



**Australian Government**

**Australian Institute of  
Health and Welfare**

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# **National palliative care performance indicators**

## **Results of the 2008 performance indicator data collection**

**July 2010**

Australian Institute of Health and Welfare  
Canberra

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# Abbreviations

ACHS	Australian Council on Healthcare Standards
AHCA	Australian Health Care Agreements
AIHW	Australian Institute of Health and Welfare
ASGC	Australian Standard Geographical Classification
DoHA	Department of Health and Ageing
EQUiP	Evaluation and Quality Improvement Program (Australian Council on Healthcare Standards)
HACC	Home and Community Care
ISO 9000	International Organization for Standardization; family of standards for quality management
METeOR	Metadata Online Registry
NHA	National Healthcare Agreement
NSAP	National Standards Assessment Program
PCA	Palliative Care Australia
PCIF	Palliative Care Intergovernmental Forum
PCOC	Palliative Care Outcomes Collaboration
PI	performance indicator
QIC	Quality Improvement Council
QICSA	Quality Improvement and Community Services Accreditation
WHO	World Health Organization

# Summary

The 2008 National Palliative Care Survey is the fourth in a series of surveys aimed at measuring performance against the four national palliative care performance indicators. These high-level performance indicators were agreed by the Palliative Care Intergovernmental Forum in 2003 and are designed to assist in the evaluation of progress against the objectives of the National Palliative Care Strategy, in relation to the planning and delivery of palliative care services.

The response rate for agencies was 66%, so the data should be interpreted with caution.

Of the 227 agencies that responded to the survey, 147 agencies reported delivering care to clients mostly in the community setting and 52 agencies reported that they provided care mostly in an inpatient setting (admitted patients in hospital). The remaining 28 agencies reported that similar proportions of time were spent on delivering services in community and inpatient settings.

Information collected for the first time showed that most agencies are relatively small with 61% employing 10 staff or fewer, and 45% providing care for 100 or fewer patients through the year.

Performance against the national palliative care performance indicators in 2008 differed from that found in the previous survey, as detailed in the following table. For example, there was a drop in the proportion of regions reporting that they met the requirements of performance indicator 1 (strategic plans), down from 63% in 2007 to 45% in 2008.

## Summary of results for nationally agreed palliative care performance indicators 2007 and 2008

Performance indicator	Proportion of regions/agencies meeting performance indicator (per cent)	
	2007	2008
<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	45
<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	32
<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	61
<i>Performance indicator 4—partnerships:</i> the proportion of palliative care agencies that have formal working partnerships with other service providers or organisations	89	89

A greater proportion of agencies delivering care mostly in a community setting collected feedback from clients and staff (65%), compared with agencies delivering care mostly in inpatient setting (50%) and agencies delivering a similar amount of care in both settings (65%).

Agencies delivering a similar amount of care in both settings more commonly assessed themselves against the Palliative Care Australia (PCA) standards (89%) compared to those agencies delivering care mostly in a community setting (75%) and those delivering care mostly in an inpatient setting (64%).



# 1 Introduction

The 2008 National Palliative Care Survey is the fourth survey in the current survey series to measure the performance of palliative care agencies against the four nationally agreed palliative care performance indicators. It is also the last of the surveys to occur under the *Australian Health Care Agreements* (AHCAs) which have been replaced by the *National Healthcare Agreement* (NHA) and associated *National Partnership Agreements*.

## 1.1 Palliative care in Australia

Palliative care is the specialised care of people who are terminally ill. The World Health Organization (WHO) describes palliative care as '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 in Australia are delivered in a range of settings, including homes and other community settings as well as to patients admitted to hospital (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:

- Goal 1:** awareness and understanding of palliative care by the community and other health-care professionals
- Goal 2:** continuous improvement in the quality and effectiveness of palliative care service delivery
- Goal 3:** 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 were included in AHCAs, from 1998 to 2009.

The National Palliative Care Strategy acknowledges the need for more knowledge of, and information about, palliative care service provision in Australia. Under the 2003–2008 AHCA, states and territories worked 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 Survey aims

The aim of the 2008 National Palliative Care Survey was to examine the performance of palliative care agencies against the four national palliative care performance indicators. Additionally, the 2008 version of the survey attempted to capture information on the characteristics of palliative care services and agencies being surveyed across Australia.

Definitions of these characteristics, such as 'setting of care', 'level of palliative care specialisation' and 'remoteness' are detailed in Section 3.

## 1.5 Methods

The survey was carried out by staff at the Australian Institute of Health and Welfare (AIHW) in consultation with the Department of Health and Ageing (DoHA), the Palliative Care Intergovernmental Forum (PCIF), Palliative Care Australia (PCA) and the Palliative Care Outcomes Collaboration (PCOC).

Data were collected from states and territories and palliative care agencies across Australia between December 2008 and March 2009, but the reported data are for the 2007–08 financial year.

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>.

### 1.5.1 About the 2008 survey

The 2008 National Palliative Care Survey was built on the design of the 2007 survey. It consists of two survey instruments: an administrative health region data reporting form (at Appendix 1) and an agency-level survey (at Appendix 2).

### 1.5.2 Administrative health region data collection

This data collection from states and territories about 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.

In 2008, 31 administrative health regions were identified across Australia by state and territory jurisdictions (Table 1.1). The jurisdictions also provided the data relating to these health regions. Whilst the overall number of regions is very similar to 2007, there are some minor differences within states and territories. For example, Tasmania identified one administrative health region in 2007 but reported three regions in 2008.

**Table 1.1: Administrative health regions in 2007 and 2008, by state and territory**

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number of regions in 2007	9	8	3	4	4	1	1	2	32
Number of regions in 2008	9	8	1	4	4	3	1	1	31

### 1.5.3 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 AHCA funding), or does not provide specialist palliative care but receives AHCA 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.

There were a number of changes made to the 2008 agency survey instrument in an attempt to improve the fidelity of the data collected for the palliative care indicator 2 – standards. For example, the question on the use of the PCA standards was revised to encompass how agencies used the standards.

Two additional questions relating to the number of palliative care patients and the number of agency employees were added to the survey instrument in order to provide a better understanding of the nature of the palliative care agencies responding to the 2008 performance indicator data collection.

In 2008, PCIF state and territory members identified 343 palliative care agencies for inclusion in the national palliative care agency data collection, an increase of nine agencies from 2007. Of these, 227 agencies returned completed questionnaires. Table 1.2 shows the distribution of responding agencies across the states and territories.

**Table 1.2: Participating palliative care agencies in 2008, by state and territory**

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number of agencies	57	48	76	17	21	4	2	2	227

Of the remaining agencies, nine (3%) did not complete survey questionnaires as they reported that they had not provided palliative care services during the last financial year (2007-08) or were established by AIHW, in consultation with PCIF, to be out of scope for the purposes of this survey. No response was received from 107 agencies. The response rate was 84% in 2007 but fell to 66% in 2008. Response rates were higher for agencies in *Inner regional* (72%) and *Outer regional* (70%) areas than in other remoteness areas.

## 2 Performance indicators

### 2.1 Overview of results 2005–2008

The 2008 survey of palliative care agencies and administrative health regions produced performance indicator results which varied from earlier years (Table 2.1).

There was a drop in the proportion of regions meeting performance indicator 1 (strategic plans) from 63% in 2007 to 45% in 2008. However, while there was a reduction in the proportion of regions meeting this performance indicator, some jurisdictions indicated that their regions did not meet the indicator because they were in the process of developing new strategic plans.

In contrast to indicator 1, performance increased for indicator 2 (assessment of agencies against PCA standards) in 2008 to 32%. This is in contrast to the reduction observed between 2005 (34%) and 2007 (11%). However, this increase may be a result of revisions made to the questions for this indicator, which are discussed in more detail in Section 4 of this report.

Performance indicator 3 (feedback) showed a decrease from 2007 to 2008 (66% to 61%) while performance indicator 4 (partnerships) showed no change over the same time period (89% in 2007 and 2008).

**Table 2.1: Changes in performance indicators 2005–2008**

Performance indicator (PI)	Proportion of regions/agencies meeting performance indicator (per cent)				Percentage point change (per cent)		
	2005	2006	2007	2008	2005–2006	2006–2007	2007–2008
PI 1: strategic plans	66	63	63	45	–3	0	–18
PI 2: standards	34	21	11	32	–13	–10	+21
PI 3: feedback	71	65	66	61	–6	+1	–5
PI 4: partnerships	96	85	89	89	–11	+4	0

*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).

## 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 2008 survey data indicates that 14 (45%) of the 31 administrative health regions had a written strategic plan that included all of the agreed specified palliative care elements (Table 2.2). This is a decrease from the results of earlier surveys where 63% of regions in 2006 and 2007, and 66% of regions in 2005, had strategic plans.

**Table 2.2: Performance indicator 1—strategic plans, 2008**

Strategic plan status	Number of administrative health regions	Proportion of health regions (per cent)
Yes—plan meets all specified criteria	14	45
No	17	55
<b>Total</b>	<b>31</b>	<b>100</b>

## 2.2.4 Discussion

Although the results show a decline in the proportion of regions meeting performance indicator 1, some jurisdictions indicated that their regions did not meet the indicator because they were in the process of developing new strategic plans. Two jurisdictions, covering 13 administrative health regions, reported that they were developing, or redeveloping, their palliative care services plans and were expecting the plans to be finalised in 2009.

In addition, another jurisdiction indicated that they were in the process of developing clinical networks with a view to developing a formal strategic plan in the future. Yet another jurisdiction reported that they were developing evidence-based 'Models of Care' to provide a blueprint for best practice clinical care, policy and planning, with the intention of implementing the 'Models of Care' in each region (subject to funding).

## 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 (DoHA 2000) 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).

### 2.3.2 Definitions

The voluntary 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 used the current PCA standards in support of continuous improvement in the delivery of palliative care services.

The 2008 survey asked agencies about their use of the *Standards for providing quality palliative care for all Australians* (4th edition; PCA 2005a). For the purposes of this collection, an agency was deemed to have met performance indicator 2 if they used the PCA standards to prepare for formal accreditation. As in previous years, the 2008 data collection also gave agencies the opportunity to provide additional information about relevant standards or frameworks they used other than the PCA standards.

### 2.3.3 What the data show

The proportion of agencies responding that they used the PCA 4th edition standards to prepare for formal accreditation has increased from 11% (30 of 280 agencies) in 2007 to 32% (73 of 227 agencies) in 2008 (Table 2.1). This increase may be due in part to revisions to the performance indicator 2 questions, which appear to have enabled agencies to more accurately report their assessment activities against the PCA standards.

Table 2.3 provides more detail on agencies' use of the PCA standards and indicates that of the 147 agencies that provided care mostly in the community setting, 37 agencies (25%) used the standards to prepare for formal accreditation. Of the 52 agencies that provided care mostly in an inpatient setting, 22 agencies (42%) used the standards and of the 28 agencies that provided care in both settings, 14 agencies (50%) used the standards. Information on the definition of 'setting of care' is presented in Section 3.3.

**Table 2.3: Performance indicator 2—use of PCA standards to prepare for formal accreditation, by agency setting of care, 2008**

PCA standards status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Yes	37	22	14	73
No	110	30	14	154
<b>Total</b>	<b>147</b>	<b>52</b>	<b>28</b>	<b>227</b>

Although use of PCA standards to prepare for formal accreditation was not widespread, use of the standards more generally was higher with 74% (168 agencies) using the PCA standards in some form (Table 2.4).

When standards other than PCA standards are taken into account, nearly all agencies (96%, 219 agencies) reported routine assessment or accreditation against an accreditation standard.

Of the 168 agencies which used the current PCA standards in some form, 65% (110 agencies) delivered care mostly in a community setting, 20% (33 agencies) delivered care mostly in an inpatient setting, with the remaining 15% (25 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 2.4: Standards used by palliative care agencies, 2008**

<b>Standards used</b>	<b>Mostly community setting</b>	<b>Mostly inpatient setting</b>	<b>Similar amount in both settings</b>	<b>Total</b>
PCA (4th edition) only	10	0	3	13
PCA plus other standards	100	33	22	155
<i>Subtotal of agencies that use PCA standards</i>	<i>110</i>	<i>33</i>	<i>25</i>	<i>168</i>
Non-PCA standards only	31	18	2	51
<i>Subtotal of agencies that use standards</i>	<i>141</i>	<i>51</i>	<i>27</i>	<i>219</i>
Agencies that do not use standards	6	1	1	8
<b>Total agencies</b>	<b>147</b>	<b>52</b>	<b>28</b>	<b>227</b>

### 2.3.4 Use of PCA standards

Agencies that routinely assessed themselves against the PCA standards were asked to indicate how they used the standards.

Over three-quarters of the 168 agencies that were using PCA standards reported using them as a 'framework for service planning or development' (76%, or 127 agencies), with a smaller number (59%, 99 agencies) using them as a 'framework for quality activities' (Table 2.5). More than one-quarter of PCA standards users (27%, 45 agencies) reported using the standards as a 'component of performance reporting or management'.

There were 13 agencies (8%) that reported they had used the PCA standards as part of the pilot of PCA's National Standards Assessment Program (NSAP).

**Table 2.5: Agencies using Palliative Care Australia standards, by type of use, 2008**

<b>Use of standards</b>	<b>Mostly community setting</b>	<b>Mostly inpatient setting</b>	<b>Similar amount in both settings</b>	<b>Total number</b>	<b>Total (per cent)<sup>(a)</sup></b>
Framework for service planning or development	83	22	22	127	76
Component of performance reporting or management	25	10	10	45	27
Framework for quality activities	62	20	17	99	59
To prepare for formal accreditation	37	22	14	73	43
Other	7	4	2	13	8
Not stated	3	0	0	3	2
<b>Total<sup>(b)</sup></b>	<b>110</b>	<b>33</b>	<b>25</b>	<b>168</b>	<b>100</b>

(a) Percentages are calculated as a proportion of the number of agencies which use PCA standards (168 agencies).

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

Although 74% of responding agencies in 2008 indicated that they used the PCA standards generally (Table 2.4), a smaller proportion (32%) indicated that they used them for formal accreditation purposes (Table 2.5). Whilst the result for 2008 is 21 percentage points higher

than 2007 (11%), there may still be concern that the PCA standards are not being used more universally. However, as discussed in the 2007 report, the apparently low uptake may be explained by a number of factors, including:

- 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 have now been developed by PCA as part of the NSAP project, which may result in greater 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 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).

In 2008, 91% (206 of 227 agencies) reported using standards other than PCA standards (Table 2.6). This is a considerable increase from 2007 when 54% (151 of 280 agencies) reported using non-PCA standards.

Of the 206 agencies that reported using standards other than PCA standards, 88% (181 agencies) reported being accredited against at least one standards framework (Table 2.6), an increase from 49% (79 of 160 agencies) in 2007.

Table 2.6 shows the number of agencies assessed and accredited against each non-PCA standards framework. The Australian Council on Healthcare Standards (ACHS) Evaluation and Quality Improvement Program (EQUIP) was the most commonly used standards framework (used by 78% of agencies; an increase from 48% in 2007), 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 26% of agencies (up from 14% in 2007).

**Table 2.6: Use of non-PCA standards for accreditation, by agency accreditation status, 2008**

<b>Standards used</b>	<b>Assessed only</b>	<b>Assessed and accredited</b>	<b>Indepth review</b>	<b>Total agencies</b>	<b>Proportion of agencies (per cent)<sup>(a)</sup></b>
ACHS Evaluation and Quality Improvement Program (EQUIP)	16	133	27	176	78
Quality Improvement Council (QIC)	6	12	..	18	8
ISO 9000 quality management system standards	10	10	..	20	9
Other standards	6	21	..	27	12
<b>Total<sup>(b)</sup></b>	<b>25</b>	<b>181</b>	<b>27</b>	<b>206</b>	<b>91</b>

(a) The proportion of agencies using each standard is calculated as a percentage of responding agencies (227 agencies).

(b) Totals may not equal to the sum of components as agencies could nominate more than one standard.

.. Not applicable. Indepth review is applicable only to the ACHS EQUIP.

Note: 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, 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 a fundamental 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).

**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).

### 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

The proportion of palliative care agencies that reported they routinely collected feedback about their services and service delivery from both clients and staff in 2008 was 61% (Table 2.7), a decrease from 2007, when 66% reported they collected feedback.

A small number of agencies collected feedback from clients only (13%, 30 agencies) or from staff only (2%, 4 agencies). Overall, 169 agencies collected feedback from clients and 143 collected feedback from staff.

Of the 147 agencies that provided care mostly in the community setting, 96 agencies (65%) collected feedback from both clients and staff. Of the 52 agencies that provided care mostly in an inpatient setting, 26 agencies (50%) collected feedback and of the 28 agencies that provided care in both settings, 17 agencies (61%) collected feedback.

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

**Table 2.7: Performance indicator 3 – collection of feedback from clients and staff, by agency setting of care, 2008**

<b>Feedback collection status</b>	<b>Mostly community setting</b>	<b>Mostly inpatient setting</b>	<b>Similar amount in both settings</b>	<b>Total</b>
Yes (from clients and staff)	96	26	17	139
Yes (from clients only)	21	7	2	30
Yes (from staff only)	2	2	0	4
No	27	17	9	53
Not stated	1	0	0	1
<b>Total</b>	<b>147</b>	<b>52</b>	<b>28</b>	<b>227</b>

### 2.4.4 Feedback methods

Table 2.8 shows the different methods used by agencies to collect feedback from clients and staff. Irrespective of the setting of care, feedback was mainly collected by questionnaire in periodic written surveys. Other commonly reported methods of collection were periodic face-to-face interview or questionnaires completed on exit, either as a written survey or telephone interview.

**Table 2.8: Agency methods to collect feedback from clients and staff, 2008**

Feedback collection method	Number of agencies using method <sup>(a)</sup>	
	Feedback from clients	Feedback from staff
Questionnaire / interview methods		
Periodic face-to-face	45	66
Face-to-face interview on exit	16	56
Periodic telephone	27	4
Telephone interview on exit	7	3
Periodic written survey	129	89
Written survey on exit	28	30
Feedback focus group	27	25
Other	18	17

(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).

### 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.

A formal working partnership, in the palliative care context, 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 seamlessly between services and service settings.

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

Partnership arrangements between palliative care agencies may occur 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

As in 2007, 89% of the palliative care agencies that responded to the survey (202 of 227 agencies) had formal working partnerships with other organisations, with 11% indicating that they did not have partnerships (Table 2.9).

Of the 147 agencies that provided care mostly in the community setting, 130 agencies (88%) had formal working partnerships. Of the 52 agencies that provided care mostly in an inpatient setting, 47 agencies (90%) had partnerships whilst of the 28 agencies that provided care in both settings, 25 agencies (89%) had formal partnerships.

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

**Table 2.9: Performance indicator 4 – formal working partnerships with other organisations, by agency setting of care, 2008**

Partnership status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Yes	130	47	25	202
No	16	5	3	24
Not stated	1	0	0	1
<b>Total</b>	<b>147</b>	<b>52</b>	<b>28</b>	<b>227</b>

### 2.5.4 Partner organisations

The survey asked agencies to identify the types of organisations with which they had formal partnerships.

Palliative care services (nominated by 74% of the 202 agencies forming partnerships) were the most common partner organisation type, followed by hospitals (71%), community nursing agencies (60%), allied health services (53%) and medical practices (53%) (Table 2.10). The same top five partner organisations were nominated in 2007, although the order was different, with hospitals (78%) being the most common type of partner in 2007.

**Table 2.10: Partner organisations, 2008**

<b>Partner organisations</b>	<b>Number of agencies</b>	<b>Proportion of agencies (per cent)<sup>(a)</sup></b>
Palliative care services	149	74
Hospitals	143	71
Community nursing agencies	122	60
Allied health services	107	53
Medical practices	107	53
Residential aged care facilities	85	42
Volunteer support services	62	31
Universities/research centres	52	26
Aboriginal health services	46	23
Integrated health centres	25	12
Other	26	13

(a) Proportions are calculated as a percentage of agencies with partnerships (202 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:

- Divisions of General Practice, through consortia or arrangements, such as memorandums of understanding
- community services, such as the Australian Meals on Wheels Association, respite care services and HACC services
- government departments, both state and commonwealth
- health service providers, such as hospices
- support services, such as cancer support groups or carer support services
- suppliers, such as equipment hire service providers or home oxygen providers.

## 3 Palliative care agency characteristics

### 3.1 Introduction

This section presents descriptive information about the palliative care agencies responding to the 2008 survey, including information on the employment of coordinators of volunteers, settings of care, level of specialisation, and remoteness. In addition, there is information presented on the number of patients seen by, and the number of employees employed by, agencies – collected for the first time in the 2008 survey.

### 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 information on 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 patient. All volunteers are screened and undertake extensive training before taking on this role.

An 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 just over half of all agencies (52%, 117 agencies) reported employing a coordinator of volunteers, down slightly from the 55% of agencies (153 of 280) in 2007.

Of the 147 agencies that provided care mostly in the community setting, 69 agencies (47%) employed a coordinator of volunteers. Of the 52 agencies that provided care mostly in an inpatient setting, 30 agencies (58%) employed a coordinator and of the 28 agencies that provided care in both settings, 18 agencies (64%) employed a coordinator.

**Table 3.1: Coordinator of volunteers, by agency setting of care, 2008**

Coordinator of volunteers status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Yes	69	30	18	117
No	78	22	10	110
<b>Total</b>	<b>147</b>	<b>52</b>	<b>28</b>	<b>227</b>

Data relating to coordinator of volunteers 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 Appendix 3.

**Table 3.2: Coordinator of volunteers, by level of specialisation, 2008**

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)	Total
Yes	25	40	25	27	117
No	59	31	7	13	110
<b>Total</b>	<b>84</b>	<b>71</b>	<b>32</b>	<b>40</b>	<b>227</b>

Specialist palliative care agencies were more likely to employ a coordinator of volunteers. Of the 143 specialist palliative care agencies (levels 1, 2 and 3), 92 (64%) employed a coordinator of volunteers. For primary palliative care agencies, 25 agencies (30%) employed a coordinator (Table 3.2).

## 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’. Consequently, 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 during the 2007–08 financial year. Categories were ‘mostly community-based setting’, ‘mostly inpatient setting’ and ‘similar amount of services in community and inpatient settings’.

‘Mostly community-based setting’ means that, during the 2007–08 financial year, substantially more than 50% of service delivery time was spent on delivering services to, and on behalf of, clients in community settings.

A community-based setting, as defined by the agency-level survey instrument, includes:

- 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.

Similarly, ‘mostly inpatient setting’ means that, during the 2007–08 financial year, substantially more than 50% of service delivery time was spent on delivering services to, and on behalf of, clients in inpatient settings. This includes all patients admitted to hospital and hospices, but excludes hospital outpatient and outreach services delivered in the community.

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

The majority of agencies (65%, or 147 of the 227 participating agencies) reported delivering care to clients mostly in the community setting, with 23% (52 agencies) reporting that they provided care mostly in inpatient settings. The remaining 12% (28 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

A high-level snapshot of the characteristics of agencies in each ‘most common setting of care’ category is provided in Table 3.3. For each category, the percentage of agencies within that category which met the performance indicator or showed the characteristic is presented.

The typical agency profile in each category can be derived by reading the data across the row for each category. For example, most agencies in the ‘mostly community setting’ category are primary palliative care agencies. Of these agencies, 25% use the PCA standards to prepare for formal accreditation while 96% use standards overall, 88% of these agencies have partnerships, 65% collect feedback, and 47% employ a coordinator of volunteers.

**Table 3.3: Profile of agencies by agency setting of care, 2008**

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	147	25	65	88	96	47	Primary palliative care
Mostly inpatient setting	52	42	50	90	98	58	Specialist palliative care (level 3)
Similar amount in both settings	28	50	61	89	96	64	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

The following patterns emerge based on the profile data:

- A greater proportion of agencies delivering care ‘mostly in a community setting’ collected feedback from clients and staff (65% compared with 61% and 50% for the ‘similar amount of care in both settings’ or ‘mostly in inpatient setting’ categories, respectively).
- Agencies in the ‘similar amount in both setting’ category more commonly assessed themselves against the PCA standards and employed a coordinator of volunteers.
- The measures that were consistent across the ‘most common setting of care’ categories were:
  - use of PCA standards (most commonly reported use being ‘framework for service planning or development’)
  - most common non-PCA standard used for assessment or accreditation (ACHS EQUIP)
  - 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 Appendix 3) with 10 or fewer employees that delivered care in private residences and residential aged care settings, and had palliative care agencies and hospitals as partners.
  - Inpatient setting agencies were most commonly specialist palliative care (level 3) agencies with more than 10 employees that had palliative care and community nursing agencies 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 hospitals and residential aged care facilities as partners.

### 3.3.4 Palliative care delivery settings

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 2007–08 financial year.

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 designated palliative care units’, including all admitted patient beds not in a unit designated for palliative care; these are usually located in acute hospital wards.

The most frequently nominated setting for palliative care delivery was ‘Private residence’, with 81% of responding agencies delivering care in this setting. Other frequently reported settings were ‘Inpatient – other than designated palliative care units’ (52% of agencies) and ‘residential – aged care’ (48% of agencies) (Table 3.4). These results matched those reported in 2007.

The data shown in Table 3.4 are not comparable with the data shown in the ‘most common setting of care’ table (Table 3.3). ‘Most common setting of care’ categories are based on proportions of time spent delivering services in community and inpatient settings, and the data record the setting responsible for the majority of the time spent delivering services. By contrast, delivery setting categories are based on whether any services were delivered in a particular care delivery setting during the reporting period.

**Table 3.4: Palliative care delivery settings, 2008**

Care delivery setting	Agencies	Proportion of agencies (per cent) <sup>(a)</sup>
<b>Community-based settings</b>		
Private residence	183	81
Residential—aged care	109	48
Residential—other	62	27
Non-residential	28	12
Outpatient—hospital or hospice	68	30
<b>Inpatient settings</b>		
Inpatient—designated palliative care unit or hospice	73	32
Inpatient—other than designated palliative care units	117	52

(a) Proportions are calculated as a percentage of responding agencies (227 agencies). Agencies could nominate more than one care delivery setting, therefore percentages do not total 100%.

Note: The data from Table 3.4 cannot be mapped to the data in Table 3.3.

## 3.4 Level of palliative care specialisation

### 3.4.1 Level of specialisation

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

There are four broad levels of specialisation within this framework:

- 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).

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 Appendix 3.

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.

The majority of agencies (68%) 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 (14% and 18%, respectively) (Table 3.5).

**Table 3.5: Agencies, by palliative care specialisation and agency setting of care, 2008**

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	69	11	4	84	37
Specialist palliative care agency (level 1)	52	14	5	71	31
Specialist palliative care agency (level 2)	17	7	8	32	14
Specialist palliative care agency (level 3)	9	20	11	40	18
<b>Total</b>	<b>147</b>	<b>52</b>	<b>28</b>	<b>227</b>	<b>100</b>

Care was delivered mostly in community settings by primary palliative care agencies and specialist palliative care agencies (levels 1 and 2), whilst specialist palliative care agencies (level 3) delivered care mostly in inpatient settings.

It is worth noting that agencies are asked to self-report the level of palliative care specialisation (or role delineation) based on a qualitative framework. These interpretations are made by agency staff and may not be consistent over time. Some agencies were not able to locate their service within the PCA service planning framework (13 agencies in 2008, a decrease compared with the 26 agencies that were unable to report their level of specialisation in 2007). Although all of these agencies were later located within the framework based on advice from state and territory PCIF 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 or across time.

### 3.4.2 Profile of agencies by level of specialisation

A high-level snapshot of the characteristics of agencies in each level of specialisation category is shown in Table 3.6. For each category, the percentage of agencies within that category which met the performance indicator or showed the characteristic is shown.

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 84 agencies in the primary palliative care category, 16% use the PCA standards to prepare for formal accreditation, and 94% use standards of some kind. A majority of agencies in this category form partnerships (80%), while 64% of agencies collect feedback and 30% 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, 2008**

Level of specialisation category	No. of agencies	Performance indicator <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	84	16	64	80	94	30	Mostly community setting
Specialist palliative care (level 1)	71	32	55	94	97	56	Mostly community setting
Specialist palliative care (level 2)	32	59	69	94	97	78	Mostly community setting
Specialist palliative care (level 3)	40	45	60	95	100	68	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.

Additional to the information presented in Table 3.6, partner organisations were similar across levels of specialisation, with the most common types being palliative care services and hospitals. One difference was that primary palliative care agencies included medical practices in their top four partner types, while specialist palliative care agencies (levels 1, 2 and 3) did not, including community nursing agencies instead. In addition, primary and specialist palliative care agencies (level 1) included allied health services in their top four partner types while specialist agencies (levels 2 and 3) did not (data not shown).

Measures which were consistent across level of specialisation were:

- ACHS EQUiP being the most common non-PCA standard used for assessment or accreditation
- 'questionnaire – periodic written survey' being the most commonly reported method for collecting feedback from both clients and staff and across all settings
- more than half of primary care agencies and specialist care agencies (level 1) employed five people or fewer
- specialist care agencies (levels 2 and 3) were more likely to employ higher numbers of staff to provide services (data not shown).

## 3.5 Remoteness

### 3.5.1 Remoteness areas

The 2008 National Palliative Care Survey data was 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 some examples of locations within each of the remoteness categories.

#### **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.

Of the 227 palliative care agencies that participated in the 2008 National Palliative Care Survey, nearly three-quarters (73%) were concentrated in *Major cities* and *Inner regional* areas.

These categories each contained just over one-third of participating palliative care agencies (36% and 37%, respectively) with fewer agencies located in more remote areas – 23% in *Outer regional* areas, 3% in *Remote* areas and 2% in *Very remote* areas (Table 3.7). The distribution of agencies by remoteness does not reflect the distribution of population especially in *Major cities* and *Outer regional* areas, nor the different sizes of the agencies.

**Table 3.7: Palliative care agencies and population, by remoteness category, 2008**

	Major cities	Inner regional	Outer regional	Remote	Very remote	Total
Number of agencies	82	84	51	6	4	227
Proportion of agencies (per cent) <sup>(a)</sup>	36	37	23	3	2	100
Population <sup>(b)</sup>	14,435,219	4,156,847	1,993,113	317,490	167,387	21,070,056
Proportion of population (per cent) <sup>(a)</sup>	69	20	9	2	1	100

(a) Components may not add to total due to rounding.

(b) Preliminary Australian estimated resident population by remoteness for 2007.

### 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 ASGC remoteness areas for agencies that participated in the 2008 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 84 agencies in the *Inner regional* category, 36% use the PCA standards, although 96% use standards overall. Most of these agencies (85%) form partnerships, and 62% collect feedback. *Inner regional* agencies are most frequently specialist palliative care (level 1) agencies with a most common setting of care of 'mostly community setting', and 64% employ a coordinator of volunteers.

Table 3.8: Profile of agencies by remoteness category, 2008

Remote-ness category	No. of agencies	Performance indicator <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	Most common level of specialisation
Major cities	82	44	65	92	96	57	Mostly community setting (45%)	Specialist palliative care (level 3)
Inner regional	84	36	62	85	96	64	Mostly community setting (79%)	Specialist palliative care (level 1)
Outer regional	51	14	55	90	100	28	Mostly community setting (73%)	Primary palliative care
Remote	6	0	50	100	100	33	Mostly community setting (83%)	Primary palliative care and Specialist palliative care (level 1) (equally frequent)
Very remote	4	0	75	100	50	0	Mostly community setting (50%)	Specialist palliative care (level 1)

(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.

Note: The small number of agencies in the *Remote* and *Very remote* categories means that proportions for those categories should be interpreted with care.

### 3.5.3 Remoteness patterns

From Table 3.8, some characteristics which showed patterns based on remoteness were:

- PCA standards – as in 2007, agencies located in *Major cities* and *Inner regional* areas were more likely to use the PCA standards.
- Other agency characteristics – agencies in *Major cities* and *Inner regional* areas tended to see a larger number of patients and employed more staff (data not shown).

Due to the small number of agencies in the *Remote* and *Very remote* categories, the results for those categories should be interpreted with caution.

## 3.6 Patients

For the first time, the 2008 survey asked agencies to report the number of palliative care patients seen during the last financial year (2007–08). Some agencies were unable to report

the number of patients seen as their data systems did not allow them to differentiate between palliative care patients and other patients.

The number of patients seen by an agency tended to increase with increasing level of specialisation (Table 3.9).

**Table 3.9: Number of palliative care patients, by level of specialisation, 2008**

No. of patients	No. of agencies	Primary palliative care agency (per cent)	Specialist palliative care agency (level 1) (per cent)	Specialist palliative care agency (level 2) (per cent)	Specialist palliative care agency (level 3) (per cent)	Total (per cent)
1–10	23	24	4	0	0	10
11–50	43	37	14	0	5	19
51–100	37	18	25	6	5	16
101–200	43	13	31	22	8	19
201–300	19	5	10	25	0	8
301–400	16	2	4	19	13	7
401–500	6	0	7	0	3	3
501–600	6	0	0	3	13	3
601–700	5	0	0	9	5	2
701–800	6	0	0	0	15	3
801–900	4	0	1	3	5	2
More than 900	15	0	3	9	25	7
Not stated	4	1	0	3	5	2
<b>Total</b>	<b>227</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>

*Note:* Components may not add due to rounding.

## 3.7 Employees

Agencies were also asked to report on the number of employees in their organisation that were employed to provide palliative care services. The survey shows that the majority of agencies (61%) had 10 employees or fewer. The number of employees in an agency increased with increasing level of specialisation. Nearly three-quarters (73%) of primary and specialist palliative care agencies (level 1) had 10 employees or fewer. By contrast, 40% of specialist palliative care agencies (level 2) had more than 20 employees, with this number increasing to 53% for specialist palliative care agencies (level 3) (Table 3.10).

**Table 3.10: Number of palliative care agency employees, by level of specialisation, 2008**

<b>No. of employees</b>	<b>No. of agencies</b>	<b>Primary palliative care agency (per cent)</b>	<b>Specialist palliative care agency (level 1) (per cent)</b>	<b>Specialist palliative care agency (level 2) (per cent)</b>	<b>Specialist palliative care agency (level 3) (per cent)</b>	<b>Total (per cent)</b>
1	28	23	11	3	0	12
2–5	70	30	49	9	18	31
6–10	40	20	13	22	18	18
11–20	25	7	10	25	10	11
21–50	43	13	14	31	30	19
51–100	11	1	1	6	18	5
101–500	4	1	0	3	5	2
Not stated	6	5	1	0	3	3
<b>Total</b>	<b>227</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>

*Note:* Components may not add due to rounding.

## 4 Notes on the data

### 4.1 Comparability of data 2005–2008

The national palliative care performance indicators survey has evolved since its inception in 2005. With each iteration of the survey, a number of enhancements have been made to the way in which some of the palliative care performance indicators are measured. These changes to the survey instrument have implications for the comparability of the survey's results over time.

For performance indicator 1 (strategic plans), which relates to administrative health regions, the survey questions and eligibility for inclusion in the collection have remained largely unchanged between 2005 and 2008. There have been some minor wording changes to make the requirements of this indicator more apparent.

The questions used to measure performance indicator 2 (standards) were modified. The question relating to PCA standards assessment methods was removed in 2008 in an attempt to allow agencies to more accurately report their assessment activities against the PCA standards. In addition, for the first time in 2008, agencies were asked to indicate the way that they used the PCA standards. Due to the continual refinements that have been made to these questions, comparisons with results from previous years should be made with caution.

The wording of the questions relating to performance indicators 3 (feedback) and 4 (partnerships) remained substantively the same between 2005 and 2008.

There were changes made to the scope of agencies eligible to participate in the survey between 2005 and 2006. Consequently, comparisons between 2006, 2007 and 2008 are likely to be more reliable than between the first two iterations of the survey (2005 and 2006).

Other enhancements made to the survey in 2008 include the collection of additional agency details, such as the number of patients using palliative care services in each agency and number of employees within each agency providing palliative care services.

Further information about changes made to the survey in previous years can be found in the 2006 and 2007 performance indicators reports (AIHW 2007, 2008).

### 4.2 Agency definitional issues

The intention of the 2008 National Palliative Care Survey was to not only report on the national palliative care performance indicators but also to capture additional information about the characteristics of palliative care agencies in Australia (also referred to as palliative care services). However, the definition of what constitutes a 'palliative care agency' has proved to be an elusive concept, which has made it difficult to determine which agencies are in-scope for the survey. This issue was identified in earlier surveys, and resulted in refinement of the definition and changes to the guidelines for agency inclusion in 2007. Despite these efforts, the 2008 performance indicators survey also encountered difficulties in determining which agencies should be included in the survey. Examples of the type of agencies that proved problematic to define include:

- 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
- agencies that operated on a part-time basis, or shared some, but not all, services and staff with other organisations.

## 4.3 Performance indicator issues

The 2007 *National palliative care performance indicators* report identified a number of potential issues with respect to the measurement and interpretation of the results for the four national palliative care performance indicators. Results from the 2008 survey have reaffirmed some of these issues as outlined below.

### Performance indicator 1 – strategic plans

The 2007 report queried 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). It suggested that the activities reported informally by jurisdictions seem to indicate that more activity is occurring than is currently measured by the indicator. This also appeared to be the case in 2008, with a number of jurisdictions indicating that their strategic plans were in transition and in the process of being redeveloped.

### Performance indicator 2 – standards

To assist in interpreting the performance against this indicator, the survey question about use of standards was expanded in 2008 to collect additional information. Despite this, there are still many aspects of standards use which are unknown.

For example, although the survey asked whether agencies used the current PCA standards, agencies were not asked whether they met the standards or how often any formal assessment against the standards was carried out. As with the 2007 survey, no time periods were specified for reporting, leading to uncertainty about whether agencies were describing current or previous practice.

The introduction of processes for self-assessment and peer review against PCA standards (developed by Palliative Care Australia as part of the NSAP project and formally launched in March 2009) is also likely to affect performance against the indicator. The questions relating to this indicator would need further amendment to recognise the implementation of this project by agencies.

### Performance indicator 3 – feedback

The observations in the 2007 report, identifying that the current survey questions collect information about how feedback is collected and from whom, but not how it is used, are still valid. This section of the survey instrument could be refined to collect additional information about how the feedback is used, or how it feeds into quality improvements.

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

The 2008 survey collected information about the existence of partnerships and the types of partner organisations. Future surveys could include collection of additional information about the nature of the partnerships, their form and duration, and how the partnerships impact palliative care quality.

### **4.4 Response rates**

A number of changes, informed by the results and experiences of previous surveys, have been made to the survey instrument over time in an effort to improve the measurement of agency performance against the agreed performance indicators. Enhancements have also been made to the survey's data collection methodology in order to limit the number of out-of-scope agencies being included in the survey. Despite these efforts, the response rate to the survey has been declining. Comparison of results over time should be undertaken with this declining response rate in mind. Additionally, any future collection of information for these performance indicators would need to take this declining response rate into consideration.

# **Appendix 1: Administrative health region data reporting form**



Australian Government

Australian Institute of  
Health and Welfare

## 2008 National palliative care performance indicators

### Administrative health region data reporting form

Please provide the required information for each administrative health region within your state/territory. Refer to the attached guidelines for relevant definitions, including the definition of a written strategic plan that includes palliative care elements.

<b>Name of state/territory:</b>	
<b>Name of administrative health region:</b>	
<b>Name of person completing this form:</b>	
<b>Contact phone number:</b>	
<b>Date completed:</b>	
<b>Does this region have a written (strategic) plan for its palliative care services?</b>	YES / NO
<b>(If applicable) Title of plan and/or publication details (including internet address):</b>	

Please indicate which of the following specific elements are contained in the plan: *(tick as many as boxes as applicable)*

- Timeframe (the beginning and end-date in years), with a minimum time period of two years to demonstrate a strategic focus.
- Measurable objectives relating to: service access, quality, 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 (can include resources identified for service delivery).
- Evidence of ongoing development in subsequent plans.

**Comments:** (e.g. *the strategic plan for this region is currently being drafted*)

## **Appendix 2: 2008 National Palliative Care Survey agency-level instrument**



Australian Government

Australian Institute of Health and Welfare

# 2008 National Palliative Care Survey

This form should be completed by a member of staff with a good knowledge of your agency's policies and procedures. Background to this survey can be accessed at [www.aihw.gov.au/pallcare](http://www.aihw.gov.au/pallcare). Comments or additional information can be provided on the 'Summary instructions and additional guidelines' sheet.

**Questions and queries?** Contact the AIHW helpline on **1800 035 938** or email [rachelle.graham@aihw.gov.au](mailto:rachelle.graham@aihw.gov.au)

Please return by **Friday, 27th February 2009** in the envelope provided or post to: MHSU, Australian Institute of Health and Welfare, GPO Box 570, CANBERRA ACT 2601.

- This is the name and address of your agency as supplied to us by your state/territory health authority. Please correct details, if necessary.

## Contact Details

Name:

Phone:

- Provide the name and phone number of a staff member who may be contacted by the AIHW project team if required.

## Agency Details

### 1a. Did your agency provide palliative care services during the last financial year (2007–08)?

(Tick one box only)

Yes  Go to Q1b▶

No  If your agency is not providing palliative care services, please note this on the form and return it in the envelope provided

### 1b. During the last financial year (2007–08), how many palliative care patients used the services provided by your agency? (Tick one box only)

1 – 10	<input type="checkbox"/>	401 – 500	<input type="checkbox"/>
11 – 50	<input type="checkbox"/>	501 – 600	<input type="checkbox"/>
51 – 100	<input type="checkbox"/>	601 – 700	<input type="checkbox"/>
101 – 200	<input type="checkbox"/>	701 – 800	<input type="checkbox"/>
201 – 300	<input type="checkbox"/>	801 – 900	<input type="checkbox"/>
301 – 400	<input type="checkbox"/>	901 – 1,000	<input type="checkbox"/>

### 1c. How many employees does your agency employ to provide palliative care services? (Tick one box only)

1	<input type="checkbox"/>	51 – 100	<input type="checkbox"/>
2 – 5	<input type="checkbox"/>	101 – 500	<input type="checkbox"/>
6 – 10	<input type="checkbox"/>	501 – 1,000	<input type="checkbox"/>
11 – 20	<input type="checkbox"/>	1,001 – 2,000	<input type="checkbox"/>
21 – 50	<input type="checkbox"/>	More than 2,000	<input type="checkbox"/>

- This is how many employees the agency providing the palliative care employs, not the number of employees employed by any parent organisation.

## Services Provided

### 2. Which category, from Palliative Care Australia's service planning framework, best describes your agency? *(Tick one box only)*

- Primary palliative care agency
- Specialist palliative care agency (Level 1)
- Specialist palliative care agency (Level 2)
- Specialist palliative care agency (Level 3)
- Unable to say

- A description of these categories can be found on the 'Summary instructions and additional guidelines' sheet.
- Agencies should assess their service against Palliative Care Australia's framework. Some states and territories have developed local role delineation frameworks but these may differ to Palliative Care Australia's framework.
- If you are not able to locate your service within this framework please select 'Unable to say'. The AIHW may contact you in the future to discuss the characteristics of your agency with a view to locating your agency in this framework.

### 3a. During the last financial year (2007–08), in which setting(s) did your agency deliver palliative care services? *(Tick as many boxes as applicable)*

- Private residences
- Residential—aged care settings
- Residential—other settings
- Non-residential settings
- Outpatient settings—in a hospital/ hospice
- Inpatient—designated palliative care units or hospices
- Inpatient—other than designated palliative care units

- Palliative care services include bereavement care that is associated with palliative care.
- 'Private residences' may include caravans, mobile homes, houseboats or units in a retirement village.
- 'Residential—aged care settings' includes high and low care residential aged care facilities. It does not include units in a retirement village.
- 'Residential—other settings' includes prisons and community living environments (including group homes). It does not include aged care facilities or inpatient settings, e.g. hospitals and hospices.
- 'Non-residential settings' includes day respite centres and day centres. It does not include hospital outpatient departments.
- 'Inpatient—designated palliative care units or hospices' includes dedicated wards or units that receive identified funding for palliative care and/or primarily delivers palliative care. The unit may be a standalone unit (i.e. a hospice).
- 'Inpatient—other than designated palliative care units' includes all admitted patient beds not in a unit designated for palliative care. These are usually located in acute hospital wards.

### 3b. During the last financial year (2007–08), in which type of setting did your agency most commonly deliver palliative care services? *(Tick one box only)*

- Mostly community-based setting
- Mostly inpatient setting
- Similar amount of services in community and inpatient settings

- 'Mostly community-based setting'—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. This includes residential settings such as private residences (including caravans, mobile homes, houseboats or units in a retirement village), residential aged care facilities, prisons, and community living environments (including group homes); and non-residential settings such as day respite centres or day centres. It includes hospital outreach services and outpatient settings where these are delivered in the community setting.
- 'Mostly inpatient setting'—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. This includes hospitals, hospices or other admitted patient settings. It excludes services delivered in outpatient settings and hospital outreach services delivered in the community setting.

### 4. Does your agency employ a coordinator of volunteers on either a paid or unpaid basis? *(Tick one box only)*

- Yes
- No

- A coordinator of volunteers may be employed part-time or full-time.
- A coordinator of volunteers' duties may include: managing the workloads of volunteer staff; liaising with clinical staff regarding clients' needs; assessing 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.

## Standards

### 5a. Does your agency (or your parent organisation) use the Palliative Care Australia (4th edition, 2005) standards? *(Tick one box only)*

- No, not aware of them  *Go to Q5c▶*
- No, aware of the standards, but not used  *Go to Q5c▶*
- Yes, used  *Go to Q5b▶*

### 5b. If applicable, how does your agency use the Palliative Care Australia standards?

*(Tick as many boxes as applicable)*

- Framework for service planning or development
- Component of performance reporting or management
- Framework for quality activities
- To prepare for formal accreditation

- You only need to answer this question if your agency uses the Palliative Care Australia (4th edition, 2005) standards, as recorded in question 5a. above.

Other (please specify below)

.....

.....

.....

### 5c. Is your agency (or your parent organisation) accredited against any standards or accreditation frameworks? *(Tick one box only)*

- Yes
- No

### 5d. Does your agency (or your parent organisation) routinely undertake or undergo formal assessment against any standards or accreditation frameworks? *(Tick as many boxes as applicable)*

	Undertake/undergo formal assessment against these standards	Accredited under this program	Indepth Review	
ACHS Evaluation and Quality Improvement Program (Equip)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<ul style="list-style-type: none"> <li>'Accredited under this program' should only be recorded where accreditation has been granted and is current.</li> <li>Where your agency has been formally assessed against specific standards with a view to achieving accreditation, but accreditation has not yet been granted, this should be recorded as 'Undertake/undergo formal assessment against these standards' only.</li> </ul>
Quality Improvement Council	<input type="checkbox"/>	<input type="checkbox"/>	n/a	
ISO 9000 Quality Management System standards	<input type="checkbox"/>	<input type="checkbox"/>	n/a	
Other standards (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	n/a	

.....

## Feedback

### 6a. Does your agency actively and routinely collect feedback relating to services and service delivery from clients and/or staff? *(Tick one box only)*

- Yes (from clients and staff)  *Go to Q6b*▶
- Yes (from clients only)  *Go to Q6b*▶
- Yes (from staff only)  *Go to Q6c*▶
- No (feedback not actively collected)  *Go to Q7a*▶

- A client is a patient and/or their carer(s), family/friends, and does not include other organisations or service providers.
  - 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 and does not rely on mechanisms such as ad hoc comments, ad hoc questionnaires, informal staff debriefing sessions, or similar casual arrangements.
- Active mechanisms include the use of periodic questionnaires (e.g. satisfaction surveys) that are implemented through either face-to-face interviews, by telephone or by mail, focus groups aimed at collecting feedback from the participants, established staff debriefing sessions, or other routine procedures the agency has in place to collect feedback.

### 6b. If applicable, which method(s) does your agency employ to actively and routinely collect feedback from clients? *(Tick as many boxes as applicable)*

- Questionnaire—periodic face-to-face interview
- Questionnaire—face-to-face interview on exit
- Questionnaire—periodic telephone interview
- Questionnaire—telephone interview on exit
- Questionnaire—periodic written survey
- Questionnaire—written survey on exit
- Feedback focus group
- Other (please specify below)
- .....
- .....

- You only need to answer this question if you answered 'Yes (from clients and staff)' or 'Yes (from clients only)' to question 6a.
- A client is a patient and/or their carer(s), family/friends. It does not include other organisations or service providers.
- 'Periodic' may mean at set intervals or at (a) specified point(s) in time during the service episode. It does not include interviews upon exit (i.e. closure of the service episode).
- The aim of the mechanism used must be to collect feedback, for example, a satisfaction survey.
- Written surveys may be returned by mail, email, or in person.
- 'Feedback focus group' is an in-depth qualitative interview with a small number of persons, held specifically to collect feedback from the participants.

### 6c. If applicable, which method(s) does your agency employ to actively and routinely collect feedback from staff? *(Tick as many boxes as applicable)*

- Questionnaire—periodic face-to-face interview
- Questionnaire—face-to-face interview on exit
- Questionnaire—periodic telephone interview
- Questionnaire—telephone interview on exit
- Questionnaire—periodic written survey
- Questionnaire—written survey on exit
- Feedback focus group
- Other (please specify below)
- .....
- .....

- You only need to answer this question if you answered 'Yes (from clients and staff)' or 'Yes (from staff only)' to question 6a.
- 'Staff' only includes people employed by your agency, including contract staff and volunteers.
- Refer to the question above for further information on selected categories.
- 'On exit' refers to the time at which the staff member ceases to be employed by the palliative care agency.

## Partnerships

### 7a. Does your agency have formal working partnership(s) with other service provider(s) or organisation(s)? *(Tick one box only)*

Yes  *Go to Q7b▶*

No

- In the palliative care context, a formal working partnership involves arrangements between an agency and other service providers and organisations, aimed at providing integrated and seamless care, so that clients are able to move smoothly between services and service settings.
- 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.
- 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; memoranda of understanding with other providers; and case conferencing.
- Palliative care partnerships may be held with, but are not limited to, organisations such as palliative care services, hospitals, allied health services and aboriginal health services.

### 7b. If applicable, with which type(s) of organisation(s) does your agency have formal working partnership(s) in place? *(Tick as many boxes as applicable)*

Palliative care services

Hospitals

Community nursing agencies

Residential aged care facilities

Allied health services

Aboriginal health services

Medical practices

Integrated health centres

Universities/research centres

Volunteer support services

Other (please specify below)

- Refer to question 7a. for a description of 'formal working partnerships'.
- Where partnerships exist for case conferencing purposes, record all partners involved.
- 'Palliative care services' includes services whose substantive work is with patients who have a life-limiting illness. These palliative care services may provide services in the community and/or in inpatient settings (including hospices).
- 'Hospitals' includes emergency departments, but excludes hospices/ designated palliative care units in a hospital, and other palliative care agencies as defined under 'Palliative care services' in the point above. It also excludes hospital-based allied health services and individual medical practitioners.
- 'Medical practices' includes practices of general practitioners and individual specialist physicians such as physicians specialised in palliative care, oncology, urology and neurology.
- 'Integrated health centres' includes multipurpose centres, aged care centres and specialist care centres such as cancer centres.
- 'Universities/research centres' includes universities that may undertake research and development projects.
- 'Other' includes organisations based in the community such as schools, clubs, workplaces, organisations that provide respite care or pastoral care, meals on wheels.

***End of survey—thank you.***

**Questions or queries? Contact the AIHW helpline on 1800 035 938 or email [rachelle.graham@aihw.gov.au](mailto:rachelle.graham@aihw.gov.au)**

# Appendix 3: 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)	Provide palliative care for patients, primary carers 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 to primary care providers and level 2 and/or 3 specialist palliative care providers to meet the needs of patients, carers and families with complex problems. Has quality and audit programme.	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 (eg 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, primary carers 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, primary carers 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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