Palliative Care Outcomes Collaboration
Three years of progress
(2010 to 2013)

July 2013
Suggested citation:
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Abbreviations

ACP       Advance Care Planning
CAS       Casemix Adjusted Score
DoHA      Australian Government Department of Health and Ageing
IT        Information Technology
MOU       Memorandum of Understanding
NSAP      National Standards and Assessment Program
PCOC      Palliative Care Outcomes Collaboration
PCPSS     Palliative Care Problem Severity Score
SAS       Symptom Assessment Scale
SNAP      Sub-Acute and Non-Acute Patients
Executive summary

The Palliative Care Outcomes Collaboration (PCOC) was established in mid-2005 and is funded under the National Palliative Care Program supported by the Australian Government Department of Health and Ageing. PCOC is an evidence-based, multi-dimensional, quality improvement initiative specifically designed to support continuous improvement in palliative care through routine clinical outcome measurement, periodic surveys and benchmarking. PCOC has divided Australia into four zones for the purpose of engaging with palliative care services, with each zone represented by a chief investigator from one of the four collaborating universities:

- Professor Kathy Eagar, Australian Health Services Research Institute, University of Wollongong
- Professor David Currow, Department of Palliative and Supportive Services, Flinders University
- Professor Patsy Yates, Institute of Health and Biomedical Innovation, Queensland University of Technology
- Assistant Professor Claire Johnson, Cancer and Palliative Care Research and Evaluation Unit, University of Western Australia.

The goal of the PCOC is to use standardised, validated, clinical assessment tools to benchmark and measure outcomes in palliative care and assist palliative care service providers to improve practice and meet the Palliative Care Australia Standards for Providing Quality Palliative Care for all Australians. Research to improve the evidence base for the clinical assessment tools is ongoing. Service providers are supported by quality improvement facilitators based in five locations across the country.

After an initial establishment phase, outcome measures were developed and introduced into the 6-monthly PCOC reports in 2009. Benchmarks for each outcome measure were then agreed on in 2009 and introduced into the PCOC reports in 2010. At that time it was anticipated that by June 2013 approximately six benchmark measures would be incorporated into the PCOC reports and annual benchmarking sessions conducted to discuss the results. For most of the time since 2010, a total of 16 benchmarks were reported to services. Currently there are 14 benchmarks.

The purpose of benchmarking is to drive palliative care service innovation and provide participating services with the opportunity to compare their service nationally. A key feature of the PCOC model is annual benchmarking workshops, attended by participating palliative care services from all over Australia, during which services compare their results and share the lessons they have learnt. Ten benchmarking workshops have been held in 2010, 2011 and 2012, attended by over 400 people from all over Australia.

Participation by palliative care services in PCOC is voluntary. It is estimated that over three-quarters of patients seen by specialist palliative care services are included in PCOC data collection. A pilot project to collect data on palliative care outcomes in residential aged care was commenced in 2012 and consultations are currently underway to examine the feasibility of establishing a system to collect data on paediatric palliative care outcomes.

During 2011, opportunities were identified to work collaboratively with the National Standards Assessment Program (NSAP) for palliative care (based at Palliative Care Australia in Canberra) and the palliative care knowledge network (CareSearch), based at Flinders University in Adelaide. The framework for this collaboration was the memorandum of understanding between the three organisations signed in December 2010. The most recent collaboration involved a series of workshops focusing on the use of evidence, standards and outcomes to improve the quality of palliative care.
The achievements of PCOC from 2010 to 2013 are impressive and include:

- A steady and consistent increase in the number of participating services (Section 2.1).
- A steady and consistent increase in the number of patients benefiting from a standardised approach to clinical assessment (Section 2.1).
- Delivery of a standardised education program to 1643 people, resulting in demonstrable improvements in confidence and understanding of clinical assessment (Section 2.2).
- Increased sophistication in data and information management (Section 3).
- Multiple, service-specific, improvements in the processes and systems of clinical assessment, care planning and care delivery (Section 4.4).
- Establishment of a system of outcome measures and benchmarks (Section 4.1), supported by benchmarking workshops (Section 4.2), to improve the quality of palliative care.
- Continual refinement in the production of user-friendly reports for participating services (Section 6.1).
- An ongoing research and development program to refine and expand the PCOC approach (Section 7).
- Development of Version 3 of the PCOC data set and incorporation of Version 3 into software systems (Section 7.1).
- Improvements in patient management, as demonstrated by reductions in the amount of time patients spend in the unstable phase of their illness (Section 8.1).
- Improvements in outcomes for symptom distress and problem severity (8.2).

These are significant and unique achievements in the field of improving outcomes for palliative care patients.
1 Introduction

The Palliative Care Outcomes Collaboration (PCOC) was established after extensive consultation within the palliative care sector over several years, advice to the Australian Government from the Palliative Care Intergovernmental Forum and several Department of Health and Ageing publications, particularly the *National Palliative Care Strategy Quality and Effectiveness Information Priorities 2003-2008*. In combination, these activities recommended the establishment of a service development centre which would fill the information gap for service providers toward achieving ‘continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia’ (Goal 2 of the National Palliative Care Strategy). PCOC evolved from this recommendation and was established in mid-2005, funded under the National Palliative Care Program supported by the Australian Government Department of Health and Ageing (DoHA).

PCOC is an evidence-based, multi-dimensional, quality improvement initiative specifically designed to support continuous improvement in palliative care through routine clinical outcome measurement, periodic surveys and benchmarking. PCOC is a collaboration between four research centres, one with expertise in health services research and three with expertise in palliative care, each led by a chief investigator:

- Professor Kathy Eagar, Australian Health Services Research Institute, University of Wollongong
- Professor David Currow, Department of Palliative and Supportive Services, Flinders University
- Professor Patsy Yates, Institute of Health and Biomedical Innovation, Queensland University of Technology
- Assistant Professor Claire Johnson, Cancer and Palliative Care Research and Evaluation Unit, University of Western Australia.

PCOC has divided Australia into four zones for the purpose of engaging with palliative care services, with each zone represented by a chief investigator. Service providers are supported by quality improvement facilitators based in five locations across the country (Wollongong, Brisbane, Melbourne, Adelaide and Perth).

The importance of data collection and the work of PCOC has been recognised in the Senate Inquiry *Palliative care in Australia*, published October 2012. The report recommended the development and introduction of consistent national data collection for palliative care and that governments encourage care providers to provide data to the PCOC and consider making the reporting of this data a condition of public funding. Considerable interest in the work of PCOC has been generated by the introduction of Activity Based Funding for sub-acute care, due to commence in July 2013.

Participation by palliative care services in PCOC is voluntary. It is estimated that over three-quarters of patients seen by specialist palliative care services are included in PCOC data collection. During 2011, opportunities were identified to work collaboratively with the National Standards Assessment Program (NSAP) for palliative care (based at Palliative Care Australia in Canberra) and the palliative care knowledge network (CareSearch), based at Flinders University in Adelaide. A memorandum of understanding between the three organisations was signed in December 2010 and has formed the basis for collaboration between the three organisations ever since.

The work of PCOC is complementary to that being undertaken by the Australian Institute of Health and Welfare, through their national palliative care performance indicators, and Palliative Care Australia, through the National Standards and Assessment Program (NSAP). The goal of PCOC is to assist palliative care services to improve practice and meet the Palliative Care Australia *Standards for Providing Quality*
Palliative Care for all Australians, supported by seven aims which are unchanged from when PCOC it was established:

1. Continue the development of a national benchmarking system to improve clinical palliative care outcomes in both the public and private sectors.
2. Produce information on the efficacy of interventions through the systematic collection of outcomes information in both the inpatient and ambulatory settings.
3. Develop clinical and management information reports based on the setting within which the service is provided; patient and carer information; the episode of care; and the phase of care or stage of illness.
4. Provide comparative quality and outcome data to participating palliative care providers for benchmarking purposes.
5. Provide ongoing education in the use and definition of quality and outcome data items, interpreting benchmark reports and outcome measures for participating services.
6. Provide annual reports that summarise the quality and outcomes of Australian palliative care services.
7. Aid in the development of research proposals and undertake research as appropriate, to refine the selected outcome measures over time.

The PCOC Management Advisory Board is responsible for executive management, with a membership that currently consists of an independent chair, a representative from each of the joint venture university research centres and a representative from the Palliative Care Working Group. The DoHA is invited to nominate an ex officio representative and the National Director of PCOC attends in an ex officio capacity. The Management Advisory Board meets twice a year.

The Executive Directors Group consists of the directors of the four collaborating centres and PCOC staff with a national managerial role. The Group is responsible for the day to day management of PCOC and for financial reporting and other accountability requirements. The governance of PCOC has been enhanced with the appointment in 2011 of Professor Katy Clark as the Clinical Director. The Executive Directors Group meets twice a year.

1.1 PCOC data structure

The purpose of the items included in the PCOC data set is to:

- provide clinicians with an approach to systematically assess individual patient experiences
- define a common clinical language to streamline communication between palliative care providers
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting, benchmarking and research.

Where possible, the PCOC dataset uses definitions from the National Health Data Dictionary. The Australian-National Sub-Acute and Non-Acute Patient classification (AN-SNAP) provides the basis for many of the data items (Eagar, Gordon et al. 2004; Eagar, Green et al. 2004). The same data are collected irrespective of setting. The data collection and reporting undertaken by PCOC occurs at three levels (Table 1) and is pivotal to understanding the PCOC model.
### Table 1  Levels of data collection

<table>
<thead>
<tr>
<th>Level</th>
<th>Data items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient level</td>
<td>Data items relating to patient demographics.</td>
</tr>
<tr>
<td>Episode level</td>
<td>Data items which focus on characterising the setting of palliative care service provision. They also provide information relating to the reasons why and how a palliative care episode starts/ends, the level of support a palliative care patient received both before and after an episode and (where applicable) the setting in which the patient died.</td>
</tr>
<tr>
<td>Phase level</td>
<td>Data items describing a palliative care patient’s stage of illness, functional impairment and levels of pain and symptom distress, using five clinical assessment tools.</td>
</tr>
</tbody>
</table>

The five clinical assessment tools provide the foundation for data collection and reporting:

1. **Phases of palliative care**, consisting of five clinically meaningful distinct periods known as phases identified by the needs of patients and their family and carers: stable, unstable, deteriorating, terminal, bereavement - post death support (Smith and Firns 1994; Smith 1996).

2. **Palliative Care Problem Severity Score (PCPSS)**, a screening tool used to measure the severity of physical and psychological problems. The PCPSS has four domains: the first three (pain, psychological/spiritual, other symptoms) are patient specific. The fourth domain measures family/carer problems associated with a patient’s condition or palliative care needs. The score triggers a more in-depth assessment (Smith and Firns 1994; Eagar, Gordon et al. 2004).

3. **Symptom Assessment Scale (SAS)** which describes a patient’s level of distress relating to individual physical symptoms. The symptoms included in the scale are the seven most common experienced by palliative patients: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. The instrument is ideally a patient-rated tool but is structured to allow either the patient, family member or clinician to assess the symptoms (Aoun, Monterosso et al. 2011).

4. **Resource Utilisation Groups - Activities of Daily Living (RUG-ADL)**, which describes level of functional dependence. It is a four-item scale measuring motor function with activities of bed mobility, toileting, transfer and eating (Fries, Schneider et al. 1994).

5. **The Australia-modified Karnofsky Performance Scale (AKPS)**, a measure of a patient’s overall performance status or ability to perform their activities of daily living. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient’s ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate reduced ability to perform activities of daily living (Abernethy, Shelby-James et al. 2005).

Data using Version 1 of the PCOC dataset were collected between January 2006 and January 2007. Version 2 of the dataset was implemented from July 2007 and Version 3 of the dataset has been progressively implemented since July 2012.

Most data items are collected and reported routinely in a 6-month cycle, but some data items which are more time consuming to collect are collected periodically. New data items are based on the Leginski data model and aim to achieve substitution rather than accumulation of data (Leginski, Croze et al. 1989; Eagar, Watters et al. 2010).

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1 The unstable phase was originally referred to as the acute phase. This caused some confusion and was changed to ‘unstable’ in 1996.
1.2  Report structure

This report summarises the work and achievements of PCOC from March 2010 to June 2013. The report is structured according to the six functions of PCOC which have remained largely unchanged since PCOC began:

1. Supporting services to join and/or participate in PCOC.
2. Data and information management.
3. Service development, quality improvement and benchmarking.
4. Communications and marketing.
5. Reporting.
6. Research and development.

The six functions are not mutually exclusive. For example, there are overlaps between the communications and marketing and reporting functions. The report is completed by a section outlining improvements in patient outcomes, followed by a discussion of the achievements since 2010 and the drawing of some conclusions.
2 Supporting services to join and/or participate in PCOC

2.1 Recruitment and participation

There has been a steady increase in the number of services participating in PCOC (Figure 1).

Figure 1 Number of participating services and data volume, 2006 to 2012

Quality improvement facilitators are the ‘face’ of PCOC for much of the time and have a vital role in promoting two-way communication with participating services. They also facilitate recruitment of services, ensure timely submission of data and work with the Data Manager, Quality Manager and services to maintain high levels of data quality.

Participation is not restricted to specialist palliative care services. Any service providing palliative care after a formal admission process that is willing and able to collect the PCOC data set is welcome to join. The scope of participating services includes community services, non-government organisations, general hospitals and private hospitals. Many of the services that have joined PCOC in recent years have been quite small and often in more remote locations. In such services, data collection can be quite problematic and this is reflected in some of the services which have joined PCOC and then left. In December 2012, the Management Advisory Board decided to introduce a PCOC Certificate of Participation, first issued to services in April 2013.

Since the first report (April to September 2006), a total of 138 services have participated in PCOC. Of these, almost three quarters (72%) joined PCOC and are still submitting data, 6% joined, left and then re-joined PCOC and 22% have a history of joining PCOC one or more times but are not currently submitting data. The reasons for services leaving PCOC are many and varied but are generally to do with the local context, including the resources necessary for data collection and data entry, small numbers of patients, turnover of staff, IT issues and lack of executive support. In some cases data entry has been done by PCOC staff to get data collection established but this is not sustainable. Most of the services that have joined PCOC but are not submitting data at the present time are in rural locations. Some of these services are still using the PCOC tools in clinical practice, they just have no resources to collect and submit the data to PCOC. Likewise, there are services using the PCOC tools who have never joined PCOC, primarily for the same reasons, particularly IT issues.
### 2.2 Assessment workshops

Since PCOC’s establishment various education models have been implemented and evaluated. The aim of education is to inform the sector about the meaning, purpose and use of PCOC as a quality improvement program for palliative care. Between 2010 and 2011 education was provided to services on-site via short individualised sessions focusing on the collection of data. Evaluation of the outcomes of this education led to the development of resources to strengthen the focus on clinical assessment, the sharing of information between services and the use of online resources.

In 2011 a model of full-day assessment workshops targeting clinicians using the PCOC assessment tools was implemented in NSW. Evaluation provided evidence for a national roll out in 2012. Between 2011 and May 2013, a total of 83 assessment workshops were delivered (Table 2), attended by 1643 people, the majority of which (93%) were nurses.

### Table 2 Location of assessment workshops

<table>
<thead>
<tr>
<th>State</th>
<th>Number of workshops 2011</th>
<th>Number of workshops 2012</th>
<th>Number of workshops 2013 (Jan-May)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>11</td>
<td>17</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Queensland</td>
<td>1</td>
<td>12</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Victoria</td>
<td>1</td>
<td>10</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>South Australia</td>
<td>0</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Western Australia</td>
<td>0</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Tasmania</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>13</strong></td>
<td><strong>50</strong></td>
<td><strong>22</strong></td>
<td><strong>85</strong></td>
</tr>
</tbody>
</table>

A suite of resources were developed for use in the workshops including, a lesson plan, evaluation form, handouts, PowerPoint presentation and Certificate of Attendance. Most of these resources are available to download from the PCOC website. In addition to the full-day workshops, some smaller, half-day workshops were also run in rural locations.

In 2012, participants were invited to complete an online survey three months after attending a workshop to gain an indication of how workshop attendance improved confidence in using the clinical assessment tools and influenced clinical practice. An open-ended question in the survey resulted in a range of responses which indicate how the clinical assessment tools promote a standardised approach to clinical assessment and influence aspects of care such as care planning and symptom management:

- *I understand the significance of using the tool effectively in my daily work life.*
- *[It is] fantastic to have a standardised tool.*
- *Continuity/tracking of symptoms is better.*
- *Previously we had not done enough patient rated scores for SAS, or rated them daily, now all staff are using this tool more effectively.*
- *Using the tools and comparing scores is a good way of assessing changes in patients symptoms and condition.*
- *I gained a greater understanding of the phases which altered my practice.*
- *Using the pcoc language has improved ability to discuss assessment with other staff members.*
- *All staff are now using the tools to plan care and communicate within the team.*
The true test of an education program is whether it results in changes in clinical practice. The post-assessment workshop survey provides evidence of how the common language of the clinical assessment tools has improved communication between team members and resulted in changes to documentation, team meetings, referrals, patient handovers and discharge arrangements (Figure 2). Eighty-one per cent of those responding to the survey said that attending an assessment workshop had changed the way they assess patients.

**Figure 2**  Using clinical assessments to improve daily practice

Have you made any changes to the way you use the assessments as a communication tool in your daily practice? Please tell us by selecting from the following:

- No Change
- Other
- Between team members
- Referrals
- Discharge
- Documentation
- Team meetings
- Handover

2.3 Development of a PCOC Assessment Toolkit

In 2010, an education review identified two main areas for improvement, the availability of standardised resources for clinicians and the use of the PCOC website as a source of information. A project commenced to develop resources for clinicians with a focus on self-directed learning. A series of assessment tool resources were released on the PCOC website in July 2011 and the PCOC Assessment Toolkit was released in July 2012 via hard-copy, USB flash drive and on the PCOC website. The Toolkit consists of self-directed modules focusing on the five PCOC assessment tools and includes case studies, a DVD, videos and Powerpoint presentations on each of the assessment tools. The expected outcomes from use of the Toolkit are an increase in services conducting their own PCOC education sessions and the PCOC assessment tools embedded in practice.

2.4 Webinars and e-learning

Since 2011, PCOC has used webinars (on-line workshops or training sessions) as a platform for education. Webinars are useful for short sessions focusing on a particular topic and have been used to provide education for data entry (two in 2012, three in 2013) and also for special interest group sessions. The latter was trialed in December 2012 and allowed individual clinicians from palliative care services to present their own quality improvement activities using data from their PCOC outcome reports to an audience of 20 other services. Three webinar-style training sessions were delivered in early 2013 to assist users with the introduction of the latest version of SNAPshot, developed to collect Version 3 of the PCOC dataset.
In recent times, requests for e-learning have increased. PCOC has identified the need for e-learning to supplement the assessment workshops, short education sessions and current web based resources. PCOC is currently investigating options for learning management systems and a development plan is underway.

2.5 Information technology support to services

Approximately 65% of participating services use the SNAPshot software which is supplied free of charge by PCOC. Between January and March 2013, services using SNAPshot were able to upgrade to version 3.90 which incorporates the Version 3 dataset. This was supported with the release of the manual *Using SNAPshot 3.90 to collect the PCOC Version 3 Dataset* to assist services with the upgrade. Ongoing practical support is provided through face-to-face visits, webinars and phone conversations. PCOC also provides assistance for newly participating services through assisted installation, training for data entry personnel and education for clinicians using the PCOC assessment tools.

Financial support, in the form of site grants, has been provided to other services to upgrade their software. Currently, the PCOC data set is in the process of being incorporated into six jurisdictional, commercial or in-house systems used by palliative care services across Australia. PCOC is also working with an additional ten IT system developers to have the data set incorporated.

The PCOC team has always provided support to developers of data entry systems, through comprehensive data set documentation and advice relating to the data items and structure. With the employment of an IT Coordinator within the Australian Health Services Research Institute, PCOC has been able to provide a higher level of technical support to new projects, such as the Northern Beaches Palliative Care data entry system, which has been approved for use in NSW.

3 Data and information management

Within this function there are two main objectives:

- Development and refinement of the PCOC data set.
- Provision of a data bureau (with associated statistical support) to undertake data collection, data analysis and data reporting.

PCOC continues to work to resolve many of the IT barriers that make it difficult for services to collect and submit the PCOC data set. To avoid burdening palliative care services with multiple data entry requirements, PCOC has committed to working with palliative care services and jurisdictions to embed the PCOC data set in existing systems, as well as systems under development.

Since 2010, the following work has been accomplished:

- Development of the Version 3 quality and outcome data set.
- Further development and refinement of data bureau systems.
- Receipt and checking of quality and outcome data.
- Statistical analysis resulting in reports to services.
- Improved software systems and processes for data checking and reporting.

The key element of this work was the development of the PCOC Version 3 data set, further details of which are provided in Section 7.1.
PCOC DataManager System

In line with the roll out of the Version 3 data set, PCOC has developed an in-house system for managing data to replace the previous Access-based data system. This system, entitled PCOC DataManager, handles both PCOC Version 2 and Version 3 data.

PCOC DataManager provides improved data submission, data quality reporting and data extraction. It is designed to be suitable for statistical analysis with vast improvements in data quality checking. The outcome is higher quality reporting due to a much improved data quality report, providing better feedback to services and more complete analysis with less records being rejected due to issues with just one (or some) data item(s).

Currently, PCOC DataManager is implemented as a Windows desktop application, requiring the manual processing of extracts submitted via email. However, the system is designed to be able to ‘plug-in’ to a web-based data submission system that would allow services to submit data securely over the internet and receive instant feedback in the form of a data quality report.

The Australasian Rehabilitation Outcomes Centre, another of the centres within the Australian Health Services Research Institute, has developed a web-based infrastructure for data submission. This system is already in use and there are opportunities to leverage this infrastructure to provide a web-based data submission system, using PCOC DataManager as the engine to process and store data.

In addition to the improvements provided by PCOC DataManager, the processes surrounding data submission and quality checking have been streamlined and refined. PCOC has developed a data summary report which highlights and summarises systemic data collection problems. This will identify those facilities that do not, for example, collect Symptom Assessment Scale scores. Another proposed amendment is to record the number of errors by error type for each service. This is to help identify training needs and will be used by PCOC staff when they visit the service as they will have an accurate record of where services are experiencing difficulties collecting data. The PCOC Data Manager will continue to work with quality improvement facilitators to interpret these reports and provide necessary training.

4 Service development, quality improvement and benchmarking

4.1 Outcome measures and benchmarking

A suite of four outcome measures and 16 benchmarks were introduced after an extensive process of consultation in 2009 and first reported to services in Report 8 (July to December 2009), distributed to services in March 2010. Establishing the level for each benchmark was based on the results achieved by the top 10% of the best-performing services. For most of the time since 2010, 16 benchmarks were reported to services. This was reduced to 14 benchmarks in early 2013 with the amalgamation of three benchmarks for time in the unstable phase into one benchmark. The rationale for this change is explained in Section 8.1. All the current outcome measures and benchmarks are summarised in Table 3.

Outcome Measure 4 includes a suite of casemix 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), referred to as the X-CAS. The X-CAS benchmarks are calculated relative to a baseline reference period (currently July-December 2008), facilitating comparisons over time.

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2 X represents the fact that multiple symptoms are included and CAS is an abbreviation for Casemix Adjusted Score
3 If X-CAS is greater than 0 then on average, patients’ change in symptom was better than similar patients in the baseline reference period.
   If X-CAS is equal to 0 then on average, 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, patients’ change in symptom was worse than similar patients in the baseline reference period.
Table 3  PCOC outcome measures and benchmarks

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>Benchmark description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcome Measure 1: Time from referral to first contact</td>
<td>Benchmark 1: Patients contacted on the day of, or the day after referral.</td>
</tr>
</tbody>
</table>
| Outcome Measure 2: Time in unstable phase (2009 to 2012) | Benchmark 2.1: Patients in the unstable phase for less than 7 days – first phase of episode.  
Benchmark 2.2: Patients in the unstable phase for less than 7 days – not first phase of episode.  
Benchmark 2.3: Median time patients are in the unstable phase. |
| Outcome Measure 2: Time in unstable phase (introduced in 2013) | Benchmark 2: Patients are in the unstable phase for 3 days or less. |
| Outcome Measure 3: change in pain | Benchmark 3.1: PCPSS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end.  
Benchmark 3.2: PCPSS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end.  
Benchmark 3.3: SAS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end.  
Benchmark 3.4: SAS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end. |
| Outcome Measure 4: problem severity | Average improvement on the 2008 baseline national average (X-CAS) for:  
Benchmark 4.1: Pain  
Benchmark 4.2: Other symptoms  
Benchmark 4.3: Family/carer  
Benchmark 4.4: Psychological/spiritual |
| Outcome Measure 4: symptom distress | Average improvement on the 2008 baseline national average (X-CAS) for:  
Benchmark 4.5: Pain  
Benchmark 4.6: Nausea  
Benchmark 4.7: Breathing problems  
Benchmark 4.8: Bowel problems |

The benchmarks have been well received and form the basis for demonstrating improvements in patient outcomes achieved over the last three years (see Section 8). The approach to feeding back information regarding the benchmarks has been constantly refined to be user-friendly (in both written and verbal form), concise and meaningful. A good example of this are the ‘wave’ diagrams used in the PCOC reports to present data for some of the benchmarks. The one figure shows the results for all services involved in PCOC (separated into inpatient and ambulatory/community settings), the level at which the benchmark has been set, and the position of the relevant service (Figure 3). This allows for easy comparison, not only with the benchmark but also with the results for all other services.

Although definitions of benchmarking vary, the common themes include measurement, comparison, identification of best practices, implementation and improvement (Anand and Kodali 2008), all of which are evident in the PCOC approach. There is good evidence regarding the use of benchmarking across a very diverse range of settings to improve quality (Dattakumar and Jagadeesh 2003). The published material focusing on health care is relatively sparse and there are opportunities for PCOC to make an important contribution to this literature.
No new benchmarks have been introduced since 2009 but two new outcome measures were proposed at the meeting of the Executive Directors Group in December 2012 and subsequently endorsed by the Management Advisory Board:

1. Family and carer outcomes as measured by the Palliative Care Problem Severity Score.
2. One additional symptom – breathing, based on the Symptom Assessment Scale.

Technical work will be undertaken before introducing new benchmarks based on these outcome measures.

### 4.2 Benchmarking workshops

Ten benchmarking workshops have been held between 2010 and 2012, with over 120 attending each year from over 70 services (Table 4). Anecdotal evidence, from some of those who have attended multiple workshops, is that discussions at the workshops have been characterised by increasing sophistication and maturity over the years, as participants gain a greater understanding of benchmarking and its role in the PCOC approach. Services have become more confident and willing to share their experiences, both positive and negative, in an environment they know and trust. This is important if services are to collaborate and learn from each other.

**Table 4: Attendance at benchmarking workshops, 2010 to 2012**

<table>
<thead>
<tr>
<th>Year</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of workshops</td>
<td>3</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Number of services represented</td>
<td>85</td>
<td>70</td>
<td>78</td>
</tr>
<tr>
<td>Number of participants</td>
<td>150</td>
<td>127</td>
<td>132</td>
</tr>
</tbody>
</table>
2010 workshops

Three benchmarking workshops were held in June/July 2010 in Sydney, Brisbane and Adelaide. Results for the outcome measures were presented, and participating services had the chance to engage and network with other services about their benchmark results. An interactive quality improvement activity on pain management was held in the afternoon session of each workshop. Evidence about changing clinical practice was presented followed by table top work on analysis of barriers to improving pain management and ways of overcoming them. Each service gave brief feedback on what their most significant barrier was and how they planned to tackle it. Based on written evaluations, many services left the workshops with a better understanding of the PCOC benchmark measures, motivation to improve consistency of data collection, plans for better policies around pain management, ideas from other services about using their PCOC data for quality improvement and generally welcomed meeting and sharing information with other services.

2011 workshops

Four benchmarking workshops were held in June 2011, one in Melbourne, one in Brisbane and two in Sydney. Services were grouped with ‘like’ services rather than on a geographical basis. The morning session aimed to stimulate discussion about the results of the four benchmark measures included in Report 10. The afternoon included speed networking sessions where participants moved around the room for short chats with other services to share information. It was an opportunity to learn from others about their experiences regarding what works and what doesn’t work, and discuss system improvement strategies in three areas – time in the unstable phase, pain management and bowel management.

Three main areas were identified as the strengths of the workshops: (1) grouping like services in the workshops, (2) the speed networking sessions and (3) improved understanding of how to use their PCOC data. Comment was made on the standard of facilitation, with a good mix of small-group work and larger discussions, with particular note made of the speed networking sessions allowing for detailed discussion and sharing of ideas and resources. Discussions in these sessions were informative and enhanced services understanding about strategies for making improvements back in their workplaces. The networking sessions allowed for cross-pollination of ideas and solutions to issues and further informed practice by listening to other services.

2012 workshops

In 2012, three workshops were held in Sydney in October on consecutive days. Services were grouped into three workshops with representatives of ‘like’ services attending on the same day. Feedback from the 2011 benchmarking workshops was used to design the format and content of the workshops.

The morning of each workshop included a presentation on the latest benchmark reports and a presentation on Activity-Based Funding to provide opportunities for questions and discussion of any implications of Activity-Based Funding for palliative care services and PCOC.

The afternoon of each workshop comprised small group-work (10-15 people) designed so that participants from services with similar models and characteristics could share ideas and experiences related to clinical practice and quality improvement. Each group was assigned a facilitator and a scribe from amongst the PCOC staff to report back to the larger group. The groups considered the use of the Symptom Assessment Scale (SAS), the Palliative Care Problem Severity Scale (PCPSS) and the six-monthly patient outcome reports. Examples given by participants in the small-group work of how use of the SAS and PCPSS can influence improvements in patient care can be found in Section 4.4.

Attendees were invited to complete an evaluation of the workshops, resulting in a response rate of 89% and very positive feedback regarding the workshops. Ninety-five per cent of respondents agreed that the
morning session on the benchmarking reports had improved their understanding of the reports and 97% of respondents agreed that the facilitation of the group-work sessions in the afternoon promoted useful discussion (Figure 4). A report on the 2012 benchmarking workshops was compiled, distributed to services in April 2013 and made available on the PCOC website.

**Figure 4 Feedback on benchmarking workshops, October 2012**

4.3 Surveys of patient and carer experiences

Surveys of patient and carer experiences were conducted in 2008, 2009, 2010 and 2011 (Table 5) using a modified version of the Patient Outcomes Scale (POS) (Hearn and Higginson 1999). The results of each survey were fed back to participating services (with the results for their own service) and the results aggregated to produce national reports which are available on the PCOC website.

**Table 5 Participation in annual patient/carer surveys**

<table>
<thead>
<tr>
<th>Year</th>
<th>No. of participating services</th>
<th>No. of responses from patients</th>
<th>No. of responses from carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>25</td>
<td>570</td>
<td>486</td>
</tr>
<tr>
<td>2009</td>
<td>22</td>
<td>477</td>
<td>435</td>
</tr>
<tr>
<td>2010</td>
<td>12</td>
<td>382</td>
<td>348</td>
</tr>
<tr>
<td>2011</td>
<td>15</td>
<td>353</td>
<td>324</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>1782</td>
<td>1593</td>
</tr>
</tbody>
</table>

The results indicate that patients can still experience high levels of pain and other symptoms despite the involvement of a specialist palliative care service, with 58% reporting mild levels of pain and 25% severe pain. The responses from patients indicate that, after adjustment for confounding, higher levels of pain, and other symptoms were associated with higher levels of patient and family anxiety, problems with
The results of the four surveys are currently being written up into two papers that will be submitted for publication in peer-reviewed journals.

### 4.4 Improvements in systems and processes of patient care

Over the last 2-3 years it has become apparent that improvements in patient care have tended to result from multiple, small, changes implemented in the course of daily practice rather than as a result of large, formal, quality improvement projects. There has been considerable work to improve the use of the tools and embed the tools within existing processes and systems. At a workshop for ‘PCOC champions’ in 2010, participants identified many benefits from implementing the PCOC clinical assessment tools (Section 4.6). Elsewhere in this report (Section 2.2) there is evidence that attendance at the assessment workshops implemented since 2011 has improved communication between team members and resulted in changes to documentation, team meetings, referrals, patient handovers and discharge arrangements.

Small-group work at the 2012 benchmarking workshops identified various ways in which one of the clinical assessment tools (the Symptom Assessment Scale) is used in daily practice:

- To trigger a referral or review.
- In handover, as a way to highlight issues.
- To guide discussion at team meetings.
- Incorporated into symptom-specific care plans.
- To target staff education e.g. complex patients with nausea.

In some services, particular scores using the Symptom Assessment Scale, trigger specific action. Service-specific examples include: a score greater than 4 has to be entered into the patient’s care plan and actioned; the symptoms with the highest scores are flagged and become the focus of care; a score of 8 or more triggers notification to a doctor.

The 2012 benchmarking workshops also provided evidence of the ways in which another of the assessment tools, the Palliative Care Problem Severity Score, is used as a screening tool and to trigger interventions and referrals:

- To direct discussion in team meetings.
- To make changes to care plans.
- To refer to other members of the team for more in-depth assessment, especially when problems are considered to be moderate or severe.
- To communicate with team members.
- To trigger medical staff involvement in clinical management of the problem.
- Provide validation to support clinicians when referrals are being made.
- Used as a communication framework during handovers.
- Useful for agency and casual staff to give them a concise, comprehensive, assessment of each patient.
- Triggers action for day-to-day changes.
- Identifies the need for allied health involvement in patient care.
- Use of the family/carer score in case conferences

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4 Results taken from abstract accepted for the 2013 National Palliative Care Conference to be held in September 2013: Pidgeon T, Johnson C, Banfield M, Eagar K Pain and other symptoms of patients in Australian palliative care services.
Further details of the ways in which the PCOC tools have been embedded in clinical practice can be found in the paper by Rawlings et al. (2011).

4.5 Working Together Change Framework

In 2012, workshops entitled ‘Working Together Change Framework’ were developed by the NSAP, CareSearch and PCOC to assist palliative care professionals where they have identified an area they need to improve and require assistance to start the process of change. The workshops were designed to support attendees to identify a problem, analyse the cause, source evidence and measures, create an implementation plan and review what happens. The model was developed and presented at 3-hour workshops held in Adelaide, Perth, Melbourne, Launceston, Dubbo and Brisbane in between August 2012 and April 2013. A PCOC quality improvement facilitator facilitated part of each workshop. The workshops focused on how services can link standards, outcomes and evidence to improve the quality of care:

An evaluation survey was provided on the day of each workshop, emails were sent out at three weeks and six weeks with further resources, and a final survey was sent at eight weeks to find out how services had used the information gained from the workshops to change their practices. The workshop surveys (n=77) had a 70% response rate, with 89% of respondents agreeing or strongly agreeing that the workshop had met their needs and 81% agreeing or strongly agreeing that they were more confident in applying an evidence-based approach to problem solving. The survey at eight weeks (n=72), had a 19% response rate. Of the 15 that responded 11 had considered the role of evidence in change activities, 8 were more confident about quality improvement activities and 8 had identified areas that they wanted to change.5

The results of the project will inform future PCOC activities to assist services with quality improvement.

4.6 PCOC Champions Workshop

A national workshop was held in Brisbane in March 2010 which brought together ‘PCOC champions’ from around the country. The workshop was attended by 26 people from 18 services, including doctors, nurses, clinical service managers and a quality manager. The purpose of the workshop was to share what had been learned about what works and what doesn’t work to embed PCOC standard clinical assessment tools into routine practice and how the PCOC data is used to trigger improvements in practice.

Common concerns identified at the workshop included the clinical assessments only being recorded at phase change (many inpatient services now undertake clinical assessments daily), the SAS often being rated by staff rather than patients, a problem with the definition of time from referral to first contact (addressed in the development of the Version 3 PCOC data set) and difficulty in interpreting the PCOC reports. It was agreed that factors enabling the use of the clinical assessment tools included executive support, having champions at various levels of the organisation, support from PCOC quality improvement facilitators, education, finalisation of documentation before use of the tools and incorporation of the clinical assessments into service policy. Barriers to implementation included resistance to change, the resources (time, money) required for data entry, lack of IT support, difficulty interpreting the PCOC reports and the time lag between collecting data and receiving reports back from PCOC.

The best things achieved by PCOC up until that time were found to be consistent, formally documented, symptom assessments; the linking of patient assessment to improved care; new referral, admission and triage tools that incorporate the assessments and discussion of phase at multi-disciplinary team meetings.

5 Results taken from abstract accepted for the 2013 National Palliative Care Conference to be held in September 2013: Rawlings D, Tieman J, Adams A, Mills S, Vaz H, Banfield M CareSearch, NSAP, PCOC: Evaluation of the Working Together Change Framework Workshops.
Participants identified many benefits from implementing the PCOC clinical assessment tools:

- Improved symptom management.
- Consistent, formal documentation of assessment.
- Assessment tools drive the focus of care.
- Consistent clinical picture of the individual patient.
- Acknowledgment of the carer/family as part of the unit of care.
- Provision of a common language.
- A seamless service between home, hospital and inpatient palliative care.
- Enhanced communication between patients, families and clinicians.
- Assessment across domains provides referral triggers.
- Complements the National Standards Assessment Program (NSAP).

5 Communications and marketing

5.1 Marketing strategy

A communication and marketing strategy was developed in 2011 which resulted in the adoption of a new logo and domain name (http://www.pcoc.org.au/), together with significant changes to the PCOC website and other project materials to reflect the rebranding of PCOC. An important change to the website has been the inclusion of materials to promote self-directed learning. Users of the website can find resources for educating themselves or their staff via the Education page. The resources can be printed or downloaded. The materials and useability of the website will continue to be revised to ensure that the best possible education is provided in response to any changes in circumstances.

PCOC continues to communicate its mission, its work and its benefits to the palliative care sector in different ways such as:

- Meeting with professional associations and state-based networks.
- Meeting with representatives of state health departments.
- Attendance at ad hoc meetings convened by groups of like-minded palliative care services requiring advice and support regarding outcomes measurement.
- Membership on various committees of professional bodies such as Palliative Care Australia and Palliative Care Nurses Australia.
- Contributions to newsletters published by other palliative care organisations.
- Exhibition stands, posters and oral presentations at state, national and international palliative care conferences. To highlight the collaboration, some conference exhibition stands were shared with NSAP and CareSearch.

5.2 Collaboration with professional organisations, government departments and other agencies

Collaborations with NSAP and CareSearch

The memorandum of understanding with NSAP and CareSearch was signed in December 2010. The purpose of the MOU is to establish a framework within which co-operation may develop between the three organisations and their respective projects. PCOC, NSAP and CareSearch have collaborated on and
jointly badged a number of items and activities including a 2012 wall planner; a fact sheet called 'Working Together: Evidence, Standards, Outcomes'; joint exhibition stands at conferences and the Working Together Change Framework Workshops (see Section 4.5). PCOC is represented on the Expert Reference Panel established by NSAP for a Support for Carers project being undertaken during 2013.

Other collaborations with NSAP and CareSearch have included:

- The annual conference of the Centre for Palliative Care Research and Education (CPCRE), held in Brisbane in April 2010. An interactive case study was presented by one of the PCOC chief investigators (Professor Patsy Yates), together with the directors of CareSearch and NSAP. The case study showcased the role that each of these national projects have to play in good pain management at the end of life.
- In September 2012, the CareSearch Director (Jen Tieman) presented a paper at the Australian and New Zealand Society of Palliative Medicine (ANZSPM) in Queenstown, New Zealand, on behalf of PCOC, NSAP and CareSearch.
- CareSearch has acted as a data repository for eight services submitting data to PCOC, two in Victoria, one in New South Wales and five in South Australia.
- The National Director of PCOC is a member of the National Advisory Group for CareSearch and the NSAP Steering Committee.
- The PCOC website contains links to other projects funded under the National Palliative Care Program and, in turn, the NSAP and CareSearch websites also include links to the PCOC website.

**Professional networks**

The PCOC team has an extensive network of contacts throughout the palliative care sector, a network that has been built up since PCOC began. These networks, both formal and informal, are vital in keeping in touch with what is going on in palliative care across the country. For example, one of the PCOC chief investigators (Professor Patsy Yates) has recently been appointed President of Palliative Care Australia, providing a good example of how those involved in PCOC play an important role in the sector more broadly.

**Links with governments and other agencies**

PCOC maintains an ongoing dialogue with jurisdictions to encourage greater national consistency and develop strategies for engagement with each jurisdiction according to local circumstances. For example, the NSW Agency for Clinical Innovation has recently established a Palliative Care Network for that state and PCOC has been involved in the Network from the beginning.

In Western Australia, PCOC is collaborating with the Western Australia Country Health Service (WACHS), the Western Australia Cancer and Palliative Care Network (WACPCN) and the Rural Palliative Care Specialist Group to implement a project to develop a network of health professionals in each WACHS region with a special interest in palliative care and to build their clinical palliative care skills to provide care for people in local communities with advanced illnesses at the end of life.

Known as the Palliative Care Quality Improvement Project, the project uses a train-the-trainer approach to train a minimum of two nursing staff in each health service within each WACHS region to become local palliative care link nurses. These nurses are provided with resources and supported to act as local mentors to train and support people within their organisation in the use of a local adaptation of the Liverpool Care Pathway and the five PCOC clinical assessment tools.

In Queensland, PCOC has been collaborating with the Metro North Hospital and Health Service (MNHHS) and the Metro North Brisbane Medicare Local to develop a project to meet an identified need for a framework to underpin community palliative care in the MNHHS. The project is funded by the Metro North
Brisbane Medicare Local which is, in turn, funded by DoHA and will be coordinated by Queensland University of Technology, under the leadership of one of the PCOC chief investigators, Professor Patsy Yates.

The project will pilot a new model of service delivery involving general practitioners, community nursing services and a specialist palliative care physician to improve coordination and communication in the management of palliative care patients in the community. The project will be delivered in two parts:

- Study 1 will examine the feasibility of implementing the new service model. The outcome of Study 1 will determine progression to Study 2.
- Study 2 will evaluate the intervention of the new service model.

**Collaboration with the Australian Institute of Health and Welfare**

In October 2012, the Australian Institute of Health and Welfare published the first of three proposed annual reports entitled *Palliative care services in Australia*. The report includes chapters on:

- Admitted patient palliative care
- Palliative care in general practice
- Services provided by palliative medicine specialists
- Palliative care in residential aged care
- Palliative care-specific medications
- Resourcing of palliative care services
- Palliative care outcomes

The chapter on palliative care outcomes is about the work of PCOC and includes sections on the PCOC data set, patient characteristics, episode length, palliative care phases and the PCOC outcome measures and benchmarks. All the data in the chapter were provided by PCOC and PCOC staff were involved in writing the chapter. In April 2013, PCOC data for the period January to December 2012 was sent to the Australian Institute of Health and Welfare to be included in the second edition of the report.

**Collaboration regarding Activity Based Funding**

Considerable interest in the work of PCOC has been generated by the introduction of Activity Based Funding for sub-acute care. Classification of inpatient palliative care for funding purposes relies on two of the five PCOC clinical assessment tools – phases and RUG-ADL (Eagar, Green et al. 2004). Since mid-2012, PCOC has provided data to be used for Activity Based Funding to the state health departments in Victoria, Queensland, Tasmania and Western Australian after obtaining consent from the relevant health services to release their data.

6 Reporting

6.1 Reporting the PCOC data

Reporting of the PCOC data set includes an individualised patient outcomes report for each participating service. The aim is to have reports back to services two weeks after the end of the data submission period to facilitate local analysis and decision making in a timely manner. In addition, reports are generated summarising the data for states and for the country as a whole, which are available on the PCOC website at
The website also includes an example of a service-level report (the *Birds Nest Palliative Care Service Report*). Participants at the 2012 benchmarking workshops repeatedly commented on the improved format and readability of the reports.

Prior to the production of the patient outcomes reports, the PCOC team meets to consider changes to the report to improve the feedback to services, particularly in respect to the benchmark measures. Programming is then required to modify the statistical program which automates the report generation process.

In the middle of 2011, a process was initiated to improve the presentation of statistical data in the 6-monthly patient outcome reports and a number of new perspectives were added to the reports, including the national benchmark profiles (see Figure 3 in Section 4.1) and pain progression charts.

The pain progression charts (Figure 5) are unique in clinical outcome improvement, as they succinctly display multi-dimensional data concepts and allow clinicians or service managers to focus patient case reviews on cases of particular concern i.e. where the care of individual patients does not meet the pain benchmarks. Since the introduction of the pain progress charts there have been an increasing number of requests to identify individual patients to conduct reviews.

**Figure 5  SAS pain at start and end of phase by phase type for Birds Nest Service**

### 6.2 Feeding back results to individual services

A key element of the PCOC model is using quality improvement facilitators to visit service providers and give verbal feedback on their six-monthly reports. Feedback by phone is provided if on-site visits are

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6 Because of the small number of services (and hence the potential to identify services) a state-level report is not produced for Tasmania.

7 “Birds Nest” is the colloquial term used to refer to a non-existent service, with dummy data compiled to illustrate how to interpret and use the data in the PCOC reports to services.
impractical. These visits have elements of two interventions for changing provider behaviour: (1) audit and feedback and (2) educational outreach visits:

- Audit and feedback is defined as any summary of clinical performance of health care over a specified period of time.
- Educational outreach visits are defined as the use of a trained person who meets with providers in their practice settings to give information with the intent of changing the provider’s practice. The information given may include feedback on the performance of the provider(s) (Cochrane Effective Practice and Organisation of Care Review Group (EPOC) 2007).

The evidence from the literature indicates that the effect of audit and feedback on professional behaviour and patient outcomes is quite variable, and that audit and feedback may be most effective when health professionals are not performing well to start out with, the person responsible for the audit and feedback is a supervisor or colleague, it is provided more than once, it is given both verbally and in writing, and it includes clear targets and an action plan (Ivers, Jamtvedt et al. 2012). The expertise of the quality improvement facilitators providing the verbal feedback, the repeated nature of the feedback and the targets provided by the PCOC benchmarks align well with this evidence about how to make audit and feedback effective. There is also evidence to suggest that differences in the characteristics of feedback (e.g. timeliness, credibility of source, format and punitive/non-punitive nature) may influence effectiveness (Hysong, Best et al. 2006), which is also reflected in the PCOC approach.

Education outreach visits (also known as university-based educational detailing, academic detailing, and educational visiting) have traditionally focused on changing the prescribing behaviour of doctors but the technique is very similar to the approach taken within PCOC of providing feedback to participating services. The evidence from the literature suggests that educational outreach visits improve the care delivered to patients although the results are quite variable (O’Brien, Rogers et al. 2007).

Report feedback sessions have been offered to services by quality improvement facilitators since the first reports were produced in April 2006. The number of these sessions has increased over time, with 78% of services receiving in-person feedback regarding their reports (Table 6).

<table>
<thead>
<tr>
<th>Year</th>
<th>No. of Reports</th>
<th>No. of in-person feedback sessions</th>
<th>Percentage of services receiving in-person feedback</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>173</td>
<td>141</td>
<td>82%</td>
</tr>
<tr>
<td>2010</td>
<td>178</td>
<td>135</td>
<td>76%</td>
</tr>
<tr>
<td>2011</td>
<td>201</td>
<td>151</td>
<td>75%</td>
</tr>
<tr>
<td>2012</td>
<td>204</td>
<td>165</td>
<td>81%</td>
</tr>
<tr>
<td>Total</td>
<td>756</td>
<td>592</td>
<td>78%</td>
</tr>
</tbody>
</table>

Attendance and participation usually ranges from executive level to data-entry personnel and provides opportunities for any member of a service to discuss quality improvement and practice change strategies. Typically, a key focus of discussion at the feedback sessions is the benchmarks for their individual service and how their service compares nationally.

A recent initiative has been the introduction (in April 2013) of a survey given to services at the time of the report feedback session. The survey asks services to agree or disagree (on a 5-point scale) with a series of statements regarding whether the feedback session was beneficial, identified opportunities for improvement, increased confidence in reading the reports and improved understanding of the report in
6.3 Reporting the results of research undertaken

Dissemination of the results of the research undertaken by PCOC are typically communicated to the palliative care community by way of conference presentations and publications in peer-reviewed journals. This activity also serves to build the evidence base that underpins the work of PCOC. Conference presentations focusing on the work of PCOC between 2010 and 2013 are detailed in Appendix A.

The following is a list of journal articles published since March 2010, based on the work of PCOC, by the chief investigators and staff employed by PCOC:


There is considerable potential to publish additional papers, with the only constraint being the availability of sufficient time and resources. There are currently several papers in various stages of preparation for publication. PCOC has a publication plan for journal articles which is reviewed twice-yearly at meetings of the Executive Directors Group.

7 Research and development

7.1 Development, testing and introduction of Version 3 data set

Version 3 of the data set was developed through broad consultation with service providers and representatives of peak organisations from across Australia, including four meetings of the PCOC Version 3 Dataset Working Group in 2010. The consultation process identified the need to ensure that the new data items are meaningful to service planners, managers and clinicians and provide outcomes that provide opportunities for quality improvement. The main changes involved improving and consolidating existing data items, and ensuring that items were appropriate in the context of palliative care. The consideration of the burden placed on palliative care services through the collection and entry of the data was also a high
consideration. Items have changed to be consistent with National Health Data Dictionary wherever possible.

Implementation of the Version 3 data set has been staggered, primarily due to the necessary IT system modifications that were required. The data items in the Version 3 data set were articulated in a specification document issued at an industry briefing held in May 2012 in Melbourne which provided an opportunity for clinical staff and software developers working with PCOC to understand the changes to the data set and how the collection and extraction of the data impacts on the measurement of patient outcomes.

A Version 3 Data Dictionary and Technical Guidelines document has been developed and was disseminated to all PCOC IT software providers during July and August 2012. A PCOC Clinical Reference Manual for the Version 3 data set has also been developed, designed for use by clinicians, managers, quality improvement personnel, administration and data-entry personnel. The Clinical Reference Manual provides a clinical guide to the collection and use of the information submitted to PCOC in order to receive a patient outcomes report. PCOC continues to work with various software providers to review and test software systems that incorporate the Version 3 data set.

It is expected that a majority of participating services will be submitting Version 3 data by July 2013. The first report on the Version 3 data set will be released in September 2013, covering the period January 2013 to June 2013.

7.2 Surveys of advance care planning in palliative care

Since the establishment of PCOC, annual periodic surveys have largely concentrated on surveying patient/carer experiences for the purposes of service development and quality improvement (Section 4.3). For the latest annual survey, PCOC collaborated with Respecting Patient Choices to develop two surveys (one for managers and one for clinicians) to collect data on the knowledge, opinions and practices regarding advance care planning (ACP) in palliative care. The two surveys were distributed to 105 PCOC services in February 2013.

The manager survey was completed by 59 palliative care service managers. Data analysis is yet to be completed but preliminary results indicate that:

- 95% of managers believed their service had a role in ACP, but only 60% of services offer ACP to half or more of their patients.
- 76% reported that their service formally record patients’ ACP wishes.
- 45% reported that ACP documents were always followed.
- 35% believed ACP was done well within their service.
- 90% reported that they discuss the patient’s end-of-life wishes.
- 57% of services had written policies and guidelines about ACP.
- 24% do not check for pre-existing ACP documents.
- 95% believed GPs have a role in ACP, yet only 35% of services routinely transfer completed ACP documents to GPs.

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8 Results taken from abstract submitted to the 2013 National Palliative Care Conference to be held in September 2013: Silvester W, Sellars M, Masso M, Johnson C, Sjanta R A national survey of palliative care service managers’ advance care planning practices and policies.
The clinician survey was completed by 73 people, with the results indicating that:

- 74% had counselled a patient or family about ACP.
- 42% had completed ACP training.
- In the past 6 months, and regardless of pre-existing training, 72-90% of staff discussed specific ACP topics, such as appointing a substitute decision maker, medical treatment options, and end of life wishes.
- Within their service, 64% were satisfied with the support provided to discuss ACP with patients.
- 82% reported that ACP documents were followed.
- 41% believed ACP was done well.
- 69% were confident initiating ACP discussions with patients, but only 39% were confident knowing the state laws about ACP.\(^9\)

The results suggest ways in which ACP in palliative care could be improved, including education to improve knowledge of ACP, better communication with general practitioners and improvements to policies and documentation. Once data analysis is completed a full report will be prepared and distributed to DoHA and services participating in PCOC.

### 7.3 Phase and problem severity study

Extensive consultation took place in 2011 to revise the definitions for the phases of palliative care, one of the five clinical assessment tools upon which PCOC is based. This resulted in definitions for when each phase ends, whereas up until this was done there were only definitions for when each phase commences. The revised definitions are now part of the PCOC education program and a toolkit including the revised definitions is available on the PCOC website. The revised definitions are included in Appendix B. This work prompted the need for a study to test the reliability and acceptability of the revised definitions. It was decided to combine this with further research on the reliability and acceptability of another of the clinical assessment tools – the Palliative Care Problem Severity Score.

The study commenced in early 2013 with data collection due to be completed in June 2013. The study involves two clinicians independently assessing patients in their care using each tool, at approximately the same time. Participating clinicians are asked to provide some details regarding their job title, profession, length of clinical experience and any training in use of the tools. For each patient they assess, clinicians are asked to rate how difficult it was to assign a phase of care or problem severity score and how well their assessment ‘fitted’ the needs of the patient.

Ten services agreed to participate, nine in NSW and one in Western Australia. The services involved in NSW are Sacred Heart, Calvary Health Care Sydney, St Joseph’s Hospital, Neringah Hospital, Greenwich Hospital, Port Kembla Hospital, David Berry Hospital, Calvary Mater Newcastle and Mt Druitt Hospital. The Western Australia service is at St John of God Hospital, Bunbury.

The results of the study will inform ongoing use of both tools in palliative care services throughout Australia and may well suggest opportunities for further research to improve the evidence base for the clinical assessment tools. The Phases of Care provide the basis for Activity Based Funding in palliative care.

\(^9\) Results taken from abstract submitted to the 2013 National Palliative Care Conference to be held in September 2013: Silvester W, Sellars M, Masso M, Johnson C, Sjanta R *Advance care planning knowledge, opinions and practice of Australian palliative care service staff*. 
7.4 Development of a paediatric data set

Initial discussions regarding the development of a paediatric palliative care data set took place in 2009 and 2011 between representatives of PCOC and paediatric palliative care services. In May 2012, two representatives from PCOC met with the Australasian Paediatric Palliative Care Reference Group and a literature review commissioned by PCOC was sent to the Reference Group in July 2012. The report of the literature review includes recommended tools for three age groups (under 5 years of age, 5 to 9 years of age and 10 to 18 years of age) for the domains of self-reported pain, observer-rated pain, health-related quality of life, function and family impacts.

Concurrently, there has been interest in New South Wales regarding the development of a paediatric data set, triggered by the publication of the NSW Health Paediatric Palliative Care Planning Framework 2011-2014. Three meetings have been held with the NSW Paediatric Palliative Care Statewide Implementation Group (in August 2012, November 2012 and February 2013) to discuss the collection of outcomes data in NSW. At the last of these meetings there was support for collecting data on phases of palliative care, the clinician-rated Palliative Care Problem Severity Score and a patient-rated pain score. It was also agreed that two representatives from PCOC would visit the three NSW paediatric palliative care services in April and May 2013 to further explore the feasibility of collecting outcomes data for paediatric palliative care.

The developments in NSW were considered at the March 2013 meeting of the Australasian Paediatric Palliative Care Reference Group. The Reference Group was supportive of the work being undertaken in NSW but did not commit to a national approach. The importance of the phases of palliative care in adult practice was acknowledged but the applicability of phases to paediatrics was considered to be uncertain and requiring more evidence. The Reference Group would like to develop a simple and meaningful method of data collection for paediatrics and requested that the NSW representatives report back to a future meeting on progress in NSW.

The ability of PCOC to develop a dataset for paediatrics very much depends on the small number of providers (10 in Australia) in this very specialised field working together to develop a common language of their own. For outcome measurement and benchmarking to be meaningful it would require virtually all the current providers to agree on a particular approach.

7.5 Pilot project in residential aged care

Since early 2012, a pilot project has been underway in one facility in Sydney to test the feasibility of using the PCOC clinical assessment tools in residential aged care. Staff from the facility attended one of the PCOC assessment workshops, which was supplemented by further on-site education. Twenty residents were assessed as being suitable for assessment using the tools. The project was strongly supported by the management of the facility and designated PCOC champions, with additional support from the local specialist palliative care service and one of the PCOC quality improvement facilitators.

The project has yet to be formally evaluated, but there is some evidence to indicate that the project has resulted in greater understanding of residents and their needs and opportunities for quality improvement have been identified from the data collected. The palliative care phases and the Palliative Care Problem Severity Score have been useful in providing a framework for discussions of terminal care. The facility submitted their data to PCOC and has been provided with an outcomes report, using the same format as for other services involved in PCOC.
7.6 Referrals to palliative care and socio-economic disadvantage

Using data from the PCOC database a study was undertaken to investigate the links between socio-economic disadvantage, referral patterns to specialist palliative care and proximity to inpatient services. Details of the study are summarised in the abstract of the article published in *BMC Health Services Research* which resulted from the research:

**Title**
Referral patterns and proximity to palliative care inpatient services by level of socio-economic disadvantage. A national study using spatial analysis

**Background**
A range of health outcomes at a population level are related to differences in levels of social disadvantage. Understanding the impact of any such differences in palliative care is important. The aim of this study was to assess, by level of socio-economic disadvantage, referral patterns to specialist palliative care and proximity to inpatient services.

**Methods**
All inpatient and community palliative care services nationally were geocoded (using postcode) to one nationally standardised measure of socio-economic deprivation – Socio-Economic Index for Areas (SEIFA; 2006 census data). Referral to palliative care services and characteristics of referrals were described through data collected routinely at clinical encounters. Inpatient location was measured from each person’s home postcode, and stratified by socio-economic disadvantage.

**Results**
This study covered July – December 2009 with data from 10,064 patients. People from the highest SEIFA group (least disadvantaged) were significantly less likely to be referred to a specialist palliative care service, likely to be referred closer to death and to have more episodes of inpatient care for longer time. Physical proximity of a person’s home to inpatient care showed a gradient with increasing distance by decreasing levels of socio-economic advantage.

**Conclusion**
These data suggest that a simple relationship of low socioeconomic status and poor access to a referral-based specialty such as palliative care does not exist. Different patterns of referral and hence different patterns of care emerge (Currow, Allingham et al. 2012).

The study provides an excellent example of how the PCOC database can be used to answer important clinical and policy questions.

8 Improvements in patient outcomes

Patient outcomes are the ultimate test of whether PCOC is achieving what it set out to achieve. This is best demonstrated by collecting data on patient outcomes at the time of care delivery, regardless of the setting in which that care takes place. This section refers to the evidence supporting improvements in patient outcomes in two areas – time in the unstable phase, and changes in patient symptoms. National data for all 16 benchmarks since benchmarking commenced are included in Appendix C.

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11 The reference for the material in this paragraph is a paper currently being prepared by the PCOC chief investigators and data manager entitled *Can hospice/palliative care outcomes be systematically improved?*
8.1 Time in the unstable phase

Outcome Measure 2 is time in the unstable phase, measured by three benchmarks:

- Benchmark 2.1: Percentage of patients in the unstable phase for less than 7 days – first phase of episode (for which the national benchmark is 85%).
- Benchmark 2.2: Percentage of patients in the unstable phase for less than 7 days – not first phase of episode (national benchmark = 90%).
- Benchmark 2.3: Median time patients are in the unstable phase (national benchmark = 2 days).

For both the percentage of services meeting each benchmark and the total number of patients in the unstable phase (across all services) there was a steady improvement in all three benchmarks between 2009 and 2012, as illustrated by the results for benchmark 2.1 (Figure 6) i.e. patients are spending less time in the unstable phase of their illness. The full results for all three benchmarks are included in Appendix C.

Feedback from services attending the 2012 PCOC Benchmarking workshops was that benchmarks 2.1 and 2.2 should be combined as the first phase/not first phase split did not provide any additional information. There was also general feedback that the ‘less than 7 days’ timeframe did not represent best practice and should be reduced. Analysis of data for Report 13, covering the period January to June 2012, identified that setting the benchmark at 90% for a length of unstable phase of 3 days or less resulted in a similar level of performance (between 91% and 100%) for the top 10 services as was achieved in 2009 for benchmarks 2.1 and 2.2. It was therefore decided to define the new benchmark as:

- Benchmark 2: 90% of patients are in the unstable phase for 3 days or less.

The new benchmark prompted reconsideration of Benchmark 2.3 which can be re-framed as ‘50% of patients remain in the unstable phase for 2 days or less’. Expressed in those terms, this benchmark was considered to be redundant and was removed from the suite of PCOC benchmarks. Benchmark 2 was
introduced into the feedback reports for Report 14 (covering the period July to December 2012), distributed to services in April 2013.

The data for time in the unstable phase since the establishment of the original benchmarks for this outcome measure provide an excellent example of the benchmarking approach, with a period of improvement being followed by a ‘lifting of the bar’ to establish a new (and more challenging) benchmark to measure performance.

8.2 Change in symptoms

Outcome measure 4 measures change in symptoms relative to a baseline national average, using the X-CAS. Eight symptoms are included in the calculation of the X-CAS: 12

<table>
<thead>
<tr>
<th>Palliative Care Problem Severity Score</th>
<th>Symptom Assessment Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Pain</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>Nausea</td>
</tr>
<tr>
<td>Family/carer</td>
<td>Breathing problems</td>
</tr>
<tr>
<td>Psychological/spiritual</td>
<td>Bowel problems</td>
</tr>
</tbody>
</table>

There have been steady, consistent, improvements in outcomes for symptom distress and problem severity for all the items included in the X-CAS (Figure 7, Figure 8 and Figure 9).

Figure 7 Percentage of services where the change in symptom score for pain is at or above the baseline national average

12 For further information about the X-CAS see Section 4.1.
Figure 8   Percentage of services where the change in symptom scores using the SAS are at or above the baseline national average

Figure 9   Percentage of services where the change in symptom scores using the PCPSS are at or above the baseline national average
9 Discussion and conclusions

The last three years have seen a steady and consistent increase in the number of participating services and the number of patients benefiting from a standardised approach to clinical assessment (Section 2.1). The education program has been continually updated and refined, resulting in demonstrable improvements in confidence and understanding of standardised clinical assessment (Section 2.2). The system of data and information management has been significantly improved, with major initiatives being the conversion from Version 2 to Version 3 of the PCOC data set and an upgrading of the central office systems of data management with the implementation of PCOC DataManager (Section 3).

The system of outcome measures and benchmarks (Section 4.1), which was in its infancy at the beginning of 2010, has matured and become well established, with the annual benchmarking workshops being well received and seen as an integral part of the PCOC model of outcome measurement and quality improvement (Section 4.2).

The 6-monthly PCOC reports have been continually refined to improve useability with, for example, initiatives such as the wave diagrams to present data for some of the benchmarks (Section 4.1) and the pain progression charts (Section 6.1). Research and development has included the development of Version 3 of the PCOC data set, a study to test the reliability and acceptability of two of the clinical assessment tools, initiatives in aged care and paediatrics and a study which used the PCOC data set to investigate the links between referrals to palliative care and socio-economic disadvantage (Section 7). The longitudinal PCOC data set is a rich source of data which presents many opportunities for further research.

PCOC has collaborated with NSAP, CareSearch, Respecting Patient Choices, the Australian Institute of Health and Welfare, professional organisations, government departments and other agencies over the last three years. In some cases these collaborations have been initiated by PCOC, in some cases by others. As a result of these collaborations, PCOC has become increasingly embedded within the palliative care sector. It is likely that in the future the distinction between what is PCOC and what is not PCOC will become more blurred, as the clinical assessment tools that provide the foundation of the PCOC model and the overall approach to outcomes measurement and quality improvement become ‘the way we do business around here’.

Improvements in patient care have tended to result from multiple, small, changes implemented in the course of daily practice rather than as a result of large, formal, quality improvement projects. There has been considerable work to improve the use of the five clinical assessment tools and embed the tools within existing processes and systems. The tools are used in all sorts of ways to improve patient care, e.g. to trigger referrals, improve communication between clinicians, guide discussion during multidisciplinary team meetings and improve care planning (Section 4.4).

In the last three years there has been a steady reduction in the amount of time patients spend in the unstable phase of their illness, to the point that the benchmark for time in the unstable phase has been made more difficult to attain, with the introduction of a new benchmark for time in the unstable phase in early 2013 (Section 8.1). This has been matched by steady, consistent, improvements in outcomes for symptom distress and problem severity (8.2).

In recent years the concept of communities of practice has become part of the language of health care, usually to describe a group the members of which do not share a common workplace. Communities of practice within health care have some or all of the following characteristics:

- Social interaction – interacting in formal or informal settings.
- Knowledge-sharing – sharing relevant information between individuals.
- Knowledge-creation – developing new ways of doing things.
- Identity-building – the process of acquiring an identity (Li, Grimshaw et al. 2009).

As communities of practice become more mature, all four characteristics tend to develop (Li, Grimshaw et al. 2009). PCOC has not generally been conceptualised in this way but clearly demonstrates features of a community of practice, with the assessment tools and the various other aspects of the PCOC model providing a ‘shared repertoire’ by which services can work together to improve the quality of care. This was evident in the most recent benchmarking workshops held in Sydney in 2012 which were characterised by a maturity of debate regarding the assessment tools, benchmarking and the sharing of information that was not present when PCOC was established.

There are no ‘magic bullets’ for improving the quality of care, in palliative care or in any other area of clinical practice. The strength of PCOC lies in the accumulated evidence across the different elements of the PCOC approach and reliance on multiple approaches to improving care delivery such as standardising clinical assessment, benchmarking, audit and feedback and various education strategies.

In conclusion, PCOC has continued to evolve and develop over the last three years, with improvements to internal systems and processes, refinements in the way PCOC interacts with the services that participate in PCOC, collaboration with a wide range of stakeholders and an increasing sophistication regarding data collection, data analysis, data reporting and data use to improve clinical care. This has resulted in demonstrable improvements in the processes and outcomes of patient care. These are significant and unique achievements in the field of improving outcomes for palliative care patients.
References


Appendices
Appendix A: Conference presentations about the work of PCOC, 2010 to 2013


Pidgeon T, Panizza N (2012) *Nurse Practitioner-Palliative Care at Royal Perth Hospital: An evaluation using the palliative care outcomes collaboration (PCOC) quality improvement program*, Australian College of Nurse Practitioners Conference, September 2012, Surfers Paradise.


Johnson C (2012) *PCOC Assessment as a quality improvement tool*, Palliative Care Western Australia Conference, October 2012, Perth.


### Appendix B: Revised phase definitions

<table>
<thead>
<tr>
<th>START</th>
<th>END</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Stable</strong></td>
<td>The needs of the patient and or family/carer increase, requiring changes to the existing plan of care.</td>
</tr>
<tr>
<td>Patient problems and symptoms are adequately controlled by established plan of care and</td>
<td></td>
</tr>
<tr>
<td>▪ Further interventions to maintain symptom control and quality of life have been planned and</td>
<td></td>
</tr>
<tr>
<td>▪ Family/carer situation is relatively stable and no new issues are apparent</td>
<td></td>
</tr>
</tbody>
</table>

**2. Unstable**

An urgent change in the plan of care or emergency treatment is required because

- Patient experiences a new problem that was not anticipated in the existing plan of care, and/or
- Patient experiences a rapid increase in the severity of a current problem; and/or
- Family/carers circumstances change suddenly impacting on patient care

The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or

- Death is likely within days (i.e. patient is now terminal)

**3. Deteriorating**

The care plan is addressing anticipated needs but requires periodic review because

- Patients overall functional status is declining and
- Patient experiences a gradual worsening of existing problem and/or
- Patient experiences a new but anticipated problem and/or
- Family/carers experience gradual worsening distress that impacts on the patient care

Patient condition plateaus (ie patient is now stable) or

- An urgent change in the care plan or emergency treatment and/or
- Family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (ie patient is now unstable) or
- Death is likely within days (i.e. patient is now terminal)

**4. Terminal**

Death is likely within days

- Patient dies or
- Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating)

**5. Bereavement – post death support**

- The patient has died
- Bereavement support provided to family/carers is documented in the deceased patient’s clinical record

Case closure

Note: If counselling is provided to a family member or carer, they become a client in their own right
## Appendix C: PCOC National Benchmark Results, 2009 to 2012

### Outcome measure 1 - Time from referral to first contact

**Benchmark 1**: 90% of patients are contacted and clinically assessed by a member of the palliative care team (either face to face or by phone) the day of, or the day after referral (including weekends).

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
</tr>
<tr>
<td>Episodes meeting criteria</td>
<td>81%</td>
<td>80%</td>
<td>75%</td>
<td>76%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>45%</td>
<td>49%</td>
<td>41%</td>
<td>42%</td>
</tr>
</tbody>
</table>

### Outcome measure 2 - Time in the unstable phase

Note: the three benchmarks for time in the unstable phase introduced in 2009 were combined into one benchmark for the reporting period July to December 2012 (see Section 8.1).

**Benchmark 2.1**: 85% of patients remain in the unstable phase for less than 7 days – first phase of episode.

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
</tr>
<tr>
<td>Phases meeting criteria</td>
<td>66%</td>
<td>67%</td>
<td>72%</td>
<td>77%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>23%</td>
<td>29%</td>
<td>40%</td>
<td>47%</td>
</tr>
</tbody>
</table>

**Benchmark 2.2**: 90% of patients remain in the unstable phase for less than 7 days – not first phase of episode.

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
</tr>
<tr>
<td>Phases meeting criteria</td>
<td>73%</td>
<td>74%</td>
<td>78%</td>
<td>80%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>20%</td>
<td>23%</td>
<td>39%</td>
<td>44%</td>
</tr>
</tbody>
</table>

**Benchmark 2.3**: The median time in the unstable phase is 2 days or less.

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
</tr>
<tr>
<td>Phases meeting criteria</td>
<td>38%</td>
<td>41%</td>
<td>44%</td>
<td>49%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>24%</td>
<td>34%</td>
<td>48%</td>
<td>49%</td>
</tr>
</tbody>
</table>

The results for the new (combined) benchmark are as follows:
**Benchmark 2:** 90% of patients are in the unstable phase for 3 days or less.

<table>
<thead>
<tr>
<th></th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jan-Jun</td>
</tr>
<tr>
<td>Phases meeting criteria</td>
<td>66%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>16%</td>
</tr>
</tbody>
</table>

Benchmark 2 was introduced into the feedback reports for Report 14 (July to December 2012) distributed to services in April 2013. Data for the period January to June 2012 were used to determine the benchmark.

**Outcome measure 3 - Change in pain (both PCPSS and SAS)**

**Benchmarks 3.1 and 3.3:** At least 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.

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
</tr>
<tr>
<td>PCPSS Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phases meeting criteria</td>
<td>81%</td>
<td>78%</td>
<td>77%</td>
<td>80%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>25%</td>
<td>12%</td>
<td>7%</td>
<td>20%</td>
</tr>
<tr>
<td>SAS Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phases meeting criteria</td>
<td>81%</td>
<td>79%</td>
<td>78%</td>
<td>80%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>13%</td>
<td>12%</td>
<td>9%</td>
<td>16%</td>
</tr>
</tbody>
</table>

**Benchmarks 3.2 and 3.4:** At least 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.

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
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<tbody>
<tr>
<td></td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
<td>Jul-Dec</td>
<td>Jan-Jun</td>
</tr>
<tr>
<td>PCPSS Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phases meeting criteria</td>
<td>41%</td>
<td>47%</td>
<td>49%</td>
<td>50%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>23%</td>
<td>32%</td>
<td>35%</td>
<td>43%</td>
</tr>
<tr>
<td>SAS Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phases meeting criteria</td>
<td>41%</td>
<td>44%</td>
<td>48%</td>
<td>49%</td>
</tr>
<tr>
<td>Services meeting benchmark</td>
<td>16%</td>
<td>24%</td>
<td>9%</td>
<td>35%</td>
</tr>
</tbody>
</table>
Outcome measure 4 - Change in symptoms relative to the national average

Percentage of services (with 10 or more valid observations) currently at or above the baseline national average:

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Problem severity (PCPSS)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>63%</td>
<td>66%</td>
<td>73%</td>
<td>76%</td>
<td>85%</td>
<td>83%</td>
<td>88%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other symptoms</td>
<td>68%</td>
<td>76%</td>
<td>78%</td>
<td>80%</td>
<td>86%</td>
<td>90%</td>
<td>95%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/carer</td>
<td>55%</td>
<td>63%</td>
<td>75%</td>
<td>76%</td>
<td>79%</td>
<td>79%</td>
<td>88%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological/spiritual</td>
<td>57%</td>
<td>71%</td>
<td>72%</td>
<td>73%</td>
<td>77%</td>
<td>84%</td>
<td>85%</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Symptom distress (SAS)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>45%</td>
<td>69%</td>
<td>63%</td>
<td>73%</td>
<td>81%</td>
<td>79%</td>
<td>73%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td>51%</td>
<td>58%</td>
<td>67%</td>
<td>76%</td>
<td>72%</td>
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<td>Breathing problems</td>
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<td>Bowel problems</td>
<td>48%</td>
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Percentage of phases with a change in symptom score that was better than the baseline national expected change:

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<tr>
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<tr>
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<tr>
<td>Family/carer</td>
<td>48%</td>
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<tr>
<td>Psychological/spiritual</td>
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