient and community palliative care. The AKPS assesses patient/client functioning and performance and can be used to indicate prognosis. The AKPS is often used in determining prognosis / survival times. The AKPS 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 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.