palliative care outcomes collaboration

PCOC Report 9

Victoria

January to June 2010

August 2010

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

WA Centre for Cancer & Palliative Care, Curtin University of Technology – PCOC West

Department of Palliative and Supportive Studies, 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*.

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), Australian-modified Karnofsky and 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 now also routinely included in each report.

For this PCOC Report 9, 97 palliative care services submitted data and 95 are included in this report. The reporting period is January to June 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 95 services. During the reporting period data were provided for a total of 10579 patients, with 12852 episodes and 27280 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	
	VIC	All Services	VIC	All Services	VIC	All Services
Number of patients*	844	7200	1030	4005	1834	10579
Number of episodes	922	8294	1113	4558	2035	12852
Number of phases	2357	18841	2104	8439	4461	27280
Percentage of patients*	46.0	68.1	56.2	37.9	100	100
Percentage of episodes	45.3	64.5	54.7	35.5	100	100
Percentage of phases	52.8	69.1	47.2	30.9	100	100
Average number of episodes per patient	1.1	1.2	1.1	1.2	1.1	1.2
Average number of phases per episode**	2.6	2.3	1.8	1.8	2.2	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.

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 all services not meeting the current benchmarks. For example if your service does not meet the 90% benchmark for Measure 1 then your target is to achieve an improvement of 10% over the next reporting period. Therefore, if you score 75% for Measure 1 in this report, your target is to score at least 82.5% for this measure in the next report which is a 10% improvement.

The following two tables provide a summary of the performance of your service in relation to the four benchmark measures for the period January to June 2010.

Table 2 Summary of benchmark measures 1-3

Measure	Description	Benchmark	Benchmark met (VIC score)			
			Overnight admitted		Not admitted overnight	
1. Time from referral to contact	Patients contacted on same or following day	90%	No	(83.8%)	No	(62.3%)
2. Time in unstable phase	Patients unstable less than 7 days - first phase	85%	No	(83.0%)	No	(43.7%)
	Patients unstable less than 7 days - subsequent phase	90%	No	(89.9%)	No	(51.6%)
	Median time in unstable phase	2 days or less	Yes	(2 days)	No	(7 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	(78.9%)	No	(77.4%)
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	No	(56.0%)	Yes	(61.8%)
Symptom Assessment Score (SAS)	Patients with absent/mild pain at phase start remaining absent/mild at phase end	90%	No	(80.5%)	No	(77.5%)
	Patients with moderate/severe pain at phase start with absent/mild at phase end	60%	No	(51.2%)	Yes	(60.5%)

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

Symptom		Benchmark	Benchmark met	VIC score
PC PSS	Pain	0 or above	Yes	(0.12)
	Other symptoms	0 or above	Yes	(0.25)
	Family/carer	0 or above	Yes	(0.11)
	Psychological/spiritual	0 or above	Yes	(0.11)
SAS	Pain	0 or above	Yes	(0.22)
	Nausea	0 or above	Yes	(0.10)
	Breathing	0 or above	Yes	(0.23)
	Bowels	0 or above	Yes	(0.26)

Section 2 - Descriptive analysis

Profile of palliative care patients

Table 4 Indigenous Status - all patients

Indigenous Status	VIC	All Services
Aboriginal but not Torres Strait Islander origin	7	104
Torres Strait Islander but not Aboriginal origin	7	15
Both Aboriginal and Torres Strait Islander origin	1	14
Neither Aboriginal nor Torres Strait Islander origin	1588	9980
Not stated/inadequately described	231	466
Total	1834	10579

Table 5 Sex - all patients

Sex	VIC	%	All Services	%
Male	985	53.7	5701	53.9
Female	848	46.2	4871	46.0
Not stated/inadequately described	1	0.1	7	0.1
Total	1834	100.0	10579	100.0

Table 6 Main language spoken at home - all patients

Main language spoken at home	VIC	%	All Services	%
English	1295	70.6	9045	85.5
Italian	95	5.2	198	1.9
Greek	44	2.4	88	0.8
Cantonese	12	0.7	49	0.5
Croatian	17	0.9	38	0.4
Arabic (including Lebanese)	10	0.5	34	0.3
Macedonian	14	0.8	33	0.3
Vietnamese	10	0.5	31	0.3
Maltese	23	1.3	30	0.3
Spanish	5	0.3	30	0.3
Mandarin	7	0.4	28	0.3
Polish	4	0.2	24	0.2
Turkish	14	0.8	18	0.2
Serbian	3	0.2	15	0.1
German	1	0.1	13	0.1
All other languages	44	2.4	213	2.0
Not stated/inadequately described	236	12.9	692	6.5
Total	1834	100.0	10579	100.0

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

Table 7 Country of birth - all patients

Country of birth	VIC	%	All Services	%
Australia	919	50.1	6698	63.3
England	65	3.5	807	7.6
Italy	153	8.3	339	3.2
Scotland	20	1.1	176	1.7
New Zealand	16	0.9	169	1.6
Greece	67	3.7	137	1.3
Netherlands	12	0.7	107	1.0
Germany	23	1.3	105	1.0
China	19	1.0	93	0.9
Poland	21	1.1	73	0.7
Malta	30	1.6	63	0.6
Croatia	27	1.5	63	0.6
Ireland	6	0.3	59	0.6
India	6	0.3	59	0.6
Vietnam	13	0.7	45	0.4
All other countries	139	7.6	862	8.1
Not stated/inadequately described	298	16.2	724	6.8
Total	1834	100.0	10579	100.0

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

Table 8 Primary diagnosis

Primary diagnosis		VIC	%	All services	%
Malignant	Bone and soft tissue	62	4.1	233	2.8
	Breast	106	7.1	628	7.5
	CNS	40	2.7	164	2.0
	Colorectal	179	11.9	899	10.8
	Gynaecological	84	5.6	448	5.4
	Haematological	83	5.5	433	5.2
	Head and neck	78	5.2	451	5.4
	Lung	263	17.5	1579	18.9
	Pancreas	92	6.1	510	6.1
	Prostate	106	7.1	519	6.2
	Skin	60	4.0	335	4.0
	Other GIT	135	9.0	667	8.0
	Other urological	66	4.4	318	3.8
	Other malignancy	102	6.8	499	6.0
	Unknown primary	46	3.1	209	2.5
	Malignant - not further defined	0	0.0	470	5.6
	All malignant	*1502*	*100.0*	*8362*	*100.0*
Non-malignant	Cardiovascular	55	18.9	304	18.4
	HIV/AIDS	1	0.3	15	0.9
	Kidney failure	40	13.7	185	11.2
	Neurological disease	62	21.3	278	16.8
	Respiratory failure	54	18.6	227	13.7
	Other non-malignancy	79	27.1	350	21.1
	Non-malignant - not further defined	0	0.0	297	17.9
	All non-malignant	*291*	*100.0*	*1656*	*100.0*

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

Profile of palliative care episodes

The 10579 patients from all services seen in the six month period had a total of 12852 episodes of palliative care. These episodes included inpatient, community and consultative episodes. For example, a patient who received both inpatient and community (home-based) palliative care during the period is generally counted as two episodes.

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

Table 9 Number of episodes by age group - all episodes

Age group	VIC	%	All Services	%
< 15	8	0.4	52	0.4
15-24	12	0.6	41	0.3
25-34	18	0.9	100	0.8
35-44	69	3.4	418	3.3
45-54	210	10.3	1210	9.4
55-64	350	17.2	2351	18.3
65-74	462	22.7	3215	25.0
75-84	606	29.8	3696	28.8
85+	299	14.7	1765	13.7
Not stated/inadequately described	1	0.0	4	0.0
Total	2035	100.0	12852	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			
	VIC	%	All Services	%	VIC	%	All Services	%
Public hospital - other than inpatient palliative care unit	393	42.6	3333	40.2	432	38.8	1857	40.7
Self, carer(s), family or friends	2	0.2	163	2.0	57	5.1	143	3.1
Private hospital - other than inpatient palliative care unit	109	11.8	735	8.9	103	9.3	397	8.7
Public palliative care inpatient unit/hospice	7	0.8	151	1.8	31	2.8	305	6.7
Private palliative care inpatient unit/hospice	2	0.2	40	0.5	1	0.1	40	0.9
General Medical Practitioner rooms	3	0.3	595	7.2	83	7.5	893	19.6
Specialist Medical Practitioner rooms	6	0.7	389	4.7	29	2.6	274	6.0
Community-based palliative care agency	227	24.6	1492	18.0	99	8.9	128	2.8
Community-based service	18	2.0	356	4.3	20	1.8	92	2.0
Residential aged care facility	5	0.5	71	0.9	79	7.1	111	2.4
Other	2	0.2	220	2.7	31	2.8	133	2.9
Not stated/inadequately described	148	16.1	749	9.0	148	13.3	185	4.1
Total	922	100.0	8294	100.0	1113	100.0	4558	100.0

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

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	165	20	37	242	16	480
Admitted from other than usual accommodation	4	1	2	6	2	15
Admitted (transferred) from another hospital	35	6	23	211	2	277
Admitted (transferred) from acute care in other ward	24	0	10	94	3	131
All other reasons*	1	0	0	0	0	1
Total	*229*	*27*	*72*	*553*	*23*	*904*
As a percentage of each start mode						
Admitted from usual accommodation	34.4	4.2	7.7	50.4	3.3	100.0
Admitted from other than usual accommodation	26.7	6.7	13.3	40.0	13.3	100.0
Admitted (transferred) from another hospital	12.6	2.2	8.3	76.2	0.7	100.0
Admitted (transferred) from acute care in other ward	18.3	0.0	7.6	71.8	2.3	100.0
All other reasons*	100.0	0.0	0.0	0.0	0.0	100.0
Total	*25.3*	*3.0*	*8.0*	*61.2*	*2.5*	*100.0*

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

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

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

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

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	2000	168	405	2406	175	5154
Admitted from other than usual accommodation	36	14	15	52	10	127
Admitted (transferred) from another hospital	293	59	134	1459	66	2011
Admitted (transferred) from acute care in other ward	125	7	29	456	15	632
All other reasons*	20	1	1	55	6	83
Total	*2474*	*249*	*584*	*4428*	*272*	*8007*
As a percentage of each start mode						
Admitted from usual accommodation	38.8	3.3	7.9	46.7	3.4	100.0
Admitted from other than usual accommodation	28.3	11.0	11.8	40.9	7.9	100.0
Admitted (transferred) from another hospital	14.6	2.9	6.7	72.6	3.3	100.0
Admitted (transferred) from acute care in other ward	19.8	1.1	4.6	72.2	2.4	100.0
All other reasons*	24.1	1.2	1.2	66.3	7.2	100.0
Total	*30.9*	*3.1*	*7.3*	*55.3*	*3.4*	*100.0*

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

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

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

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

Mode of episode start	Mode of episode end					
	Discharged/ case closure	Admitted for inpatient palliative care	Admitted for inpatient acute care	Transfer for primary care	Death	Total
VIC						
New referral	200	231	143	18	287	879
Transfer from being an o/n PC patient	13	45	12	2	40	112
Total	*213*	*276*	*155*	*20*	*327*	*991*
As a percentage of each start mode						
New referral	22.8	26.3	16.3	2.0	32.7	100.0
Transfer from being an o/n PC patient	11.6	40.2	10.7	1.8	35.7	100.0
Total	*21.5*	*27.9*	*15.6*	*2.0*	*33.0*	*100.0*
All services						
New referral	686	728	681	57	1130	3282
Transfer from being an o/n PC patient	72	156	151	12	164	555
Total	*758*	*884*	*832*	*69*	*1294*	*3837*
As a percentage of each start mode						
New referral	20.9	22.2	20.7	1.7	34.4	100.0
Transfer from being an o/n PC patient	13.0	28.1	27.2	2.2	29.5	100.0
Total	*19.8*	*23.0*	*21.7*	*1.8*	*33.7*	*100.0*

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

Table 14 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
VIC					
Private residence	341	2	16	26	385
Residential aged care (low level care)	1	1	2	0	4
Residential aged care (high level care)	1	2	28	0	31
All other	2	0	0	8	10
Total	*345*	*5*	*46*	*34*	*430*
As a percentage of each start accommodation					
Private residence	88.6	0.5	4.2	6.8	100.0
Residential aged care (low level care)	25.0	25.0	50.0	0.0	100.0
Residential aged care (high level care)	3.2	6.5	90.3	0.0	100.0
All other	20.0	0.0	0.0	80.0	100.0
Total	*80.2*	*1.2*	*10.7*	*7.9*	*100.0*
All services					
Private residence	2473	20	98	279	2870
Residential aged care (low level care)	5	25	17	8	55
Residential aged care (high level care)	9	4	137	13	163
All other	69	3	10	91	173
Total	*2556*	*52*	*262*	*391*	*3261*
As a percentage of each start accommodation					
Private residence	86.2	0.7	3.4	9.7	100.0
Residential aged care (low level care)	9.1	45.5	30.9	14.5	100.0
Residential aged care (high level care)	5.5	2.5	84.0	8.0	100.0
All other	39.9	1.7	5.8	52.6	100.0
Total	*78.4*	*1.6*	*8.0*	*12.0*	*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 (and hence do not have an episode end date) are also excluded. The all other category includes: Community group home; Boarding house; Transitional living unit.

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

Level of support at episode start	Level of support at episode end				
	Without support (lives alone)	Without support (lives with others)	With support (lives alone or with others)	Other arrangements	Total
VIC					
Without support (lives alone)	5	0	6	0	11
Without support (lives with others)	0	17	10	0	27
With support (lives alone or with others)	0	2	269	1	272
Other arrangements	0	0	0	1	1
Total	*5*	*19*	*285*	*2*	*311*
As a percentage of each start support					
Without support (lives alone)	45.5	0.0	54.5	0.0	100.0
Without support (lives with others)	0.0	63.0	37.0	0.0	100.0
With support (lives alone or with others)	0.0	0.7	98.9	0.4	100.0
Other arrangements	0.0	0.0	0.0	100.0	100.0
Total	*1.6*	*6.1*	*91.6*	*0.6*	*100.0*
All services					
Without support (lives alone)	44	4	106	0	154
Without support (lives with others)	2	51	117	1	171
With support (lives alone or with others)	7	30	1922	5	1964
Other arrangements	0	0	0	1	1
Total	*53*	*85*	*2145*	*7*	*2290*
As a percentage of each start support					
Without support (lives alone)	28.6	2.6	68.8	0.0	100.0
Without support (lives with others)	1.2	29.8	68.4	0.6	100.0
With support (lives alone or with others)	0.4	1.5	97.9	0.3	100.0
Other arrangements	0.0	0.0	0.0	100.0	100.0
Total	*2.3*	*3.7*	*93.7*	*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 16 Length of Stay (LOS) summary - overnight admitted patients

Length of stay	VIC	All services
Average length of episode	13.3	11.9
Median length of episode	8	7
Average number of phases per episode	2.6	2.3

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

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

Length of stay	VIC	%	All Services	%
Same day	29	3.2	298	3.7
1-2 days	166	18.4	1497	18.8
3-4 days	112	12.4	1067	13.4
5-7 days	135	15.0	1242	15.6
8-14 days	182	20.2	1632	20.5
15-21 days	93	10.3	859	10.8
22-30 days	72	8.0	570	7.2
31-60 days	83	9.2	606	7.6
61-90 days	20	2.2	109	1.4
Greater than 90 days	11	1.2	72	0.9
Total	903	100.0	7952	100.0

Note: Bereavement phase records are excluded and episodes that remain open at the end of the reporting period (and hence do not have an episode end date), are also excluded.

Table 18 Place of death - patients not admitted overnight

Place of death	VIC	%	All Services	%
Private residence	188	57.5	759	58.1
Residential aged care setting	90	27.5	178	13.6
Other location*	44	13.5	227	17.4
Not stated/inadequately described	5	1.5	143	10.9
Total	327	100.0	1307	100.0

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

Profile of palliative care phases

Table 19 Number of phases by phase type and episode type

Phase	Overnight admitted				Not admitted overnight			
	VIC	%	All services	%	VIC	%	All services	%
Stable	668	28.3	4447	23.6	808	38.4	2758	32.7
Unstable	696	29.5	5809	30.8	514	24.4	1754	20.8
Deteriorating	570	24.2	4716	25.0	581	27.6	2896	34.3
Terminal	383	16.2	3090	16.4	175	8.3	806	9.6
Bereaved	40	1.7	779	4.1	26	1.2	225	2.7
All phases	2357	100.0	18841	100.0	2104	100.0	8439	100.0

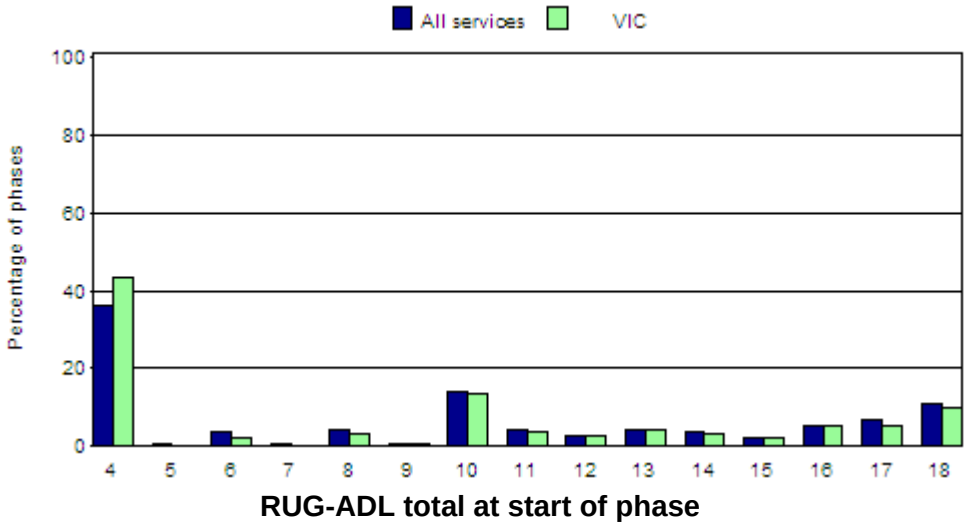
Table 20 Average phase length (in days) by phase and episode type

Phase	Overnight admitted		Not admitted overnight	
	VIC	All services	VIC	All services
Stable	8.0	7.8	23.3	22.0
Unstable	3.9	5.6	11.1	11.2
Deteriorating	7.6	5.9	14.2	17.1
Terminal	1.8	2.2	3.5	3.2
Bereaved	1.2	1.3	14.5	3.0

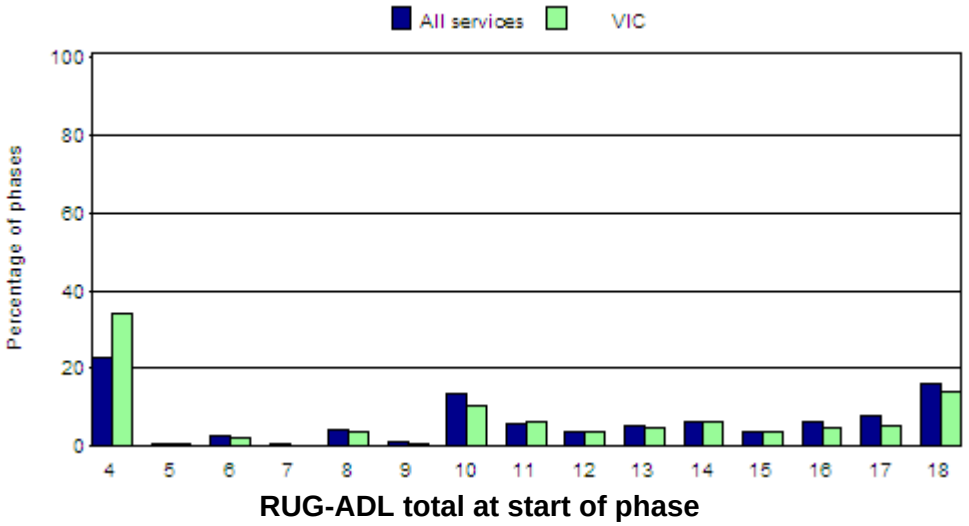
Note: Phase records where length of phase was greater than 90 days were considered to be outliers and are excluded from the average calculations.

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

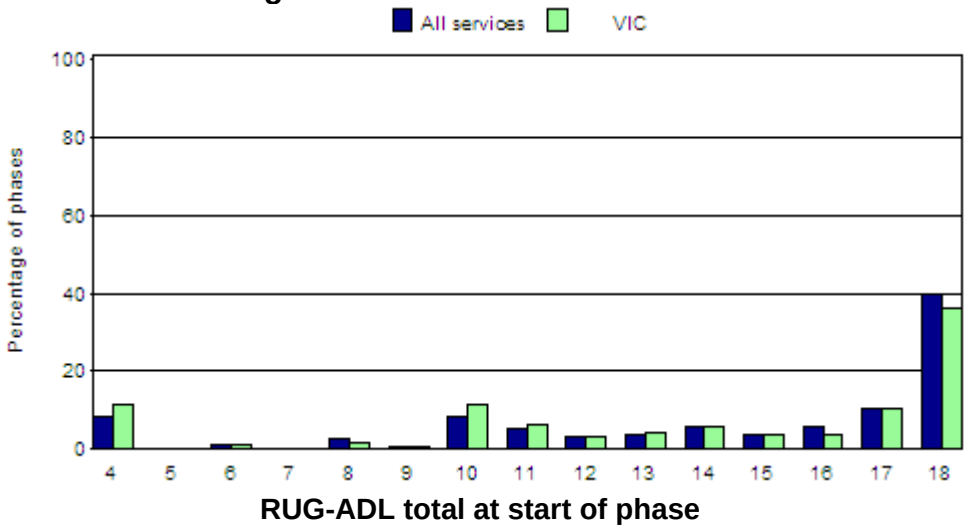
Stable Phase



Unstable Phase



Deteriorating Phase



Terminal Phase

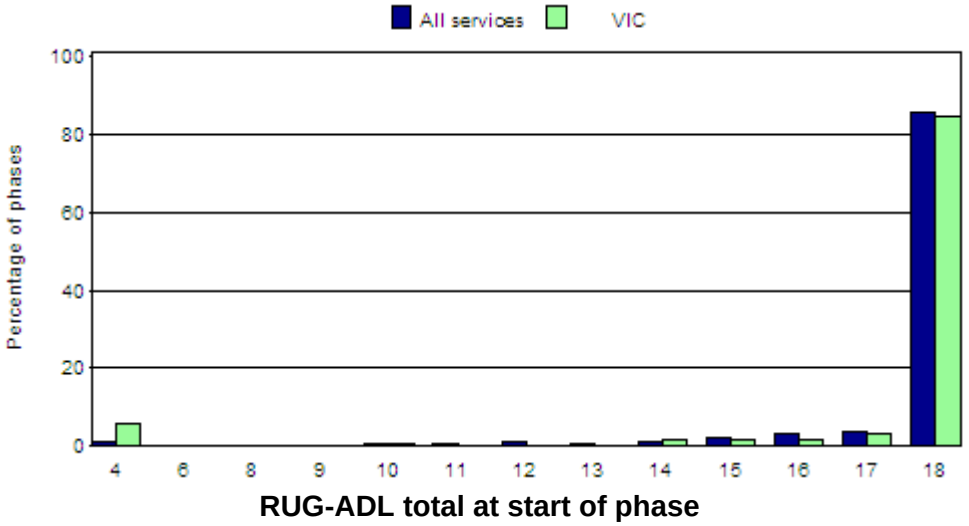
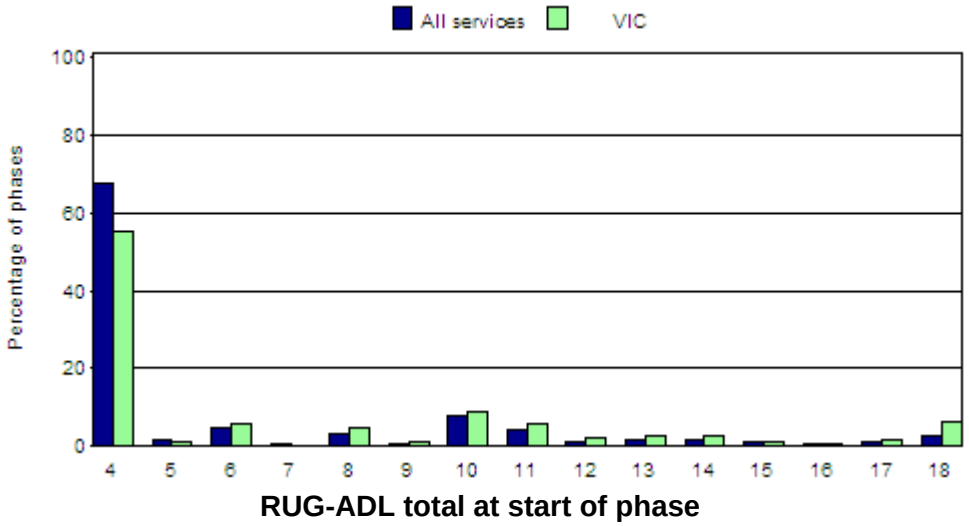
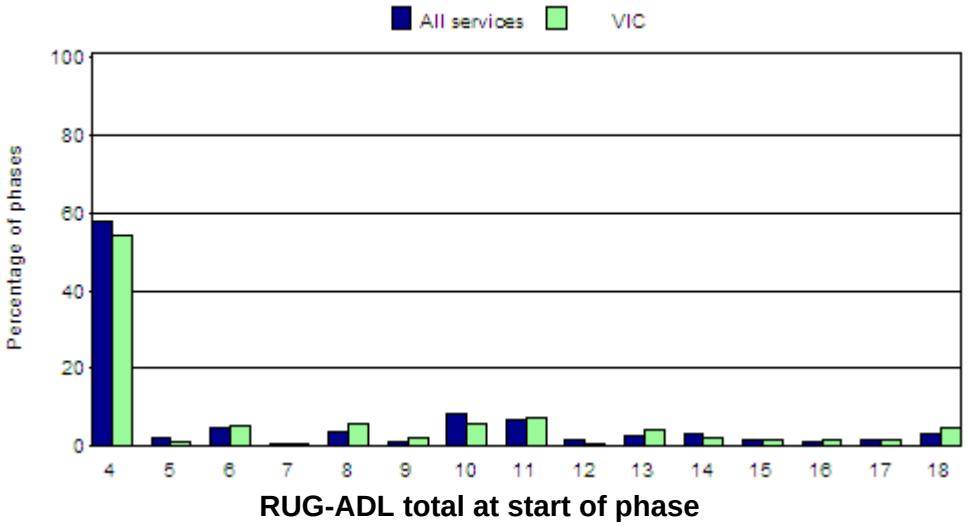


Figure 2 Total RUG-ADL at beginning of phase – patients not admitted overnight

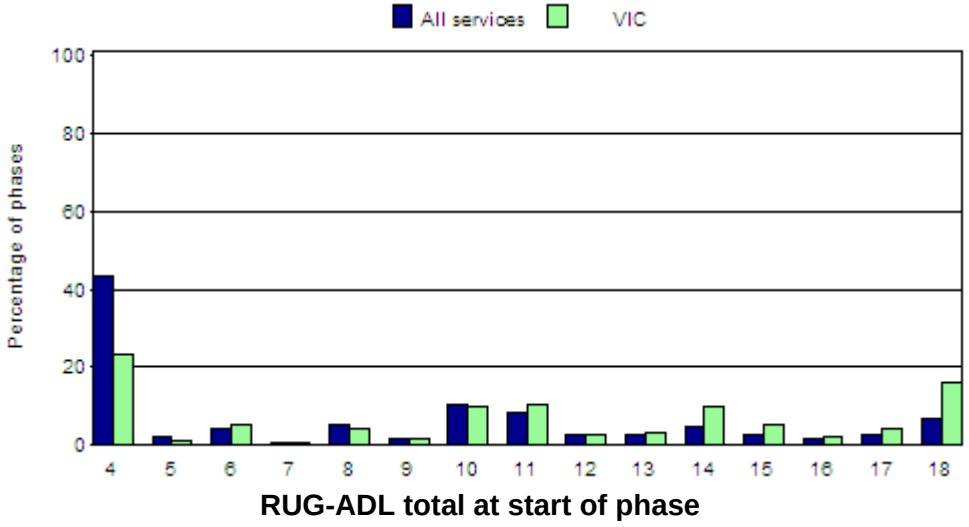
Stable Phase



Unstable Phase



Deteriorating Phase



Terminal Phase

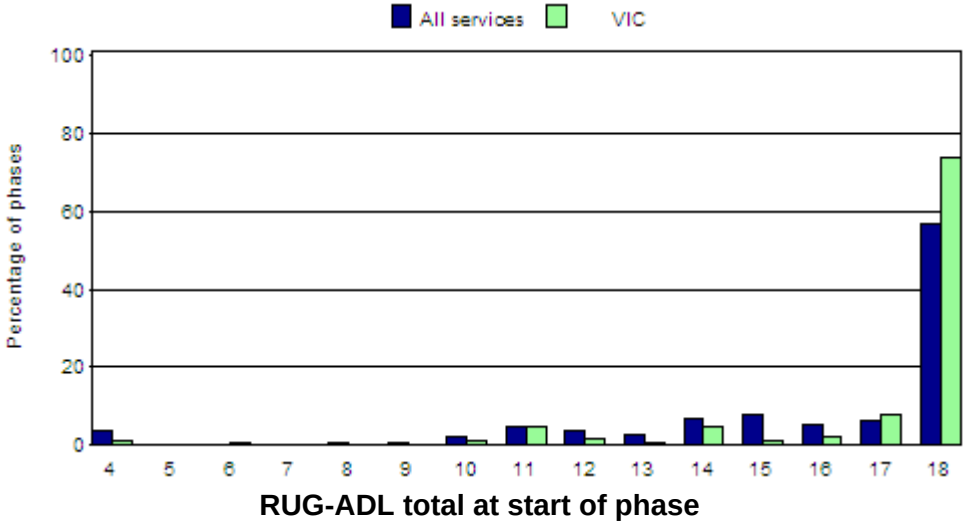


Table 21 Profile of PC Problem Severity Scores (percentages) at beginning of phase by phase type - overnight admitted patients

Phase	Problem severity	VIC				All services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	49.6	32.6	13.8	4.0	33.8	43.6	18.4	4.3
	Other Symptom	20.6	48.9	24.1	6.5	14.1	43.4	31.5	11.0
	Psychological/Spiritual	27.8	45.1	19.5	7.6	19.6	47.5	23.4	9.6
	Family/Carer	39.2	35.8	15.6	9.4	26.8	40.4	21.8	11.0
Unstable	Pain	33.6	24.4	28.9	13.1	18.8	27.6	33.1	20.4
	Other Symptom	7.4	33.6	42.9	16.2	5.7	21.1	42.6	30.6
	Psychological/Spiritual	14.2	44.0	30.4	11.4	9.9	34.3	33.5	22.3
	Family/Carer	33.0	30.7	22.4	13.8	16.1	30.2	30.9	22.8
Deteriorating	Pain	40.4	28.9	20.4	10.4	24.6	33.3	27.4	14.6
	Other Symptom	8.1	33.0	38.0	20.9	6.4	20.9	39.3	33.3
	Psychological/Spiritual	17.4	41.8	28.4	12.5	12.1	33.3	32.7	21.9
	Family/Carer	20.7	34.4	27.7	17.2	14.1	27.1	34.1	24.7
Terminal	Pain	39.5	30.1	19.4	11.0	31.1	31.1	22.3	15.5
	Other Symptom	19.1	25.7	29.1	26.2	17.0	22.0	26.5	34.5
	Psychological/Spiritual	37.7	26.4	20.9	14.9	30.5	27.2	21.8	20.5
	Family/Carer	16.2	27.7	28.5	27.5	10.3	24.1	31.2	34.3

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

Phase	Problem severity	VIC				All services			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	32.5	52.8	13.1	1.6	35.3	50.7	12.5	1.6
	Other Symptom	15.0	58.6	23.6	2.9	15.0	55.7	26.0	3.3
	Psychological/Spiritual	23.6	54.1	19.3	3.0	24.8	51.1	20.7	3.4
	Family/Carer	20.7	42.9	30.5	5.9	23.6	44.5	26.9	5.1
Unstable	Pain	15.4	31.1	36.5	17.0	16.7	29.7	36.2	17.4
	Other Symptom	7.3	32.4	46.9	13.3	5.2	24.9	51.0	18.9
	Psychological/Spiritual	14.3	47.2	33.9	4.6	11.6	38.1	40.1	10.2
	Family/Carer	18.2	33.5	35.9	12.4	12.8	30.4	40.3	16.5
Deteriorating	Pain	23.5	46.9	23.3	6.3	25.3	42.2	25.5	6.9
	Other Symptom	3.4	35.8	46.3	14.5	3.3	30.7	49.7	16.3
	Psychological/Spiritual	11.9	48.9	30.5	8.7	12.8	43.7	35.1	8.3
	Family/Carer	6.5	36.0	40.1	17.3	10.2	33.5	40.6	15.8
Terminal	Pain	23.2	45.2	22.6	8.9	29.8	39.5	22.9	7.8
	Other Symptom	17.2	36.2	24.5	22.1	17.5	29.5	31.2	21.8
	Psychological/Spiritual	34.4	40.6	13.8	11.3	30.1	34.8	24.2	10.9
	Family/Carer	8.2	27.6	40.0	24.1	6.9	25.9	41.2	25.9

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

Phase	Symptom Assessment Score	Overnight admitted		Not admitted overnight	
		VIC	All services	VIC	All services
Stable	Insomnia	1.0	1.6	1.5	1.6
	Appetite	2.4	2.7	2.9	2.6
	Nausea	0.6	0.9	0.7	0.8
	Bowels	1.2	1.9	1.3	1.4
	Breathing	1.3	1.6	1.6	1.7
	Fatigue	4.0	4.4	4.1	4.4
	Pain	1.4	2.3	1.8	1.8
Unstable	Insomnia	1.4	2.6	2.2	2.7
	Appetite	3.5	4.1	4.1	4.1
	Nausea	1.3	2.0	1.7	1.8
	Bowels	1.8	3.1	1.8	2.2
	Breathing	1.8	2.5	2.2	2.3
	Fatigue	5.3	5.6	5.4	5.8
	Pain	2.7	4.0	3.6	3.7
Deteriorating	Insomnia	1.3	2.0	1.9	1.9
	Appetite	3.4	4.0	4.0	3.7
	Nausea	1.0	1.5	1.5	1.1
	Bowels	1.8	2.9	1.7	1.7
	Breathing	1.8	2.8	2.4	2.3
	Fatigue	5.6	5.9	5.9	5.9
	Pain	2.5	3.4	2.5	2.4

Continued...

Phase	Symptom Assessment Score	Overnight admitted		Not admitted overnight	
		VIC	All services	VIC	All services
Terminal	Insomnia	0.4	0.8	1.2	1.4
	Appetite	1.8	2.3	4.5	4.0
	Nausea	0.4	0.7	1.1	0.8
	Bowels	1.4	2.0	1.4	1.4
	Breathing	2.8	3.2	2.3	2.6
	Fatigue	3.8	4.2	6.7	6.4
	Pain	2.2	2.7	2.6	2.2

Table 24 Karnofsky score at phase start by episode type

Karnofsky score	Overnight admitted				Not admitted overnight			
	VIC	%	All Services	%	VIC	%	All Services	%
Comatose or barely rousable	233	10.1	1820	10.1	68	3.3	281	3.5
Totally bedfast and requiring extensive nursing care	462	20.0	3477	19.3	191	9.2	699	8.6
Almost completely bedfast	214	9.3	1743	9.7	158	7.6	449	5.5
In bed more than 50% of the time	407	17.6	2583	14.3	236	11.4	725	8.9
Requires considerable assistance	517	22.4	3113	17.3	507	24.4	1637	20.1
Requires occasional assistance	329	14.2	2206	12.3	457	22.0	1865	22.9
Cares for self	101	4.4	737	4.1	241	11.6	1276	15.7
Normal activity with effort	34	1.5	291	1.6	99	4.8	663	8.1
Able to carry on normal activity; minor signs or symptoms	9	0.4	97	0.5	33	1.6	232	2.8
Normal; no complaints; no evidence of disease	1	0.0	4	0.0	0	0.0	13	0.2
Not stated/inadequately described	5	0.2	1934	10.7	87	4.2	304	3.7
Total	2312	100.0	18005	100.0	2077	100.0	8144	100.0

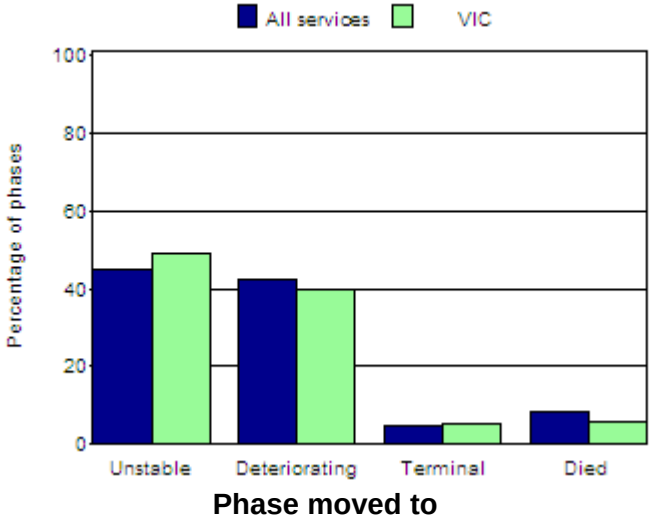
Note: Bereavement phase and records where Karnofsky was 0 (dead) are excluded from the table.

Table 25 Reason for phase end by phase and episode type

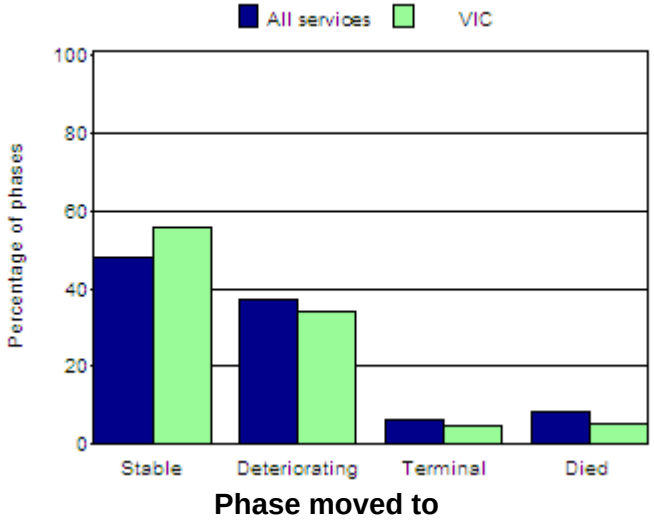
Phase	Phase end reason	Overnight admitted				Not admitted overnight			
		VIC	%	All services	%	VIC	%	All services	%
Stable	Phase change	407	60.9	2208	49.7	217	26.9	1388	50.3
	Discharge/case closure	240	35.9	2099	47.2	189	23.4	827	30.0
	Died	20	3.0	125	2.8	22	2.7	153	5.5
	Bereavement phase end	0	0.0	0	0.0	0	0.0	0	0.0
	Not stated/inadequately described	1	0.1	15	0.3	380	47.0	390	14.1
	Total	*668*	*100.0*	*4447*	*100.0*	*808*	*100.0*	*2758*	*100.0*
Unstable	Phase change	597	85.8	4604	79.3	241	46.9	1126	64.2
	Discharge/case closure	62	8.9	737	12.7	106	20.6	390	22.2
	Died	37	5.3	377	6.5	12	2.3	76	4.3
	Bereavement phase end	0	0.0	5	0.1	0	0.0	0	0.0
	Not stated/inadequately described	0	0.0	86	1.5	155	30.2	162	9.2
	Total	*696*	*100.0*	*5809*	*100.0*	*514*	*100.0*	*1754*	*100.0*
Deteriorating	Phase change	411	72.1	3131	66.4	152	26.2	1365	47.1
	Discharge/case closure	39	6.8	593	12.6	127	21.9	980	33.8
	Died	119	20.9	967	20.5	59	10.2	303	10.5
	Bereavement phase end	1	0.2	12	0.3	0	0.0	1	0.0
	Not stated/inadequately described	0	0.0	13	0.3	243	41.8	247	8.5
	Total	*570*	*100.0*	*4716*	*100.0*	*581*	*100.0*	*2896*	*100.0*
Terminal	Phase change	40	10.4	285	9.2	2	1.1	139	17.2
	Discharge/case closure	4	1.0	75	2.4	12	6.9	45	5.6
	Died	338	88.3	2706	87.6	78	44.6	539	66.9
	Bereavement phase end	1	0.3	18	0.6	0	0.0	0	0.0
	Not stated/inadequately described	0	0.0	6	0.2	83	47.4	83	10.3
	Total	*383*	*100.0*	*3090*	*100.0*	*175*	*100.0*	*806*	*100.0*

Figure 3 Phase progression by phase - all phases

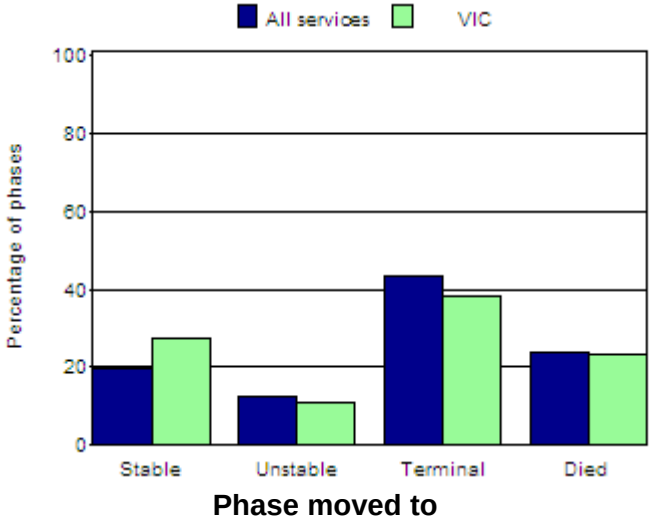
Stable Phase



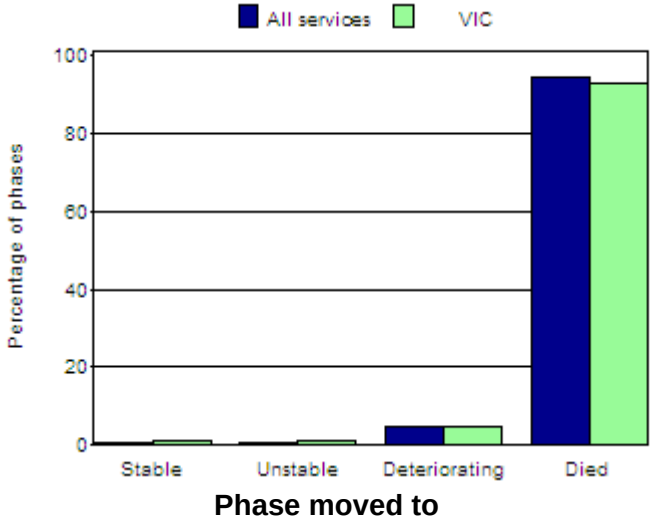
Unstable Phase



Deteriorating Phase



Terminal Phase



Benchmark Measure 1 - Time from referral to first contact

Table 26 and Figures 4 and 5 below present descriptive data on the first benchmark measure. This measure is the percentage of patients seen 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.

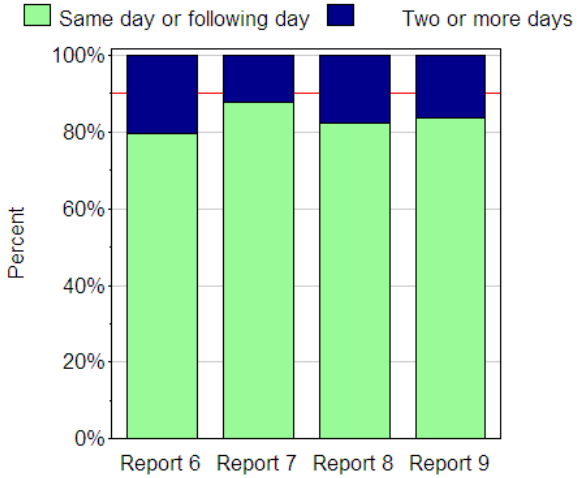
Table 26 Time from referral to first contact by episode type

Time (in days)	Overnight admitted patients				Patients not admitted overnight			
	VIC	%	All Services	%	VIC	%	All Services	%
Same day or following day	770	83.8	6957	89.2	693	62.3	2188	61.6
2-7 days	126	13.7	682	8.7	246	22.1	855	24.1
8-14 days	12	1.3	94	1.2	100	9.0	281	7.9
Greater than 14 days	11	1.2	70	0.9	73	6.6	228	6.4
Average	1.5	na	1.3	na	2.7	na	2.6	na
Median	1	na	1	na	1	na	1	na

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

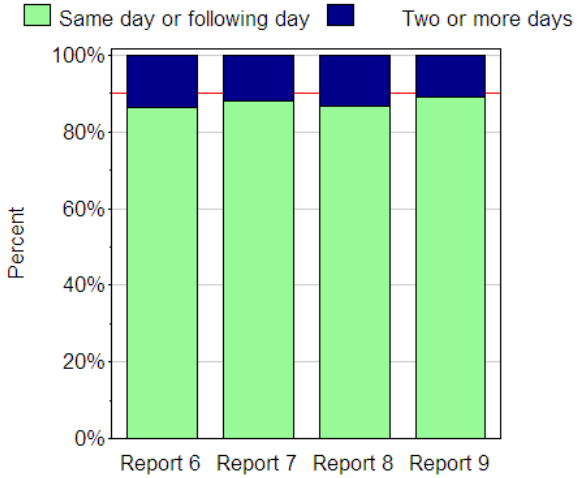
Figure 4 Time from referral to first contact - overnight admitted patients

VIC



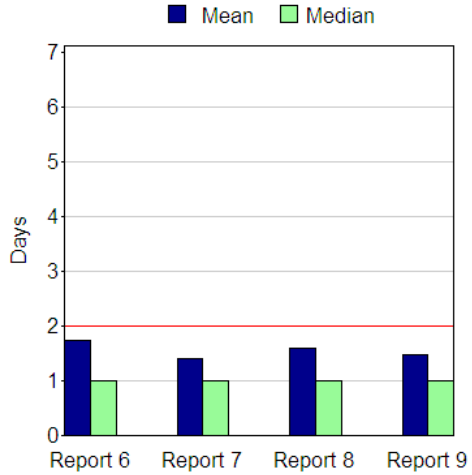
Time from referral to first contact

All services



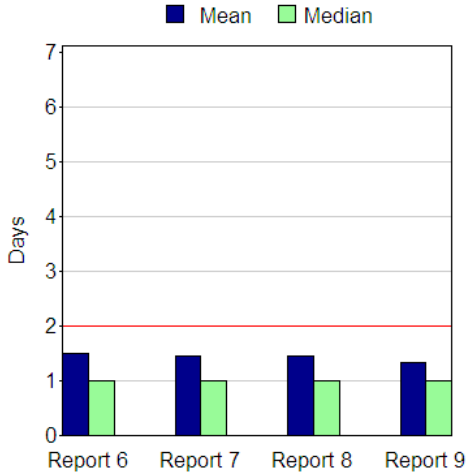
Time from referral to first contact

VIC



Mean and median time from referral to first contact

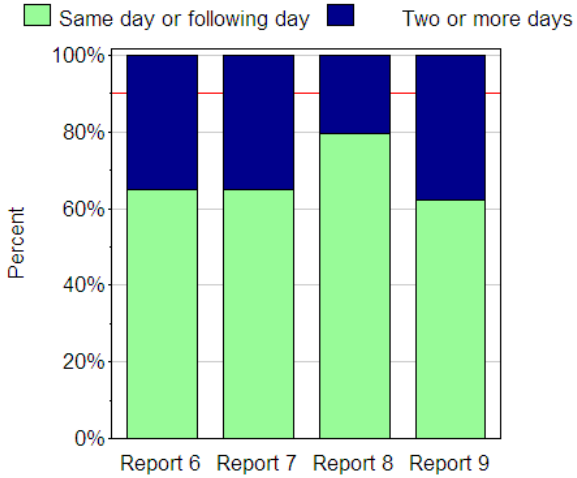
All services



Mean and median time from referral to first contact

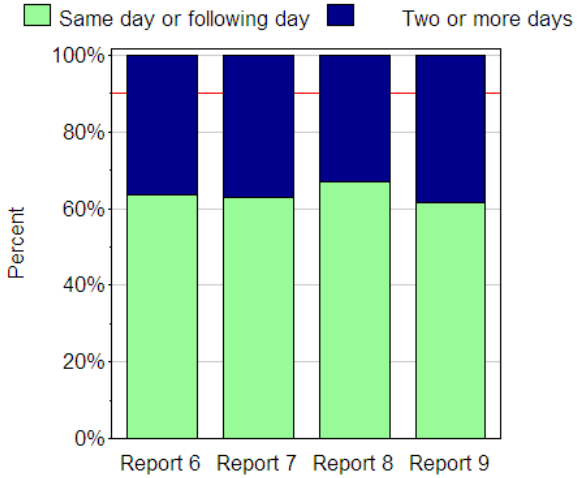
Figure 5 Time from referral to first contact - patients not admitted overnight

VIC



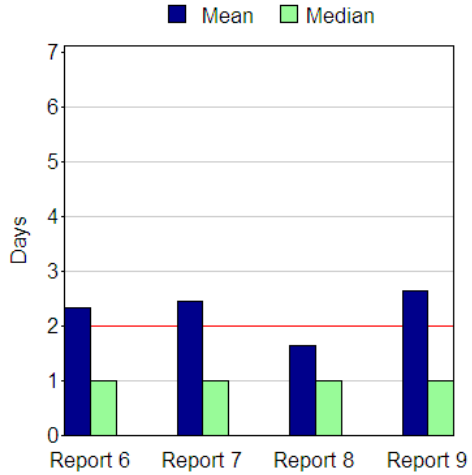
Time from referral to first contact

All services



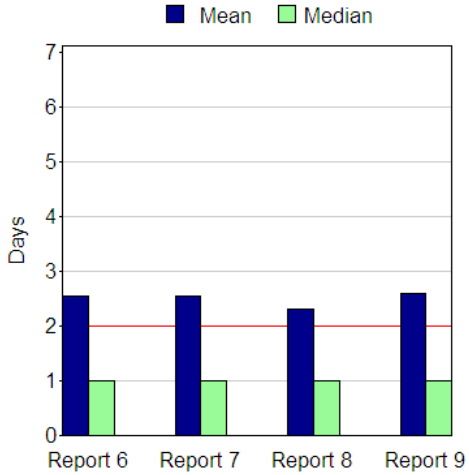
Time from referral to first contact

VIC



Mean and median time from referral to first contact

All services



Mean and median time from referral to first contact

Benchmark Measure 2 - Time in unstable phase

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

Table 27 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	
		VIC	All Services	VIC	All Services	VIC	All Services
Overnight admitted	First phase	389	4197	83.0	71.8	2	3
	Subsequent phase	307	1612	89.9	82.0	2	2
	Total	*696*	*5809*	*86.1*	*74.7*	*2*	*3*
Not admitted overnight	First phase	295	864	43.7	44.9	7	8
	Subsequent phase	219	890	51.6	60.3	6	4
	Total	*514*	*1754*	*47.1*	*52.7*	*7*	*6*

Benchmark Measure 3 - Change in pain

Change in pain PC Problem Severity Score (PCPSS)

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

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

Episode type		VIC				All Services			
		Report 6	Report 7	Report 8	Report 9	Report 6	Report 7	Report 8	Report 9
Overnight admitted	Number	345	758	630	771	1650	2485	2166	2860
	%	83.9	83.7	75.5	78.9	79.5	82.3	75.9	79.0
Not admitted overnight	Number	10	455	515	554	607	1201	1336	1441
	%	83.3	83.9	76.6	77.4	82.4	79.1	77.1	75.8

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

Episode type		VIC				All Services			
		Report 6	Report 7	Report 8	Report 9	Report 6	Report 7	Report 8	Report 9
Overnight admitted	Number	97	201	234	257	731	1024	1031	1257
	%	49.5	39.4	52.9	56.0	36.7	38.1	40.8	44.0
Not admitted overnight	Number	11	83	148	199	122	270	382	485
	%	84.6	45.1	56.9	61.8	31.4	38.1	54.0	55.7

Change in pain Symptom Assessment Score (SAS)

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

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

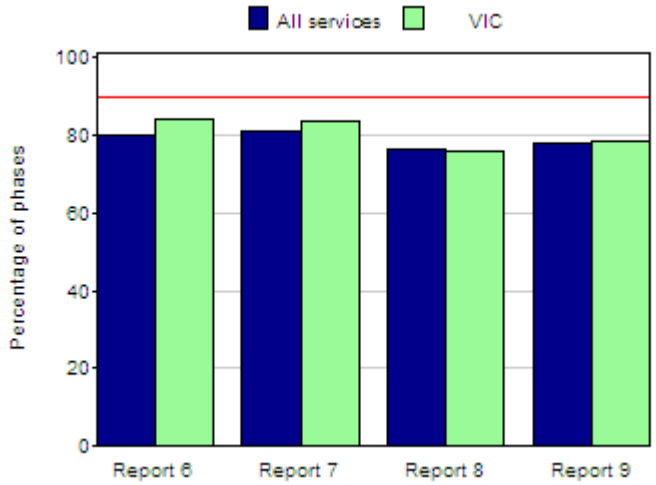
Episode type		VIC				All Services			
		Report 6	Report 7	Report 8	Report 9	Report 6	Report 7	Report 8	Report 9
Overnight admitted	Number	303	718	649	728	1771	3107	2950	3370
	%	80.6	82.2	78.9	80.5	80.4	82.4	76.7	79.8
Not admitted overnight	Number	268	389	486	511	3696	2624	2008	1978
	%	77.7	78.3	72.1	77.5	83.3	81.6	76.8	78.2

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

Episode type		VIC				All Services			
		Report 6	Report 7	Report 8	Report 9	Report 6	Report 7	Report 8	Report 9
Overnight admitted	Number	95	208	199	185	843	1235	1339	1453
	%	42.8	40.8	46.8	51.2	38.9	41.2	41.0	41.3
Not admitted overnight	Number	70	107	177	158	625	552	598	591
	%	55.6	48.0	60.0	60.5	38.6	40.4	50.1	53.1

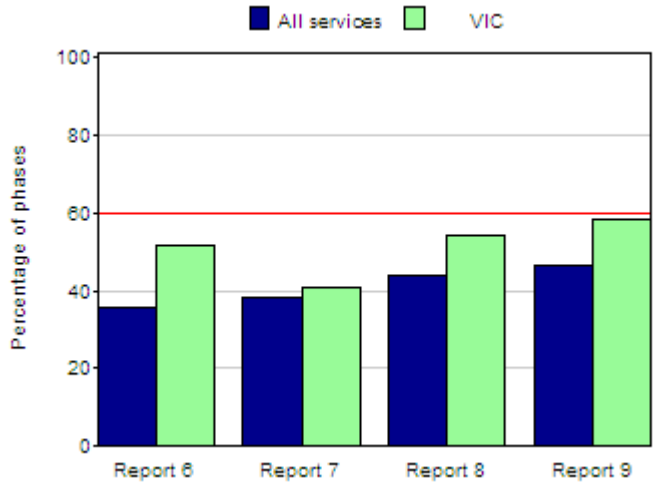
Figure 6 Change in pain benchmark measures - all phases

Pain PCPSS



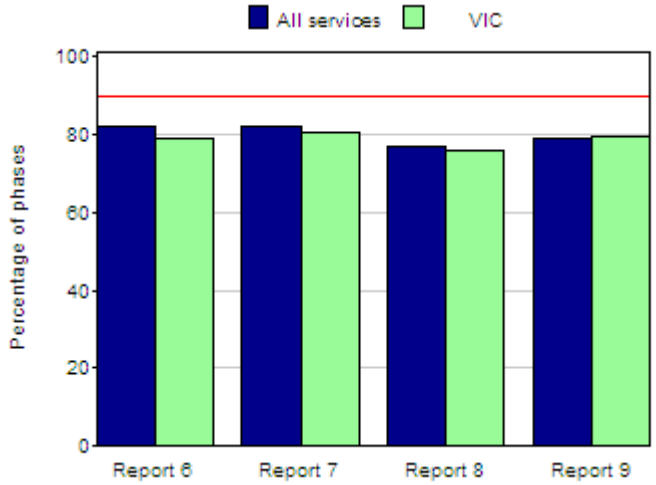
Absent/mild pain at both start and end of phase

Pain PCPSS



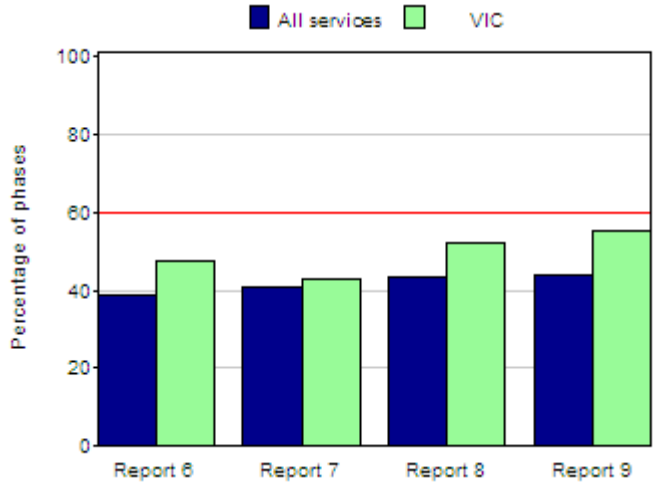
Mod/severe pain at start with absent/mild pain at end

Pain SAS



Absent/mild pain at both start and end of phase

Pain SAS



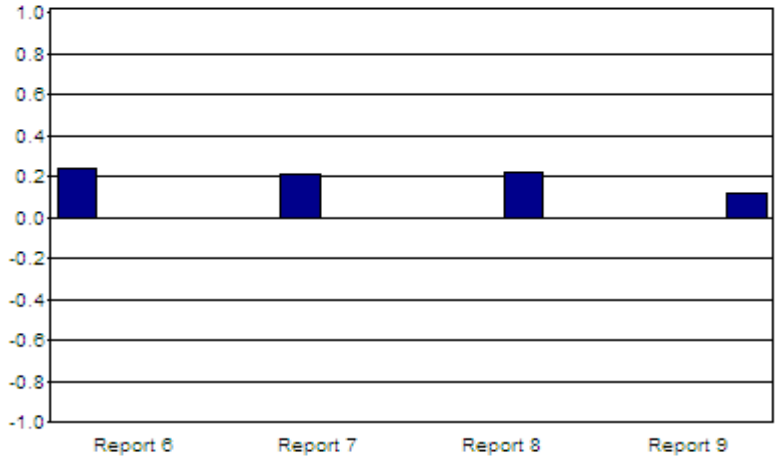
Mod/severe pain at start with absent/mild pain at end

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

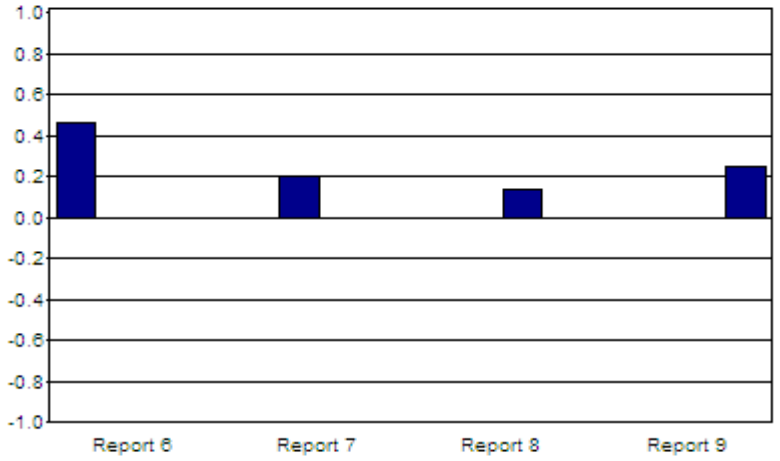
Please refer to the glossary section for a detailed explanation of the following analysis. The benchmark for this measure is 0 or above.

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

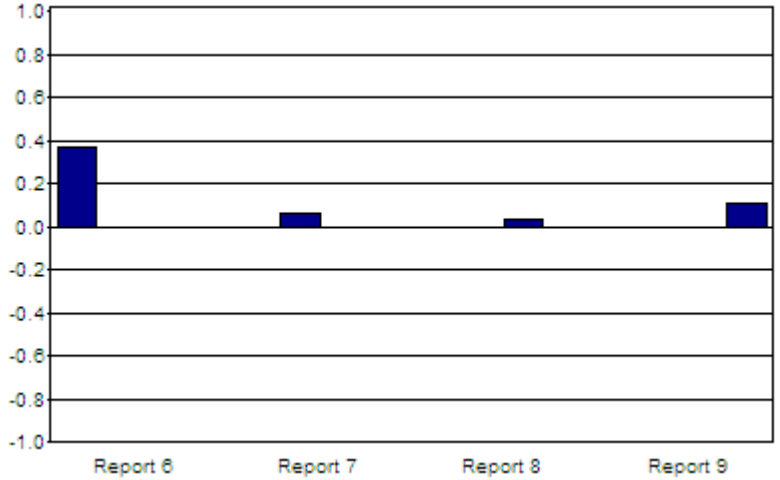
Pain



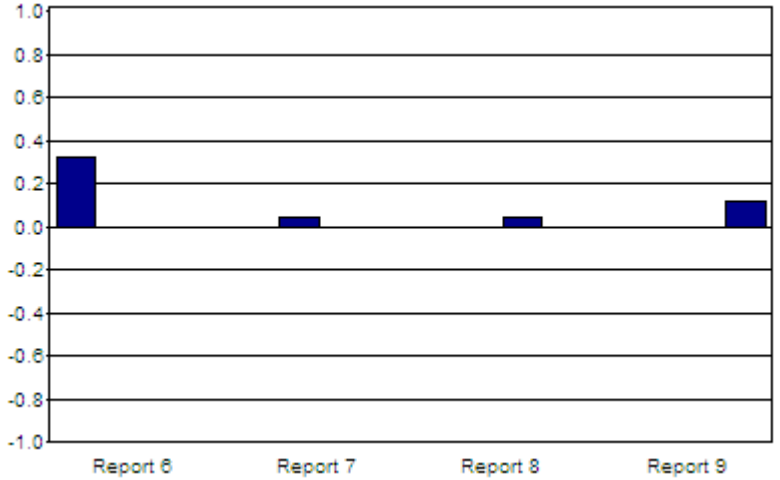
Other symptoms



Family/Carer



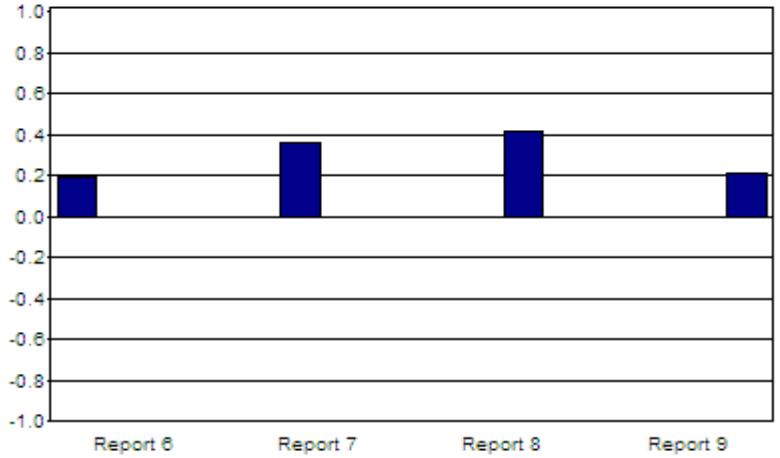
Psychological/spiritual



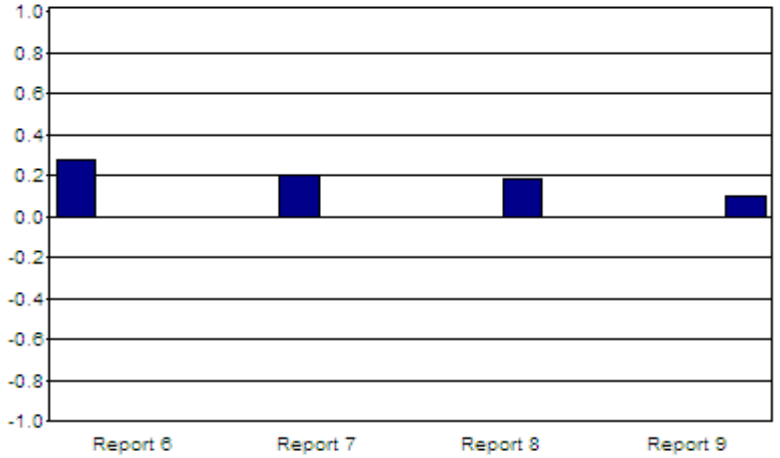
Note: Only services with 10 or more valid observations are included in the above graphs.

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

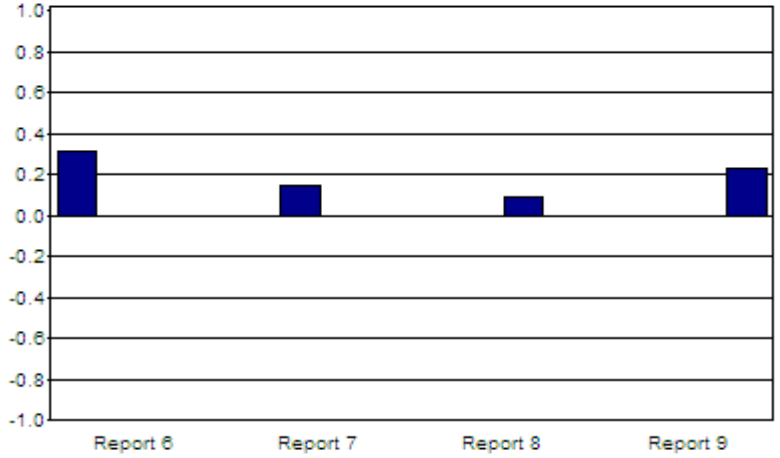
Pain



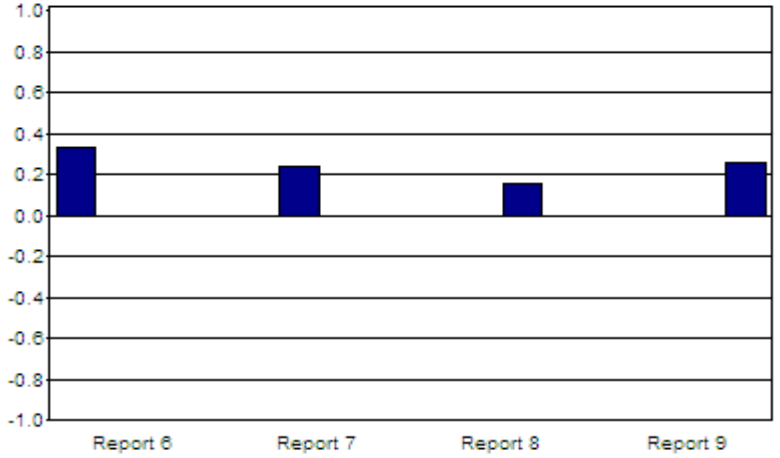
Nausea



Breathing



Bowels



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

Appendix 1 - Services included in this report

This report includes data from the following 95 services:

Table 32 Services providing data

Palliative Care Service	State	Begin date	End date	Months
Baringa Private Hospital	NSW	February 2010	May 2010	4
Calvary Health Care Sydney	NSW	January 2010	June 2010	6
Calvary Health Care Riverina	NSW	January 2010	June 2010	6
Calvary Mater Newcastle	NSW	January 2010	June 2010	6
Camden Hospital	NSW	January 2010	May 2010	5
Coffs Harbour Palliative Care Service	NSW	January 2010	June 2010	6
David Berry Hospital	NSW	January 2010	June 2010	6
Hope Healthcare - Braeside Hospital	NSW	January 2010	June 2010	6
Hope Healthcare - Greenwich Hospital	NSW	January 2010	June 2010	6
Hope Healthcare - Neringah Hospital	NSW	January 2010	June 2010	6
Lourdes Hospital	NSW	January 2010	June 2010	6
Manning Rural Referral Hospital	NSW	January 2010	June 2010	6
Mercy Care Centre - Young	NSW	January 2010	June 2010	6
Mercy Health Service Albury	NSW	January 2010	June 2010	6
Mt Druitt Hospital	NSW	January 2010	June 2010	6
Murwillumbah Community Health Service	NSW	April 2010	June 2010	3
Port Kembla Hospital	NSW	January 2010	June 2010	6
Sacred Heart Palliative Care Service	NSW	January 2010	June 2010	6
St Joseph's Hospital	NSW	January 2010	June 2010	6
St Vincent's Hospital Lismore	NSW	January 2010	June 2010	6
St Vincent's Hospital, Sydney - Palliative Care Consult Service	NSW	January 2010	June 2010	6
Tamworth Base Hospital	NSW	January 2010	June 2010	6

Continued...

Palliative Care Service	State	Begin date	End date	Months
Tweed, Byron, Murwillumbah Community Health Service	NSW	January 2010	June 2010	6
Westmead Hospital	NSW	January 2010	June 2010	6
Banksia Palliative Care Services	Vic	January 2010	June 2010	6
Caritas Christi - Fitzroy	Vic	January 2010	June 2010	6
Caritas Christi - Kew	Vic	January 2010	June 2010	6
Eastern Palliative Care	Vic	March 2010	June 2010	4
Gandarra Palliative Care Unit - Ballarat	Vic	January 2010	June 2010	6
Goulburn Valley Hospice Inc.	Vic	January 2010	June 2010	6
Lower Hume Palliative Care	Vic	January 2010	June 2010	6
Melbourne Citymission Palliative Care	Vic	January 2010	June 2010	6
Mercy Palliative Care - Medical Consultant	Vic	January 2010	June 2010	6
Mercy Palliative Care - Sunshine	Vic	January 2010	June 2010	6
Northern Health Broadmeadows Palliative Care Unit	Vic	January 2010	June 2010	6
Northern Health Palliative Care Consult Team	Vic	March 2010	June 2010	4
Peter MacCallum Cancer Centre	Vic	April 2010	June 2010	3
Royal Melbourne Hospital	Vic	June 2010	June 2010	1
South East Palliative Care	Vic	January 2010	June 2010	6
Sunraysia Community Palliative Care Service Clinic	Vic	January 2010	May 2010	5
Werribee Mercy Hospital	Vic	January 2010	June 2010	6
Western Health - Community	Vic	February 2010	May 2010	4
Bundaberg Palliative Access	Qld	January 2010	June 2010	6
Cairns and Gordonvale Hospital	Qld	January 2010	June 2010	6
Caloundra Hospital	Qld	January 2010	June 2010	6
Canossa Private Hospital	Qld	January 2010	June 2010	6
Gladstone Hospital	Qld	January 2010	June 2010	6
Gympie Hospital	Qld	January 2010	June 2010	6
Hervey Bay & Fraser Coast Palliative Care Service	Qld	January 2010	June 2010	6
Hopewell Hospice	Qld	January 2010	June 2010	6

Continued...

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

Continued...

Palliative Care Service	State	Begin date	End date	Months
Southern Adelaide Palliative Services	SA	January 2010	June 2010	6
Stirling District Hospital	SA	January 2010	June 2010	6
Yorke Peninsula Palliative Care	SA	January 2010	June 2010	6
Albany Palliative Care Service	WA	January 2010	January 2010	1
Bethesda Hospital	WA	January 2010	May 2010	5
Geraldton Palliative Care Community Service	WA	January 2010	June 2010	6
Northam Palliative Care	WA	January 2010	June 2010	6
Peel Community Palliative Care Service	WA	January 2010	February 2010	2
Royal Perth Hospital	WA	January 2010	June 2010	6
Silver Chain Hospice Care Service	WA	January 2010	June 2010	6
St John of God Hospital - Bunbury	WA	January 2010	April 2010	4
St John of God Hospital - Geraldton	WA	January 2010	June 2010	6
St John of God Murdoch Community Hospice	WA	January 2010	June 2010	6
St John of God Subiaco	WA	January 2010	June 2010	6
Calvary Health Care Tasmania - St John's	Tas	January 2010	May 2010	5
JW Whittle Palliative Care Unit	Tas	January 2010	June 2010	6
Calvary Health Care Canberra (Clare Holland House)	ACT	January 2010	June 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 VIC and for all services has been calculated. Consistency refers to completion of data items used within this report with valid entries based on the PCOC version 2 item codes.

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

Table 33 Data consistency - patient level items

Data item	VIC	All Services
	% Complete	% Complete
Date of birth	100.0	100.0
Sex	99.9	99.9
Indigenous status	87.4	95.6
Country of birth	83.8	93.2
Main language	87.1	93.5
Primary diagnosis	97.8	94.7

Table 34 Data consistency - episode level items

Data item	VIC	All Services
	% Complete	% Complete
Date of first contact/assessment	98.6	92.8
Referral date	99.8	88.4
Referral source	85.5	92.7
Episode start date	100.0	100.0
Mode of episode start	92.5	96.6
Accommodation at episode start	94.8	92.5
Episode end date	99.9	99.2
Level of support at episode start	98.2	76.8
Mode of episode end	93.5	96.3
Accommodation at episode end	80.1	80.7
Level of support at episode end	90.8	93.3
Place of death	98.5	89.1

Table 35 Data consistency - phase level items

Data item	Sub-Category (where applicable)	VIC %Complete	All Services %Complete
Phase start date		100.0	100.0
Phase		100.0	100.0
RUG-ADL at phase start	Bed Mobility	87.5	96.1
	Toileting	87.6	96.0
	Transfers	87.6	97.1
	Eating	87.5	95.3
PC Problem Severity at phase start	Pain	97.6	69.4
	Other Symptom	96.1	74.5
	Psychological/Spiritual	97.0	87.7
	Family/Carer	97.4	86.1
Symptom Assessment Score at phase start	Insomnia	84.0	84.7
	Appetite	87.0	84.8
	Nausea	82.7	84.7
	Bowels	84.3	84.8
	Breathing	84.1	84.3
	Fatigue	87.8	84.7
	Pain	86.2	84.7
Phase end reason		80.2	96.0
Karnofsky at phase start		97.9	91.8

Appendix 3 – Glossary

Overnight admitted and not admitted overnight groups

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

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

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

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

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

Episode of care

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

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

An episode of palliative care ends when:

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

Phase of care

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

Phase 1: Stable

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

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

Phase 2: Unstable

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

Phase 3: Deteriorating

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

Phase 4: Terminal

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

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

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

Phase 5: Bereaved

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

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

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

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

PC Problem Severity Score (PCPSS)

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

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

Each item is given a score from 0-3:

0 =Absent

1 = Mild

2= Moderate

3 = Severe

Karnofsky (Australian) Performance Scale

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

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

Symptom Assessment Scale (SAS)

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

Change in symptoms relative to the national average

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

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

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

Your service is then able to see if you are doing the same, better or worse than the national average for similar patients. The baseline period for calculating the national averages is July-December 2008 (report 6 period) and this will remain as such 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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- The PCOC Quality Improvement Facilitators for working closely with services to support the data collection and data quality improvement processes
- The Australian Government Department of Health and Ageing for their funding of this initiative

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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