About the Palliative Care Outcomes Collaboration (PCOC)

PCOC is a unique national program that utilises standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in PCOC is voluntary and assists palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) *Standards for Providing Quality Palliative Care for all Australians*. PCOC is funded under the *National Palliative Care Program* and is supported by the Australian Government Department of Health and Ageing.

PCOC is a collaboration between four centres, each with a Chief Investigator, and is divided into four zones for the purpose of engaging with palliative care service providers. The four PCOC zones and their Chief Investigators are:

- **Central Zone**  
  *Professor Kathy Eagar*, Australian Health Services Research Institute, University of Wollongong

- **North Zone**  
  *Professor Patsy Yates*, Institute of Health and Biomedical Innovation, Queensland University of Technology

- **South Zone**  
  *Professor David Currow*, Department of Palliative and Supportive Services, Flinders University

- **West Zone**  
  *Assistant Professor Claire Johnson*, Cancer and Palliative Care Research and Evaluation Unit, University of WA

The National office is located within the Australian Health Services Research Institute at the University of Wollongong.

The items included in the PCOC dataset (Version 2) serve the dual purpose of:

- Defining a common clinical language to allow communication between palliative care providers
- Facilitating the routine collection of national palliative care data for the purpose of reporting and benchmarking to drive quality improvement

The dataset includes the clinical assessment tools: Phase Type of Care, Palliative Care 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). These are used to measure the quality and outcomes of palliative care. For more information on the PCOC clinical tools or data items please visit [www.pcoc.org.au](http://www.pcoc.org.au)
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Introduction

PCOC aims to assist services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this, the twelfth PCOC report, data submitted for the July – December 2011 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

This report is broken into three sections:

Section 1 summarises each of the four major benchmark measures and subsets and presents national benchmarking results for these benchmarks
Section 2 presents additional analysis for each of the sixteen benchmarks
Section 3 provides descriptive analysis of the data items at each of the patient, episode and phase levels

In each of the three sections, data and analysis for QLD is presented alongside the national figures for comparative purposes. The national figures reflect all palliative care services who submitted data for the July - December 2011 period. A full list of these services can be found at www.pcoc.org.au

If you would like more information regarding this report please contact:

The PCOC National Director, email: pcoc@uow.edu.au or phone (02) 4221 4411

“PCOC is an excellent example of a national and voluntary programme using benchmarking to measure outcomes in palliative care”

PRISMA (Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-Life Care) in their recent publication Outcome Measurement in Palliative Care – The Essentials, www.prismafp7.eu
Section 1 – QLD at a Glance

Table 1: Summary of benchmark measures 1-3

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
<th>Benchmark</th>
<th>Inpatient</th>
<th>Ambulatory &amp; Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Time from referral to contact</td>
<td>Benchmark 1: Patients contacted on same or following day</td>
<td>90%</td>
<td>94.8</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Time in unstable phase</td>
<td>Benchmark 2.1: Unstable phases lasting for less than 7 days - first phase of episode</td>
<td>85%</td>
<td>84.0</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Benchmark 2.2: Unstable phases lasting for less than 7 days - not first phase of episode</td>
<td>90%</td>
<td>89.4</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Benchmark 2.3: Median time in unstable phase</td>
<td>2 days</td>
<td>2 days</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Change in pain</td>
<td>PC Problem Severity Score (PCPSS)</td>
<td>Benchmark 3.1: Phases starting with absent/mild pain, that end with absent/mild pain</td>
<td>90%</td>
<td>86.4</td>
</tr>
<tr>
<td></td>
<td>Symptom Assessment Score (SAS)</td>
<td>Benchmark 3.2: Phases starting with moderate/severe pain, that end with absent/mild pain</td>
<td>60%</td>
<td>62.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Benchmark 3.3: Phases starting with absent/mild pain, that end with absent/mild pain</td>
<td>90%</td>
<td>87.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Benchmark 3.4: Phases starting with moderate/severe pain, that end with absent/mild pain</td>
<td>60%</td>
<td>51.7</td>
</tr>
</tbody>
</table>

Table 2: Summary of benchmark measure 4: Average improvement on the 2008 baseline national average (X-CAS)

<table>
<thead>
<tr>
<th>Clinical Tool</th>
<th>Description</th>
<th>Average improvement on baseline</th>
<th>Benchmark met?</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCPSS</td>
<td>Benchmark 4.1: Pain</td>
<td>0.23</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Benchmark 4.2: Other symptoms</td>
<td>0.45</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Benchmark 4.3: Family/carer</td>
<td>0.21</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Benchmark 4.4: Psychological/spiritual</td>
<td>0.25</td>
<td>Yes</td>
</tr>
<tr>
<td>SAS</td>
<td>Benchmark 4.5: Pain</td>
<td>0.44</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Benchmark 4.6: Nausea</td>
<td>0.20</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Benchmark 4.7: Breathing</td>
<td>0.47</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Benchmark 4.8: Bowels</td>
<td>0.28</td>
<td>Yes</td>
</tr>
</tbody>
</table>

For more information on the benchmark measures, see Section 2 and Appendix B
Measure 1: Time from referral to first contact - Inpatient Setting

Benchmark 1: 90% of patients contacted the day of, or the day after, referral

Services ordered from highest to lowest level of achievement

- National Profile
- Benchmark
- Qld services
Measure 1: Time from referral to first contact - Ambulatory & Community Settings

Benchmark 1: 90% of patients contacted the day of, or the day after, referral

% of patients contacted the day of, or the day after, referral

Level of achievement

Services ordered from highest to lowest level of achievement

National Profile
Benchmark
Qld services
Measure 2: Time in unstable phase - Inpatient Setting

Benchmark 2.1: 85% of unstable phases (that are the first phase of the episode) last less than 7 days.
Measure 2: Time in unstable phase - Ambulatory & Community Settings

Benchmark 2.1: 85% of unstable phases (that are the first phase of the episode) last less than 7 days

% of unstable phases lasting less than 7 days - first phase in episode

Services ordered from highest to lowest level of achievement

- National Profile
- Benchmark
- Qld services

Level of achievement
Measure 2: Time in unstable phase - Inpatient Setting

Benchmark 2.2: 90% of unstable phases (that are not the first phase of the episode) last less than 7 days

Services ordered from highest to lowest level of achievement

- National Profile
- Benchmark
- Qld services
Measure 2: Time in unstable phase - Ambulatory & Community Settings

Benchmark 2.2: 90% of unstable phases (that are not the first phase of the episode) last less than 7 days
Measure 3: Change in Pain - Inpatient Setting

Benchmark 3.3 - SAS: 90% of phases with absent/mild pain at start, end with absent/mild pain

Services ordered from highest to lowest level of achievement

- National Profile
- Benchmark
- Qld services
Measure 3: Change in Pain - Ambulatory & Community Settings

Benchmark 3.3 - SAS: 90% of phases with absent/mild pain at start, end with absent/mild pain

% of phases with absent/mild pain at start, ending with absent/mild pain

Level of achievement

Services ordered from highest to lowest level of achievement

- National Profile
- Benchmark
- Qld services
Measure 3: Change in Pain - Inpatient Setting

Benchmark 3.4 - SAS: 60% of phases with moderate/severe pain at start, end with absent/mild pain

% of phases with moderate/severe pain at start, ending with absent/mild pain

Level of achievement

Services ordered from highest to lowest level of achievement

- National Profile
- Benchmark
- Qld services
Measure 3: Change in Pain - Ambulatory & Community Settings

Benchmark 3.4 - SAS: 60% of phases with moderate/severe pain at start, end with absent/mild pain

Services ordered from highest to lowest level of achievement

- National Profile
- Benchmark
- Qld services
Section 2 – Benchmark Analysis

Measure 1 – Time from referral to first contact

Time from referral to first contact reports responsiveness of palliative care services to patient needs. This benchmark was set after consultation with participants at the PCOC national benchmarking workshops in 2008. Participants acknowledged that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating 5 days a week (Monday-Friday) are benchmarked against services operating 7 days a week.

Benchmark 1: This measure relates to the time taken for patients to be contacted and clinically assessed, once the palliative care team has received the patient’s referral. To meet this benchmark, at least 90% of patients must be contacted within two days of receipt of referral.

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

Table 3 Time from referral to first contact by episode type

<table>
<thead>
<tr>
<th>Time (in days)</th>
<th>Inpatient</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>%</td>
<td>All Services</td>
<td>%</td>
<td>QLD</td>
<td>%</td>
<td>All Services</td>
<td>%</td>
</tr>
<tr>
<td>Within 2 days</td>
<td>2687</td>
<td>94.8</td>
<td>9503</td>
<td>90.6</td>
<td>708</td>
<td>60.3</td>
<td>3521</td>
<td>53.0</td>
</tr>
<tr>
<td>2-7 days</td>
<td>131</td>
<td>4.6</td>
<td>798</td>
<td>7.6</td>
<td>334</td>
<td>28.4</td>
<td>2028</td>
<td>30.5</td>
</tr>
<tr>
<td>8-14 days</td>
<td>7</td>
<td>0.2</td>
<td>72</td>
<td>0.7</td>
<td>78</td>
<td>6.6</td>
<td>655</td>
<td>9.9</td>
</tr>
<tr>
<td>Greater than 14 days</td>
<td>10</td>
<td>0.4</td>
<td>112</td>
<td>1.1</td>
<td>54</td>
<td>4.6</td>
<td>440</td>
<td>6.6</td>
</tr>
<tr>
<td>Average</td>
<td>1.1</td>
<td>Na</td>
<td>1.3</td>
<td>Na</td>
<td>2.5</td>
<td>Na</td>
<td>2.9</td>
<td>Na</td>
</tr>
<tr>
<td>Median</td>
<td>1</td>
<td>Na</td>
<td>1</td>
<td>Na</td>
<td>1</td>
<td>Na</td>
<td>1</td>
<td>na</td>
</tr>
</tbody>
</table>

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 atypical and were assumed to equal 7 days for the purpose of calculating the average and median time.
Figure 1  Trend in time from referral to first contact measure

Inpatient episodes for **QLD**

![Inpatient episodes for QLD](image1.png)

Inpatient episodes for **all services**

![Inpatient episodes for all services](image2.png)

Ambulatory and community episodes for **QLD**

![Ambulatory and community episodes for QLD](image3.png)

Ambulatory and community episodes for **all services**

![Ambulatory and community episodes for all services](image4.png)
Measure 2 – Time in unstable phase

The unstable phase type, by nature of its definition, alerts clinical staff to the need for urgent changes to the patient’s plan of care or that emergency intervention is required. Those patients assessed to be in the unstable phase require intense review for a short period of time. An unstable phase is triggered if:

- A patient experiences a new, unanticipated problem, and/or
- A patient experiences a rapid increase in the severity of an existing problem, and/or
- A patient’s family/carers experience a sudden change in circumstances that adversely impacts the patient’s care

Unstable phases are ended in one of two ways:

- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom/crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient’s care. In this situation, the patient will move to either the Stable or Deteriorating Phase
- The patient is likely to die within a matter of days. In this situation, the patient will be moved into Terminal Phase

There are three benchmarks relating to the time in unstable phase measure:

**Benchmark 2.1:** This benchmark relates to unstable phases that are the first phase in an episode of care (for example, a patient is admitted to an inpatient palliative care unit and is immediately assessed as being in the unstable phase). To meet this benchmark, at least 85% of these unstable phases must last for less than 7 days.

**Benchmark 2.2:** This benchmark relates to unstable phases that are not the first phase in an episode of care (for example, a patient’s condition changes during an episode of care, and the patient’s phase type is changed to unstable). To meet this benchmark, at least 90% of these unstable phases must last for less than 7 days.

**Benchmark 2.3:** This benchmark relates to all unstable phases, regardless of where they occur in the episode. To meet this benchmark, the median length of all unstable phases must be 2 days or less.

Table 4 presents descriptive data for these three benchmarks.
### Table 4  Time in unstable phase by episode type and occurrence in episode

<table>
<thead>
<tr>
<th>Episode type</th>
<th>Occurrence of unstable phase</th>
<th>Number of unstable phases</th>
<th>Percent unstable for &lt; 7 days</th>
<th>Median days in unstable phase</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>All Services</td>
<td>QLD</td>
<td>All Services</td>
</tr>
<tr>
<td>Inpatient</td>
<td>First phase of episode</td>
<td>1289</td>
<td>4958</td>
<td>84.0</td>
</tr>
<tr>
<td></td>
<td>Not first phase of episode</td>
<td>414</td>
<td>2356</td>
<td>89.4</td>
</tr>
<tr>
<td></td>
<td><strong>Total unstable phases</strong></td>
<td><strong>1703</strong></td>
<td><strong>7314</strong></td>
<td><strong>85.3</strong></td>
</tr>
<tr>
<td>Ambulatory &amp; Community</td>
<td>First phase of episode</td>
<td>112</td>
<td>1123</td>
<td>67.9</td>
</tr>
<tr>
<td></td>
<td>Not first phase of episode</td>
<td>176</td>
<td>1180</td>
<td>69.9</td>
</tr>
<tr>
<td></td>
<td><strong>Total unstable phases</strong></td>
<td><strong>288</strong></td>
<td><strong>2303</strong></td>
<td><strong>69.1</strong></td>
</tr>
</tbody>
</table>

**Interpretation hint:**
For QLD, 1289 patients commenced their **inpatient episode** of care in the unstable phase. Of these unstable phases, 84% lasted for less than 7 days. This was **about the same** as the 84.8% seen across all participating services.
Measure 3 – Change in pain

Pain management is acknowledged as a core business of palliative care services. The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS) provide two different perspectives of pain: the SAS is patient rated, while the PCPSS is clinician rated. There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain, and the other relating to the management of pain for patients with moderate or severe pain.

Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to be included in the benchmarks.

**Benchmark 3.1:** This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild pain. Table 5 shows trends in this benchmark over the last four reports.

**Table 5** Trends in Benchmark 3.1: Phases with absent or mild pain at start, which end with absent or mild pain (PCPSS)

<table>
<thead>
<tr>
<th>Episode type</th>
<th>QLD</th>
<th>All Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>507</td>
<td>898</td>
</tr>
<tr>
<td>%</td>
<td>83.8</td>
<td>83.1</td>
</tr>
<tr>
<td>Ambulatory &amp; Community</td>
<td>344</td>
<td>406</td>
</tr>
<tr>
<td>%</td>
<td>78.9</td>
<td>75.5</td>
</tr>
</tbody>
</table>

**Benchmark 3.2:** This benchmark relates to patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 60% of these phases must end with the patient’s pain reduced to being absent or mild. Table 6 shows trends in this benchmark over the last four reports.

**Table 6** Trends in Benchmark 3.2: Phases with moderate or severe pain at start, which end with absent or mild pain (PCPSS)

<table>
<thead>
<tr>
<th>Episode type</th>
<th>QLD</th>
<th>All Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>334</td>
<td>510</td>
</tr>
<tr>
<td>%</td>
<td>57.8</td>
<td>52.4</td>
</tr>
<tr>
<td>Ambulatory &amp; Community</td>
<td>88</td>
<td>110</td>
</tr>
<tr>
<td>%</td>
<td>44.4</td>
<td>53.9</td>
</tr>
</tbody>
</table>
Benchmark 3.3: This benchmark relates to patients who have absent or mild pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 90% of these phases end with the patient still experiencing only absent or mild pain. Table 7 shows trends in this benchmark over the last four reports.

Table 7 Trends in Benchmark 3.3: Phases with absent or mild pain at start, which end with absent or mild pain (SAS)

<table>
<thead>
<tr>
<th>Episode type</th>
<th>QLD</th>
<th>All Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>617</td>
<td>836</td>
</tr>
<tr>
<td>%</td>
<td>82.3</td>
<td>84.6</td>
</tr>
<tr>
<td>Ambulatory &amp; Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>314</td>
<td>356</td>
</tr>
<tr>
<td>%</td>
<td>75.1</td>
<td>74.2</td>
</tr>
</tbody>
</table>

Benchmark 3.4: This benchmark relates to patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 60% of these phases must end with the patient’s pain reduced to being absent or mild. Table 8 shows trends in this benchmark over the last four reports.

Table 8 Trends in Benchmark 3.4: Phases with moderate or severe pain at start, which end with absent or mild pain (SAS)

<table>
<thead>
<tr>
<th>Episode type</th>
<th>QLD</th>
<th>All Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>379</td>
<td>512</td>
</tr>
<tr>
<td>%</td>
<td>44.6</td>
<td>46.6</td>
</tr>
<tr>
<td>Ambulatory &amp; Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>111</td>
<td>125</td>
</tr>
<tr>
<td>%</td>
<td>45.5</td>
<td>48.1</td>
</tr>
</tbody>
</table>
Figure 2 Change in pain benchmark measures - all phases

PCPSS Pain

- **Absent/mild pain at both start and end of phase**
  - Report 9
  - Report 10
  - Report 11
  - Report 12

SAS Pain

- **Absent/mild pain at both start and end of phase**
  - Report 9
  - Report 10
  - Report 11
  - Report 12

- **Mod/severe pain at start with absent/mild pain at end**
  - Report 9
  - Report 10
  - Report 11
  - Report 12
Measure 4 – Change in symptoms relative to the baseline national average (X-CAS)

Measure 4 includes a suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included this report:

<table>
<thead>
<tr>
<th>Measure 4.1 Pain - PCPSS</th>
<th>Measure 4.2 Other symptoms- PCPSS</th>
<th>Measure 4.3 Family/carer - PCPSS</th>
<th>Measure 4.4 Psychological/spiritual- PCPSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measure 4.5 Pain - SAS</td>
<td>Measure 4.6 Nausea - SAS</td>
<td>Measure 4.7 Breathing - SAS</td>
<td>Measure 4.8 Bowels - SAS</td>
</tr>
</tbody>
</table>

The suite of benchmarks included in Measure 4 are generally referred to as X-CAS – CAS standing for Case-mix Adjusted Score, and the X to represent that multiple symptoms are included.

**How to interpret X-CAS:**

The X-CAS benchmarks are calculated relative to a baseline reference period (currently July-December 2008). As a result:

- If X-CAS is **greater than 0** then on average, the patients’ change in symptom was better than similar patients in the baseline reference period.
- If X-CAS is **equal to 0** then on average, the patients’ change in symptom was about the same as similar patients in the baseline reference period.
- If X-CAS is **less than 0** then on average, the patients’ change in symptom was worse than similar patients in the baseline reference period.

As the X-CAS measures look at change in symptom, they are only able to be calculated on phases which ended in phase change or discharge (as the phase end scores are required to determine the change). Bereavement phases are excluded from the analysis.

A more technical explanation of X-CAS is included in Appendix B.
Figure 3  Trend in average improvement on 2008 baseline - Palliative Care Problem Severity Score

Benchmark 4.1: Pain - PCPSS

Benchmark 4.2: Other symptoms - PCPSS

Benchmark 4.3: Family/carer - PCPSS

Benchmark 4.4: Psychological/spiritual - PCPSS
Figure 4  Trend in average improvement on 2008 baseline - Symptom Assessment Scale

Benchmark 4.5: Pain - SAS

Benchmark 4.6: Nausea - SAS

Benchmark 4.7: Breathing - SAS

Benchmark 4.8: Bowels - SAS
Section 3 - Descriptive analysis

There are three levels of PCOC data items – Patient, Episode and Phase.

The broad detail is found at the patient level, where the data items look at patient demographics.

At the episode level, the items focus on characterising each setting of palliative care. They also describe the reasons behind why and how palliative care episodes start/end, the level of support patients receive both before and after an episode and (where applicable) the setting in which the patient died.

The clinical focus of PCOC is at the phase level. The items at this level describe the patient’s stage of illness, functional impairment as well as their levels of pain and symptom distress. The items at the phase level are used to quantify patient outcomes, and are the focus of the PCOC Benchmarks in the previous sections.

This section provides an overview of the data submitted by QLD at each level for the current reporting period. Summaries of the national data are included for comparative purposes.

Some tables throughout this section 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/unable to be calculated due to missing or invalid data.

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

The information collected on each patient includes Indigenous status, sex, main language spoken at home and country of birth. Table 9 shows the Indigenous status for all patients for QLD and nationally. Non-disclosure of Indigenous status can result in cultural issues not being identified. A number of programs exist that can assist services to encourage Indigenous persons to identify.

Table 9 Indigenous Status - all patients

<table>
<thead>
<tr>
<th>Indigenous Status</th>
<th>QLD</th>
<th>%</th>
<th>All Services</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal but not Torres Strait Islander origin</td>
<td>27</td>
<td>0.9</td>
<td>133</td>
<td>0.9</td>
</tr>
<tr>
<td>Torres Strait Islander but not Aboriginal origin</td>
<td>5</td>
<td>0.2</td>
<td>25</td>
<td>0.2</td>
</tr>
<tr>
<td>Both Aboriginal and Torres Strait Islander origin</td>
<td>2</td>
<td>0.1</td>
<td>13</td>
<td>0.1</td>
</tr>
<tr>
<td>Neither Aboriginal nor Torres Strait Islander origin</td>
<td>2941</td>
<td>96.6</td>
<td>13749</td>
<td>93.0</td>
</tr>
<tr>
<td>Not stated/inadequately described</td>
<td>69</td>
<td>2.3</td>
<td>867</td>
<td>5.9</td>
</tr>
<tr>
<td>Total</td>
<td>3044</td>
<td>100.0</td>
<td>14787</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 10 shows a breakdown of malignant and non-malignant diagnosis for the patients for QLD and at the national level. The development of Version 3 Data Set will include further opportunity to expand on diagnosis for both malignant and non-malignant categories.
<table>
<thead>
<tr>
<th>Diagnosis category</th>
<th>Primary diagnosis</th>
<th>QLD</th>
<th>% of category</th>
<th>% of total</th>
<th>All Services</th>
<th>% of category</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malignant</td>
<td>Bone and soft tissue</td>
<td>41</td>
<td>1.7</td>
<td>1.3</td>
<td>244</td>
<td>2.1</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>Breast</td>
<td>208</td>
<td>8.4</td>
<td>6.8</td>
<td>990</td>
<td>8.4</td>
<td>6.7</td>
</tr>
<tr>
<td></td>
<td>CNS</td>
<td>40</td>
<td>1.6</td>
<td>1.3</td>
<td>194</td>
<td>1.6</td>
<td>1.3</td>
</tr>
<tr>
<td></td>
<td>Colorectal</td>
<td>283</td>
<td>11.4</td>
<td>9.3</td>
<td>1297</td>
<td>11.0</td>
<td>8.8</td>
</tr>
<tr>
<td></td>
<td>Gynaecological</td>
<td>124</td>
<td>5.0</td>
<td>4.1</td>
<td>530</td>
<td>4.5</td>
<td>3.6</td>
</tr>
<tr>
<td></td>
<td>Haematological</td>
<td>153</td>
<td>6.2</td>
<td>5.0</td>
<td>659</td>
<td>5.6</td>
<td>4.5</td>
</tr>
<tr>
<td></td>
<td>Head and neck</td>
<td>164</td>
<td>6.6</td>
<td>5.4</td>
<td>679</td>
<td>5.8</td>
<td>4.6</td>
</tr>
<tr>
<td></td>
<td>Lung</td>
<td>526</td>
<td>21.2</td>
<td>17.3</td>
<td>2310</td>
<td>19.6</td>
<td>15.6</td>
</tr>
<tr>
<td></td>
<td>Pancreas</td>
<td>129</td>
<td>5.2</td>
<td>4.2</td>
<td>650</td>
<td>5.5</td>
<td>4.4</td>
</tr>
<tr>
<td></td>
<td>Prostate</td>
<td>205</td>
<td>8.3</td>
<td>6.7</td>
<td>780</td>
<td>6.6</td>
<td>5.3</td>
</tr>
<tr>
<td></td>
<td>Skin</td>
<td>125</td>
<td>5.0</td>
<td>4.1</td>
<td>444</td>
<td>3.8</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>Other GIT</td>
<td>167</td>
<td>6.7</td>
<td>5.5</td>
<td>929</td>
<td>7.9</td>
<td>6.3</td>
</tr>
<tr>
<td></td>
<td>Other urological</td>
<td>136</td>
<td>5.5</td>
<td>4.5</td>
<td>485</td>
<td>4.1</td>
<td>3.3</td>
</tr>
<tr>
<td></td>
<td>Other malignancy</td>
<td>112</td>
<td>4.5</td>
<td>3.7</td>
<td>622</td>
<td>5.3</td>
<td>4.2</td>
</tr>
<tr>
<td></td>
<td>Unknown primary</td>
<td>70</td>
<td>2.8</td>
<td>2.3</td>
<td>335</td>
<td>2.8</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>Malignant - not further defined</td>
<td>0</td>
<td>0.0</td>
<td>0.0</td>
<td>660</td>
<td>5.6</td>
<td>4.5</td>
</tr>
<tr>
<td></td>
<td>All malignant</td>
<td>2483</td>
<td>100.0</td>
<td>81.6</td>
<td>11808</td>
<td>100.0</td>
<td>79.9</td>
</tr>
<tr>
<td>Non-malignant</td>
<td>Cardiovascular</td>
<td>133</td>
<td>25.2</td>
<td>4.4</td>
<td>530</td>
<td>20.7</td>
<td>3.6</td>
</tr>
<tr>
<td></td>
<td>HIV/AIDS</td>
<td>1</td>
<td>0.2</td>
<td>0.0</td>
<td>2</td>
<td>0.1</td>
<td>0.0</td>
</tr>
<tr>
<td></td>
<td>Kidney failure</td>
<td>73</td>
<td>13.8</td>
<td>2.4</td>
<td>272</td>
<td>10.6</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td>Neurological disease</td>
<td>105</td>
<td>19.9</td>
<td>3.4</td>
<td>540</td>
<td>21.1</td>
<td>3.7</td>
</tr>
<tr>
<td></td>
<td>Respiratory failure</td>
<td>102</td>
<td>19.3</td>
<td>3.4</td>
<td>434</td>
<td>17.0</td>
<td>2.9</td>
</tr>
<tr>
<td></td>
<td>Other non-malignancy</td>
<td>114</td>
<td>21.6</td>
<td>3.7</td>
<td>685</td>
<td>26.8</td>
<td>4.6</td>
</tr>
<tr>
<td></td>
<td>Non-malignant - not further defined</td>
<td>0</td>
<td>0.0</td>
<td>0.0</td>
<td>95</td>
<td>3.7</td>
<td>0.6</td>
</tr>
<tr>
<td></td>
<td>All non-malignant</td>
<td>528</td>
<td>100.0</td>
<td>17.3</td>
<td>2558</td>
<td>100.0</td>
<td>17.3</td>
</tr>
<tr>
<td>Not Stated</td>
<td></td>
<td>33</td>
<td>100.0</td>
<td>1.1</td>
<td>421</td>
<td>100.0</td>
<td>2.8</td>
</tr>
</tbody>
</table>
Profile of palliative care episodes

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 – for the purposes of this report, either as an Inpatient or an Ambulatory and Community patient.

An episode of care refers to the care received 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
- the patient is formally separated from the hospital/hospice/community or,
- the patient dies

Referral source refers to the service or organisation from which the patient was referred to for each individual episode of care. Table 11 presents referral source by episode type. Review of referral source can identify opportunities to connect with referral sources that are currently lower than the national referral profile (e.g. a community service with few GP referrals may want to re-address referral or triage practices and look to working more collaboratively).
### Table 11  Referral source by episode type

<table>
<thead>
<tr>
<th>Referral source</th>
<th>Inpatient</th>
<th></th>
<th>All Services</th>
<th></th>
<th>Ambulatory &amp; Community</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>%</td>
<td>All Services</td>
<td>%</td>
<td>QLD</td>
<td>%</td>
</tr>
<tr>
<td>Public hospital - other than inpatient palliative care unit</td>
<td>1522</td>
<td>53.4</td>
<td>4927</td>
<td>45.6</td>
<td>462</td>
<td>39.2</td>
</tr>
<tr>
<td>Self, carer(s), family or friends</td>
<td>106</td>
<td>3.7</td>
<td>268</td>
<td>2.5</td>
<td>45</td>
<td>3.8</td>
</tr>
<tr>
<td>Private hospital - other than inpatient palliative care unit</td>
<td>336</td>
<td>11.8</td>
<td>761</td>
<td>7.0</td>
<td>93</td>
<td>7.9</td>
</tr>
<tr>
<td>Public palliative care inpatient unit/hospice</td>
<td>92</td>
<td>3.2</td>
<td>363</td>
<td>3.4</td>
<td>189</td>
<td>16.0</td>
</tr>
<tr>
<td>Private palliative care inpatient unit/hospice</td>
<td>26</td>
<td>0.9</td>
<td>93</td>
<td>0.9</td>
<td>42</td>
<td>3.6</td>
</tr>
<tr>
<td>General medical practitioner</td>
<td>202</td>
<td>7.1</td>
<td>555</td>
<td>5.1</td>
<td>156</td>
<td>13.2</td>
</tr>
<tr>
<td>Specialist medical practitioner</td>
<td>114</td>
<td>4.0</td>
<td>382</td>
<td>3.5</td>
<td>113</td>
<td>9.6</td>
</tr>
<tr>
<td>Community-based palliative care agency</td>
<td>332</td>
<td>11.6</td>
<td>2186</td>
<td>20.2</td>
<td>10</td>
<td>0.8</td>
</tr>
<tr>
<td>Community-based service</td>
<td>51</td>
<td>1.8</td>
<td>405</td>
<td>3.7</td>
<td>37</td>
<td>3.1</td>
</tr>
<tr>
<td>Residential aged care facility</td>
<td>22</td>
<td>0.8</td>
<td>81</td>
<td>0.7</td>
<td>11</td>
<td>0.9</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>0.6</td>
<td>104</td>
<td>1.0</td>
<td>6</td>
<td>0.5</td>
</tr>
<tr>
<td>Not stated/inadequately described</td>
<td>30</td>
<td>1.1</td>
<td>679</td>
<td>6.3</td>
<td>14</td>
<td>1.2</td>
</tr>
<tr>
<td>Total</td>
<td>2850</td>
<td>100.0</td>
<td>10804</td>
<td>100.0</td>
<td>1178</td>
<td>100.0</td>
</tr>
</tbody>
</table>

### Table 12  Place of death – ambulatory and community episodes

<table>
<thead>
<tr>
<th>Place of death</th>
<th>QLD</th>
<th>%</th>
<th>All Services</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private residence</td>
<td>98</td>
<td>32.0</td>
<td>1152</td>
<td>54.8</td>
</tr>
<tr>
<td>Residential aged care setting</td>
<td>13</td>
<td>4.2</td>
<td>360</td>
<td>17.1</td>
</tr>
<tr>
<td>Other location*</td>
<td>88</td>
<td>28.8</td>
<td>390</td>
<td>18.5</td>
</tr>
<tr>
<td>Not stated/inadequately described</td>
<td>107</td>
<td>35.0</td>
<td>201</td>
<td>9.6</td>
</tr>
<tr>
<td>Total</td>
<td>306</td>
<td>100.0</td>
<td>2103</td>
<td>100.0</td>
</tr>
</tbody>
</table>

* Includes patients who have died in a hospital setting without the episode of non-admitted palliative care being ended. Patients whose community episode has ended when admitted to hospital are excluded from this table.
Table 13 gives a summary of the length of episode for patients for this service and nationally. The term “elapsed days” refers to the number of days between the episode starting and ending. For inpatient episodes, elapsed days and length of stay are equivalent. In the ambulatory and community settings, the number of elapsed days may more than the number of occasions of service.

**Table 13  Length of episode summary (elapsed days)**

<table>
<thead>
<tr>
<th>Length of episode</th>
<th>Inpatient</th>
<th>Ambulatory &amp; Community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>All Services</td>
</tr>
<tr>
<td>Average length of episode</td>
<td>10.9</td>
<td>11.9</td>
</tr>
<tr>
<td>Median length of episode</td>
<td>7.0</td>
<td>7.0</td>
</tr>
</tbody>
</table>

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 180 days were considered to be atypical and are excluded from the average calculations. The number of episodes excluded can be seen in Table 14.

Table 14 details the length of episode in the number of elapsed days.

**Table 14  Length of episode breakdown (elapsed days)**

<table>
<thead>
<tr>
<th>Length of episode</th>
<th>Inpatient</th>
<th>Ambulatory &amp; Community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>% All Services</td>
</tr>
<tr>
<td>Same day</td>
<td>116</td>
<td>4.3</td>
</tr>
<tr>
<td>1-2 days</td>
<td>564</td>
<td>20.9</td>
</tr>
<tr>
<td>3-4 days</td>
<td>389</td>
<td>14.4</td>
</tr>
<tr>
<td>5-7 days</td>
<td>435</td>
<td>16.1</td>
</tr>
<tr>
<td>8-14 days</td>
<td>596</td>
<td>22.0</td>
</tr>
<tr>
<td>15-21 days</td>
<td>253</td>
<td>9.4</td>
</tr>
<tr>
<td>22-30 days</td>
<td>150</td>
<td>5.5</td>
</tr>
<tr>
<td>31-60 days</td>
<td>149</td>
<td>5.5</td>
</tr>
<tr>
<td>61-90 days</td>
<td>32</td>
<td>1.2</td>
</tr>
<tr>
<td>Greater than 90 days</td>
<td>19</td>
<td>0.7</td>
</tr>
<tr>
<td>Total</td>
<td>2703</td>
<td>100.0</td>
</tr>
</tbody>
</table>

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.
Profile of palliative care phases

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. There are five palliative care phases; stable, unstable, deteriorating, terminal and bereaved.

<table>
<thead>
<tr>
<th>Phase</th>
<th>Inpatient</th>
<th>Ambulatory &amp; Community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>%</td>
</tr>
<tr>
<td>Stable</td>
<td>1530</td>
<td>22.8</td>
</tr>
<tr>
<td>Unstable</td>
<td>1703</td>
<td>25.4</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>1835</td>
<td>27.4</td>
</tr>
<tr>
<td>Terminal</td>
<td>1057</td>
<td>15.8</td>
</tr>
<tr>
<td>Bereaved</td>
<td>574</td>
<td>8.6</td>
</tr>
<tr>
<td>All phases</td>
<td>6699</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 16 Average phase length (in days) by phase and episode type

<table>
<thead>
<tr>
<th>Phase</th>
<th>Inpatient</th>
<th>Ambulatory &amp; Community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>All Services</td>
</tr>
<tr>
<td>Stable</td>
<td>6.3</td>
<td>6.9</td>
</tr>
<tr>
<td>Unstable</td>
<td>3.7</td>
<td>3.6</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>6.4</td>
<td>5.5</td>
</tr>
<tr>
<td>Terminal</td>
<td>2.3</td>
<td>2.2</td>
</tr>
<tr>
<td>Bereaved</td>
<td>1.2</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Note: Phase records where length of phase was greater than 90 days were considered to be atypical and are excluded from the average calculations.
Table 17  Profile of PC Problem Severity Scores at beginning of phase by phase type – inpatient episodes (percentages)

<table>
<thead>
<tr>
<th>Phase</th>
<th>Problem severity</th>
<th>QLD</th>
<th>All Services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Absent</td>
<td>Mild</td>
</tr>
<tr>
<td>Stable</td>
<td>Pain</td>
<td>39.7</td>
<td>45.0</td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>28.0</td>
<td>50.3</td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>30.2</td>
<td>51.9</td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>41.2</td>
<td>41.9</td>
</tr>
<tr>
<td>Unstable</td>
<td>Pain</td>
<td>20.0</td>
<td>32.1</td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>8.7</td>
<td>27.3</td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>13.5</td>
<td>39.2</td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>25.9</td>
<td>29.7</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>Pain</td>
<td>32.9</td>
<td>38.8</td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>12.6</td>
<td>37.6</td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>23.9</td>
<td>45.1</td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>23.4</td>
<td>37.0</td>
</tr>
<tr>
<td>Terminal</td>
<td>Pain</td>
<td>44.0</td>
<td>37.6</td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>33.1</td>
<td>33.7</td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>50.6</td>
<td>31.6</td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>19.8</td>
<td>33.5</td>
</tr>
</tbody>
</table>
### Table 18  Profile of PC Problem Severity Scores at beginning of phase by phase type – ambulatory and community episodes (percentages)

<table>
<thead>
<tr>
<th>Phase</th>
<th>Problem severity</th>
<th>QLD</th>
<th>All Services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Absent</td>
<td>Mild</td>
</tr>
<tr>
<td>Stable</td>
<td>Pain</td>
<td>45.2</td>
<td>42.0</td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>30.1</td>
<td>49.9</td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>44.9</td>
<td>39.2</td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>44.7</td>
<td>34.9</td>
</tr>
<tr>
<td>Unstable</td>
<td>Pain</td>
<td>19.1</td>
<td>31.3</td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>6.3</td>
<td>27.4</td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>19.8</td>
<td>37.8</td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>22.4</td>
<td>30.8</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>Pain</td>
<td>31.3</td>
<td>36.3</td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>9.0</td>
<td>32.2</td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>23.3</td>
<td>45.1</td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>17.5</td>
<td>39.1</td>
</tr>
<tr>
<td>Terminal</td>
<td>Pain</td>
<td>32.8</td>
<td>33.6</td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>22.4</td>
<td>28.4</td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>38.8</td>
<td>31.3</td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>12.7</td>
<td>38.1</td>
</tr>
</tbody>
</table>
Figure 5  Total RUG-ADL at beginning of phase – inpatients

Stable Phase

Unstable Phase

Deteriorating Phase

Terminal Phase
Figure 6  Total RUG-ADL at beginning of phase – ambulatory and community patients

- Stable Phase
- Unstable Phase
- Deteriorating Phase
- Terminal Phase

Percentage of phases

RUG-ADL total at start of phase

All services
QLD

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RUG-ADL (shown on the previous two pages) consists of 4 items (bed mobility, toileting, transfers and eating) and should be assessed on admission, at phase change and at episode end.

The Karnofsky Performance Status Scale used in PCOC is the Australia-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 in determining prognosis /survival times.

Karnofsky & RUG-ADL can be used together to provide a profile of both patient dependency, equipment requirements, need for allied health referrals and carer burden/respite requirements.

### Table 19  Karnofsky score at phase start by episode type

<table>
<thead>
<tr>
<th>Karnofsky score</th>
<th>Inpatient</th>
<th></th>
<th>Ambulatory &amp; Community</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>%</td>
<td>All Services</td>
<td>%</td>
</tr>
<tr>
<td>Comatose or barely rousable</td>
<td>685</td>
<td>11.2</td>
<td>2416</td>
<td>9.4</td>
</tr>
<tr>
<td>Totally bedfast and requiring extensive nursing care</td>
<td>1224</td>
<td>20.0</td>
<td>4899</td>
<td>19.1</td>
</tr>
<tr>
<td>Almost completely bedfast</td>
<td>741</td>
<td>12.1</td>
<td>2920</td>
<td>11.4</td>
</tr>
<tr>
<td>In bed more than 50% of the time</td>
<td>1070</td>
<td>17.5</td>
<td>4130</td>
<td>16.1</td>
</tr>
<tr>
<td>Requires considerable assistance</td>
<td>1042</td>
<td>17.0</td>
<td>5102</td>
<td>19.9</td>
</tr>
<tr>
<td>Requires occasional assistance</td>
<td>891</td>
<td>14.6</td>
<td>3341</td>
<td>13.0</td>
</tr>
<tr>
<td>Cares for self</td>
<td>302</td>
<td>4.9</td>
<td>1048</td>
<td>4.1</td>
</tr>
<tr>
<td>Normal activity with effort</td>
<td>102</td>
<td>1.7</td>
<td>391</td>
<td>1.5</td>
</tr>
<tr>
<td>Able to carry on normal activity; minor signs or symptoms</td>
<td>38</td>
<td>0.6</td>
<td>113</td>
<td>0.4</td>
</tr>
<tr>
<td>Normal; no complaints; no evidence of disease</td>
<td>1</td>
<td>0.0</td>
<td>4</td>
<td>0.0</td>
</tr>
<tr>
<td>Not stated/inadequately described</td>
<td>20</td>
<td>0.3</td>
<td>1333</td>
<td>5.2</td>
</tr>
<tr>
<td>Total</td>
<td>6116</td>
<td>100.0</td>
<td>25697</td>
<td>100.0</td>
</tr>
</tbody>
</table>

|                                                      | QLD       | %        | All Services           | %        |
| Comatose or barely rousable                          | 53        | 2.7      | 573                    | 4.2      |
| Totally bedfast and requiring extensive nursing care | 161       | 8.2      | 1200                   | 8.9      |
| Almost completely bedfast                            | 126       | 6.5      | 863                    | 6.4      |
| In bed more than 50% of the time                     | 262       | 13.4     | 1539                   | 11.4     |
| Requires considerable assistance                     | 458       | 23.5     | 3164                   | 23.4     |
| Requires occasional assistance                       | 551       | 28.2     | 3114                   | 23.0     |
| Cares for self                                       | 238       | 12.2     | 1864                   | 13.8     |
| Normal activity with effort                          | 69        | 3.5      | 680                    | 5.0      |
| Able to carry on normal activity; minor signs or symptoms | 20    | 1.0      | 199                    | 1.5      |
| Normal; no complaints; no evidence of disease        | 0         | 0.0      | 15                     | 0.1      |
| Not stated/inadequately described                    | 15        | 0.8      | 334                    | 2.5      |
| Total                                                | 1953      | 100.0    | 13545                  | 100.0    |
Table 20 presents information relating to the manner in which stable phases ended, both for QLD and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or the patient dies. For those stable phases that ended because the patient was deemed to be in another phase (phase change), Figure 7 and Figure 8 summarise subsequent the phase that the patient moved into, for both the Inpatient and Ambulatory & Community settings respectively. This movement from one phase to another is referred to as Phase Progression. The phase progression information is derived by PCOC. The “Unknown” category has been included to account for situations where subsequent phase records have not been submitted to PCOC, meaning the phase progression cannot be determined.

Similar information is presented for the unstable, deteriorating and terminal phases on the following pages.

**Table 20 How stable phases end**

<table>
<thead>
<tr>
<th>Phase end reason</th>
<th>Inpatient</th>
<th></th>
<th>Ambulatory &amp; Community</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>All Services</td>
<td>QLD</td>
<td>All Services</td>
</tr>
<tr>
<td>Phase change (see figures below)</td>
<td>695 45.4%</td>
<td>4121 57.4%</td>
<td>377 51.3%</td>
<td>3482 66.4%</td>
</tr>
<tr>
<td>Discharge/case closure</td>
<td>794 51.9%</td>
<td>2903 40.4%</td>
<td>279 38.0%</td>
<td>1384 26.4%</td>
</tr>
<tr>
<td>Died</td>
<td>14 0.9%</td>
<td>118 1.6%</td>
<td>42 5.7%</td>
<td>332 6.3%</td>
</tr>
<tr>
<td>Bereavement phase end</td>
<td>1 0.1%</td>
<td>7 0.1%</td>
<td>0 0.0%</td>
<td>2 0.0%</td>
</tr>
<tr>
<td>Not stated/inadequately described</td>
<td>26 1.7%</td>
<td>32 0.4%</td>
<td>37 5.0%</td>
<td>46 0.9%</td>
</tr>
<tr>
<td>Total</td>
<td>1530 100%</td>
<td>7181 100%</td>
<td>735 100%</td>
<td>5246 100%</td>
</tr>
</tbody>
</table>

**Figure 7 Stable phase progression – inpatient**

**Figure 8 Stable phase progression - ambulatory & community**
<table>
<thead>
<tr>
<th>Phase end reason</th>
<th>Inpatient</th>
<th>Ambulatory &amp; Community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>All Services</td>
</tr>
<tr>
<td>Phase change (see figures below)</td>
<td>1455</td>
<td>6389</td>
</tr>
<tr>
<td></td>
<td>85.4%</td>
<td>87.4%</td>
</tr>
<tr>
<td>Discharge/case closure</td>
<td>145</td>
<td>495</td>
</tr>
<tr>
<td></td>
<td>8.5%</td>
<td>6.8%</td>
</tr>
<tr>
<td>Died</td>
<td>41</td>
<td>347</td>
</tr>
<tr>
<td></td>
<td>2.4%</td>
<td>4.7%</td>
</tr>
<tr>
<td>Bereavement phase end</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>0.1%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Not stated/inadequately described</td>
<td>60</td>
<td>72</td>
</tr>
<tr>
<td></td>
<td>3.5%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Total</td>
<td>1703</td>
<td>7314</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

**Figure 9 Unstable phase progression - inpatient**

**Figure 10 Unstable phase progression - ambulatory & community**
Table 22  How deteriorating phases end

<table>
<thead>
<tr>
<th>Phase end reason</th>
<th>Inpatient</th>
<th>Ambulatory &amp; Community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD %</td>
<td>All Services %</td>
</tr>
<tr>
<td>Phase change (see figures below)</td>
<td>1052  57.3</td>
<td>4817  68.0</td>
</tr>
<tr>
<td>Discharge/case closure</td>
<td>549   29.9</td>
<td>1040  14.7</td>
</tr>
<tr>
<td>Died</td>
<td>220   12.0</td>
<td>1183  16.7</td>
</tr>
<tr>
<td>Bereavement phase end</td>
<td>8     0.4</td>
<td>37    0.5</td>
</tr>
<tr>
<td>Not stated/inadequately described</td>
<td>6     0.3</td>
<td>11    0.2</td>
</tr>
<tr>
<td>Total</td>
<td>1835  100.0</td>
<td>7088  100.0</td>
</tr>
</tbody>
</table>

Figure 11  Deteriorating phase progression - inpatient

Figure 12  Deteriorating phase progression - ambulatory & community
Table 23  How terminal phases end

<table>
<thead>
<tr>
<th>Phase end reason</th>
<th>Inpatient</th>
<th></th>
<th>Ambulatory &amp; Community</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>%</td>
<td>All Services</td>
<td>%</td>
</tr>
<tr>
<td>Phase change (see figures below)</td>
<td>90</td>
<td>8.5</td>
<td>489</td>
<td>11.5</td>
</tr>
<tr>
<td>Discharge/case closure</td>
<td>26</td>
<td>2.5</td>
<td>93</td>
<td>2.2</td>
</tr>
<tr>
<td>Died</td>
<td>850</td>
<td>80.4</td>
<td>3437</td>
<td>81.2</td>
</tr>
<tr>
<td>Bereavement phase end</td>
<td>91</td>
<td>8.6</td>
<td>212</td>
<td>5.0</td>
</tr>
<tr>
<td>Not stated/inadequately described</td>
<td>0</td>
<td>0.0</td>
<td>3</td>
<td>0.1</td>
</tr>
<tr>
<td>Total</td>
<td>1057</td>
<td>100.0</td>
<td>4234</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Figure 13  Terminal phase progression - inpatient

Figure 14  Terminal phase progression - ambulatory & community

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38
Appendix A – Summary of data included in this report

A1 – Data Summary

This report includes data from a total of 102 services. During the reporting period, data were provided for a total of 14787 patients who between them had 18555 episodes of care and 40890 palliative care 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 (Section A3 contains a more detailed explanation of this process). Table 24 shows the number of patients, episodes and phases included in this report – both for QLD and nationally.

A consequence of the data scoping method is that it is likely that not all phases related to a particular episode are included in this report. Hence, the average number of phases per episode calculation shown in Table 24 may be an underestimate (due to episodes that cross-over 2 or more reporting periods) as it only includes phases that ended within the current reporting period.

Table 24  Number and percentage of patients, episodes and phases - by episode type

<table>
<thead>
<tr>
<th>Episode Type</th>
<th>Inpatient</th>
<th>Ambulatory &amp; Community</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>QLD</td>
<td>All Services</td>
<td>QLD</td>
</tr>
<tr>
<td>Number of patients*</td>
<td>2350</td>
<td>9247</td>
<td>991</td>
</tr>
<tr>
<td>Number of episodes</td>
<td>2850</td>
<td>10804</td>
<td>1178</td>
</tr>
<tr>
<td>Number of phases</td>
<td>6699</td>
<td>27135</td>
<td>2039</td>
</tr>
<tr>
<td>Percentage of patients*</td>
<td>77.2</td>
<td>62.5</td>
<td>32.6</td>
</tr>
<tr>
<td>Percentage of episodes</td>
<td>70.8</td>
<td>58.2</td>
<td>29.2</td>
</tr>
<tr>
<td>Percentage of phases</td>
<td>76.7</td>
<td>66.4</td>
<td>23.3</td>
</tr>
<tr>
<td>Average number of phases per episode**</td>
<td>2.2</td>
<td>2.4</td>
<td>1.7</td>
</tr>
</tbody>
</table>

* Patients seen in both settings 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.
A2 – Data Item Completion

Overall, the quality of data submitted to PCOC is very good and, as shown in Tables 25, 26 and 27 below, the rate of data completion is very high. In reviewing this table, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for non-admitted patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

PCOC strongly encourages services to complete and submit the whole data set on every patient as non-completion may result in services being excluded from relevant benchmarking activities or erroneous conclusions being drawn. Low completion of data items may also distort percentages and tables in some sections.

**Table 25 Item completion - patient level**

<table>
<thead>
<tr>
<th>Data item</th>
<th>% Complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of birth</td>
<td>100.0</td>
</tr>
<tr>
<td>Sex</td>
<td>99.9</td>
</tr>
<tr>
<td>Indigenous status</td>
<td>97.7</td>
</tr>
<tr>
<td>Country of birth</td>
<td>97.6</td>
</tr>
<tr>
<td>Main language</td>
<td>98.3</td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td>98.9</td>
</tr>
</tbody>
</table>

**Table 26 Item completion - episode level**

<table>
<thead>
<tr>
<th>Data item</th>
<th>% Complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of first contact/assessment</td>
<td>99.1</td>
</tr>
<tr>
<td>Referral date</td>
<td>99.5</td>
</tr>
<tr>
<td>Referral source</td>
<td>98.9</td>
</tr>
<tr>
<td>Episode start date</td>
<td>100.0</td>
</tr>
<tr>
<td>Mode of episode start</td>
<td>97.2</td>
</tr>
<tr>
<td>Accommodation at episode start</td>
<td>99.1</td>
</tr>
<tr>
<td>Episode end date</td>
<td>98.2</td>
</tr>
<tr>
<td>Level of support at episode start</td>
<td>97.7</td>
</tr>
<tr>
<td>Mode of episode end</td>
<td>99.1</td>
</tr>
<tr>
<td>Accommodation at episode end</td>
<td>81.8</td>
</tr>
<tr>
<td>Level of support at episode end</td>
<td>98.9</td>
</tr>
<tr>
<td>Place of death</td>
<td>65.0</td>
</tr>
</tbody>
</table>
### Table 27  Item completion - phase level

<table>
<thead>
<tr>
<th>Data item</th>
<th>Sub-Category</th>
<th>% Complete</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(where applicable)</td>
<td>QLD</td>
<td>All Services</td>
<td></td>
</tr>
<tr>
<td>Phase start date</td>
<td>-</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Phase</td>
<td>-</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>RUG-ADL at phase start</td>
<td>Bed Mobility</td>
<td>91.0</td>
<td>95.2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Toileting</td>
<td>91.0</td>
<td>95.1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transfers</td>
<td>91.0</td>
<td>94.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Eating</td>
<td>91.0</td>
<td>94.4</td>
<td></td>
</tr>
<tr>
<td>PC Problem Severity at phase start</td>
<td>Pain</td>
<td>94.0</td>
<td>81.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other Symptom</td>
<td>89.7</td>
<td>85.3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychological/Spiritual</td>
<td>96.6</td>
<td>92.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family/Carer</td>
<td>96.4</td>
<td>91.7</td>
<td></td>
</tr>
<tr>
<td>Symptom Assessment Score at phase start</td>
<td>Insomnia</td>
<td>86.9</td>
<td>88.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appetite</td>
<td>86.9</td>
<td>90.1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nausea</td>
<td>86.9</td>
<td>90.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bowels</td>
<td>86.9</td>
<td>89.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Breathing</td>
<td>86.9</td>
<td>90.4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fatigue</td>
<td>86.9</td>
<td>90.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pain</td>
<td>86.9</td>
<td>90.9</td>
<td></td>
</tr>
<tr>
<td>Phase end reason</td>
<td>-</td>
<td>98.2</td>
<td>99.4</td>
<td></td>
</tr>
<tr>
<td>Karnofsky at phase start</td>
<td>-</td>
<td>99.6</td>
<td>95.8</td>
<td></td>
</tr>
</tbody>
</table>

Some tables throughout this 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/unable to be calculated due to missing or invalid data.

In addition, interpret all figures carefully as results may appear distorted due to low frequencies being represented as percentages.
A3 – Data scoping methodology

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be “in scope” and would be included in the report. The episode and patient records associated with these phases are also deemed to be “in scope” and hence would also be included in the report.

Figure 15 below displays four examples to help visualize this process.

**Figure 15  Diagram of the PCOC data scoping process**

In **Example 1**, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

In **Example 2**, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). For the phases relating to the second episode, only the first three end within the period, so only these would be included in the report. Both of the episode records and the patient record would also be reported on.

In **Example 3**, the patient has one episode and five phases. Only the last three phases will be reported on as they are the only ones ending within the reporting period. The episode and patient records would be included in the report.

In **Example 4**, the patient again has one episode and five phases. This time, only the first three phases will be included in the report. Again, the episode and patient records would be included in the report on as they have associated phases ending within the period.
Appendix B – Benchmark Notes

B1 – Outline of Benchmark Measures and Targets

There is strong sectoral support for national benchmarks and a consensus that such benchmarks can drive service innovation regardless of model of care. Benchmarking provides opportunities to understand the services that are provided, the outcomes patients experience and also to generate research opportunities focused on how to demonstrate variations in practice and outcomes.

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

<table>
<thead>
<tr>
<th>Measure</th>
<th>Benchmark</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Time from referral to first contact</td>
<td>90% of patients are contacted on the day of, or the day after referral</td>
</tr>
<tr>
<td>2. Time in unstable phase</td>
<td>85% in their first phase remain unstable for less than 7 days</td>
</tr>
<tr>
<td></td>
<td>90% in a subsequent phase remain unstable for less than 7 days</td>
</tr>
<tr>
<td></td>
<td>The median time in unstable phase is 2 days or less</td>
</tr>
<tr>
<td>3. Change in pain (both PCPSS and SAS)</td>
<td>90% of phases that start with absent/mild pain start pain have absent/mild</td>
</tr>
<tr>
<td></td>
<td>end pain</td>
</tr>
<tr>
<td></td>
<td>60% of phases with moderate/severe start pain have absent/mild end pain</td>
</tr>
<tr>
<td>4. Change in symptoms relative to the national average (8 symptoms are included)</td>
<td>A score of 0 or above</td>
</tr>
</tbody>
</table>

It is recognised that services aspire to achieve best practice, and to reflect this, current benchmarks have intentionally been set at a high level. Where a service does not meet the benchmark, PCOC has adopted a target of improvement of 10% per year.
B2 – National profile graphs

In each national profile graph, the shaded region describes the national profile for that benchmark. QLD services are highlighted as dots on the graph. Graphs may have differing numbers of dots, caused by services not qualifying for inclusion in a particular benchmark. This may be caused by insufficient data item completion, or services not having any records falling into a particular category, for example, no phases starting with moderate/severe SAS pain.

B3 – X-CAS technical notes

The procedure for calculating X-CAS is as follows:

**Step 1.** Using the baseline data, calculate the average change in symptom for all patients in the same phase, having the same symptom start score. This is called the expected change.

**Step 2.** For each individual phase, calculate the change in symptom score (start score minus end score)

**Step 3.** For each individual phase, calculate the difference between their change in symptom score (calculated in step 2) and the relevant expected change (calculated in step 1).

**Step 4.** Average all of the values calculated in step 3 to produce the service’s Symptom Casemix-Adjusted Score (e.g. PCAS).

**Example:**

<table>
<thead>
<tr>
<th>Phase</th>
<th>PCPSS Pain at start</th>
<th>PCPSS Pain at end</th>
<th>Step 1: Expected PCPSS Pain change (from Report 6 National Database)</th>
<th>Step 2: PCPSS Pain change (start score minus end score)</th>
<th>Step 3: Difference (Step 2 minus Step 1)</th>
<th>Step 4: Average of values in step 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>0</td>
<td>1</td>
<td>-0.8</td>
<td>-1</td>
<td>-0.2</td>
<td>-0.2+0.9+0.4+0.4 = 4</td>
</tr>
<tr>
<td>Stable</td>
<td>1</td>
<td>1</td>
<td>-0.9</td>
<td>0</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td>Unstable</td>
<td>3</td>
<td>1</td>
<td>1.6</td>
<td>2</td>
<td>0.4</td>
<td>0.4</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>2</td>
<td>1</td>
<td>1.4</td>
<td>1</td>
<td>-0.4</td>
<td>-0.4+0.9+0.4 = 0.4 = .175</td>
</tr>
</tbody>
</table>
Acknowledgements

Contributions
PCOC wishes to acknowledge the valuable contribution made by:

- Members of the Management Advisory Board of PCOC
- 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
- The PCOC National staff at the Australian Health Services Research Institute, University of Wollongong, for the collation, analysis and reporting of the data
- 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 funding 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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