



National palliative care performance indicators

Results of the 2006 performance indicator data collection

In summary

- ✦ This report sets out the findings of the 2006 national collection of performance indicator information for the palliative care sector in Australia.
- ✦ In 2003, the Palliative Care Intergovernmental Forum, which comprises members from state and territory governments and the Australian Government, developed and agreed four national performance indicators. The performance indicators reflect the goals and objectives contained in the National Palliative Care Strategy (DoHA 2000), which outlines national priorities designed to inform palliative care policy and service development in Australia. The performance indicator results are summarised in the table below.

Summary of results for nationally agreed palliative care performance indicators

Performance indicator 1: The proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements	63%
Performance indicator 2: The proportion of palliative care agencies that routinely undertake or undergo formal assessment against the Palliative Care Australia Standards	21%
Performance indicator 3: The proportion of palliative care agencies that actively collect feedback from clients and staff (within the workforce) relating to services and service delivery	65%
Performance indicator 4: The proportion of palliative care agencies that have formal working partnerships with other service provider(s) or organisation(s)	85%

(summary continued overleaf)

Contents

In summary	1
1 Introduction	2
2 Performance indicators and results	8
3 Discussion	20
Appendix: Palliative Care Australia's service planning framework	26
Acknowledgments	26
References	27

- ✦ While the 2006 palliative care performance indicator data collection has suggested that performance, as measured against the four nationally agreed performance indicators, has fallen since the 2005 collection, it is difficult to know what specific effect amendments to the survey forms/questions and a change in scope for the palliative care agency survey might have had on responses and results. These amendments are outlined in Section 3, as are the results of a specific analysis that investigated changes in results for those agencies and health regions that participated in both the 2005 and 2006 data collections.
- ✦ Given the 'trial' nature of the 2005 collection, and that some finetuning and further development of questions occurred in light of that collection, it is likely that the 2006 collection results should be considered more reliable. The third collection of national palliative care performance information data is currently being planned for late 2007. This collection will largely be a reiteration of the 2006 collection and it may be best to await results of that data collection to better understand changes in performance.

1 Introduction

1.1 Palliative care services in Australia

Palliative care is the specialised care of people who are terminally ill. The World Health Organization describes palliative care as 'an approach that improves the quality of life of patients and their families facing the problem 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 2003).

Palliative care is provided both by primary palliative care and specialist palliative care providers¹ recognising that people who are terminally ill experience different levels of need ranging from relatively uncomplicated to complex care requirements. Ideally, patients and their family/carers have access to a range of services (based on need and preference) which ensures that appropriate services are delivered in the right place at the right time.

1.2 National framework for palliative care

In Australia, the discipline of palliative care is a relative newcomer to the healthcare system, largely emerging since the 1970s to provide people who are terminally ill (and their families) with quality end of life care. Prior to this, care of the terminally ill was largely the province of religious orders with a focus on spiritual aspects of terminal care. However, a range of factors (including improvements in the availability of medical options for palliative care patients—particularly with respect to pharmaceutical options for the control of pain, the rise of cancer as a contributor to mortality, and the establishment of a vocal consumer movement) fuelled the emergence of palliative care as a specialised health discipline.

¹ Characteristics of these different types of palliative care services are further discussed in sub-section 1.4.2.

In recent times, the ongoing development of palliative care services at a national level has been guided by two initiatives: the development of a national strategy for palliative care services, and the inclusion of palliative care-related initiatives within the current and previous Australian Health Care Agreements. These initiatives recognise that palliative care services, in many areas, are not yet fully integrated within the mainstream health system and are continuing to mature.

The National Palliative Care Strategy (DoHA 2000) provides a national framework for palliative care service development and acknowledges the requirement for improved knowledge of, and information about, palliative care service provision in Australia. The Strategy is a consensus document between the Australian Government, state and territory governments, palliative care service providers and advocacy groups that outlines national priorities designed to inform palliative care policy and service development in Australia. It proposes a number of strategies that contribute to goals relating to:

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

Implementation of the Strategy is underpinned by the inclusion of palliative care requirements within the current Australian Health Care Agreements (AHCAs). Specifically, these outline the responsibility of jurisdictions and the Australian Government to improve the provision of palliative care services (Part 2, clause 8(g)) and to implement the National Palliative Care Strategy (Part 3, clause 14(d)). The AHCAs also oblige states/territories to work collaboratively through the agreed information management governance arrangements to develop and refine appropriate performance indicators including 'indicators of access to and quality of palliative care services' (Schedule C, clause 13(g)). Nationally agreed high-level performance indicators relating to palliative care have been developed which provide some information on the extent to which the Strategy has been implemented. The first collection of data against the performance indicators occurred in 2005 (AIHW 2006).

1.3 Objectives of the performance indicators

The purpose of this report is to present the findings of the 2006 palliative care performance indicator data collection, and to consider changes that may have occurred between the 2005 and 2006 collections. The report also presents data that describe the palliative care sector that were obtained through the 2006 national palliative care agency survey.

The four national palliative care performance indicators were developed and agreed by the Palliative Care Intergovernmental Forum (PCIF) in 2003. The PCIF, which comprises representatives of all state/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 national palliative care performance indicators are presented in Box 1.

The performance indicators were developed as 'high-level' indicators to provide information on the extent to which the goals and objectives of the Strategy have been achieved nationally. The four national performance indicators present indicative information only. They do not measure actual outcomes for patients and their families, but rather attempt to quantify the existence of strategic plans for palliative care at the regional-level of government, and the extent to which appropriate quality improvement mechanisms are implemented at the agency or service-level. They are not intended to measure performance on a state and territory basis, nor individual agencies' performance, and accordingly, are not reported at an agency or jurisdictional level.

It is acknowledged that the four agreed performance indicators are limited to obtaining information in regards to certain aspects of the planning and delivery of palliative care services, and do not reflect performance about other specific aspects of palliative care that might be considered valuable, for example, bereavement support provided to carers and family members, the range of assistance provided by palliative care services and the effectiveness of the services delivered.

Box 1: 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 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 provider(s) or organisation(s).

1.4 Methodology

The performance indicator data collection involved two separate data collections:

- ♦ Administrative health region data collection—designed to collect, from health regions across Australia, information to support the calculation of national palliative care performance indicator 1.
- ♦ National palliative care agency data collection—designed to collect, from palliative care agencies across Australia, information to support the calculation of national palliative care performance indicators 2–4.

These data collections are described in further detail below. Both data collections were conducted in September/October 2006, although follow-up with agencies and health regions continued until December 2006.

The project was carried out by staff of the Australian Institute of Health and Welfare (AIHW) in consultation with the Palliative Care Data Working Group (PCDWG). The PCDWG, which reports to the PCIF, comprises members of all state/territory health departments, the Australian Government Departments of Health and Ageing and Veterans' Affairs, Palliative Care Australia, and the Palliative Care Outcomes Collaboration. Throughout the project, the AIHW project team was guided by PCDWG decisions in regards to the survey questions and its underlying definitions and collection guidelines.

1.4.1 Administrative health region data collection

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'. A total of 30 administrative health regions were identified—Table 1 provides a breakdown, by state and territory, of the number of administrative health regions across Australia.

Table 1: Administrative health regions, by state and territory

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Number of regions	9	8	3	3	4	1	1	1	30

1.4.2 National palliative care agency data collection

Data for reporting against performance indicators 2–4 were obtained through a survey of all government-funded palliative care agencies. For the purpose of this collection a 'palliative care agency' was defined as:

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

- 'Specialist palliative care' services work substantively in the area of palliative care. They would usually provide consultative and ongoing care for people with a life-limiting illness and provide support for primary carers and family members, provide multi-disciplinary healthcare and employ healthcare professionals who have qualifications or experience in palliative care.
- Care may be provided in admitted patient and/or community settings. Community settings include 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.

Of the 326 agencies that were considered to be in scope for the national palliative care agency data collection, as identified by PCDWG members, 243 agencies (75%) participated in the collection. Table 2 shows the distribution of agencies across the states and territories that responded to the survey.

Table 2: Distribution of palliative care agencies that participated, by state and territory

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Number of agencies	70	43	90	18	15	3	2	2	243

It should be noted that the definition used here of palliative care agency differs from that used in the 2005 collection, in which eligibility for inclusion in the survey was based on whether the agency employed one or more palliative care practitioners. However, as it became evident that the criterion of 'one or more practitioners' was not consistently understood, nor was the concept of defining a 'palliative care practitioner', the scope was amended in 2006. Results of the 2005 survey are reported for comparison in this report; however, because of the change in scope that occurred between these collections, differences in performance as measured by the indicators over this time period should be interpreted with caution.

To assist analysis of the reporting of performance indicators 2–4, information was also obtained from these agencies on the settings in which the agencies most commonly provided care, and their level of palliative care specialisation within Palliative Care Australia's service planning framework.

Most common setting of care

The wording of the agreed performance indicators that collect data from agencies requires some analysis of results by 'setting of care'. Accordingly, agencies were asked to report on the type of setting of care in which the majority of their agency's services were delivered over the previous 12 months. The three categories of service delivery settings for palliative care were:

- ✦ *community-based settings*: which include residential settings, such as a person's private residence (which could include a caravan, mobile home, houseboat or unit in a retirement village); residential aged care facilities; other residential facilities (which could include prisons, or community living environments including group homes); non-residential settings (including day respite centres and day centres); and outpatient settings (including hospital outreach services)
- ✦ *inpatient settings*: which include all admitted patient settings but exclude outpatient settings and hospital outreach services delivered in the community setting
- ✦ *similar amount of services in community-based and inpatient settings*: for use where a similar proportion of time was spent by agencies delivering services in community and inpatient settings.

Most agencies reported mainly delivering care to clients in the community (63%; 153 agencies), compared with 23% (56) of agencies reporting that they mainly provided care

in inpatient settings (Table 3). Fourteen per cent of agencies (34) reported that a similar proportion of time was spent on delivering services in community and inpatient settings. Some further information on the specific settings in which agencies were involved in delivering services is provided in sub-section 2.5.1.

Table 3: Agencies, by setting of care in which most services were delivered

Most common agency setting	Number of agencies	Proportion of agencies (%)
Mostly community-based setting	153	63
Mostly inpatient setting	56	23
Similar amount of services in community/ inpatient settings	34	14
Total	243	100

Level of specialisation

Additionally, to enable analysis of these performance indicators by an agency's level of palliative care specialisation, agencies were asked to report their level of palliative care specialisation by selecting the level within Palliative Care Australia's (PCA) service planning framework classification which best described the services they provide. This framework recognises four broad levels of specialisation: primary palliative care providers and specialist palliative care providers (levels 1–3). Primary palliative care providers are those whose substantive work is not in the area of palliative care, but who have a primary, or 'first contact', relationship with people with a life-limiting illness and adopt a palliative approach to their care. Specialist palliative care providers, on the other hand, do work substantively in the area of palliative care, and provide care to patients who have more complicated needs. This care may be provided either on an ongoing basis or on a consultative basis, and may be provided in community settings or inpatient settings.

The three levels of specialisation are differentiated by their different capabilities and their typical resource profile and 'represent the minimal (level 1), moderate (level 2) and maximal (level 3) points along a hypothetical continuum of resource availability and expected capability' (PCA 2005a:20). The 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 healthcare team; and the size of the population base the service provides care for. It should be noted that the level of specialisation is not related to the quality of care that is provided, but reflects their main relationship with people who are terminally ill and their caregivers, and their relationships with other palliative care providers. The service planning framework is provided in full in the Appendix.

While the PCA's service planning framework identifies four categories of service capability (as outlined above), for the purposes of presenting the performance indicator data in this report the data analysis only distinguishes between 'primary' and 'specialist' palliative care agencies (that is, all data for specialist level agencies have been aggregated). This approach was taken because:

- ♦ This information is based on self-reported data for which the extent to which agencies have been able to reliably report their level of specialisation is untested. It is considered

likely, however, that agencies would be able to reliably identify whether they are 'primary' or 'specialist' palliative care providers.²

- ✦ For the purposes of performance information reporting, the distinction between primary and specialist agencies is conceptually the most important.

Seventy-seven agencies (32%) nominated their service as a primary palliative care agency and 165 agencies (68%) reported that they were a specialist (level 1, 2 or 3) palliative care agency (Table 4). More detailed data on the number of agencies in each category are reported in sub-section 2.5.2.

Table 4: Agencies, by level of palliative care specialisation (broad grouping)

Level of specialisation	Number of agencies	Proportion of agencies (%)
Primary palliative care agency	77	32
Specialist palliative care agency (levels 1–3)	165	68
Not stated	1	0
Total	243	100

2 Performance indicators and results

2.1 Performance indicator 1

2.1.1 Description

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

For the purposes of the 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 satisfy the criteria for what constituted a written plan, the palliative care elements in each plan were required to include the following aspects:

- ✦ time frame (the beginning and end date in years), with a minimum period of two years to demonstrate a strategic focus
- ✦ measurable objectives relating to service access, quality, use, responsiveness and evaluation

² Some discussion of the problems agencies experienced in reporting these data are outlined in sub-section 2.5.2.

- ✦ 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.

2.1.2 Rationale

Performance indicator 1 serves to provide 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 Strategy, but particularly indicates the extent to which National Strategy Objective 1.5 has been achieved. National Strategy Objective 1.5 states:

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

2.1.3 What the data show

- ✦ Of the 30 administrative health regions nationally, 19 (63%) recorded having a written strategic plan incorporating palliative care, which satisfies all of the agreed specified palliative care elements (Table 5).
- ✦ This represented a reduction in the proportion of health regions that reported in 2005 that they had a strategic plan incorporating palliative care elements (66%). Section 3 considers issues around the change in scope of these collections and how this may have affected the results.

Table 5: Performance indicator 1—administrative health regions that have a written strategic plan for palliative care

Strategic plan status	Number of administrative health regions	Proportion of health regions (%)
Yes – plan meets all specified criteria	19	63
Yes – plan does not meet all specified criteria	2	7
No	9	30
Total	30	100

- ✦ Since 2005, regional restructuring had occurred in which certain health areas were amalgamated into larger regions. Strategic plans were in place for all regions that were subject to the amalgamation and it was acknowledged that in assessing performance indicator 1, consideration must be taken of the need for a lag time between the reorganisation of new health areas and the creation and implementation of strategic plans for these new regions. This allowed existing strategic plans operating under the previous administrative structures, still actively operating within the new health area, to be accepted for calculation of performance indicator 1 for a period of one year.

- ✦ Two administrative health regions across the jurisdictions reported having a written strategic plan in operation that did not meet all of the agreed specific criteria. In the first instance, the relevant administrative health region's strategic plan met five of the six specified requirements and, in the second instance, the region's strategic plan met three of the six specified criteria.
- ✦ One jurisdiction reported that, at the time of the administrative health region data collection, it was in the final stages of drafting a strategic plan. However, because the plan had not been finally endorsed, it was not accepted as being a strategic plan that satisfied the agreed criteria for the purposes of this performance indicator.

2.2 Performance indicator 2

2.2.1 Description

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

These voluntary standards describe the key elements and dimensions for providing quality palliative care and have been developed by PCA for use alongside other, more general, healthcare standards. The standards are outlined in the publications *Standards for palliative care provision* (3rd edn., PCA 1999) and *Standards for providing quality palliative care for all Australians* (4th edn., PCA 2005a).

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

The data do not provide information about how often agencies undergo formal assessment against the PCA standards nor capture information about those agencies that assess themselves against standards or benchmarks other than the PCA standards.

2.2.2 Rationale

Performance indicator 2 provides information on the extent to which goal 2 of the Strategy has been achieved. Goal 2 promotes quality and effectiveness in service provision, and supports continuous improvement in the delivery of palliative care services across Australia. In particular, performance indicator 2 provides information on the proportion of palliative care agencies that have implemented the nationally agreed best practice standards for palliative care, and accordingly, the extent to which National Strategy Objective 2.1 has been achieved. National Strategy Objective 2.1 states:

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

2.2.3 What the data show

- ✦ Twenty-one per cent of agencies (50 agencies) reported that they formally assess themselves against the PCA standards (Table 6). This indicates that the majority of palliative care agencies do not formally monitor and evaluate their service against these standards. This may mean that these agencies do not evaluate their service against any standards or they evaluate their service against other standards not recognised within the scope of this collection. Alternatively, agencies may undertake assessment against the PCA standards on an informal or ad hoc basis.
- ✦ This figure represents a reduction since 2005 in the proportion of agencies that reported that they formally assess themselves against the PCA standards. In that year 34% of agencies reported that they formally assess themselves against the PCA standards. Section 3 considers issues around the change in scope of these collections and how this may have affected the results.
- ✦ Of those agencies that reported formally assessing themselves against the PCA standards, 56% most commonly provided care in a community setting, followed by 22% most commonly providing care in inpatient settings and 22% providing a similar amount of services in both community and inpatient settings. Within each setting of care, however, agencies that delivered a similar amount of care in both settings were more likely to formally assess themselves against the PCA standards (32%; 11 of 34 agencies), followed by agencies that mostly provide care in inpatient settings (20%; 11 of 56 agencies) and those that mostly provide care in community settings (18%; 28 of 153 agencies).

Table 6: Performance indicator 2—agencies, by formal assessment status and main setting of care

Assessment status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Number				
Yes	28	11	11	50
No	123	44	23	190
Not stated	2	1	0	3
Total	153	56	34	243
Per cent				
Yes	12	5	5	21
No	51	18	9	78
Not stated	1	0	0	1
Total	63	23	14	100

- ✦ Formal assessment against the PCA standards was more commonly undertaken by specialist palliative care agencies (46 of 165 agencies; 28%) than by primary palliative care agencies (4 of 77 agencies; 5%).

- ✦ Agencies were asked to specify which version of the PCA standards they assessed themselves against. Of those agencies that reported routinely undertaking or undergoing formal assessment against the PCA standards, 9 (18%) reported that they did so against the 3rd edition standards (PCA 1999), and 40 (80%) reported that they did so against the 4th edition standards (PCA 2005a).
- ✦ It should be noted that the format of the 4th edition standards represented a major shift in the approach to specifying standards for palliative care services. While previous versions had outlined a set of agreed 'philosophical standards', the 4th edition standards introduced the approach that standards should specify graduated criteria dependent on the level of specialisation of the service (PCA 2005a). In this way primary palliative care agencies would assess themselves against a specific standard using different criteria from those used by specialist (level 3) palliative care providers (for example). While the revised structure of these standards ensures that the standards remain relevant across the entire palliative care sector, the complexity of this approach (relative to previous versions) may have influenced the extent of use of these standards.
- ✦ Agencies were also asked what method they used to formally assess themselves against the PCA standards. Table 7 indicates that most agencies (45 agencies; 90%) that reported undertaking formal assessment against the standards used a formal self-assessment method. In-depth external review was undertaken by 17 agencies (34%) that undertook formal assessment against the standards.

Table 7: Agencies that formally assess themselves against the PCA standards, by assessment method and main setting of care

Assessment method	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Formal self-assessment	26	8	11	45
In-depth external review	5	8	4	17
Total^(a)	28	11	11	50

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

2.3 Performance indicator 3

2.3.1 Description

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.

For the purposes of this collection the 'client' includes the patient and their carer(s), family or friends, and 'staff' includes paid and unpaid individuals providing palliative care services on behalf of the agency.

2.3.2 Rationale

Feedback is an integral aspect of quality improvement and relates to goal 2 of the Strategy regarding quality and effectiveness in service provision. In addition, performance indicator 3 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 National Strategy Objectives 2.4 and 3.1 have been achieved. National Palliative Care Strategy Objectives 2.4 and 3.1 are:

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

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

2.3.3 What the data show

- ♦ The survey found that most agencies (157 agencies; 65%) actively and routinely collect feedback from both clients and staff (Table 8). A further 25 agencies (10%) reported only collecting feedback from clients, and 6 agencies (2%) reported collecting feedback from staff only. The remaining agencies may still collect feedback from clients and/or staff but not on an active or routine basis.
- ♦ Again, this figure represented a reduction since 2005 in the proportion of agencies meeting the performance indicator. Previously, 71% of agencies reported that they actively and routinely collected feedback from both clients and staff. Section 3 considers issues around the change in scope of these collections and how this may have affected the results.

Table 8: Performance indicator 3—agencies, by feedback collection status (clients and staff) and main setting of care

Feedback collection status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Number				
Yes	105	31	21	157
No	46	25	13	84
Not stated	2	0	0	2
Total	153	56	34	243
Per cent				
Yes	43	13	9	65
No	19	10	5	34
Not stated	1	0	0	1
Total	63	23	14	100

- ✦ Of those agencies that collect feedback from clients and staff, 67% mainly delivered care in the community, 20% mainly delivered care in inpatient settings, and 13% provided a similar amount of care in both settings. Within these settings of care, 69% of agencies that mostly deliver care in community settings (105 of 153 agencies) reported collecting feedback from clients and staff, followed by 62% of agencies that deliver a similar amount of care in both settings (21 of 34 agencies) and 55% of services that mostly provide care in inpatient settings (31 of 56 agencies).
- ✦ The collection of feedback from clients and staff on an active and routine basis was more common among primary palliative care agencies (55 of 77 agencies; 71%) than among specialist palliative care agencies (102 of 165 agencies; 62%).
- ✦ Two additional questions were included in the 2006 survey to gather further information about the types of methods used by palliative care agencies to collect feedback. Tables 9 and 10 indicate that, for agencies that collect feedback from clients and staff, the most common method used was the periodic use of a written survey (reported by 126 agencies to collect feedback from clients; and by 101 agencies to collect feedback from staff).
- ✦ Of the 13 palliative care agencies that reported using feedback mechanisms other than those listed to collect feedback from clients, informal methods such as the evaluation of compliments and complaints, informal meetings with patients and their families, and the use of brochures that invite feedback/suggestions were the most common. Of the 29 palliative care agencies that reported using feedback mechanisms other than those listed to collect feedback from staff, staff meetings, case conferences/reviews and staff performance appraisals were the most common.
- ✦ The periodic use of written surveys was also the most popular method used to collect feedback from clients among those 25 agencies that only collected feedback from clients (used by 18 of these agencies); whereas the most popular methods used to collect feedback from staff (among those 6 agencies that only collected feedback from staff) were face-to-face questionnaires administered either periodically or on exit (both used by 3 of these agencies).

Table 9: Agencies that collect feedback from clients and staff, by methods used to collect feedback from clients and main setting of care

Feedback collection method	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Questionnaire—periodic face-to-face	34	5	3	42
Questionnaire—face-to-face interview on exit	10	0	1	11
Questionnaire—periodic telephone	13	5	4	22
Questionnaire—telephone interview on exit	2	1	0	3
Questionnaire—periodic written survey	89	21	16	126
Questionnaire—written survey on exit	6	8	5	19
Feedback focus group	26	2	1	29
Other	5	6	2	13
Total^(a)	105	31	21	157

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

Table 10: Agencies that collect feedback from clients and staff, by methods used to collect feedback from staff and main setting of care

Feedback collection method	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Questionnaire—periodic face-to-face	38	9	5	52
Questionnaire—face-to-face interview on exit	33	5	9	47
Questionnaire—periodic telephone	3	0	1	4
Questionnaire—telephone interview on exit	3	1	0	4
Questionnaire—periodic written survey	68	23	10	101
Questionnaire—written survey on exit	21	9	8	38
Feedback focus group	19	2	5	26
Other	19	6	4	29
Total^(a)	105	31	21	157

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

2.4 Performance indicator 4

2.4.1 Description

Performance indicator 4 measures the proportion of palliative care agencies, within their setting of care, that have formal working partnerships with other service provider(s) or organisation(s).

A formal working partnership is a written or verbal agreement between two or more parties. It specifies the roles and responsibilities of each party, including the expected outcomes of the agreement. In the palliative care context, a formal working partnership involves arrangements between an agency and other service providers and organisations, aimed at providing integrated and seamless care, so that clients are able to move smoothly 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.

2.4.2 Rationale

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

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

2.4.3 What the data show

- ✦ A high proportion of agencies (206 agencies; 85%) reported having formal working partnerships with other service provider(s) or organisation(s) (Table 11).
- ✦ While the proportion of agencies that reported having in place formal working partnerships was relatively high, this figure was again a reduction in the proportion of agencies who met this performance indicator in 2005. In 2005, the corresponding figure was 96% of agencies. Section 3 considers issues around the change in scope of these collections and how this may have affected the results.
- ✦ Of the agencies that did report having formal working partnerships, 64% mostly delivered care in community-based settings, 23% mostly delivered care in inpatient settings, and 13% delivered a similar amount of care in both settings. Within each setting of care, the data show that most palliative care agencies had formal working partnerships in place: 86% of agencies that mostly deliver community-based care (132 of 153 agencies), followed by 84% of agencies that mostly deliver care in inpatient settings (47 of 56 agencies) and 79% of agencies that deliver a similar amount of care in both settings (27 of 34 agencies).

Table 11: Performance indicator 4—agencies, by formal partnership status and main setting of care

Partnership status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Number				
Yes	132	47	27	206
No	21	8	7	36
Not stated	0	1	0	1
Total	153	56	34	243
Per cent				
Yes	54	19	11	85
No	9	3	3	15
Not stated	0	0	0	0
Total	63	23	14	100

- ✦ Sixty-one primary palliative care agencies (79% of 77) reported having formal working partnerships with other service providers, compared to 144 (87% of 165) specialist palliative care agencies.
- ✦ An additional question was included in the survey to gather further information about the types of organisations with which palliative care agencies reported having formal working partnerships. Most commonly, palliative care agencies reported having formal working partnerships with hospitals (172 agencies; 83% of agencies that reported having formal partnerships in place), other palliative care services (142 agencies; 69%), and community nursing agencies (125 agencies; 61%) (Table 12). Additionally, over half of all agencies that had formal working partnerships in place reported having

partnerships with medical practices (114 agencies; 55%), and half of the agencies stated that they had partnerships with allied health services (103 agencies; 50%).

- Of the 18 palliative care agencies that reported having formal working partnerships with organisations other than those listed, respite services, local governments, and volunteer organisations were the most common partners reported.

Table 12: Agencies, by type of partner organisation and main setting of care

Partner organisations	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Palliative care services	85	39	18	142
Hospitals	114	37	21	172
Community nursing agencies	65	37	23	125
Residential aged care facilities	49	19	15	83
Allied health services	70	21	12	103
Aboriginal health services	34	6	8	48
Medical practices	85	18	11	114
Integrated health centres	18	4	6	28
Universities/research centres	24	14	10	48
Volunteer support services	38	17	13	68
Other	14	1	3	18
Total^(a)	132	47	27	206

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

2.5 Supplementary survey questions

This section presents data obtained from three additional questions that were asked of palliative care agencies as part of the national palliative care agency survey. These data provide a further description of agencies from across Australia that provide palliative care.

2.5.1 Settings of care in which services are delivered

- To further examine the types of settings in which palliative care agencies delivered services, agencies were asked to report on the specific setting(s) in which their agency delivered palliative care services in the previous 12 months.
- Eighty-seven per cent (212 agencies) had delivered services in a community setting in the previous 12 months, while 65% (157 agencies) had delivered services in an inpatient setting in this period. The most common specific setting in which agencies were involved in delivering palliative care services was 'private residences' (reported by 202 agencies, 83%; Table 13). Over half of palliative care agencies (130 agencies; 53%) reported delivering services in an 'inpatient setting—other than a designated palliative care unit', and almost half (119 agencies; 49%) reported providing services in residential aged care settings.

Table 13: Agencies, by specific settings in which services were delivered

Setting of care	Number of agencies	Proportion of agencies (%)
Community-based settings		
Private residences	202	83
Residential—aged care settings	119	49
Residential—other settings	58	24
Non-residential settings	33	14
Outpatient—in a hospital/hospice	73	30
Inpatient settings		
Inpatient—designated palliative care unit or hospice	81	33
Inpatient—other than a designated palliative care unit	130	53
Total number of agencies^(a)	243	100

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

2.5.2 Level of palliative care specialisation

- One survey question requested information on the specific level of palliative care specialisation (from the Palliative Care Australia's service planning framework) that best described the agency. This framework was previously described in sub-section 1.4.2, and the full framework classification is available in the Appendix.
- The most common level of specialisation reported by agencies that participated in the survey was 'specialist palliative care agency (level 1)' (reported by 91 agencies; 38%). The next most common category was 'primary palliative care agency' (77 agencies; 32%), and 'specialist palliative care (level 2) and (level 3)' agencies accounted for 16% (38 agencies) and 15% (36 agencies) of responding agencies respectively (Table 14).
- Agencies that mostly provided care in community settings were most likely to classify themselves as primary or specialist (level 1) palliative care agencies (both accounted for 41% of agencies that mostly delivered care in the community); and agencies that mostly delivered care in inpatient settings were most likely to classify themselves as specialist (level 1) or (level 3) agencies (accounting for 29% and 27% of agencies that mostly delivered care in inpatient settings respectively). Agencies that delivered a similar amount of care in both settings were most likely to classify themselves as specialist (level 3) or (level 1) palliative care agencies (accounting for 38% and 35% of these agencies respectively).
- It should be noted that this information was self-reported and based on a capability and resource matrix developed by PCA (2005a) that has not previously been used in surveys of this kind. This may result in agencies under- or over-estimating their place within the PCA framework.
- Seventeen agencies, at the time of completing the survey, reported that they were unable to locate their service within the PCA service planning framework. The project team followed up, either directly with agencies or through state and territory PCDWG members, to determine where these agencies would be best placed within the PCA service planning framework. All but one agency was placed in accordance with this process.

- Some agencies reported having difficulty placing their service within the PCA framework, commenting that they were 'in between' categories. Most commonly agencies reported having difficulty distinguishing their service between that of a specialist palliative care agency (level 1) and a specialist palliative care agency (level 2) or a specialist palliative care agency (level 2) and a specialist palliative care agency (level 3).

Table 14: Agencies, by level of palliative care specialisation and main setting of care

Level of specialisation	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
Primary palliative care agency	62	12	3	77
Specialist palliative care agency (level 1)	63	16	12	91
Specialist palliative care agency (level 2)	20	12	6	38
Specialist palliative care agency (level 3)	8	15	13	36
Not stated	0	1	0	1
Total	153	56	34	243

2.5.3 Employment of a coordinator of volunteers

- Agencies were asked whether they employ a coordinator of volunteers on either a paid or unpaid basis. This question was designed to provide insight into the extent to which volunteers are used in the palliative care sector.
- Volunteers are regarded as valued members of the palliative care workforce who complement the care provided by paid palliative care professionals. Volunteers frequently assist patients and carers in practical ways (for example, providing transport, preparing snacks, letter writing), and provide respite to carers, companionship, and bereavement contact with families following the death of the person. All volunteers are screened and undertake extensive training before taking on this role. The duties of a coordinator of volunteers in the palliative care sector might 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.
- Just over half of all agencies (124 agencies; 51%) reported employing a coordinator of volunteers on either a paid or unpaid basis (Table 15). Most of these agencies mainly delivered care in community settings (72 agencies; 30% of all agencies), followed by 30 agencies (12%) that reported most commonly providing services in an inpatient setting. Proportionately, however, agencies that delivered a similar amount of care in both community and inpatient settings and agencies that mostly delivered care in inpatient settings were more likely to employ a coordinator of volunteers (65% of 34 agencies that delivered a similar amount of care in both community and inpatient settings; 54% of 56 agencies that mostly deliver care in inpatient settings; compared to 47% of 153 agencies that mostly deliver care in community settings).

Table 15: Agencies, by employment of a coordinator of volunteers and main setting of care

Coordinator of volunteers status	Mostly community setting	Mostly inpatient setting	Similar amount in both settings	Total
	Number			
Yes	72	30	22	124
No	81	26	12	119
Total	153	56	34	243
	Per cent			
Yes	30	12	9	51
No	33	11	5	49
Total	63	23	14	100

- ✦ The employment of a coordinator of volunteers (on either a paid or unpaid basis) was more common among specialist palliative care agencies—99 specialist palliative care agencies (60% of 165 agencies) employed a coordinator of volunteers compared to 25 primary palliative care agencies (32% of 77 agencies) that reported employing a coordinator of volunteers.
- ✦ In some areas volunteer assistance may be accessed through separate agencies that work in partnership with the palliative care service (rather than directly through the palliative care service itself). The organisation of services in this way will affect whether the palliative care agency would need to employ a volunteer coordinator directly.

3 Discussion

The results of the 2006 palliative care performance information data collection have suggested that the performance of the palliative care sector has fallen against each of the measured performance indicators since 2005. This fall in performance is particularly marked for two of the performance indicators: the proportion of palliative care agencies that routinely undertake or undergo formal assessment against the Palliative Care Australia standards, and the proportion of agencies that have formal working partnerships with other service providers or organisations.

Given the high-level nature of these performance indicators, and their focus on activities that may take time to plan and introduce (which is particularly true for the development of a strategic plan for palliative care), it may not be surprising not to have seen large *increases* in performance against these performance indicators. However, the apparent *decrease* in performance among the health regions and agencies that participated was unexpected. While this apparent fall in performance may reflect a real reduction in performance on these indicators, these results may also be due to changes in the questions and additions to guidelines which may have influenced the way in which agencies responded, and/or changes in scope for both data collections.

This section considers the possible impact that these factors may have had on the performance indicator results, particularly those arising from the national palliative care

agency data collection, and considers the performance indicator results by main setting of care and level of specialisation.

3.1 Possible impact of changes to the questions/ guidelines and changes in scope

The performance indicator data collection was first conducted as a trial in 2005. The responses and feedback to that trial were used by the AIHW project team and the PCDWG to finetune the questions and the accompanying guidelines for subsequent data collections. This resulted in minor amendments to all of the questions that collected the data on which the performance indicator information is based for the 2006 survey. These changes did not alter the intent of the questions but may have influenced the way in which agencies responded. The changes to the questions are summarised in Table 16.

Table 16: Summary of changes made to survey questions on which performance indicator calculations are based

Performance indicator	Summary of changes made between 2005 and 2006 survey forms
<i>PI 1:</i> Proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements	<ul style="list-style-type: none"> Response requirements amended such that responses needed to indicate that the strategic plan met each of the six specified characteristics.
<i>PI 2:</i> Proportion of agencies that routinely undertake or undergo assessment against the PCA standards	<ul style="list-style-type: none"> Additional question included to obtain information on which version(s) of the PCA standards the agency uses for assessment.
<i>PI 3:</i> Proportion of agencies that actively collect feedback from clients and staff relating to services and service delivery	<ul style="list-style-type: none"> Response codes were amended in 2006 to allow agencies to specifically report that they collect feedback from: both staff and clients, from clients only, from staff only, or that they did not collect feedback. In 2005, respondents were required just to indicate that they collected feedback from clients and/or staff, and the follow-up questions on the type(s) of feedback mechanisms used were used to derive data on whether the agency collected feedback from clients only or staff only.
<i>PI 4:</i> Proportion of agencies that have formal working partnerships with other service provider(s) or organisation(s)	<ul style="list-style-type: none"> Some minor additions to the guidelines to further clarify the term 'formal working partnership'.

In addition, changes were made to the scope of the national palliative care agency data collection. The scope of the first performance indicator data collection (conducted in 2005) was any healthcare agency involved in delivering palliative care services that employed one or more palliative care practitioners. However, because of the lack of guidelines provided to agencies in defining 'one or more palliative care practitioners', and the apparent inconsistent application of these criteria by palliative care agencies, the scope was revised for the 2006 collection. For this collection the scope was deemed to be all specialist palliative care agencies and those primary palliative care agencies that received Australian Health Care Agreement funding to provide care that incorporates a palliative approach.

In order to investigate the effect that changes to the questions/guidelines and changes in scope might have had, the project team conducted separate analyses of those agencies/health regions that responded to both the 2005 and 2006 surveys to investigate trends across collection years. Agencies and health regions that responded to both the 2005 and 2006 data collections were identified based on their organisation identifier or the name of the health region (as applicable). These results should be regarded as indicative, as the

matching of organisation identifiers and health region names may not exactly represent the same agency/region. For example, the boundaries of health regions may have altered between the two survey periods, or agencies may have been incorporated into other agencies.

Based on this analysis, 26 health regions and 124 palliative care agencies were found to have responded to both the 2005 and 2006 performance indicator surveys. This represented 87% of health regions that responded in 2006 and 68% of health regions that responded in 2005; and 51% of agencies that responded in 2006, and 69% of agencies that responded in 2005.

Table 17 summarises the proportion of these health regions/agencies that met the performance indicators in each collection year, and summarises the percentage change that occurred across these years. It should be noted that the health regions/agencies included in this analysis are limited to those that responded to both surveys—accordingly, the proportions of health regions/agencies meeting each performance indicator will be different from those reported elsewhere in this report and in the report of the 2005 performance indicator collection (AIHW 2006). From this table it is evident that, even among agencies/health regions that responded to both surveys, there has been a fall in performance across each of the performance indicators.

Table 17: Percentage change in proportion of health regions/agencies meeting performance indicators for health regions/agencies that responded to both the 2005 and 2006 surveys

Performance indicator	Proportion of selected regions/agencies ^(a) meeting performance indicator—2005 (%)	Proportion of selected regions/agencies ^(a) meeting performance indicator—2006 (%)	Percentage change (%)
PI 1: Proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements	81	73	-8
PI 2: Proportion of agencies that routinely undertake or undergo assessment against the PCA standards	35	24	-11
PI 3: Proportion of agencies that actively collect feedback from clients and staff relating to services and service delivery	73	66	-7
PI 4: Proportion of agencies that have formal working partnerships with other service provider(s) or organisation(s)	96	84	-12

(a) The health regions/agencies included in this analysis are limited to those that responded to both surveys. Accordingly, the proportions of health regions/agencies meeting each performance indicator will be different from those reported elsewhere in this report and in the report of the 2005 performance indicator collection (AIHW 2006).

The fact that performance appears to have fallen even among those health regions/agencies that participated in the data collection in 2005 suggests that the changes to the wording/guidelines may have influenced the performance indicator results by tightening the criteria specified for agencies/health regions to meet the performance indicators. It is also possible, of course, that in the intervening period agencies/health regions ceased to conduct the activities that were measured by the performance indicators. For example, a palliative care strategic plan may have 'expired' in this period, and a replacement plan not finalised in a particular region.

Given the 'trial' nature of the 2005 collection, and that some finetuning and further development of questions occurred in light of that collection, it is likely that the 2006 collection results should be considered more reliable. The third collection of national palliative care performance information data is currently being planned for late 2007. Since the feedback sought on the questions included in 2006 did not suggest that any further refinement of the questions will be needed to ensure consistent interpretation of the survey questions, the 2007 collection will largely be a reiteration of the 2006 collection. Therefore, it may be best to await results of that data collection to better understand changes in performance.

3.2 Consideration of performance indicators by main setting of care

This section summarises the performance indicator results (for performance indicators 2–4) by the agencies' main setting of care (that is, whether the agency mostly delivered palliative care in community settings or inpatient settings or provided a similar amount of services in both settings).

There were no clear patterns in the performance indicator results when analysed by most common setting of care. Agencies that delivered a similar amount of services in both settings were most likely to assess themselves against the PCA standards, agencies that mostly delivered care in the community were mostly likely to seek feedback from clients and staff, and agencies that delivered care in the community and those that mostly delivered care in inpatient settings were almost equally likely to have formal working partnerships with other agencies.

Given the broad range of settings in which palliative care services may be delivered, and also the broad range of service models under which services may be delivered, it is perhaps not surprising that there were no clear patterns in these data. For example, agencies that mostly deliver care in inpatient settings may represent agencies that only provide inpatient care, or agencies that mostly provide advice to staff/patients in inpatient settings on a consultative basis. The nature of these different 'relationships' with patients (that is, whether the agency directly cares for patients and their carers or provides care 'indirectly' by providing advice to staff of other agencies) may influence the way in which some management practices (such as those reflected in the agreed national performance indicators) are implemented.

3.3 Consideration of performance indicators by level of specialisation

This section summarises the performance indicator results (for performance indicators 2–4) against the level of palliative care specialisation reported by the agency. These results need to be considered in light of the fact that level of specialisation (according to the PCA framework) was self-reported and based on a capability and resource matrix that was untested, though it is considered likely that agencies could accurately report their status as either a 'primary' or 'specialist' palliative care agency.

For performance indicator 2, the proportion of agencies that undertake or undergo assessment against the PCA standards, there was a marked difference in achievement

of this performance indicator by level of specialisation. Specifically, 28% of specialist agencies met this performance indicator, while only 5% of primary care agencies met the indicator. To a large extent this type of difference might be expected—because primary palliative care agencies are involved in delivering a range of healthcare services, and are not substantively involved in delivering palliative care, they would be more likely to undertake assessment against standards that reflect this more general approach. Specialist palliative care agencies, however, who substantively work in the area of palliative care, would be expected to consider the palliative care standards highly relevant to their practice.

This difference also goes some way to explaining the relatively poor achievement of this performance indicator—because 32% of the respondents were primary palliative care agencies, and because their achievement of this performance indicator was particularly low, this has impacted on the overall results.

For both performance indicators 3 and 4 (proportion of agencies that actively and routinely collect feedback from clients and staff, and proportion of agencies that have formal working partnerships with other service providers), the differences in achievement of the performance indicators by level of specialisation was not as distinct. Again, these results, to a large extent, are to be expected as the collection of feedback from clients and staff can be regarded as a potentially relevant quality assurance activity that may be suitable in a range of healthcare settings, as is the establishment of partnerships with other service providers, which again may be relevant to other health service providers to facilitate seamless care for patients.

The slightly lower proportion of specialist palliative care agencies that actively and routinely collect feedback from clients and staff may reflect particular sensitivity around the collection of feedback (particularly from clients) in a palliative care context. Similarly, the slightly higher proportion of specialist palliative care agencies that have in place formal working partnerships (compared to primary palliative care providers) may reflect the particular requirements of a palliative care service which is provided by a multi-disciplinary team (whether this is provided directly by the agency or by an 'affiliated' service provider).

3.4 Use of volunteers within the palliative care sector

The extent to which volunteers are used in the palliative care sector was evident from the results of the survey. Half of the agencies (51%) reported that they employed a coordinator of volunteers either on a paid or unpaid basis, which is likely to underestimate the actual use of volunteers since volunteers may be used by agencies that do not employ a coordinator of volunteers.

The employment of a volunteer coordinator was more common among agencies that deliver a similar amount of care in community and inpatient settings and among specialist palliative care agencies. This latter finding, in particular, probably reflects the special role that volunteers play in delivering non-health-related care for those agencies that are substantively involved in delivering palliative care and reinforces that volunteers are frequently considered core members of interdisciplinary palliative care teams.

3.5 Performance indicator reporting in the future

Under the authority of the current agreements between the Australian Government Department of Health and Ageing, state and territory health authorities and the AIHW, the final performance indicator data collection will occur in late 2007 (for reporting in 2008). As suggested previously, given that the 2006 data collection incorporated some changes that arose out of the 'trial' 2005 collection, and that the 2007 collection will largely be a reiteration of the 2006 collection, it may be best to await results of that data collection to better understand changes in performance.

In the longer term, the Palliative Care Data Working Group have proposed that future performance monitoring data collections would also present an opportunity to include additional 'clusters' of questions related to special interest topics in addition to the core performance monitoring questions. These special interest topics may be related to the core performance indicators and expand on these indicators (for example, considering aspects of the implementation of strategic plans that exist for palliative care, or considering how feedback received from clients and staff is used by agencies to improve practices and processes). Other topics may reflect particular interest in thematic aspects of palliative care delivery (such as the use of volunteers in the delivery of palliative care-related services, or bereavement care provided by palliative care services).

This approach would not only be effective in containing the growth of the number of questions asked on each survey form, and thereby minimising respondent burden, but would also recognise the high-level nature of the current performance indicators. This is an approach that has been accepted (in principle) by the PCDWG, but will be dependent on further funding to continue these collections and further agreement by PCIF to this approach.

The ongoing collection of performance monitoring data (on either an annual or periodic basis) may also be appropriate given the likelihood that it will take time for the results of each collection to flow through government departments and palliative care agencies and instigate improvements. While some of the aspects of service delivery assessed by these performance indicators could be planned and implemented by palliative care agencies relatively quickly (for example, the collection of feedback from clients and staff), other activities (particularly the development and agreement of a strategic plan for palliative care at an administrative health region level) necessarily take time. Thus the current annual cycle of performance indicator reporting may not allow enough time for health regions and agencies to respond to the results of the previous collections.

Appendix: Palliative Care Australia's service planning framework

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

Source: PCA 2005b.

Acknowledgments

This project was funded by the Australian Government Department of Health and Ageing.

The authors of this report are Shari Beaumont, Clara Jellie and Meera Rajendran of the National Data Development and Standards Unit of the AIHW. The authors extend their thanks to the members of the Palliative Care Data Working Group and the Palliative Care Intergovernmental Forum for their valuable advice and comment, and to the palliative care agencies that participated.

References

- AIHW (Australian Institute of Health and Welfare) 2006. National palliative care performance indicators: report on the National Palliative Care Performance Indicator Data Collection 2005. Cat. no. HWI 89. Canberra: AIHW.
- DoHA (Australian Government Department of Health and Ageing) 2000. National Palliative Care Strategy: a national framework for palliative care service development. Canberra: DoHA.
- PCA (Palliative Care Australia) 1999. Standards for palliative care provision. 3rd edn. Canberra: PCA.
- PCA 2005a. Standards for providing quality palliative care for all Australians. 4th edn. Canberra: PCA.
- PCA 2005b. A guide to palliative care service development: a population-based approach. Canberra: PCA.
- WHO (World Health Organization) 2003. WHO definition of palliative care. Viewed 24 May 2007, <<http://www.who.int/cancer/palliative/definition/en/>>.

bulletin 54

© Australian Institute of Health and Welfare 2007

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced without prior written permission from the Australian Institute of Health and Welfare. Requests and enquiries concerning reproduction and rights should be directed to the Head, Business Promotion and Media, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

This publication is part of the Australian Institute of Health and Welfare's bulletin series. A complete list of the Institute's publications is available on the Institute's website <www.aihw.gov.au>.

AIHW cat. no. AUS 94

ISSN 1446-9820

ISBN 978 1 74024 719 1

Suggested citation

Australian Institute of Health and Welfare 2007. National palliative care performance indicators: results of the 2006 performance indicator data collection. Bulletin no. 54. Cat no. Aus 94. Canberra: AIHW.

Australian Institute of Health and Welfare

Board Chair

Hon. Peter Collins, AM, QC

Director

Penny Allbon

Any enquiries about or comments on this publication should be directed to:

Clara Jellie

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

Phone: 02 6244 1250

Published by the Australian Institute of Health and Welfare