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

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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: Comprehensiveness 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)

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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: Comprehensiveness 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.

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
Australia	*(158)*	*(79)*
New Zealand	*(2)*	*(1)*
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
English	*(185)*	*(92)*
Non English	*(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
Co-resident carer	*(161)*	*(80)*
Non-resident carer	*(14)*	*(7)*
Unknown	*(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.

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.

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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).

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; NCCH 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).

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.

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.

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.

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 client (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.