

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.