

## 4 Finalising the client data set specification

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

### 4.1 Episodes of grief and bereavement counselling

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

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

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

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

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

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

<p><b>Recommendation(s)</b></p> <p>The project team recommends:</p> <ul style="list-style-type: none"><li>• the PCDWG reconsider the current ability of agencies to collect consistent and comparable data on grief and bereavement counselling episodes as part of the client DSS</li><li>• if data are required specifically on episodes of grief and bereavement then further development of the data requirements and definitions will be required in line with suggested improvements made in Chapter 3 of this report</li><li>• the PCDWG advise on the most suitable methods for collecting data in this area to meet high-level information needs.</li></ul>
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## 4.2 Service contact data

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

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

#### **Recommendation(s)**

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

### **4.3 Client/patient identifiers**

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

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

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

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

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

### **Recommendation(s)**

The project team recommends that the PCDWG consider:

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

## **4.4 Statistical linkage of data**

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

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

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

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

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

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

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

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

### **Recommendation(s)**

The project team recommends that:

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

## **4.5 Scope of the data collection**

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

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

#### **4.5.1 Which agencies?**

Agreement to report an NMDS requires some certainty about the scope of the data collection, that is, that states/territories need to be able to apply the statement of scope and be clear about which agencies they fund that would be required to report the data. While previous consultations undertaken by the AIHW resulted in a clear preference for primary palliative care providers<sup>6</sup> to be included in the national palliative care data collection in recognition of the fact that much palliative care is provided by those non-specialist palliative care services (AIHW 2004), some further consideration needs to be given to the practical consequences of this view. In particular, any service participating in the data collection would need to identify which patients that they care for need to be reported as part of the national collection. For non-specialist services (such as community nursing agencies), agreement would need to be reached on how patients would be identified as 'palliative', and therefore should be reported as part of the national data set. For example, would this decision need to be made by a medical practitioner? Is this likely to occur in the normal course of service delivery? How do practices for identifying palliative patients vary from state to state?

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

#### **4.5.2 Which service contacts?**

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

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6 Primary palliative care providers include any medical, nursing or allied health professional who adopts a palliative approach, has a primary or first contact relationship with the person with a life-limiting illness, and whose substantive work is not with patients with a life-limiting illness.

### **Recommendation(s)**

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

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

## **4.6 Phased implementation**

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

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

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

### **Recommendation(s)**

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

## 4.7 Next steps

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

### 4.7.1 Finalise the client DSS

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

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

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

### 4.7.2 Submit the DSS items to the Health Data Standards Committee

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

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

### 4.7.3 Develop a business case

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



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

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

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

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

## 4.8 Conclusions and summary of recommendations

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

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

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

*(continued)*

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

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

*(continued)*

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

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

(continued)

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

<b>Recommendations in relation to finalising data items (continued)</b>	
[Episode of grief and bereavement counselling]	Then project team suggests that the definition of an episode of grief and bereavement counselling needs to be improved. In particular, the conceptual basis of an episode of grief and bereavement counselling needs to be better defined, and not dependent on describing operational/administrative processes that may vary across palliative care agencies.
Type of assistance provided	<p>The project team suggests:</p> <ul style="list-style-type: none"> <li>• 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</li> <li>• changing the category 'other counselling' to 'other'.</li> </ul>
Occupation of service provider and specialist palliative care provider indicator (for grief and bereavement counselling service contacts)	<p>The project team suggests:</p> <ul style="list-style-type: none"> <li>• 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</li> <li>• adopting changes recommended earlier in this report for the 'specialist palliative care flag' item as it applies to the an episode of palliative care to ensure continuing consistency between these data items.</li> </ul>
Service contact method (for grief and bereavement counselling service contacts)	The project team suggests adopting changes recommended earlier in this report for the 'service contact method' item as it applies to an episode of palliative care to ensure continuing consistency between these data items.