National palliative care performance indicators

Report on the

National Palliative Care Performance Indicator

Data Collection 2005

August 2006

Suggested citation

Australian Institute of Health and Welfare

Board Chair
Hon. Peter Collins, AM, QC

Director
Penny Allbon

Contents

List of tables

List of figures

Abbreviations

AHCA	Australian Health Care Agreement
AIHW	Australian Institute of Health and Welfare
DoHA	Department of Health and Ageing
DSS	data set specification
HACC	Home and Community Care (Program)
METeOR	Metadata Online Registry
NCSDD	National Community Services Data Dictionary
NDDSU	National Data Development and Standards Unit
NHDD	National Health Data Dictionary
NHPC	National Health Performance Committee
NHPF	National Health Performance Framework
NMDS	national minimum data set
NPCP	National Palliative Care Program
NPCS	National Palliative Care Strategy
PCA	Palliative Care Australia
PCDWG	Palliative Care Data Working Group
PCIF	Palliative Care Intergovernmental Forum
PI	performance indicator
PIDWG	Performance Indicator Development Working Group

Acknowledgments

Executive summary

This report presents the findings of the first national collection of performance indicator data for Australia's palliative care sector. The information collected was designed to support the calculation of four national performance indicators that were developed and agreed in 2003 by the Palliative Care Intergovernmental Forum (PCIF) which consists of representatives of the states and territories and the Australian Government. The four performance indicators are based on the goals and objectives that make up the National Palliative Care Strategy (DoHA 2000), which provides the basis for informing palliative care policy and service development. The performance indicators provide some information on the extent to which the Strategy has been implemented.

The Australian Government Department of Health and Ageing commissioned the Australian Institute of Health and Welfare to undertake data development work to enable the capture of information that supports the calculation of the four performance indicators, and to run a trial data collection. The project thus aimed both to provide data for the derivation of the agreed performance indicators and to trial data collection processes and definitions.

This work was carried out in 2005, in collaboration with the Palliative Care Data Working Group (PCDWG), a working group of the PCIF, and involved two collections:

- the Regional Strategic Plan Collection—referred to as the Strategic Plan Collection
- the National Palliative Care Agency Data Collection—referred to as the Agency Collection.

The two collections are collectively known as the National Palliative Care Performance Indicator Data Collection (referred to as the PI Collection). Data definitions, survey instruments and feedback mechanisms were developed for each collection.

Scope

Strategic Plan Collection

The criteria for what constituted the scope of the Strategic Plan collection were developed by the PCDWG. Each of the states and territories then applied the criteria to identify their administrative health regions. Thirty-eight regions were nominated across the jurisdictions (see Appendix 1).

Agency Collection

The PCDWG also developed criteria for what constituted a palliative care agency. Based on these criteria, agency listings were compiled by each of the jurisdictions; all agencies on these listings were surveyed (395 Australia-wide), although 103 agencies were subsequently excluded following further consultation with the states and territories. Of the remaining 292 agencies that were thought to be in scope for the Agency collection, 180 agencies participated in the collection.

Chapters 2 and 5 discuss the problems encountered in defining palliative care agencies in scope for this collection. Work on refining the definitions is continuing, and recommendations will be made for use in future collections.

Performance indicator results

The performance indicator results are summarised below. Details about these results and how they relate to the Strategy are presented in Chapter 2.

Regional Strategic Plan Collection 2005

PI 1: The proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements	**66%**

National Palliative Care Agency Data Collection 2005[a]

PI 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

Mostly community setting	**36%**
Mostly inpatient setting	**25%**
Similar amount of service in both settings	**41%**
Total across all settings	**34%**

PI 3: The proportion of palliative care agencies, within their setting of care, that actively collect feedback from patients/consumers and staff (within the workforce) relating to services and service delivery

Mostly community setting	**75%**
Mostly inpatient setting	**65%**
Similar amount of service in both settings	**68%**
Total across all settings	**71%**

PI 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)

Mostly community setting	**95%**
Mostly inpatient setting	**96%**
Similar amount of service in both settings	**100%**
Total across all settings	**96%**

(a)   Results are presented by 'most common setting of care'. For more detail on care settings, see Section 2.3.2.

The figures suggest that, on the whole, palliative care services are meeting the important aspects of the National Palliative Care Strategy that are identified through the performance indicators. Although the performance indicators do not specify benchmarks (i.e. the optimal or desirable proportion of services that should meet the performance indicator criteria), the one performance indicator that suggested there is room for improvement related to the proportion of services that routinely undertake or undergo formal assessment against the Palliative Care Australia (PCA) Standards. The majority of agencies reported that they do not formally monitor and evaluate their service against these standards, although this may be because the agencies evaluate their services against other standards not recognised within the scope of the Agency Collection or they may assess their services against the PCA Standards on an informal basis only or as an ad hoc activity only.

No major differences in the achievement of the performance indicators were obvious across the different palliative care settings (i.e. between services that mainly deliver care in community settings, those that mainly deliver care in inpatient settings, and those that provide a similar amount of services in both settings), although agencies that mostly provided inpatient services were somewhat less likely to undertake or undergo formal assessment against the PCA Standards than the other agency categories.

Issues related to the collections and definitions

Overall, feedback and analysis of data indicated that both trial collections ran successfully. A number of lessons were, however, learnt and will inform future collections.

Strategic Plan Collection

- There is a need for further definition of common situations where it may be unclear whether a strategic plan exists—for example, where a regional restructure takes place and certain health areas under which the existing palliative care plan had been written are now amalgamated into a larger region or where a region has a current draft strategic plan.

Agency Collection

- Some agencies experienced computer disk failure when they tried to save the survey and feedback forms to the disk provided. This was able to be overcome (for agencies that sought help) but the technology would need to be more carefully tested prior to any future collection.
- Some data entry errors were identified. Wherever possible, these were followed up with agencies and corrected.
- Some users reported problems related to difficulty in understanding and/or answering some questions, suggesting the need to further develop some definitions. In particular, participants requested further definition of the terms 'at least one staff member' and 'palliative care practitioner' (Question 6) and 'formal working relationships' (Question 10).

Chapter 4 provides details of feedback provided by respondents in relation to specific questions.

Lessons learnt and future directions

The project obtained important information relating to implementation of four aspects of the National Palliative Care Strategy across the palliative care sector. The project team recommend that continued reporting against the agreed performance indicators occur and that the data obtained through this trial be used as baseline data to monitor changes in implementation over time.

In addition to the performance indicator reporting, a major aim of the project was to assess the data collection process—including the integrity of the data definitions used and other aspects of implementation of the data collection. A detailed discussion of specific issues and recommendations for future data collections is provided in Chapter 5.

1 Introduction

1.1 Performance information: what does it mean?

In recent years there has been increasing interest in and focus within the health system on outcomes. These outcomes can be partially or fully attributed to one or more interventions and represent changes in the health or wellbeing of individuals or a population (NHPC 2001:4). In the area of palliative care, outcomes may range from reduced symptoms or improved emotional wellbeing and better quality of life for the patient and their family to better health and wellbeing of the family in the years following the patient's death.

Many factors are involved in achieving better health-related outcomes for a population. They can be grouped into two categories: the general determinants of health that affect the population; and health system interventions. The latter can be measured at different levels. For example, in the health system it is possible to monitor the level of human resources, capital input, the quality of the facilities and equipment, and so on. It is also possible to measure the system's output, such as the number of service events, preventive actions or hospital separations. And, finally, the actual changes in the health status of the population may be measured. The challenge in evaluating whether the health system is providing appropriate care to those who need it most is to find suitable measures (NHPC 2001:4).

1.1.1 The four national palliative care performance indicators

In 2003 Australia's eight state and territory government health authorities endorsed four national performance indicators (PIs) for palliative care that had been developed by the Performance Indicator Development Working Group (PIDWG). The work of the PIDWG was based on a suite of high-level national performance indicators developed by the then South Eastern Sydney Area Health Service in 2001 (SESAHS 2001). Further development of that performance indicator work was carried out by the Australian Institute of Health and Welfare in 2002–03 (AIHW 2004).

The PIDWG was a temporary sub-group of the Palliative Care Intergovernmental Forum (PCIF), which is an advisory body with representatives from the Australian Government Department of Health and Ageing (DoHA) and each state and territory health authority. During the first half of 2005 one of the four performance indicators was amended and two were slightly reworded. They were subsequently re-endorsed by the PCIF in August 2005.

As agreed by these government representative bodies, the indicators are referred to as 'high level' to show the extent to which the goals and objectives of the National Palliative Care Strategy have been achieved. The indicators are not intended to measure individual agencies' performance and are not reported at agency or jurisdictional level.

A performance indicator can be defined as 'a measure that quantifies the level of performance for a particular aspect of (health) service provision…' (NHPC 2000:91). Performance indicators present indicative information only, and should have a clear relationship to the objectives of the program being delivered. The four national performance indicators presented in this report are the first national indicators developed for palliative care in Australia. They do not measure actual outcomes for patients and their families;

Region level

PI 1: The proportion of administrative health regions that have a written plan for palliative care which incorporates palliative care elements

Agency level

Common setting of care:
Mostly community setting
Mostly inpatient setting
Similar amount of service in both settings

PI 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

Assessment method:

1. Formal self-assessment
2. In-depth external review

PI 3: The proportion of palliative care agencies, within their setting of care, that actively collect feedback from patients/consumers and staff (within the workforce) relating to services and service delivery

Feedback collection method:

1. Questionnaire—periodic face-to-face interview
2. Questionnaire—face-to-face interview upon exit
3. Questionnaire—telephone
4. Questionnaire—other
5. Feedback focus group
6. Other
7. Not applicable

PI 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)

Type of partnerships:

1. Palliative care services
2. Hospitals—includes emergency departments
3. Community nursing agencies
4. Residential aged care facilities
5. Allied health services
6. Aboriginal health services
7. Medical practices
8. Integrated health centres
9. Universities/research centres
10. Other

Figure 1.1: National Palliative Care Performance Indicator Framework

nor do they measure the number of clients who receive palliative care or the types of intervention they receive. However, they are a first step in an attempt to quantify the level of awareness of palliative care at the regional level and the degree of commitment at the service-level to implement appropriate quality improvement mechanisms.

The final performance indicators are shown in Figure 1.1, along with the corresponding additional details about the indicators that were collected as part of the survey.

1.1.2 Relevant national structures and processes

The National Palliative Care Strategy

The National Palliative Care Strategy (NPCS) was developed as a consensus document and a framework that sets out national priorities intended to inform palliative care policy and service development across the Australian, state and territory governments (DoHA 2000:3). It represents the commitment of all governments, palliative care service providers and community-based organisations to the development and implementation of palliative care policies, strategies and services across Australia and to the delivery of quality palliative care that is accessible to all people who are dying. This supports the policy objective of developing and providing best-practice palliative care so that those with life-limiting illness and their families and carers have access to an appropriate service at the right time and in the right place (DoHA 2000:9).

The strategy has three goals, each of which has a set of objectives. The goals are as follows:

1. awareness and understanding, which seeks to 'improve community and professional awareness and understanding of, and professional commitment to, the role of palliative care practices in supporting the care needs of people who are dying and their families of care' (DoHA 2000:10)

2. quality and effectiveness, which seeks to 'support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia' (DoHA 2000:16)

3. partnerships in care, which seeks to 'promote and support partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, to support delivery of high quality, effective palliative care across all settings' (DoHA 2000:20).

Performance indicator 1 informs all three NPCS goals. It asks what proportion of administrative health regions have a written plan for palliative care that incorporates palliative care elements. The elements must include:

*   a 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, use and responsiveness

*   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.

These elements provide an indication that work against all three goals is occurring in a systematic and organised way.

Performance indicator 2 informs NPCS goal number 2. It asks what proportion of palliative care agencies routinely undergo formal assessment against the industry-agreed standards developed by Palliative Care Australia (PCA 2005a). These standards have been developed to support quality management and improvement activities in conjunction with, or as part of, agency accreditation: 'Accreditation remains the predominant model for improving safety and quality in health organisations. It promotes a range of benefits, including risk minimisation, improved patient outcomes, increased efficiency and best practice' (DoHA 2000:9). The fourth edition of the Standards has been designed for use by specialist palliative care services as well as other health care services that care for people who have a life-limiting illness.

Where formal assessment against these standards exists, there is a systematic and organised attempt to improve quality and effectiveness in a continuous manner. Measurement of this indicates the extent to which goal 2 of the Strategy is being achieved.

Performance indicator 3 asks what proportion of agencies actively collect feedback from patients/consumers and staff. It informs both goal 2 and goal 3 of the Strategy, providing an indication of consumer involvement in health service delivery decision making. The term 'actively' was used to differentiate between ad hoc and routine procedures that are used by agencies.

Where active procedures exist, it indicates that there is a systematic attempt to seek the opinion of consumers and staff. Measurement indicates the extent to which the objectives of goal 2 and goal 3 of the Strategy are implemented.

Performance indicator 4 asks what proportion of agencies have formal working partnerships with other service providers or organisations. It provides an indication of the extent to which goal 3 has been achieved. The term 'formal' was used to differentiate between ad hoc and formal working partnerships.

National reporting of the four performance indicators meets one of the key objectives of the NPCS under goal 2, that of 'Accountability and reporting.' This objective aims 'To achieve nationally consistent reporting on palliative care service provision in both public and private sectors and across all service delivery settings (inpatient palliative care unit, acute hospital, home and community)'(DoHA 2000:18).

Reporting against the high-level performance indicators does not provide a comprehensive and definitive explanation of achievement against the goals of the Strategy. However, it does provide, in a manner that has minimised the administrative burden, information that can be taken as an indication of the extent to which implementation has occurred and the goals have been achieved.

Australian Health Care Agreements

The Australian Health Care Agreements (AHCAs) have the objective of improving the provision of palliative care services (2003–2008 AHCAs: part 2, clause 8g). They describe how this can be achieved, identifying implementation of the National Palliative Care Strategy as a shared responsibility of all governments (2003–2008 AHCAs: part 3, clause 14d). They also state that the Australian Government and the states and territories will work together through the Australian Health Ministers' Advisory Council information management and information technology governance arrangements, to develop and refine appropriate performance indicators. This includes '(a) continuing the development of data

items, national minimum data sets...and (b) continuing the development of performance indicators...these indicators will relate to both admitted and/or non-admitted patient services and will include...(g) indicators of access to and quality of palliative care services...' (2003–2008 AHCAs: schedule C, clauses 12 and 13). The development of the four high level performance indicators that were agreed by the PCIF help meet the requirements of the AHCAs and provides some information that indicates progress towards implementing the National Palliative Care Strategy and improving access to and the quality of palliative care services.

National Health Performance Framework

The National Health Performance Framework (NHPF) was developed by the National Health Performance Committee, in consultation with the jurisdictions, government and non-government providers and health system consumers. The aim of the framework is to provide a structure that can assist with evaluation of the health status of the Australian population and health system performance (NHPC 2001).

The framework has three tiers: Health status and outcomes, Determinants of health, and Health system performance (Figure 1.2). The tiers reflect the fact that health status and health outcomes are influenced by various factors (health determinants) and health system performance.

The 'Health system performance' tier is the most relevant to palliative care service delivery and considers health systems in terms of the following nine dimensions: effective, appropriate, efficient, responsive, accessible, safe, continuous, capable and sustainable. For this tier, two questions are posed: 'How well is the health system performing in delivering quality health actions to improve the health of all Australians? Is it the same for everyone?' Since equity is integral to all three tiers, the second question—'Is it the same for everyone?'—is asked across the whole framework. Quality is integral to the 'Health system performance' tier, and the nine dimensions all contribute to assessment of the quality of the system. Both quality and equity are therefore not included as separate dimensions.

While all four national performance indicators have been developed to provide information about regions' and agencies' efforts to provide quality care on an equitable basis, each of the indicators also relates to a number of specific dimensions in the Health System Performance tier of the framework.

Performance indicator 1 evaluates activity at a regional level, but the activity it measures (a written strategic plan with specific characteristics) is highly relevant to the care provided within that region. In particular, the indicator fits well into the responsive, capable and sustainable NHPF dimensions. Performance indicator 2 relates to the 13 Palliative Care Australia Standards aimed at quality service provision, which cover a wide spectrum of service provision aspects. The Standards can be associated with all nine dimensions. Performance indicator 3 relates to two NHPF dimensions—responsiveness and sustainability. Performance indicator 4 relates to the continuous, capable and sustainable dimensions of the NHPF.

Figure 1.3 shows the relationships between the national palliative care performance indicators and both the National Health Performance Framework and the National Palliative Care Strategy.

Health status and outcomes

**How healthy are Australians? Is it the same for everyone?
Where is the most opportunity for improvement?**

Health conditions	Human function	Life expectancy and wellbeing	Deaths
Prevalence of disease, disorder, injury or trauma or other health-related states.	Alterations to body, structure or function (impairment), activities (activity limitation) and participation (restrictions in participation).	Broad measures of physical, mental, and social wellbeing of individuals and other derived indicators such as Disability Adjusted Life Expectancy (DALE).	Age and/or condition specific mortality rates.

Determinants of health

**Are the factors determining health changing for the better? Is it the same for everyone?
Where and for whom are they changing?**

Environmental factors	Socioeconomic factors	Community capacity	Health behaviours	Person-related factors
Physical, chemical and biological factors such as air, water, food and soil quality resulting from chemical pollution and waste disposal.	Socioeconomic factors such as education, employment, per capita expenditure on health, and average weekly earnings.	Characteristics of communities and families such as population density, age distribution, health literacy, housing, community support services and transport.	Attitudes, beliefs knowledge and behaviours, for example, patterns of eating, physical activity, excess alcohol consumption and smoking.	Genetic-related susceptibility to disease and other factors such as blood pressure, cholesterol levels and body weight.

Health system performance

**How well is the health system performing in delivering quality health actions to
improve the health of all Australians? Is it the same for everyone?**

Effective	Appropriate	Efficient
Care, intervention or action achieves desired outcome.	Care/intervention/action provided is relevant to the client's needs and based on established standards.	Achieving desired results with most cost effective use of resources.
Responsive	**Accessible**	**Safe**
Service provides respect for persons and is client oriented and includes respect for dignity, confidentiality, participation in choices, promptness, quality of amenities, access to social support networks, and choice of provider.	Ability of people to obtain health care at the right place and right time irrespective of income, physical location and cultural background.	The avoidance or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered.
Continuous	**Capable**	**Sustainable**
Ability to provide uninterrupted, coordinated care or service across programs, practitioners, organisations and levels over time.	An individual's or service's capacity to provide a health service based on skills and knowledge.	System or organisation's capacity to provide infrastructure such as workforce, facilities and equipment, and be innovative and respond to emerging needs (research, monitoring).

Source: NHPC 2001.

Figure 1.2: National Health Performance Framework

Figure 1.3: Palliative care performance indicators and links to the National Health Performance Framework and the National Palliative Care Strategy
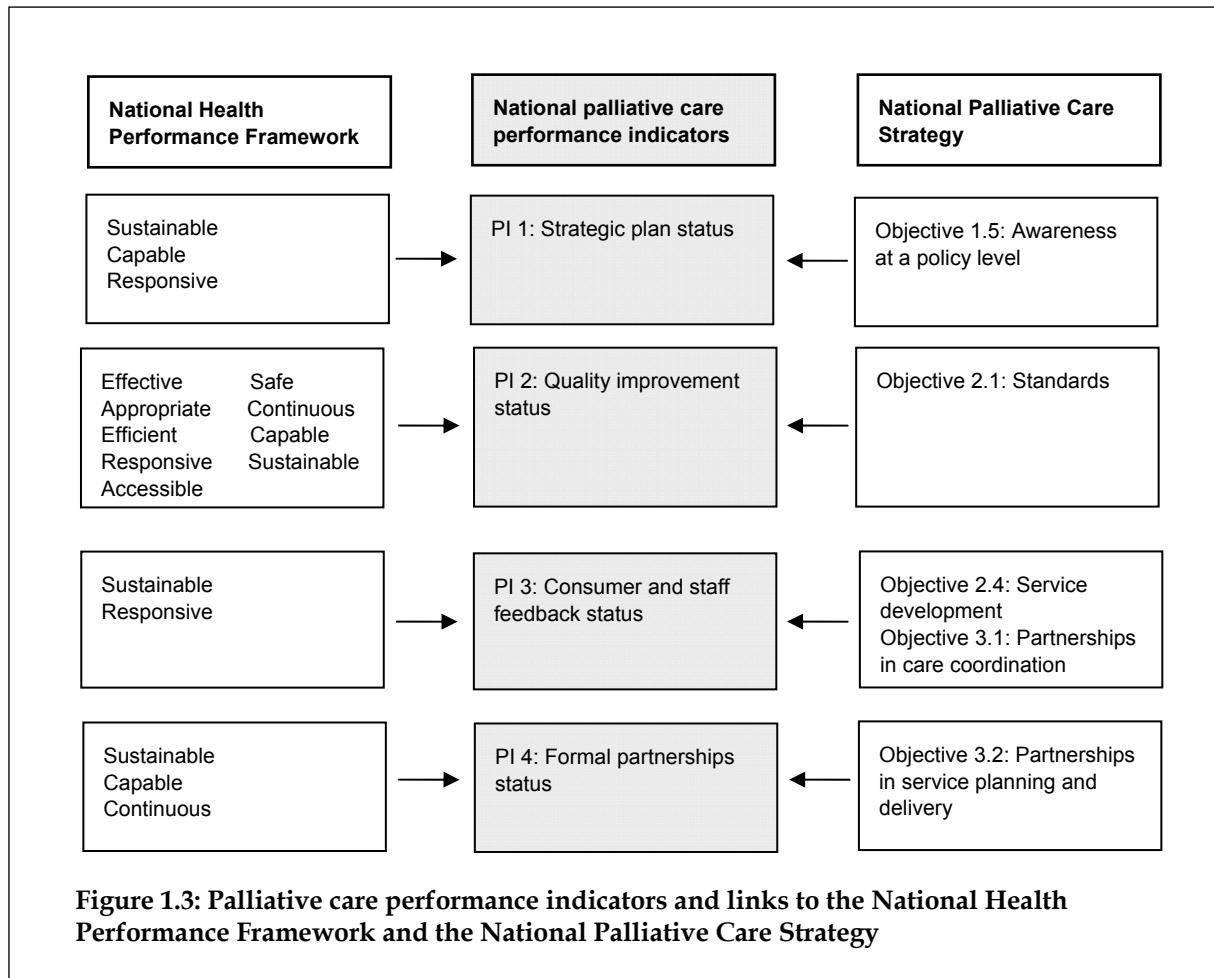
1.2 Palliative care provision in Australia

1.2.1 What is palliative care?

Palliative care is 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO 2003). Box 1 lists the principles of palliative care, as identified by the World Health Organisation.

Palliative care is the specialised care of people who are dying, and as a specialised health care field it has developed in Australia since the 1980s. Originally the emphasis was on the provision of care in hospices, but more recently it has been recognised that it is crucial to offer a range of services, from care in hospitals and hospices to care in a person's home (LCMHC 2003).

> **Box 1: World Health Organization principles of palliative care**
>
> *Palliative care:*
>
> - *provides relief from pain and other distressing symptoms*
> - *affirms life and regards dying as a normal process*
> - *intends neither to hasten nor postpone death*
> - *integrates the psychological and spiritual aspects of patient care*
> - *offers a support system to help patients live as actively as possible until death*
> - *offers a support system to help the family cope during the patient's illness and in their own bereavement*
> - *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
> - *will enhance quality of life, and may also positively influence the course of illness*
> - *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*
>
> *Source:* WHO 2003.

1.2.2 Who provides palliative care?

Most palliative care providers in Australia would agree on the importance of the aspects of palliative care endorsed by the World Health Organisation. However, there are many differences in the models of care applied across agencies, and these have often developed in response to patients' needs. Sometimes particular models have developed as a result of local preferences or the availability of resources, rather than being based on patients' needs.

Recognising the need for guidance in the development of palliative care services, Palliative Care Australia (PCA) has recently published *A guide to palliative care service development: a population-based approach* (PCA 2005b). The population-based approach advocated by PCA provides a service planning framework to meet the needs of patients with life-limiting illness and is based on the complexity of the needs of patients and their families. It acknowledges that resources are limited and aims to support equitable access for all Australians.

The service planning framework has been developed to assist health service planners, funding bodies and care providers to ensure that health services are designed to meet the needs of the population. The framework comprises four tiers, based on the lowest to the highest level of need: primary care providers, and specialist palliative care services (which are further differentiated as levels one to three). Movement between tiers is dependent on patient, family/carer or service provider needs, with services aligned in order to most appropriately, effectively and efficiently meet those needs. The framework provides for a collaborative approach to the delivery of palliative care services and incorporates public health initiatives and community participation.

Although many agencies that were surveyed in the Agency Collection would be defined as a 'specialist provider', as described in the PCA service delivery framework, some would fall into the category of 'primary care provider'. This was deliberate, because some of these

agencies receive government funding (from the Australian Government and/or a state or territory government) to provide palliative care in the community and/or in the inpatient setting. The decision to include both categories of agency has brought up some issues to do with scope and questions about the inclusion or exclusion of some agencies. Section 1.3 provides a more detailed description of the collection's scope. Scope-related issues that have arisen both before and during the collection are described throughout Chapters 3 to 5.

1.3 The National Palliative Care Performance Indicator Data Collection 2005

In 2004 the Palliative Care Section of the Department of Health and Ageing commissioned the Australian Institute of Health and Welfare (AIHW) to undertake work to facilitate information development in palliative care. The resulting project, the Palliative Care Information Development project Phase 2 was funded through the National Palliative Care Program (NPCP), which helps meet the Australian Government's commitment to the National Palliative Care Strategy. The NPCP is funded by the Australian Government from two sources: through the Palliative Care in the Community program, which provides $55 million over four years (2002 to 2006) and aims to improve the standard of palliative care in the community; and $13.2 million from the 2003–2008 Australian Health Care Agreements. The latter amount has been allocated to support national initiatives, from a total amount of $201.2 million provided for palliative care under the 2003–2008 AHCAs. The NPCP is implemented across six broad priority areas, with the Palliative Care Information Development project Phase 2 being one of the initiatives under the sixth area, 'Performance information development'.

 The Palliative Care Information Development project Phase 2 involved two distinct streams of work. One stream dealt with the development of the specifications to support the collection of the four PCIF-endorsed national palliative care performance indicators and included the collection of these data (the PI Collection); the other related to the development of a palliative care client data set specification. This report does not cover the latter stream: it focuses on findings from the survey of palliative care agencies and administrative health regions conducted to support reporting against the four performance indicators.

1.3.1 Objectives of the collection

The objectives of the PI Collection were to:

- collect, from health regions, information to support the calculation of national palliative care performance indicator 1
- collect, from palliative care agencies, data to support the calculation of the three other national palliative care performance indicators
- improve current knowledge about palliative care agencies and the settings in which they provide care
- improve current understanding of the approaches used by these agencies to provide quality palliative care.

1.3.2 Project management

The project was carried out by a team from the National Data Development and Standards Unit (NDDSU) of the AIHW. The NDDSU aims to improve the comparability, consistency, relevance and availability of national health and community services information. It manages and promotes Australia's national health and community services data standards and also specialises in identifying and developing national information requirements in specific program/policy areas or sectors.

The work on this project was overseen by the Palliative Care Data Working Group (PCDWG), which was set up at the start of 2005 specifically to provide guidance and expert advice to the AIHW project team. The PCDWG is a sub-group of the Palliative Care Intergovernmental Forum and provides advice to that forum; it consults with the Health Data Standards Committee and other relevant groups on palliative care data issues and has representatives from the Australian Government Department of Health and Ageing (Palliative Care Section), all states and territories, the AIHW, Palliative Care Australia, the Community Care Section of the Australian Government Department of Health and Ageing, and the Australian Government Department of Veterans' Affairs.

1.3.3 Methodology

Methods for collection of data for the national performance indicators were agreed in the first half of 2005 in conjunction with members of the PCDWG. This allowed input from the states and territories and the other organisations represented on the PCDWG. Many aspects of the PI Collection were considered, among them the type of information required to support calculation of the performance indicators; other types of information regarded as desirable or important in the context of the collection; the health regions and agencies to be included (scope/size); the logistics of the collection; the technology available to data providers; the ease of collection and the collection burden; and the varied environments in which data collection would take place.

Information collected

The information collected falls into two categories because the performance indicators refer to two levels within the health sector: administrative health regions (performance indicator 1; the Strategic Plan Collection) and agencies (performance indicators 2–4; the Agency Collection). This has resulted in two separate collections and data definitions were developed to support collection of performance indicator data at each of these levels.

Data requirements for each performance indicator were determined on the basis of the information to be reported and the level of detail required for each indicator. For performance indicator 1 information was collected on whether administrative health regions had strategic plans consistent with the definition developed by the PCDWG. For performance indicators 2–4 information about palliative care agencies, stratified by their settings of care, was collected.

A number of supplementary questions were added to the Agency Collection. These were included to help the project team screen agencies on whether they were in scope, and to gather information about contracting arrangements in order to investigate hierarchical structures of palliative care agencies within their states and territories.

Scope

Inclusion in the Strategic Plan Collection (performance indicator 1) was based on the ability of a health area to meet the definitional criteria of an administrative health region. The following definition was developed specifically for the purposes of the collection: '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.'

The state and territory health departments provided listings of administrative health regions to be included within their jurisdiction (Appendix 1).

Inclusion in the Agency Collection (performance indicators 2–4) was based on the ability of an agency to meet the definitional criteria of a palliative care agency. Box 2 shows the definition developed specifically for the purposes of this collection.

Box 2: The National Palliative Care Agency Data Collection: definition of a palliative care agency

Definition

A palliative care agency is an organisation or organisational sub-unit that is either a government service or an incorporated business with an ABN, which employs one or more palliative care practitioners, and is responsible for the provision of palliative care to patients and/or their carer(s)/family/friends and/or related services to health professionals, counsellors and volunteers.

The agency may provide paid or unpaid palliative care for people who are dying and their carer(s), family and friends. Care may be provided in an inpatient and/or a community setting.

Related services include palliation clinical support and advice for health professionals, and/or palliative care education and training for health professionals, counsellors and volunteers to enable them to care for palliative care clients.

Government funding (Australian and/or state or territory government) is received by the agency to provide palliative care or related services.

Further clarification

An agency may or may not directly provide the palliative care services to clients, but is responsible for their provision, whether directly, administratively or via allocation of funds.

Sometimes agencies may contract out or broker the assistance required by their clients to other service providers. Although the agency may not directly provide the palliative care in these cases, the agency paying for the palliative care to the clients is considered responsible for the provision of palliative care and should be able to report on those clients and the care they receive. Regardless of the way in which an organisation is funded, an agency is the level of the organisation responsible for service provision to clients. In some instances one organisation will have more than one agency.

As discussed in section 1.2, the definition was designed to capture all agencies that would be regarded as 'specialist palliative care services' in the PCA service planning framework (PCA 2005b) and those 'primary palliative care providers' that provide a significant amount of palliative care (as evidenced by the fact that they employ at least one palliative care practitioner).

This data collection does not capture information on agencies/service providers that receive no government funding (i.e. health services that are wholly privately funded), general practitioners, and services outside the core health system. These services—such as residential

aged care facilities and Home and Community Care (HACC) funded agencies[1], which are substantial providers of health-related services—may provide palliative care to their clients (either as primary palliative care or specialist palliative care providers).

The states and territories provided listings of palliative care agencies to be surveyed by the AIHW. For some states and territories this was a difficult task because a collection of this kind had not occurred before and there was some uncertainty about which agencies met the criteria. Additionally, recent restructuring of services within some states and territories created difficulties.

Limitations of the data

The state and territory health departments provided lists of agencies considered to be in scope for the Agency Collection. This initial listing consisted of nearly 400 palliative care agencies Australia-wide. However, the list proved somewhat changeable, with the lists in two large states decreasing by over 10%. National reporting was limited by the lack of uniformity in agency reporting levels between states and territories (see Section 2.3). This medium-sized data collection is not fully representative of the palliative care industry, but as a trial collection it is a first step to obtaining good-quality data about palliative care agencies on a nationally consistent basis.

The scope for the collection is based on the definition of a palliative care agency, which was developed specifically for this collection. Not all organisations that provide palliative care are in scope; this includes some 'generalist' palliative care agencies, agencies relying on volunteers, and agencies that do not employ a palliative care practitioner, as well as agencies that do not receive any government funding to provide palliative care—for example, private hospitals. Some agencies that may not be classified as 'specialist' palliative care providers are included in the definition.

The scope for future National Palliative Care Agency Data Collections is to be finalised after refinement of the definition of agencies in scope. In particular, the criterion of employing at least one palliative care practitioner requires further clarification or reconsideration.

Data issues were expected to arise due to the trial nature of the PI Collection. Resolution of the few issues highlighted from the trial will assist in improving future collections.

Logistics

For performance indicator 1 (Strategic Plan Collection) the state and territory health departments identified which administrative health regions had a strategic plan. Where such a plan existed, it was then assessed by the PCIF member and one or two health department staff members to determine whether it was consistent with the definition developed. The outcome of this assessment was documented on a form and returned to the AIHW.

For performance indicators 2–4 (Agency Collection), the state and territory health departments distributed to palliative care agencies all materials required for collection of the agency data. The state and territory departments collated completed survey returns and forwarded them to the AIHW. Information provided to agencies, via the states and territories, included cover letters, survey and feedback forms (electronic and paper) and guidelines to the data collection (AIHW unpublished).

---

1 Some palliative care agencies may receive HACC funding for the provision of ancillary services (e.g. patient transport) but palliative care agencies should not be substantially HACC funded.

Technology

The regional strategic plan data collection (performance indicator 1) did not require the use of specific technology. A Microsoft Word document (see Appendix 2) was sent to state and territory PCIF members, who coordinated responses on behalf of their jurisdictions. The PCIF members, along with one or two other health department staff members, assessed the strategic plans for each administrative health region in their state or territory as required. Responses to the strategic plan survey were stored securely as Word documents at the AIHW.

In recognition of the variety of agency computer systems, the varying technical skills of staff completing the survey, and the availability of software, it was decided to use Microsoft Excel for the agency survey (performance indicators 2–4; see Appendix 3). The survey was designed for use in a hard-copy (paper) or electronic format so users could respond in the format that best suited them. The ability to respond using paper copies of the survey also provided an alternative in the event of technology failures. All documents for the Agency Collection were made available on a website developed for the trial of the National Palliative Care Agency Data Collection 2005.

Responses to the agency survey were stored securely in an Oracle database developed by the AIHW. An interface to the database was created to allow data to be easily loaded, validated, edited and extracted. Where errors in survey responses were identified, agencies were contacted by the AIHW and corrections were made.

National data standards

Development of the data set specification (DSS) that supports the collection of the four performance indicators was guided by existing national data standards in the health and community sectors. National data standards are contained in the *National health data dictionary* (NHDD)(HDSC 2006) and the *National community services data dictionary* (NCSDD)(NCSDC forthcoming) respectively. Under the National Health Information Agreement, the NHDD is the authoritative source of health data definitions where national consistency is required or desired. Similarly, the NCSDD is the authoritative source of community services data definitions where national consistency is required under the National Community Services Information Agreement.

National data standards in the NHDD and the NCSDD are subject to a process of endorsement by a group of committees established to ensure that information is collected consistently on a national basis. The National Health Information Group and the National Community Services Information Management Group are the management groups responsible for the endorsement of all new and revised national standards. These groups are guided in their decisions by the Health Data Standards Committee, the Statistical Information Management Committee and the National Community Services Data Committee which meet regularly to discuss submissions for revisions to the data dictionaries.

It is envisaged that following some amendments to the DSS that supports the four national palliative care performance indicators (as a result of the PI Collection findings) the DSS will go through these committee processes and be endorsed as a national standard. This will have a number of advantages, including the following:

- It ensures there is agreement on the meaning and representation of each piece of information.
- Information collected can be compared across different jurisdictions, settings and sectors.

- It promotes the comparability, consistency and relevance of national health and community services information.
- It makes data collection more efficient by reducing the duplication of effort in the field and more effective by ensuring that information to be collected is appropriate to its purpose.
- It will assist system designers as they re-engineer state and territory health information systems.

Metadata online registry (METeOR)

The DSS was built within the AIHW's online metadata registry, METeOR, Australia's central repository for national data standards. METeOR provides a number of tools to help data developers through the data development cycle, from defining data items to submission of items to the relevant authorities for agreement. Once the DSS that supports these data collections is endorsed by the relevant authorities it will be made publicly available via METeOR, which can be found at <http://meteor.aihw.gov.au>.

2 Performance indicator results and issues

This chapter presents the results of the National Palliative Care Performance Indicator Data Collection 2005 (PI Collection), both in terms of analysis of results and the (data) issues that were identified by the collection. The four high-level performance indicators, together with the data set specification that assists their implementation and measurement, support the assessment of performance information against the National Palliative Care Strategy. Reporting against the high-level performance indicators does not provide a comprehensive and definitive description of achievement against the goals of the Strategy. It does however, provide, in a manner that minimises the administrative burden, information that can be taken as an indication of the extent to which implementation has occurred and the goals have been achieved.

Each of the sections that relate to one of the four performance indicators provides a description of the performance indicator, the purpose of the survey question, data analysis results, and a discussion of any (data) issues. Information on data issues is presented to inform the future administration of the PI Collection. In particular, for the Agency Collection, information about scope and stratification of performance indicators by care settings is presented. In addition to collecting data to calculate the national performance indicators, the Agency Collection included a number of other related questions that were included in order to gather more detailed information relevant to performance indicators 2–4. These questions and the corresponding findings are also discussed in this chapter.

2.1 Summary of results

Table 2.1 presents the overall results of the four national palliative care performance indicators. Data were obtained through two data collections: the Regional Strategic Plan Collection and the National Palliative Care Agency Data Collection. More detailed information is presented in Sections 2.2 and 2.3.

The figures suggest that, on the whole, palliative care services are meeting the important aspects of the National Palliative Care Strategy that are identified through these performance indicators. Although the performance indicators do not specify benchmarks (i.e. the optimal or desirable proportion of services that should meet the performance indicator criteria), the one performance indicator that suggested that there is some room for improvement related to the proportion of services that routinely undertake or undergo formal assessment against the Palliative Care Australia Standards.

No major differences in the achievement of the performance indicators was obvious across the different palliative care settings—that is, between services that mainly deliver care in community settings, those that mainly deliver care in inpatient settings, and those that provide a similar amount of services in both settings)—although agencies that mostly provided inpatient services were somewhat less likely to undertake or undergo formal assessment against the PCA Standards than the other agency categories (performance indicator 2).

Table 2.1: Palliative care performance indicator results

Regional Strategic Plan Collection 2005

PI 1: The proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements	**66%**

National Palliative Care Agency Data Collection 2005[a]

PI 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

Mostly community setting	**36%**
Mostly inpatient setting	**25%**
Similar amount of service in both settings	**41%**
Total across all settings	**34%**

PI 3: The proportion of palliative care agencies, within their setting of care, that actively collect feedback from patients/consumers and staff (within the workforce) relating to services and service delivery

Mostly community setting	**75%**
Mostly inpatient setting	**65%**
Similar amount of service in both settings	**68%**
Total across all settings	**71%**

PI 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)

Mostly community setting	**95%**
Mostly inpatient setting	**96%**
Similar amount of service in both settings	**100%**
Total across all settings	**96%**

(a)   Results are presented by 'most common setting of care'. For more detail on care settings, see Section 2.3.2.

2.2 Strategic Plan Collection: performance indicator 1

State and territory health departments were asked to assess the strategic plan(s) of each of their administrative health regions. There were a total of 38 regions, as identified by the jurisdictions, for the Strategic Plan Collection (Table 2.2).

Table 2.2: Administrative health regions, by State and Territory

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Number of regions	8	8	3	5	11	1	1	1	38

Description

The proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements is calculated as:

Number of administrative health regions with a written palliative care plan
_____

Total number of administrative health regions

The denominator for performance indicator 1 is derived from the total number of administrative health regions as nominated by the jurisdictions. Health region administrators are responsible for administering health services in a region, area, district or zone and for developing and implementing strategic and other plans for health service delivery (Appendix 1 lists the 38 health regions). A written strategic plan is specified as a plan that may be specifically for palliative care or a general health service plan that includes palliative care elements. A palliative care strategic plan may be a regional plan or an aggregation of the region's sub-units' plans. A strategic plan typically has a mission statement, outlines a vision, values and strategies, and includes goals and objectives. It 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 be counted in this performance indicator, 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
- 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.

A plan incorporating all these elements provides an indication that work against all three goals of the NPCS is occurring in a systemic and organised manner.

Purpose

Performance indicator 1 assists with measurement of the level of awareness and understanding of palliative care in the government and service sectors. A strategic plan helps to build a picture of the delivery and direction of services as well as defining the target population. The existence of a palliative care strategic plan indicates whether palliative care policy is being applied across the jurisdictions.

A strategic plan may reflect key aspects of effective palliative care, such as philosophy, workforce description and estimates of future service requirements for a population and

may identify linkages between palliative care and other relevant services. Strategic planning can assist in identifying gaps in the existing local service delivery model and future needs.

Performance indicator 1 informs all three goals of the National Palliative Care Strategy. In particular, it relates to the objective of awareness at a policy level:

> **National Strategy Objective 1.5: Awareness at a 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.

Data results

Of the 38 administrative health regions nationally, 25 (66%) stated they had a written strategic plan, that incorporates palliative care elements and all compulsory strategic plan aspects (Table 2.3). Existence of strategic plans for state and territory administrative health regions ranged from nil to 100%. Six of the eight jurisdictions demonstrated a high level of awareness and understanding of palliative care at the policy level by stating that all or nearly all of their administrative health regions had a written strategic plan. This level of recognition, at the health policy and decision-making level, indicates that palliative care services understand the need for strategic planning. This goes some way towards the desired outcome of the NPCS, that all health regions have a strategic plan for palliative care.

Table 2.3: PI 1 health regions that have a written strategic plan for palliative care

Strategic plan status	Number of health regions	Proportion of health regions (%)
Yes	25	66
No	13	34
Total	**38**	**100**

Data issues

- One state had undergone a regional restructuring whereby certain health areas under which the existing palliative care plan had been written became amalgamated into a larger region. This was problematic, requiring a mapping exercise from previous health areas to the current amalgamated regions to assess whether existing strategic plans covered the new health regions. The PCDWG agreed post-collection that only plans that had been signed off and rolled-up at the nominated regional level should be accepted. It was acknowledged that in assessing performance indicator 1, account must be taken of the fact that there may be a lag time between the reorganisation of new health areas and creation and implementation of strategic plans for these new regions. This allows existing strategic plans 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.

- Another jurisdiction had a statewide strategic plan that takes into consideration service provision in all Administrative health regions, and future planning may continue in the same manner. Since this overarching plan does not specifically provide for the needs of each individual health region, the plan did not meet the criteria for performance indicator 1.

- At the time of the Strategic Plan Collection one jurisdiction had a strategic plan that was in the final stages of drafting. Although the draft contents of the plan met the criteria for performance indicator 1, the plan was not counted as a 'yes' in the numerator of performance indicator 1 because of its non-endorsed status. In addition, no prior plan was in operation.

2.3 Agency Collection: performance indicators 2–4

2.3.1 Background to performance indicators 2–4

This section presents information on the response rate for the National Palliative Care Agency Data Collection 2005, the screening of agencies in scope for this collection, and the sub-categories by which agency performance indicators were stratified.

Agency survey responses

Each jurisdiction was required to nominate agencies that were to participate in the Agency Collection. Since this was the first time that an agency listing had been compiled for national reporting purposes, some jurisdictions were aware of the possibility that their listing may need to be amended because the selected agencies might not meet the definitional criteria for a palliative care agency.

Following are notes detailing how the response rate for the Agency Collection was calculated:

- A total of 395 agencies were sent surveys from the original lists provided by the states and territories.

- After the collection was run 103 agencies were dropped from the agency listing. They were assessed by jurisdictions as either not receiving Australian Government or state/territory funding, as not employing a palliative care practitioner, as duplicates already incorporated as another agency, or as having merged with other agencies (Table 2.4).

- This resulted in a revised total of 292 agencies that should have been surveyed.

- Of the collection packs distributed, 226 completed surveys were returned by agencies. This resulted in a final response rate for the Agency Collection of 77% (226 out of the 292 agencies). Response rates from agencies in states and territories ranged from 57% to 100%.

After initial analysis of the 226 responding agencies, it was determined that an additional 46 of those agencies were out of scope for the Agency Collection because they did not employ a palliative care practitioner. Thus, the total number of participating agencies considered in scope for this trial collection was 180.

The following should be noted:

- The largest agency amendments affected two states, while three other states had a minor number of agencies excluded.

- It is not possible to determine how many non-responding agencies were in scope for this collection. That is, it is possible that agencies assessed their service as out of scope and therefore did not respond.

- All states and territories made a concerted effort to follow up late responses and collate results.

- There was much variation in the reporting level of agencies between states. Of the three largest states, the number of agencies ranged from 53 to 93. This highlighted the need to review agencies in scope so that there was uniformity in agency reporting levels between and within states and territories. A small advisory group consisting of PCDWG members will help the AIHW review agency lists and reporting levels before future Agency Collections.

The denominators for performance indicators 2–4 are derived from the total number of responding agencies in scope (i.e. 180 agencies). All calculations in this chapter are based on this figure.

Table 2.4 shows the distribution of agencies across the states and territories for the Agency Collection.

Table 2.4: Distribution of responding palliative care agencies in scope, by State and Territory

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Number of agencies	48	45	53	11	17	2	2	2	180

Figure 2.1 shows the screening process used to determine the number of agencies in scope. It shows the two main points at which the number of agencies for the Agency Collection was revised and how the final figure of 180 agencies was calculated.

Agency Collection scope: minimum one palliative care practitioner

For the purposes of the Agency Collection, a palliative care agency needed to have a minimum of one palliative care practitioner with recognised professional training in palliative care. A few states and territories experienced some uncertainty as to whether all agencies included on the original listing were in scope for their jurisdiction, so an additional question was included in the survey to help to filter out agencies that failed to meet this criterion.

Data results

Survey question 6 asked, 'Does your agency employ at least one staff member who is a palliative care practitioner?'

Of the 226 agencies that completed the survey, 46 respondents did not employ a palliative care practitioner, as defined in the guidelines document. These agencies were excluded from any performance indicator reporting because they were considered outside the scope of the Agency Collection. The 46 out-of-scope responding agencies also meant that the number of palliative care agencies in scope for the collection dropped further. Figure 2.1 shows the changes in the number of agencies considered in scope of the Agency Collection.

Data issues

A number of agencies reported problems answering question 6 because of difficulties understanding the guidelines. Some agencies were uncertain if their staff qualified against the definition of 'palliative care practitioner' and queried the number of hours that a staff member had to work to be counted. Section 4.2 provides further details about this.

Note: Data received from agencies that did not employ a palliative care practitioner were excluded from any performance indicator reporting because they are out of scope for the Agency Collection.

Figure 2.1: Scope and responses to the National Palliative Care National Data Collection
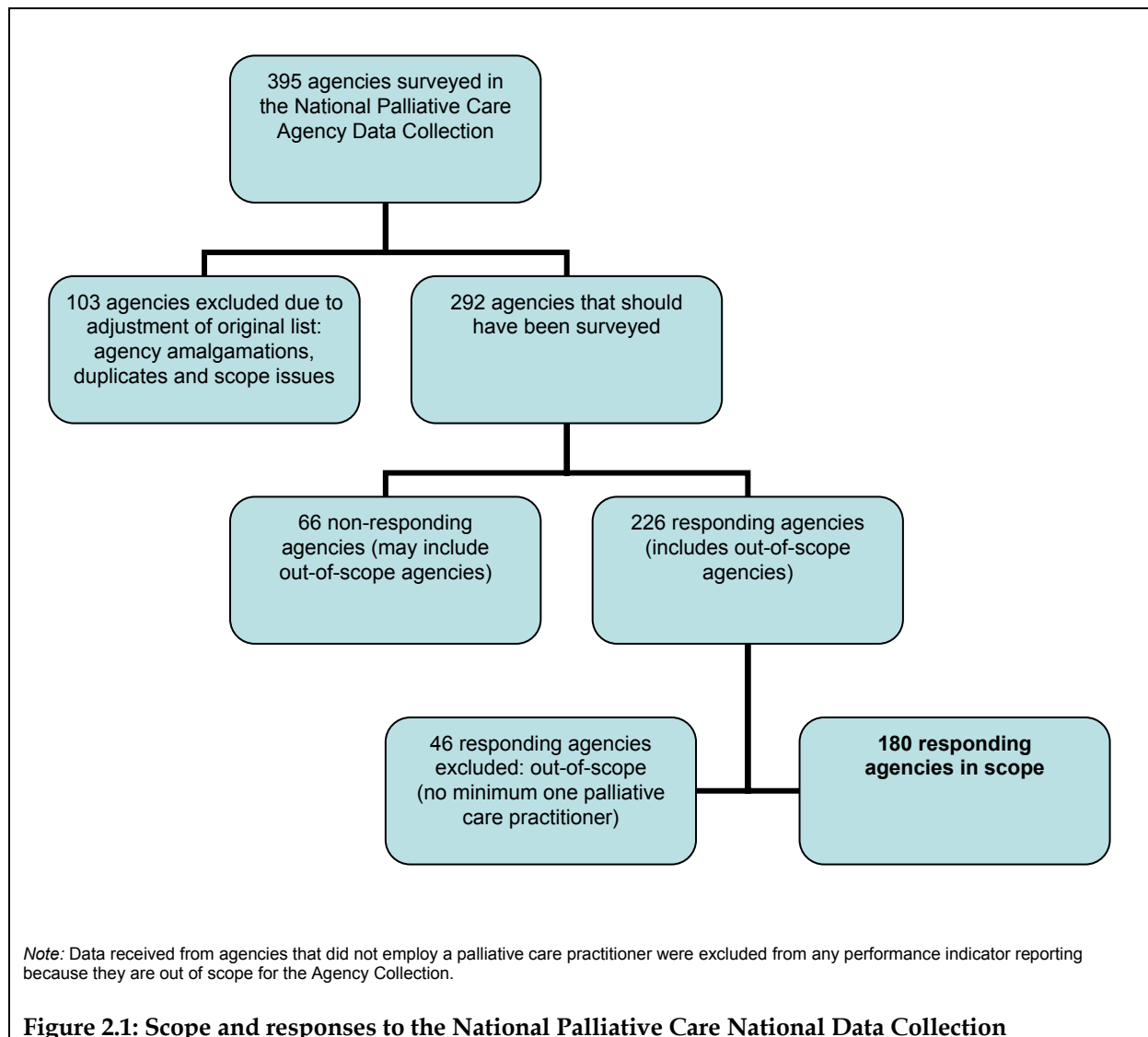
2.3.2 Stratification of agency performance indicators

Most common setting of care

Information was collected on the most common settings in which palliative care agencies provided care, to stratify performance indicators 2–4 by the 'most common setting of care'.

Agencies were asked to choose the category that best represented the setting in which more than 50% (approximately) of the agency's services were delivered during the previous 12 months. The categories representing service delivery settings for palliative care were:

- community setting
- inpatient setting
- similar amount of service in both community and inpatient settings.

The community setting was defined as including residential settings such as a residential aged care facility; a person's private residence which could be a house, flat, caravan, mobile

home, houseboat or a unit in a retirement village; a residential facility other than an aged care facility; a prison; a community living environment, including a group home; and a non-residential setting such as a day respite centre or other day centre. It also included outpatient settings and hospital outreach services where patients are cared for on a non-admitted basis.

Inpatient settings were defined as those that provided care in licensed hospital, hospice or admitted patient settings. Outpatient settings and hospital outreach services are excluded.

Data results

Survey question 5 asked, 'During the past 12 months, in which setting(s) nominated in Q4, did your agency most commonly deliver palliative care services?'

Table 2.5 shows that the community setting was the most common environment in which agencies delivered services to palliative care clients. Sixty per cent of agencies (107) mostly provided care to clients in the community compared with 28% of agencies mainly providing care in an inpatient setting. Twenty-two agencies (12%) stated they provided palliative care equally in both settings.

Table 2.5: The most common setting of care in which palliative care agencies delivered services

Most common agency setting	Number of agencies	Proportion of agencies (%)
Mostly community-based setting	107	60
Mostly inpatient setting	51	28
Similar amount of service in both settings	22	12
Total	**180**	**100**

Data issues

A few agencies incorrectly used the lower level code set answers of question 4, which referred to specific care settings, instead of the rolled-up categories developed for answering question 5. Corrections were made after consultation with the agencies involved.

Additional information on setting of care

Another question was included to further investigate the range and possible combinations of settings in which palliative care agencies provided services.

Data results

Survey question 4 asked, 'During the past 12 months, in which setting(s) did your agency deliver palliative care services?'

The private residence was the most common setting of care (145 agencies, or 81%) in which agencies were involved in the delivery of palliative care (Table 2.6, Figure 2.2), although it should be noted that table 2.6 does not provide information on the frequency with which services are provided in these setting. Inpatient (non-designated beds) and residential aged care settings both accounted for 53% to 56% of responding agencies, followed by designated inpatient palliative care units and outpatient settings (44%).

Of the 180 palliative care agencies, 47 (26%) delivered care in one setting only, while 90 (50%) agencies delivered services in two to four settings of care.

Table 2.6: Settings of care in which palliative care agencies delivered services

Setting of care	Number of agencies	Proportion of agencies (%)
Community-based settings		
Private residence	145	81
Residential—aged care setting	95	53
Residential—other setting	48	27
Non-residential setting	27	15
Outpatient—in a hospital/hospice	70	39
Inpatient settings		
Inpatient—designated palliative care unit	79	44
Inpatient—other than a designated palliative care unit	100	56
Total number of agencies[(a)]	**180**	**100**

(a)   Because more than one answer could be selected in this question/category for each agency, 'Total number of agencies' is not the sum of the columns.

Figure 2.2: Settings of care in which palliative care agencies delivered services
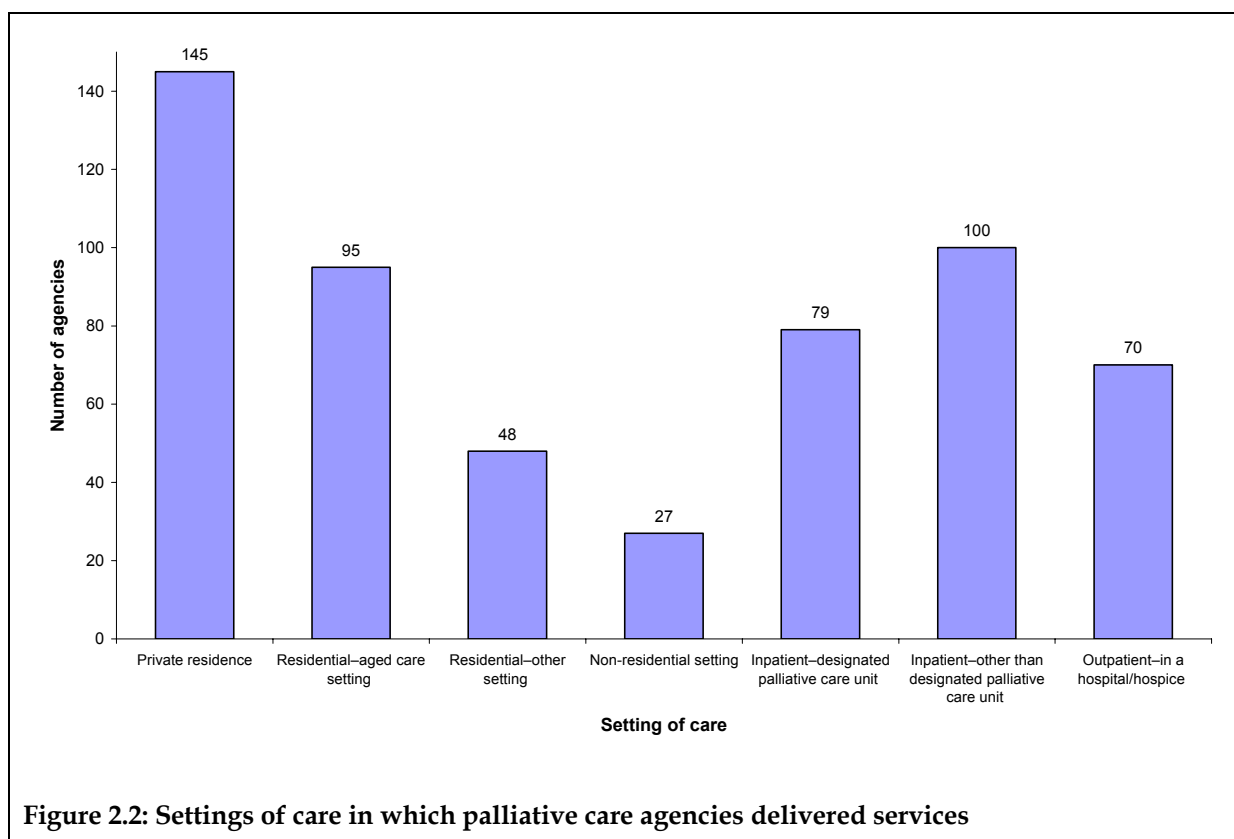
Data issues

No specific data issues were identified in relation to the collection of these data.

2.3.3 Performance indicator 2

Description

The proportion of palliative care agencies, within their setting of care, that routinely undertake or undergo formal assessment against the Palliative Care Australia Standards calculated as:

Number of responding palliative care agencies with formal PCA assessment
(by most common setting of care)

_____

Total number of responding palliative care agencies in scope

Performance indicator 2 measures the level of commitment to quality improvement, using the industry-endorsed standards developed by Palliative Care Australia (PCA). An earlier version of this performance indicator, endorsed by the PCIF in 2003, referred quite generally to 'quality improvement mechanisms'. The indicator was refined by making it more specific to the area of palliative care and by referring to the palliative care industry-agreed standards. The revised indicator acknowledges the importance of the standards and the desirability of palliative care agencies measuring themselves and their practices against them. The PCIF endorsed the revised indicators in 2005.

The acceptable standards for this indicator are those developed by PCA, as outlined in the publications *Standards for providing quality palliative care for all Australians* (PCA 2005b) and *Standards for palliative care provision* (PCA 1999). The standards describe the dimensions and elements of quality in specialist palliative care (see Appendix 6) and have been developed to support quality management and improvement activities in conjunction with, or as part of, agency accreditation. 'Accreditation remains the predominant model for improving safety and quality in health organisations. It promotes a range of benefits, including risk minimisation, improved patient outcomes, increased efficiency and best practice' (DoHA 2000:9). The PCA Standards can be used in combination with generic health care quality standards such as EQuIP (Australian Council on Healthcare Standards) or Quality Management Services (formerly the Community Health Accreditation and Standards Program).

The methods for assessment against the PCA Standards that were considered acceptable were:

- self–assessment, including 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/or the use of validated tools where these are available

- formal in–depth review 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.

Purpose

Standards can be used for implementing and monitoring quality activities, accreditation, benchmarking, performance management, service planning and policy development. Undertaking or undergoing formal assessment against these accepted benchmarks is one

important way in which agencies can show that quality improvement processes specific to palliative care are in place.

The need for consistent use of standards in palliative care nationally is specifically recognised by the 'development and implementation standard' objective, under Goal 2 of the National Palliative Care Strategy:

> **National Strategy 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.

Data results

Survey question 12 asked, 'Does your agency routinely undertake or undergo formal assessment against the Palliative Care Australia Standards?'

Table 2.7 shows that one-third of palliative care agencies (61 agencies; 34%) routinely undertake formal self-assessment or undergo in-depth review against the PCA Standards. The majority of agencies reported that they do not formally monitor and evaluate their service against these standards. This may mean that these agencies do not evaluate their service against any minimum standards or they evaluate their service against other standards not recognised within the scope of this Agency Collection. Alternatively, agencies may undertake assessment against the PCA Standards but on an informal basis or as an ad hoc activity only.

Table 2.7: PI 2 agencies, by formal assessment status and setting of care

Assessment status	Community setting	Inpatient setting	Similar amount in both settings[a]	Total
		number		
Yes	39	13	9	61
No	68	38	13	119
Total	**107**	**51**	**22**	**180**
		per cent		
Yes	36	25	41	34
No	64	75	59	66
Total	**100**	**100**	**100**	**100**

(a) Refers to agencies that provide a similar amount of services in the community and inpatient settings.

Of the total surveys returned, an average of two-thirds of agencies in each common care setting responded that they did not undergo any type of formal assessment at all on a routine basis. Of the three common settings of care, the largest proportion that undertook or underwent formal assessment were agencies that provide a similar amount of services in both settings (41%); this was followed by community settings (36%).

This level of uptake of national standards for palliative care demonstrates support in service quality improvements, but there is room for improvement. Development of national quality assurance programs and benchmarking systems would also assist in improving palliative care outcomes.

Of the 61 agencies that have adopted the PCA Standards, the community care setting is the most common care setting for 39 agencies (64% of 61 agencies), followed by 13 agencies commonly providing inpatient care (21%) and 9 agencies (15%) who provide a similar amount of services in both community and inpatient settings.

Data issues

- Agencies commented that the term 'routine' was subjective and not defined in the guidelines. This may result in performance indicator 2 being under- or over-estimated for a small number of agencies.

- This performance indicator does not capture those agencies that have in place palliative care quality improvement mechanisms other than the PCA Standards.

- From the survey question asked, it is not apparent how often agencies undergo formal assessment and compliance against the PCA Standards. Future Agency Collections could investigate this further.

Additional information

To gather more detail about performance indicator 2, palliative care agencies that assess themselves against the PCA Standards (61 agencies) were asked about the method(s) of assessment they use.

Data results

Survey question 13 asked, 'What method(s) is used to assess your agency against the Palliative Care Australia Standards?'

The most common method of assessment against the PCA Standards was formal self-assessment (55 agencies). Palliative care agencies for which the most common setting of care was the community environment accounted for the greatest proportion of agencies undertaking formal self-assessment (Table 2.8). In every common setting of care, agencies were more likely to use formal self-assessment over in-depth external reviews as an assessment method. Of the 21 agencies that underwent an in-depth external review, 15 performed a formal self-assessment as well (Table 2.9).

Table 2.8: Agencies by assessment method and common setting of care

Assessment method	Community setting	Inpatient setting	Similar amount in both settings[a]	Total
Formal self assessment	36	11	8	55
In-depth external review	10	7	4	21
Total number of agencies [b]	**39**	**13**	**9**	**61**

(a)   Refers to agencies that provide a similar amount of services in the community and inpatient settings.
(b)   As more than one answer can be selected in this question/category for each agency, the 'Total number of agencies' is not the sum of the columns.

Table 2.9: Assessment methods by common setting of care

Assessment method	Community setting	Inpatient setting	Similar amount in both settings[a]	Total
Formal self assessment only	29	6	5	40
In-depth external review only	3	2	1	6
Both formal assessment and in-depth review	7	5	3	15
Total number of agencies [b]	**39**	**13**	**9**	**61**

(a)   Refers to agencies that provide a similar amount of services in the community and inpatient settings.
(b)   As more than one answer can be selected in this question/category for each agency, the 'Total number of agencies' is not the sum of the columns.

Twenty-five percent of agencies (15 agencies) undertook both formal assessment and in-depth reviews (Figure 2.3).

Both formal assessment and in-depth review
25% (15 agencies)

In-depth external review only
10% (6 agencies)

Formal self-assessment only
66% (40 agencies)

Note: Due to rounding percentages do not add to 100%.

Figure 2.3: Assessment methods used by agencies

Data issues

Only palliative care agencies undertaking assessment against the PCA Standards were required to respond to this question. However, four respondents had mistakenly answered this question where their response to assessment against the standards was 'no'. Follow-up with agencies revealed that in certain instances the agency in question met 'generalised' accreditation requirements of programs such as EQuIP. These agencies were not aware that an in-depth external review such as EQuIP must contain the palliative care-specific components of that accreditation that link to the PCA Standards.

2.3.4 Performance indicator 3

Description

The proportion of palliative care agencies, within their setting of care, that actively collect feedback from patients/consumers and staff (within the workforce) relating to services and service delivery is calculated as:

Number of responding palliative care agencies that actively collect feedback from patients/consumers and staff (by most common setting of care)
_____

Total number of responding palliative care agencies in scope

Performance indicator 3 investigates whether agencies have routine and active mechanisms for collecting feedback specifically to measure client/staff satisfaction. The term 'client' as used in the survey question includes the patient, and their carer(s), family or friends. Staff may be paid or unpaid individuals who provide the palliative care services.

The active and routine collection of feedback from clients and/or 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 that are implemented through 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.

Purpose

Feedback is an integral aspect of quality improvement, demonstrating that palliative care services are staff oriented and are respectful of and responsive to patients'/consumers' needs. This may include respect for dignity, confidentiality, participation in choices, promptness, quality of amenities, access to social support networks, and choice of provider.

Performance indicator 3 relates to Goals 2 and 3 of the National Palliative Care Strategy. It particularly relates to two objectives under these goals:

> **National Strategy 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.

> **National Strategy 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.

Data results

Survey question 7 asked, 'Does your agency actively and routinely collect feedback relating to services and service delivery from clients and/or staff?'

The survey question differed slightly from the performance indicator endorsed by the PCDWG. At some stage the term 'clients and staff' was misinterpreted to be 'clients and/or

staff'. However, performance indicator 3 was not calculated directly from Question 7 responses but from agencies that listed at least one feedback mechanism each for both survey Questions 8 and 9.

The number of agencies that actively and routinely collected feedback from patients/consumers and staff totalled 128 (71%) (Table 2.10). Five agencies collected feedback from staff only and eight agencies collected feedback from patients/consumers only. These 13 agencies are excluded from the analysis here.

Over two-thirds of agencies in each care setting collected feedback in some form, ranging from 65% in inpatient settings to 75% in community settings. Ideally, feedback would translate into improved service provision, further evaluation and continued monitoring. Only 52 agencies stated that they do not collect any feedback.

Table 2.10: PI 3 agencies, by feedback collection status (clients and staff) and setting of care

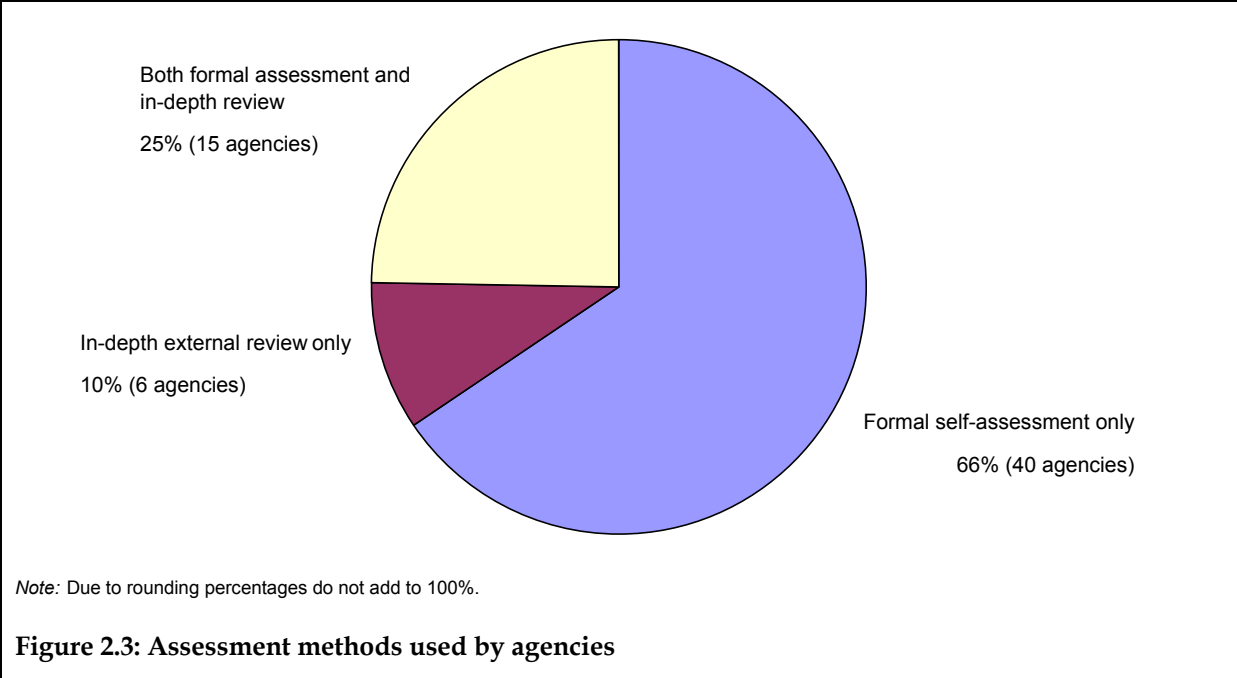| Feedback status	Community setting	Inpatient setting	Similar amount in both settings[a]	Total
		number		
Yes	80	33	15	128
No	27	18	7	52
Total	**107**	**51**	**22**	**180**
		per cent		
Yes	75	65	68	71
No	25	35	32	29
Total	**100**	**100**	**100**	**100**

(a)   Refers to agencies that provide a similar amount of services in the community and inpatient settings.

Data issues

- Those agencies that indicated that they did not collect feedback may collect feedback but not on an active or routine basis.
- Some respondents reported that the meaning of the term 'actively and routinely' was unclear or subjective and that more information should be added to the guidelines for clarification.

Additional information

To investigate agencies' different methods of collecting feedback (from either clients or staff), two additional questions were included in the survey.

Data Results

Survey question 8 asked, 'Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from clients?'

Survey question 9 asked, 'Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from staff?'

The types of mechanisms used by palliative care agencies that collected feedback from clients are presented in Table 2.11.

Table 2.11: Agencies, by mechanisms employed to collect feedback from clients and settings of care

Feedback method	Community setting	Inpatient setting	Similar amount in both settings[a]	Total
Questionnaire—periodic face-to-face interview	23	9	6	38
Questionnaire—face-to-face interview upon exit	11	4	2	17
Questionnaire—telephone	11	3	5	19
Questionnaire—other	58	25	9	92
Feedback focus group	18	3	5	26
Other	22	7	4	33
Total number of agencies[b]	**80**	**33**	**15**	**128**

(a)   Refers to agencies that provide a similar amount of services in the community and inpatient settings.
(b)   As more than one answer can be selected in this question/category for each agency, the 'Total number of agencies' is not the sum of the columns.

The use of questionnaires was the predominant mechanism for collecting feedback from clients. A total of 92 agencies reported using 'Questionnaire—other' and this was consistent for agencies regardless of their most common setting of care. Of these agencies, many identified postal questionnaires as a common method of collecting feedback from clients.

Over half (66) of the 128 agencies collecting feedback used only one feedback method, while 37 agencies used two feedback mechanisms to collect feedback from clients.

The different types of mechanisms employed by palliative care agencies to collect feedback from staff are presented in Table 2.12.

Table 2.12: Agencies, by mechanisms employed to collect feedback from staff and settings of care

Feedback method	Community setting	Inpatient setting	Similar amount in both settings[a]	Total
Questionnaire—periodic face-to-face interview	29	9	5	43
Questionnaire—face-to-face interview upon exit	28	8	9	45
Questionnaire—telephone	3			3
Questionnaire—other	41	18	7	66
Feedback focus group	25	9	8	42
Other	35	14	5	54
Total number of agencies[b]	**80**	**33**	**15**	**128**

(a)   Refers to agencies that provide a similar amount of services in the community and inpatient settings.
(b)   As more than one answer can be selected in this question/category for each agency, the 'Total number of agencies' is not the sum of the columns.

The least common method of collecting feedback from staff was telephone questionnaires (three agencies). Those agencies that selected 'Other' (54) identified team meetings as a common method of collecting staff feedback.

Just under half (52) of the agencies used only one feedback method; with 67 agencies used two or three feedback mechanisms to collect feedback from staff.

Figure 2.4 presents a comparison of the feedback mechanisms used for collection of feedback from clients and staff.
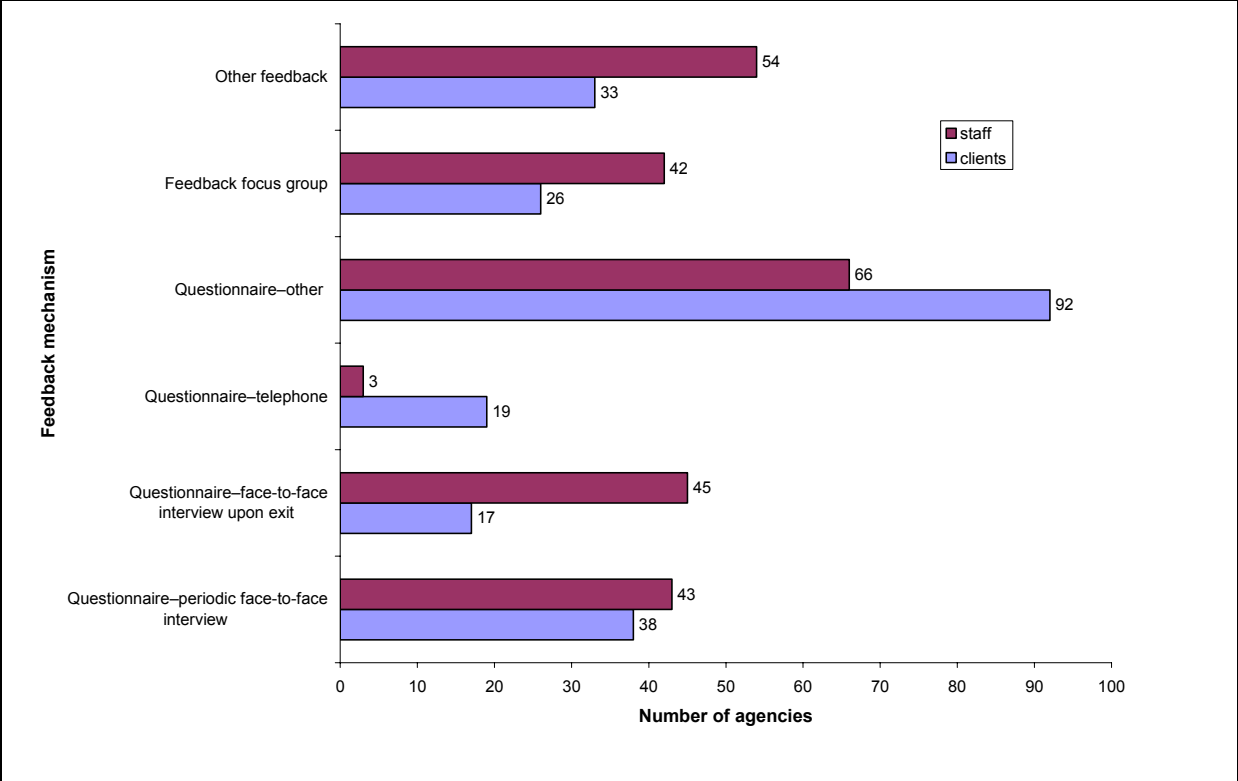
Figure 2.4: Feedback mechanisms used for clients and staff

Data issues

- Some respondents recorded information in the text boxes available for option 6, 'Other', in questions 8 and 9 to record information about option 4, 'Questionnaire—other.' This information was collected but not reported; changes to the survey form are suggested in Section 5.2.1 to avoid incorrect entries in future collections.
- The high rates of 'Questionnaire—other' and 'Other' suggest a new code set value (for example, written postal surveys) should be added for future collections.

2.3.5 Performance indicator 4

Description

The proportion of palliative care agencies, within their setting of care, that have formal working partnerships with other service provider(s) or organisation(s) is calculated as:.

Number of responding palliative agencies with formal working partnerships
(by most common setting of care)

_____

Total number of responding palliative care agencies in scope

Performance indicator 4 captures whether formal partnerships are in place between agencies and other service providers or organisations. The National Palliative Care Strategy identifies partnership as collaboration between service providers to '…enable people to move smoothly between services and service settings to meet their clinical and social needs' (DoHA 2000: 21). The use of the term 'formal' was used to differentiate between ad hoc and formal working partnerships. A formal working partnership may involve any of the following arrangements: written service agreements; formal liaison, referral and discharge planning processes; formal and routine consultations; protocols; partnership working groups; and memoranda of understanding with other providers. The nature of formal working partnerships should be organised, routine, collaborative and systematic. Case conferencing is included if these elements are in place.

Purpose

Performance indicator 4 investigates the ability of palliative care agencies to provide integrated, seamless, coordinated care or service across programs, practitioners and organisations, so that clients are able to move smoothly between services and service settings. Establishing linkages to a range of palliative care services that clients can access when and where they are required facilitates continuity of care. Models of service partnerships encompass administrative arrangements; links with rural health networks; coordination of information and services that are accessible to clients, health providers and the community; and the provision of specialist palliative care consultancy support. Formalised networks/linkages of palliative care agencies promote access for patients to a wider range of interrelated components of the health care system, such as referrals and consultations, enabling more effective and appropriate delivery of services by agencies.

Performance indicator 4 provides an indication of the extent to which goal 3 of the National Palliative Care Strategy has been achieved. It specifically relates to the service partnerships objective under this goal:

> **National Strategy 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.

Data results

Survey question 10 asked, 'Do you have formal working partnership(s) with other service provider(s) or organisation(s)?'

Table 2.13 shows that a very high proportions (96%) of agencies had formal working relationships with other service provider(s) or organisation(s).

In all three common settings of care nearly all agencies had formal partnership arrangements. The proportion by common care setting ranged from 95% in both the community and inpatient settings to 100% for those agencies providing a similar amount of services in both settings.

The prevalence of partnership networks by agencies implies good coordination between different settings of care and is consistent with an emphasis by agencies on providing integrated care.

Table 2.13: PI 4 agencies by formal partnership status and setting of care

Partnership status	Community setting	Inpatient setting	Similar amount in both settings[a]	Total
	number			
Yes	102	49	22	173
No	5	2	0	7
Total	**107**	**51**	**22**	**180**
	per cent			
Yes	95	96	100	96
No	5	4	0	4
Total	**100**	**100**	**100**	**100**

(a)   Refers to agencies that provide a similar amount of services in the community and inpatient settings.

Data Issues

- The term 'formal working partnership' caused some confusion because some users were not sure whether it applied to the palliative care service or their health organisation as a whole. In future Agency Collections this will need to be specified.

- Some respondents were not clear on which types of organisations were acceptable in relation to this question. While the types of organisations were listed in the guidelines for question 11, they were not specifically mentioned in the guidelines for Question 10. This list will be added to the guidelines for question 10 in future Agency Collections.

Additional information

A question was included in the survey to expand on information related to performance indicator 4. The additional question detailed the specific types of organisations with which palliative care agencies may have formal working partnerships.

Data results

Survey question 11 asked, 'With which type(s) of organisation(s) does your agency have formal working partnership(s) in place?'

The types of organisations with which palliative care agencies had formal working partnerships are outlined in Table 2.14.

The most common types of organisations in a formal working partnership with palliative care agencies were hospitals and other palliative care services (134 agencies each) (Figure 2.5). Of the 39 palliative care agencies that stated they had formal working partnerships with organisations other than those listed, partnerships with volunteer services, volunteer coordinators and volunteers were the most common (seven agencies).

Table 2.14: Agencies by formal partnership status and setting of care

Partner organisations	Community setting	Inpatient setting	Similar amount in both settings[a]	Total
Palliative care services	78	40	16	134
Hospitals	83	34	17	134
Community nursing agencies	59	39	20	118
Residential aged care facilities	39	12	11	62
Allied health services	52	17	13	82
Aboriginal health services	25	7	9	41
Medical practices	69	22	15	106
Integrated health centres	15	5	6	26
University/research centres	25	23	8	56
Other	26	7	6	39
Total number of agencies[b]	**102**	**49**	**22**	**173**

(a)   Refers to agencies that provide a similar amount of services in the community and inpatient settings.
(b)   As more than one answer can be selected in this question/category for each agency, the 'Total number of agencies' is not the sum of the columns.
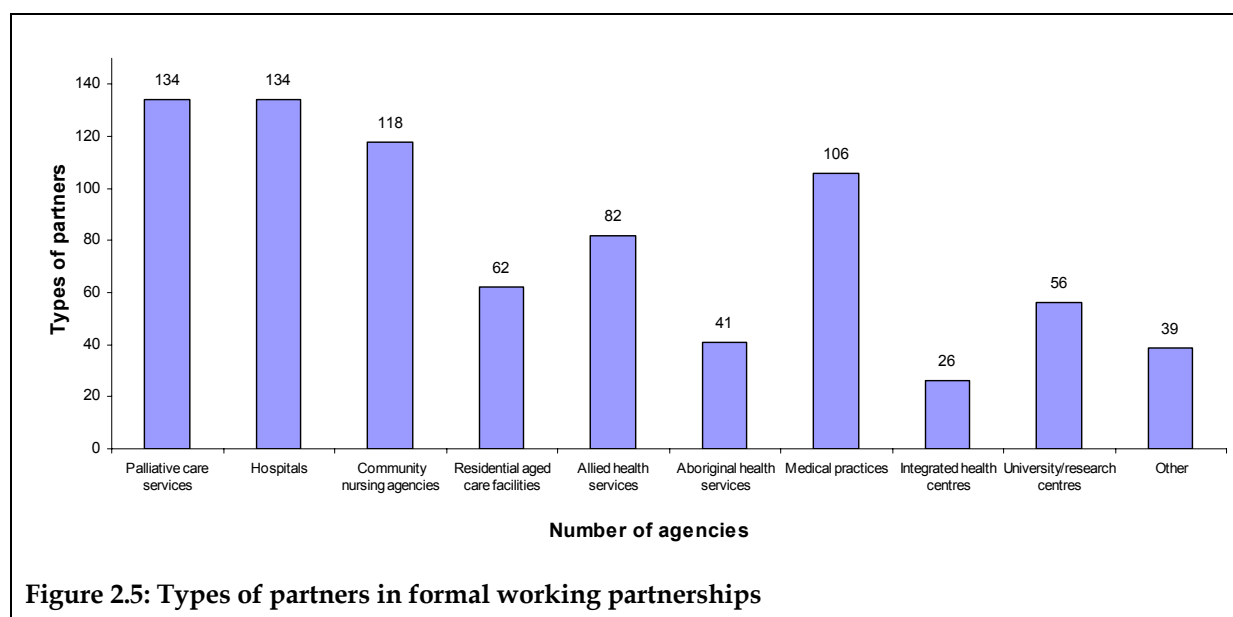
Figure 2.5: Types of partners in formal working partnerships

Data issues

No data issues were identified for this question.

3 Supplementary survey questions

Three supplementary questions (questions 14, 15 and 16) were included in the agency survey to investigate the hierarchical levels of agencies within state and territory health service delivery models. These questions collected data on sub-contracting arrangements between agencies. They were included to help provide information that would indicate the level of reporting for the agencies participating in the Agency Collection, and were developed to identify any differences related to reporting structures that may exist nationally.

Before the survey was conducted, it appeared that in some areas, particularly some rural areas, only the 'higher level' agencies were identified to participate in the collection—that is, agencies that sub-contract, but not those that were the sub-contractors. In other rural areas, however, both types of agencies seemed to be included.

These supplementary questions were also designed to expose any possible overlap between participating agencies. For example, a larger agency may sub-contract a smaller agency that was already included in the collection. This is in itself not an issue; however, if the larger agency answered the questions in the survey on behalf of the sub-contracted agency, and the latter also returned a completed survey form, the results would be duplicated.

Differences such as these affect the scope of the collection and the denominator used in the calculation of the performance indicators. The responses to questions 14, 15 and 16 have therefore provided important information that will assist with future performance indicator collections.

The results that follow are for all agencies that returned a response—that is, not just those agencies deemed in scope following analysis of question 6 (whether the agency employs a palliative care practitioner). All agency responses were included because the focus of these questions was to investigate the way palliative care services are provided and the levels of reporting for the agencies participating in the Agency Collection, not just those in scope.

3.1 Sub-contracting another agency

A question on sub-contracting was included to gain an understanding of agencies that contracted out or brokered others to provide palliative care to their clients. It provided a top-down hierarchical overview of agencies, and organisations sub-contracted by those agencies, delivering palliative care services at the state and territory level.

Sometimes agencies contracted out or brokered the assistance required by their clients to other service providers. An agency may or may not directly provide palliative care services to clients but is responsible for the services' provision, whether directly, administratively or via allocation of funds.

Data results

Survey question 14 asked, 'Does your agency sub-contract (an)other agency(ies) to provide services to palliative care clients?'

Table 3.1: Agencies that sub-contract to others

Sub-contracting to others status	Number of agencies	Proportion of agencies (%)[a]
Yes	72	32
No	154	68
Total	**226**	**100**

(a) The denominator includes all agencies that returned a response—that is, not just those agencies deemed in scope following analysis of question 6.

- Seventy-two agencies, or 32% of all agencies that responded, reported that they contracted out or brokered services to a variety of organisations including other palliative care agencies and generalist nursing agencies within their own jurisdictions.

- Contracting out or brokering of services to other agencies/organisations varied considerably across the states and territories but was consistent within jurisdictions. For example, Queensland reported that a number of hospitals classified as palliative care agencies sub-contracted their palliative care services to Blue Care. This included domiciliary nursing agencies considered to be palliative care agencies according to the collection's definition and more 'generalist' (or 'primary care') domiciliary nursing agencies. Victoria, on the other hand, reported that most sub-contracting arrangements were with other types of organisations that are not classified as palliative care agencies.

Data issues

- Feedback from some agencies indicated that they had difficulty understanding and answering this question due to the term 'sub-contracting' not being defined.

3.2 Answering on behalf of the sub-contracted agency(ies)

Another question was included to expose any issues with double-counting of agency responses. It provided a mechanism to cross-check sub-contracting agencies with the agency(ies) they sub-contracted (where they could be matched) to determine if more than one response had been provided for an agency.

An agency could have answered questions on behalf of the agencies they sub-contracted. Where this occurred and the sub-contracted agency also responded, this resulted in inaccurate reporting because responses for a palliative care agency were counted twice.

Data results

Survey question 15. 'Did you answer the questions in this palliative care agency collection on behalf of the sub-contracted agency(ies)?'

Table 3.2: Agencies that answered the survey on behalf of sub-contracted agencies

Answered survey on behalf of sub-contracted agencies	Number of agencies	Proportion of agencies (%) [a]
Yes	20	9
No	52	23
Not applicable [b]	154	68
Total	**226**	**100**

(a)   The denominator includes all agencies that returned a response—that is, not just those agencies deemed in scope following analysis of question 6.

(b)   Agencies that answered 'no' to Question 14 were not required to respond to question 15.

- Twenty agencies (9%) answered on behalf of sub-contracted agencies/organisations. Of these, five reported on behalf of six other agencies included in the survey and 11 reported on behalf of other types of organisations.

- Five of the sub-contracted agencies provided survey responses in addition to the agencies that reported on their behalf. One of these responses was excluded from the agency collection due to the criterion for a palliative care practitioner being applied.

- There were 102 agencies (45%) that reported that they did not answer on behalf of sub-contracted agencies/organisations. Of these, 52 responses were correctly recorded since these agencies answered 'yes' to question 14 and were required to provide this information; 50 responses were incorrectly reported since these agencies answered 'no' to question 14 and were not required to respond to question 15.

- There were 104 agencies that did not complete this question. This was a correct response since these agencies reported 'no' to question 14 and were not required to respond to question 15.

Data issues

The total non-responses to this question should have been 154, not 104. Fifty agencies completed the question even though they had indicated by their response of 'no' to question 14 that they did not sub-contract agencies/organisations. This may have been the result of users misinterpreting or incorrectly reading the follow-on instructions for question 14 on the survey form.

3.3 Providing palliative care on behalf of another agency

An agency or organisation may be contracted or brokered to provide palliative care services on behalf of another agency. This question was designed to assist with gaining an understanding of agencies contracted or brokered to provide palliative care to clients on behalf of another agency/organisation. It provided a bottom-up hierarchical overview of agencies/organisations sub-contracted by other agencies to deliver palliative care services.

Information collected was used to cross-check the contracting/brokerage arrangements identified by agencies in Question 14.

Data results

Survey question 16 asked, 'Is your agency ever responsible for providing palliative care to clients on behalf of another agency/organisation, for example through a sub-contracting arrangement?'

Table 3.3: Agencies sub-contracted by another agency

Sub-contracted by another agency status	Number of agencies	Proportion of agencies (%)[a]
Yes	58	26
No	168	74
Total	**226**	**100**

(a)   The denominator includes all agencies that returned a response—that is, not just those agencies deemed in scope following analysis of question 6.

- Just over a quarter of agencies (26%) reported that they were sub-contracted by other agencies/organisations to provide palliative care services. Most of these arrangements involved agencies providing direct care to clients on behalf of agencies/organisations at a higher level within the health service delivery models of each jurisdiction. Examples reported included sub-contracting arrangements on behalf of the Department of Veterans' Affairs and major regional hospitals.

- There were 168 agencies (74%) not sub-contracted by other agencies or organisations to provide palliative care services.

Data issues

In most cases it was not possible to cross-reference sub-contracting agencies identified in this question to agencies reporting they sub-contracted other agencies to provide palliative care services (question 14). Names of agencies/organisations could not be matched with confidence because most sub-contracted agencies used general statements when nominating who sub-contracted them (for example, 'state hospitals', 'region health service'). If this question were to be used in future collections, the agency sub-contracting the work would need to be named.

4 Feedback results

A feedback form developed by the AIHW was provided to all agencies participating in the Agency Collection. While completion of the form was optional, all participating agencies were encouraged to submit a completed form. The aim of the form was to collect general information about the collection and specific feedback on whether participants had difficulty understanding or answering each question. Appendix 4 presents a copy of the feedback form.

Out-of-scope agencies are included for the purposes of reporting respondents' feedback. A total of 207 completed feedback forms were received from the 226 agencies that participated in the Agency Collection.

4.1 General feedback

Appendix 5 summarises general feedback and comments provided by respondents.

The main recurring themes can be categorised as:

- user-friendliness of the electronic survey form
- usefulness of the guidelines document.

A few respondents questioned the relevance or benefit of the collection and commented on the short amount of time available to complete the survey form by the due date.

4.1.1 User-friendliness of the electronic survey form

The majority of those who completed the survey using the electronic survey form found the form easy to complete. Respondents made comments such as:

- '[The] electronic collection form very easy to complete. Boxes dropped down, selection was easy and tick boxes worked as anticipated.'
- 'It was very easy to complete. Also the Guidelines made it very clear.'

Difficulties experienced by respondents included having problems accessing the drop-down menus and difficulties saving the form.

A small number of respondents reported frustration because of difficulties accessing forms on the disks provided.

4.1.2 Usefulness of the guidelines document

Many respondents reported that the guidelines document accompanying the Agency Collection was helpful and well set out. A number of respondents who reported having difficulties understanding or answering the questions commented that the guidelines document provided the information they needed to resolve their issues.

4.2 Feedback on specific questions

The feedback form asked participants to comment on two separate aspects for each question presented on the Agency Collection survey form. Participants were asked to first comment on whether they had difficulty understanding the question or the corresponding guidelines for the question. Second, they were asked to comment on whether they had difficulty answering the question.

Table 4 summarises the feedback about the questions on the survey form.

Table 4.1: Summary of respondent feedback

Question	Respondents who had difficulty understanding the question and corresponding guidelines		Respondents who had difficulty answering the question	
	Number	%	Number	%
1. Agency ID	12	6	13	6
2. Agency name	3	1	3	1
3. Agency state/territory	0	0	1	0
4. During the past 12 months, in which setting(s) did your agency deliver palliative care services?	3	1	3	1
5. During the past 12 months, in which setting(s) nominated in Q4, did your agency most commonly deliver palliative care services?	10	5	10	5
6. Does your agency employ at least one staff member who is a palliative care practitioner?	15	7	10	5
7. Does your agency actively and routinely collect feedback relating to service delivery from clients and/or staff?	7	3	5	2
8. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from clients?	6	3	6	3
9. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from staff?	6	3	6	3
10. Do you have formal working partnership(s) with other service provider(s) or organisation(s)?	19	9	11	5
11. With which type(s) of organisation(s) does your agency have formal working partnership(s) in place?	10	5	9	4
12. Does your agency routinely undertake or undergo formal assessment against the Palliative Care Australia Standards?	8	4	16	8
13. What method(s) is used to assess your agency against the Palliative Care Australia Standards?	3	1	4	2
14. Does your agency sub-contract (an)other agency(ies) to provide services to palliative care clients?	11	5	11	5
15. Did you answer to the questions in this palliative care agency collection on behalf of the sub-contracted agency(ies)?	7	3	8	4
16. Is your agency ever responsible for providing palliative care to clients on behalf of another agency/organisation, for example through a sub-contracting arrangement?	9	4	13	6

4.2.1 Agency identifier

Twelve agencies reported difficulty in understanding and completing the agency ID question. This was mainly due to respondents not knowing where to find their agency ID. Most of these issues were addressed easily by the respondents either referring to the guidelines document or contacting the Agency Collection helpline or their returning officer.

4.2.2 Minimum one palliative care practitioner

Over 90% of respondents reported no difficulty with this question. Of the 7% of respondents who reported difficulty understanding it and the corresponding guidelines, the difficulty was attributed to the fact that they felt the term 'palliative care practitioner' was not defined in sufficient detail.

The guidelines document stated, 'palliative care practitioners include medical practitioners, clinical nurse specialists/consultants and allied health staff, who have skills and experience in palliative care and who have successfully completed recognised professional training in palliative care.'

One respondent commented on the lack of guidelines related to total hours worked and/or full-time equivalency of staff.

4.2.3 Formal working partnerships

Feedback suggests that respondents had more difficulty answering this question than any other (9% of all respondents).

Even though the guidelines provided a fairly detailed description, respondents commented that they had difficulty understanding the question and that the term 'formal working partnership' needed to be further defined.

The guidelines for this question were as follows:

> Elements of a formal working partnership are that it is organised, routine, collaborative and systematic. Case conferencing is included if these elements are in place. It excludes ad hoc arrangements.

> A formal working partnership may involve any of the following arrangements: written service agreement, formal liaison, partnership working group, and memorandum of understanding with other providers.

> 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.

One respondent commented that, despite the fact that they had difficulty understanding the question, the guidelines document provided satisfactory help to resolve their issue.

Some respondents also commented that they were not sure whether this question related to the palliative care service or their health organisation as a whole and whether formal working partnerships could be with any type of organisation or with palliative care services alone.

4.2.4 Assessment against Palliative Care Australia Standards

Less than 5% of respondents reported that they experienced difficulty understanding this question and the corresponding guidelines. There was, however, a slightly higher percentage of respondents (8%) who reported they had difficulty answering this question.

Respondents commented that the term 'routine' was subjective and was not defined in the guidelines.

4.2.5 Sub-contracting other agencies

Approximately 5% of respondents reported that they had difficulty understanding this question and the corresponding guidelines. Respondents commented that they had difficulty understanding the term 'sub-contracting'.

4.2.6 Provision of services on behalf of another agency/organisation

Seven respondents reported that they had trouble answering this question because a definition of the term 'sub-contracting' was not provided in the guidelines document.

4.3 Looking forward

It should be noted that it was often not possible to ascertain from the feedback provided whether all respondents who experienced difficulties either understanding or answering a particular question consulted the guidelines or the Agency Collection helpline. A number of respondents commented that they did refer to the guidelines document and that the information provided resolved the problems they encountered. However, it is not possible to know whether respondents had difficulties due to insufficient or inadequate resources or whether it was due to respondents not using the resources that were available.

Respondents' feedback has highlighted certain areas of the Agency Collection that require further refinement prior to a future collection. The feedback suggests that while the guidelines document was a very helpful resource, the document could provide more information and guidance on answering particular questions. The information garnered from the feedback has informed a number of the recommendations in Chapter 5.

5 Lessons learnt and future directions

5.1 Future data collections

This project represents a significant step since the release of the National Palliative Care Strategy (DoHA 2000) since it provides important information relating to the implementation of four aspects of the Strategy across the palliative care sector. As a result, the project team suggest that continued reporting against the agreed performance indicators occurs, and that the data obtained through this trial be used as baseline data to monitor changes in implementation over time.

It is recommended that the data collection occur annually, at least while the current Australian Health Care Agreements are in place (currently until 2008), but it could be conducted periodically after this time within the life of the National Palliative Care Strategy. Annual collection of the data, at least in the short term, would enable further testing and refinement of the data definitions and would provide an indication of the rate of change occurring in the palliative care sector. The Palliative Care Data Working Group and the Palliative Care Intergovernmental Forum have supported this recommendation.

This trial has also identified a number of areas where improvements can be made to future PI Collections. Some of these improvements have already been incorporated into the documentation that supports the Strategic Plan and Agency Collections (see Section 5.2.1) because resolution of these issues was required in order to finalise the analysis and reporting of the results of the 2005 trial collection. Other areas for improvement are suggested in Section 5.2.2.

5.2 Recommended modifications to the PI Collection

5.2.1 Agreed changes that have been incorporated in the analysis of the 2005 PI Collection

Improvements that were made following the trial PI Collection are outlined in this section. These minor changes have been made with PCDWG approval and were required in order to finalise the analysis of data from the trial PI Collection. The changes should be incorporated in future collections to ensure consistency.

Strategic Plan Collection changes

Counting issues

The Strategic Plan collection identified that regional reorganisation can occur and that written strategic plans are not immediately updated to reflect new organisational

boundaries. The specifications applying at the time of the Strategic Plan Collection did not take account of this situation. The specifications have since been refined to deal with this and, where necessary, were applied to calculate the results for this trial collection.

Similarly, an underlying assumption was made that only finalised written strategic plans would be considered for the calculation of performance indicator 1. However, there was ambiguity in answering this question for one administrative health region whose written strategic plan had draft status only.

Resulting changes

The guidelines for this question have been updated so that, where a regional reorganisation has taken place, any already existing and current written strategic plans that meet the criteria are counted, providing the newly formed region is fully covered by these plans, and a time limit of one year is applied.

The specifications for performance indicator 1 were also amended to explicitly state that only finalised plans meet the performance indicator 1 standard. For the purposes of this report, the existence of the draft strategic plan is noted, but it was not included in the calculation of performance indicator 1.

Agency Collection changes

Performance indicator 3

Survey question 7 asked, 'Does your agency actively and routinely collect feedback relating to services and service delivery from clients and/or staff?'

This question asked agencies whether they collected feedback from either staff or clients. Following the Agency Collection, the PCDWG advised that the intention of performance indicator 3 was to identify the proportion of agencies collecting feedback from both clients and staff. As a result, in the Agency Collection performance indicator 3 was calculated by using the two related questions in the survey.

Resulting changes

This question has been amended to 'Does your agency actively and routinely collect feedback relating to services and service delivery from clients *and* staff?' to reflect the initial purpose of the performance indicator.

The guidelines have been updated to highlight that only agencies collecting feedback from both clients and staff can respond to this question in the affirmative.

5.2.2 Areas for further development and recommendations for future collections

This section briefly outlines areas that have been identified as requiring further development and puts forward recommendations for consideration by the PCDWG and/or the PCIF before the next iteration of the PI Collection.

Performance indicators

The four national performance indicators did not specify a desired quantitative proportion. This was due to the lack of information available to determine appropriate levels.

Further, the wording format for performance indicator 3 differs slightly from that for performance indicators 2 and 4. Reference to 'patients/consumers' within this performance indicator also makes the wording unclear.

Future directions

It is recommended that the four national performance indicators be refined to include the desired outcome—for example, 'xx% of palliative care agencies within their setting of care routinely undertake or undergo formal assessment against the Palliative Care Australia Standards'. Information resulting from this trial PI Collection can be used to inform the desired outcome.

It is also recommended that the PCIF reword performance indicator 3 to read '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'.

Strategic Plan Collection updates

Survey design

Whilst respondents did not report any difficulties completing the question collecting data for performance indicator 1, the PCDWG has proposed that changes be made to the format of the performance indicator 1 form.

Future directions

The PCDWG recommends that the performance indicator 1 collection form be modified to include checkboxes for each of the six aspects necessary to meet the requirements of a written strategic plan. This is expected to ensure that respondents actively identify whether each aspect exists within the plan.

Agency Collection updates

Scope

After the 2005 trial data collection it became apparent that the definition of 'palliative care agency' that was developed for the collection (see Box 2) was not defined adequately for agencies to be clear about whether they were in the scope of the collection. As outlined in Section 1.2.2, the definition was developed specifically to ensure inclusion of 'generalist' health services that provide a significant amount of palliative care and not just limit the scope to specialist palliative care agencies only. The criterion that an agency must 'employ one or more palliative care practitioners' was included to distinguish between agencies that were in the scope of the collection and those outside of the scope, and this question was separately asked on the data collection form (question 6) as a data quality check. The question did, however, provide some problems for agencies and, given that it was included as a filter question to ensure that all responding agencies were in scope, it highlighted inadequacies in the definition of a palliative care agency developed for this data collection.

Specifically, the question 'Does your agency employ at least one staff member who is a palliative care practitioner?' resulted in comments from respondents that they had difficulties with the question because the definition of 'palliative care practitioner' was not clear. Feedback from respondents highlighted the variations in interpretation of this criterion and the need to include guidelines about full-time equivalency or the hours worked by the palliative care practitioner.

A second problem identified in relation to the scope of the collection was that at least one jurisdiction separately funds two agencies that provide volunteer assistance specifically to palliative care clients. It was recognised by the PCDWG that these agencies should be included in the scope for the Agency Collection but that they do not meet the previously defined criterion of employing one or more palliative care practitioners.

Future directions

At present the PCDWG is considering limiting the scope of future collections to agencies that are funded to provide palliative care under the Australian Health Care Agreements. This will, however, require further discussion with jurisdictions, particularly to ensure that it would continue to capture primary palliative care agencies and to ensure some consistency across jurisdictions. It may also be possible that the role delineation frameworks that are being developed by most jurisdictions will provide a framework to better define the scope of the Agency Collection. In most cases these are based on PCA's service development framework (see further discussion below).

The PCDWG has also agreed that any future definition should ensure that volunteer services that specifically provide assistance to palliative care clients are in scope.

Inclusion of question 6 ('Does your agency employ at least one staff member who is a palliative care practitioner?') is not likely to be required once the scope is redefined; however, if this criterion is retained the question should be asked at the beginning of the survey, and instructions should be provided that a 'no' response to the question puts an agency out of scope and further completion of the survey is not required. This would help reduce the burden on agencies that are deemed out of scope at the time of collection. Agencies would still be asked to submit their survey form so that agency listings can be reconciled.

Similarly, if this question is to be retained some further guidelines are required to better define the term 'palliative care practitioner'. The guidelines for this question could be expanded to include:

- examples of qualifications that a practitioner may hold that determine whether they are a palliative care practitioner for the purposes of the collection
- minimum requirements regarding the number of hours worked or the full-time equivalency of the practitioner.

Additional questions

The PCDWG has recognised that the Agency Collection presents a good opportunity to collect some descriptive-type data on the agencies involved in providing palliative care. It suggests that, prior to any future collections, some consideration be given to including specific questions that could usefully describe palliative care services. These questions might aim to collect information on the types of services provided by the agency, the occupation types of staff employed by the agency, or other aspects of the agency.

The PCDWG has agreed that future Agency Collections should also collect information from each agency on where the agencies are located in the PCA's service development framework (PCA 2005b), which identifies agencies as being either primary palliative care providers or specialist palliative care providers. Specialist palliative care providers are further classified as belonging to levels 1 to 3 which represent increasing levels of resources and specialisation. This information would provide important descriptive information on the palliative care sector in terms of the availability and distribution of palliative care services with differing capacities; it would also greatly assist reporting of the performance indicators and understanding of the results. For example, the low rates of assessment against the PCA Standards (performance indicator 2) may be because a large proportion of responding agencies might have been primary palliative care providers whose substantive work is not in the area of palliative care. For these agencies, it may be appropriate to undertake quality assessments against more general standards.

Another area in which additional questions would prove beneficial relates to performance indicator 2. The results gathered for this indicator were not able to show how often agencies undergo formal assessment and compliance against PCA Standards. Future Agency Collections could investigate this further.

Future directions

Consultation will need to occur to identify questions for inclusion in the survey that would provide valuable information to policy makers or others and/or would assist in the interpretation of the performance indicator results. Future collections should collect information on the level of the agency in the PCA framework and should consider other potentially relevant questions, including the following:

- What is the total number of staff employed by your agency?
- What types of staff are employed by your agency?
- What is the full-time equivalency of/number of hours per week worked by staff employed by your agency?
- Does you agency employ a volunteer coordinator?
- How often does your agency undergo formal assessment/compliance against the PCA Standards?
- When did your agency last undergo formal assessment/compliance against the PCA Standards?

Inclusion of these questions would be dependent on clarifying the purpose of this information and developing adequate supporting definitions and guidelines.

Definition of a formal working partnership

Survey question 10 asked, 'Do you have formal working partnership(s) with other service provider(s) or organisation(s)?'

As reported in Chapter 4, a number of respondents who stated that they had difficulties understanding or answering this question due to insufficient guidelines. The question asked agencies to identify the types of service providers or organisations with which they had formal working partnerships.

Future directions

The guidelines for this question have been amended to:

- further clarify the term 'formal working partnership'
- indicate the types of service providers or organisations with which a formal working partnership may be held.

The new guidelines for this question are as follows:

> A formal working partnership outlines a verbal or written 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.

> 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. These partnerships may be held with, but are not limited to, organisations such as palliative care services, hospitals, allied health services and aboriginal health services. For the purposes of this question, partnerships must be implemented at the palliative care service level.

Client/staff feedback questions

For the questions asking agencies to report on what feedback mechanism(s) they use to obtain feedback from staff and clients (Questions 8 and 9), there were high response rates for the options 'Questionnaire—other' and 'Other'. This suggests that the list of permissible values for types of feedback mechanisms should be expanded.

Future directions

It is recommended that the list of valid options for types of feedback mechanisms used in questions 8 and 9 be expanded to include 'Written postal surveys'.

General form design

Minor changes are recommended to the layout of the survey form, including removal of selected questions.

The final three questions (questions 14 to 16), relating to sub-contracting arrangements, were included in the Agency Collection to gain an understanding of the hierarchical levels at which participating palliative care agencies were placed within a state or territory health service. While the data collected from these questions provided an insight to help further develop future collections, they did not present a complete picture of the information the questions hoped to collect.

Questions 8 and 11 of the Agency Collection survey form required respondents to record a specific answer where the option 'Other' was selected. The manner in which a few respondents answered questions 8 and 11 suggests that the instructions provided were misleading or inadequate.

The responses recorded for questions 10 and 12 determined whether respondents were required to complete the related questions immediately following on from those questions. The manner in which a few respondents completed their survey forms suggests that the instructions given on the survey form were not understood or were inadequate.

Future directions

It is recommended that:

- questions relating to sub-contracting arrangements (questions 14 to16) be excluded from future collections. Removal of these questions will mean that participating agencies are not responding to questions that cannot be used to deduce meaningful and relevant information

- the instructions on the survey form for recording specific answers for an 'Other' response be labelled more clearly. The label should be changed from 'If other, please specify (100 char limit)' to 'If other (*option N only*), please specify (100 character limit)'

- The instructions on the survey form providing directives about which questions require completion be made clearer. The label should be changed from 'If yes, go to QN. If no, go to QN' to 'If *YES*, go to QN. If '*NO*, go to QN.'

Hard-copy form design

A small number of agencies that completed survey forms in hard-copy format suggested that users may experience problems completing questions where valid options for the questions were not listed. An example of this was identified in some responses to question 5, 'During the past 12 months, in which setting(s) nominated in Q4, did your agency most commonly deliver palliative care services?' This question required participants to choose from one of three options. The options were listed in the guidelines document and on the electronic form but not listed individually on the hard-copy survey form.

Future directions

It is recommended that the hard-copy form be redesigned to provide listings of valid options for all questions.

Guidelines

Because it was imperative that survey respondents read the guidelines supplied while completing the survey form, each question on the survey form directed the reader to the appropriate page of the guidelines document. The covering letter provided to agencies and the beginning of the survey form also highlighted that the guidelines should be used when completing the survey.

In spite of this, answers provided by participants in some instances indicate that they may have misinterpreted or not read the guidelines for the question.

Future directions

The importance of reading the guidelines document, both before to and while completing the survey, is to be further highlighted in the covering letter to agencies, at the top of the survey form, and at each question on the survey.

Survey time frame

Feedback provided by some respondents indicated that the time frame allowed for completion of the Agency Collection survey form was too short.

Future directions

It is recommended that for future collections participating agencies be given a four-week time frame to complete the survey form.

It is also recommended that the collection be run at a time when agencies are not participating in other national collections.

Survey methodology

A number of agencies reported that they do not have access to a floppy disk drive on their computers. These agencies suggested the use of CDs or emailing as the method of receiving and/or returning the electronic survey forms. It should be noted, however, that all agencies received hard-copy survey forms and information on how to access the survey forms from the Agency Collection website.

Future directions

At present, it would appear that most agencies do have access to floppy disk drives. In addition to this, there are two methods of completing the survey without accessing the disk provided. It is therefore recommended that future collections continue to be conducted by distributing survey forms on disk and in hard-copy format. The survey forms should continue to be made accessible via the collection website. This ensures that there are a variety of mechanisms by which participants can access and return the survey forms.

Saving completed surveys

Difficulties were experienced by some users in saving the survey and feedback forms on the floppy disks provided. It was later found that the files, when used on certain operating systems, could not be re-saved to the floppy disk.

Future directions

It is recommended that instructions for saving the survey and feedback forms included in the guidelines document contain a troubleshooting section for possible technology problems. This should encompass instructions on saving completed survey forms to a local hard drive and copying to the A: drive, emailing completed survey forms if forms cannot be saved due to disk errors, and printing completed survey forms that cannot be saved.

Feedback

All participants in the Agency Collection were encouraged to complete the feedback form enclosed in the collection pack. This being a trial collection, gaining feedback was essential to help improve possible future collections.

Future directions

It is not necessary that feedback be sought for current questions repeated in future collections, but it is recommended that feedback be sought for any new questions introduced in future collections.

Appendix 1: Administrative health regions

New South Wales (8 health regions)	Victoria (8 health regions)
Metropolitan Northern Sydney/Central Coast South Eastern Sydney/Illawarra Sydney South West Sydney West *Rural* Greater Southern Greater Western Hunter/New England North Coast	*Metropolitan* North Western Metropolitan Eastern Metropolitan Southern Metropolitan *Rural* Barwon South Western Region Gippsland Region Grampians Region Hume Region Loddon Mallee Region
Queensland (3 health regions)	**Western Australia (5 health regions)**
Northern Area Health Service Central Area Health Service Southern Area Health Service	*Metropolitan* North Metropolitan Health Service South Metropolitan Health Service Women's and Children's Health Service *Rural* South West Area Health Service WA Country Health Service
South Australia (11 health regions)	**Tasmania**
Metropolitan Southern Adelaide Health Service Central Northern Adelaide Health Service Children, Youth and Women's Health Service Other *Country* Eyre Hills, Mallee, Southern South East Mid North Northern & Far Western Riverland Wakefield	Tasmania constitutes one region
Australian Capital Territory	**Northern Territory**
The ACT constitutes one region	The NT constitutes one region

Appendix 2: Regional strategic plan survey form

The following text and table were sent to each state and territory health department for completion.

National palliative care performance indicator 1

August/September 2005

This document provides information and a tool for state/territory health authorities for the purpose of reporting National Palliative Care Performance Indicator one. Together with three other performance indicators, this indicator was endorsed by the PCIF in 2003, and re-endorsed in August 2005 following small amendments to the wording. The indicator reads:

> **'The proportion of administrative health regions that have a written plan for palliative care which incorporates palliative care elements.'**

Collection process and timeline:

5 September – 7 October	State/territory health departments collect and assess the strategic plan(s) from the agreed administrative health regions in their state/territory. Note that in Tasmania, the ACT and the NT only one plan is required. It is suggested that assessment is carried out by two to three departmental staff, including the PCIF-member.
7 October	Due date for sending the results to the AIHW (by email).

Definitions:

Administrative health region: 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.

Written strategic plan[2] which incorporates palliative care elements: a regional plan, or an aggregation of the region's sub-units' plans. The plan may be specifically for palliative care or a general health service plan that includes palliative care elements.

---

[2] 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 & involve; assist benchmarking & performance monitoring; stimulate change and become a building block for the next plan.

Important further guidelines

The palliative care elements in the plan <u>must</u> include all of the following aspects:

- 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, utilisation, 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.

Name of state: STATE

Name of person completing this form: …

Contact phone number: …

Date completed: ../../2005

Please indicate below whether the region has a written plan for palliative care which incorporates palliative care elements and which is according to the definitions provided.

Meaning of the possible answers:

Yes: the administrative health region has a written strategic plan which incorporates palliative care elements, and which includes all compulsory strategic plan aspects.

No: the administrative health region does not have a written strategic plan which incorporates palliative care elements, or the region has a plan with only partial coverage of the compulsory strategic plan aspects.

Please complete this table:

Administrative health region	Yes/No please cross	Title of plan (where one exists)
	Yes [ ] No [ ]	

THANK YOU FOR COMPLETING THIS FORM

Appendix 3: Agency survey form

Australian Government
Australian Institute of
Health and Welfare

Trial National Palliative Care Agency Data Collection

IMPORTANT:
* This form is to be completed, **in conjunction with the Guidelines document**, by a member of staff with a good knowledge of agency policy and procedure.
* **Return by** the 23rd September 2005.
* **Return to** your state/territory department Returning Officer. See pages 8 and 9 of the guidelines document.
* To **Save** this file follow the instructions provided in the guidelines document on page 7.

Agency Details

1. Agency identifier
Supplied by the AIHW
For instructions go to page 10 of the guidelines

2. Agency name
For instructions go to page 10 of the guidelines

3. State or territory
Select one code only
For instructions go to page 10 of the guidelines

Other territories includes Cocos (Keeling) Islands, Christmas Island and Jervis Bay Territory

4. During the past 12 months, in which setting(s) did your agency deliver palliative care services?

Tick as many checkboxes as applicable
For instructions go to page 11 of the guidelines

☐ 1 Private residence

☐ 2 Residential - aged care setting

☐ 3 Residential - other setting

☐ 4 Non-residential setting

☐ 5 Inpatient - designated palliative care unit

☐ 6 Inpatient - other than a designated palliative care unit

☐ 7 Outpatient - in a hospital/hospice

5. During the past 12 months, in which setting(s) nominated in Q4, did your agency most *commonly* deliver palliative care services?
Select one code only
For instructions go to page 11 of the guidelines

* Community-based settings include private residences, residential aged care, other residential settings, non-residential settings and outpatient settings.

6. Does your agency employ at least one staff member who is a palliative care practitioner?
Select one code only
For instructions go to page 12 of the guidelines

Feedback Collection

7. Does your agency actively and routinely collect feedback relating to services and service delivery from clients and/or staff?
Select one code only   *If yes, go to Q8. If no, go to Q10*
For instructions go to page 13 of the guidelines

8. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from clients?

Tick as many checkboxes as applicable
For instructions go to page 13 of the guidelines

☐ 1 Questionnaire - periodic face-to-face interview

☐ 2 Questionnaire - face-to-face interview upon exit

☐ 3 Questionnaire - telephone

☐ 4 Questionnaire - other

☐ 5 Feedback focus group

☐ 6 Other

☐ 7 Not applicable

If other, please specify (100 char limit)

54

9. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from staff?

Tick as many checkboxes as applicable
For instructions go to page 14 of the guidelines

☐ 1 Questionnaire - periodic face-to-face interview

☐ 2 Questionnaire - face-to-face interview upon exit

☐ 3 Questionnaire - telephone

☐ 4 Questionnaire - other

☐ 5 Feedback focus group

☐ 6 Other

☐ 7 Not applicable

If other, please specify (100 char limit)

Partnerships

10. Do you have formal working partnership(s) with other service provider(s) or organisation(s)?

Select one code only
For instructions go to page 15 of the guidelines

[   ]   *If yes, go to Q11. If no, go to Q12*

11. With which type(s) of organisation(s) does your agency have formal working partnership(s) in place?

Tick as many checkboxes as applicable
For instructions go to page 16 of the guidelines

☐ 1 Palliative care services

☐ 2 Hospitals

☐ 3 Community nursing agencies

☐ 4 Residential aged care facilities

☐ 5 Allied health services

☐ 6 Aboriginal health services

☐ 7 Medical practices

☐ 8 Integrated health centres

☐ 9 Universities/research centres

☐ 10 Other

If other, please specify (100 char limit)

Palliative Care Australia Standards

12. Does your agency routinely undertake or undergo formal assessment against the Palliative Care Australia standards?

Select one code only   [   ]   *If yes, go to Q13. If no. go to Q14*
For instructions go to page 17 of the guidelines

13. What method(s) is used to assess your agency against the Palliative Care Australia standards?

Tick as many checkboxes as applicable
For instructions go to page 18 of the guidelines

☐ 1 Formal self-assessment

☐ 2 In-depth external review

Subcontracting Arrangements

This information is being collected to gain insight into the subcontracting arrangements that are in place between organisations that provide palliative care.

14. Does your agency subcontract (an)other agency(ies) to provide services to palliative care clients?

Select one code only   [   ]   *If yes, go to Q15. If no, go to Q16*
For instructions go to page 18 of the guidelines

15. Did you answer the questions in this palliative care agency collection on behalf of the subcontracted agency(ies)?

Select one code only   [   ]
For instructions go to page 19 of the guidelines

16. Is your agency ever responsible for providing palliative care to clients on behalf of another agency/organisation, for example through a subcontracting arrangement?

Select one code only   [   ]
For instructions go to page 19 of the guidelines

Thank you for completing this form. Please go to the Feedback form.

Appendix 4: Agency feedback form

This feedback form provides your agency with an opportunity to comment on the Palliative Care Agency Trial Data Collection.

Please take some time to complete this form, and return it, together with the completed MS Excel worksheet to your state/territory health department.

AGENCY NAME	
AGENCY IDENTIFIER	

Name and contact number of Agency staff completing this form	

1.   Did your agency have any difficulty opening the MS Excel Collection form?

....

....

2.   Did your agency find the electronic collection form easy to complete? e.g. tick boxes easy to fill, drop down menu options easily selected

....

....

3.   Did your agency access the collection help line or the collection help website? If so, did you receive the help you required?

....

....

4.   Palliative Care Agency Collection questions

4.1   The following table lists the questions that formed the Palliative Care Agency Trial Data Collection. For each question, outline whether you had difficulties understanding the question, the guidelines to the question, and answering the question. If your agency's response is *Yes* to any of these questions, please provide further explanation in the space provided.

Agency details		
	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	**Did you have any difficulty <u>answering</u> this question?**
1. Agency identifier	YES/NO	YES/NO ....
2. Agency name	YES/NO	YES/NO ....
3. Agency state/territory	YES/NO	YES/NO ....
4. During the past 12 months, in which setting(s) did your agency deliver palliative care services?	YES/NO	YES/NO ....
5. During the past 12 months, in which setting(s) nominated in Q4, did your agency most *commonly* deliver palliative care services?	YES/NO	YES/NO ....
6. Does your agency employ at least one staff member who is a palliative care practitioner?	YES/NO	YES/NO ....

Feedback collection		
	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	**Did you have any difficulty <u>answering</u> this question?**
7. Does your agency actively and routinely collect feedback relating to services and service delivery from clients and/or staff?	YES/NO	YES/NO ....
8. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from clients?	YES/NO	YES/NO ....
9. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from staff?	YES/NO	YES/NO ....

Partnerships		
	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	**Did you have any difficulty <u>answering</u> this question?**
10. Do you have <u>formal</u> working partnerships with other service provider(s) or organisation(s)?	YES/NO	YES/NO ....
11. With which type(s) of organisations does your agency have formal working partnerships in place?	YES/NO	YES/NO ....
Palliative Care Australia Standards		
	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	**Did you have any difficulty <u>answering</u> this question?**
12. Does your agency routinely undertake or undergo formal assessment against the Palliative Care Australia Standards?	YES/NO	YES/NO ....
13. What method(s) is used to assess your agency against the Palliative Care Australia Standards?	YES/NO	YES/NO ....
Subcontracting Arrangements		
	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	**Did you have any difficulty <u>answering</u> this question?**
14. Does your agency subcontract (an)other agency(ies) to provide services to palliative care clients?	YES/NO	YES/NO ....
15. Did you answer the questions in this palliative care agency collection on behalf of the subcontracted agency(ies)?	YES/NO	YES/NO ....
16. Is your agency ever responsible for providing palliative care to clients on behalf of another agency/organisation, for example through a subcontracting arrangement?	YES/NO	YES/NO ....

5. **General comments on the Palliative Care Agency Collection**

....

....

....

....

6. **If you answered yes to question 14 of the collection, please provide the name(s) of the agencies with which you have this arrangement.**

....

....

....

....

7. **If you answered yes to question 16, please provide the name(s) of the agencies with which you have this arrangement.**

....

....

....

....

The suggestions and comments made by your agency are invaluable and much appreciated.

THANK YOU!

Appendix 5: Summary of general respondent feedback

Following is a selection of comments received from agencies that completed the survey feedback form:

Prefer hard copy surveys, too much reading, not enough time, is this useful, I'm sure you can't get a proper picture with these questions.

Clear concise guidelines.

Easy to use. Doesn't take too much time to complete.

Very easy forms to understand and complete.

Easy to follow, easy to do. Need to reduce some of the space made available for the answers.

Found guidelines to be useful in completing the survey.

Easy to follow, easy to do. Perhaps need to reduce some of the space made available for the answers.

This has been challenging due to area health services amalgamating which may suggest that data may be incomplete or inconsistent.

It took more time to complete this evaluation than the actual questionnaire.

Disk was fine until it wouldn't be saved. Therefore sent in paper form. Honestly don't have time to look up websites to clarify why disk isn't working.

I found the form relatively easy to complete with good explanations in the guidelines.

Easy to follow instructions and complete. Unfortunately disk did not accept changes (i.e. saving). The questionnaire does not leave room to expand on the situation existing at the Royal North Shore Hospital.

It is exceptionally painful to have to do this on the computer and written form!!! Disk would not allow me to save the data I had entered!!

Please don't make this so difficult—we are all busy with our clinical loads and don't have time or the enthusiasm to mess around with dodgy disks! An information collation is so important for palliative care but no one will do it if it is not well thought out.

After completing the data required on the disk it would not save as the diskette was full! On Excel and had not even started the feedback form. Certainly took MORE than 5 minutes. At least 2 hrs on the computer.

The document was very easy to complete. User friendly and with the provision of a variety of ways to return the form it caters to everyone needs. Guidelines were thorough to ensure you understood question. Clearly demonstrated what was acceptable to meet the questions standard. E.g. formal agreement was well defined to ensure the reader could be certain if their agreements met the Data standards.

Easy to do other than opening Excel file then saving to email off—hence mailed off.

Was fairly simple to complete, particularly if I can do it electronically. It would have taken me 10 minutes if I had done it freehand, it's taken me two hours to get to this stage!

Seems pretty straight forward. Size and length of the instruction booklet is a bit daunting.

The survey was clear and user friendly. Definitions and terminology of phrases would eliminate ambiguity regarding 'palliative care practitioner'.

I found the Data Collection format to be user friendly on the whole.

Improved awareness of the need to be assessed against the Palliative Care Standards.

Easy and quick. Guidelines reference book very handy. Just a comment re floppy disks—not all computers have A: drives anymore (mine did but not all do).

Very easy to follow and did not take a lot of time.

Too short a time frame between receipt of form and required return.

Timeframe very short for completion. Floppy disk 'full' unable to accept data. Excel programme seemed to deliver the 'drop down' facility to some questions.

It arrived quite close to the deadline. When relying on internal mail etc. things can get quite held up. Nevertheless I was still late sending it back due to my own actions.

Information booklet was helpful. Timeframes to complete short and no significant pre notification.

Superb form. [What is] point of exercise, given there is no differentiation between specialist palliative care services and primary care palliative care services it will be hard to make any meaningful conclusions on this data. Would be happy to discuss creation of survey relevant to actual service provision models and resourcing.

Appendix 6: Palliative Care Australia Standards

Following is a summary of the current standards for palliative care as defined by Palliative Care Australia (PCA 2005a):

Standard 1: Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, their caregiver's and family's needs and wishes are acknowledged and guide decision-making and care planning.

Standard 2: The holistic needs of the patient, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.

Standard 3: Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

Standard 4: Care is coordinated to minimise the burden on patient, their caregiver/s and family.

Standard 5: The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.

Standard 6: The unique needs of dying patients are considered, their comfort maximized and their dignity preserved.

Standard 7: The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

Standard 8: Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.

Standard 9: Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.

Standard 10: Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

Standard 11: The service is committed to quality improvement and research in clinical and management practices.

Standard 12: Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Standard 13: Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

Glossary

Administrative health region	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.
Agency data	Information that is collected about each agency—for example, the agency's setting of care or feedback mechanism. It does not refer to aggregated information about patients.
Community-based palliative care	Palliative care delivered in residential and non-residential community-based settings, which include the person's private residence; a community-living environment such as an aged or supported care facility; a day centre such as a day respite centre, a day therapy centre or a palliative care day centre; or an outpatients department.
Formal working partnership	A formal working arrangement with other organisations that enable clients to move smoothly between services and service settings to meet their clinical and social needs. It can involve any of the following arrangements: service agreement, formal liaison, referral and discharge planning process, formal and routine consultation, protocol, partnership working group, and memorandum of understanding with other providers.
Hospice	An establishment dedicated to providing inpatient palliative care to patients with life-limiting illness.
Life-limiting illness	An illness that can be reasonably expected to cause the death of a patient in the foreseeable future.
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting 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 agency	An organisation or organisational sub-unit that is either a government service or an incorporated business with an ABN, which manages one or more palliative care practitioners, and is responsible for the provision of palliative care to patients and/or their carer(s)/family/friends and/or related services to health professionals, counsellors and volunteers.
Performance indicator	A measure that quantifies the level of performance for a particular aspect of (health) service provision and allows comparison between service providers, modes of service provision, or both (NHPC 2000).
Primary care provider (in the palliative care context)	A medical, nursing or allied health professional who adopts a palliative approach, has a primary or first-contact relationship with the person with a life-limiting illness, and whose substantive work is not with patients with a life-limiting illness.
Setting of care	The type of physical setting in which a service is actually provided or could be provided to a client, irrespective of whether or not this is the same as the usual location of the service-providing agency.

63

Strategic plan   A written document that describes a plan for the delivery and direction of services. The plan may be specifically for palliative care or a general health service plan that includes palliative care elements.

References

AIHW (Australian Institute of Health and Welfare) 2004. National palliative care information collection: a way forward for community-based palliative care. Canberra: AIHW.

AIHW (unpublished). Guidelines to the Trial National Palliative Care Agency Data Collection 2005. Canberra: AIHW.

DoHA (Department of Health and Ageing) 2000. National Palliative Care Strategy: a national framework for palliative care service development. Canberra: DoHA.

HDSC (Health Data Standards Committee) 2006. National health data dictionary. Version 13. Canberra: AIHW.

LCMHC (Little Company of Mary Health Care) 2003. A snapshot of palliative care in Australia. Canberra: Australian Government Department of Health and Ageing.

NCSDC (National Community Services Data Committee) (forthcoming). National community services data dictionary. Version 4. Canberra: AIHW.

NHPC (National Health Performance Committee) 2000. Fourth national report on health sector performance indicators: a report to the Australian Health Ministers' Conference. Sydney: NSW Health.

NHPC 2001. National health performance framework report. Brisbane: Queensland Health.

PCA (Palliative Care Australia) 1999. Standards for palliative care provision. 3rd ed. Canberra: PCA.

PCA 2005a. Standards for providing quality palliative care for all Australians. 4th ed. Canberra: PCA.

PCA 2005b. A guide to palliative care service development: A population-based approach. Canberra: PCA.

SESAHS (South Eastern Sydney Area Health Service) 2001. Development of national higher level performance indicators for palliative care: final report. Prepared for Commonwealth Department of Health and Ageing. Sydney: SESAHS.

WHO (World Health Organization) 2003. WHO definition of palliative care. Viewed November 2005,
<http://www.who.int/cancer/palliative/definition/en/>.