

**Report on the pilot test of the
community-based palliative care
client data collection**

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Report on the pilot test of the community-based palliative care client data collection

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Australian Institute of Health and Welfare
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Abbreviations

ABS	Australian Bureau of Statistics
AHCA	Australian Health Care Agreement
AIHW	Australian Institute of Health and Welfare
ASGC	Australian Standard Geographical Classification
COPD	chronic obstructive pulmonary disease
DSS	data set specification
DoHA	(Australian Government) Department of Health and Ageing
HACC	Home and Community Care (Program)
HDSC	Health Data Standards Committee
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification
MDS	minimum data set
METeOR	Metadata (electronic) Online Registry
NDDSU	National Data Development and Standards Unit
NMDS	national minimum data set
PCDWG	Palliative Care Data Working Group
PCIF	Palliative Care Intergovernmental Forum
PCOC	Palliative Care Outcomes Collaboration
SLA	Statistical Local Area

Summary

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. This report outlines efforts to develop a proposed data set for community-based palliative care services that is relevant to national policy development and accountability, 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. This work has been funded by the Australian Government Department of Health and Ageing and has been conducted by the Australian Institute of Health and Welfare in collaboration with the Palliative Care Data Working Group. This group includes representatives of all state and territory health departments and other stakeholders.

This data set lays the foundation for the future agreement of a national minimum data set, which would see the collection of ongoing data about community-based palliative care clients for national collection and reporting. The data items within the draft client data set specification (client DSS) include items that relate to: the patient (that is, the person with the life-limiting illness), the episode of palliative care, the episode of grief and bereavement counselling, and each service contact within these episodes.

The pilot test of the client DSS involved a national 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 relevant data to assess whether the data could be collected by palliative care agencies delivering services in community settings. The data items were then assessed in terms of: their practicality and the consistency of interpretation of the questions; the comprehensiveness of the range of possible answers; the quality of reported data; and respondent burden.

Overall, the pilot test was considered successful in demonstrating that data of this kind can be collected by palliative care agencies involved in delivering care to patients based in the community and that the quality of data collected was generally of a high standard. In particular, the pilot test demonstrated that data items relating to the patient and the episode of palliative care can be readily collected in a consistent manner by palliative care agencies but that some palliative care service contact data require finetuning. Further work will also be required to better define concepts relating to episodes of grief and bereavement counselling to ensure their consistent application by palliative care agencies. Suggestions to finetune a number of data items to further enhance the quality and consistency of data collected and to ensure comparability with other data collections are included in Chapter 3.

The issue of how best to collect service contact data (whether as part of an ongoing administrative data collection or a regular 'snapshot' survey) is raised, particularly because it is this component of the data set that is likely to be the greatest burden to service providers.

The report also draws attention to the need to consider a phased implementation of the data set, with items relating to the patient and the episode of palliative care being collected in the first instance, while further development and improvement is made to items relating to episodes of grief and bereavement counselling and service contacts. This will also allow time for palliative care agencies to modify their information systems and processes to capture the required data. The next steps to be taken in finalising the data set specification are also outlined.

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 forum¹ 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

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.

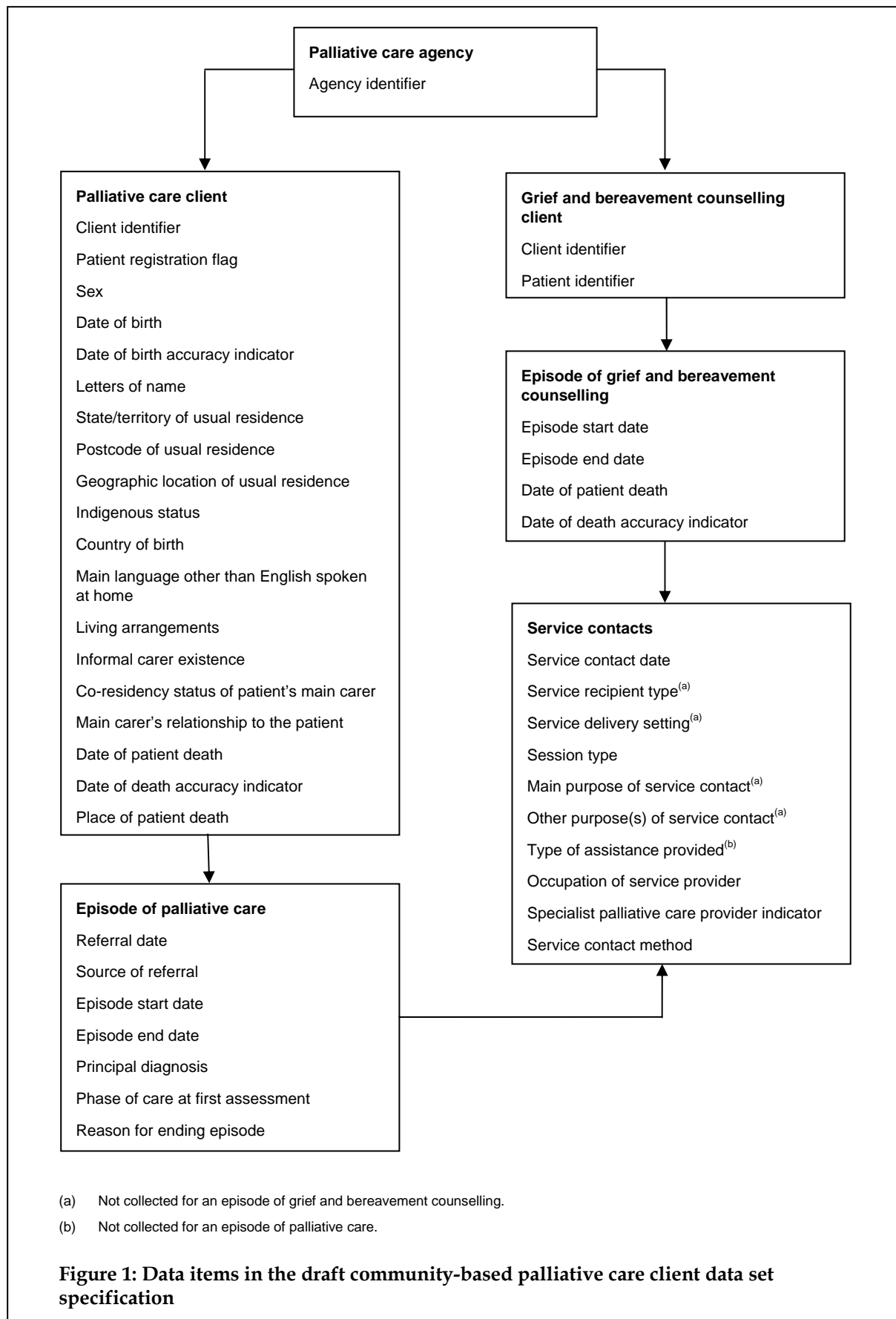
Where agreed national standards are not available for a specific data item, the project team has attempted to ensure consistency with other agreed standards, especially where they are part of data sets that represent significant reporting requirements. These other data sets may include data sets that 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



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).

All care provided at hospitals or hospices, where the patient is admitted as an inpatient, was excluded from this collection.

Service contacts that are counted in this pilot collection are services that are provided to, or on behalf of, the patient and/or their carer(s)/family/friends, that result in a dated entry being made in the client record, except where the service is primarily of an administrative nature (for example, making an appointment on behalf of a client). A palliative care client may receive more than one service contact per day, and may receive different types of assistance within one service contact. The types of care provided at a service contact may, for example, include medical care, nursing care and spiritual care. Group sessions, where a service is delivered to more than one client (group) simultaneously, were also included.

2.6 Data collection instruments

The data collection occurred via the use of paper-based forms. Four forms were developed to collect data relating to patients, episodes of palliative care, service contact information and episodes of bereavement care and related service contacts. Copies of all forms used are attached at Appendixes B2–B5. More detailed information about the data collected by each form is provided below:

- Form A collected information about patients who received palliative care from the agency during the pilot collection period, including:
 - static information provided once only, for example, sex, Indigenous status and country of birth; or
 - information that may change during the patient's episode of palliative care at the agency, for example, informal carer existence and living arrangements. The agency was asked to update this information during a service contact or as the agency was made aware of the change.
- Form B requested information about the episode of palliative care for each client who received palliative care from the agency during the collection period.
- Form C collected information about service contacts provided to clients during an episode of palliative care.
- Form D requested information about each episode of grief and bereavement counselling including service contacts for carer(s)/family/friends (usually following the death of the patient, but may be prior to this event).

A feedback form which gathered information about filling out the collection forms and the ability of agencies to report 'letters of name' and 'geographic location of usual residence' was also provided (Appendix B6). Agencies were asked, if possible, to complete one form per agency using a collaborative approach which incorporated feedback from all staff responsible for completing the forms. However, staff members wishing to provide direct feedback were invited to complete this form separately as well.

There was no training provided to agencies participating in the pilot collection; however, the agencies were provided with a guidelines document that described the purpose of the data collection, described the collection requirements and provided some further information on some of the data items (AIHW unpublished). Assistance in completing forms was provided by the AIHW project team via a '1800' telephone helpline and an email address. A website

was also developed to provide access to electronic versions of all data collection materials and background to the pilot test.

2.6.1 Data items not included in the pilot test

Two data items, 'letters of name' and 'geographic location of usual residence', are included in the client DSS, but were not included in the pilot test:

- 'Letters of name' is the combination of the 2nd, 3rd and 5th letters of a person's legal family name and the 2nd and 3rd letters of a person's legal first given name. It is used in combination with a person's date of birth and sex in order to derive a linkage key for the statistical linkage of client records.² As it does not produce a unique identifier, this linkage key is used for statistical purposes only, where a small amount of error may be acceptable, and should not be used for other purposes.
- 'Geographic location of usual residence' requests information on the person's usual address as a five-digit statistical local area (SLA) code, where the first digit represents the state or territory and the remaining digits represent the more specific locality within the state or territory. These codes are defined in the Australian Standard Geographical Classification (ASGC), which is updated annually by the Australian Bureau of Statistics (ABS 2006b), and are used to apply remoteness classifications. For the majority of localities, the locality name (suburb or town, for example) is sufficient to assign a SLA. However, some localities have the same name (in which case postcode may be required) and some localities cross one or more SLA boundaries.

These items were not included in the pilot test as the PCDWG preferred to firstly gather information on agencies' capacity to report these data before subjecting the items to testing. In particular, the PCDWG was interested to know whether this information could be derived within the service provider's information systems, rather than whether service providers could report the information manually on the data collection forms. Some privacy concerns were also raised in relation to 'letters of name', and so it was decided not to include these items for the purposes of pilot testing of the data set. Instead, agencies were asked to provide feedback on their ability to report these items on a feedback form.

2.7 Distribution and collation of data collection instruments

All data collection packs (including covering letters, instructions, all forms and the guidelines document) were collated and printed by the AIHW project team. These were then sent directly to the participating agencies, except in Queensland and Tasmania where the data collection forms were first sent to the respective health authority for distribution to the nominated agencies.

2 This linkage key has been adopted as a standard linkage key in a number of community services collections and is used in those collections to link records to generate person-based statistics (which is particularly important in community-based programs where clients commonly receive services from more than one service provider).

All completed forms were returned directly to the AIHW, except in Queensland and Tasmania, where the forms were returned to a contact officer in the relevant health authority who then forwarded the forms to the AIHW.

All data entry and analysis was undertaken by staff of the AIHW.

3 Findings

This chapter presents the results of the pilot test of the community-based palliative care client DSS and outlines suggested changes to specific data items. It should be noted that data presented in this report were collected from a small sample of clients who received services over a short period of time from a small number of agencies. While this sample was sufficient to test the proposed data items against the stated objectives, the results should not be used to make inferences about the palliative care sector, nor as the basis for policy evaluation or service planning.

Suggested improvements to data items have been made in this chapter where the pilot test provided information that supported the further development of items. Chapter 4 provides a broader-level discussion of areas identified for further development and other issues for resolution prior to the implementation of this data set as a mandatory data collection, and includes recommendations in relation to these aspects.

3.1 The pilot test sample

Twenty-three palliative care agencies were recruited by the state and territory health authorities to participate in this collection. Table 3.1 provides information on the distribution of participating palliative care agencies across the states and territories.

Table 3.1: Agencies that participated in the pilot test, by state and territory

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Number of agencies	2	5	7	4	2	1	1	1	23
Per cent of agencies	9	22	30	17	9	4	4	4	100

Table 3.2: Number of forms collected during the pilot collection

Form	Number of forms	Number of clients
Patient details (Form A)	201	201
Episodes of palliative care (Form B)		
Patients and their carer(s)/family/friends ^(a)	191	191
Carer(s)/family/friends only ^(b)	1	1
Palliative care service contacts (Form C)		
Patients and their carer(s)/family/friends	832	201
Carer(s)/family/friends only ^(b)	1	1
Episodes of grief and bereavement counselling (Form D)	36	36
Grief and bereavement service contacts (Form D)	71	36

(a) Episode of palliative care details (Form B) was not completed for 10 patients from one agency.

(b) Indicates that only the carer(s)/family and friends received care from the palliative care service, that is, the person with the life-limiting illness was not a client of the agency.

These agencies collected data about 202 clients who received services in the pilot test period, of whom 201 included a patient (that is, a person with a life-limiting illness); there was one client group which included the carer(s)/family and friends only. Agencies collected this information via the use of four data collection forms during the pilot test period; a breakdown of the number of forms completed is provided in Table 3.2.

3.2 Feedback about the pilot test processes

The pilot test ran successfully during June–July 2006 with 22 feedback forms being received from 20 of the agencies who participated in the pilot,³ including at least one feedback form from each jurisdiction. Specific feedback in relation to each data item is summarised throughout this chapter, but overall:

- Eighteen respondents (82%) indicated that the survey was ‘very easy’ to ‘easy’ to complete. The remaining four respondents reported that the survey was neither ‘easy’ nor ‘difficult’ to complete.
- Seventeen of the 18 respondents (94%) who used the guidelines found them to be helpful. Four respondents did not use the guidelines document when completing their surveys.
- Five respondents accessed the website to seek help with completing their surveys. Two reported that the website was ‘very helpful’ and the remaining three indicated that the website was neither ‘helpful’ nor ‘unhelpful’.
- Assistance was provided to 11 agencies via the helpline (16 calls). Most queries made via the helpline related to administrative arrangements for the pilot test (for example, requesting replacement forms, requesting information on how to select patients to participate). Five agencies requested clarification of particular data items or related concepts via the helpline.⁴ Of the seven agencies that used the helpline and returned a feedback form, six agencies reported that the information provided by the helpline was ‘very helpful’ to ‘helpful’.

3.3 Client consent

Gaining consent from clients to participate in the pilot collection did not appear to create any problems. Eighteen agencies reported that no clients refused to give their consent, although one agency reported that no bereavement surveys were collected as staff reported that they found it too difficult to ask for consent when relatives were distressed.

Formal notification of a client’s consent to participate in the pilot collection was provided by staff recording a tick in the consent boxes provided on forms B and D which collected information on episodes of palliative care and episodes of grief and bereavement counselling respectively. Ninety forms (79 Form Bs, 11 Form Ds) were returned with the consent boxes not ticked. Where this occurred, agencies were contacted to confirm, or otherwise, each

3 Three feedback forms were received from one agency.

4 Where queries related to specific data items or associated concepts, these queries are noted in the discussion against each respective data item.

client's consent to participate in the pilot test. Of the 90 missing consents, 84 were confirmed as being given by the client, five as not given and one where it was not possible to find out. Data for the six clients who did not give consent or where it could not be confirmed were excluded from the pilot collection.

Discussions with agencies identified that staff had not experienced problems gaining client consent but had just overlooked the need to tick the consent boxes. Some staff suggested that in future, if consent boxes were used to indicate that consent was obtained, they should be more prominent or appear on the privacy statement which is read out to clients.

It should be noted that in an ongoing collection where specific consent to participate in the data collection would not be required (although information on use of the data for statistical purposes would need to be provided to the patient), these issues would not arise.

3.4 Assessment of data items

This section provides a summary of the data collected, discussion of those data items where issues were identified, a summary of feedback received from participating agencies and suggestions for the future development of items (where applicable). Table 3.3 provides a list of the data items collected, with an indication of whether suggested improvements have been made and an indication of the objective to which the improvements relate (if applicable). The specific objectives against which the items have been assessed (as outlined in Section 2.1) are:

1. *the practicality and consistency of interpretation of questions* – which assessed items in terms of: whether they appeared to capture the information intended, the way in which the items 'worked' in relation to other data items and the way in which the definition appears to have been applied in a 'real' setting
2. *the comprehensiveness of the range of possible answers* – which assessed the list of permissible values (where applicable) to identify where major response categories were not available in the existing list of response codes
3. *the quality of reported data* – which assessed the data quality in terms of the level of missing data and the application of the permissible values and related guidelines provided for the data item
4. *respondent burden* – which assessed whether the data item requirements might introduce unreasonable additional workload for staff within palliative care agencies.

It should be noted that where suggested improvements have been made, it does not necessarily mean that the objective was not met. In most cases, the issues identified were relatively minor, but nevertheless provided some information on the way in which the item could be improved.

Table 3.3: Data items for which suggested improvements have been made, by relevant objective

Item level	Data item name	Objective 1: Practicality and consistency of interpretation	Objective 2: Comprehen- siveness of range of answers	Objective 3: Quality of data	Objective 4: Respondent burden
Client (of an episode of palliative care)	Client identifier ^(a)	✓	..	✓	—
	Patient registration flag	—	—	—	—
	Sex	—	—	—	—
	Date of birth	—	..	—	—
	Date of birth accuracy indicator ^(a)	—	—	—	—
	State/territory of usual residence	—	—	—	—
	Postcode of usual residence	—	..	—	—
	Indigenous status	—	—	—	—
	Country of birth	—	..	—	—
	Main language other than English spoken at home	✓	..	—	—
	Living arrangements	—	—	—	—
	Informal carer existence	✓	—	—	—
	Co-residency status of patient's main carer	—	—	—	—
	Main carer's relationship to the patient	—	—	—	—
	Date of patient death	—	—	—	—
	Date of death accuracy indicator ^(a)	—	—	—	—
	Place of patient death	—	—	—	—
Episode of palliative care	Referral date	—	..	—	—
	Source of referral	—	—	✓	—
	Episode start date	✓	..	—	—
	Episode end date	—	..	—	—
	Principal diagnosis	—	✓	—	—
	Phase of care at first assessment	—	—	—	—
	Reason for ending episode	—	—	✓	—
Palliative care service contacts ^(a)	Service contact date	—	—	—	—
	Service recipient type	—	—	✓	—
	Service delivery setting	✓	✓	—	—
	Session type	—	—	—	—

(continued)

Table 3.3 (continued): Data items for which suggested improvements have been made, by relevant objective

Item level	Data item name	Objective 1: Practicality and consistency of interpretation	Objective 2: Comprehen- siveness of range of answers	Objective 3: Quality of data	Objective 4: Respondent burden
Palliative care service contacts ^(a) (continued)	Main purpose of service contact	✓	✓	✓	—
	Other purpose(s) of service contact	—	✓	✓	—
	Occupation of service provider	—	✓	—	—
	Specialist palliative care provider indicator	✓	—	—	—
	Service contact method	—	—	✓	—
Episode of grief and bereavement counselling ^(a)	Client identifier ^(a)	?	..	—	—
	Patient identifier ^(a)	?	..	—	—
	Episode start date	?	..	—	—
	Episode end date	?	..	—	—
	Date of death of patient	—	..	—	—
	Date of death accuracy indicator ^(a)	—	..	—	—
Grief and bereavement counselling service contacts	Service contact date	—	..	—	—
	Session type	—	—	—	—
	Type of assistance provided	—	✓	—	—
	Occupation of service provider	—	✓	—	—
	Specialist palliative care provider indicator	✓	—	—	—
	Service contact method	—	—	✓	—
Palliative care agency	Agency identifier ^(b)

(a) These items are further discussed in Chapter 4, 'Finalising the client data set specification'.

(b) Agency identifier was assigned by the AIHW and was therefore not tested during the pilot test.

✓ Indicates that suggested improvements have been made in relation to this objective for this data item. Note that this does not indicate that the item did not meet the particular objective, but merely the fact that suggestions for improvement have been made.

— Indicates that the item met the objective and no suggested improvements have been made.

? Indicates that the data items were not able to be fully assessed against this objective because the 'episode' definitions were not applied in the way intended.

.. not applicable

3.4.1 Information relating to palliative care clients

The information collected at the patient-level, as reported in this section, was mainly demographic. This information was only collected when the patient was registered to receive palliative care directly from the palliative care service, and therefore is not available for patients not receiving direct palliative care from the agency (that is, where the carer(s)/family/friends received palliative support on behalf of the patient).

Note that in this report the term 'client' is used to refer to client groups who may receive care from a palliative care agency. A client (group) may include a patient only or a patient and their carer(s), family members and friends. Where the term 'patient' is used, the concept applies to the person with the life-limiting illness only.

Client identifier

The client identifier is the identifier assigned by the palliative care agency to the patient and/or their carer(s)/family/friends who are registered to receive palliative care from their agency. A client may be an individual or a group of people from the patient and carer(s)/family/friends group.

Client identifiers were to be recorded on each of the data collection forms (that is, forms A-D) to enable the project team to link the different data collection forms back to a specific client.

Data item discussion

- Eight palliative care clients were missing at least some of the client identifiers. For most of these cases this was because one agency omitted to enter some client identifiers for clients who had multiple forms.
- Thirty-three client identifiers were incorrectly recorded and had to be reallocated before data entry could occur. Most errors were the result of inconsistent entry of identifiers across forms A, B and C.
- Five agencies reported via the feedback forms that they had difficulty understanding what number was required when entering the client identifier.
- Three agencies contacted the project team via the telephone helpline to clarify requirements for reporting the client identifier. All three appeared to have been confused by the request for information (on the feedback form) on whether agencies could report 'letters of name' for data linkage purposes. This resulted in some confusion about whether the client identifier required was the registration number used within their own agency, or a nominal identifier based on 'letters of name'.
- The problems that arose in relation to this item were largely a result of the use of the client identifier in relation to the four data collection forms. In an ongoing data collection, it is likely that these problems would not arise as the client identifier would be extracted as part of the data request, and specific multiple recording of this information would not be required.
- One agency commented via the feedback form that their agency does not have unique client identifiers and that they used a hospital unit record number wherever possible. This suggests that guidelines may need to be provided to palliative care agencies on the need for them to allocate unique identifiers for their patients as part of the national data set.

Suggested improvements

The project team suggests:

- improving the wording of this item to emphasise that the identifier required is that already used by the palliative care agency
- including guidelines on the need for each agency to allocate a unique patient identifier for all patients cared for.

Some broader issues in relation to client and patient identifiers are discussed in Section 4.3.

Patient registration flag

The patient registration flag is an indicator of whether the client group in receipt of care involved the carer(s)/family and friends only, that is, a patient (person with a life-limiting illness) was not registered with the agency to receive care.

Of the 192 episodes of palliative care reported there was only one episode, involving one service contact, which included the carer(s), family and friends only (Table 3.4).

No issues were raised by the pilot test in relation to this item.

Table 3.4: Episode of palliative care client, by client type

Patient registration flag	Number of clients	Per cent
Patient only or patient and carer(s)/family/friends ^(a)	191	99
Carer(s)/family/friends only	1	1
Total	192	100

(a) Ten patients are excluded as Form B (which collected information on the episode of palliative care) was not completed for these clients.

Patient sex and date of birth

Fifty-five per cent of patients who participated in the pilot test were male. Almost three-quarters of patients were in the 60–89 year age group (Table 3.5).

No issues were raised by the pilot test in relation to these items.

Table 3.5: Patients, by age group and sex

Age group (years) ^(a)	Male	Female	Not stated	Number of patients	Per cent
Under 30	0	1	0	1	0
30–39	4	2	1	7	3
40–49	6	4	0	10	5
50–59	19	14	0	33	16
60–69	25	22	0	47	23
70–79	29	28	1	58	29
80–89	25	13	1	39	19
90+	3	2	0	5	2
Not stated	0	1	0	1	0
Total	111	87	3	201	100

(a) Age at 5 June, that is, the nominal beginning of the pilot test period.

Date of birth accuracy indicators

The date of birth and death accuracy indicators flag the accuracy of the day, month and year components of a patient's reported date of birth and death (if applicable). A value of 'A' was assigned if a component was accurate, 'E' if it was estimated, and 'U' if it was unknown. For example, 'AAU' means that the reported day and month of birth were accurate but the year was unknown.

These items were included in the data set to provide an indication of the accuracy of the dates recorded which assists in the statistical linkage of data (both across episodes of care and linkage to other data sets).

Responses for each of the date of birth accuracy indicators fell within category 'A', indicating that all dates (and date components) were known to be accurate.

Data item discussion

Agencies were instructed to only collect this information for patients who started their care after 5 June 2006, that is, the nominal start of the pilot collection period. Date of birth accuracy indicators were completed for 25 of the 32 patients who were accepted for care after 5 June 2006.

Date of birth accuracy indicators were also provided for an additional 95 patients, although this was not required. One other agency commented via the feedback form that, although they had evidence of the accuracy of the dates of birth of their patients, they did not complete these fields (as instructed). Only one agency commented via the feedback form that some of their staff had not understood this data item, but that the coordinator had completed the information later on. On balance, these responses suggest that information on the accuracy of dates of birth could have been easily reported if required. As a result, no suggestions for further improvement of this item are recommended, although some broader issues in relation to these items are discussed in Section 4.4.

State/territory of usual residence

Just over one-quarter of patients participating in the pilot test lived in Queensland (Table 3.6).

No issues were raised by the pilot test in relation to this item.

Table 3.6: Patients, by state or territory of usual residence

State/territory	Number of patients	Per cent
New South Wales	20	10
Victoria	37	18
Queensland	55	27
Western Australia	38	19
South Australia	26	13
Tasmania	12	6
Australian Capital Territory	6	3
Northern Territory	7	3
Total	201	100

Postcode of usual residence

Information was sought on the postcode of usual residence of the patient, which allows more detailed geographical analyses of patient distribution to be undertaken, in particular, analyses of data for rural and remote populations. Information on postcode of usual residence is required in addition to information on the state or territory of usual residence as postcodes do not have a 1:1 concordance with state and territory boundaries.

Over half (59%) of the patients participating in the pilot test usually lived in an area classified as a 'Major City', 23% lived in an 'Inner Regional' area and 16% in an 'Outer Regional' area (Table 3.7).

Postcode of usual residence was not reported for two patients. No issues were raised by the pilot test in relation to this item.

Table 3.7: Patients, by remoteness area

State/territory	Number of patients	Per cent
Major City	118	59
Inner Regional	47	23
Outer Regional	33	16
Remote	1	0
Very Remote	0	0
Not stated	2	1
Total	201	100

Indigenous status

This data item is an indicator of whether the patient identified as being of Aboriginal or Torres Strait Islander origin. One client who participated in the pilot collection was identified as being of Aboriginal origin (Table 3.8).

Table 3.8: Patients, by Indigenous status

Indigenous status	Number of patients	Per cent
Aboriginal but not Torres Strait Islander origin	1	0
Torres Strait Islander but not Aboriginal origin	0	0
Neither Aboriginal nor Torres Strait Islander origin	195	97
Not stated	5	2
Total	201	100

Data item discussion

All missing data for this item were attributable to one agency that did not report Indigenous status for its five clients, whose episodes of care all began prior to the pilot test. It is likely that this information was not routinely recorded within their existing information system and therefore was not able to be reported from existing records. This is unlikely to be an issue in an ongoing collection where information systems would need to be modified to capture this information for each patient at first registration. As a result, no suggestions for further improvement of this item are recommended.

Country of birth

Over three-quarters of patients who participated in the pilot test were born in Australia (79%, Table 3.9). For those born outside Australia, the most common country of birth was England (16 patients, 8%).

No issues were raised by the pilot test in relation to this item.

Table 3.9: Patients, by country of birth grouping

Country of birth grouping	Number of patients	Per cent
Oceania and Antarctica	160	80
<i>Australia</i>	<i>(158)</i>	<i>(79)</i>
<i>New Zealand</i>	<i>(2)</i>	<i>(1)</i>
North-west Europe	23	11
Southern and Eastern Europe	8	4
South-east Asia	4	2
North-east Asia	3	1
Not stated	3	1
Total	201	100

Main language other than English spoken at home

This item captured information on the language reported by the patient as the main language other than English spoken by him/her at home (or most recent private residential setting occupied by the patient) to communicate with other residents of the home or setting and regular visitors. Seven per cent of patients participating in the pilot test (14 patients) spoke a language other than English at home (Table 3.10).

Table 3.10: Patients, by main language other than English spoken at home (broad group)

Main language (broad group)	Number of patients	Per cent
Northern European	187	93
<i>English</i>	(185)	(92)
<i>Non English</i>	(2)	(1)
Southern European	6	3
Southeast Asia	2	1
Eastern Asian	3	1
Australian Indigenous languages	1	0
Not stated	2	1
Total	201	100

Data item discussion

While agencies participating in the pilot test did not experience any problems reporting this information, the Victorian Department of Human Services has expressed, on behalf of their data working group that oversees the development of their palliative care unit record data collection, a preference to replace this item with ‘preferred language’ as this may be more relevant for services in determining whether an interpreter is required for the patient. In deciding the preferred standard for the community-based palliative care context it should be noted that:

- ‘preferred language’ is not directly equivalent with the concept of whether an interpreter is required, although would provide acceptable population-level data on the language profile of patients receiving palliative care
- ‘main language other than English spoken at home’ and ‘preferred language’ are different concepts, but both are agreed national data standards for the health care sector
- both require coding to the Australian Standards Classification of Languages (ASCL; ABS 2005).

Suggested improvements

The project team suggests that the PCDWG should advise whether this item should be retained or replaced with ‘preferred language’.

Living arrangements

This item provided an indicator of whether a patient lived alone or not. Almost one-fifth of the patients who participated in the pilot test lived alone (Table 3.11). This was the same for both males and females.

No issues were raised by the pilot test in relation to this item.

Table 3.11: Patients, by living arrangements

Living arrangements	Number of patients	Per cent
Lives alone	36	18
Lives with others	165	82
Total	201	100

Informal carer existence, co-residency status, and relationship to the patient

‘Informal carer existence’ is an indicator of whether a patient had someone, such as a family member, friend or neighbour, who provided regular and sustained informal care and assistance during the pilot period. A carer may be a person who receives a pension or benefit for their caring role but is not someone appointed by a community service or healthcare agency. The majority of patients participating in this pilot test had an informal carer (88%, Table 3.12).

Information was also collected on the carer’s co-residency status, that is, whether the carer, where one existed, lived with the patient or not. Carer co-residency was reported in relation to the patient’s *main* carer. The main carer is the person who provides the most care to the patient, that is, the person who provides the most significant care and assistance related to the person’s capacity to remain living at home or in a community setting. Of those patients who had an informal carer, a little over 90% of carers lived with the patient.

Information on the main carer’s relationship to the patient was also collected. Almost three-quarters (130) of main carers were a spouse or partner of the patient. Of the remaining main carers, 28 were children or a child-in-law, six were another relative, six were a friend or neighbour and five were a parent.

Table 3.12: Patients, by informal carer existence and co-residency status

Informal carer existence and co-residency status	Number of patients	Per cent
Has an informal carer	177	88
<i>Co-resident carer</i>	(161)	(80)
<i>Non-resident carer</i>	(14)	(7)
<i>Unknown</i>	(2)	(1)
Has no informal carer	23	11
Not stated	1	0
Total	201	100

Data item discussion

One agency contacted the project team via the telephone helpline to request information on how to report informal carer existence status for a patient who was living in a residential aged care service. This query highlighted the inappropriateness of this data item to people living in residential care or supported independent living settings. This could be overcome with the addition of a response category to the ‘informal carer existence’ data item that indicated that a response was not applicable as the person lived in a residential care or a supported independent living setting.

Suggested improvements

The project team suggests the addition of an additional response code to the 'informal carer existence' item for use on behalf of clients who live in residential care or supported independent living settings to indicate that the item has not been reported for this client because they live in such a setting.

Date and place of death of patient (and date of death accuracy indicators)

Eight patients died during the pilot collection period. The place of death for these clients was recorded as 'residential aged care setting' (3), 'private residence' (3), and 'inpatient setting – other than designated palliative care unit' (2).

Date of death accuracy indicators were reported for seven of the eight episode of palliative care clients who died during the pilot test. All of these were categorised as accurate for day, month, and year.

No issues were raised by the pilot test in relation to these items, although some broader issues in relation to date of death accuracy indicators are discussed in Section 4.4.

3.4.2 Information relating to episodes of palliative care

Section 1.4 provides a description of an episode of palliative care as it applies to the community-based palliative care client data set specification. There were 192 episodes of palliative care reported for clients during the pilot collection. One agency did not report this information (Form B) for any of their clients (10 clients) due to an administrative error.

Over three-quarters (81%) of the episodes of palliative care reported as part of the pilot test began before the pilot test start date, indicating that the majority of clients who participated in the pilot test were existing clients of the agencies. Fourteen episodes of care ended during the pilot test which was not unexpected given its short timeframe. Information on episode-end items is limited because of this.

It should be noted that 'episode of palliative care' as defined in this data collection, for most patients, will be akin to an 'episode of illness'. This definition varies from that currently used in other collections, such as the Palliative Care Outcomes Collaboration (PCOC), where an episode of illness could be made up of multiple episodes of care. Specifically, the PCOC currently requires a new episode of care to be reported whenever a setting change occurs for a palliative care patient either because the principal clinical intent of the care changes, the patient is admitted to hospital as an overnight patient, or at discharge/case closure. While these episodes are mappable to the episodes as defined in the client DSS, it may create some confusion for palliative care service providers, particularly for those that are participating in both collections. As such, it may be preferable to change the name of an 'episode of palliative care' to 'period of community-based palliative care' or similar.

Despite this potential for confusion, the definition used in the client DSS appeared to be accepted by service providers participating in the pilot test and probably reflects the most common practice. On the feedback form most agencies reported that they do not discharge their clients when they go to hospital unless there is an expectation that they will not return. Examples of reasons cited for non-return include: the client died, the client moved out of the area, and that palliative care services are no longer required.

Defining episodes of care in community-based services is often problematic, and is usually much easier to define for residential-type services. Statistical requirements, however, need to be balanced against practical considerations – such as the burden placed on service providers who may need to re-report a range of data at the commencement of each episode of care. Also, in the palliative care context, it is likely that there is relative ‘stability’ in the healthcare providers involved in care. Because of this, the PCOC is currently reviewing its requirements, and may consider allowing some ‘interruptions’ to care (for example, to allow for short hospital stays) within an episode of care. In light of this, the project team recommends that the agreed definition of ‘episode of care’ be retained at this stage (that is, episode of care is the period of care when a client receives services to improve their quality of life).

Suggested improvements

The project team suggests that the PCDWG consider whether ‘episode of palliative care’ should be renamed to ‘period of community-based palliative care’ or similar.

Referral date

The referral date relates to the date on which the agency received a referral for a specific client from another party for palliative care services.

Referral date was missing for one patient only (1%), although in a further eight instances (4%), the date reported was the patient’s date of birth.

Data item discussion

Reporting of ‘date of birth’ instead of ‘referral date’ occurred across five agencies, and is most likely attributable to the location of this item as the first data item on one of the data collection forms (Form B). As such, a small number of respondents have obviously assumed that this item was requesting ‘date of birth’. This error is unlikely to occur in an ongoing collection where the information requirements would be built into each agency’s information management systems which would locate this item in an appropriate context. As a result, no suggestions for further improvement of this item are recommended.

Source of referral

Respondents were asked to record the source of referral for each patient. Where referrals were made by medical practitioners on behalf of community-based palliative care agencies, inpatient facilities or residential aged care services, it was requested that the referral should be regarded as a referral from that particular agency/service/organisation rather than as a referral from the medical practitioner.

Just over one-third of referrals (67 referrals) for patients participating in this pilot were from inpatient facilities (Table 3.13). Medical practitioners, general (43 referrals) and specialist (29 referrals), also accounted for more than one-third of referrals.

‘Other sources’ of referral that were reported were: Motor Neurone Disease Association (3), ‘clinic’ (2), emergency department (1), employer of spouse (1), outpatient department (1), palliative care clinical nurse consultant based at a hospital (1), and a palliative care team (1).

Table 3.13: Episodes of palliative care, by referral source

Source of referral	Number of clients	Per cent
Self, carer(s), family or friends	18	9
Medical practitioner—general practitioner	43	22
Medical practitioner—specialist	29	15
Community-based palliative care agency	11	6
Community-based agency—other	11	6
Inpatient facility	67	35
Residential aged care service	1	1
Other source	10	5
Not stated	2	1
Total	201	100

Data item discussion

Less than 5% of cases had an ‘other source’ reported as the source of referral; however, most of these responses should probably have been recorded using existing categories. For example, Motor Neurone Disease Association should have been reported against the category ‘community-based agency – other’.

Suggested improvements

The project team suggests the addition of further guidelines to the ‘source of referral’ item to assist users in their selection of the categories available. In particular, more instructions are required on the use of the ‘community-based agency – other’ and ‘other source’ categories.

Episode (of palliative care) start date and end date

Information was requested on the date on which the patient was first assessed and accepted for palliative care by the agency (episode start date) and the date on which the episode ended. The episode end date may be the date of last service contact which follows the patient’s death (to complete immediate follow-up activity) or case closure for other reasons.

Information on episode start and end dates allows us to calculate the length of an episode of palliative care. In this pilot test, the average duration of an episode for episodes that ended (14 episodes) was 74 days. The average duration of an episode for episodes that had not yet ended, but where the pilot test end date was applied, was 172 days. Table 3.14 provides further information on the duration of episodes of care for continuing episodes (that is, for those episodes that had not yet ended at the time of reporting).

‘Episode start date’ was missing for two patients (1%), and in two further cases (1%) the date supplied pre-dated the referral date.

The average period of time between referral and episode start (excluding cases where erroneous data were supplied) was 5.5 days.

Table 3.14: Episodes of palliative care, by duration of episode of palliative care for continuing episodes of care

Duration of episode (days) ^(a)	Number of clients	Per cent
0–30	47	27
31–60	27	16
61–90	19	11
91–120	17	10
121–150	7	4
151–500	44	25
501+	13	7
Total^(b)	174	100

(a) Actual pilot period end dates were used in calculating the duration of an episode. For most agencies the pilot period ended on 18 June 2006; five agencies started their pilot period later—the end date for these agencies was 30 June 2006.

(b) Four records without an end date were excluded as the start dates for these records were either missing or later than the pilot test end date.

Data item discussion

Although agencies participating in the pilot test did not experience any problems reporting this information, comments made by the Victorian Department of Human Services on behalf of their data working group that oversees the development of their palliative care unit record data collection, suggest that some further work on defining the point at which an episode commences will be needed. Specifically, the Victorian Data Working Group, in reviewing requirements for their palliative care minimum data set, found that approximately 15% of clients who are referred to a palliative care agency that provides community-based care do not go on to receive care from that agency in a community setting (even though significant work may have occurred to assess the patient, develop care plans, and so on; Perry, personal communication). In most cases, these patients remain in hospital until their death. This raises the need to clearly define which episodes of care should be reported as part of a national data set: all episodes that have commenced (that is, once the client has been accepted for care regardless of whether a service contact has occurred)? Or only those episodes that have commenced and where at least one service contact has occurred? In developing guidelines on this issue, it should be noted that:

- a service contact can occur on behalf of a patient, and the patient or their carer/family/friend(s) need not be present at all service contacts – therefore, there may be service contacts associated with an episode even though the patient has not been seen directly by the agency in a community setting
- where a patient or their carer/family/friend(s) has not been seen directly there is likely to be a significant level of missing data. For example, a referral to a community palliative care agency from a hospital may include some basic clinical data and details such as date of birth and sex, but it is not likely to include ‘country of birth’ or ‘Indigenous status’
- the PCOC data set defines an episode of community-based palliative care as commencing when the patient ‘meets the criteria for palliative care and is first seen by the palliative care service’ (PCOC 2006).

Suggested improvements

To provide greater consistency with the PCOC-defined episodes of palliative care, the project team suggests that an episode of palliative care should commence at the time that the patient is first seen by the palliative care service provider.

Principal diagnosis

Information was requested on the diagnosis mainly responsible for occasioning a patient's episode of palliative care in terms of whether it was a malignant neoplasm or other diagnosis. Eighty-six per cent of patients (166 patients) who participated in the pilot test presented with a principal diagnosis of 'malignant neoplasm' (Table 3.15).

Eight other types of principal diagnosis were identified: motor neurone disease (7), respiratory disease (6), renal failure (5), liver disease (2), cardiac failure (1), lymphoma (1), inclusion body myositis (1), and mesothelioma (1) with differing uses of terminology. For example, terms such as 'COPD 1' and 'end-stage COPD' were used.

Table 3.15: Episodes of palliative care, by principal diagnosis

Principal diagnosis	Number of clients	Per cent
Malignant neoplasm	166	86
Other diagnosis	24	13
Not applicable—patient not receiving care	1	1
Not stated	1	1
Total	192	100

Data item discussion

- At least two of the responses reported as an 'other diagnosis' should have been coded to 'malignant neoplasm' (mesothelioma and lymphoma).
- The PCDWG should review the information gathered during the pilot test and decide whether the current permissible values should be retained as tested or expanded. If the PCDWG prefers to retain the current code set, it is suggested that the item 'principal diagnosis' should be renamed as a 'malignancy indicator'. If an expanded code set is needed then a 'principal diagnosis grouping' item should be developed. This item would need to be based on groupings within the International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification (ICD-10-AM; NCHH 2006) which provides the current national standard for reporting of principal diagnosis in other data collections (HDSC 2005). Groupings could occur at 'chapter' levels (for example, Certain infectious and parasitic diseases; Neoplasms; Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism; Endocrine, nutritional and metabolic diseases) or a listing of the most common diagnoses could be developed (based on admitted patient data).

Suggested improvements

The project team suggests that the PCDWG review the information gathered during the pilot test and decide whether the current code set should be retained or expanded so as to be able to capture information on the most common diagnosis groupings responsible for palliative care services.

Phase of care at first assessment

This item collected information on the client's stage of illness at their first assessment by the palliative care agency and provides some information on the appropriateness of the referral to the palliative care service. Stage of illness is reported against five phases of palliative care: stable, unstable, deteriorating, terminal, and bereavement. The phase of care at first assessment for 42% of the clients participating in this pilot test was reported as 'unstable' (Table 3.16).

Table 3.16: Episodes of palliative care, by phase of care at first assessment

Phase of care	Number of clients	Per cent
Stable phase	52	27
Unstable phase	81	42
Deteriorating phase	52	27
Terminal phase	2	1
Bereavement phase	0	0
Not stated	5	3
Total	201	100

Data item discussion

For two of the five patients for whom this information was not reported, their episodes of care commenced within the pilot test period and this information should have been reported. Both were attributable to one agency.

For the remaining three patients for whom this information was missing, their episodes of palliative care began more than two months before the pilot test period. It is likely, therefore, that this information was not reported in the pilot test because this information was not available in the patient's medical record and it was not possible to report this information retrospectively. This is not likely to be an issue in an ongoing collection where information systems and processes would need to be modified to capture this information at the beginning of the episode of care. As a result, no suggestions for the further improvement of this item are recommended.

Reason for ending episode

This item collected information on the reason a client's episode of palliative care ended, if applicable. Fourteen episodes of palliative care ended during the pilot collection period. The main reason for ending an episode was 'patient death or bereavement phase end' (8 episodes, Table 3.17).

One episode was reported as ending for an 'other' reason, which was given as the patient entering a residential aged care facility.

Table 3.17: Reason for ending an episode of palliative care

Reason	Number of clients	Per cent
Patient death or bereavement phase end	8	57
Discharged to specialist palliative care provider	3	21
Discharged to other health care provider	1	7
Other reason	1	7
Not stated	1	7
Total	14	100

Data item discussion

Only one response suggested that an episode of care ended for an 'other reason' and this appears to have been correctly reported to this category. Nevertheless, there may be some ambiguity about coding responses where the episode of care ended because the patient entered a residential aged care facility and the PCDWG may wish to consider providing firm guidelines on the most appropriate response code for this scenario.

Suggested improvements

The project team suggests that further guidelines be provided to clarify that patients who are discharged to a residential aged care facility should be coded to 'other reason'.

3.4.3 Information relating to palliative care service contacts

For all clients participating in the pilot test, information was requested on (up to) 10 service contacts provided during the episode of palliative care that occurred within the pilot test period, in addition to information on all service providers involved in these service contacts. Information on the types of service contacts and service providers that were in scope for this collection is provided in Section 2.6.

There were 833 service contacts provided as part of an episode of palliative care during the pilot period. The average number of service contacts in the pilot test period for each client was 4.1, with the number of service contacts provided to any one client ranging between 1 and 15. (It should be noted that, for the purposes of the pilot test, agencies were only required to report on a maximum of 10 service contacts for any one patient. Information was, however, reported on more than 10 service contacts for seven patients.)

These service contacts involved 1,066 service provider contacts, although information on service providers was missing for 18 service contacts. Excluding service contacts where the service provider information was not reported, the average number of service providers in attendance at a service contact was 1.3. Eighty per cent of service contacts involved one service provider, 13% two service providers, and 8% three or more service providers.

Participating agencies did not report any difficulties applying the definition of 'service contact' within an episode of palliative care.

Service contact date(s)

In the pilot test period most service contacts (679 service contacts) involved the delivery of only one service contact to the client on that particular day. Sixty-eight clients received two service contacts on the same day, and a small number of clients received three service contacts on the same day (six clients).

Information on the date of the service contact was missing from two service contact records – in one case ‘date of birth’ was supplied, and in the other the information was missing.

No issues were raised by the pilot test in relation to this item.

Service recipient type

In this pilot test almost half of all service contacts (47%) involved the patient and their carer(s)/family/friends (Table 3.18). One-third of service contacts (34%) involved patients only.

Table 3.18: Episodes of palliative care service contacts, by recipient type

Recipient type	Number of service contacts	Per cent
Patient	283	34
Patient and carer(s)/family/friends	394	47
Carer(s)/family/friends	46	6
Other professional(s)/service provider(s) only	102	12
Other recipient	2	0
Not stated	6	1
Total	833	100

Data item discussion

- Multiple entries for service recipient type were recorded for 10 service contacts. Six of these were easily corrected as they were combinations that actually represented code 2 ‘patient and carer(s)/family/friends’. However, there were four entries where respondents recorded codes 1 (patient) or 2 (patient and carer(s)/family/friends) in combination with code 4 ‘other professional(s)/service provider(s) only’, probably indicating that the service contact involved all of these parties. Instructions on how to code the type of recipient when the categories ‘patient’, ‘patient and carer(s)/family/friends’, or ‘carer(s)/family/friends’ also involved ‘other professional(s)/service provider(s)’ were not provided in the guidelines.
- One agency suggested via the feedback form that this item needs to further qualify the role that the parties played in the service contact by being able to nominate whether each party was involved ‘directly’ or ‘indirectly’ in the service contact.

Suggested improvements

Although this was a relatively minor problem affecting just over 1% of service contact records, the project team suggests:

- changing the permissible value labels to clarify that each of these recipient types would (by definition) involve a service provider
- the addition of instructions to the guidelines to make it clear that the codes 'patient', 'patient and carer(s)/family/friends', and 'carer(s)/family/friends' can also include 'other professional(s)/service provider(s)'.

Service delivery setting

This item provides information on the type of setting in which the client was located when the palliative care service was provided. In the pilot test, three-quarters of service contacts (632 service contacts) were delivered in private residences (Table 3.19).

Respondents who reported that the service contact occurred in a 'residential – other setting' or 'non-residential setting' were asked to specify the setting. For those who reported 'residential – other', the specific settings were reported as: hospital/hospice (6), independent living unit (2), and 'private rooms' (1). For those who reported 'non-residential setting', the specific settings were reported as: 'clinic' or outpatient department (23), 'palliative care office' (3), GP's surgery (2), hospital (2), inpatient (1), emergency department (1), 'community health' (1), work setting (1), and 'independent living' (1). The specific setting was not reported for one service contact.

Table 3.19: Episode of palliative care service contacts, by service delivery setting

Service delivery setting	Number of service contacts	Per cent
Private residence	632	76
Residential—aged care setting	28	3
Residential—other setting	9	1
Non-residential setting	36	4
Not applicable (client not present at service contact) ^(a)	104	12
Not stated	24	3
Total	833	100

(a) A response was only required where the type of service recipient was reported as 'patient', 'patient and carer(s)/family/friends', or 'carer(s)/family/friends only'.

Data item discussion

- Errors were found in the data provided for six service contacts (1%). In these cases, respondents reported the service delivery setting when it was not required because there was no patient or other client involved in the service contact. In a further four cases, the service delivery setting was reported, but because information on the service recipient type was not available, it is not possible to assess whether these cases have been reported correctly.
- Data on the service delivery setting was missing for 24 service contacts (3%). In these cases respondents either did not complete the question on service delivery setting

(5 service contacts) or selected 'not applicable (patient not present at service contact)' (code 99), although they had indicated in the previous question that a patient or other member of the client group was present at the service contact (19 service contacts).

- Information on service delivery setting was only required when there was a patient or other client member involved in the service contact. However, a minor error occurred in the data collection forms whereby respondents who selected 'other professional(s)/service provider(s) only' or 'other recipient' to the question on service recipient type were instructed to 'Go to question 4' and therefore not complete details on service delivery setting. Additionally, one of the permissible values for 'service delivery setting' was 'not applicable (patient not present at service contact)'. This was problematic as respondents in one question were being asked to skip the question, but in the other question were being asked to select a code that suggested that the question was 'not applicable'. While these instructions are not inconsistent, they may have confused respondents.
- At least some of the missing data for this question may also be attributable to errors made in the previous question relating to service recipient type. Specifically, where respondents may have (erroneously) selected 'patient' and 'other professional(s)/service provider(s) only' they may have seen the instruction to 'Go to question 4' and therefore failed to complete the service contact setting. This type of error is unlikely to occur in an ongoing collection.
- It is likely that some of the responses coded to 'residential – other' and 'non-residential setting' should have been coded to other response codes or were out of scope for the collection as the service was not provided in a non-admitted patient setting. For the nine 'residential – other' responses, it is likely that three should have been coded to other response codes and the remaining six may not be in scope for this collection; for the 36 'non-residential setting' responses, one should probably have been coded elsewhere and three were potentially out of scope.
- One agency suggested via the feedback form that it was not clear whether this referred to the setting of the patient or the provider. Although the guidelines do specify that it is the setting of the 'client' that is of interest, this comment does suggest that this point needs to be clearer.

Suggested improvements

The project team suggests:

- simplifying the item so that this information is only required in respect of the *patient* and that reporting therefore should only occur when a patient is involved in a service contact. This would mean, in the future, this information would not be collected where the recipient of the service contact is a carer/family/friend of the patient only
- removing code 99 ('not applicable (patient not present at service contact)') from the list of options available.

Session type

Information was requested on whether each service contact provided during an episode of palliative care was to an individual client (group) or group of clients. Note that services

delivered to an individual client may actually have involved more than one person. For example, a service provided to a patient and their carer is considered to involve one client only.

Ninety-seven per cent of service contacts (805 service contacts) were provided to an individual client group. There were 23 service contacts which involved a group of people, that is, more than one client (group). Information on the session type was missing for five service contacts.

No issues were raised by the pilot test in relation to this item.

Main and other purpose(s) of service contact

Agencies were asked to nominate the main purpose of each service contact and any other purpose(s) of the service contact. The pilot test found that the main purpose of over half of all service contacts (480 contacts; 58%) was to provide symptom control/pain management for clients (Table 3.20). This was followed by case management and/or care coordination which accounted for 160 service contacts (19%). Responses for the category 'other purpose' for the item 'main purpose of service contact' included: provision of equipment (9), provision of domestic assistance (1), social work (1), assistance with transport (1), chemotherapy (2), liaison with services (1), and 'monitoring' (1).

The most common purpose reported for the item 'other purpose(s) of service contact' was 'spiritual care or support of the patient/carer(s)/family/friends' (31%). Support of this kind included social support, emotional support, respite care, spiritual care and bereavement support. The category 'other purpose' for the item 'other purpose(s) of service contact' was selected for 47 service contacts (4%). Responses included: provision of equipment (18), provision of domestic assistance (7), social support (5), education (4), assistance with transport (2), counselling (2), hospital transfer (1), liaison (1), psychosocial assessment (1), in-home respite (1), medication use supervision (1), crisis intervention (1) and 'life extinct' (1). Details about the specific purpose of two service contacts were not provided.

Table 3.20: Main and other purpose of service contact, by client type

Client type/ purpose(s)	Main		Other	
	Number	Per cent	Number	Per cent
Patient and carer(s)/family/friends				
Symptom control/pain management	480	58	156	13
Other clinical or health related care	76	9	256	21
Case management and/or care coordination	160	19	234	19
Spiritual care or support of the patient/carer(s)/family/friends	50	6	379	31
Personal care	45	5	150	12
Other purpose	16	2	46	4
Not stated	5	1	0	0
Carer(s)/family/friends only				
Spiritual care or support of the patient/carer(s)/family/friends	1	0	0	0
Other purpose	0	0	1	0
Total	833^(a)	100	1,222^(b)	100

(a) Total number of 'main' purpose items reported (single selection only allowed).

(b) Total number of 'other purpose(s)' items reported (multiple selection allowed).

Data item discussion

- Eighteen records were submitted with more than one selection ticked for the 'main' purpose of the service contact. Extra entries recorded were moved to question 6 ('other purpose of service contact') wherever possible. This may indicate that staff found it difficult to identify only one main purpose, especially for patients with complex problems.
- Just over one-quarter of all service contact returns (218) contained an error for the 'other purpose(s)' question. Most errors occurred when respondents entered the answer they gave to the previous question (which asked staff to nominate the 'main purpose' of the service contact) in addition to their answer to this question which asked staff to nominate the purpose(s) 'other than the main purpose' of the service contact. This may have occurred because, where a number of tasks are carried out at a service contact (including more than one task carried out for the same purpose), it appears that the 'main purpose' may have been re-reported as an 'other' purpose so that all tasks undertaken are captured even though it was intended that responses to question 6 ('other purpose') should exclude those provided at question 5 ('main purpose').
- At least four of the 'other' responses provided for main purpose of service contact, and 12 of the 'other' responses provided for other purpose of service contact should probably have been reported against other existing codes. For example, 'counselling' and 'social support' should have been reported as 'spiritual care or support of the patient/carer/family/friends', and 'liaison' should probably have been coded as 'case management and/or care coordination'.
- Responses to these questions suggest some changes/additions to the options available for the 'main' and 'other purpose(s)' of the service contact items could be made, namely:
 - splitting of code 4 'spiritual care or support of the patient/carer/family/ friends' to 'spiritual care', 'support care', and 'bereavement support' (or similar)
 - addition of codes for provision of equipment, domestic assistance, transport, and education to assist agencies to accurately record this information.
- Feedback from three agencies highlighted difficulties experienced with these items:
 - One agency commented on the requirement to nominate the 'main' purpose of a contact when palliative care involves a 'holistic' approach: 'It concerns me that assumptions are made that you can "reduce" palliative care to tasks—I feel this is a damaging assumption. "Holistic" means just that in palliative care'.
 - One agency commented that the permissible values were not specific enough.
 - A third agency commented (in relation to 'other purpose of service contact' where multiple responses can be selected) that in many cases you could tick all of the categories provided, and therefore they were not sure how useful or relevant the data item is.

Suggested improvements

The project team suggests:

- that the PCDWG amend the list of options available for the main and other purpose(s) items so that code 4 'spiritual care or support of the patient/carer/family/friends' is split into separate categories. The PCDWG would need to consider which specific categories should be included, for example, 'bereavement support', 'social support' and 'spiritual care'
- that the PCDWG decide if separate categories are required to capture activity such as provision of equipment, domestic assistance, counselling, transport, education, and social work (currently captured under the category 'other' for the main and other purpose(s) items)
- providing further information in relation to each code to assist service providers to report against these codes
- adding guidelines to the 'main purpose of service contact' item acknowledging that palliative care usually involves a holistic approach but that in a routine data collection there is a need to focus just on reporting the principal activities that occur in order to manage the burden that the data collection may impose on data providers.

Occupation of service provider and specialist palliative care provider indicator

Service providers were asked to nominate their occupation and provide an indication of whether they had completed training or held qualifications in providing care specifically to palliative care clients. The pilot test found that three-quarters of all service contacts involved registered nurses (Table 3.21). Of these, 77% reported themselves to be 'specialist' palliative care providers. For most states and territories the percentage of specialist palliative care registered nurses was 80% or higher. One state reported that 61% of their registered nurses were specialist providers.

Medical practitioners (general and specialist) represented 9% of service providers present at a service contact. The remaining professions combined accounted for 18% of all service providers.

Across all staff categories, 71% of service provider contacts for which information was obtained in the pilot test involved a 'specialist' palliative care provider.

Participants provided information on the occupations of 'other' staff who may be involved in palliative care service contacts. Three service contacts involved volunteer coordinators/managers, three palliative care coordinators, two enteral tube specialists, and one a stomal therapist.

Table 3.21: Episode of palliative care service contact, by occupation of service provider and specialist flag

Occupation of service provider	Specialist status ^(a)			Total	Per cent
	Non-specialist	Specialist	Unknown		
Medical practitioner—specialist	3	53	0	56	5
Medical practitioner—general practitioner	26	9	1	36	3
Registered nurse	174	608	4	786	74
Enrolled nurse	15	30	0	45	4
Spiritual carer	1	5	0	6	1
Grief counsellor	4	2	0	6	1
Psychologist	3	2	0	5	0
Physiotherapist	6	8	0	14	1
Occupational therapist	15	13	0	28	3
Speech pathologist	2	0	0	2	0
Social worker	4	13	0	17	2
Dietitian	4	0	0	4	0
Podiatrist	5	0	0	5	0
Aboriginal and Torres Strait Islander health worker	0	0	1	1	0
Personal care assistant	33	8	0	41	4
Other counsellor	0	0	0	0	0
Other occupation	4	7	3	14	1
Total	299	758	9	1,066	100

(a) A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients.

Data item discussion

- It was suggested via feedback from one agency that experience in the area of palliative care should also qualify as a criterion for a 'yes' response to this question. Two agencies also queried what the term 'training' meant and suggested that the current guidelines were not specific enough or may need to be defined within each occupational field.
- The Victorian Department of Human Services, on behalf of the data working group that oversees the development of their palliative care unit record data collection, also reported concerns that the permissible values may not be mutually exclusive. In particular, it was suggested that the role of 'grief counsellor' is often performed by social workers, psychologists and nurses.

Suggested improvements

The project team suggests:

- adopting a broader level categorisation for the 'occupation of service provider' item which retains consistency with the Australian and New Zealand Standard Classification of Occupations (ABS 2006a)
- removal of the category 'grief counsellor' and redeveloped broader categorisation to include occupations that provide formal grief and bereavement counselling (a subset of this item is used when collecting the occupation of a service provider who provides care during an episode of grief and bereavement counselling)
- addition of guidelines to the 'specialist provider flag' item to clarify the term 'training'.

Service contact method

This item provided information on the method used by a service provider to make contact with, or on behalf of, a client at a service contact. Almost three-quarters of service contacts were provided face-to-face (760 service contacts), with most of the remaining contacts occurring via telephone (Table 3.22). Twenty per cent of service contacts (167 service contacts) involved more than one contact method.

Nine service providers reported an 'other method' for the service contact method. Eight of these were described as either a 'case meeting' or 'palliative care case conference'. The other service contact involved collecting medicine from a pharmacy on behalf of a patient. All of these responses were provided by just two palliative care agencies.

Table 3.22: Service provider (episode of palliative care service contact), by contact method

Service contact method	Number	Per cent
Face-to-face	760	71
Telephone	261	24
Written	24	2
Telehealth	—	—
Other method	9	1
Not stated	12	1
Total	1,066	100

Data item discussion

- No agencies reported using 'telehealth' as their method of contact.
- While this was a minor problem (affecting less than 1% of service provider records), the eight service providers who were reported as being involved in service contacts occurring via 'case meeting' or 'palliative care case conference' should all have been coded to existing permissible values based on the mode by which the service provider participated in the case conference/meeting.

Suggested improvements

The project team suggests that the guidelines for this item be further developed to provide guidance for selection of the contact method where a service provider is involved in a 'case meeting' or 'case conference'. Instructions should make it clear that each service provider should record their method of contact during the case meeting/conference.

3.4.4 Information relating to episodes of grief and bereavement counselling

Information collected about episodes of grief and bereavement counselling included start and end dates and the date of death of the patient (if available). All other information collected during an episode of this kind related to service contacts. The client DSS does not contain data items that describe the carer(s)/family or friends who are the grief and bereavement counselling client(s) – it only describes the services they receive.

Thirty-six episodes of grief and bereavement counselling were reported by 11 agencies (average of 3.3 clients per agency that reported any episodes of grief and bereavement care). However, in analysing the data provided for these episodes of grief and bereavement counselling, it was clear that the conceptual basis of an episode of grief and bereavement counselling may not have been well understood or applied. In particular, it was not clear that palliative care agencies had differentiated between grief and bereavement *counselling*, which referred to the provision of formal grief/bereavement counselling and would usually be evidenced by the fact that a separate patient record would be created for the client(s), and bereavement *support*, which implies a less formal level of care that would be expected to be provided as part of almost all episodes of palliative care. Most of these errors were identified because the occupations of the service providers did not match that expected for staff providing formal bereavement/grief counselling. Also, two agencies initiated, within the pilot period, episodes with services other than 'bereavement/grief counselling' (which would be the main type of assistance expected in most cases). These difficulties were not evident from feedback provided via the feedback form or from queries to the telephone helpline (where only one query was received about how to apply the definition of an episode of grief and bereavement counselling).

These apparent problems in applying the guidelines led the project team to follow-up with a number of agencies to clarify their responses. This follow-up found that half (6) of the agencies involved in the pilot who reported episodes of grief and bereavement counselling appeared to recognise that an 'episode of grief and bereavement' was initiated by a carer/family/friend's need for formal bereavement/grief counselling. The other half (5) of the agencies who reported episodes of grief and bereavement counselling did not apply the guidelines/method requested in the pilot test documentation. These five agencies reported 15 episodes of grief and bereavement counselling, involving 30 service contacts. Follow-up with these agencies confirmed that some palliative care staff:

- believed that 'bereavement support' was reportable within an 'episode of grief and bereavement counselling' regardless of whether a client required formal bereavement/grief counselling
- interpreted 'bereavement/grief counselling' to mean 'bereavement support'. Almost all of the agencies who reported in this manner informed the project team that their services do not provide formal 'bereavement/grief counselling services'. Most clients are

referred on to other organisations or staff do their best and provide informal 'bereavement/grief counselling'.

The feedback form asked agencies to provide information about circumstances under which they would create a new client record for a carer/family/friend who is receiving bereavement support or bereavement counselling. Almost one-third of agencies (seven agencies; three from one jurisdiction) stated that they create new client records for bereavement support or bereavement counselling clients. New records are created either immediately following a patient's death or six weeks after a patient's death (if it appears ongoing support is needed). As a result it appears that receipt of bereavement counselling alone is not a trigger to create a new client record for some agencies; it would seem that a new record is created if ongoing bereavement support and/or counselling is required. While some caution needs to be taken in interpreting this information (as it appears that these new records are used to record both bereavement support and/or bereavement counselling and it is not clear that all of these agencies provide formal grief or bereavement counselling), it does support the view that the definition of an episode of grief and bereavement counselling needs to be more specific about the conceptual distinction between it and an episode of palliative care. In particular, the definition should not rely on definitions based on operational/administrative processes (such as an episode of grief and bereavement counselling commencing when a new health care record is created to record details of care provided to the carer(s)/family/ friends who are cared for in the new episode) as these practices appear to vary widely.

Suggested improvements

The project team suggests that the definition of an episode of grief and bereavement counselling needs to be improved. In particular, the conceptual basis of an episode of grief and bereavement counselling needs to be better defined, and not dependent on describing operational/administrative processes that may vary across palliative care agencies.

Some broader issues in relation to recording information about episodes of grief and bereavement counselling are also discussed in Section 4.1.

Information obtained on the 36 episodes of grief and bereavement counselling that were reported as part of the pilot test are presented in the following sections, but it is acknowledged that some of the assessments of the data items are necessarily limited because of the inconsistent application of the concept of an 'episode of grief and bereavement counselling'. This will have confounded some of the resulting data. Suggested improvements have been made, however, these should be considered in the context of the possible re-development of this episode definition.

Client/patient identifiers

Two client identifiers were requested for each episode of grief and bereavement counselling reported: the client identifier assigned by the palliative care agency to the carer(s)/family/friends who were registered for grief and bereavement counselling, and the patient identifier assigned by the palliative care agency to the related patient (the person with a life-limiting illness), if applicable. This approach was taken so that record linkage between episodes of palliative care and episodes of grief and bereavement counselling could occur.

Data item discussion

- Client identifiers (for the carer(s)/ family/ friends who were receiving grief and bereavement counselling) were missing for 10 of the 36 clients who received grief and bereavement care, although a patient identifier was provided for all of these clients.
- There were seven episodes of grief and bereavement counselling where the client and patient identifiers were the same. These forms were completed by three agencies; one agency completed these details for five of the episodes of grief and bereavement counselling.
- There was one client where the client identifier used for registering a patient for an episode of palliative care was used as both the client and patient (patient) identifiers for an episode of grief and bereavement counselling (Form D).
- These errors are likely to have occurred because:
 - staff have not understood that the carer(s)/ family/ friends were to be registered as a client in their own right when receiving grief and bereavement care, and that collection of the patient identifier was purely for linking the carer(s)/ family and friends to the person with a life-limiting illness, or
 - staff saw collection of this information as a continuation of an episode of palliative care, suggesting that the care provided to the carer(s)/ family/ friends was really bereavement support and did not include any formal grief and bereavement counselling.
- Patient identifiers were not provided for three of the 36 episode of grief and bereavement clients. A client identifier was provided for all of these clients. This information may not have been available, or the patient may not have been a client at the service.

Many of the problems experienced by palliative care agencies in completing this information were likely a direct result of problems experienced in applying the proposed definition of an episode of grief and bereavement counselling (outlined above), and perhaps some uncertainty about identifying the 'client' and the 'patient'. No suggested improvements have been proposed, but it is acknowledged that some further development of this item is required and this item is further discussed in Section 4.3.

Episode (of grief and bereavement counselling) start date and end date

Twenty-seven of the 36 episodes for which data were reported began before the start of the pilot collection. Two episodes of grief and bereavement ended during the pilot test. One episode finished on the same day that it commenced, the other lasted one day. The average duration of an episode for episodes that did not end, but where the pilot test end date was applied, was 68 days.

'Episode start date' was supplied for all episodes of grief and bereavement counselling, that is, there were no missing data for this item.

No issues were raised by the pilot test in relation to this item.

Date of death of patient (and date of death accuracy indicator)

Information was sought on the date of death of the patient where this was known and if applicable. Dates of death were supplied for 32 episodes of grief and bereavement

counselling. For 25 of these cases the episode of grief and bereavement counselling started on the same day as the patient death or later; for the remaining seven cases, the episode of grief and bereavement counselling started before the patient had died. In the former case the average length of time between patient death and the start of the episode of grief and bereavement counselling was 90 days; and in the latter case, the average time between commencement of the episode and patient death was 31 days.

Date accuracy indicators were supplied for just over half of the dates of death (19). Eighteen of these were categorised as accurate for day, month, and year.

Data item discussion

- There were four episodes of grief and bereavement counselling where a date of death of the patient was not provided. This most likely indicates that the patient had not died at the time of the pilot test (although an episode of grief and bereavement had commenced), but could also indicate that the date of death was not known which may be the case if the patient was not actually a client of the palliative care agency providing the grief and bereavement counselling.
- The rate of missing data for the date (of death) accuracy indicators is relatively high (41%). This may be related to the retrospective nature of this item in the pilot test, that is, agencies were being asked to extract information from existing records rather than asking them to collect the information prospectively. It is also possible, in at least some cases, that the information would have been provided by the patient's family members and palliative care agencies may have considered it inappropriate to have questioned the family members further about the accuracy of the date provided.

Although the rate of missing data for the date accuracy indicators was high, suggested improvements have not been made to this item in light of the need to firstly review and redevelop the concept of an episode of grief and bereavement counselling, and also the need to further specify specific intentions in relation to statistical data linkage (see Section 4.4). Some focus-testing of this item may be required in the future to specifically identify the issues that palliative care agencies had in providing information on the accuracy of the date of death of the patient.

3.4.5 Information relating to grief and bereavement counselling service contacts

For all clients participating in the pilot test, information was requested on (up to) five service contacts provided during their episode of grief and bereavement counselling that occurred within the pilot test period. Information on the types of service contacts that were in scope for this collection is provided in Section 2.5.

Information collected about services provided to clients during an episode of grief and bereavement counselling was limited by the number of agencies that provided these services in the reporting period.

On the whole, participating agencies did not report any difficulties applying the definition of 'service contact' within an episode of palliative care, although one agency contacted the project team via the telephone helpline to clarify whether data should be reported on service contacts provided by telephone within an episode of grief and bereavement counselling.

Service contact date

Seventy-one service contacts were provided to clients during the pilot period. The average number of service contacts for an episode of grief and bereavement counselling was 2.0, with the number of service contacts for any one client ranging between 1 and 4. Most clients received only one service contact on a particular day (58 service contacts), although five clients received two service contacts on one day, and one client received three service contacts on one day.

No issues were raised by the pilot test in relation to this item.

Session type

This item provides an indication of whether the service provided during an episode of grief and bereavement counselling was provided to an individual client (group) or a group of clients. The pilot test found that almost all service contacts were provided to clients on an individual basis (99%). There was only one service contact that involved a group of people, that is, people from more than one client group.

No issues were raised by the pilot test in relation to this item.

Type of assistance provided

This item requested information on the main type of assistance provided to the client at each service contact during an episode of grief and bereavement counselling. During the pilot test period almost three-quarters of service contacts (52 contacts) mainly involved the provision of bereavement/grief counselling (Table 3.23).

‘Other counselling’ was recorded as the type of assistance provided during eight service contacts. All of these services were described by data providers as bereavement/grief ‘support’ or ‘informal counselling’ and seven were provided by palliative care nurses.

Table 3.23: Episode of grief and bereavement counselling service contacts, by type of assistance

Type of assistance	Number	Per cent
Bereavement/grief counselling	52	73
Spiritual care	3	4
Social support	8	11
Other counselling	8	11
Total	71	100

Data item discussion

- All of the service contacts reported as ‘other counselling’ should probably have been recorded as ‘social support’, based on the information provided.
- Clients who received bereavement ‘support’ under the category ‘other counselling’ did not receive bereavement/grief counselling during the pilot collection period, although they may have received this prior to the pilot test start date. For one client, there was one service contact for bereavement support where the start of the episode of grief and bereavement care was the same as the date of the first service contact. This suggests that this client’s service should have been recorded against an episode of palliative care.

- One agency commented via the feedback form that many service contacts with clients may encompass all of the types of assistance outlined in this data item.

Suggested improvements

The project team suggests:

- PCDWG consider replacing the category 'social support' with 'bereavement support'. Addition of this category to options available may assist in identifying which clients are receiving bereavement support services during an episode of palliative care versus an episode of grief and bereavement counselling (assuming that 'bereavement support' is added to the 'main purpose of service contact' item as recommended earlier in this report). The final codes decided for this item should be consistent with the codes decided for the 'Main purpose of service contact' reported for episode of palliative care service contacts
- changing the category 'other counselling' to 'other'.

Occupation of service provider and specialist palliative care provider indicator

Service providers were asked to nominate their occupation and provide an indication of whether they had completed training or held qualifications in providing care specifically to palliative care clients. 'Other counsellors' and social workers provided most of the grief and bereavement service contacts (35% and 34% respectively) and a further 23% were provided by grief counsellors (Table 3.24). Specific 'other counsellor' occupations were reported as palliative care nurse (10), clinical nurse (8), loss and grief coordinator (3), support volunteer (2), enrolled nurse (1), and general practitioner (1).

Eighty-seven percent of services (62 service contacts) were provided by 'specialist' providers, that is, a person who has completed training or has qualifications in providing care specifically to palliative care clients.

Table 3.24: Episode of grief and bereavement counselling service contact, by occupation of service provider and specialist flag

Occupation of service provider	Non-specialist	Specialist status ^(a)	Specialist status unknown	Total	Per cent
Grief counsellor	—	16	—	16	23
Psychologist	3	1	—	4	6
Spiritual carer	2	—	—	2	3
Social worker	—	24	—	24	34
Other counsellor	3	21	1	25	35
Total	8	62	1	71	100

(a) A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients.

Data item discussion

- Analysis of occupations of service providers by type of assistance provided revealed there may be a need for clearer guidelines and better definitions around who can provide grief and bereavement counselling. Bereavement/grief counselling was provided at 52 (out of 71) of the episode of grief and bereavement counselling service

contacts and, of these, 22 were provided by spiritual carers, 15 by grief counsellors, 6 by registered nurses, 4 by psychologists, 3 by palliative care nurses, 1 by a general practitioner, and 1 by an enrolled nurse. Given that 'grief and bereavement counselling' was intended to refer to formal counselling only by a qualified counsellor, it is likely that the care being provided by many of these professionals was more akin to 'bereavement support' rather than 'bereavement counselling'. While people within a range of occupation groups may possess the relevant skills and/or have undertaken appropriate training to conduct formal counselling, the data do suggest that the guidelines have been interpreted more broadly.

- One agency commented via the feedback form that there was no provision to record information on volunteers (who provide most of their services). Services provided by volunteers were explicitly excluded from the pilot test as discussed previously (Section 2.5) and 'volunteers' were therefore not included in the list of permissible values. However, this comment again reinforces the view that the conceptual basis of an episode of grief and bereavement counselling, and particularly its focus on providing *formal* grief and bereavement counselling, has not been well understood as it is unlikely that volunteers would be delivering the kind of formal grief and bereavement counselling that was intended.

Suggested improvements

The project team suggests:

- reworking the options available (and supporting guidelines) for the 'occupation of service provider' to reflect those re-developed for 'occupation of service provider(s)' as it applies to an episode of palliative care (see recommendations made earlier in this report) to ensure continuing consistency between these data items
- adopting changes recommended earlier in this report for the 'specialist palliative care flag' item as it applies to an episode of palliative care to ensure continuing consistency between these data items.

Service contact method

This item collected information on the method used by a service provider to make contact with, or on behalf of, a client at a service contact. The pilot test found that 65% of services were provided face-to-face; most other services were provided via telephone (28%, Table 3.25).

Suggested improvements

The project team suggests adopting changes recommended earlier in this report for the 'service contact method' item as it applies to an episode of palliative care to ensure continuing consistency between these data items.

Table 3.25: Service provider (episode of grief and bereavement counselling service contact), by contact method

Contact method	Number	Per cent
Face-to-face	46	65
Telephone	20	28
Written	4	6
Telehealth	—	—
Other method	—	—
Not stated	1	1
Total	71	100

3.5 Ability of palliative care agencies to report the draft DSS

The pilot test demonstrated that palliative care agencies were able to report the data requested and that the quality of the data provided was generally of a high standard. In particular, the data provided in this chapter demonstrate that the data set can be used to describe community-based palliative care against the major areas of interest outlined by Leginski and others, ‘who receives what services, from whom, at what cost, and with what effect’ (Leginski et al. 1989). Specifically:

- *who receives?:* clients and patients are described in terms of major demographic characteristics, existence of a carer, principal diagnosis grouping and phase of care at first assessment
- *what services?:* the services these clients and patients receive are described in terms of referral details, the period of time over which they receive care, and details about service contacts that are provided to the patient/client – including service contact date, whether the patient was present, and the setting of the service delivery (that is, residential setting, non-residential setting, and so on)
- *from whom?:* staff involved in each service contact are described in terms of their occupation and whether they are a specialist palliative care provider
- *with what effect?:* the outcomes of the patient’s care are broadly described by information about the patient’s death, including the place of the patient’s death.

The following sections provide a summary of the pilot test results against each of the specific aims of the pilot test as outlined in Section 2.1.

3.5.1 Practicality and consistency of interpretation of questions

The pilot test found that, on the whole, the data items in the client DSS appeared to be interpreted in a consistent manner and worked in a practical manner, although there were seven items across the client DSS where suggestions for further improvement of the items have been made to improve the practicality and/or consistency of interpretation of the item (see Table 3.3). These items are: client identifier, main language other than English spoken at home, informal carer existence, episode of palliative care start date, service delivery setting,

main purpose of service contact and specialist palliative care provider indicator. Three of these seven items collect information on patient characteristics, three collect information on different aspects of palliative care service contacts, and one is related to episodes of palliative care. In most cases, the issues raised by the pilot test were relatively minor, and could be overcome by further development of the definitions.

In addition to the seven items identified above, the ‘practicality and consistency of interpretation’ of four items was not able to be fully assessed against this objective because of problems experienced by palliative care agencies in applying the definition provided for an ‘episode of grief and bereavement counselling’. This was the major concept identified through this pilot test that will require a significant amount of redevelopment. Further discussion of this item is included in Section 4.1.

3.5.2 Comprehensiveness of the range of responses

A number of permissible values within the pilot test included an ‘other (please specify)’ response category. This enabled the project team to investigate what responses were being coded to the ‘other’ category (and to assess the quality of data reported – see Section 3.5.3 below), and gives the PCDWG an opportunity to consider whether the value domains provided should be expanded to capture further information of interest.

While none of the permissible value sets were found to be lacking (that is, they all appeared to capture all major areas of interest), there are six data items where suggestions for improvement have been made in relation to the permissible values of the item (Table 3.3). These items are: principal diagnosis, service delivery setting, main purpose of service contact, other purpose(s) of service contact, type of assistance provided, and occupation of service provider.

Five of these items collect information on different aspects of palliative care/grief and bereavement service contacts, and three of these data items are related and capture information on the purpose of the assistance provided either within the episode of palliative care or the episode of grief and bereavement counselling. For these items, the project team has suggested that the list of permissible values could be expanded to capture other (possible) areas of interest, to clarify the use of existing categories, and to better align the response categories across these items. For ‘occupation of service provider’, a reduced codelist is suggested (unless the PCDWG express a strong desire to retain the current level of detail); for ‘principal diagnosis’, an expanded codelist is suggested as there may be wider interest in these data; and for ‘service delivery setting’, the removal of a redundant category is suggested.

3.5.3 Quality of data reported

The quality of the data (in terms of the level of missing data and the application of the permissible values and related guidelines provided for the data) was assessed indirectly by analysing the data received, patterns of responses, and information provided via the feedback forms. The quality of the data was generally considered to be high, although improvements have been suggested to the guidelines for the permissible values of seven data items as indicated in Table 3.3: client identifier, source of referral, reason for ending episode, service recipient type, main purpose of service contact, other purpose(s) of service contact, and service contact method. In most cases, the suggested improvements relate to just one specific code or circumstance.

Four of these seven data items collect information on palliative care (or grief and bereavement) service contacts, whereas the issues identified in relation to data items that collect information on clients and episodes of palliative care were less significant.

It should be noted that this pilot test was not able to assess the validity or reliability of reporting of data items. For example, the 'phase of care at first assessment' was reported for 98% of palliative care clients, but it is not possible through this study to be sure that the definitions provided for each phase were applied consistently. Some further information on data quality, however, can be gleaned from analysis of missing data and where reporting occurred against the incorrect codes. Discussion of these aspects is provided below.

Missing data

The rate of 'missing' data across all data items was low with the exception of two data items. This suggests that the information requested was of the type already recorded by service providers, or that they saw that the information requested was relevant to service provision at some level. It is likely that if service providers had considered the data requested to be intrusive, irrelevant or too confusing, then the rate of incomplete responses, or missing data, would have been higher.

The highest rates of missing data were reported for two items that related to episodes of grief and bereavement counselling – client identifier and date of death accuracy indicator. In part, the high rates of missing data for these items might be attributable to the low numbers of clients who received grief and bereavement counselling (36 episodes of grief and bereavement counselling were reported by 11 agencies). The missing data for the client identifier (within an episode of grief and bereavement counselling) may also have been compounded by uncertainty about applying the definition of an 'episode of grief and bereavement counselling' and resulting uncertainty about identifying 'patients' and 'clients' within these episodes. The issue of client identifier is further discussed in Section 4.3.

In some other cases (such as 'Indigenous status' and 'phase of care at first assessment') at least some of the missing data may be attributable to the fact that not all agencies would have recorded all of the information requested within their medical records. At least some of this information (for example, 'phase of care at first assessment') would not be able to be reported retrospectively, although other items (such as 'Indigenous status') could be; however, it is understandable that service providers might have been reluctant to collect more data directly from their client. This problem, which arose in the context of the pilot test because of the 'snapshot' nature of the data collection, would not be relevant to an ongoing collection, where information management practices would need to be modified to ensure the capture of all required data.

Reporting against incorrect codes

The quality of the data reported was also able to be assessed, to some extent, through analysis of responses to 'other (please specify)' codes. Primarily these were included to investigate whether there were any major response codes that were not already included in the value domain (see Section 3.5.2), but responses to these codes also provided some insight into the quality of the data collected. Specifically, the project team were able to assess whether the responses being recorded should have been recorded against other response codes, which, in turn, highlights areas where the guidelines provided may have been

inadequate. Chapter 3 notes that problems of this kind were evident (to varying extents) for the following items:

- Source of referral – where 5% of codes were reported as ‘other source’ and probably 3% should have been coded to existing codes
- Service delivery setting – where 5% of codes were reported as either ‘residential – other setting’ or ‘non-residential setting’, 1% should probably have been coded to existing codes, and another 1% were potentially not in scope of the collection
- Main purpose of service contact – where 2% of codes were reported as ‘other purpose’ and 1% should probably have been coded to existing codes
- Other purpose(s) of service contact – where 4% of codes were reported as ‘other purpose’ and 1% should probably have been coded to existing codes
- Type of assistance – where 11% of codes were reported as ‘other counselling’ and all of these should probably have been coded to existing codes.

As can be seen, the problem of reporting against incorrect codes is relatively minor in terms of the percentage of responses reporting against incorrect codes. For most of these items, specific recommendations have been made to improve the guidelines relating to the questions and/or the value domain label or its associated guide for use.

3.5.4 Respondent burden

As reported in Section 3.2, 18 of the 22 respondents who provided feedback via the feedback forms reported that the survey forms were ‘very easy’ or ‘easy’ to complete. This suggests that it is likely that the information requested through these forms was either already recorded within the patient’s record in a way that this information could be extracted, or the information was able to be obtained in ‘real time’ either from the patient or recorded by staff (for example, in the case of information on service contacts).

More specific questions to assess respondent burden were not included in the feedback form as it was likely that information gathered would be confounded by the fact that this was a paper-based survey that represented an additional reporting requirement for the pilot test period. That is, participating agencies were likely to have been recording at least some of the information twice in this period – once in their own information systems, and once on the pilot test survey forms. However, if this were to become a mandatory data set reported as an ongoing data collection for all palliative care clients, it would be expected that the reporting requirements would be ‘embedded’ in the agencies’ information management systems, and extracted at the required intervals for reporting.

It is acknowledged that these agencies were largely self-selected. Nevertheless, this pilot test has confirmed that palliative care service providers were able to report this kind of data and accepted the relevance of the data to their role and/or the role of governments in making decisions about providing healthcare services. Further information quantifying respondent burden will emerge in compiling the business case which will capture more detailed information about the ability of existing systems to capture data and the amount of system changes that would be required. This is further discussed in Section 4.7.3 below.

In considering an ongoing collection, it is clear that the area of data collection that is likely to result in the most significant respondent burden, in terms of volume of data collected, is the collection of data in relation to palliative care and grief and bereavement service contacts. In

this short pilot test involving 23 agencies, data were collected about 904 service contacts (833 palliative care contacts and 71 grief and bereavement service contacts). These service contacts involved 1,137 service provider contacts (1,066 palliative care service provider contacts and 71 grief and bereavement counselling service provider contacts). As a result of the respondent burden that this component of the DSS may involve, some further discussion about these items is included in Section 4.1.

4 Finalising the client data set specification

This chapter focuses on drawing conclusions about the practicality of the client DSS and identifying areas for further development. It also discusses implementation possibilities for the data set and describes the next steps in reaching agreement to implement the data set. A summary table of all recommendations made in this report is provided at the end of this chapter.

4.1 Episodes of grief and bereavement counselling

The pilot test revealed that the major concept that created problems for participating palliative care agencies was that of an ‘episode of grief and bereavement counselling’. These episodes were intended to be reported when a carer/family/friend was receiving formal grief and bereavement counselling from a qualified counsellor. In these cases, the carer/family/friend was considered to be a client of the agency in their own right and would have a separate client record opened to record details of the care they received. The data reported within episodes of grief and bereavement counselling in the pilot test suggest that these episodes and related definitions had not been implemented in the way intended. This was confirmed by further follow-up with the agencies that reported episodes of grief and bereavement counselling – the major problem being the lack of distinction between (formal) grief/bereavement counselling (which must be provided by a qualified counsellor) and (informal) grief/bereavement support (which may be provided by any staff member).

Information received via the feedback form also suggests that practices vary widely in relation to record-keeping for bereavement support and bereavement counselling. Nine agencies made some comment about record-keeping in relation to this aspect of client care (although it should be noted that use of the terms ‘bereavement support’ and ‘bereavement counselling’ are likely to vary from agency to agency):

- Two agencies reported that they currently record all support to carer(s)/family/friends on the patient’s medical record.
- Four agencies reported that they create separate files for recording assistance provided to carer(s)/family/friends, although the point at which this occurs was not provided in all cases – one reported that this occurs as soon as the patient dies, and another reported that a new record is opened ‘when warranted’.
- One agency records all assistance provided to carers/family/friends in a diary rather than a medical record.
- One agency reported that, where the patient is a client of their program, the same identifying number is used but a new record created. Where the patient is not a client, then the carer/family/friend is allocated a new identifying number and a new medical record.
- One agency indicated that they are currently developing a policy/process in relation to record-keeping in this area.

Feedback from the Victorian Department of Human Services (Perry, personal communication) has also suggested that practices in that jurisdiction are known to vary in relation to whether or not palliative care agencies open separate health care records to record information relating to carers and friends of a palliative patient.

The information obtained via the feedback form also highlighted an additional problem – at least seven of the 20 agencies that did provide feedback reported that they refer clients to other services for bereavement counselling. This means that capturing data on grief/bereavement counselling that is conducted by palliative care services will not provide a complete picture of the amount of grief/bereavement counselling related to palliative care that is occurring, because a significant proportion of this activity will occur outside of the palliative care sector. This trend may become more pronounced as at least one jurisdiction has recently established a statewide service to provide universal specialist bereavement services for people bereaved through any cause (Victorian Department of Human Services 2007). As a result, the PCDWG may wish to consider removing the requirement to collect data on grief and bereavement counselling provided by palliative care services.

Capturing data on grief/bereavement counselling does, however, provide information on the volume of work undertaken by the palliative care sector in this area. If it is decided that it is important to capture information on grief and bereavement assistance provided to carer(s)/family/friends within the palliative care sector, then the PCDWG could consider collecting aggregate counts of service contacts provided, rather than unit record data on clients receiving grief and bereavement counselling. As with unit record data (that is, where data are reported on each patient or client), aggregate counts would enable some information on the *volume* of formal grief and bereavement counselling that is performed by palliative care agencies to be obtained, but would not allow any detailed analysis of patterns of service, and so on. While the modifications needed to information systems to report aggregate counts would be minimal (and probably within the current capacity of palliative care service providers), these aggregate counts would still need to be underpinned by robust definitions of ‘grief and bereavement counselling’ and ‘bereavement support’.

Recommendation(s)

The project team recommends:

- the PCDWG reconsider the current ability of agencies to collect consistent and comparable data on grief and bereavement counselling episodes as part of the client DSS
- if data are required specifically on episodes of grief and bereavement then further development of the data requirements and definitions will be required in line with suggested improvements made in Chapter 3 of this report
- the PCDWG advise on the most suitable methods for collecting data in this area to meet high-level information needs.

4.2 Service contact data

As indicated in Table 3.3, the group of data items that will require the most significant level of further development are those that relate to palliative care and grief and bereavement

service contacts. Additionally, Section 3.5.4 identifies this group of items to be the area that is likely to result in the most respondent burden (due to the volume of data that will be collected). Accordingly, it is suggested that the PCDWG could consider some alternative data collection strategies for these data. In particular, information on service contacts could be implemented as a regular (or occasional) data collection to be implemented over a limited time period (for example, a two-week period). A number of options for the methods used to collect these data may need to be provided. For those agencies that can collect this information within their current electronic information management systems, data could be submitted as an electronic file. For those agencies that cannot report this information from within their patient management systems, provisions would need to be made to be able to submit paper-based forms.

Recommendation(s)

The PCDWG should consider whether palliative care service contact data should be included in a potential national minimum data set specification, or should be proposed as a data set module that could be implemented for a limited time period as a one-off (or regular) data collection.

4.3 Client/patient identifiers

The use of client and patient identifiers within the pilot test represented an area of some confusion for participating agencies. For client identifiers associated with episodes of palliative care, these problems were perhaps largely attributable to the nature of the pilot test as a paper-based data collection that required multiple recording of the patient's identifier; and for client and patient identifiers associated with episodes of grief and bereavement counselling, this was probably largely attributable to a discordance between the definition provided for an 'episode of grief and bereavement counselling' and participating services' understanding of an episode of this kind which made identification of the 'patient' and 'client' problematic. Nevertheless, these issues, alongside feedback obtained from agencies in relation to information management practices, do suggest that some reconsideration of these data items will be required.

Additionally, while it is common within palliative care for care providers to espouse the view that 'the family is the unit of care' (Palliative Care Expert Group 2005), the primary relationship in both an ethical and legal sense is between the healthcare provider and the person with the life-limiting illness. Data collection in this field needs to recognise the primacy of this relationship and recognise that this is likely to be further reinforced by the uptake of electronic healthcare records within palliative care environments which will reinforce requirements for separate healthcare records for patients and related people who may receive care from a healthcare service.

In light of this, it is proposed that the definitions be re-defined in terms of capturing data on care delivered to *patients* only, that is, the data set would only be concerned with capturing data on service contacts that are primarily focussed on the care delivered to the patient, whether or not the patient is present at the service contact, and not include service contacts that are exclusively concerned with the wellbeing of the carer(s)/family/friends. This also does not preclude situations where the patient themselves is not registered to receive direct

care from the agency (for example, where the person with the life-limiting illness has refused palliative care, but family members receive care from the agency and deliver palliative care indirectly to the patient). The fact that the patient is not directly receiving palliative care would be identifiable through the 'patient registration flag' data item.

Similarly, if data are to continue to be captured on episodes of grief and bereavement counselling, again, data elements need to be re-worded in terms of capturing data on the *patient* (rather than *client*), on the understanding that, at the point that a carer/family/friend is assessed as requiring formal assistance for grief and bereavement issues, they should be individually registered for care and recognised as a patient in their own right.

Recommendation(s)

The project team recommends that the PCDWG consider:

- limiting service contacts reported within an episode of palliative care to those service contacts where there is a patient-care component (whether this is the main purpose of the service contact or not)
- re-wording all data items to ensure that it is an individual patient that is the subject of the data items. For an episode of palliative care, this will be the person with a life-limiting illness; for an episode of grief and bereavement counselling, this will be the carer/family member/friend receiving formal counselling.

4.4 Statistical linkage of data

Statistical linkage of data refers to the probabilistic matching of data records either within a data set or across related databases to enhance analysis of data. Record linkage can only be undertaken when both data sets contain some common items that can be used to construct a statistical linkage key. It should be noted that a statistical linkage key does not generate a unique identifier for a patient or client group, but does enable the derivation of a linkage key with sufficient specificity for data analysis at a population level. That is, statistical linkage of data is done to enhance analysis of the data, not for tracking individuals through the system for case management or other purposes.

In a number of community services program areas, selected letters of name are used in combination with date of birth and sex to develop a statistical linkage key. Inclusion of this data linkage key in the community-based palliative care client data set would enable linkage of patient data where the patient received care from more than one palliative care agency, and linkage with other data sets that might provide additional information about the patient and the services that they were receiving, such as the Home and Community Care Minimum Data Set (HACC MDS).

To prepare for the possibility of data linkage using the existing community services linkage key, two items were included in the draft community-based palliative care client DSS – 'letters of name' and the date accuracy indicators.⁵ 'Letters of name', as outlined in

5 It should be noted that date of birth and sex, which are also used to construct the community services data linkage key, were also included in the draft DSS; however, these were primarily included on other grounds and not primarily for data linkage purposes.

Section 2.6.1, requires a specific combination of some of the letters of a person's name, which is a key component of the record linkage key. This item was not included directly in the pilot test, although some feedback on agencies' ability to report this information was sought via the feedback form.

Most agencies reported that they would need to modify their existing information systems to collect 'letters of name' if it were required for record linkage, although no further details on the effort or costs involved to do this were collected as part of the pilot test. Some further consultation with state/territory health authorities should also occur to see if they could extract 'letters of name' from the patient's full name on behalf of agencies that are required to submit data as part of a national mandatory data set.

The date accuracy indicators, which were requested for both the patient's date of birth and date of death (if applicable), required the agency to report on the known accuracy of each reported date component (that is, day, month and year). This information assists the linkage process by identifying dates for which the agency cannot be confident of the information they hold. Uncertainty about birth dates may be a particular issue in Indigenous communities and in some overseas-born population groups. The date of death may also be uncertain where an agency was not formally notified of the death of a patient, and the date of death has been estimated.

Although 'date accuracy indicator' has been agreed as a national data standard, it is not currently included in any nationally agreed mandatory health-related data sets, and would not need to be included in the community-based palliative care client DSS unless there were a clear intention to undertake record linkage.

Recommendation(s)

The project team recommends that:

- the PCDWG consider which data sets, if any, it may be interested in linking data with. If these data sets include the linkage key used in community services programs (based on 'letters of name', date of birth and sex), then 'letters of name' should be retained in the community-based palliative care client DSS
- jurisdictions also consider whether they could support agencies to report 'letters of name' by extracting these data from name information supplied by agencies (if required)
- if the record linkage key is not required at this time, then 'letters of name' be removed from the draft DSS until it is required.

4.5 Scope of the data collection

Before this data set can be agreed as a national minimum data set, that is, as mandatory for collection by palliative care agencies, some further detail relating to scope will be required. While it has been previously agreed that the clients in scope of the community-based palliative care client data collection would be any client who receives community-based palliative care from a service provider who is employed or subcontracted by the palliative care agency, implementation of this data set as an NMDS would also require agreement on

the scope in terms of which agencies would be required to report such data, and in relation to which service contacts. These issues and related recommendations are further described below.

4.5.1 Which agencies?

Agreement to report an NMDS requires some certainty about the scope of the data collection, that is, that states/territories need to be able to apply the statement of scope and be clear about which agencies they fund that would be required to report the data. While previous consultations undertaken by the AIHW resulted in a clear preference for primary palliative care providers⁶ to be included in the national palliative care data collection in recognition of the fact that much palliative care is provided by those non-specialist palliative care services (AIHW 2004), some further consideration needs to be given to the practical consequences of this view. In particular, any service participating in the data collection would need to identify which patients that they care for need to be reported as part of the national collection. For non-specialist services (such as community nursing agencies), agreement would need to be reached on how patients would be identified as 'palliative', and therefore should be reported as part of the national data set. For example, would this decision need to be made by a medical practitioner? Is this likely to occur in the normal course of service delivery? How do practices for identifying palliative patients vary from state to state?

If agreement cannot be reached on a suitable way of identifying palliative patients within primary palliative care agencies, it is likely that primary palliative care providers would need to be excluded from the national data collection relating to palliative care (that is, client-level data would be required from specialist palliative care agencies only). Some further work may also be required to ensure that the data set could be implemented by palliative care agencies operating under a range of service models, for example, agencies delivering palliative care 'consultative' services.

4.5.2 Which service contacts?

Service contacts delivered by volunteers were excluded from the draft data set (and hence the pilot test) primarily on the grounds of reducing the burden on volunteer staff. This meant that no data were captured on assistance provided to clients by volunteers. In the context of the pilot test this also ensured optimal testing of the data items, recognising that no training on the data collection and data concepts would be provided to those agencies participating in the pilot test. However, given the widespread use of volunteers by palliative care agencies, it is timely to reconsider whether services provided by volunteers should continue to be out-of-scope for the data set. Including volunteers would enable a more complete picture of services delivered by palliative care agencies to be provided and recognise the role that palliative care agencies play in facilitating volunteers to care for people with life-limiting illnesses and bereaved carers and family members.

6 Primary palliative care providers include any 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.

Recommendation(s)

The PCDWG should provide advice on the proposed scope of the community-based palliative care data collection in terms of:

- the agencies that would be required to collect the data (that is, only specialist palliative care agencies or primary palliative care services also)
- whether or not service contacts delivered by volunteers on behalf of palliative care agencies should continue to be excluded from the data collection.

4.6 Phased implementation

There is considerable scope within the community-based palliative care client DSS for phased implementation of the data set. The two components of the data set that would be particularly suited to phased implementation are those areas relating to the 'service contact' component of the DSS and episodes of grief and bereavement counselling (as discussed previously in Sections 4.1 and 4.2).

The requirement to collect data on all service contacts within an episode of care is likely to represent the component of the DSS that will be the greatest burden on palliative care service providers – both in terms of the need to modify information systems and ongoing collection burden. While most agencies (17 of the 20 agencies that provided feedback) reported that they are able to collect service contact information (and some agencies stated that they routinely carry out this activity), the type of information, the level of detail, and the method of collection are likely to differ greatly across agencies. A phased introduction of this component of the data set would allow time for services to build these requirements into their information systems. In the meantime, if some data on service contacts are wanted, some alternative methodologies could be considered (see Section 4.2 above) or aggregate data on service contacts could be collected as an interim strategy.

Similarly, given the issues raised by the pilot test in relation to implementing 'episodes of grief and bereavement counselling', these episodes could also be a candidate for phased implementation. This would mean that agreement to collect data relating to episodes of palliative care could be implemented in the first instance, with agreement to collect data relating to an episode of grief and bereavement counselling occurring at a later date once the relevant definitions are further developed and tested, and following a suitable time period to allow palliative care services to adapt information systems to accommodate the reporting requirements.

Recommendation(s)

The project team recommends that the PCDWG consider a phased implementation of the community-based palliative care client data set if warranted. Data items relating to the patient and episodes of palliative care could be implemented in the first instance. Data items relating to service contacts and episodes of grief and bereavement counselling could be added at a later date.

4.7 Next steps

This section outlines the remaining steps in finalising the draft client DSS. All tasks will be undertaken by the AIHW project team in consultation with the Palliative Care Data Working Group (PCDWG).

4.7.1 Finalise the client DSS

The first stage in finalising the community-based palliative care client DSS will involve finalising all data items with reference to the 'suggested improvements' outlined in Chapter 3 of this report, and making decisions on preferred approaches to the additional issues raised in this chapter. In some cases responses to these issues will influence the development of specific data items and, as in previous data development phases, it will be important to be aware of developments occurring in related data sets to ensure, wherever possible, that information requirements are consistent with other known reporting requirements.

In particular, the possibility of a staged implementation of the client DSS has been suggested, particularly in relation to obtaining data on palliative care service contacts and obtaining data on episodes of grief and bereavement counselling. This would allow time for services to adapt systems to collect the finer level of detail required to collect data on service contacts, and also allow time for necessary development and testing of new data concepts (especially around defining an episode of grief and bereavement counselling). Decisions such as these will determine priorities for the finalisation of proposed data items.

New items or significantly revised items may require specific focus-testing to ensure consistent interpretation of requirements and application to different palliative care services.

4.7.2 Submit the DSS items to the Health Data Standards Committee

Once data items have been finalised by the PCDWG, the items need to be agreed by the Palliative Care Intergovernmental Forum (PCIF), before submission to the Health Data Standards Committee (HDSC) for approval. The HDSC, which includes membership from all states and territories, the Australian Government Departments of Health and Ageing and Veterans' Affairs, the Australian Bureau of Statistics and other interested parties, approves, maintains and promotes the use of appropriate health metadata standards. Once approved, this set of items would then become available through METeOR, the AIHW's on-line metadata registry to systems developers, service providers and others who may be involved in designing and building information systems.

Final endorsement of all nationally agreed data standards must then occur through the National Health Information Management Principal Committee.

4.7.3 Develop a business case

The AIHW will then coordinate the development of a business case to support the implementation of the community-based palliative care client DSS as a mandatory data set. The business case would need to clearly outline the origins and rationale of the proposed data set, provide details of consultations and pilot testing undertaken in the development of the data set, and outline the benefits of implementing an ongoing data

collection to capture data on community-based palliative care, including the strategic case for an NMDS in this field.

The business case will be developed in consultation with all states and territories, which will be asked to provide a summary of the resource implications of implementing the proposed data set, including ‘one-off’ costs to re-design information systems and related costs, and ongoing costs which would largely be staff time involved in additional data collection.

In doing this, jurisdictions may also be asked to consider costs associated with different aspects of the collection. For example, it is likely that a significant proportion of the ongoing costs of the collection would be related to the collection of data on each service contact. As a result, the PCIF could recommend the phased implementation of the data set, with ‘episode-based’ information being implemented in the first instance, and service contact data requirements being implemented in the future. This would allow all relevant decision-making committees (PCIF, the Statistical Information Management Committee, which provides initial approval for the mandatory collection of agreed data sets, and the National Health Information Principal Committee, which provides final endorsement of all health-related data standards and data sets) to clearly balance the costs of each component of the data collection against the perceived benefits.

The business case should also outline the costs of training that will be required to support the ongoing collection of the data set.

4.8 Conclusions and summary of recommendations

The pilot test has been successful in demonstrating that the range of data proposed for the community-based palliative care client DSS can be reported by agencies involved in the delivery of palliative care, notwithstanding the need to amend some items and finalise some broader decisions relating to the proposed data set. A summary of all recommendations made in this report is provided in the table below.

Table 4.1: Summary of recommendations for the finalisation of the community-based palliative care client DSS

Recommendations in relation to finalising data set details	
Episodes of grief and bereavement counselling	<p>The project team recommends that:</p> <ul style="list-style-type: none"> the PCDWG reconsider the current ability of agencies to collect consistent and comparable data on grief and bereavement counselling episodes as part of the client DSS if data are required specifically on episodes of grief and bereavement then further development of the data requirements and definitions will be required in line with suggested improvements made in Chapter 3 of this report the PCDWG advise on the most suitable methods for collecting data in this area to meet high-level information needs.
Service contact data	<p>The PCDWG should consider whether palliative care service contact data should be included in a potential national minimum data set specification, or should be proposed as a data set module that could be implemented for a limited time period as a one-off (or regular) data collection.</p>

(continued)

Table 4.1 (continued): Summary of recommendations for the finalisation of the community-based palliative care client DSS

Recommendations in relation to finalising data set details (continued)	
Client/patient identifiers	<p>The project team recommends that the PCDWG consider:</p> <ul style="list-style-type: none"> limiting service contacts reported within an episode of palliative care to those service contacts where there is a patient care component (whether this is the main purpose of the service contact or not) re-wording all data items to ensure that it is an individual patient that is the subject of the data items. For an episode of palliative care, this will be the person with a life-limiting illness; for an episode of grief and bereavement counselling, this will be the carer/family member/friend receiving formal counselling.
Statistical linkage of data	<p>The project team recommends that:</p> <ul style="list-style-type: none"> the PCDWG consider which data sets, if any, it may be interested in linking data with. If these data sets include the linkage key used in community services programs (based on 'letters of name', date of birth and sex), then 'letters of name' should be retained in the community-based palliative care client DSS jurisdictions also consider whether they could support agencies to report 'letters of name' by extracting these data from name information supplied by agencies (if required) if the record linkage key is not required at this time, then 'letters of name' be removed from the draft DSS until it is required.
Scope of the collection	<p>The PCDWG should provide advice on the proposed scope of the community-based palliative care data collection in terms of:</p> <ul style="list-style-type: none"> the agencies that would be required to collect the data (that is, only specialist palliative care agencies or primary palliative care services also) whether or not service contacts delivered by volunteers on behalf of palliative care agencies should continue to be excluded from the data collection.
Phased implementation	<p>The project team recommends that the PCDWG consider a phased implementation of the community-based palliative care client data set if warranted. Data items relating to the patient and episodes of palliative care could be implemented in the first instance. Data items relating to service contacts and episodes of grief and bereavement counselling could be added at a later date.</p>
Recommendations in relation to finalising data items	
Client identifier (for a palliative care client)	<p>The project team suggests:</p> <ul style="list-style-type: none"> improving the wording of this item to emphasise that the identifier required is that already used by the palliative care agency including guidelines on the need for each agency to allocate a unique patient identifier for all patients cared for.
Main language other than English spoken at home	<p>The project team suggests that the PCDWG should advise whether this item should be retained or replaced with 'preferred language'.</p>
Informal carer existence	<p>The project team suggests the addition of an additional response code to the 'informal carer existence' item for use on behalf of clients who live in residential care or supported independent living settings to indicate that the item has not been reported for this client because they live in such a setting.</p>
[Episode of palliative care]	<p>The project team suggests that the PCDWG consider whether 'episode of palliative care' should be renamed to 'period of community-based palliative care' or similar.</p>
Source of referral	<p>The project team suggests the addition of further guidelines to the 'referral source' item to assist users in their selection of the categories available. In particular, more instructions are required on the use of the 'community-based agency—other' and 'other source' categories.</p>
Episode (of palliative care) start date	<p>To provide greater consistency with the PCOC-defined episodes of palliative care, the project team suggests that an episode of palliative care should commence at the time that the patient is first seen by the palliative care service provider.</p>

(continued)

Table 4.1 (continued): Summary of recommendations for the finalisation of the community-based palliative care client DSS

Recommendations in relation to finalising data items (continued)	
Principal diagnosis	The project team suggests that the PCDWG review the information gathered during the pilot test and decide whether the current code set should be retained or expanded so as to be able to capture information on the most common diagnosis groupings responsible for palliative care services.
Reason for ending episode	The project team suggests that further guidelines be provided to clarify that patients who are discharged to a residential aged care facility should be coded to 'other reason'.
Service recipient type	<p>Although this was a relatively minor problem affecting just over 1% of service contact records, the project team suggests:</p> <ul style="list-style-type: none"> changing the permissible value labels to clarify that each of these recipient types would (by definition) involve a service provider the addition of instructions to the guidelines to make it clear that the codes 'patient', 'patient and carer(s)/family/friends', and 'carer(s)/family/friends' can also include 'other professional(s)/service provider(s)'.
Service delivery setting	<p>The project team suggests:</p> <ul style="list-style-type: none"> simplifying the item so that this information is only required in respect of the <i>patient</i> and that reporting therefore should only occur when a patient is involved in a service contact. This would mean, in the future, this information would not be collected where the recipient of the service contact is a carer/family/friend of the patient only removing code 99 ('not applicable (patient not present at service contact)') from the list of options available.
Main and other purpose(s) of service contact	<p>The project team suggests:</p> <ul style="list-style-type: none"> that the PCDWG amends the list of options available for the main and other purpose(s) items so that code 4 'spiritual care or support of the patient/carer/family/friends' is split into separate categories. The PCDWG would need to consider which specific categories should be included, for example, 'bereavement support', 'social support' and 'spiritual care' that the PCDWG decide if separate categories are required to capture activity such as provision of equipment, domestic assistance, counselling, transport, education, and social work (currently captured under the category 'other' for the main and other purpose(s) items) providing further information in relation to each code to assist service providers to report against these codes adding guidelines to the 'main purpose of service contact' item acknowledging that palliative care usually involves a holistic approach but that in a routine data collection there is a need to focus just on reporting the principal activities that occur in order to manage the burden that the data collection may impose on data providers.
Occupation of service provider and specialist palliative care provider indicator (for palliative care service contacts)	<p>The project team suggests:</p> <ul style="list-style-type: none"> adopting a broader level categorisation for the 'occupation of service provider' item which retains consistency with the Australian and New Zealand Standard Classification of Occupations (ABS 2006a) removal of the category 'grief counsellor' and redeveloped broader categorisation to include occupations that provide formal grief and bereavement counselling (a subset of this item is used when collecting the occupation of a service provider who provides care during an episode of grief and bereavement counselling) addition of guidelines to the 'specialist provider flag' item to clarify the term 'training'.
Service contact method (for palliative care service contacts)	The project team suggests that the guidelines for this item are further developed to provide guidance for selection of the contact method where a service provider is involved in a 'case meeting' or 'case conference'. Instructions should make it clear that each service provider should record their method of contact during the case meeting/conference.

(continued)

Table 4.1 (continued): Summary of recommendations for the finalisation of the community-based palliative care client DSS

Recommendations in relation to finalising data items (continued)	
[Episode of grief and bereavement counselling]	Then project team suggests that the definition of an episode of grief and bereavement counselling needs to be improved. In particular, the conceptual basis of an episode of grief and bereavement counselling needs to be better defined, and not dependent on describing operational/administrative processes that may vary across palliative care agencies.
Type of assistance provided	<p>The project team suggests:</p> <ul style="list-style-type: none"> PCDWG consider replacing the category 'social support' with 'bereavement support'. Addition of this category to options available may assist in identifying which clients are receiving bereavement support services during an episode of palliative care versus an episode of grief and bereavement counselling (assuming that 'bereavement support' is added to the 'main purpose of service contact' item as recommended earlier in this report). The final codes decided for this item should be consistent with the codes decided for the 'Main purpose of service contact' reported for episode of palliative care service contacts changing the category 'other counselling' to 'other'.
Occupation of service provider and specialist palliative care provider indicator (for grief and bereavement counselling service contacts)	<p>The project team suggests:</p> <ul style="list-style-type: none"> reworking the options available (and supporting guidelines) for the 'occupation of service provider' to reflect those re-developed for 'occupation of service provider(s)' as it applies to an episode of palliative care (see recommendations made earlier in this report) to ensure continuing consistency between these data items adopting changes recommended earlier in this report for the 'specialist palliative care flag' item as it applies to the an episode of palliative care to ensure continuing consistency between these data items.
Service contact method (for grief and bereavement counselling service contacts)	The project team suggests adopting changes recommended earlier in this report for the 'service contact method' item as it applies to an episode of palliative care to ensure continuing consistency between these data items.

Appendix A: Palliative Care Data Working Group membership

Membership current as at February 2007:

Julie Barnes, Department of Health and Community Services (NT)

Kathryn Beacham, Queensland Health

Shari Beaumont, Australian Institute of Health and Welfare

Sarah Bellinger, Department of Health and Community Care (ACT)

Andrew Brown, Department of Human Services (Victoria)

Jennie Della, Australian Government Department of Health and Ageing

Susan Hanson, Department of Health and Human Services (Tasmania)

Meryl Horsell, SA Department of Health (Chair)

Clara Jellie, Australian Institute of Health and Welfare

Mick O'Hara, consultant to Australian Government Department of Health and Ageing

Graham Pegler, NSW Health

Stan Piperoglou, Australian Government Department of Health and Ageing

Meera Rajendran, Australian Institute of Health and Welfare

Camilla Rowland, Palliative Care Australia

Tony Satti, WA Department of Health

James Sizer, Community Care Branch, Australian Government Department of Health and Ageing

Bill Weir, Australian Government Department of Veterans' Affairs

Appendix B1: Privacy/consent statement



CONSENT TO PROVIDE INFORMATION FOR THE PILOT COMMUNITY-BASED PALLIATIVE CARE CLIENT DATA COLLECTION 2006

This palliative care agency is taking part in a small survey of palliative care agencies that provide services to clients in community settings. The survey is being run by the Australian Institute of Health and Welfare (AIHW) for the Australian Government Department of Health and Ageing. During the two-week period, some agencies throughout Australia will be filling in survey forms about people who receive palliative care from them and about the services they receive.

This information is needed to find out what information is available, and can be collected, about palliative care being provided to clients in community settings.

All information sent to the AIHW is non-identifying, i.e. your name and address will not be recorded on the survey forms.

Part of the information that will be reported in this survey will come from your file in this centre. You have the right to see that file.

The completed forms will be collated by state and territory health departments and forwarded to the AIHW for processing. By law, all the forms must be kept confidential at the health department and at the AIHW. None of your information can be given to anyone outside of these organisations. It will only be used to produce statistics about palliative care provided by palliative care agencies in community settings. Once the statistics are produced, all forms will be destroyed. The statistics will be used to produce a report on palliative care.

Consistent with privacy legislation, the AIHW goes to great lengths to ensure that a person's identity cannot be established in any published material. For example, data are not published according to small geographic areas (e.g. postcodes) where it may be possible that only a small number of people with certain characteristics live.

Participation in this survey is voluntary. You are not required to participate if you do not wish to. If you choose to not participate, let one of your attending agency staff members know of your decision. You are not required to provide any refusal statements in writing.

Appendix B2: Form A (Patient details)



Australian Government

Australian Institute of
Health and Welfare

Pilot Community-based Palliative Care Client Data Collection Form A—Patient Details

- This form is to be completed by an agency staff member for the person with the life limiting illness (patient).
- This form should be completed in conjunction with the Guidelines document.

Agency ID	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	(supplied by the AIHW)
Client ID	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
(The identifier assigned by your agency to the patient i.e. the person with the life limiting illness)		

Patient Details

For each question, record the most up-to-date information that is available.

1 Sex <div style="text-align: right; margin-top: 10px;"> Male <input type="checkbox"/> 1 Female <input type="checkbox"/> 2 Intersex or indeterminate <input type="checkbox"/> 3 </div>	<ul style="list-style-type: none"> Tick one box only. Intersex or indeterminate, refers to a patient, who because of a genetic condition, was born with reproductive organs or sex chromosomes that are not exclusively male or female or whose sex has not yet been determined for whatever reason. 												
2 Date of birth <div style="text-align: center; margin-top: 20px;"> <table style="margin: auto;"> <tr> <td style="text-align: center;">D D</td> <td style="text-align: center;">M M</td> <td style="text-align: center;">Y Y Y Y</td> </tr> <tr> <td style="text-align: center;"> <input type="text"/> <input type="text"/> </td> <td style="text-align: center;"> <input type="text"/> <input type="text"/> </td> <td style="text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> </td> </tr> <tr> <td style="text-align: center;"> <input type="text"/> </td> <td style="text-align: center;"> <input type="text"/> </td> <td style="text-align: center;"> <input type="text"/> </td> </tr> <tr> <td style="text-align: center; font-size: x-small;">day accuracy indicator</td> <td style="text-align: center; font-size: x-small;">month accuracy indicator</td> <td style="text-align: center; font-size: x-small;">year accuracy indicator</td> </tr> </table> </div>	D D	M M	Y Y Y Y	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	day accuracy indicator	month accuracy indicator	year accuracy indicator	<ul style="list-style-type: none"> Complete the date of birth as best as you can. Only record the date accuracy indicator for patients who are accepted for care by the agency after 5th of June 2006. For each date component (day, month, year) record the accuracy indicator. <ul style="list-style-type: none"> If the date component is accurate record 'A' in the appropriate 'accuracy indicator' box. If the date component is estimated record 'E' in the appropriate 'accuracy indicator' box. If the date component is unknown record 'U' in the appropriate 'accuracy indicator' box. For example if the day is correct, record 'A' in the 'day accuracy indicator' box; if the month is estimated, record 'E' in the 'month accuracy indicator' box; and if the year is unknown, record 'U' in the 'year accuracy indicator' box. If a date component is unknown, an entry does not need to be made for that date component, however the accuracy indicator 'U' must be recorded.
D D	M M	Y Y Y Y											
<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>											
<input type="text"/>	<input type="text"/>	<input type="text"/>											
day accuracy indicator	month accuracy indicator	year accuracy indicator											
3 State/Territory where the patient usually resides <div style="margin-top: 10px;"> New South Wales <input type="checkbox"/> 1 Victoria <input type="checkbox"/> 2 Queensland <input type="checkbox"/> 3 South Australia <input type="checkbox"/> 4 Western Australia <input type="checkbox"/> 5 Tasmania <input type="checkbox"/> 6 Northern Territory <input type="checkbox"/> 7 Australian Capital Territory <input type="checkbox"/> 8 Other territories <input type="checkbox"/> 9 </div>	<ul style="list-style-type: none"> Tick one box only. Usual residence is the place where the patient has or intends to reside, or the place that the patient regards as their main residence, or where the patient has no other residence, the place they currently reside. Other territories include Cocos (Keeling) Islands, Christmas Island and Jervis Bay Territory. 												
4 Postcode of usual residence <div style="text-align: center; margin-top: 10px;"> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> </div>	<ul style="list-style-type: none"> Record the patient's postcode according to their place of usual residence. 												
5 Indigenous status <div style="margin-top: 10px;"> Aboriginal but not Torres Strait Islander origin <input type="checkbox"/> 1 Torres Strait Islander but not Aboriginal origin <input type="checkbox"/> 2 Both Aboriginal and Torres Strait Islander origin <input type="checkbox"/> 3 Neither Aboriginal nor Torres Strait Islander origin <input type="checkbox"/> 4 </div>	<ul style="list-style-type: none"> Tick one box only. When the patient is not able to answer for themselves, the person answering for them should be in a position to do so, i.e. this person must know the patient well and feel confident to provide accurate information about them. An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander. 												

Continued on next page

If you have any problems completing this form please telephone 1800 443 182 or email pcdwgsec@aihw.gov.au

Pilot Community-based Palliative Care Client Data Collection — Form A Patient (Continued)

<p>6 Country of birth</p> <p align="right">Australia <input type="checkbox"/> 1</p> <p>Other country (please specify) _____ <input type="checkbox"/></p>	<ul style="list-style-type: none"> Tick one box only. Where the patient's country of birth is not Australia, tick 'Other country' and record the name of the country in which the patient was born.
<p>7 Main language other than English spoken at home</p> <p align="right">English only <input type="checkbox"/> 1</p> <p>Other language (please specify) _____ <input type="checkbox"/></p>	<ul style="list-style-type: none"> Tick one box only. Record the main language other than English spoken by the patient in their home (or most recent private residential setting occupied by the patient) on a regular basis, to communicate with other residents of the home or setting and regular visitors. Where a language other than English is spoken at home, tick 'Other language' and record the name of the language.
<p>8 Living arrangements</p> <p align="right">Lives alone <input type="checkbox"/> 1</p> <p align="right">Lives with others <input type="checkbox"/> 2</p>	<ul style="list-style-type: none"> Tick one box only. 'Lives with others' includes both family and non-family members. Patients living in accommodation settings such as boarding houses, hostels, group homes, retirement villages and residential aged care facilities are considered as living alone, except where they are sharing their own private space/room within the premises with a significant other such as a partner, sibling or close friend.
<p>9 Carer availability status</p> <p align="right">Has a carer <input type="checkbox"/> 1</p> <p>Go to Question 10 _____ If 'Has a carer' is recorded go to question 10</p> <p align="right">Has no carer <input type="checkbox"/> 2</p> <p>If the patient 'Has no carer' you are not required to complete the rest of this form.</p>	<ul style="list-style-type: none"> Tick one box only. A patient may have more than one carer. Carers include those people who receive a pension or benefit for their caring role but does not include paid or volunteer carers organised by formal services. Family, friends or neighbours providing care can be a patient's carer(s).
<p>10 Co-residency status of patient's main carer</p> <p align="right">Co-resident carer <input type="checkbox"/> 1</p> <p align="right">Non-resident carer <input type="checkbox"/> 2</p>	<ul style="list-style-type: none"> Tick one box only. Select the co-residency status for the main carer. The main carer is the person who provides the most care to the patient. If a patient has more than one carer (e.g. a spouse and a son), the response should relate to the carer who provides the most significant care and assistance related to the patient's capacity to remain living at home. The expressed views of the patient and/or their carer(s)/family/friends should be used as the basis for determining this. A 'co-resident carer' is a person who provides care and assistance on a regular and sustained basis to a patient who lives in the same household. A 'non-resident carer' is a person who provides care and assistance on a regular and sustained basis to a patient who lives in a different household.
<p>11 Main carer's relationship to the patient</p> <p align="right">Spouse/partner <input type="checkbox"/> 1</p> <p align="right">Parent <input type="checkbox"/> 2</p> <p align="right">Child <input type="checkbox"/> 3</p> <p align="right">Child-in-law <input type="checkbox"/> 4</p> <p align="right">Other relative <input type="checkbox"/> 5</p> <p align="right">Friend/neighbour <input type="checkbox"/> 6</p>	<ul style="list-style-type: none"> Tick one box only. Record the relationship of the main carer to the patient for whom they care. For example, if a woman were caring for her aged mother, record that the carer is the child. 'Spouse/partner' includes de facto and same sex partnerships.

Thank you for completing this form.

If you have any problems completing this form please telephone 1800 443 182 or email pcdwgsec@aihw.gov.au

Appendix B3: Form B (Episode of palliative care)



Australian Government

Australian Institute of
Health and Welfare

Pilot Community-based Palliative Care Client Data Collection Form B—Episode of Palliative Care

- This form is to be completed by an agency staff member for each episode of palliative care provided to a client. The client may be the patient and/or their carer(s)/family/friends.
- This form should be completed in conjunction with the Guidelines document.

CONSENT

☐

Tick the box to indicate that the privacy statement has been read or provided to the client (the patient and/or their carer(s)/family/ friends) and they have agreed that their information can be collected.

Agency ID

(supplied by the AIHW)

Client ID

(Patient and/or their carer(s)/family/friends)

Where the patient is receiving care from your agency, record the identifier assigned by your agency to the patient (and their carer(s)/family/friends) for the episode of palliative care.

Where there is no patient receiving care, record the identifier assigned by your agency to the carer(s)/family/friends and tick the box below.

☐

Tick this box if a person with a life-limiting illness is **NOT** a client of your agency i.e. only the carer(s)/family/friends receive care.

Episode of Palliative Care Details

An episode of palliative care is the period of care when a client (the patient with life-limiting illness and/or their carer(s)/family/friends) receives services to improve their quality of life. See page 10 of the Guidelines document for more information on episodes of palliative care.

For each question, record the most up-to-date information that is available.

1 Referral date (if applicable)

D	D	M	M	Y	Y	Y	Y
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

- Record the date on which your agency received a referral for this client from another party for palliative care services.

2 Source of referral to agency

- Self, carer(s), family or friends ☐ 1
- Medical practitioner – general practitioner ☐ 2
- Medical practitioner – specialist ☐ 3
- Community-based palliative care agency ☐ 4
- Community-based agency – other ☐ 5
- Inpatient facility ☐ 6
- Residential aged care service ☐ 7
- Other source (please specify) ☐ 8

- Tick one box only.
- Referrals made by medical practitioners on behalf of community-based palliative care agencies, inpatient facilities and residential aged care services should be recorded as a referral from that particular agency/service/organisation and not as a referral from the medical practitioner.
- Referrals from hospices should be coded as 'Inpatient facility'.
- 'Inpatient facility' includes designated and non-designated palliative care units/beds in hospitals and hospices.
- 'Other source' includes outpatient departments at hospices and hospitals.

3 Episode start date

D	D	M	M	Y	Y	Y	Y
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

- Record the date on which the client is first assessed and accepted for palliative care by your agency.

Continued on next page

If you have any problems completing this form please telephone 1800 443 182 or email pcdwgsec@aihw.gov.au

4 Patient's principal diagnosis (for requiring palliative care)

Malignant neoplasm ☐ 1
 Other diagnosis (please specify) _____ ☐ 8
 Not applicable – patient not receiving care ☐ 9

- Tick one box only.
- If the principal diagnosis is not a malignant neoplasm, tick 'Other diagnosis' and record the diagnosis mainly responsible for the patient requiring palliative care.
- 'Other diagnosis' includes, but is not limited to, HIV/AIDS, motor neurone disease, muscular dystrophy, cystic fibrosis, multiple sclerosis, end-stage dementia, end-stage respiratory, cardiac, renal and liver disease. Benign neoplasms are also included in this category.

5 Phase of care at first assessment (by agency)

Stable phase ☐ 1
 Unstable phase ☐ 2
 Deteriorating phase ☐ 3
 Terminal phase ☐ 4
 Bereavement phase ☐ 5

- Tick one box only.
- The first assessment is the assessment that initiates the start of an episode of palliative care.
- Where the patient (person with a life-limiting illness) does not receive care from the agency, assess the phase of care according to the carer(s)/family/friend(s) who are receiving care.
- 'Stable phase'
 The patient's symptoms are adequately controlled by established management.
 The situation of the carer(s)/family/friends is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.
- 'Unstable phase'
 The patient experiences the development of a new problem or a rapid increase in the severity of existing problems, either of which requires an urgent change in management or emergency treatment.
 The carer(s)/family/friends experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team.
- 'Deteriorating phase'
 The patient experiences a gradual worsening of existing symptoms or the development of new but expected problems.
 The carer(s)/family/friends experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the patient.
- 'Terminal phase'
 Death of patient with life-limiting illness is likely in a matter of days and no acute intervention is planned or required.
 The carer(s)/family/friends recognise that death is imminent and care is focussed on emotional and spiritual issues as a prelude to bereavement.
- 'Bereavement phase'
 During the bereavement phase, the patient may receive grief and bereavement counselling and support, but the carer(s)/family/friends can only receive grief and bereavement support.

6 Episode end date (if applicable)

D	D	M	M	Y	Y	Y	Y
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

- Leave blank if an episode of care has not ended.
- Episode end date may be the date of last service contact which follows the patient's death (to complete immediate follow-up activity) or case closure for other reasons.
- Case closure for other reasons includes when the client moves out of the service provision area, or is transferred/discharged to another service and is no longer expected to return to the palliative care agency, or care is dismissed by the client.

Continued on next page

7 Reason for ending episode (if applicable)

Patient death or bereavement phase end ☐ 1
Go to Questions 8

Discharged to specialist palliative care provider ☐ 2

Discharged to other health care provider ☐ 3

Other reason (please specify) _____ ☐ 8

→ You are not required to complete the rest of this form

- Tick one box only.
- Leave blank if an episode of care has not ended.
- 'Patient death or bereavement phase end' refers to the death/bereavement of the person with the life-limiting illness and the finalisation of all routine bereavement support provided to the carer(s)/family/friends.
- 'Discharged to other health care provider' excludes an episode end due to client being discharged to a specialist palliative care provider. It may include discharge to a primary palliative care provider.
- 'Other reason' includes when the client moves out of the service provision area (and your agency has not referred them on to a health service provider in that area), or care is dismissed by the client.

8 Date of death (if applicable)

D D	M M	Y Y Y Y
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
day accuracy indicator	month accuracy indicator	year accuracy indicator

- Leave blank if the person with a life-limiting illness is not deceased.
 - Where applicable, complete the patient's date of death as best as you can.
 - For each date component (day, month, year) record the accuracy indicator.
 - If the date component is accurate record 'A' in the appropriate 'accuracy indicator' box.
 - If the date component is estimated record 'E' in the appropriate 'accuracy indicator' box.
 - If the date component is unknown record 'U' in the appropriate 'accuracy indicator' box.
- For example if the day is correct, record 'A' in the 'day accuracy indicator' box; if the month is estimated, record 'E' in the 'month accuracy indicator' box; and if the year is unknown record 'U' in the 'year accuracy indicator' box.
- If a date component is unknown, an entry does not need to be made for that date component, however the accuracy indicator 'U' must be recorded.

9 Place of death (if applicable)

- Private residence ☐ 1
- Residential – aged care setting ☐ 2
- Residential - other setting ☐ 3
- Non-residential setting ☐ 4
- Inpatient setting – designated palliative care unit ☐ 5
- Inpatient setting – other than designated palliative care unit ☐ 6
- Other location (please specify) _____ ☐ 8

- Tick one box only.
- Leave blank if the person with a life-limiting illness is not deceased.
- 'Private residence' includes caravans, mobile homes, houseboats, or units in a retirement village.
- 'Residential - aged care setting' includes high and low care residential aged care facilities. It does not include units in a retirement village.
- 'Residential - other setting' includes residential facilities other than aged care facilities, e.g. a prison; or a community living environment including a group home. This code does not include inpatient settings e.g. hospitals and hospices.
- 'Non-residential setting' includes day respite centres, day centres, palliative care day centres, community health centres and outpatient departments (hospitals/hospices).
- 'Inpatient setting - designated palliative care unit' - a dedicated ward or unit that receives identified funding for palliative care and/or primarily delivers palliative care. The unit may be a standalone unit.
- 'Inpatient setting - other than designated palliative care unit' includes all beds not designated for palliative care, usually located in acute hospital wards. Excludes designated palliative care units.
- 'Other location' includes, but is not limited to, an accident and emergency department (casualty department) prior to the patient being admitted. If the patient is admitted to the accident and emergency department, record the place of death as 'Inpatient – designated palliative care unit' or 'Inpatient – other than designated palliative care unit' as applicable.

Thank you for completing this form.

If you have any problems completing this form please telephone 1800 443 182 or email pcdwgsec@aihw.gov.au

Appendix B4: Form C (Episode of palliative care service contact)



Australian Government

Australian Institute of
Health and Welfare

Pilot Community-based Palliative Care Client Data Collection Form C—Episode of Palliative Care Service Contact

This form is to be completed by an agency staff member each time a service contact is provided by a service provider(s) who is employed or subcontracted by the palliative care agency.

- Volunteers providing care are not required to complete this form.
- Service contacts may be provided to, or on behalf of, the patient and/or their carers(s)/family/friends.
- A service contact is a contact between a client and a palliative care provider(s), which results in a dated entry being made in the client record.
- Administrative contacts are not considered to be service contacts. An administrative contact is a contact that is not directly related to client care e.g. booking an appointment for care.
- Service contacts can include group sessions, where services are provided to more than one client at once e.g. a bereavement support activity.

Agency ID	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	(supplied by the AIHW)
Client ID	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
(Patient and/or their carer(s)/family/friends)		
Where the patient is receiving care from your agency, record the identifier assigned by your agency to the patient (and their carer(s)/family/friends) for the episode of palliative care. Where there is no patient receiving care, record the identifier assigned by your agency to the carer(s)/family/friends and tick the box below.		
<input type="checkbox"/> Tick this box if a person with a life-limiting illness is NOT a client of your agency i.e. only the carer(s)/family/friends receive care.		

Service Contact Details

1 Service contact date <div style="display: flex; justify-content: space-around; align-items: flex-end;"> <div style="text-align: center;"> D D <input type="text"/> <input type="text"/> </div> <div style="text-align: center;"> M M <input type="text"/> <input type="text"/> </div> <div style="text-align: center;"> Y Y Y Y <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> </div> </div>	<ul style="list-style-type: none"> • Record the date of the service contact. • Service providers are required to record the date of each service contact, including the same date where multiple visits are made on one day, except where the visits may be regarded as a continuation of the one service contact. • Where a client participates in a group activity, a service contact date is recorded if the person's participation in the group activity results in a dated entry being made in the client's record. 															
2 Service recipient type <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%; text-align: right;">Patient</td> <td style="width: 10%; text-align: center;"><input type="checkbox"/></td> <td style="width: 20%; text-align: center;">1</td> </tr> <tr> <td style="text-align: right;">Patient and carer(s)/family/friends</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;">2</td> </tr> <tr> <td style="text-align: right;">Carer(s)/family/friends</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;">3</td> </tr> <tr> <td style="text-align: right;">Other professional(s)/service provider(s) only</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;">4</td> </tr> <tr> <td style="text-align: right;">Other recipient</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;">8</td> </tr> </table>	Patient	<input type="checkbox"/>	1	Patient and carer(s)/family/friends	<input type="checkbox"/>	2	Carer(s)/family/friends	<input type="checkbox"/>	3	Other professional(s)/service provider(s) only	<input type="checkbox"/>	4	Other recipient	<input type="checkbox"/>	8	<ul style="list-style-type: none"> • Tick one box only. • 'Patient and carer(s)/family/friends' indicates that the patient was present at the service contact with at least one other person who is considered a carer or family member or friend. • 'Other professional(s)/service provider(s)' may include, but is not limited to, staff in community-based palliative care agencies, hospitals, hospices, community nursing agencies, allied health care workers, Aboriginal health services, residential aged care facilities, allied health workers and medical practitioners. It does not include carers. A contact with other professional(s)/service provider(s) is usually on behalf of the client. • 'Other recipient' includes volunteers, but does not include carers.
Patient	<input type="checkbox"/>	1														
Patient and carer(s)/family/friends	<input type="checkbox"/>	2														
Carer(s)/family/friends	<input type="checkbox"/>	3														
Other professional(s)/service provider(s) only	<input type="checkbox"/>	4														
Other recipient	<input type="checkbox"/>	8														

Overleaf

Continued on next page

If you have any problems completing this form please telephone 1800 443 182 or email pcdwgsec@aihw.gov.au

3 Service delivery setting

- Private residence ☐ 1
- Residential - aged care setting ☐ 2
- Residential - other setting (please specify) _____ ☐ 3
- Non-residential setting (please specify) _____ ☐ 4
- Not applicable (patient not present at service contact) ☐ 99

- Tick one box only.
- This is the setting in which the client is located.
- 'Private residence' includes caravans, mobile homes, houseboats, or units in a retirement village.
- 'Residential - aged care setting' includes high and low care residential aged care facilities. It does not include units in a retirement village.
- 'Residential - other setting' includes a residential facility other than an aged care facility; a prison; or a community living environment including a group home. This code does not include inpatient settings e.g. hospitals and hospices.
- 'Non-residential setting' includes day respite centres, day centres, palliative care day centres, community health centres and outpatient departments (hospitals/hospices).

4 Session type

- Individual session ☐ 1
- Group session ☐ 2

- Tick one box only.
- A 'Group session' is defined as two or more clients receiving services at the same time from the same service provider.
- 'Group session' excludes the situation where individuals all belong to the same client group. In such cases, the service is being provided to the client group and as a result the session should be counted as an individual session.

5 Main purpose of service contact

- Symptom control/pain management ☐ 1
- Other clinical or health related care ☐ 2
- Case management and/or care co-ordination ☐ 3
- Spiritual care or support of the patient/care/family/friends ☐ 4
- Personal care ☐ 5
- Other purpose (please specify) _____ ☐ 98

- Tick one box only.
- The main purpose of the service contact is the main focus of the activity that occurred during the service contact.
- 'Case management and/or care co-ordination' includes formal case conference activities or discussion/review of a case between two or more service providers, liaison with, and referral to, other service providers.
- 'Support of the patient/carer/family/friends' includes social support, emotional support, respite care, spiritual care & bereavement support provided to the patient and/or their carer/family/friends.
- 'Personal care' refers to assistance with daily self-care tasks such as eating, bathing, toileting and grooming.
- 'Other' care would include social work, domestic assistance, provision of goods & equipment, transport and other types of care not listed above.

6 Other purpose(s) of service contact

- Symptom control/pain management ☐ 1
- Other clinical or health related care ☐ 2
- Case management and/or care co-ordination ☐ 3
- Spiritual care or support of the patient/care/family/friends ☐ 4
- Personal care ☐ 5
- Other purpose (please specify) _____ ☐ 98

- Tick as many boxes as applicable.
- Any options selected should reflect the purpose of the service contact that was in addition to the main purpose of the service contact.
- 'Case management and/or care co-ordination' includes formal case conference activities or discussion/review of a case between two or more service providers, liaison with, and referral to, other service providers.
- 'Support of the patient/carer/family/friends' includes social support, emotional support, respite care, spiritual care & bereavement support provided to the patient and/or their carer/family/friends.
- 'Personal care' refers to assistance with daily self-care tasks such as eating, bathing, toileting and grooming.
- 'Other' care would include social work, domestic assistance, provision of goods & equipment, transport and other types of care not listed above.

Continued on next page

For each service provider involved in the service contact, indicate their occupation and the contact method for this service.

SERVICE PROVIDER 1

7a Occupation of service provider 1

- Medical practitioner – specialist ☐ 1
- Medical practitioner – general practitioner ☐ 2
- Registered nurse ☐ 3
- Enrolled nurse ☐ 4
- Spiritual carer ☐ 5
- Grief counsellor ☐ 6
- Psychologist ☐ 7
- Physiotherapist ☐ 8
- Occupational therapist ☐ 9
- Speech pathologist ☐ 10
- Social worker ☐ 11
- Dietician ☐ 12
- Podiatrist ☐ 13
- Aboriginal and Torres Strait Islander health worker ☐ 14
- Personal care assistant ☐ 15
- Other counsellor (please specify) _____ ☐ 16
- Other occupation (please specify) _____ ☐ 98

- Tick one box only. See page 22 of the Guidelines for more information about service providers.
- The service provider can only be someone who is **employed by the palliative care agency or is subcontracted** to provide services to clients on behalf of the agency. **Volunteers are not included.**
- 'Spiritual carer' is often referred to as a pastoral carer, and may be a priest, Minister of religion, Aboriginal ceremonial celebrant, Buddhist monk or nun, rabbi, Muslim imam, Hindu Brahmin or other spiritual leader/carer.
- A 'Grief counsellor' may be known as a bereavement counsellor.
- An 'Aboriginal and Torres Strait Islander health worker' liaises with patients, clients and visitors to health clinics and works with team members to arrange, coordinate or provide health care delivery in Aboriginal and Torres Strait Islander community health clinics.
- A 'Personal care assistant' assists with the care of patients in a range of health care facilities, or in the client's home.
- 'Other counsellor' includes marriage and family counsellor.
- 'Other occupation' includes but is not limited to acupuncturists, podiatrists, massage therapists, aromatherapists, music therapists and art therapists. Volunteers are not included.

7b Is service provider 1 a specialist palliative care provider?

- Yes ☐ 1
- No ☐ 2

- Tick one box only.
- A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients.

7c Contact method of service provider 1

- Face to face ☐ 1
- Telephone ☐ 2
- Written ☐ 3
- Telehealth ☐ 4
- Other method (please specify) _____ ☐ 8

- Tick one box only.
- 'Face to face' contact includes one-to-one contact as well as contact made as a group i.e. two or more people.
- 'Written contact' is contact that is not of an administrative nature but is required for case management e.g. care notes for forwarding to other service providers at the end of an episode of palliative care. Written contact may include email or fax.
- 'Telehealth' is the delivery of health related services, enabled by use of technology without the need for travel. It includes videoconferencing, but does not include telephone contact.

Continued on next page

SERVICE PROVIDER 2

8a Occupation of service provider 2

- Medical practitioner – specialist ☐ 1
 Medical practitioner – general practitioner ☐ 2
 Registered nurse ☐ 3
 Enrolled nurse ☐ 4
 Spiritual carer ☐ 5
 Grief counsellor ☐ 6
 Psychologist ☐ 7
 Physiotherapist ☐ 8
 Occupational therapist ☐ 9
 Speech pathologist ☐ 10
 Social worker ☐ 11
 Dietician ☐ 12
 Podiatrist ☐ 13
 Aboriginal and Torres Strait Islander health worker ☐ 14
 Personal care assistant ☐ 15
 Other counsellor (please specify) _____ ☐ 16
 Other occupation (please specify) _____ ☐ 98

- Tick one box only. See page 22 of the Guidelines for more information about service providers.
- The service provider can only be someone who is **employed by the palliative care agency or is subcontracted to provide services to clients on behalf of the agency. Volunteers are not included.**
- 'Spiritual carer' is often referred to as a pastoral carer, and may be a priest, Minister of religion, Aboriginal ceremonial celebrant, Buddhist monk or nun, rabbi, Muslim imam, Hindu Brahmin or other spiritual leader/carer.
- A 'Grief counsellor' may be known as a bereavement counsellor.
- An 'Aboriginal and Torres Strait Islander health worker' liaises with patients, clients and visitors to health clinics and works with team members to arrange, coordinate or provide health care delivery in Aboriginal and Torres Strait Islander community health clinics.
- A 'Personal care assistant' assists with the care of patients in a range of health care facilities, or in the client's home.
- 'Other counsellor' includes marriage and family counsellor.
- 'Other occupation' includes but is not limited to acupuncturists, podiatrists, massage therapists, aromatherapists, music therapists and art therapists. Volunteers are not included.

8b Is service provider 2 a specialist palliative care provider?

- Yes ☐ 1
 No ☐ 2

- Tick one box only.
- A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients.

8c Contact method of service provider 2

- Face to face ☐ 1
 Telephone ☐ 2
 Written ☐ 3
 Telehealth ☐ 4
 Other method (please specify) _____ ☐ 8

- Tick one box only.
- 'Face to face' contact includes one-to-one contact as well as contact made as a group i.e. two or more people.
- 'Written contact' is contact that is not of an administrative nature but is required for case management e.g. care notes for forwarding to other service providers at the end of an episode of palliative care. Written contact may include email or fax.
- 'Telehealth' is the delivery of health related services, enabled by use of technology without the need for travel. It includes videoconferencing, but does not include telephone contact.

Continued on next page

SERVICE PROVIDER 3

9a Occupation of service provider 3

- Medical practitioner – specialist ☐ 1
- Medical practitioner – general practitioner ☐ 2
- Registered nurse ☐ 3
- Enrolled nurse ☐ 4
- Spiritual carer ☐ 5
- Grief counsellor ☐ 6
- Psychologist ☐ 7
- Physiotherapist ☐ 8
- Occupational therapist ☐ 9
- Speech pathologist ☐ 10
- Social worker ☐ 11
- Dietician ☐ 12
- Podiatrist ☐ 13
- Aboriginal and Torres Strait Islander health worker ☐ 14
- Personal care assistant ☐ 15
- Other counsellor (please specify) _____ ☐ 16
- Other occupation (please specify) _____ ☐ 98

- Tick one box only. See page 22 of the Guidelines for more information about service providers.
- The service provider can only be someone who is **employed by the palliative care agency or is subcontracted to provide services to clients on behalf of the agency. Volunteers are not included.**
- 'Spiritual carer' is often referred to as a pastoral carer, and may be a priest, Minister of religion, Aboriginal ceremonial celebrant, Buddhist monk or nun, rabbi, Muslim imam, Hindu Brahmin or other spiritual leader/carer.
- A 'Grief counsellor' may be known as a bereavement counsellor.
- An 'Aboriginal and Torres Strait Islander health worker' liaises with patients, clients and visitors to health clinics and works with team members to arrange, coordinate or provide health care delivery in Aboriginal and Torres Strait Islander community health clinics.
- A 'Personal care assistant' assists with the care of patients in a range of health care facilities, or in the client's home.
- 'Other counsellor' includes marriage and family counsellor.
- 'Other occupation' includes but is not limited to acupuncturists, podiatrists, massage therapists, aromatherapists, music therapists and art therapists. Volunteers are not included.

9b Is service provider 3 a specialist palliative care provider?

- Yes ☐ 1
- No ☐ 2

- Tick one box only.
- A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients.

9c Contact method of service provider 3

- Face to face ☐ 1
- Telephone ☐ 2
- Written ☐ 3
- Telehealth ☐ 4
- Other method (please specify) _____ ☐ 8

- Tick one box only.
- 'Face to face' contact includes one-to-one contact as well as contact made as a group i.e. two or more people.
- 'Written contact' is contact that is not of an administrative nature but is required for case management e.g. care notes for forwarding to other service providers at the end of an episode of palliative care. Written contact may include email or fax.
- 'Telehealth' is the delivery of health related services, enabled by use of technology without the need for travel. It includes videoconferencing, but does not include telephone contact.

Continued on next page

SERVICE PROVIDER 4

10a Occupation of service provider 4

- Medical practitioner – specialist ☐ 1
- Medical practitioner – general practitioner ☐ 2
- Registered nurse ☐ 3
- Enrolled nurse ☐ 4
- Spiritual carer ☐ 5
- Grief counsellor ☐ 6
- Psychologist ☐ 7
- Physiotherapist ☐ 8
- Occupational therapist ☐ 9
- Speech pathologist ☐ 10
- Social worker ☐ 11
- Dietician ☐ 12
- Podiatrist ☐ 13
- Aboriginal and Torres Strait Islander health worker ☐ 14
- Personal care assistant ☐ 15
- Other counsellor (please specify) _____ ☐ 16
- Other occupation (please specify) _____ ☐ 98

- Tick one box only. See page 22 of the Guidelines for more information about service providers.
- The service provider can only be someone who is **employed by the palliative care agency or is subcontracted to provide services to clients on behalf of the agency. Volunteers are not included.**
- 'Spiritual carer' is often referred to as a pastoral carer, and may be a priest, Minister of religion, Aboriginal ceremonial celebrant, Buddhist monk or nun, rabbi, Muslim imam, Hindu Brahmin or other spiritual leader/carer.
- A 'Grief counsellor' may be known as a bereavement counsellor.
- An 'Aboriginal and Torres Strait Islander health worker' liaises with patients, clients and visitors to health clinics and works with team members to arrange, coordinate or provide health care delivery in Aboriginal and Torres Strait Islander community health clinics.
- A 'Personal care assistant' assists with the care of patients in a range of health care facilities, or in the client's home.
- 'Other counsellor' includes marriage and family counsellor.
- 'Other occupation' includes but is not limited to acupuncturists, podiatrists, massage therapists, aromatherapists, music therapists and art therapists. Volunteers are not included.

10b Is service provider 4 a specialist palliative care provider?

- Yes ☐ 1
- No ☐ 2

- Tick one box only.
- A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients.

10c Contact method of service provider 4

- Face to face ☐ 1
- Telephone ☐ 2
- Written ☐ 3
- Telehealth ☐ 4
- Other method (please specify) _____ ☐ 8

- Tick one box only.
- 'Face to face' contact includes one-to-one contact as well as contact made as a group i.e. two or more people.
- 'Written contact' is contact that is not of an administrative nature but is required for case management e.g. care notes for forwarding to other service providers at the end of an episode of palliative care. Written contact may include email or fax.
- 'Telehealth' is the delivery of health related services, enabled by use of technology without the need for travel. It includes videoconferencing, but does not include telephone contact.



If there are more than 4 service providers involved in the same service contact, photocopy a blank copy of questions 7a, 7b, 7c and attach it to this form.

Thank you for completing this form.

If you have any problems completing this form please telephone 1800 443 182 or email pcdwgsec@aihw.gov.au

Appendix B5: Form D (Episode of grief and bereavement counselling)



Australian Government
Australian Institute of
Health and Welfare

Pilot Community-based Palliative Care Client Data Collection Form D – Episode of Grief and Bereavement Counselling

- This form should be completed by an agency staff member in conjunction with the Guidelines document.
- For clients accepted for care after the 5th of June 2006, this form should be completed by an agency staff member present at the initial contact.

An episode of grief & bereavement counselling is the period of time when the carer(s)/family/friends of the person with a life-limiting illness receives formal grief and bereavement counselling and associated support.

This form should be completed each time a service contact is provided to the client registered for grief and bereavement counselling by a service provider(s), who is employed or subcontracted by the palliative care agency. Volunteers providing care are not required to complete this form.

The client can only be the carer(s)/family/friends of the person with a life-limiting illness. The client may be an individual or a group of people from the carers/family/friends group. They are registered with the agency using their own client identifier.

CONSENT

- ☐ Tick the box to indicate that the privacy statement has been read or provided to the client and they have agreed that their information can be collected.

Agency ID

(supplied by the AIHW)

Client ID

Record the identifier assigned by your agency to the carer(s)/family/friends. The client may be an individual or a group of people from the carers/family/friends group.

Client (patient) ID

Record the identifier assigned by your agency to the patient, if the patient was cared for by your agency and the identifier is known. The patient is the person who had the life-limiting illness.

Episode of Grief and Bereavement Counselling Details

1 Episode start date

D	D	M	M	Y	Y	Y	Y
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

- Record the date on which the carer(s)/family/friends first received formal grief and bereavement counselling i.e. first service contact.

2 Episode end date (if applicable)

D	D	M	M	Y	Y	Y	Y
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

- Record the date on which the carer(s)/family/friends last received formal grief and bereavement counselling i.e. last service contact.
- Leave blank if an episode of grief and bereavement counselling has not ended.

3 Date of death of patient (person with a life-limiting illness) (if known and applicable)

D	D	M	M	Y	Y	Y	Y
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
day accuracy indicator		month accuracy indicator		year accuracy indicator			

- Leave blank if the person with a life-limiting illness is not deceased.
- If known, record the date on which the person with a life-limiting illness died.
- For each date component (day, month, year) record the accuracy indicator.
 - If the date component is accurate record 'A' in the appropriate 'accuracy indicator' box.
 - If the date component is estimated record 'E' in the appropriate 'accuracy indicator' box.
 - If the date component is unknown record 'U' in the appropriate 'accuracy indicator' box.
- For example if the day is correct, record 'A' in the 'day accuracy indicator' box; if the month is estimated, record 'E' in the 'month accuracy indicator' box; and if the year is unknown record 'U' in the 'year accuracy indicator' box.
- If a date component is unknown, an entry does not need to be made for that date component, however the accuracy indicator 'U' must be recorded.

Continued on next page

If you have any problems completing this form please telephone 1800 443 182 or email pcdwgsec@aihw.gov.au

Service Contact Details & Date Summary

For each service contact during the episode of grief and bereavement counselling, provide the following information. Record the service contact details for a maximum of five (5) service contacts during the episode of grief and bereavement counselling.

1a Service contact date	<table style="width: 100%; text-align: center; border-collapse: collapse;"> <tr> <td style="border: 1px solid black; padding: 2px;">D</td> <td style="border: 1px solid black; padding: 2px;">D</td> <td style="border: 1px solid black; padding: 2px;">M</td> <td style="border: 1px solid black; padding: 2px;">M</td> <td style="border: 1px solid black; padding: 2px;">Y</td> <td style="border: 1px solid black; padding: 2px;">Y</td> <td style="border: 1px solid black; padding: 2px;">Y</td> <td style="border: 1px solid black; padding: 2px;">Y</td> </tr> <tr> <td style="border: 1px solid black; width: 25px; height: 25px;"></td> <td style="border: 1px solid black; width: 25px; height: 25px;"></td> <td style="border: 1px solid black; width: 25px; height: 25px;"></td> <td style="border: 1px solid black; width: 25px; height: 25px;"></td> <td style="border: 1px solid black; width: 25px; height: 25px;"></td> <td style="border: 1px solid black; width: 25px; height: 25px;"></td> <td style="border: 1px solid black; width: 25px; height: 25px;"></td> <td style="border: 1px solid black; width: 25px; height: 25px;"></td> </tr> </table>	D	D	M	M	Y	Y	Y	Y								
D	D	M	M	Y	Y	Y	Y										
1b Session type <div style="text-align: right;"> Individual session <input type="checkbox"/> 1 Group session <input type="checkbox"/> 2 </div>	<ul style="list-style-type: none"> • Tick one box only. • A group is defined as two or more persons receiving services at the same time from the same service provider. • 'Group session' excludes the situation where individuals all belong to the same client group. In such cases, the service is being provided to the client group and as a result the session should be counted as an individual session. 																
1c Type of assistance provided <div style="text-align: right;"> Bereavement/grief counselling <input type="checkbox"/> 1 Spiritual care <input type="checkbox"/> 2 Social support <input type="checkbox"/> 3 Other counselling (please specify) _____ <input type="checkbox"/> 8 </div>	<ul style="list-style-type: none"> • Tick one box only. • 'Spiritual care' refers to care relating to the spirit or soul as distinguished from a person's physical condition. • 'Social support' refers to assistance primarily directed towards meeting the person's need for social contact and/or accompaniment in order to participate in community life. • 'Other counselling' includes marriage and family counselling. 																
1d Occupation of service provider <div style="text-align: right;"> Grief counsellor <input type="checkbox"/> 1 Psychologist <input type="checkbox"/> 2 Spiritual carer <input type="checkbox"/> 3 Social worker <input type="checkbox"/> 4 Other counsellor (please specify) _____ <input type="checkbox"/> 8 </div>	<ul style="list-style-type: none"> • Tick one box only. • The service provider can only be someone who is employed by the palliative care agency or is subcontracted to provide services to clients on behalf of the agency. Volunteers are not included. • A 'Grief counsellor' may be known as a bereavement counsellor. • 'Spiritual carer' is often referred to as a pastoral carer, and may be a priest, Minister of religion, Aboriginal ceremonial celebrant, Buddhist monk or nun. • 'Other counsellor' includes marriage and family counsellors 																
Is the service provider a specialist palliative care provider? <div style="text-align: right;"> Yes <input type="checkbox"/> 1 No <input type="checkbox"/> 2 </div>	<ul style="list-style-type: none"> • Tick one box only. • A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients. 																
1e Contact method of service provider <div style="text-align: right;"> Face to face <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Written <input type="checkbox"/> 3 Telehealth <input type="checkbox"/> 4 Other method (please specify) _____ <input type="checkbox"/> 8 </div>	<ul style="list-style-type: none"> • Tick one box only. • 'Face to face' contact includes one-to-one contact as well as contact made as a group i.e. two or more people. • 'Written contact' is contact that is not of an administrative nature but is required for case management e.g. care notes for forwarding to other service providers at the end of an episode of palliative care. Written contact may include email or fax. • 'Telehealth' is the delivery of health related services, enabled by use of technology without the need for travel. It includes videoconferencing, but does not include telephone contact. 																

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Service Contact Details & Date Summary

2a Service contact date	<table style="width: 100%; text-align: center;"> <tr> <td style="width: 12.5%;">D</td><td style="width: 12.5%;">D</td> <td style="width: 12.5%;">M</td><td style="width: 12.5%;">M</td> <td style="width: 12.5%;">Y</td><td style="width: 12.5%;">Y</td> <td style="width: 12.5%;">Y</td><td style="width: 12.5%;">Y</td> </tr> <tr> <td><input style="width: 30px; height: 20px;" type="text"/></td><td><input style="width: 30px; height: 20px;" type="text"/></td> <td><input style="width: 30px; height: 20px;" type="text"/></td><td><input style="width: 30px; height: 20px;" type="text"/></td> <td><input style="width: 30px; height: 20px;" type="text"/></td><td><input style="width: 30px; height: 20px;" type="text"/></td> <td><input style="width: 30px; height: 20px;" type="text"/></td><td><input style="width: 30px; height: 20px;" type="text"/></td> </tr> </table>	D	D	M	M	Y	Y	Y	Y	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>
D	D	M	M	Y	Y	Y	Y										
<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>										
2b Session type <div style="text-align: right;"> Individual session <input type="checkbox"/> 1 Group session <input type="checkbox"/> 2 </div>	<ul style="list-style-type: none"> Tick one box only. A group is defined as two or more persons receiving services at the same time from the same service provider. 'Group session' excludes the situation where individuals all belong to the same client group. In such cases, the service is being provided to the client group and as a result the session should be counted as an individual session. 																
2c Type of assistance provided <div style="text-align: right;"> Bereavement/grief counselling <input type="checkbox"/> 1 Spiritual care <input type="checkbox"/> 2 Social support <input type="checkbox"/> 3 Other counselling (please specify) _____ <input type="checkbox"/> 8 </div>	<ul style="list-style-type: none"> Tick one box only. 'Spiritual care' refers to care relating to the spirit or soul as distinguished from a person's physical condition. 'Social support' refers to assistance primarily directed towards meeting the person's need for social contact and/or accompaniment in order to participate in community life. 'Other counselling' includes marriage and family counselling. 																
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Service Contact Details & Date Summary

3a Service contact date	<table style="width: 100%; text-align: center;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;">D</td> <td style="border: 1px solid black; width: 20px; height: 20px;">D</td> <td style="border: 1px solid black; width: 20px; height: 20px;">M</td> <td style="border: 1px solid black; width: 20px; height: 20px;">M</td> <td style="border: 1px solid black; width: 20px; height: 20px;">Y</td> <td style="border: 1px solid black; width: 20px; height: 20px;">Y</td> <td style="border: 1px solid black; width: 20px; height: 20px;">Y</td> <td style="border: 1px solid black; width: 20px; height: 20px;">Y</td> </tr> </table>	D	D	M	M	Y	Y	Y	Y
D	D	M	M	Y	Y	Y	Y		
3b Session type <div style="text-align: right;"> Individual session <input type="checkbox"/> 1 Group session <input type="checkbox"/> 2 </div>	<ul style="list-style-type: none"> Tick one box only. A group is defined as two or more persons receiving services at the same time from the same service provider. 'Group session' excludes the situation where individuals all belong to the same client group. In such cases, the service is being provided to the client group and as a result the session should be counted as an individual session. 								
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Service Contact Details & Date Summary

4a Service contact date	<table style="width: 100%; text-align: center;"> <tr> <td style="border: 1px solid black; width: 25px; height: 25px;">D</td> <td style="border: 1px solid black; width: 25px; height: 25px;">D</td> <td style="border: 1px solid black; width: 25px; height: 25px;">M</td> <td style="border: 1px solid black; width: 25px; height: 25px;">M</td> <td style="border: 1px solid black; width: 25px; height: 25px;">Y</td> <td style="border: 1px solid black; width: 25px; height: 25px;">Y</td> <td style="border: 1px solid black; width: 25px; height: 25px;">Y</td> <td style="border: 1px solid black; width: 25px; height: 25px;">Y</td> </tr> </table>	D	D	M	M	Y	Y	Y	Y
D	D	M	M	Y	Y	Y	Y		
4b Session type <div style="text-align: right;"> Individual session <input type="checkbox"/> 1 Group session <input type="checkbox"/> 2 </div>	<ul style="list-style-type: none"> Tick one box only. A group is defined as two or more persons receiving services at the same time from the same service provider. 'Group session' excludes the situation where individuals all belong to the same client group. In such cases, the service is being provided to the client group and as a result the session should be counted as an individual session. 								
4c Type of assistance provided <div style="text-align: right;"> Bereavement/grief counselling <input type="checkbox"/> 1 Spiritual care <input type="checkbox"/> 2 Social support <input type="checkbox"/> 3 Other counselling (please specify) _____ <input type="checkbox"/> 8 </div>	<ul style="list-style-type: none"> Tick one box only. 'Spiritual care' refers to care relating to the spirit or soul as distinguished from a person's physical condition. 'Social support' refers to assistance primarily directed towards meeting the person's need for social contact and/or accompaniment in order to participate in community life. 'Other counselling' includes marriage and family counselling. 								
4d Occupation of service provider <div style="text-align: right;"> Grief counsellor <input type="checkbox"/> 1 Psychologist <input type="checkbox"/> 2 Spiritual carer <input type="checkbox"/> 3 Social worker <input type="checkbox"/> 4 Other counsellor (please specify) _____ <input type="checkbox"/> 8 </div>	<ul style="list-style-type: none"> Tick one box only. The service provider can only be someone who is employed by the palliative care agency or is subcontracted to provide services to clients on behalf of the agency. Volunteers are not included. A 'Grief counsellor' may be known as a bereavement counsellor. 'Spiritual carer' is often referred to as a pastoral carer, and may be a priest, Minister of religion, Aboriginal ceremonial celebrant, Buddhist monk or nun. 'Other counsellor' includes marriage and family counsellors 								
Is the service provider a specialist palliative care provider? <div style="text-align: right;"> Yes <input type="checkbox"/> 1 No <input type="checkbox"/> 2 </div>	<ul style="list-style-type: none"> Tick one box only. A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients. 								
4e Contact method of service provider <div style="text-align: right;"> Face to face <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Written <input type="checkbox"/> 3 Telehealth <input type="checkbox"/> 4 Other method (please specify) _____ <input type="checkbox"/> 8 </div>	<ul style="list-style-type: none"> Tick one box only. 'Face to face' contact includes one-to-one contact as well as contact made as a group i.e. two or more people. 'Written contact' is contact that is not of an administrative nature but is required for case management e.g. care notes for forwarding to other service providers at the end of an episode of palliative care. Written contact may include email or fax. 'Telehealth' is the delivery of health related services, enabled by use of technology without the need for travel. It includes videoconferencing, but does not include telephone contact. 								

Continued on next page

Service Contact Details & Date Summary

5a Service contact date		D	D	M	M	Y	Y	Y	Y
		<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

5b Session type Individual session <input type="checkbox"/> 1 Group session <input type="checkbox"/> 2		<ul style="list-style-type: none"> • Tick one box only. • A group is defined as two or more persons receiving services at the same time from the same service provider. • 'Group session' excludes the situation where individuals all belong to the same client group. In such cases, the service is being provided to the client group and as a result the session should be counted as an individual session.
5c Type of assistance provided Bereavement/grief counselling <input type="checkbox"/> 1 Spiritual care <input type="checkbox"/> 2 Social support <input type="checkbox"/> 3 Other counselling (please specify) _____ <input type="checkbox"/> 8		<ul style="list-style-type: none"> • Tick one box only. • 'Spiritual care' refers to care relating to the spirit or soul as distinguished from a person's physical condition. • 'Social support' refers to assistance primarily directed towards meeting the person's need for social contact and/or accompaniment in order to participate in community life. • 'Other counselling' includes marriage and family counselling.
5d Occupation of service provider Grief counsellor <input type="checkbox"/> 1 Psychologist <input type="checkbox"/> 2 Spiritual carer <input type="checkbox"/> 3 Social worker <input type="checkbox"/> 4 Other counsellor (please specify) _____ <input type="checkbox"/> 8		<ul style="list-style-type: none"> • Tick one box only. • The service provider can only be someone who is employed by the palliative care agency or is subcontracted to provide services to clients on behalf of the agency. Volunteers are not included. • A 'Grief counsellor' may be known as a bereavement counsellor. • 'Spiritual carer' is often referred to as a pastoral carer, and may be a priest, Minister of religion, Aboriginal ceremonial celebrant, Buddhist monk or nun. • 'Other counsellor' includes marriage and family counsellors
Is the service provider a specialist palliative care provider? Yes <input type="checkbox"/> 1 No <input type="checkbox"/> 2		<ul style="list-style-type: none"> • Tick one box only. • A specialist palliative care provider is a provider who has completed training or has qualifications in providing care specifically to palliative care clients.
5e Contact method of service provider Face to face <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Written <input type="checkbox"/> 3 Telehealth <input type="checkbox"/> 4 Other method (please specify) _____ <input type="checkbox"/> 8		<ul style="list-style-type: none"> • Tick one box only. • 'Face to face' contact includes one-to-one contact as well as contact made as a group i.e. two or more people. • 'Written contact' is contact that is not of an administrative nature but is required for case management e.g. care notes for forwarding to other service providers at the end of an episode of palliative care. Written contact may include email or fax. • 'Telehealth' is the delivery of health related services, enabled by use of technology without the need for travel. It includes videoconferencing, but does not include telephone contact.

Thank you for completing this form.

If you have any problems completing this form please telephone 1800 443 182 or email pcdwgsec@aihw.gov.au

Appendix B6: Feedback Form



Pilot Community-based Palliative Care Client Data Collection 2006 Feedback Form

Information provided on this feedback form will help to ensure that future collections can be improved and made more user-friendly to complete.

The feedback provided by palliative care agencies will be collated and may be included in a national report. Please be assured that all feedback will be treated with strict confidentiality and feedback cited in published sources will not be identifiable.

If possible, complete one form on behalf of your agency's experience. If this is not possible, you can submit multiple copies.

If you have any concerns or need any help completing this form, please contact the Helpline on 1800 443 182 or pcdwgsec@aihw.gov.au

Please return this feedback form and the other completed client forms to your state/territory returning officer (see Guidelines document page 13).

Please complete:

AGENCY NAME: _____

AGENCY IDENTIFIER: _____

*CONTACT NAME/PHONE: _____

* (Optional) A member of the project team may contact you to discuss your answers in this form.

Pilot Community-based Palliative Care Client Data Collection - Feedback Form

Note that additional comments on questions 1-7 below can be provided at question 10 (page 3) of this form.

1. Overall, how easy/difficult did your agency find the survey form to complete? e.g. survey form layout, questions easy to comprehend.

very easy 1 2 3 4 5 very difficult

2. Did you use the guidelines document? YES / NO

If yes, how helpful did you find the Guidelines document?

very helpful 1 2 3 4 5 not helpful

3. Did anyone in your agency access the collection help line and/or the collection help website?

YES / NO If yes, which? HELPLINE/WEBSITE

If so,

HELPLINE—how helpful was this service?

very helpful 1 2 3 4 5 not helpful

WEBSITE—how helpful was this service?

very helpful 1 2 3 4 5 not helpful

4. Appendix A of the Collection Guidelines provides information on 'Letters of name'. From the information provided, would your agency be able to report letters of name for patients? If yes, how would it be collected and recorded?

YES / NO

(If yes).....
.....
.....
.....

5. Is your agency able to report on the statistical local area (SLA) of the place of usual residence of the patient receiving palliative care? (see Appendix A of the Guidelines for more information).

YES / NO

(If yes).....
.....
.....
.....

6. Approximately how many clients refused consent and therefore did not participate in this collection?

7. Service contacts—Questions 5 and 6 on Form C collect information about the purpose of each service contact. What information (if any) does your agency systematically record about service contacts? Is your agency able to record information about the types of assistance provided in more detail, e.g. medical care, nursing care, physiotherapy, domestic assistance, etc. If so, do you record the primary (main) type of assistance or all types of assistance?

.....

.....

.....

.....

.....

Pilot Community-based Palliative Care Client Data Collection - Feedback Form

8. We are interested in learning more about your agency's practices in relation to admitting/discharging patients. For example, are patients discharged every time they go to hospital? If not, in what circumstances are they discharged? Is a comprehensive assessment routinely undertaken for patients returning from hospital or other care?

9. We are also interested in learning more about bereavement support and bereavement counselling that is provided by palliative care agencies—including when and how it is provided. For example, does your agency provide bereavement support and/or bereavement counselling? Under what circumstances is a new client record created for a carer/family/friend who is receiving bereavement support or bereavement counselling?

10. General comments on the Pilot Community-based Palliative Care Client Data Collection:

The following table lists selected questions that formed the Pilot Community-based Palliative Care Client Data Collection. For each question, note 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.

Did you have difficulty <u>understanding or answering</u> this question or the corresponding guidelines for this question?		
Client ID (identifier)	YES/NO	Comments

Pilot Community-based Palliative Care Client Data Collection - Feedback Form

Did you have difficulty understanding or answering this question or the corresponding guidelines for this question?

FORM A (Patient Details)

A2. Date of birth and date of birth accuracy indicator YES/NO Comments

.....

A5. Indigenous status YES/NO Comments

.....

A8. Living arrangements YES/NO Comments

.....

A9. Carer availability status YES/NO Comments

.....

A10. Co-residency status of patient's main carer YES/NO Comments

.....

A11. Main carer's relationship to the patient YES/NO Comments

.....

FORM B (Episode of Palliative Care)

B2. Source of referral to agency YES/NO Comments

.....

B3. Episode start date YES/NO Comments

.....

B4. Patient's principal diagnosis YES/NO Comments

.....

B5. Phase of care at first assessment YES/NO Comments

.....

Pilot Community-based Palliative Care Client Data Collection - Feedback Form

Did you have difficulty <u>understanding or answering</u> this question or the corresponding guidelines for this question?	
B6. Episode end date	YES/NO Comments

B7. Reason for ending episode	YES/NO Comments

B8. Date of death and date of death accuracy indicator	YES/NO Comments

B9. Place of death	YES/NO Comments

FORM C (Episode of Palliative Care Service Contact)	
C2. Service recipient type	YES/NO Comments

C3. Service delivery setting	YES/NO Comments

C4. Session type	YES/NO Comments

C5. Main purpose of service contact	YES/NO Comments

C6. Other purpose(s) of service contact	YES/NO Comments

C7a-10a. Occupation of service providers 1-4	YES/NO Comments

Pilot Community-based Palliative Care Client Data Collection - Feedback Form

Did you have difficulty understanding or answering this question or the corresponding guidelines for this question?

C7b-10b. Is service provider a specialist palliative care provider 1-4 YES/NO Comments

C7c-10c. Contact method of service providers 1-4 YES/NO Comments

FORM D (Episode of Grief and Bereavement Counselling)

D1. Episode start date YES/NO Comments

D2. Episode end date YES/NO Comments

D3. Date of death of patient and accuracy indicator YES/NO Comments

D1a-5a Service contact date 1-5 YES/NO Comments

D1b-5b Session type 1-5 YES/NO Comments

D1c-5c Type of assistance provided 1-5 YES/NO Comments

D1d-5d Occupation of service provider 1-5 YES/NO Comments

D1e-5e Contact method of service provider 1-5 YES/NO Comments

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

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