Patient Outcomes in Palliative Care for South Australia

July to December 2015

PCOC is a national palliative care project funded by the Australian Government Department of Health
The Palliative Care Outcomes Collaboration (PCOC) wishes to acknowledge the valuable contribution made by the many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible.

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If you would like more information, a detailed state report is available on the PCOC website www.pcoc.org.au.

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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 this report. We would advise readers to use their professional judgement in considering all information contained in this report.

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Patient outcomes in Palliative Care for South Australia, July – December 2015
In **July to December 2015** there were **12** specialist palliative care services in **South Australia** that submitted data to PCOC.

Of these:

1. was an inpatient only services
2. 8 were community only services and
3. 3 were both inpatient and community

Combined, these services provided **1,803** episodes of care to **1,299** patients.

69% of care occurred in the home or aged care facilities.

84% of patients had a malignant diagnosis.

During this period **594** patients died.

Of these, **54%** died in hospital.

There are **4** outcome measurement areas. These are:

1. benchmark on **timeliness of care** that **11** services* have met
2. benchmark on **responsiveness to urgent needs** that **5** services* have met
3. **4** benchmarks on **pain management** where **7** services* have met at least one benchmark
4. **8** benchmarks on **symptom management** where **11** services* have met at least one benchmark

*Service providers with an inpatient and community setting are counted twice

For more information, a detailed South Australian state report is available at [www.pcoc.org.au](http://www.pcoc.org.au)
Section 1 - Introduction

The Palliative Care Outcomes Collaboration (PCOC) is a voluntary program partnering with palliative care services from across Australia to improve patient outcomes through benchmarking. There are 14 South Australian palliative care services participating in PCOC. Of these, 12 submitted information for the July to December 2015 reporting period. These 12 services include:

- 1 inpatient palliative care service. Inpatient services include patients who have been seen in designated palliative care beds as well as non-designated bed (in-reach and consultative).
- 8 community palliative care services (in the home or residential aged care facility).
- 3 palliative care services which provide both inpatient and community care.

The information contained in this report is based on 1,299 patients that were seen by South Australian services participating in PCOC during the reporting period July to December 2015. This report contains some national figures and South Australian figures from previous reporting periods for comparative purposes. Figure 1 summarises the volume of information included in South Australia’s six monthly reports produced by PCOC between 2013 and 2015. Data for January to June 2013 has not been included in this report due to an insufficient number of services submitting data to PCOC in this reporting period.

In July – December 2015:

South Australian community services provided 1,248 (69%) episodes of care for 1,024 patients

South Australian inpatient services provided 555 (31%) episodes of care for 462 patients
Service locations

Figure 2 shows the location of South Australian services that submitted data for the July to December 2015 reporting period. There were four services located in major cities, four services located in inner regional areas and four services located in outer regional areas. For a full list of services in South Australia that have contributed data since January 2013, please see Appendix A.

In July – December 2015:

- 4 services are located in major cities
- 4 services are located in inner regional areas
- 4 services are located in outer regional areas
Section 2 – Outcome measures

Timely admission to service

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care.

**Benchmark 1:** 90% of patients must have their episode commence on the day of, or the day after date ready for care.

In July – December 2015:

- **96.0%** of patients in the inpatient setting had their episode commence the day of or day after date ready for care.
- **86.2%** of patients in the community setting had their episode commence the day of or day after date ready for care.

For the current report period, three inpatient services and eight community services met this benchmark (Figure 4).

![Figure 3 Percentage of patients with episodes that commenced the day of or the day after the date ready for care – over time](image)

![Figure 4 National service profile for benchmark 1, July to December 2015](image)
Responsiveness to urgent needs

The unstable phase alerts clinical staff to the need for urgent changes to the patient’s plan of care or that emergency intervention is required. Patients assessed to be in the unstable phase require intense review for a short period of time.

**Benchmark 2: 90% of unstable phases must last for 3 days or less.**

In July – December 2015:

- **88.1%** of unstable phases in the inpatient setting were 3 days or less.
- **76.8%** of unstable phases in the community setting were 3 days or less.

For the current report period, two inpatient services and three community services met this benchmark (Figure 6).

![Figure 5 Percentage of unstable phases lasting 3 days or less – over time](image)

![Figure 6 National service profile for benchmark 2, July to December 2015](image)
Pain management

Pain management is acknowledged as a core business of palliative care services. The PCPSS is clinician rated and measures the severity of pain as a clinical problem. The change in pain is measured from the start of a phase to the end of the same phase. There are two benchmarks associated with this tool.

**Benchmark 3.1:** 90% of patients with absent or mild pain* at the beginning of their phase of palliative care have absent or mild pain* at the end of the phase.

In July – December 2015:

- **88.5%** of patients in the inpatient setting had absent or mild pain* at phase start, remaining absent or mild at phase end.
- **82.8%** of patients in the community setting had absent or mild pain* at phase start, remaining absent or mild at phase end.

*pain as measured by the PCPSS tool

For the current report period, one inpatient service and two community services met this benchmark (Figure 8).

![Figure 7](image-url) Percentage of patients with absent or mild pain* at phase start, remaining absent or mild at phase end - over time

![Figure 8](image-url) National service profile for benchmark 3.1, July to December 2015
**Benchmark 3.2:** 60% of patients with moderate or severe pain* at the beginning of their phase of palliative care have absent or mild pain* at the end of the phase.

In July – December 2015:

- **58.6%** of patients in the **inpatient** setting had moderate or severe pain* at phase start, with absent or mild pain* at phase end.

- **50.0%** of patients in the **community** setting had moderate or severe pain* at phase start, with absent or mild pain* at phase end.

*pain as measured by the PCPSS tool

For the current report period, two inpatient services and four community services met this benchmark (Figure 10).
The Symptom Assessment Scale (SAS) is primarily patient rated and measures distress caused by pain. The change in distress from pain is measured from the start of a phase to the end of the same phase. There are two benchmarks associated with this tool.

**Benchmark 3.3:** 90% of patients with absent or mild distress from pain** at the beginning of their phase of palliative care have absent or mild distress from pain** at the end of the phase.

In July – December 2015:

- **83.2%** of patients in the inpatient setting had absent or mild distress from pain** at phase start, remaining absent or mild at phase end.

- **77.9%** of patients in the community setting had absent or mild distress from pain** at phase start, remaining absent or mild at phase end.

**pain as measured by the SAS tool**

For the current report period, no inpatient services and one community service met this benchmark (Figure 12).
**Benchmark 3.4:** 60% of patients with moderate or severe distress from pain** at the beginning of their phase of palliative care have absent or mild distress from pain** at the end of the phase.

In July – December 2015:

- **51.0%** of patients in the **inpatient** setting had moderate or severe distress from pain** at phase start, with absent or mild pain* at phase end.

- **39.0%** of patients in the **community** setting had moderate or severe distress from pain** at phase start, with absent or mild pain* at phase end.

**pain as measured by the SAS tool**

For the current report period, no inpatient services and no community services met this benchmark (Figure 14).
Case-mix adjusted symptoms and problems

This outcome measure includes a suite of case-mix adjusted scores used to compare the change in symptoms and problems for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms and problems are included in this report and the baseline reference period is January to June 2014. The following graphs show the proportion of patient phases at or above the national average baseline.

**Figure 15** Percentage of patients at or above the national average baseline over time - PCPSS

**Figure 16** Percentage of patients at or above the national average baseline over time - SAS
Section 3 – Patient demographics

For the current reporting period, there were 1,299 patients in South Australia, who between them had 1,803 episodes of care and 3,192 palliative care phases. The community setting provided 1,248 (69.2%) episodes of care and the inpatient setting provided 555 (30.8%) episodes of care.

Age and sex

For the current reporting period, the average age for patients in South Australia was 71.8 years and the median was 73 years. Figure 17 shows the distribution of age for males and females in South Australia for the current reporting period.

For the current reporting period, the average age for patients nationally was 71.8 years and the median was 74 years.

In July – December 2015, for SA:

- 57.0% of patients were males
- Average age was 71.8 years
- Median age was 74 years

- 43.0% of patients were females
- Average age was 71.6 years
- Median age was 72 years

NOTE: Age has been calculated at the beginning of the patient’s episode.

Indigenous Status

Of the 1,299 patients in South Australia for the current reporting period, 14 (1.1%) identified as Aboriginal or Torres Strait Islander. This compares to 1.3% of patients nationally across all PCOC services who identified as Aboriginal or Torres Strait Islander.
Diagnosis

In South Australia for the current reporting period, there were 1,087 (83.7%) patients with a malignant diagnosis and 212 (16.3%) patients with a non-malignant diagnosis.

The most common malignant diagnoses in South Australia were lung cancer (n=223), colorectal cancer (n=133) and other gastrointestinal cancers (n=118).

The most common non-malignant diagnoses were respiratory failure (n=50), cardiovascular disease (n=38) and motor neurone disease (n=20).

Figure 18 shows the percentage of malignant and non-malignant diagnosis for South Australia over the past six reporting periods.

Place of death

For the current reporting period, there were a total of 594 deaths in South Australian palliative care services that submit data to PCOC.

Figure 19 shows the percentage of deaths by setting over time for South Australia. In the current reporting period, there were 322 (54.2%) deaths in hospital and 272 (45.8%) in the community.

Nationally, for services that submit data to PCOC, 70.1% of deaths were in the hospital and 29.9% of deaths were in the community.

In July – December 2015, for South Australia:

- 45.8% of deaths occurred in the community
- 54.2% of deaths occurred in hospital
Inpatient setting

For the current reporting period, inpatient services provided 555 episodes of care to patients in South Australia. This represented 30.8% of all PCOC episodes in South Australia.

The average length of these inpatient episodes was 12.3 days and the median was 7 days. Nationally, the average length of inpatient episodes was 10.3 days.

South Australian inpatient services had an average episode length of 12.3 days

How episodes started

In South Australia for the current reporting period, the main referral sources for inpatient palliative care were; community based palliative care services (44.5%), public hospitals (41.1%) and private hospitals (12.6%).

Figure 20 shows the problems and distress from symptoms patients were experiencing on admission to inpatient palliative care units in South Australia for the current reporting period. The symptoms with the highest number of moderate / severe scores were distress from fatigue (51.5%), distress from pain (39.5%), and other symptoms (all symptoms other than pain) (28.2%).

In July – December 2015, for South Australia:

- 380 patients were admitted from the community
- 84 patients were admitted from another hospital
- 83 patients were admitted from acute care on another ward

*as measured by the PCPSS
** as measured by the SAS
How episodes ended

In South Australia, there were 544 inpatients that had their episode of care end in the current reporting period. Of these 322 (59.2%) ended because the patient died and 222 (40.9%) ended because the patient was discharged.

Nationally, for the current reporting period, 53.7% of inpatient episodes ended in death and 46.3% of inpatient episodes ended in discharge.

Figure 21 shows the problems and distress from symptoms patients were experiencing on discharge from inpatient palliative care. There are very few severe scores on discharge. The symptoms with the highest number of absent scores were distress from nausea (79.5%), distress from breathing problems (64.9%), and distress from difficulty sleeping (64.3%).

Top discharge reasons from inpatient care in South Australia:

- 201 patients were discharged to the community
- 15 patients were discharged to another hospital
## Community setting

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. Under this definition, a patient receiving palliative care is likely to have more than one episode of care.

For the current reporting period, community services provided 1,248 episodes of care to patients in South Australia. This represented 69.2% of all PCOC episodes in South Australia.

The average length of these community episodes was 43.4 days and the median was 34 days. Nationally, the average length of community episodes was 37.8 days.

South Australian community services had an average episode length of 43.4 days

## How episodes started

In South Australia for the current reporting period, the main referral sources for community palliative care were; public hospitals (55.9%), general medical practitioners (15.1%) and private hospitals (11.4%).

Figure 22 shows the problems and distress from symptoms patients were experiencing on episode start for community palliative care in South Australia for the current reporting period. The symptoms with the highest number of moderate / severe scores were distress from fatigue (60.4%), other symptoms (all symptoms other than pain) (33.3%) and distress from appetite problems (32.1%).

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Level of distress / problem (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family / carer*</td>
<td>Absent</td>
</tr>
<tr>
<td>Psychological / spiritual*</td>
<td></td>
</tr>
<tr>
<td>Other symptoms*</td>
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<td>Pain*</td>
<td></td>
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<tr>
<td>Pain**</td>
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<td>Fatigue**</td>
<td></td>
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<tr>
<td>Breathing problems**</td>
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<td>Bowel problems**</td>
<td></td>
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<tr>
<td>Nausea**</td>
<td></td>
</tr>
<tr>
<td>Appetite problems**</td>
<td></td>
</tr>
<tr>
<td>Difficulty sleeping**</td>
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</tbody>
</table>

*as measured by the PCPSS
** as measured by the SAS

At the beginning of community episodes:

- 1,116 patients were living in a private residence
- 127 patients were living in residential aged care facilities
How episodes ended

In South Australia, there were 1,135 community patients that had their episode of care end in the current reporting period. Of these 272 (24.0%) ended because the patient / person died and 863 (76.0%) ended because the setting or intent of care changed (discharge).

Nationally, for the current reporting period, 26.6% of community episodes ended because the patient / person died and 73.4% of community episodes ended in discharge.

Figure 23 shows the problems and distress from symptoms patients were experiencing on discharge from community palliative care. The symptom with the most moderate / severe distress was fatigue (61.8%), followed by family / carer problems (47.8%) and other symptoms (all symptoms other than pain) (47.5%).

**Figure 23** Symptom and problem scores on discharge from community palliative care in South Australia, July – December 2015

*as measured by the PCPSS
** as measured by the SAS
NOTE: only patients that are discharged are included in the graph. Symptoms and problems are not measured at death.

Top discharge reasons from community care in South Australia:

- 403 patients were admitted for inpatient acute care
- 279 patients were admitted for inpatient palliative care
Appendix A – List of South Australian services

The following table lists the South Australian services that have been participating in PCOC reporting over the past three years.

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<tbody>
<tr>
<td>Adelaide Hills Community Health Service</td>
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<tr>
<td>Calvary Health Care Adelaide (Mary Potter Hospice)</td>
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<td>Central Adelaide Palliative Service</td>
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<td>Inner North Palliative Care</td>
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<td>Murray Mallee</td>
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<td>Northern Adelaide Palliative Service</td>
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<td>Yorke Peninsula Palliative Care</td>
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Note: grey squares indicated time periods where data was submitted to PCOC by service and included in the national dataset. However, this data is not included in this state report.
Appendix B – Glossary

**Episode**
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. An episode of care ends when either; the patient is formally separated from the current setting of care; the patient dies; or the principal clinical intent of the care changes and the patient is no longer receiving palliative care. Under this definition, a patient receiving palliative care is likely to have more than one episode of care.

**Patient**
PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record. Family / carers are included in this definition if interventions relating to them are recorded in the patient medical record. As a result, if a patient is seen in two different services with different medical record systems they will be counted twice in the total number of patients.

**PCPSS**
Palliative Care Problem Severity Score (PCPSS) is a clinical tool used for initial screening and ongoing coordination of specialist palliative care. Clinician rated, it facilitates the global assessment of four palliative care domains: pain, psychological / spiritual, other symptoms and family / carer.

**Phase**
Palliative care phase identifies a clinically meaningful period in a patient’s condition. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. The phases provide a framework for referrals, triage and care planning.

**SAS**
Symptom Assessment Scale (SAS) describes the patient’s level of distress relating to individual physical symptoms. The symptoms in the scale are the seven most commonly experienced by palliative patients; difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. The instrument is designed to be a patient rated tool but also allows for rating by proxy (e.g. family, carer or clinician).
Appendix C – How to interpret the national profile graphs

The national profile graphs present South Australian services in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. South Australian inpatient services are highlighted as black dots on the graph. South Australian community services are highlighted as grey triangles on the graph.

If the number of dots or triangles does not correspond to the number of services on a particular graph, this means that a service(s) has not met the criteria for inclusion in this measure. This may be caused by insufficient data item completion, or the service not having any data falling into a particular category, for example, no phases starting with moderate or severe pain.

The red line on the graph indicates the benchmark for that outcome measure.

![Figure 24 National service profile for benchmark 1, July to December 2015](image-url)