

# 1 Introduction

The National Palliative Care Strategy (DoHA 2000), a consensus document and framework for the development of palliative care provision in Australia, identifies the need for high-quality data to support the delivery of effective and accountable palliative care services. The Strategy, which all Australian governments have committed to implement, identifies a range of information development activities as common goals in the development of palliative care services, especially in relation to 'accountability and reporting' objectives. In particular, strategy 2.3.2 proposes to 'implement a national data set and collect agreed state/territory and national level data to monitor palliative care service use and describe the client group, including administrative data and clinically significant data as appropriate at each reporting level' (DoHA 2000:18). This report outlines efforts to develop a proposed data set that is relevant to national policy development and accountability that could be used in community-based palliative care settings, and provides details of a pilot test of the data set which aimed to evaluate the data items and their permissible values.

This project also occurs in the context of the 2003–08 Australian Health Care Agreements, which are the major mechanism by which the Australian Government disperses funds to the states and territories for the provision of healthcare services and outlines the states' and territories' obligations in respect of this funding. The current Agreements include an objective relating to improving the provision of palliative care services (Part 2 clause 8g) and require all governments to work towards implementation of the National Palliative Care Strategy as a shared responsibility (Part 3 clause 14d). The Agreements also require the Australian Government and the states and territories to work together through the Australian Health Ministers' Advisory Council information management governance arrangements to develop relevant data items and national minimum data sets.

The main audience for this report will be government officers working in palliative care policy areas and those working in health information management areas. Managers working within the palliative care sector will also be interested insofar as the proposed data set provides a core data set for palliative care services and specific data standards. Adoption of these standards would ensure that palliative care agencies could compare their service against other agencies by establishing a common vocabulary.

This report is organised around four chapters:

- Chapter 1 outlines the background to the project, including the need for a data set for the community-based palliative care sector, development of the draft data set, and describes the draft data set that was pilot-tested.
- Chapter 2 describes the pilot test methods.
- Chapter 3 describes the findings of the pilot test in relation to each data item and evaluates the data set as a whole against the objectives of the pilot test.
- Chapter 4 provides a broader-level discussion of the feasibility of implementing a national minimum data set for community-based palliative care, identifies areas for further development prior to implementation, outlines the steps needed to finalise the data set, and summarises the recommendations made throughout this report.

## **1.1 Background**

Currently, national data on palliative care are only available on admitted patients through the Admitted Patient Palliative Care National Minimum Data Set. This data set, which is provided annually to the Australian Institute of Health and Welfare (AIHW) by all hospitals in Australia, collects demographic, administrative and clinical information on all hospital separations from public and private hospitals in Australia where the patient was receiving palliative care (HDSC 2006). This includes patients in designated palliative care beds and patients receiving care where the principal clinical intent is palliative. While the admitted palliative care patient data set is limited, it does provide some means of national reporting on palliative care activity occurring in admitted patient settings.

The lack of comparable national data on palliative care activity occurring in community (that is, non-admitted patient) settings has been well recognised (NHIMG 2002), and remains an obvious gap given the emphasis within palliative care on providing palliative care patients and their families with choices about settings of care. In recognition of the lack of data in this area and state and territory commitment to improving information available about palliative care services, the Australian Government Department of Health and Ageing (DoHA) funded the AIHW to undertake a Palliative Care Information Development project in this area.

## **1.2 Assessment of the feasibility of obtaining community-based palliative care data**

The first stage of the Palliative Care Information Development project was conducted in 2003–04 and explored the possibility of collecting information on community-based palliative care. Project staff undertook a range of consultations with palliative care service providers, government representatives and other stakeholders to gather information on data needs, existing reporting requirements, existing reporting infrastructure and the capacity of services to report data. These activities revealed that most jurisdictions had at least some community-based palliative care data reporting requirements in place although these requirements varied greatly in terms of the amount of information reported, reporting format (for example, as unit record versus aggregate data) and the number and types of services that were required to report the data.

These consultations led the project team to conclude that a patient-level data set for community-based palliative care services was feasible in the medium term. They further recommended that a data set specification (DSS) be developed to support future data collection. This DSS, which would be a detailed specification of the proposed data elements and the conditions under which the data items would be collected, would not be mandatory for collection in the first instance, but would be available to service providers and people involved in the development of software and information systems to assist in the standardisation of data that might be collected by agencies that deliver palliative care. Development of the DSS would involve identifying specific data of common interest across the jurisdictions and developing data definitions (including definitions, a statement of context, value domains and guides for use) to underpin data collection to ensure comparability of the data.

This data set specification would also lay the foundation for the future agreement of a national minimum data set (NMDS), a data set specification that is agreed on by the relevant

national information management forum<sup>1</sup> for mandatory collection and national reporting. An NMDS agreement would enable data to be made available at a national level and would specify the scope of services required to report the data and specific data elements that are required. Locally, either within a jurisdiction, area health region or within a health service itself, it is assumed that health service managers would require more data, and more detailed data to be collected and reported for management purposes, but that agreement of an NMDS would identify those core items that are suitable for reporting nationally because there is common interest in these data and because common data definitions can be agreed.

In the health arena all NMDSs that report data on patients receiving care are established as ongoing data collections, that is, data are collected on all patients within scope in the collection period. This allows a comprehensive picture of clients, and the services they receive, to be established, based on a common language which allows national comparisons to be made comparing 'like' with 'like'. The major disadvantage of this mode of collection relates to the potential burden on service providers and the related cost of collecting data, although these disadvantages can be effectively minimised by services that build the information requirements into their information systems (whether electronic or paper-based). To enable services to do this it is important (wherever possible) that data requirements are relatively stable (that is, not changing year-by-year), that data standards request data that are directly relevant to service delivery, and that the data items required are consistent with other reporting requirements or data standards in other relevant program areas. This eliminates conflicting reporting requirements that might be introduced if services are required to report the same information to different funders in an inconsistent fashion.

A draft set of candidate items (including draft data definitions) was outlined in the project report, *National palliative care information collection: a way forward for community-based palliative care* (AIHW 2004). This suggested data set was based on consideration of information needs, analysis of data that was currently collected by the states and territories, and consideration of what could be collected by palliative care services.

### **1.3 Development of the draft community-based palliative care client data set specification**

In 2005 DoHA funded the AIHW to undertake further work to progress a number of the recommendations arising from the first phase of the Palliative Care Information Development project, including to further develop the proposed data set that collects key information on clients who receive palliative care in the community, the care they receive and providers of that care, and to test this data set. The community-based palliative care client data set specification (client DSS) was further developed in 2005–06 and includes data

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1 The committees involved in agreeing national data standards differ across the health, housing and community services sectors. In the health sector, data standards are initially agreed by the Health Data Standards Committee which ensures that the data standards are of high quality and are consistent with other relevant national standards. Where a data set is to become a NMDS, the Statistical Information Management Committee agrees to implement the collection. The National Health Information Principal Committee provides final endorsement of data standards and related data set specifications. All committees include members of all state and territory health authorities, the Australian Government and other relevant parties.

elements that collect information on the patient (that is, the person with the life-limiting illness), the episode of care, and each service contact within the episode of care. Further information on the content of the client DSS is provided in Section 1.4.

All items in the draft community-based palliative care client data set specification were developed by the AIHW in conjunction with the Palliative Care Data Working Group (PCDWG, previously the Palliative Care Information Development Working Group). Development of the draft data set occurred within an environment of negotiation and consensus. The main mechanism for reaching agreement was through discussion and decisions reached by the PCDWG. The following sections describe the process used to develop the draft data set for pilot testing.

### **1.3.1 Identifying candidate data set items**

Potential data set items were identified by the PCDWG, drawing on the results of the consultations that had occurred with service providers (as outlined in AIHW 2004), and by broadly considering the following questions: 'who receives what services from whom, at what cost, and with what effect?' (Leginski et al. 1989). This model for determining information needs was developed for the mental health sector by Leginski and others, who proposed that most information needs of clinical and administrative managers of mental health services in the United States could be met by responding to these questions in some way. This model for identifying information needs was also used as the basis of national consultations that were conducted on behalf of DoHA with government-based health information managers and other stakeholders to identify gaps and weaknesses in relation to achieving the National Palliative Care Strategy's stated objectives relating to 'quality and effectiveness' (DoHA unpublished).

This model presents a very broad framework in which to work and, as a result, requirements drawn from this model can invite responses at a number of levels. For example, at a national policy level it may be sufficient to understand patients' health conditions at reasonably broad diagnosis groupings. At a service management level, some further information may be needed to decide optimal staffing and equipment needs, whereas at a clinical level, the most specific diagnosis will be needed (along with other information) to devise optimal treatment plans. Given the national focus of the data set being developed, it was necessary for the PCDWG members to consider their answers to these questions from the point of view of deciding on data that is relevant for national analysis and that responds to policy issues that are relevant nationally. The national level represents the broadest level at which data will be captured, representing the minimum information to satisfy policy and accountability requirements.

### **1.3.2 Selecting items suitable for a national minimum data set**

While the questions outlined in the previous section can be used for determining the range of information that might be considered for a national minimum data set, the PCDWG and project team also needed to consider whether the candidate items were suitable for inclusion in a national minimum data set. Some of the issues and principles used to determine which data items might be suitable are:

- Is the information requested quantitative, able to be coded, or otherwise able to be reported in a straightforward manner?

- Is the information sought, and the response categories available, able to be expressed in an unambiguous and succinct way?
- Is the information requested likely to represent an unreasonable data collection burden for clinical and administrative staff who will be involved in capturing, recording and reporting the data, and can the burden be minimised while still ensuring that the data captured will be useful to policy makers and service planners?

At this stage it becomes clear that, in terms of the model proposed by Leginski et al. (1989), a national minimum data set reported at the client-level will not be able to collect data that provides an answer to the questions 'at what cost?' and 'with what effect?'. The issue of cost could not be reasonably requested as part of a client-based data collection, although information on expenditure could be built into a later data request to capture data on expenditure at an agency level. The total costs of providing palliative care would then need to be considered in the context of the care provided to the entire patient population for that agency (who may not all be palliative care patients).

The issue of 'effect' (or outcome) in the context of palliative care is particularly difficult because deterioration in clients is expected over the course of their care, and the goal of care is to optimise the patient's quality of life. Outcomes for palliative care patients and their carers can be measured by using comprehensive symptom-assessment scales, though these are generally not considered suitable for use in a national minimum data set because of the data collection burden they would introduce. Thus, the proposed data set will not provide information on patient outcomes at this level, though some very basic outcomes data will be available through items such as 'date of death', 'place of death' and 'reason for ending episode'. In recognition of this, DoHA has also funded a concurrent project, the Palliative Care Outcomes Collaboration (PCOC) to obtain more comprehensive data on outcomes in palliative care. The PCOC data set, which has drawn on national standards and the draft client DSS to ensure consistency between data requirements, can be found at: <http://chsd.uow.edu.au/pcoc/>.

### **1.3.3 Deciding relevant data standards**

The next stage was to draft the data set specifications (including codesets where relevant). In doing this, the project team and PCDWG considered, firstly, whether there were any national standards relating to the concepts required, and secondly, whether there were any other relevant standards that needed to be taken into account.

All nationally agreed data standards for the health, housing and community services sectors are available through METeOR, AIHW's online registry of national data standards. METeOR is an implementation of the international standard for the management of metadata (ISO/IEC 2003). METeOR promotes the re-use of existing national data standards by providing easy access to the relevant standards and promotes consistency with those that may be under development by providing private on-line workspaces for individuals and groups. These workspaces allow for the sharing of drafts among workgroup members and promote the use and re-use of existing metadata items within METeOR. Items that are being put forward as data standards for the health, housing and community services sectors are made publicly available. Data standards that are under development and have met basic quality checks and/or have been partially approved are also made available as 'candidate' items.

It is intended that the draft community-based palliative care client DSS will become publicly available through METeOR once it has been submitted to the Health Data Standards Committee (HDSC). Agreement to make the items available as national standards will be dependent on HDSC's assessment that the proposed standards meet quality data standards requirements and are consistent with other agreed national standards.

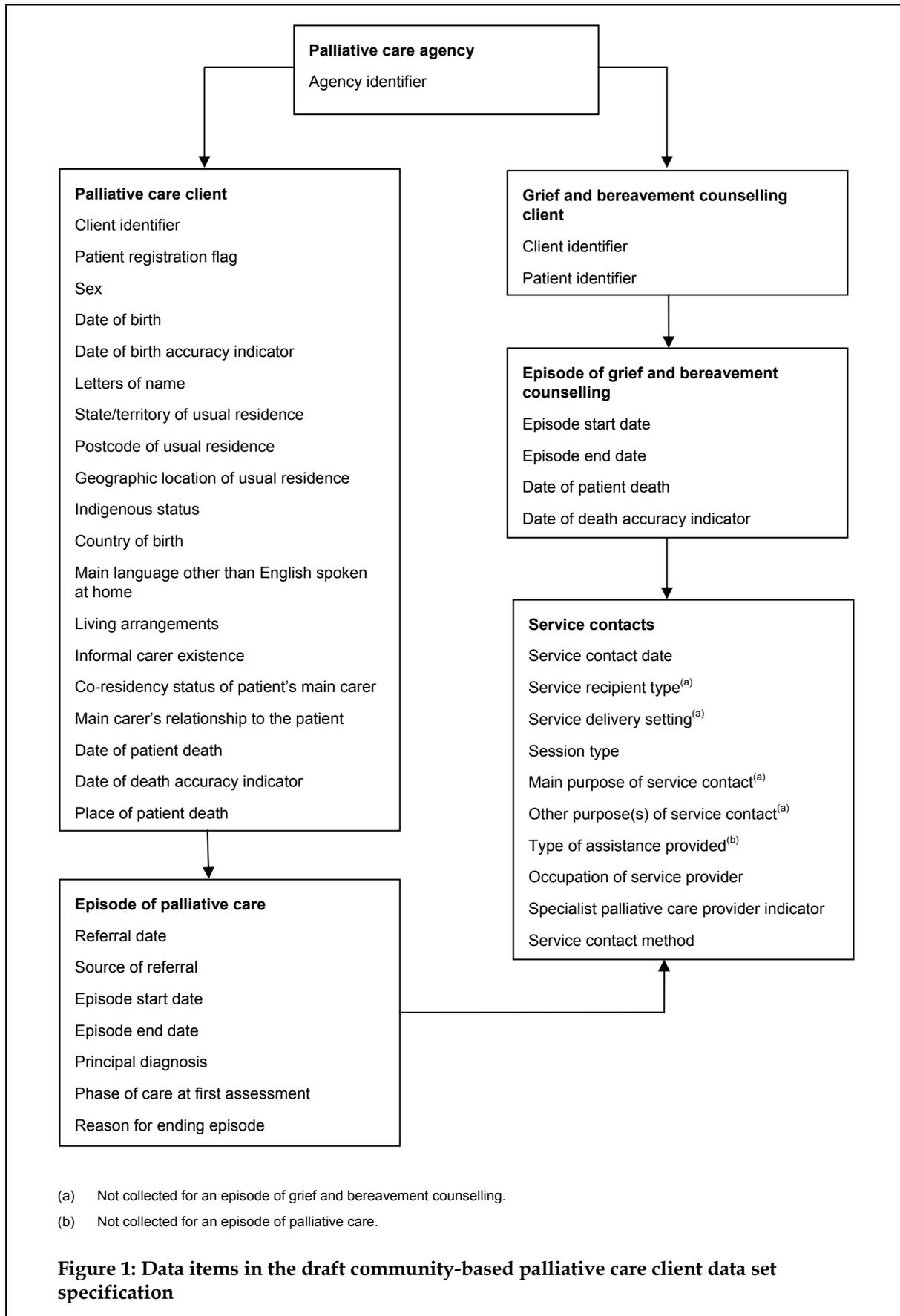
Where agreed national standards are not available for a specific data item, the project team has attempted to ensure consistency with other agreed standards, especially where they are part of data sets that represent significant reporting requirements. These other data sets may include data sets that relate to other national programs that palliative care agencies may participate in (for example, the Home and Community Care MDS; DoHA 2006), or other data sets required by their jurisdiction (for example, the Victorian Palliative Care Reporting System MDS; Victorian Government Department of Human Services 2004). The report on the outcomes of the first phase of information development work (AIHW 2004) summarises a number of other information sources that may be relevant to palliative care. These include data sets relating to aged and community care, cancer (clinical) data sets, and the Australian Government Department of Veterans' Affairs data sets.

Consistency with these data sets has been sought wherever possible. The benefits of achieving consistency within data reporting standards across collections is twofold: it enables cross-comparisons of data from different programs and sectors, and it avoids creating the need for the multiple entry and reporting of data by a specific agency (and thereby reduces the data reporting burden on agencies which, in turn, helps to maintain the quality of the data reported). In saying this it should be noted that 'consistency' does not necessarily mean that the *same* information needs to be collected – it may be sufficient for one data requirement to be able to be mapped to another. Also, in some instances consistency will not be able to be achieved because the information needs of the two programs may be genuinely different. In these cases, alternative arrangements may need to be made to avoid imposing unnecessary burden on health care services.

## 1.4 The proposed client data set specification

Figure 1 provides a diagrammatic representation of all information included in the draft palliative care client DSS that was subject to the pilot test and two further items ('letters of name' and 'geographic location of usual residence') that were not included in the pilot test but were part of the draft DSS. Further information on these two items is provided in Chapter 2. The data items within the client DSS include items that relate to: the patient (that is, the person with the life-limiting illness), the episode of palliative care or episode of grief and bereavement counselling and each service contact within these episodes. There is one further item (agency identifier) that relates to each agency participating in the collection.

Figure 1 indicates that the information required for collection is based around two different episodes of care – episodes of palliative care and episodes of grief and bereavement counselling. An episode of palliative care relates to the period of care when a person (or group of people) receives services to improve their quality of life. An episode of palliative care begins when the client is first assessed and accepted for care by the palliative care agency. It would usually end shortly after the death of the patient or the close of the episode for another reason, for example, when a client is referred to another agency to receive care and is not expected to return. When the episode ends because of the death of the patient the



**Figure 1: Data items in the draft community-based palliative care client data set specification**

episode may continue for a short period beyond the date of death to provide some support to the carer(s)/family/friends of the patient and to finalise administrative issues.

A client receiving care in an episode of palliative care may be: the patient (that is, the person with the life-limiting illness), the patient and their carer(s)/family/friends or (occasionally) the carer(s)/family/friends only. This may occur when a patient refuses palliative care but their family and carers receive palliative support in relation to the patient. Only very limited data, however, are collected on carer(s)/family/friends.

A client receiving care for the purposes of an episode of grief and bereavement counselling is an individual or group from the carer(s)/family/friends group, who has been assessed and accepted for formal grief and bereavement counselling by the palliative care agency. In these cases, the carer(s)/family/friends are registered with the agency as clients in their own right with a unique client identifier. Until the point at which the carer(s)/family/friends are registered for care in their own right, it would be expected that any care they have received would be regarded as bereavement, social or spiritual 'support' and would be recorded on the patient's medical record (that is, as part of the episode of palliative care and not an episode of grief and bereavement counselling). However, following the commencement of the episode of grief and bereavement counselling, it would be expected that any bereavement, social or spiritual support provided (in conjunction with formal grief and bereavement services) would be recorded on the grief and bereavement client's record rather than on the palliative care patient's record.

Episodes of grief and bereavement counselling would normally commence after the death of the patient, but in some circumstances may begin prior to this. It should be noted that not all palliative care agencies provide formal grief and bereavement counselling services directly – more commonly these clients would be referred to another agency that does provide these services.

## **1.5 Project management**

This project – to develop and test a proposed data set for use in community-based palliative care settings – was funded by DoHA and was carried out by a project 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. The NDDSU also specialises in identifying and developing national information requirements in specific program/policy areas or sectors.

The project was overseen by the Palliative Care Data Working Group (PCDWG), which was established at the start of 2005 specifically to provide guidance and expert advice to the AIHW project team. The PCDWG includes representatives from all state and territory governments, Palliative Care Australia, the Palliative Care Outcomes Collaboration, the Australian Government Department of Health and Ageing, the Australian Government Department of Veterans' Affairs and the AIHW. Representatives of this group have a variety of expertise in data collection, data development, palliative care service provision and policy development. A list of PCDWG members can be found at Appendix A.

The PCDWG, in turn, reports to the Palliative Care Intergovernmental Forum (PCIF), which consists of representatives from all state and territory health authorities and the Australian Government and is convened by DoHA to consider strategic policy issues and provide advice on activities funded under the National Palliative Care Program.

## 2 Pilot test methods

The pilot test of the community-based palliative care client data set specification (client DSS) involved a sample of palliative care agencies recruited by state and territory health authorities. The pilot test was conducted as a 'snapshot' survey conducted over a two-week period and used paper-based survey forms to collect the relevant data. This methodology differs from that which would be used if the data set were to become a mandatory data collection (where palliative care agencies would incorporate the data collection requirements within their existing information systems), but given the objectives of the pilot test and the focus on testing the questions and permissible values this was seen as an appropriate methodology that limited the burden placed on participating agencies (recognising that these paper-based forms would likely mean at least partial duplication of existing data collection for the period of the pilot test).

Ethics approval to conduct the pilot test was granted in August 2005 by the AIHW Ethics Committee.

### 2.1 Objectives of the pilot test

This pilot test was designed to assess whether specific data could be collected by palliative care agencies delivering services in community settings. Specifically, the pilot test evaluated:

- the practicality and consistency of interpretation of questions
- the comprehensiveness of the range of possible answers
- the quality of reported data
- respondent burden.

### 2.2 Collection period

The pilot test was conducted over a two-week collection period, Monday 5 June to Sunday 18 June 2006, for most agencies. Data collection occurred over later time periods in a small number of cases, particularly for agencies in Victoria, Queensland and Western Australia, due to the late recruitment of agencies.

### 2.3 Recruitment of agencies

Agencies were recruited to the pilot test by the relevant state and territory health authorities. As the primary purpose of the pilot test was to assess the application of the proposed data set for community-based palliative care clients in 'real' settings and not for data analysis purposes, a strict representative sample of palliative care agencies was not sought, although state and territory health authorities were asked, where possible, to ensure that a range of service models were represented. At least one agency from each jurisdiction participated in the pilot test.

## 2.4 Eligible clients

Clients eligible for inclusion in the pilot collection were patients and/or their carer(s)/family/friends who received services in the community from the palliative care agency during the two-week pilot period and who consented to participate in the pilot. A client could be an individual or a group of people. Agencies were asked to report information on up to 10 clients who received community-based palliative care services from their agency in the data collection period, and up to 5 clients who received grief and bereavement counselling from their agency (if they provide these services).

### 2.4.1 Obtaining consent

Each palliative care agency was responsible for informing their eligible clients during the pilot collection period that data about them might be sent to the AIHW, and for obtaining their clients' consent to submit the data.

A privacy statement was provided in each client form collection pack (Appendix B1), and could either be provided to the patient (or a person responsible for the patient), or read out to them. This statement:

- outlined the purpose of the trial
- reaffirmed that the information collected was non-identifying
- outlined the responsibilities of the health departments and the AIHW to maintain the confidentiality of the data and to store the data securely
- reaffirmed that participation was voluntary and that consent (or refusal) was not required to be provided in writing.

Agencies were also invited to allow clients to view copies of the data collection forms.

Once consent was obtained, agency staff were instructed to check the relevant box on the data collection forms to confirm that consent had been obtained.

## 2.5 Community-based service contacts

Agencies were only required to report on care they provided in community-based settings where the care was provided by a service provider (or service providers) who was employed or subcontracted by the palliative care agency. Care provided by volunteers (even when this was coordinated by a palliative care agency or part of a care plan) was not in scope for this collection.

Community settings are all non-admitted patient settings, including:

- private residences (including caravans, mobile homes, houseboats or units in a retirement village)
- residential aged care facilities
- other residential settings (including prisons, or community living environments such as group homes)
- non-residential settings (including day respite centres, day centres, palliative care day centres, community health centres and outpatient departments).