

# **National palliative care performance indicators**

**Results of the 2007 performance indicator  
data collection**

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data collection**

**June 2008**

Australian Institute of Health and Welfare  
Canberra

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## Abbreviations

ACHS	Australian Council on Healthcare Standards
AIHW	Australian Institute of Health and Welfare
EQUiP	Evaluation and Quality Improvement Program (Australian Council on Healthcare Standards)
ISO 9000	International Organization for Standardization; family of standards for quality management
PCA	Palliative Care Australia
PCDWG	Palliative Care Data Working Group
PCIF	Palliative Care Intergovernmental Forum

# Summary

The 2007 national collection of data on palliative care performance indicators is the third in a series of collections measuring performance against the high-level performance indicators agreed by the Palliative Care Intergovernmental Forum in 2003. The indicators are designed to assist evaluation of progress against the objectives of the National Palliative Care Strategy in relation to the planning and delivery of palliative care services (but not against clinical performance). Previous reports in this series analysed performance of palliative care agencies against the performance indicators in 2005 and 2006.

This report is the last report on palliative care performance indicators to be produced under the authority of the Australian Health Care Agreements (2003–2008). Some methodological issues with the current performance indicators and data definitions are identified in this report and could be considered in any future reporting arrangements.

Overall, palliative care services reported a similar level of performance against indicators as in 2006, with the exception of assessment of agencies against Palliative Care Australia (PCA) standards (performance indicator 2), which continued the decline observed between 2005 and 2006.

While it is difficult to determine the reasons for the reported reduction in the proportion of agencies assessing themselves against PCA standards, this report does identify a number of factors which may have affected responses and performance. While a minority of agencies reported routinely using the PCA standards for assessment, more than 50% of agencies did report undertaking routine assessment or accreditation against standards generally.

## Summary of results for nationally agreed palliative care performance indicators 2007

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<i>Performance indicator 1—strategic plans:</i> the proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements.	63%
<i>Performance indicator 2—standards:</i> the proportion of palliative care agencies that routinely undertake or undergo formal assessment against the current Palliative Care Australia standards.	11%
<i>Performance indicator 3—feedback:</i> the proportion of palliative care agencies that actively collect feedback from clients and staff (within the workforce) relating to services and service delivery.	66%
<i>Performance indicator 4—partnerships:</i> the proportion of palliative care agencies that have formal working partnerships with other service providers or organisations.	89%

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# 1 Introduction

## 1.1 Palliative care in Australia

Palliative care is the specialised care of people who are terminally ill. It is 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO 2002).

Palliative care services are delivered in a range of settings, including homes and other community settings as well as inpatient settings, and by a range of organisations. In recent years, the focus has been on expanding the practice of palliative care specialist teams to support primary palliative care providers, often through consultative or consortium arrangements.

The development of these services is consistent with the emphasis on patient choice of care options and care settings that is a hallmark of the palliative care philosophy.

## 1.2 National framework for palliative care

The National Palliative Care Strategy (DoHA 2000) provides a national framework and national priorities for palliative care policy and service development in Australia. The strategy is a consensus document agreed between the Australian Government, state and territory governments, palliative care service providers and peak bodies.

The strategy emphasises a partnership approach to service development, and proposes specific strategies that contribute to the following goals:

- awareness and understanding of palliative care by the community and other health-care professionals
- continuous improvement in the quality and effectiveness of palliative care service delivery
- partnerships between health and welfare service providers to support the delivery of high-quality palliative care (DoHA 2000).

The National Palliative Care Program was established to support specific national initiatives, and palliative care requirements continued to be included in Australian Health Care Agreements, as they had been since 1998.

The strategy acknowledges the need for more knowledge of, and information about, palliative care service provision in Australia. Under the 2003–2008 Australian Health Care Agreements, states and territories work collaboratively, through the agreed information management governance arrangements, to develop appropriate performance indicators including 'indicators of access to and quality of palliative care services'.

## 1.3 Palliative care performance indicators

Nationally agreed high-level performance indicators relating to palliative care were developed by the Palliative Care Intergovernmental Forum (PCIF; see Box 1.1) in 2003.

### **Box 1.1: Palliative Care Intergovernmental Forum (PCIF)**

*The PCIF, which has representatives from all state and territory governments and the Australian Government Department of Health and Ageing, considers strategic policy issues and provides advice on activities funded under the National Palliative Care Program.*

The four high-level performance indicators (see Box 1.2) developed and agreed by the PCIF provide indicative information on the extent to which the goals and objectives of the National Palliative Care Strategy have been achieved nationally. Later sections of this report describe the indicators in more detail and present data relating to each indicator.

### **Box 1.2: The national palliative care performance indicators**

#### ***Regional level***

*Performance indicator 1: the proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements.*

#### ***Agency level***

*Performance indicator 2: the proportion of palliative care agencies, within their setting of care, that routinely undertake or undergo formal assessment against the current Palliative Care Australia standards.*

*Performance indicator 3: the proportion of palliative care agencies, within their setting of care, that actively collect feedback from clients and staff (within the workforce) relating to services and service delivery.*

*Performance indicator 4: the proportion of palliative care agencies, within their setting of care, that have formal working partnerships with other service providers or organisations.*

The agreed performance indicators are limited to obtaining information about the planning and delivery of palliative care services. The indicators were not designed to measure the performance of individual jurisdictions or agencies and are not reported at that level of detail. In addition, the indicators do not measure outcomes for patients and their families, or the scope or effectiveness of palliative care service delivery.

## 1.4 Methods

The project was carried out by staff of the Australian Institute of Health and Welfare (AIHW) in consultation with the Palliative Care Data Working Group (PCDWG; see Box 1.3).

Throughout the project, the AIHW project team was guided by PCDWG decisions about the survey questions, underlying definitions and collection guidelines.

### **Box 1.3: Palliative Care Data Working Group (PCDWG)**

*The PCDWG, which reports to the Palliative Care Intergovernmental Forum (PCIF), has members from all state and territory health departments, the Australian Government Department of Health and Ageing and Department of Veterans' Affairs, Palliative Care Australia (PCA), and the Palliative Care Outcomes Collaboration.*

Data were collected from health regions and palliative care agencies across Australia between September and December 2007.

Definitions for data in this report were taken from the *Palliative care performance indicators data set specification*, developed and agreed by the PCIF, and available from the AIHW's Metadata Online Registry (METeOR), <http://meteor.aihw.gov.au/content/index.phtml/itemId/295806>.

## **1.4.1 Administrative health region data collection**

This data collection from administrative health regions supports the calculation of national palliative care performance indicator 1.

States and territories identified the administrative health regions in their jurisdiction for inclusion in the collection. For the purpose of this collection, 'administrative health region' was defined as:

the administrative unit with responsibility for administering health services in a region, area, district or zone, and for developing and implementing strategic and other plans for health service delivery, as specified by each state and territory.

Table 1.1 provides a breakdown by state and territory of the 32 administrative health regions identified across Australia. Data were provided by states and territories on behalf of all administrative health regions in their jurisdictions.

**Table 1.1: Administrative health regions, by state and territory**

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Number of regions	9	8	3	4	4	1	1	2	32

## **1.4.2 National palliative care agency data collection**

This data collection from palliative care agencies supports the calculation of national palliative care performance indicators 2-4.

The survey sought to include all government-funded palliative care agencies. For the purpose of this collection, a 'palliative care agency' was defined as:

an organisation or organisational sub-unit that provides specialist palliative care and receives Australian or state/territory government funding (including Australian Health Care Agreements funding), or does not provide specialist palliative care but receives Australian Health Care Agreements funding to provide care incorporating a palliative approach or palliative care-related services.

Specialist palliative care services work substantially in the area of palliative care. They provide consultative and ongoing care for people with a life-limiting illness and provide support for primary carers and family members, provide multidisciplinary health-care and employ health-care professionals who have qualifications or experience in palliative care.

Care may be provided in admitted patient (inpatient) settings or community settings (including outpatient facilities).

A palliative care agency represents the level of an organisation that is responsible for the care provided to clients (that is, care coordination) regardless of whether the agency provides this care directly or purchases the care on behalf of clients.

PCDWG state and territory members identified 334 agencies for inclusion in the national palliative care agency data collection, of which 280 agencies (84%) returned completed questionnaires. Table 1.2 shows the distribution of responding agencies across the states and territories.

**Table 1.2: Participating palliative care agencies, by state and territory**

	<b>NSW</b>	<b>Vic</b>	<b>Qld</b>	<b>WA</b>	<b>SA</b>	<b>Tas</b>	<b>ACT</b>	<b>NT</b>	<b>Aust</b>
Number of agencies	74	52	111	18	18	3	2	2	280

Of the remaining agencies, 16 agencies (5%) did not complete survey questionnaires for a range of reasons, including not having any palliative care patients or having been amalgamated into a larger organisation and no longer operating as a separate agency. No response was received from 38 agencies.

## 2 Performance indicators

### 2.1 Overview of results 2005–2007

The 2007 survey of palliative care agencies and administrative health regions produced performance indicator results which were generally consistent with earlier years (Table 2.1).

The exception was performance indicator 2, the assessment of agencies against Palliative Care Australia (PCA) standards. Performance against this indicator fell in 2007, continuing the reduction observed between 2005 and 2006.

Detailed discussion of performance indicator results for the 2007 data collection is presented below and in Section 4.

**Table 2.1: Changes in performance indicators 2005–2007**

Performance indicator (PI)	Proportion of regions/agencies meeting performance indicator (per cent)			Percentage point change (per cent)	
	2005	2006	2007	2005–2006	2006–2007
PI 1: strategic plans	66	63	63	–3	0
PI 2: standards	34	21	11	–13	–10
PI 3: feedback	71	65	66	–6	+1
PI 4: partnerships	96	85	89	–11	+4

*Note:* Data comparability issues are discussed in Section 4.

### 2.2 Performance indicator 1—strategic plans

#### 2.2.1 Understanding the indicator

**Performance indicator 1 measures the proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements.**

This indicator provides information about the level of awareness and understanding of palliative care in the government and service sectors. It is relevant to all three goals of the National Palliative Care Strategy, but particularly indicates the extent to which Objective 1.5 has been achieved.

**Objective 1.5—awareness at policy level:** to build systemic awareness and recognition, at the health policy and decision-making level, that quality care for people who are dying and their families is an integral part of a health system that meets the needs of individuals, families and populations across the lifespan, and that such care underpins effective use of health resources. (DoHA 2000:15)

## 2.2.2 Definitions

For the purposes of the performance indicators collection, ‘a written plan that incorporates palliative care elements’ was defined as:

a regional plan, or an aggregation of the region’s sub-units’ plans which may be specifically for palliative care or a general health service plan that includes palliative care elements. A strategic plan typically has a mission statement, outlines a vision, values and strategies, and includes goals and objectives. A strategic plan may: serve as a framework for decisions; provide a basis for more detailed planning; explain the business to others in order to inform, motivate and involve; assist benchmarking and performance monitoring; stimulate change; and become a building block for the next plan.

To comply with this definition, a plan was required to include the following characteristics:

- time frame (the beginning and end date in years), with a minimum period of 2 years to demonstrate a strategic focus
- measurable objectives relating to service access, quality, use, responsiveness and evaluation
- demonstrated stakeholder involvement in plan development, such as the inclusion of a description of the consultation process in the strategic plan document
- demonstrated links with the National Palliative Care Strategy
- implementation strategies (could include resources identified for service delivery)
- evidence of ongoing development in subsequent plans.

## 2.2.3 What the data show

The 2007 survey found that 20 (63%) of the 32 administrative health regions had a written strategic plan that included all the agreed specified palliative care elements (Table 2.2). This result is consistent with earlier surveys – 63% of regions in 2006 and 66% in 2005 had such plans.

**Table 2.2: Performance indicator 1 – strategic plans**

Strategic plan status	Number of administrative health regions	Proportion of health regions (per cent)
Yes—plan meets all specified criteria <sup>(a)</sup>	20	63
Yes—plan does not meet all specified criteria <sup>(b)</sup>	1	3
No	11	34
<b>Total</b>	<b>32</b>	<b>100</b>

(a) Where a plan was reported to be the first such plan for a particular health region, the plan was not required to demonstrate evidence of ongoing development.

(b) One jurisdiction reported a strategic plan for a specific population group that did not include all required characteristics and therefore did not count towards performance indicator results.

## 2.2.4 Discussion

Although the performance indicator 1 results show little or no change from previous surveys, there is ongoing activity in palliative care strategic planning.

Two jurisdictions, with coverage of 13 administrative health regions, reported that they were in the process of developing, or redeveloping, palliative care services plans which were expected to be completed in 2008.

In addition, several jurisdictions advised informally that, although strategic plans were not in place, either jurisdiction frameworks or strategic plans were under development.

The report on the 2006 palliative care performance indicators survey noted that time lags had been identified between health sector reorganisation and the review or creation of strategic plans which aligned with new structures. These time lags may still need to be taken into account in interpreting the 2007 survey results in at least one jurisdiction.

## 2.3 Performance indicator 2—standards

### 2.3.1 Understanding the indicator

**Performance indicator 2 measures the proportion of palliative care agencies, within their setting of care, that routinely undertake or undergo formal assessment against the current Palliative Care Australia standards.**

Performance indicator 2 provides information on the extent to which Goal 2 of the National Palliative Care Strategy has been achieved. Goal 2 promotes quality and effectiveness in service provision, and supports continuous improvement in the delivery of palliative care services across Australia.

In particular, performance indicator 2 provides information on the proportion of palliative care agencies that have implemented the nationally agreed best practice standards for palliative care, and accordingly, the extent to which Objective 2.1 of the National Palliative Care Strategy has been achieved.

**Objective 2.1 – standards:** to establish agreed, evidence-based, best practice standards in palliative care service provision and to support and encourage implementation of those standards nationally. (DoHA 2000:17)

### 2.3.2 Definitions

The voluntary Palliative Care Australia (PCA) standards describe the key elements and dimensions for providing high-quality palliative care and have been developed by PCA for use alongside other, more general, health-care standards. The focus of the data collection was on whether agencies assessed themselves against the current PCA standards in support of continuous improvement in the delivery of palliative care services.

The 2007 collection asked agencies about their use of the *Standards for providing quality palliative care for all Australians* (4th edition; PCA 2005a). The 2007 data collection also gave agencies the opportunity to provide information about relevant standards or frameworks they used other than the PCA standards.

### 2.3.3 What the data show

Use of PCA 4th edition standards is low, with only 11% of agencies (30 of 280 agencies) responding that they routinely assess themselves against these standards (Table 2.3). This is

a decrease from the 21% (50 of 243 agencies) and the 34% (61 of 180 agencies) of agencies that assessed themselves against the PCA standards (either the 3rd edition or 4th edition) in 2006 and 2005, respectively. This decline was observed despite increasing numbers of survey respondents in successive years.

Although use of PCA standards was not widespread, use of standards more generally was considerably higher (Table 2.3). When standards other than PCA standards are taken into account, slightly more than half of all agencies (57%, 160 agencies) reported routine assessment or accreditation against standards.

Of the 30 agencies which used the current PCA standards, 63% (19 agencies) delivered care mostly in a community setting, 17% (5 agencies) delivered care mostly in an inpatient setting, with the remaining 20% (6 agencies) categorised as delivering a similar amount of care in both settings.

For additional analysis of the characteristics of agencies using standards, see Section 3.

**Table 2.3: Performance indicator 2 – standards**

Standards used	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
	<b>Number</b>			
Palliative Care Australia (PCA) (4th edition) only	5	1	3	9
PCA plus other standards	14	4	3	21
<i>Total agencies that use PCA standards</i>	<i>19</i>	<i>5</i>	<i>6</i>	<i>30</i>
Non-PCA standards only	81	31	18	130
<i>Total agencies that use standards</i>	<i>100</i>	<i>36</i>	<i>24</i>	<i>160</i>
Agencies that do not use standards	74	31	15	120
<b>Total agencies</b>	<b>174</b>	<b>67</b>	<b>39</b>	<b>280</b>
	<b>Per cent<sup>(a)</sup></b>			
PCA (4th edition) only	2	—	1	3
PCA plus other standards	5	1	1	8
<i>Total agencies that use PCA standards</i>	<i>7</i>	<i>2</i>	<i>2</i>	<i>11</i>
Non-PCA standards only	29	11	6	46
<i>Total agencies that use standards</i>	<i>36</i>	<i>13</i>	<i>9</i>	<i>57</i>
Agencies that do not use standards	26	11	5	43
<b>Total agencies</b>	<b>62</b>	<b>24</b>	<b>14</b>	<b>100</b>

(a) Percentages were calculated as a proportion of all responding agencies (280 agencies).

Note: — means nil or rounded to zero. Components may not add to total due to rounding.

### 2.3.4 Use of PCA standards

Although 57% of responding agencies used quality standards overall, the number of agencies assessing themselves against the PCA standards was lower, at only 11%.

Possible factors affecting this result are:

- Removal of the superseded earlier *Standards for palliative care provision* (3rd edition, PCA 1999) as a reporting option from the 2007 survey – although it had been included in previous years – may have excluded some agencies.
- Limitation of the survey question to formal assessment activities may have excluded the use of the standards as part of informal quality improvement practices within agencies. Although these activities, if they are occurring, are excluded from the performance indicator definition, they may be furthering the use of quality standards in the sector.
- The location of many palliative care agencies within larger health-care organisations which have a broader focus than palliative care may have resulted in those agencies being required to use other standards frameworks in their organisational environment.
- The voluntary nature of the standards may have created a perception of lack of immediate value to health-care organisations, resulting in a lack of resources or commitment to their use.
- Agencies may have been discouraged from using the PCA standards by the lack of an accreditation process for these standards. Processes for self-assessment and peer review are now being developed by Palliative Care Australia as part of the National Standards Assessment Program project, which may result in more use of the PCA standards in the future.
- Data collected about assessment and accreditation against standards may have been inconsistent. The survey was often completed by agency staff working in the palliative care area, who may not have been in a position to report accurately on organisation-wide standards use, particularly in larger organisations with greater differentiation of management roles.

### **2.3.5 PCA standards assessment methods**

Agencies that routinely assessed themselves against the PCA standards were asked to select the assessment methods used. The methods considered acceptable were formal self-assessment and in-depth external review.

- Formal self-assessment includes aspects such as planning and development of a clear structure for the assessment process, the use of an accepted evaluation method such as a peer review, and the use of validated tools where these are available.
- In-depth external review includes formal review against the PCA standards by an independent external reviewer. This may take place in the context of an accreditation process for the palliative care agency or the organisation of which the palliative care agency is a sub-unit.

Most of the 30 agencies that were PCA standards users reported using formal self-assessment methods (90%, or 27 agencies) with a smaller number (27%, 8 agencies) using in-depth external review methods (Table 2.4). Almost one-quarter of PCA standards users (23%, 7 agencies) reported using both assessment methods (data not shown).

Information about the assessment or review processes used by agencies responding to this survey was not collected.

**Table 2.4: Agencies using Palliative Care Australia (PCA) standards, by assessment method**

Assessment method	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total number	Total per cent <sup>(a)</sup>
Formal self-assessment	16	5	6	27	90
In-depth external review	4	2	2	8	27
Not stated	2	—	—	2	7
<b>Total<sup>(b)</sup></b>	<b>19</b>	<b>5</b>	<b>6</b>	<b>30</b>	<b>100</b>

(a) Percentages are calculated as a proportion of the number of agencies which use PCA standards (30 agencies).

(b) Agencies could select more than one assessment method category. Accordingly, the column totals are not the sums of the rows.

Note: — means nil or rounded to zero.

### 2.3.6 Accreditation

Agencies that indicated they used a standards framework were asked to specify the standards used, and whether they undertook formal assessment against the standards or were also accredited under those standards (see Box 2.1). Agencies could also list other standards or frameworks which they used.

Agencies were asked to record ‘Accredited under this program’ if accreditation had been granted and was current in relation to a particular standards framework. Where an agency had been formally assessed with a view to achieving accreditation, but accreditation had not been granted at the time of the survey, agencies were asked to record ‘Undertake/undergo formal assessment against these standards’.

#### Box 2.1: Quality standards frameworks

*Quality improvement standards may be used to gain and retain accreditation. Some relevant standards in the Australian health-care sector include:*

- *EQUiP – a standard framework for accreditation and quality improvement in health-care organisations from the Australian Council on Healthcare Standards, <[www.achs.org.au](http://www.achs.org.au)>*
- *QIC – a standards and accreditation program for community and health organisations from the Quality Improvement Council, <[www.qic.org.au](http://www.qic.org.au)>*
- *ISO 9000 – a family of international standards on quality management systems from the International Organization for Standardization, <[www.iso.org](http://www.iso.org)>.*

*Source: Standards were included based on the Report on government services 2006 (SCRGSP 2006:9.44).*

Of the 160 agencies that reported using standards, 57% (91 agencies) reported that they were routinely assessed (without accreditation) against at least one standards framework, with 49% (79 agencies) being accredited against at least one standards framework.

Table 2.5 shows the number of agencies assessed and accredited against each standards framework. The Australian Council on Healthcare Standards (ACHS) Evaluation and Quality Improvement Program (EQUiP) was the most commonly used standards framework (used by 48% of agencies), with other non-PCA standards including the Quality Improvement Council (QIC) and the International Organization for Standardization (ISO) ISO 9000 quality management system standards being used by 14% of agencies.

**Table 2.5: Standards, by agency accreditation status**

Standards used	Assessed only	Assessed and accredited	Total agencies <sup>(a)</sup>	Proportion of agencies (%) <sup>(b)</sup>
Palliative Care Australia (4th edition)	30	.. <sup>(c)</sup>	30	11
ACHS Evaluation and Quality Improvement Program (EQUIP)	61	72	133	48
Quality Improvement Council (QIC)	2	—	2	1
ISO 9000 quality management system standards	5	3	8	3
Other standards	16	12	28	10

(a) Agencies could nominate more than one standard.

(b) The proportion of agencies using each standard is calculated as a percentage of responding agencies (280 agencies).

(c) Not applicable. There is currently no formal accreditation process for the Palliative Care Australia (4th edition, 2005) standards.

Note: — means nil or rounded to zero; ACHS = Australian Council on Healthcare Standards; ISO = International Organization for Standardization

Other quality frameworks listed by agencies included:

- Home and Community Care (HACC; a joint Commonwealth, state and territory initiative)
- Australian Government Department of Veterans' Affairs
- Australian Institute for Primary Care's Quality Improvement and Community Services Accreditation (QICSA)
- aged care standards.

Corporate quality management standards such as occupational health and safety, risk management, governance and training standards were also listed. Some agencies commented that their use of standards occurred within the context of their parent organisation.

## 2.4 Performance indicator 3—feedback

### 2.4.1 Understanding the indicator

**Performance indicator 3 measures the proportion of palliative care agencies, within their setting of care, that actively collect feedback from clients and staff (within the workforce) relating to services and service delivery.**

Feedback is an integral aspect of quality improvement and relates to Goal 2 of the National Palliative Care Strategy regarding quality and effectiveness in service provision.

Performance indicator 3 also relates to Goal 3 of the strategy, which recognises the need for promotion and support of partnerships in care.

Specifically, performance indicator 3 serves to provide information about the extent to which Objectives 2.4 and 3.1 of the National Palliative Care Strategy have been achieved.

**Objective 2.4—service development:** to promote ongoing evaluation and research into client care needs, best practice palliative care, service delivery models, and resource allocation models; and to implement the results of such research. (DoHA 2000:19)

**Objective 3.1 – partnerships in care coordination:** to support the coordination of care for the person who is dying and their family, through partnerships between the person, the family, and the service providers and volunteers involved. (DoHA 2000:21)

## 2.4.2 Definitions

For the purposes of this collection, the following definitions apply:

- ‘Client’ includes the patient and their carer or carers, family or friends, but not other organisations or service providers.
- ‘Staff’ includes paid and unpaid individuals employed by an agency and providing palliative care services, including contract staff and volunteers.
- The ‘active and routine collection of feedback from clients and staff’ means that, as a matter of routine, the agency initiates and implements feedback mechanisms, instead of relying on ad hoc comments, ad hoc questionnaires, informal staff debriefing sessions, or similar casual arrangements.
- ‘Active mechanisms’ include the use of periodic questionnaires such as satisfaction surveys, focus groups aimed at collecting feedback from participants, established staff debriefing sessions, or other routine procedures the agency has in place to collect feedback. The aim of the mechanism used must be to collect feedback.
- ‘Periodic’ may mean at set intervals or at specified points in time during the service episode. It does not include interviews on exit (that is, closure of the service episode).
- A ‘feedback focus group’ is an in-depth qualitative interview with a small number of persons, held specifically to collect feedback from the participants.
- Written surveys may be returned by mail, email, or in person.
- For clients, ‘on exit’ means when leaving the care of an agency, while for staff it means ceasing employment at an agency.

## 2.4.3 What the data show

About two-thirds (66%) of palliative care agencies actively and routinely collected feedback about services and service delivery from both clients and staff (Table 2.6). This result shows little change from 2006, when 65% collected feedback.

A small number of agencies collected feedback from clients only (10%, 29 agencies) or from staff only (3%, 9 agencies). Overall, 147 agencies collected feedback from clients and 132 collected feedback from staff (data not shown).

Of the 185 agencies that collected feedback from both clients and staff, 69% (127 agencies) delivered care mostly in a community setting, 20% (37 agencies) delivered care mostly in an inpatient setting, while the remaining 11% (21 agencies) delivered a similar amount of care in both settings.

For additional analysis of the characteristics of agencies collecting feedback, see Section 3.

**Table 2.6: Performance indicator 3 – feedback**

Feedback collection status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total <sup>(a)</sup>
	<b>Number</b>			
Yes (from clients and staff)	127	37	21	185
Yes (from clients only)	20	5	4	29
Yes (from staff only)	5	1	3	9
No	22	24	11	57
<b>Total</b>	<b>174</b>	<b>67</b>	<b>39</b>	<b>280</b>
	<b>Per cent</b>			
Yes (from clients and staff)	45	13	8	66
Yes (from clients only)	7	2	1	10
Yes (from staff only)	2	—	1	3
No	8	9	4	20
<b>Total</b>	<b>62</b>	<b>24</b>	<b>14</b>	<b>100</b>

(a) Percentages are calculated as a proportion of total responding agencies (280 agencies).

Note: — means nil or rounded to zero. Components may not add to total due to rounding.

## 2.4.4 Feedback methods

Methods used by agencies to collect feedback from clients and staff are shown in Table 2.7. Feedback was mainly collected by questionnaire in periodic written surveys, irrespective of the setting of care. Other commonly reported methods of collection were periodic face-to-face questionnaires or questionnaires completed on exit, either as a written survey or telephone interview.

**Table 2.7: Feedback methods**

Feedback collection method	Number of agencies using method <sup>(a)</sup>	
	Feedback from clients	Feedback from staff
Questionnaire / interview methods		
Periodic face-to-face	53	96
Face-to-face interview on exit	19	67
Periodic telephone	23	6
Telephone interview on exit	8	7
Periodic written survey	165	108
Written survey on exit	27	53
Feedback focus group	38	44
Other	19	21

(a) Counts include all reported use of feedback methods by agencies, whether the agency collected feedback from both clients and staff, from clients only or from staff only.

## 2.5 Performance indicator 4—partnerships

### 2.5.1 Understanding the indicator

Performance indicator 4 measures the proportion of palliative care agencies, within their setting of care, that have formal working partnerships with other service providers or organisations.

Performance indicator 4 provides an indication of the extent to which Goal 3 of the National Palliative Care Strategy has been achieved. In particular, it relates to Objective 3.2 regarding partnerships in service planning and delivery.

**Objective 3.2 – partnerships in service planning and delivery:** to develop strong partnerships between palliative care service providers, other health service providers, and the service system infrastructure, including administrative arrangements, to ensure the delivery of palliative care that is geographically accessible and integrated across service delivery settings. (DoHA 2000:22)

### 2.5.2 Definitions

A ‘formal working partnership’ is a written or verbal agreement between two or more parties. It specifies the roles and responsibilities of each party, including the expected outcomes of the agreement.

In the palliative care context, a formal working partnership involves arrangements between an agency and other service providers and organisations with the aim of providing integrated and seamless care, so that clients are able to move smoothly between services and service settings. The following comment from one agency highlights the importance of partnerships:

At times we receive clients in their final stages and feel like strangers to both family and patient. A partnership would be great so the bridge of trust could be achieved in the final stages of dying with dignity.

Key elements of a formal working partnership are that it is organised, routine, collaborative, and systematic. It excludes ad hoc arrangements. Examples of formal working partnerships include the existence of:

- written service agreements
- formal liaison, referral and discharge planning processes
- formal and routine consultation
- protocols
- partnership working groups
- memorandums of understanding with other providers
- case conferencing.

There is no single model for forming partnerships. One agency commented that ‘Written formal arrangements exist with some agencies but not all. Some are verbal and may at times seem to be ad hoc, but they seem to work in what is an ever-changing environment.’

Partnership arrangements with other palliative care agencies may occur between agencies at different levels of specialisation (for example, between a primary palliative care agency and a specialist palliative care agency) or between agencies with a different focus (for example, between a paediatric palliative care agency and a community nursing agency providing palliative care).

### 2.5.3 What the data show

Most of the 280 palliative care agencies that responded to the survey (89%) had formal working partnerships with other organisations, with 11% indicating that they did not have partnerships (Table 2.8). This is an increase from the 85% of agencies that had partnerships in 2006.

Of the 249 agencies that reported formal partnerships with other organisations, 63% (157 agencies) delivered care mostly in a community setting, 22% (55 agencies) delivered care mostly in an inpatient setting, with the remaining 15% (37 agencies) categorised as delivering a similar amount of care in both settings.

For additional analysis of the characteristics of agencies forming partnerships, see Section 3.

**Table 2.8: Performance indicator 4 – partnerships**

Partnership status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
	<b>Number</b>			
Yes	157	55	37	249
No	17	12	2	31
<b>Total</b>	<b>174</b>	<b>67</b>	<b>39</b>	<b>280</b>
	<b>Per cent</b>			
Yes	56	20	13	89
No	6	4	1	11
<b>Total</b>	<b>62</b>	<b>24</b>	<b>14</b>	<b>100</b>

### 2.5.4 Partner organisations

Agencies were asked to identify the types of organisations with which they had formal partnerships.

The most common partner organisation types were hospitals (nominated by 78% of the 249 agencies forming partnerships), followed by palliative care services (71%), community nursing agencies (64%) and medical practices (61%) (Table 2.9).

**Table 2.9: Partner organisations**

<b>Partner organisations</b>	<b>Number of agencies</b>	<b>Proportion of agencies (%)<sup>(a)</sup></b>
Hospitals	193	78
Palliative care services	177	71
Community nursing agencies	160	64
Medical practices	151	61
Allied health services	138	55
Residential aged care facilities	106	43
Volunteer support services	84	34
Aboriginal health services	66	27
Universities/research centres	65	26
Integrated health centres	34	14
Other	34	14

(a) Proportions are calculated as a percentage of agencies with partnerships (249 agencies). Agencies could nominate more than one partner type, therefore percentages do not total 100%.

Agencies also listed additional types of organisations with which they formed partnerships in delivering palliative care, including:

- consortia or arrangements, such as memorandums of understanding, with other groups such as Divisions of General Practice
- health service providers, such as oncology services or private nursing services
- community services, such as the Australian Meals on Wheels Association, respite care or Home and Community Care
- police for watchhouse clinic services
- support services, such as pastoral care, church groups, Lifeline or carer support services
- associations such as the Motor Neurone Disease Association or the Cancer Council
- suppliers such as equipment hire service providers or home oxygen providers.

## 3 Palliative care agency characteristics

### 3.1 Introduction

This section presents descriptive data about agencies that provide palliative care, including information on the employment of a coordinator of volunteers, settings of care, level of specialisation, and remoteness.

In addition to tables showing collected data, three profile tables are included. These provide a high-level snapshot of the characteristics of agencies in selected categories, based on the information collected in the performance indicator survey. Individual palliative care agencies can use these tables to see how similar they are to typical agencies in the same category. Profile tables are provided for the categories within 'most common setting of care', 'level of specialisation' and 'remoteness area'.

### 3.2 Coordinator of volunteers

Agencies were asked whether they employed a coordinator of volunteers on either a paid or unpaid basis. This question was designed to provide insight into the extent to which volunteers are used in the palliative care sector. Box 3.1 describes the role of volunteers in palliative care.

#### **Box 3.1: The role of volunteers**

*Volunteers are valued members of the palliative care workforce who complement the care provided by paid palliative care professionals. Volunteers frequently assist patients and carers in practical ways (for example, providing transport, preparing snacks, letter writing), and provide respite to carers, companionship, and bereavement contact with families following the death of the person. All volunteers are screened and undertake extensive training before taking on this role.*

*A volunteer agency perspective: 'We receive referrals from doctors, hospitals, community nurses etc. All our assistance is on a voluntary basis. We are involved in regular weekly hospital visiting – sometimes more frequently.'*

*The duties of a coordinator of volunteers in the palliative care sector might include managing the workloads of volunteer staff, liaising with clinical staff about clients' needs, assessing the human resource needs of the organisation, recruiting volunteers, developing orientation kits and programs, developing volunteer policies, arranging training and development opportunities, and maintaining volunteer records.*

The survey data (Table 3.1) showed that about half of all agencies (55%, 153 agencies) reported employing a coordinator of volunteers.

Of the 153 agencies that employed a coordinator of volunteers, 60% (92 agencies) delivered care mostly in a community setting, 22% (33 agencies) delivered care mostly in an inpatient setting, with the remaining 18% (28 agencies) categorised as delivering a similar amount of care in both settings.

**Table 3.1: Coordinator of volunteers, by most common setting of care**

Coordinator of volunteers status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total <sup>(a)</sup>
<b>Number</b>				
Yes	92	33	28	153
No	81	34	10	125
Not stated	1	—	1	2
<b>Total</b>	<b>174</b>	<b>67</b>	<b>39</b>	<b>280</b>
<b>Per cent</b>				
Yes	33	12	10	55
No	29	12	4	45
Not stated	—	—	—	1
<b>Total</b>	<b>62</b>	<b>24</b>	<b>14</b>	<b>100</b>

(a) Percentages are calculated as a proportion of responding agencies (280 agencies).

Note: — means nil or rounded to zero. Components may not add to total due to rounding.

Survey data were also analysed by agency level of specialisation (Table 3.2). The level of palliative care specialisation of an agency is determined by its place within Palliative Care Australia's service planning framework classification, described in detail in Section 3.4 and included in the Appendix.

**Table 3.2: Coordinator of volunteers, by level of specialisation**

Coordinator of volunteers status	Primary palliative care agency	Specialist palliative care agency (level 1)	Specialist palliative care agency (level 2)	Specialist palliative care agency (level 3)	Not stated / unable to say	Total <sup>(a)</sup>
<b>Number</b>						
Yes	31	62	24	30	6	153
No	71	29	11	10	4	125
Not stated	—	1	1	—	—	2
<b>Total</b>	<b>102</b>	<b>92</b>	<b>36</b>	<b>40</b>	<b>10</b>	<b>280</b>
<b>Per cent</b>						
Yes	11	22	9	11	2	55
No	25	10	4	4	1	45
Not stated	—	—	—	—	—	1
<b>Total<sup>(b)</sup></b>	<b>36</b>	<b>33</b>	<b>13</b>	<b>14</b>	<b>4</b>	<b>100</b>

(a) Percentages are calculated as a proportion of responding agencies (280 agencies).

Note: — means nil or rounded to zero. Components may not add to total due to rounding.

Of the 153 agencies which employed a coordinator of volunteers, 41% (62 agencies) were specialist palliative care agencies (level 1). Fewer agencies in other categories employed coordinators of volunteers: 20% (31 agencies) were primary palliative care agencies, 16% (24 agencies) were specialist palliative care agencies (level 2) and 20% (30 agencies) were specialist palliative care agencies (level 3).

## 3.3 Settings of care

### 3.3.1 Most common setting of care

The wording of the agreed performance indicators requires some analysis of results by 'setting of care'. Accordingly, agencies were asked to report on the most common setting of care – the category within which the majority of their agency's services were delivered over the previous 12 months. Categories were 'mostly community-based setting', 'mostly inpatient setting' and 'similar amount of services in community-based and inpatient settings'.

'Mostly community based setting' means that, during the past 12 months, substantially more than 50% of service delivery time was spent on delivering services to, and on behalf of, clients in community settings.

Community settings include:

- residential settings, including a person's private residence, caravan, mobile home, houseboat or unit in a retirement village
- residential aged care facility
- a residential facility other than an aged care facility, including prison, or a community living environment, including a group home
- non-residential settings, including day respite centres and day centres
- hospital outreach services and outpatient settings where these are delivered in the community setting.

'Mostly inpatient setting' means that, during the past 12 months, substantially more than 50% of service delivery time was spent on delivering services to, and on behalf of, clients in inpatient settings. Inpatient settings include all hospital, hospice or other admitted patient settings, but excludes outpatient settings and hospital outreach services delivered in the community setting.

'Similar amount of services in community-based and inpatient settings' applies where a similar proportion of time was spent by agencies delivering services in community and inpatient settings.

In summary, most agencies reported mainly delivering care to clients in the community (62%, or 174 of the 280 participating agencies), with only 24% (67 agencies) reporting that they mainly provided care in inpatient settings. The remaining 14% (39 agencies) reported that a similar proportion of time was spent on delivering services in community and inpatient settings (Table 3.3).

### 3.3.2 Profile of agencies by most common setting of care

Table 3.3 provides a high-level snapshot of the characteristics of agencies in each most common setting of care category, based on the information collected in the 2007 performance indicator survey. For each category, the percentage of agencies within that category which met the performance indicator or showed the characteristic is displayed.

A profile of a typical agency in each category can be derived by reading the data across the row for each category. For example, most agencies in the 'mostly inpatient setting category'

are primary palliative care agencies, 7% of these agencies use the PCA standards while 54% use standards overall, 82% of these agencies have partnerships, 55% collect feedback, and 49% employ a coordinator of volunteers.

**Table 3.3: Profile of agencies by most common setting of care**

Most common setting of care category	No. of agencies	Performance indicator (PI) <sup>(a)</sup>			Agency characteristic <sup>(a)</sup>		
		PI 2— standards (per cent)	PI 3— feedback (per cent)	PI 4— partnerships (per cent)	Assessed/ accredited against any standards (per cent)	Coordinator of volunteers (per cent)	Most common level of specialisation
Mostly community setting	174	11	73	90	57	53	Primary palliative care
Mostly inpatient setting	67	7	55	82	54	49	Primary palliative care
Similar amount in both settings	39	15	54	95	62	72	Specialist palliative care (level 3)

(a) Performance indicator and agency characteristic proportions in this table are calculated as a percentage of the number of agencies within each most common setting of care category. As different variables are being described, neither rows nor columns can be added.

### 3.3.3 Most common setting of care patterns

Based on the profile data, the following patterns emerge:

- Agencies in the ‘similar amount in both settings’ category more commonly assessed themselves against the PCA standard, had formal working partnerships, and employed a coordinator of volunteers.
- A greater proportion of agencies delivering care ‘mostly in a community setting’ collected feedback from clients and staff (73% compared with 55% and 54% for the ‘mostly in inpatient setting’ or ‘similar amount of care in both settings’ categories, respectively).
- Measures that were consistent across the most common setting of care categories were PCA assessment method (mostly formal self-assessment), most common non-PCA standard used for assessment or accreditation (ACHS EQUiP), and methods for collecting feedback (‘questionnaire – periodic written survey’ being the most commonly reported method across all settings and for collecting feedback from both clients and staff)(data not shown).

- Brief profiles:
  - Community setting agencies were most commonly primary palliative care agencies (details in Section 3.4 and the Appendix) which delivered care in private residences and residential aged care settings, and had hospitals and palliative care agencies as partners.
  - Inpatient setting agencies were most commonly primary palliative care agencies which delivered care in inpatient settings and had community nursing agencies and hospitals as partners.
  - Agencies which delivered a similar amount of care in both community and inpatient settings were most commonly specialist palliative care (level 3) agencies which delivered care in private residences and inpatient settings other than designated palliative care units, and had community nursing agencies and hospitals as partners.

### 3.3.4 Palliative care delivery settings

In addition to nominating the ‘most common setting of care’ category, agencies were asked to list all the settings within which they had delivered palliative care services, including bereavement care associated with palliative care, during the past 12 months.

Delivery setting categories were defined as:

- ‘private residence’, including caravans, mobile homes, houseboats or units in a retirement village
- ‘residential – aged care’, including high and low care residential aged care facilities, but excluding units in a retirement village
- ‘residential – other’, including prisons and community living environments such as group homes, but excluding aged care facilities and inpatient settings such as hospitals or hospices
- ‘non-residential’, including day respite centres and day centres, but excluding hospital outpatient departments
- ‘outpatient – hospital or hospice’
- ‘inpatient – designated palliative care unit or hospice’, including dedicated wards or units that receive identified funding for palliative care and/or primarily deliver palliative care; including stand-alone units such as hospices
- ‘inpatient – other than a designated palliative care unit’, including all admitted patient beds not in a unit designated for palliative care; these are usually located in acute hospital wards.

‘Private residence’ was the most frequently nominated setting for palliative care delivery, with 80% of responding agencies delivering care in this setting. ‘Inpatient – other than a designated palliative care unit’ (51% of agencies) and ‘residential – aged care’ (48% of agencies) were also frequently reported settings (Table 3.4).

As noted earlier, these categories are not comparable with the ‘most common setting of care’ categories, and the data from Table 3.4 cannot be mapped to the data in Table 3.3.

**Table 3.4: Palliative care delivery settings**

Setting of care	Agencies	Proportion of agencies (per cent) <sup>(a)</sup>
<b>Community-based settings</b>		
Private residence	225	80
Residential—aged care	133	48
Residential—other	74	26
Non-residential	30	11
Outpatient—hospital or hospice	70	25
<b>Inpatient settings</b>		
Inpatient—designated palliative care unit or hospice	94	34
Inpatient—other than a designated palliative care unit	144	51

(a) Proportions are calculated as a percentage of responding agencies (280 agencies). Agencies could nominate more than one setting of care, therefore percentages do not total 100%.

*Note:* The delivery setting categories shown in Table 3.4 are not comparable with the most common setting of care categories shown in Table 3.3 because the categories are defined on different criteria (time versus location). ‘Most common setting of care’ categories are based on proportions of time spent in delivering services in each ‘most common setting of care’ category. In contrast, delivery setting categories are based on whether any episodes of care at all have taken place in a particular delivery setting during the reporting period. Although the category values appear similar, direct comparisons cannot be made, because the categories are defined differently.

## 3.4 Level of palliative care specialisation

### 3.4.1 Level of specialisation

Agencies were asked to report their level of palliative care specialisation by selecting the level within Palliative Care Australia’s (PCA’s) service planning framework classification which best described the services they provide.

This framework recognises four broad levels of specialisation:

- Primary (non-specialist) palliative care providers are those whose substantive work is not in the area of palliative care, but which have a primary, or ‘first contact’, relationship with people with a life-limiting illness and adopt a palliative approach to their care. Primary palliative care providers may include general practitioners, geriatricians, community nurses and staff of residential aged care facilities.
- Specialist palliative care providers (levels 1–3) are those who work substantively in the area of palliative care, and provide care to patients who have more complicated needs. They provide consultative and ongoing care for people with a life-limiting illness, provide support for primary carers and family members, provide multidisciplinary health care, and employ health-care professionals who have qualifications or experience in palliative care. This care may be provided in community or inpatient settings. More information is provided in Box 3.2.

### Box 3.2: Levels of specialisation differentiation

*The three levels of specialisation are differentiated by their different capabilities and their typical resource profile and 'represent the minimal (level 1), moderate (level 2) and maximal (level 3) points along a hypothetical continuum of resource availability and expected capability' (PCA 2005a:20).*

*Palliative Care Australia's service planning framework considers the differences in these levels, among other things, in terms of the role of the service in education, research and teaching, the composition of a typical health-care team and the size of the population base for which the service provides care. The framework is provided in full in the Appendix.*

The level of specialisation is not related to the quality of care that is provided, but reflects the agency's main relationship with people who are terminally ill and their caregivers, and their relationships with other palliative care providers.

Table 3.5 shows the distribution of agencies across the palliative care level of specialisation and most common setting of care categories.

**Table 3.5: Agencies, by palliative care specialisation and most common setting of care**

Level of specialisation	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total number of agencies	Proportion of agencies (per cent)
Primary palliative care agency	79	19	4	102	36
Specialist palliative care agency (level 1)	63	18	11	92	33
Specialist palliative care agency (level 2)	18	11	7	36	13
Specialist palliative care agency (level 3)	9	16	15	40	14
Not stated/unable to say	5	3	2	10	4
<b>Total</b>	<b>174</b>	<b>67</b>	<b>39</b>	<b>280</b>	<b>100</b>

Overall, 69% of agencies identified themselves as either primary palliative care or specialist palliative care (level 1) agencies, with a smaller proportion of agencies identifying as specialist palliative care levels 2 and 3 (13% and 14%, respectively) (Table 3.5).

Primary palliative care agencies and specialist palliative care agencies (Level 1) delivered care mostly in community settings.

The accuracy of the data in Table 3.5 may have been affected by the following factors:

- The level of palliative care specialisation (or role delineation) is self-reported, and based on a qualitative framework which agencies may not have interpreted consistently.
- Some agencies were not able to locate their service within the PCA service planning framework (26 agencies in 2007, an increase on the 17 agencies who were unable to report their level of specialisation in 2006). Although all but 10 of these agencies were later located within the framework based on advice from state and territory PCDWG members, these difficulties suggest that agencies are still developing expertise in use of the framework and may not be applying it consistently in all cases.

- It is possible that some agencies may have met the criteria for a level of specialisation without being funded to provide services at that level. The survey did not collect this information.

### 3.4.2 Profile of agencies by level of specialisation

Table 3.6 provides a high-level snapshot of the characteristics of agencies in each level of specialisation category, based on the information collected in the 2007 performance indicator survey. For each category, the percentage of agencies within that category which met the performance indicator or showed the characteristic is displayed.

A profile of a typical agency in each category can be derived by reading the data across the row for each category. For example, of the 102 agencies in the primary palliative care category, only 2% use the PCA standards, although 49% use standards of some kind. A majority of agencies in this category collect feedback (75%) and form partnerships (83%), while 30% of agencies in this category employ a coordinator of volunteers. Primary palliative care agencies most frequently report that 'mostly community setting' is their most common setting of care category.

**Table 3.6: Profile of agencies by level of specialisation**

Level of specialisation category	No. of agencies	Performance indicators <sup>(a)</sup>			Agency characteristics <sup>(a)</sup>		
		PI 2—standards (per cent)	PI 3—feedback (per cent)	PI 4—partnerships (per cent)	Assessed/ accredited against any standards (per cent)	Coordinator of volunteers (per cent)	Most common setting of care category
Primary palliative care	102	2	75	83	49	30	Mostly community setting
Specialist palliative care (level 1)	92	7	62	91	58	67	Mostly community setting
Specialist palliative care (level 2)	36	19	58	94	67	67	Mostly community setting
Specialist palliative care (level 3)	40	35	65	95	70	75	Mostly inpatient setting

(a) Performance indicator and agency characteristic proportions in this table are calculated as a percentage of the number of agencies within each level of specialisation category. As different variables are being described, neither rows nor columns can be added.

### 3.4.3 Level of specialisation patterns

The breakdown by level of specialisation shows some clear differences between primary palliative care agencies and specialist palliative care agencies (particularly specialist agencies at level 2 and level 3 of specialisation), which is consistent with results reported in 2006.

It is worth noting that, with the exception of performance indicator 3 (feedback), the proportion of agencies meeting indicators or displaying characteristics of interest increases with increased level of specialisation (Table 3.6).

- *Standards*

Reported use of standards increases with agency level of specialisation. Specialist palliative care agencies (levels 2 and 3) more commonly assessed against the PCA standards (19% and 35%, respectively, of agencies in these categories) than did primary care agencies (2%) or specialist agencies (level 1) (7%). This pattern was also found for use of standards generally; specialist agencies (levels 2 and 3) more commonly reported using standards (67% and 70%, respectively) than primary care agencies (49%).

- *Partnerships*

The existence of working partnerships with one or more partner organisations also increases with agency level of specialisation. Specialist palliative care agencies (levels 1, 2 and 3) more commonly formed partnerships (91%, 94% and 95% of agencies, respectively) than did primary care agencies (83%).

Partner organisations were similar across levels of specialisation, with the most common types being hospitals, palliative care services and community nursing agencies. One difference was that primary and specialist palliative care agencies (level 1) included allied health partners in their top four partner types, while specialist palliative care agencies (level 3) did not, including instead universities/research centres. In addition, primary and specialist agencies (levels 1 and 2) included medical practices in their top four partner types while specialist agencies (level 3) did not (data not shown).

- *Coordinator of volunteers*

Reported employment of a coordinator of volunteers increases with agency level of specialisation. Specialist palliative care agencies (levels 1, 2 and 3) more commonly employed a coordinator of volunteers (67%, 67% and 75% of agencies at these levels, respectively) than did primary care agencies (30% of primary care agencies).

- *Settings of care*

The settings in which care was delivered showed an interesting pattern across levels of specialisation. Primary and specialist palliative care agencies (levels 1 and 2) most commonly delivered care in community settings, while specialist palliative care agencies (level 3) most commonly delivered care in inpatient settings.

- *Other agency characteristics*

Measures which were consistent across level of specialisation were PCA assessment method (mostly formal self-assessment), most common non-PCA standard used for assessment or accreditation (ACHS EQUiP), and methods for collecting feedback ('questionnaire – periodic written survey' being the most commonly reported method across all settings and for collecting feedback from both clients and staff) (data not shown).

## **3.5 Remoteness**

### **3.5.1 Remoteness areas**

The 2007 data collection included agencies from across Australia, in a range of locations from capital cities to remote areas.

Data were analysed using the Australian Standard Geographical Classification (ASGC). This classification specifies remoteness area categories which are based on indexes of distance from service centres, and are an indication of the level of access to goods and services (ABS 2006; AIHW 2004).

Box 3.3 shows examples of locations within each remoteness category.

**Box 3.3: Remoteness areas with example locations**

*Major Cities: Randwick, Parkville, Southport, Modbury, Fremantle, Canberra*

*Inner Regional: Bathurst, Warrnambool, Toowoomba, Mt Gambier, Bunbury, Hobart*

*Outer Regional: Griffith, Horsham, Mackay, Port Pirie, Geraldton, Casuarina*

*Remote: Mount Isa, Port Lincoln, Broome, Alice Springs*

*Very Remote: Cunnamulla, Thursday Island, Weipa*

For the purposes of this analysis, the remoteness area for each agency was based on that agency’s postal address. The results do not indicate the remoteness area serviced by that agency, or the remoteness area of patients of that agency. For example, an agency based in a remote area town may provide services to people living in very remote areas. This limitation is not significant in the context of this report, which focuses on the administrative aspects of palliative care delivery.

The analysis shows that palliative care agencies that participated in the performance indicator survey are concentrated in Major Cities and Inner Regional areas. These categories each contained just over one-third of the 280 participating palliative care agencies (37% and 35%, respectively) with fewer agencies located in more remote areas – 23% in Outer Regional areas, 4% in Remote areas and 1% in Very Remote areas (Table 3.7).

**Table 3.7: Agencies, by remoteness category**

	Major Cities	Inner Regional	Outer Regional	Remote	Very Remote	Total
No. of agencies	103	98	64	11	4	280
Proportion of agencies (per cent)	37	35	23	4	1	100

### 3.5.2 Profile of agencies by remoteness

Table 3.8 provides a high-level snapshot of the characteristics of palliative care agencies located in Australian Standard Geographical Classification remoteness areas for agencies that participated in the 2007 data collection. For each category, the percentage of agencies within that category which met the performance indicator or showed the characteristic is displayed.

A profile of a typical agency in each remoteness category can be derived by reading the data across the row for each category. For example, of the 98 agencies in the Inner Regional category, 10% use the PCA standards, although 61% use standards overall. Most of these agencies (86%) form partnerships, but only 66% collect feedback. Inner Regional agencies are most frequently specialist palliative care agencies (level 1) with a most common setting of care of ‘mostly community setting’, and 63% employ a coordinator of volunteers.

**Table 3.8: Profile of agencies by remoteness category**

Remoteness category	Performance indicators <sup>(a)</sup>				Agency characteristics <sup>(a)</sup>			
	No. of agencies	PI 2—standards (per cent)	PI 3—feedback (per cent)	PI 4—partnerships (per cent)	Assessed/ accredited against any standards (per cent)	Coordinator of volunteers (per cent)	Most common setting of care	Most common level of specialisation
Major Cities	103	17	66	90	59	64	Mostly community setting	Specialist palliative care (level 3)
Inner Regional	98	10	66	86	61	63	Mostly community setting	Specialist palliative care (level 1)
Outer Regional	64	3	70	92	53	36	Mostly community setting	Primary palliative care
Remote	11	—	55	91	36	18	Mostly community setting	Primary palliative care
Very Remote	4	—	25	75	25	—	Mostly community setting and Mostly inpatient setting (equally frequent)	Primary palliative care and Specialist palliative care (level 1) (equally frequent)

(a) Performance indicator and agency characteristic proportions in this table are calculated as a percentage of the number of agencies within each remoteness category. As different variables are being described, neither rows nor columns can be added.

*Notes*

1. The small number of agencies in the 'Remote' and 'Very Remote' categories means that proportions for those categories should be interpreted with care.
2. — means nil or rounded to zero.

### 3.5.3 Remoteness patterns

Characteristics which showed clear patterns based on remoteness (Table 3.8) were:

- PCA standards – use of the PCA standards was limited mostly to agencies located in Major Cities and Inner Regional areas.
- Most common setting of care – the 'mostly community setting' category was the most frequently reported setting of care for all but Very Remote areas. This pattern was most pronounced for Inner Regional areas, where 79% of agencies reported 'mostly community setting' as their most common setting of care (detailed data not shown in Table 3.8).
- Level of specialisation – the majority of agencies located in Outer Regional, Remote and Very Remote areas were primary palliative care agencies (64%, 64% and 50%, respectively, of agencies in those remoteness categories). Specialist palliative care agencies (level 1) were mostly found in Inner Regional and Very Remote areas (49% and 50%, respectively).

Specialist palliative care agencies (levels 2 and 3) were mostly located in Major Cities (22% and 32%, respectively, as a proportion of Major Cities agencies)(detailed data not shown in Table 3.8).

- Coordinator of volunteers – agencies were less likely to employ a coordinator of volunteers the more remote their location category.

It should be noted that the small number of agencies in the Remote and Very Remote categories means that results for those categories should be interpreted with care.

## **4 Conclusions**

### **4.1 Performance indicator results 2005–2007**

#### **4.1.1 Summary**

The 2007 survey of palliative care agencies and administrative health regions produced performance indicator results which were generally consistent with earlier years (see Table 2.1).

The exception was performance indicator 2, the assessment of agencies against Palliative Care Australia (PCA) standards. Performance against this indicator fell in 2007, continuing the reduction observed between 2005 and 2006.

The proportion of administrative health regions with strategic plans incorporating palliative care (performance indicator 1) showed no change between 2006 and 2007.

Results in 2007 for the feedback and partnerships indicators (performance indicators 3 and 4) were also consistent with 2006, and showed a small improvement in performance. The collection of feedback and formation of formal working partnerships with other service providers appear to be part of ongoing management practice and 'business as usual' for individual agencies, within the context of any larger organisation of which they are a part.

#### **4.1.2 Comparability of data 2005–2007**

There were significant changes between the 2005 pilot collection and the 2006 data collection, particularly in the scope of agencies eligible to participate in the survey, questions asked and wording of questions. These changes are described in detail in the report on the 2006 collection (AIHW 2007:21).

In contrast, there were no participation eligibility changes between 2006 and 2007, and the survey questions and wording for 2007 were largely consistent with those of the 2006 collection. The only significant change was the expansion of the question relating to use of quality standards, to collect additional information about standards other than the PCA standards and about assessment or accreditation status. This question was also amended to exclude reporting of use of the superseded PCA 3rd edition standard (PCA 1999); however, reported use of that standard had been low (9 agencies) in the previous data collection in 2006 (AIHW 2007).

As a result, comparisons between 2006 and 2007 are likely to be more reliable than between 2005 and 2006 for performance indicators 2, 3 and 4, which relate to palliative care agencies. For performance indicator 1, which relates to administrative health regions, the survey questions and eligibility for inclusion in the collection were relatively unchanged between 2005 and 2007.

### 4.1.3 Other analysis dimensions

Analysis of the 2007 performance indicator survey data by most common setting of care and by level of specialisation produced results consistent with those of the 2006 survey.

Patterns of results for level of specialisation showed a clear continuum from primary palliative care agencies through to specialist palliative care agencies (level 3), with the proportion of agencies meeting each indicator generally increasing with increasing level of specialisation (although there is no obvious pattern for the feedback performance indicator).

In contrast, patterns for most common setting of care showed that agencies which provided care in either community or inpatient settings were distinct from agencies providing a 'similar amount of care in both settings' on most measures. Agencies that provide a similar amount of care in both settings tend to be specialist palliative care agencies (level 3); it therefore seems likely that the setting of care is not fully independent of level of specialisation.

The remoteness area analysis was included to provide an additional perspective on palliative care agencies. The analysis shows that more than half of participating agencies are located in Major Cities and Inner Regional areas.

## 4.2 Future reporting

### 4.2.1 Definitional issues

The palliative care performance indicator survey is intended to measure the characteristics of palliative care agencies (also referred to as palliative care services). If the definition of a 'palliative care agency' is ambiguous, it is difficult to decide which agencies are in scope for the survey.

This problem was identified in earlier surveys, and resulted in refinement of the definition and scope changes for agency inclusion. Despite these efforts, the 2007 performance indicators survey encountered difficulties such as:

- agencies which had been consolidated into larger health entities but seemed to remain operationally distinct
- consultative and consortium arrangements which blurred the boundaries between agencies, with services shared between hospitals, or between hospitals and community agencies, or between private and public health-sector organisations
- situations where one organisation contracted with another to supply palliative care services for its patients
- agencies that operated on a part-time basis, or shared some, but not all, services and staff with other organisations.

Agencies were included in the survey based on information provided by states and territories. When updated information became available during the survey, the inclusion or exclusion of particular agencies was determined in consultation with the states and territories. The survey itself did not collect information that could have been used to decide whether it was appropriate to include a particular agency; such a data collection would depend upon the availability of an objectively measurable definition of a 'palliative care agency'.

As a result, the size and type of agencies surveyed in 2007, and the scale and level of aggregation of their operations, is likely to have varied considerably, which makes interpretation of the results more difficult.

It may not be practical to encompass the complexity of palliative care provision into a single definition of an agency. An alternative would be to collect additional information about agencies that could be used to allow comparison based on known attributes. This would need investigation, but could include quantitative measures of agency operation, such as number of palliative care patients during a year, number of employees, or types of services provided.

## **4.2.2 Performance indicator issues**

The 2007 results suggest that some changes to the performance indicators may need to be considered to ensure that they are providing the required information.

### **Reporting period specification**

All performance indicators should be time based, and the reporting period specified, to remove possible uncertainty in reporting.

### **Performance indicator 1 – strategic plans**

Survey responses showed that, generally, in jurisdictions with strategic plans in place, the palliative care components of those plans were derived from a jurisdiction-wide framework and seemed to be consistent across administrative health regions. This suggests that this indicator could be measured at jurisdiction level rather than administrative health region level. However, a different situation may exist for administrative health regions that did not report having strategic plans with palliative care elements.

The value of performance indicator 1 as a measure of progress towards Objective 1.5 of the National Palliative Care Strategy (awareness at policy level) is uncertain. The activities reported informally by jurisdictions seem to indicate that more activity (and therefore awareness at policy level) is occurring than is measured by the endorsement of strategic plans.

### **Performance indicator 2 – standards**

The survey question about standards use was expanded to collect additional information in 2007 to assist in interpreting the performance against the indicator. However, there are still many aspects of standards use which are unknown.

For example, although the survey asked whether agencies assessed themselves against the current PCA standards, agencies were not asked whether they met the standards, how often any formal assessment against the standards was carried out, or whether the PCA standards were used informally or as part of other standards activities. No time periods were specified for reporting, leading to uncertainty about whether agencies were describing current or previous standards use.

The introduction of processes for self-assessment and peer review against PCA standards (under development by Palliative Care Australia as part of the National Standards Assessment Program project) is likely to affect performance against the indicator. Future performance measures may need to include information about use of these processes.

### **Performance indicator 3 – feedback**

The current survey questions collect information about how feedback is collected and from whom, but no information is collected about how that feedback is used, or how it feeds through into quality improvements.

### **Performance indicator 4 – partnerships**

The current survey questions collect information about the existence of partnerships and types of partner organisations, but no information is collected about the nature of the partnerships, their form and duration, whether they operate at a service planning and coordination level, a service delivery level, or at both levels, or how the partnerships impact palliative care quality.

## **4.2.3 Dimensions of analysis**

The 2007 results suggest that analysis by level of specialisation may be more revealing of agency and sector characteristics than analysis by most common setting of care. The analyses in Section 3 show clearer patterns for performance indicators and other agency characteristics when analysed by palliative care level of specialisation than by most common setting of care.

A problem with this approach is that 26 agencies (9% of all responding agencies) were not able to identify their level of palliative care specialisation when completing the survey, with the status of 10 agencies (4%) remaining unresolved after investigation. This suggests that this self-reported information may not be reliable in all cases.

## **4.2.4 Future collections**

The 2007 performance indicator collection was the last to occur under the authority of the current Australian Health Care Agreements. Future data development, performance reporting, or research into the administrative aspects of palliative care provision, would need to be planned in the context of the next Australian Health Care Agreements, taking into account other research projects into the clinical aspects of palliative care and the need to minimise respondent burden.

Methodological issues for future collections identified during the conduct of the 2007 performance indicator data collection include:

- whether integration of reporting into mainstream data collections might provide ongoing data about the sector which could be of greater value than annual surveys
- the need to ensure that the populations and measures used in future collections to support policy development and quality and performance measurement are closely aligned with identified information needs; in particular, the performance indicators should be reviewed for their effectiveness in measuring the concepts of interest
- whether more precisely focused surveys on specific and tightly defined populations, such services delivered in the community, or specialist palliative care providers, or on the impact of developments in the PCA standards, might be more useful for planning and evaluation purposes than the current sector-wide survey approach
- the opportunity for the value of all data collections to be increased through better definitions of concepts of interest that can be applied consistently.

# Appendix: Palliative Care Australia's service planning framework

Level	Capability	Typical resource profile
Primary care	Clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with uncomplicated needs associated with a life-limiting illness and/or end of life care. Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.	General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff.  Specialist health care providers in other disciplines would be included at this level.
Specialist palliative care (level 1)	Provides specialist palliative care for patients, caregiver/s and families whose needs exceed the capability of primary care providers. Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers.  Has formal links with primary care providers and level 2 and/or level 3 specialist palliative care providers to meet the needs of patients and family/carers with complex problems. Has quality and audit program.	Multi-disciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available coordinates a volunteer service.
Specialist palliative care (level 2)	As for level 1, able to support higher resource level due to population base (for example, regional area). Provides formal education programs to primary care and level 1 providers and the community. Has formal links with primary care providers and level 3 specialist palliative care services for patients, caregiver/s and families with complex needs.	Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.
Specialist palliative care (level 3)	Provides comprehensive care for the needs of patients, caregiver/s and families with complex needs. Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. Has a comprehensive research and teaching role.  Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professorial chairs where available.	Interdisciplinary team including a medical director and clinical nurse consultant/nurse practitioner and allied health staff with specialist qualifications in palliative care.

Source: PCA 2005b.

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