

National palliative care information collection

A way forward for community-based palliative care

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A way forward for community-based palliative care

November 2004

Australian Institute of Health and Welfare
Canberra

AIHW cat. no. HWI 77

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ISBN 74024 417 6

Suggested citation

Australian Institute of Health and Welfare (AIHW) 2004. National palliative care information collection: a way forward for community-based palliative care. AIHW Cat. No. HWI 77. Canberra: AIHW.

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Published by the Australian Institute of Health and Welfare

Printed by Elect Printing

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Acknowledgments

The authors of this report were Mieke Van Doeland, Kay Grzadka and Robyn Kingham Edwards.

The authors would like to thank the members of the Palliative Care Information Development Working Group (see Appendix B) and the members of the Palliative Care Intergovernmental Forum for their valuable advice and comment, and for their assistance and cooperation in setting up the various consultation meetings and field visits.

Special thanks go to all the service providers around the country who gave up their valuable time to meet with the team members during the consultation phase of this project. The project has benefited greatly from their feedback and expertise.

The authors also wish to acknowledge the support and input from the staff of the Palliative Care Section of the Australian Government Department of Health and Ageing, in particular Rita Evans, Steve Dunlop, Vanessa Mayer and Julie Mueller, and the contributions from Mick O'Hara, consultant to the Palliative Care Section.

Thanks are also extended to those staff from the Australian Government Department of Veterans' Affairs and from Palliative Care Australia who provided input into this project. Valuable assistance and support from Trish Ryan and Meera Rajendran of the Australian Institute of Health and Welfare is gratefully acknowledged.

The authors would like to acknowledge the financial support of the Australian Government Department of Health and Ageing which requested the Australian Institute of Health and Welfare to undertake this project.

Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ADL	activities of daily living
AHMAC	Australian Health Ministers' Advisory Council
AHMC	Australian Health Ministers' Council
AHS	Area Health Service
AIDS	Acquired immune deficiency syndrome
AIHW	Australian Institute of Health and Welfare
AN-SNAP	Australian National Sub-Acute and Non-Acute Patient classification
ASGC	Australian Standard Geographical Classification
BEACH	Bettering the Evaluation and Care of Health
CACP	Community Aged Care Program
CCHP	Community Client Health Profile
CCIS	Community Care Information System
CHIME	Community Health Information Management Enterprise
CIS	client information system
CME	Client Management Engine
DHAC	Department of Health and Aged Care
DMIS	Departmental Management Information System
DoHA	Department of Health and Ageing
DOHRS	Department of Health Reporting System
DSS	data set specification
DVA	Department of Veterans' Affairs
EACH	Extended Aged Care at Home
GP	General Practitioner
HACC	Home and Community Care
HDSC	Health Data Standards Committee
HIE	Health Information Exchange
HIV	human immunodeficiency virus
ICD	International Classification of Diseases
IM&T	information management and technology
ISC	Inpatient Statistics Collection
LMO	local medical officer
MBS	Medical Benefits Schedule
MDS	minimum data set
MND	motor neurone disease

MRN	medical record number
NCSDC	National Community Services Data Committee
NCSDD	National Community Services Data Dictionary
NCSIA	National Community Services Information Agreement
NCSIMG	National Community Services Information Management Group
NGO	non-government organisation
NHDD	National Health Data Dictionary
NHIG	National Health Information Group
NHIMG	National Health Information Management Group
NHPC	National Health Performance Committee
NHPF	National Health Performance Framework
NMDS	national minimum data set
NPCP	National Palliative Care Program
PalCID (WG)	Palliative Care Information Development Working Group
PalCIS	Palliative Care Information System
PBS	Schedule of Pharmaceutical Benefits
PCA	Palliative Care Australia
PCIF	Palliative Care Intergovernmental Forum
PCS	Palliative Care System
PDA	personal digital assistant
PIDS	performance indicators data set
RACS	Residential Aged Care Services
RUG-ADL	Resource Utilisation Groups Activities of Daily Living
SACC	Standard Australian Classification of Countries
SIMC	Statistical Information Management Committee
WHO	World Health Organization

Executive summary

Purpose

The purpose of this report is to:

1. report on current data collection, data flows and reporting requirements in the area of community-based palliative care provision;
2. report on the feasibility and recommended scope of a National Minimum Data Set (NMDS) for community-based palliative care;
3. outline and recommend strategies to support future reporting systems;
4. present definitions of core concepts underpinning a community-based palliative care NMDS; and
5. present a draft core minimum set of data items for a future community-based palliative care NMDS.

While national information on admitted patient palliative care has now been reported for a number of years through the National Minimum Data Set for Admitted Patient Palliative Care, no nationally consistent information is available at this stage about community-based palliative care provision. Because of the need for information in this area, the focus of this report is on community-based palliative care, which is described by Palliative Care Australia (PCA) as 'palliative care delivered in community-based settings, which include the person's private home or a community-living environment such as an aged or supported care facility' (PCA 2003).

Main findings

Current systems

- There is a large range of data collection methods and systems currently used by agencies involved in the provision of community-based palliative care, ranging from paper-based systems to spreadsheets to sophisticated client information systems and any combination of these.
- The use of a purpose-built client information system (CIS) greatly assists service providers in managing their patients, running their business and complying with reporting requirements. However, in a majority of cases, service provision information is initially collected on paper and entered into the CIS later. This duplication of effort and inefficient use of resources increase the burden of data collection for these service providers.
- There is a range of new information and communication technologies available which are of particular interest to community-based palliative care services, e.g. wireless networks and mobile computing devices. With these new technologies,

patient and service provision information needs only to be entered once at the point of care. This reduces the burden of data collection on service providers and can make the information immediately accessible to all users of the system.

- There are also new directions in the area of health information that may impact on services involved in the provision of palliative care, such as projects in the area of electronic health records, including the *HealthConnect* project. Although some information about palliative care provision will be available through *HealthConnect*, the voluntary nature of participation by consumers and providers means that it may not provide a complete picture of palliative care. Also, a lot of work is still to be done in *HealthConnect* in relation to data definitions. The palliative care sector would need to ensure that there are nationally accepted standard definitions for palliative care-specific data before their inclusion in *HealthConnect*.

Current data collection and reporting

- Reporting requirements across the states and territories differ greatly. Some states and territories receive aggregated tables from their palliative care-specific funded agencies, while in several other states/territories data are reported in non-aggregated form. However, generally state/territory data collections do not have full coverage of all funded agencies, and information received from agencies is not always complete.

Outcomes of consultation with service providers

While it is acknowledged that not all service providers would agree, much of the feedback that was received from providers could be described as follows:

1. 'The collection of data is important and has many benefits, but the time and cost involved needs to be in proportion to the benefits, and the resulting information needs to be of good quality, otherwise it is not worth doing.'
2. 'By and large the suggested data items in the draft minimum data set presented for comment during consultation are already currently being collected by services, or are able to be collected, and most would be worth including in a potential future state/territory/national data collection.'
3. It is of high importance to service providers that they receive timely feedback on what they report.

Feasibility of a NMDS

- The project team believes that the development and implementation of a National Minimum Data Set (NMDS) for palliative care is feasible, provided it has certain attributes and the patient-level information is implemented in the medium term, in approximately two to four years, and in stages, i.e. some states and territories earlier than others. The collection of agency information is believed viable at an earlier stage. For definitions of 'patient-level information' and 'agency information', refer to the Glossary.

Recommendations

A summary of the recommended approach for a 'way forward' in palliative care national data collection is outlined below. It is recommended that:

- A palliative care data set specification (DSS) be developed as a first step. A data set specification could be described as a core set of data items, and definitions for these items, that has been agreed by stakeholders as an important set of items to be collected by providers in relation to particular types of patients/clients and their care, and that has been endorsed by the National Health Information Group (NHIG) for inclusion in the National Health Data Dictionary. A crucial feature of a DSS is that there does not need to be any obligation to collect or report it, i.e. the collecting or reporting of all or any of the DSS data items can be mandatory or optional.
- A set of agency data items is developed as part of that DSS, as well as patient-level data items.
- A set of agreed agency data is collected nationally before the implementation of any national patient-level data collection.
- A national mandated palliative care data collection be implemented in the medium term and:
 - Be a requirement of those service providers that provide community-based palliative care and who receive palliative care-specific funding;
 - Include consultative visits to residents of residential aged care facilities by community-based palliative care service providers;
 - Have a patient-level and an agency component;
 - Be a 'by-product' of state/territory data collections;
 - Include the core data set items outlined in Chapter 6 of this report, including basic socio-demographic information and activity and service episode data items, subject to pilot testing;
 - Include data items that can support a number of performance indicators;
 - Specify the rules governing the transmission of data to a national collection repository.
- Of the four strategies (see Section 6.3) for data collection and transmission of a future NMDS, strategy 2 *not* be implemented and that each of the other three strategies be considered depending on the circumstances of each state and territory; and that, in relation to strategy 4, investigation is undertaken closer to the time of implementation into the amount of interest within the palliative care sector in developing a data collection and reporting computer system for use by those regions, states or territories where no system is yet in place.
- Any future work in the area of palliative care information development keep abreast of developments related to other sources of data relevant to palliative care provision (as outlined in Section 3.3), and further explore their potential.

Further details on the scope and other recommended characteristics of a palliative care NMDS are discussed in *Chapter 6*. The main recommendations of this report are outlined in detail in *Chapter 7*.

1. Introduction

During the past decade, a number of projects have been undertaken in palliative care information development. These have all been aimed at improving the amount of information that is available about palliative care provision. Some have focused on community-based palliative care, others on admitted patient palliative care (i.e. palliative care provided in hospitals). Some of this work has been specifically focused on performance measurement, through the development of performance indicators for palliative care.

While information on admitted patient palliative care has now been reported for a number of years through the National Minimum Data Set for Admitted Patient Palliative Care, no nationally consistent information is available at this stage about community-based palliative care provision. Because of the need for information in this area, the focus of this report is on community-based palliative care, which is described by Palliative Care Australia (PCA) as 'palliative care delivered in community-based settings, which include the person's private home or a community-living environment such as an aged or supported care facility' (PCA 2003).

The Palliative Care Information Development (PalCID) project is one of the most recent projects in this area, undertaken during 2003–2004, focusing on community-based palliative care in particular. This report describes the outcomes of that project. A description of the project is provided in Section 1.2 of this chapter, but first some background information is presented in Section 1.1.

1.1 Background

1.1.1 A definition of palliative care

Palliative care has developed as a specialised health care field in Australia since the 1980s. This development has been part of a worldwide movement to address the needs of people who are dying and their families. While caring for people who are dying and those around them is not new and is sometimes referred to as 'palliative care' or care with 'a palliative intent', the recent movement in palliative care advocates a particular, holistic, approach to this end-of-life care.

Where the term 'palliative care' is used in this report, it refers to this particular approach, which is described by the World Health Organization (WHO) definition of palliative care as follows:

'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' (WHO 2003)

Box 1 outlines a list of further characteristics of palliative care identified by WHO.

Box 1: World Health Organization (WHO) characteristics of palliative care

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten nor postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

Source: WHO 2003.

While most palliative care providers in Australia would aim to apply the above definition in their day-to-day care, different approaches are used to achieve this, depending on the type of agency delivering the care, the setting, the geographical location and the individual circumstances of the patient. This has resulted in many different models of care being applied across agencies and even within agencies. No final agreement on how to describe these models of care has been reached, however at the time of writing, work on this topic is being undertaken by Palliative Care Australia.

Even though a variety of models are employed to deliver palliative care, there appears to be consensus among service providers that a number of aspects of palliative care are crucial to good practice. Some of these aspects are: the role of the family as part of the team as well as its role as the client of the service; the importance of the client's access to support (24 hours a day); the importance of loss, grief and bereavement support, both before and after the patient's death; the need for continuity and coordination of care and an interdisciplinary approach; the important role of the patient's general practitioner (GP) and volunteers; and the importance of education (PCA 2003).

It is crucial that any information development in palliative care takes into account these important aspects of palliative care as well as the variety in models of care.

1.1.2 Palliative care provision and information development

While in recent years a number of research projects have contributed to the body of knowledge about palliative care provision in Australia, there is a need for comprehensive and consistent national information in this area. Although national information about palliative care services provided to admitted patients (i.e. patients admitted to hospitals, including hospices) is currently collected, the quality of this

information is poor and requires further development. Furthermore, there is a particular information gap in the area of community-based palliative care.

This section provides a discussion of a range of existing strategies, agreements and standards relevant to information collection and development in the area of palliative care.

The National Strategy for Palliative Care

The need for information about palliative care provision is acknowledged in the National Strategy for Palliative Care (the Strategy). The Strategy is a national framework for palliative care service development. It sets national priorities intended to inform policy and service development in Australia, and is a consensus document between the Australian and state and territory governments, palliative care service providers and advocacy groups. The Strategy has three goals:

1. Awareness and understanding:

To improve community and professional awareness of, and professional commitment to, the role of palliative care practices in supporting the care needs of people who are dying and their families of care.

2. Quality and effectiveness:

To support continuous improvement in the quality and effectiveness of palliative care service delivery across Australia.

3. Partnerships in care:

To promote and support partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, to support delivery of high quality, effective palliative care across all settings (DHAC 2000).

Good quality information will contribute to the attainment of each of these three goals. However, information development is particularly relevant to the second goal, which has as one of its objectives (Objective 2.3) 'to achieve nationally consistent reporting on palliative care provision in both the public and private sectors and across all service delivery settings (inpatient palliative care unit, acute hospital, home and community)'.

The Strategy outlines three specific strategies aimed at achieving Objective 2.3 that are particularly relevant to the information development work described in this report. These are:

Strategy 2.3.2: Implement a national data set and collect agreed state/territory and national level data to monitor palliative care service use and describe the client group, including administrative data and clinically significant data as appropriate at each reporting level.

Strategy 2.3.4: Develop performance indicators for palliative care service provision, as agreed under the Australian Health Care Agreements.

Strategy 2.3.5: Report on and monitor performance against service benchmarks, performance indicators and agreed items.

National data standards

Australia's health and community services data standards are contained in the *National Health Data Dictionary* (NHDD) and the *National Community Services Data Dictionary* (NCSDD) respectively. Under the National Health Information Agreement, the NHDD is the authoritative source of health data definitions where

national consistency is required or desired (NHDC 2003). Similarly, the NCSDD is the authoritative source of community services data definitions where national consistency is required under the National Community Services Information Agreement (NCSDC 2004).

A national data standard specifies the agreed meaning and representation of a piece of information; when that information is collected according to the data standard it can be compared across different jurisdictions, settings and sectors. The use of national health and community services data standards promotes the comparability, consistency and relevance of national health and community services information. National data standards also make data collection activities more efficient by reducing the duplication of effort in the field and more effective by ensuring information to be collected is appropriate to its purpose. National data standards are therefore highly relevant and important to the area of palliative care information development.

National data standards in the NHDD and the NCSDD are subject to a process of endorsement via a group of committees established to ensure that information is collected consistently on a national basis. The National Health Information Group (NHIG) and the National Community Services Information Management Group (NCSIMG) are the management groups responsible for the endorsement of all new and revised national standards. These groups are guided in their decisions by the Health Data Standards Committee, the Statistical Information Management Committee and the National Community Services Data Committee which meet regularly to discuss submissions for revisions to the data dictionaries.

Health Information Development Priorities

The Health Information Development Priorities aim to guide the development of national information, and are current until 2005. They were produced in a planning process undertaken in 2002 by the then National Health Information Management Group (NHIMG), which was established by the Australian Health Ministers' Advisory Council (AHMAC).

Two of the 27 priorities that are particularly relevant to (community-based) palliative care are:

- Priority 5 'Develop and expand national minimum data set (NMDS) modules to cover services delivered in emergency, other ambulatory and community health settings, according to priorities of service providers, funders and consumers'; and
- Priority 19 'Undertake data development, expanded collections and, where necessary, implement new collections to facilitate the National Health Performance Committee's reporting of performance indicators under the National Health Performance Framework and the AIHW's reporting of indicators for National Health Priority Areas' (NHIMG 2003).

Australian Health Care Agreements

In the Australian Health Care Agreements between the Australian Government and the states and territories 2003–2008, the states and territories have agreed to work together with the Australian Government and each other through the AHMAC-agreed governance arrangements for information management and information technology to develop and refine appropriate performance indicators.

This work includes the development of data items, minimum data sets and performance indicators related to both admitted and non-admitted patient services, including palliative care.

Data on inpatient palliative care provision in hospitals are already being reported by all states and territories through the Admitted Patient Care NMDS. As mentioned earlier, further work to improve the data quality of the Admitted Patient Palliative Care NMDS is required.

Australian Council for Safety and Quality in Health Care

The Australian Council for Safety and Quality in Health Care was established in January 2000 by Australian health ministers to lead national efforts to improve the safety and quality of health care provision in Australia. The Council reports annually to all health ministers. Its fourth report included a discussion on safety and quality in the health reform agenda and called for a consistent national approach in relation to: national definitions and minimum data sets; incident reporting and management; performance review criteria; information management systems; and standards setting (Australian Council for Safety and Quality in Health Care 2003).

National Health Performance Committee

In 2001, the National Health Performance Committee (NHPC) published the *National Health Performance Framework Report*, which describes a national health performance framework (the framework) intended to support performance measurements at all levels of the health system. The overall vision of the NHPC is: 'a health system that searches for, compares, and learns from the best and improves performance through the adoption of benchmarking practices across all levels of the system' (NHPC 2001).

Before the 2001 framework was developed, reports on performance focused on indicators relating mostly to institutional care and acute care settings. The framework was developed to also accommodate indicators for services such as community health, general practice and public health (NHPF 2001, p v).

PCIF information development principles

The Palliative Care Intergovernmental Forum (PCIF) is an advisory body with representatives from the Australian Government Department of Health and Ageing (DoHA) and each state/territory health department. In 2003, the PCIF agreed to a set of Information Development Principles, and agreed that the overall aim of palliative care information development is the 'collection of meaningful data at both a national and jurisdiction level to inform policy and planning for palliative care in Australia'. The full set of PCIF information development principles can be found in Appendix A of this report.

National Palliative Care Strategy Quality and Effectiveness Information Priorities

In 2003, a consultant was contracted by DoHA to prepare an information development plan for palliative care in close consultation with the Australian and state and territory governments. This work recognises that achieving agreement and implementation requires a framework that provides guidance on what data are wanted, why these are wanted, and how a nationally consistent reporting mechanism may be designed and implemented.

This work complements the Palliative Care Information Development (PalCID) project by the Australian Institute of Health and Welfare (the subject of this report), by providing an agreed policy context and plan of action to progress possible future data and information collections.

1.2 The Palliative Care Information Development project

In 2003, the DoHA asked the Australian Institute of Health and Welfare (AIHW) to explore the possibility of collecting palliative care information nationally. The resulting project, the Palliative Care Information Development project, was undertaken during the second half of 2003 and the first half of 2004. It has focused on community-based palliative care in particular, and has taken into account the relevant national data standards in health and community services. It has also taken into account the outcomes of previous projects carried out in the area of palliative care information development during the past decade.

Objectives

The objectives of the project were to:

1. explore and reach agreement on the scope of a future National Minimum Data Set (NMDS) for community-based palliative care;
2. define core concepts underpinning the NMDS;
3. Explore current data collection, data flows and reporting requirements at service provider, jurisdictional and national levels, collating and providing documentation collected;
4. develop technology and change management strategies and recommendations to support a palliative care NMDS and other reporting systems; and
5. identify a core minimum set of data items for the community-based Palliative Care NMDS, including the purpose or justification for inclusion.

National Palliative Care Program

The PalCID project was funded through the National Palliative Care Program (NPCP). The NPCP is a program under the National Palliative Care Strategy, funded by the Australian Government, which involves \$55 million in funding over four years from 2002. It comprises national activities to support improvements in the standard of palliative care offered in local communities. The NPCP is implemented across six broad priority areas, with the PalCID project one of the initiatives under the sixth area, 'Performance information development'.

Palliative Care Information Development Working Group

The Palliative Care Information Development Working Group (PalCID WG) was formed towards the end of 2003, under the auspices of the PCIF, to oversee the project. This group includes a representative from each state and territory, including two palliative care providers, a representative from DoHA, a consultant for DoHA responsible for developing a medium-term Palliative Care National Information Development Plan, and the project team.

A list of PalCID WG members can be found in Appendix B.

Project management

The project was carried out by a project team from the National Data Development and Standards Unit, a unit of the Australian Institute of Health and Welfare (AIHW). The Unit aims to improve the comparability, consistency, relevance and availability of national health and community services information. The Unit manages and promotes Australia's national health and community services data standards. It also specialises in identifying and developing national information requirements in specific program/policy areas or sectors.

Consultation

One very important aspect of this project was consultation with service providers and other stakeholders, including the PalCID Working Group members, staff in the state and territory health departments, Palliative Care Australia peak bodies, the Health Data Standards Committee, staff in DoHA (in the palliative care section as well as other areas, such as the Home and Community Care (HACC) Outcomes Section), palliative care researchers and the Australian Government Department of Veterans' Affairs.

The broad consultation served to ensure that service providers who work with palliative care patients and their families, and others with an interest in palliative care policy and information, had input into the project.

In some states and territories the consultation with service providers was done through meetings/workshops with existing palliative care reference groups. In other jurisdictions the project team held more ad hoc meetings with individual service providers. The project team also made a number of field visits to service providers involved in the delivery of palliative care. These field visits provided the team with valuable understanding of the day-to-day running of these services, as well as first-hand knowledge of their information collection practices, from the types of forms used to the interface with their information technology systems.

The outcomes of the consultation meetings have informed the recommendations made in this report.

2. Data collection systems

This chapter describes the collection methods and the mechanisms or vehicles currently used to capture, store and transmit community-based palliative care data. Information has been gathered from:

- state/territory health department representatives;
- service providers during site visits; and
- questionnaires completed by participants at consultation meetings.

A significant amount of information has been collected to give a broad picture of palliative care data collection nationally, even though it was not possible to get information about every system in Australia used by community-based palliative service providers.

Also discussed in this chapter are future directions for data collection systems.

2.1 Current systems

It has been observed that the most common method of data collection for community-based palliative care services involves visiting the patient in their home or other community setting and recording information about the service provided to the patient in a patient file. The patient file normally remains with the client. A copy of the service provision information, and in most cases with some more detailed information added, is stored on a patient record at the premises of the service provider.

There is a variety of means used to collect and record these service provision data ranging from entirely paper-based systems to sophisticated computerised client information systems. Appendix C details the data collection systems currently used within state and territory health regions. These data collection systems were in effect at the time of investigation by the project team from September 2003 to March 2004.

There have been considerable effort and resources put in by health service providers and governments over the past few years to enhance and streamline data collection and information management. At present there is a lot of activity across the nation involved with the development and implementation of these systems, such as:

- Western Australia rolling out the Palliative Care Information System (PalCIS) across regional areas and training users under a Commonwealth-funded project;
- New South Wales progressively rolling out CHIME to community-based health services across the state. This process will take some years; and
- Tasmania developing a version of the community-based system Community Client Health Profile (CCHP) with palliative care specifications in 2004–2005 to be used by palliative care clinicians in all regions.

The data collection systems in use by community-based palliative care service providers can be divided into two types:

- paper based with electronic spreadsheets or databases; and
- specialised client information systems (often used in combination with paper-based systems).

2.1.1 Paper-based and electronic spreadsheet/database

One method of data collection is to use standard paper forms to record information about the client and about the service event. The completed forms are kept in a file for each patient.

Information from the paper forms may later be transferred by staff to an electronic spreadsheet or database such as Microsoft's Excel or Access software products for future use.

Typically electronic spreadsheets and databases are used by service providers to enable them to meet their jurisdictional reporting requirements. The data are normally aggregated and the spreadsheets and databases are used wholly within one service.

A significant disadvantage of these types of systems is the inability to efficiently re-use the data contained in the paper forms, without re-entering the data to an electronic medium, for other service activities such as patient management and staff resource planning.

2.1.2 Client information systems

The term client information system (CIS) is used in this context to denote computer applications that have been purpose built for the management of health service clients. These systems may or may not cater solely for palliative care clients.

There are many client information systems used by community-based palliative care providers that differ not only across jurisdictions but within them as well. There can be differences in the:

- number and types of data items collected;
- definitions applied to the data; and
- functionality provided.

Functionality provided by the client information systems can include:

- management of patients, staff or equipment;
- meeting of national reporting requirements such as HACC and Department of Veterans' Affairs; and
- financial capabilities such as invoicing.

There are two methods currently in place for capturing data in these client information systems:

- Data entry by staff; and
- Automatic upload from hand-held computing devices.

Data entry

Information may be entered directly into the system by service provision staff, by administrative staff or by specialist data entry operators.

In most cases the information is entered from paper forms that were completed at the point of care or from staff notes.

In metropolitan Perth, Western Australia, information about general services as well as palliative care services provided to a Silver Chain client is entered by a team of data entry operators directly into Silver Chain's client information system, ComCare. Silver Chain is a charitable organisation that provides a range of services to people at home, in residential care facilities and in clinics. The information is relayed to an operator in the data entry team by the service provider using the patient's telephone at the point of care. This makes the service provision information immediately available to all users of the ComCare system but the facility is costly to maintain.

Hand held computing devices

Hand-held computer devices and personal digital assistants (PDAs) provide a simple, effective means of transporting electronic information.

Client data are downloaded from the client information system into the PDA prior to visiting clients. Details of the service provided to each client are entered into the PDA at point of care and then uploaded to the client information system when the service provider returns with the PDA to the office.

The processes to download data to the PDA and upload data to the client information system are automated once the PDA is connected to the network from which the CIS is being served. The information about a particular occasion of service provision is not available to all users of the CIS until that information has been uploaded from the PDA.

An example of a client information system that can use PDAs is the Palliative Care Information System, PalCIS, which is being used widely in Western Australia as well as in Griffith, New South Wales and the Phillip Oakden House Hospice in Launceston, Tasmania.

Issues

There are many advantages in using client information systems including the automation of reporting and financial functions, the facilitation of patient and resource management and the ability to re-use information once entered into the system.

Within the palliative care sector however, client information systems are mostly used in conjunction with paper-based systems with information first recorded on paper before subsequent entry into the CIS. The problems with using this method are the added cost in time and staff resources needed to double enter information and the inability to access the most up-to-date information due to the delay between providing a service and having information about that occasion of service recorded in the CIS.

These problems could be overcome by using a data entry facility such as the one used by Silver Chain in Perth (although there is considerable cost involved in running this type of facility) or by using mobile computing devices such as hand-held computers or new-generation mobile phones with appropriate networks that could allow real-time entry of information at the point of care.

Specific client information systems

Some of the client information systems used across the nation to collect community-based palliative care data are:

- **BDNH** – a Microsoft Access program that was originally developed for district nurses in Ballarat. It is currently being used by approximately 18 services across seven health regions in Victoria.
- **ComCare** – used by metropolitan Silver Chain services in Perth, Western Australia and Royal District Nursing Service in South Australia.
- **Community Care Information System (CCIS)** – used across the Northern Territory for the collection of health and community services data including palliative care information.
- **CERNER HNA Millennium Patient Administration System** – used in South Western Sydney Area Health Service captures both inpatient and non-inpatient services.
- **CHIME** – Community Health Information Management Enterprise (CHIME) software. The New South Wales state government is in the process of a state-wide implementation of CHIME and it is also intended for use in Queensland Health community-based palliative care services.
- **Client Management Engine (CME)** – used widely throughout South Australia, primarily in the non-acute community-based sector but is also used by Allied Health in three of the metropolitan teaching hospitals. Only two of the 27 palliative care sites in South Australia do not use CME.
- **IBA Eclipse** – used by two palliative care service providers in two health regions in Victoria.
- **JADE Coordinated Care** – used in one Victorian health region.
- **Palliative Care Information System (PalCIS)** – used widely in Western Australia as well as in Griffith, New South Wales and the Phillip Oakden House Hospice in Launceston, Tasmania.
- **Palliative Care Systems (PCS)** – used by the Northern Sector of the South Eastern Sydney Area Health Service.
- **PJB Data Manager** – used by approximately seven palliative care service providers across three Victorian health regions.
- **SNAPShot** – used in New South Wales in parts of South Eastern Sydney Area Health Service, Northern Sydney Area Health Service, Macquarie Area Health Service, Mid Western Area Health Service, Greater Murray Area Health Service and Southern Area Health Service.

2.2 Future directions

2.2.1 Mobile computing and wireless technology

The mobile workforce

The nature of community-based palliative care provision lends itself to the use of mobile computing and wireless technology to facilitate the running of the business.

In many rural communities, services are provided to clients situated long distances from the provider premises and staff use up considerable time traveling to and fro.

In other remote areas there are outreach services that do not have any direct access to the central system. For example, in the Northern Territory none of the communities or homelands have access to the Territory's information system and communication is by phone or fax. For the Broome region in Western Australia there are six outreach services located in small towns some distance from Broome that do not have access to the central information system.

Technology

Mobile telephone network connections are very common in Australia and mobile phones are becoming more sophisticated having the ability to provide services other than mere phone calls.

Wireless technologies allow data to be transmitted across distances without the need for components to be attached to wired networks thus enabling communication between different parties from any place at any time.

The combination of mobile and wireless telephone computer technologies in client information systems allows service providers to access the latest information about their clients from any location and to input information at the point of care. This information immediately becomes accessible to other users of the same client information system.

Some current client information systems use hand-held computers and others are being updated to take advantage of wireless connections and hardware such as mobile phones, to cater for a mobile workforce. Two examples where mobile and wireless technologies are currently planned for use are the ComCare and Palliative Care System client information systems.

ComCare

Silver Chain in Western Australia is in the process of implementing a wireless implementation of their ComCare system. The mobile application has been designed to utilise the latest standards, be low cost, and be phone carrier and mobile device independent. The application will provide real-time access to information for both administrative and care delivery purposes.

The quality of care delivery is also expected to increase for two main reasons. First, general efficiencies in data collection processes will leave more time for actual delivery of care. Reduced travel times as well as the reduction of wasted visits due to improved communications will also contribute to this.

The second factor will be the ability to more effectively use specialist personnel. Silver Chain performs a lot of wound care and has a number of experts in this area.

Using the inbuilt camera in the phone a nurse in the home will be able to take an image of a wound, send it to one of these experts and receive their recommendation for treatment in a few minutes. This will effectively provide access to the experts in every single home in Western Australia.

To cover the circumstance where a network becomes unavailable, the system has been devised to retain any data entered and to automatically resubmit it when the network becomes available again.

Personal safety is also becoming a very important issue particularly for providers who work alone at night. Numerous technologies have been around for a while to 'track' employees geographically but they are expensive and not always reliable. GPS is one such technology but is not always practical in areas of dense building. Using the SmartPhone to record provider visits and when and where the provider is going, allows the system to monitor their progress and raise alerts if they don't meet their planned schedule. The devices can also be programmed to immediately send a distress SMS, which when combined with their planned visit schedule, considerably increases the chances of emergency services locating them.

In summary, the financial and operational benefits from the SmartPhone technology are considerable. In addition they are easily used (providers see them as phones not computers) and easy to carry around. In comparison, laptops are complex to use and maintain and are intimidating to many clients. The vast majority of providers already carry a mobile phone so this project simply replaces their existing one.

PCS

There are plans to upgrade the Palliative Care System (PCS) used in the South East Sydney Area Health Service, New South Wales to use PDAs such as palm pilots and 3G or GPRS wireless networks so that staff can enter clinical information while on the road and have it immediately available to other users of PCS.

2.2.2 HealthConnect

HealthConnect is the proposed national system for the collection, storage and exchange of summary electronic health records. It has been trialed in Tasmania, the Northern Territory and Queensland and preparations are under way for state-wide roll-out in Tasmania and South Australia.

HealthConnect is part of the future scenario for health information sharing across Australia. However, the question is to what extent this system will be capable of delivering meaningful data for national analysis.

Below is an outline of a number of features of the *HealthConnect* system as understood at the time of writing. However, it should be noted that the approach to the implementation of this system continues to evolve, with the outcomes of the trials feeding into this process. For updated information refer to the *Healthconnect* website <www.healthconnect.gov.au>.

Participation

Participation in *HealthConnect* is voluntary for both providers and consumers of health care.

Health care providers who wish to participate in *HealthConnect* will be registered with its provider directory.

To ensure privacy of information, health care consumers can give or refuse consent to having their service summary events included in *HealthConnect*. Consumers will control user access to their health records by being able to view, grant and revoke consent settings maintained by the system.

Client information systems (CIS)

HealthConnect is not a replacement for current health care provider client information systems.

It is expected that CIS vendors will modify their products to provide *HealthConnect* integration for health care providers. There is a realisation by the *HealthConnect* project team that there may need to be incentives to ensure this happens.

Access

According to the *HealthConnect* Draft Systems Architecture, access to *HealthConnect* from client information systems (CIS) can be provided in three ways:

- **Messaging model** – involves the client system sending and receiving messages from the *HealthConnect* Record System. These messages need to be compiled, validated, interpreted and presented in a format acceptable to the user by the client system.
- **Transaction model** – involves access to the *HealthConnect* record system via the Internet. The user needs only a generic web browser to display information from *HealthConnect* and to fill in web forms to update information on the *HealthConnect* record system.
- **Subscription model** – involves a CIS accessing a local copy of the *HealthConnect* data held on a server located in the provider organisation's premises. The local system would be automatically updated with new data via a batch process controlled by the *HealthConnect* record system. Subscription would be subject to a registration process and to consumer consent, and provider organisations would only subscribe to those consumers that are currently under their care. (DHAC 2003)

Of the three access models, the subscription model provides the best option with regard to performance, efficiency and cost. However, it relies on CIS vendors embedding *HealthConnect* record system interfaces into their products.

Electronic health records

Event summaries

The clinical and demographic information within *HealthConnect* will be in the form of event summaries. An event summary is a subset of the complete information recorded by providers for events such as home visits by a community nurse, general practice and specialist consultations and hospital inpatient stays.

Views, lists and reports

Three of the functions that can be applied to an electronic health record in *HealthConnect* are views, lists and reports:

- views – a subset of a consumer’s electronic health record;
- lists – views that define a set of observations of current interest for a target audience, for example, current medications;
- reports – formatted across a number of consumer electronic health records.

Information exchange

At this stage there is no detailed definition of what information will be exchanged by *HealthConnect*. A component of the Clinical Information Project is to develop data content definitions for *HealthConnect* and this work is expected to be completed by the end of this year.

Information sources

HealthConnect aims to draw on external information systems as information sources where they exist. These include data dictionaries as a source of electronic health record format definitions and provider directories as a source of provider registration information.

Work is in progress to integrate *HealthConnect* and *MediConnect*, which stores information about medicines used within Australia.

Issues

There would be some potential benefits for the palliative care sector when *HealthConnect* is implemented nationally, such as:

- *HealthConnect* reports could be a possible source of information for researchers in the palliative care field as well as for state and Australian Government health departments; and
- Community-based palliative care service providers will know when one of their clients has been admitted to hospital. (This is not always the case at present.)

However, the proposed ‘opt-in’ basis for *HealthConnect* could limit its statistical reporting potential unless a representative and relatively high participation rate is achieved. Other potentially limiting factors include the feasibility of identifying palliative care in *HealthConnect* data sets, the range of data collected for *HealthConnect*, and the ability for *HealthConnect* data to be classified according to national statistical standards.

3. Current data reporting

This chapter describes the reporting process and requirements at the state and territory level for community-based palliative care. Section 3.1 provides information on reporting arrangements in each state and territory. Section 3.2 includes two tables in which those data items currently reported in non-aggregate form (four states/territories) are mapped against a number of potential data items for national collection. A number of relevant sources or potential sources of information about community-based palliative care provision are discussed in Section 3.3.

3.1 Reporting in each state and territory

Most states/territories have at least some community-based palliative care data reported at the state/territory level, either as unit record data or in aggregate form. However, the coverage in terms of services and the extent of information reported varies greatly. It should be noted that, for the purposes of this report, each state and territory has to some degree provided slightly different information about their state or territory's palliative care reporting arrangements, resulting in some variation in content and length between these segments.

Australian Capital Territory

The Australian Capital Territory has one hospice, Clare Holland House, which operates as part of Calvary Public Hospital. As well as providing inpatient services, Clare Holland House provides a day care centre and community-based palliative care for the whole of the Territory.

Data about the community-based component are collected on paper forms and statistical data are stored in Microsoft Excel spreadsheets and an Access database.

Information currently reported

The information reported covers community-based palliative care occasions of service with regard to the type of service provider and the type of service. Services reported include those provided by the director of palliative care, palliative care specialists and home-based palliative care nurses. Information is also reported about after-hours phone consultations from the community, if the calls were taken at Clara Holland House. Also included is the provision of services by the day care centre, art classes, physiotherapist, hospice bereavement counsellor, occupational therapist and pastoral care. The setting of service event is also collected, i.e. whether the visits were conducted in the home, in the hospital setting or at other locations. An example of a monthly report is included in Appendix G.

New South Wales

New South Wales has a minimum set of data (MDS) for hospital non-admitted care. Any client information system in use in non-admitted services may implement this core data set. At this stage, services have a choice whether to report unit record data

or aggregate data to the Area Health Service. The information reported to the Department of Health is all aggregate information, i.e. unit record data are not provided to the Department. In addition, Area Health Services have implemented a number of methods to measure activity and monitor non-admitted performance at the local level.

There is currently one source of community palliative care activity measures at the statewide level – the Department of Health Reporting System (DOHRS).

Department of Health Reporting System (DOHRS)

DOHRS is used to record non-inpatient occasions of service provided by all public health facilities in New South Wales. Since DOHRS contains aggregate data at considerable detail (occasions of service classified by financial class, provider type, setting type, and service type – including several palliative service types), some facilities with client information systems prefer to submit the MDS in the form of unit record data, which are automatically extracted as aggregate data on load to the Local Area Warehouse.

Australian National Sub-Acute and Non-Acute Patient classification (AN–SNAP)

Designated non-acute inpatient facilities in New South Wales use the Australian National Sub-Acute and Non-Acute Patient classification (AN – SNAP classification). AN–SNAP measures the phase of care within the episode of care and includes data items that capture specialist palliative care liaison and consultation services that occur in an inpatient setting. Palliative care is one of the five case types into which AN-SNAP initially separates sub-acute and non-acute patients. AN-SNAP data items have been included in the CHIME system. This has significance for the collection of data on community-based palliative care, as those community-based services that use, or will in future use, CHIME software will be able to collect those data items currently included in the AN-SNAP classification.

Information currently collected

As stated above, non-inpatient occasions of service are reported by all public health facilities in New South Wales. In addition, nine data items are mandatory for reporting through DOHRS. These are: Establishment identifier, Person identifier, Service type code, Provider type code, Payment status code, Procedure type code, Setting type code, Mode of service delivery type code and Date of service event. The DOHRS core data set includes a further 14 data items that may be reported about community-based palliative care service provision on a voluntary basis. Data are collected at the client level and for each occasion of service. An extract of the core data set from CHIME to the Local Area Warehouse is already in use in some Areas and will form the basis of patient-level community palliative care reporting in New South Wales. The list of DOHRS data items is included in Appendix G.

Northern Territory

Hospital inpatient palliative care data for the Northern Territory are currently collected on the Northern Territory Hospital Information System (CareSys) while community-based information is collected on the Community Care Information System (CCIS). Each client's demographic information is registered in the Client Master Index and is shared between CareSys and CCIS.

CCIS is a multi-discipline program across the different community services, sharing information throughout the Territory. It is a case managed system that was implemented in 1998–1999. CCIS security and data framework is determined for each specific service and is customised to address the different program requirements for data entry and reporting at the operational and management level. CCIS has the ability to locally develop defined data collection forms, designed to specifications. (Any minimum data set items can be collected using this function.)

Programs using CCIS include: Family and Children's Services, Mental Health, Disease Control, Aged Care and Disability (including HACC and Territory Independence and Mobility Equipment Scheme information), Alcohol and Other Drugs, Sexual Assault Referral Centre, Community Health (including Child & Maternal Health and Women's Health) and Palliative Care.

The 'Top End Palliative Care' team members are the case coordinators and managers for all palliative care and bereavement care clients in the Darwin Urban, Katherine and Nhulunbuy regions. In Alice Springs, the palliative care specialists are part of the Alice Springs Community Health Team which provides services to clients within the Alice Springs and Tennant Creek/Barkly regions. These providers' in conjunction with the community health nursing staff and selected community allied health staff, record service events for their clients in CCIS. Alice Springs also has a locally developed Access database, currently in use for the collection of some palliative care data.

Information currently collected

Information recorded in CCIS can be reported upon to assist in individual client management, the operation of the work unit and the management of the service and organisation. There are two main types of reports that meet these requirements: operational and management reports. Operational reports are created based on Program requirements and can be scheduled or initiated by the users within CCIS from the report menu. Management reports are created based on CCIS data being extracted into the Data Warehouse. Examples of some of the current reports available are included in Appendix G.

Assessment / review

An assessment of the best information system for both inpatient and community-based palliative care is being conducted as part of a current project to develop a strategic plan for palliative care, to be completed towards the end of 2004.

Queensland

The Queensland Palliative Care Program receives both Australian Government and state funding. The quantum of funds provided each year by Queensland Health is not governed by any matching arrangements.

Essentially, Australian Government funding is allocated to the 38 Health Service Districts for direct service provision. However, the funds may be used to purchase palliative care services from the non-government sector where required.

Queensland Health's funding contribution to the Palliative Care Program is directed to the non-government organisations (NGOs) providing community based care and hospice services.

Queensland Health is introducing a State-wide and Non-government Health Services Performance Framework to report the performances of NGOs funded by Queensland Health in the areas of:

- service delivery;
- consumer involvement;
- quality improvement activities; and
- management.

Under this framework all organisations (including Health Service Districts) will be required to submit qualitative and quantitative information. Health Service Districts will only be required to submit statistical reports based on activity. NGOs will be required to report on quality issues as well as activity through performance and statistical reports. Data may be collected using MS Word or MS Excel collection tools provided or online via Quality Performance Reporting Information Management System.

Queensland Health has one corporate IT system for admitted patients called Hospital Based Corporate Information System, which is used in all public hospitals. CHIME is currently being trialled in one District and implementation of CHIME is only intended for Queensland Health community-based (government) services.

Information currently collected

Community-based information currently received by Queensland Health from Health Service Districts about government service providers includes occasions of service, service provided and service providers. The data are aggregated from Health Service data on a six-monthly basis. These data are usually reported manually using MS Excel or Access.

At this stage, only some basic financial reporting is required of most of the community-based NGOs involved in palliative care.

South Australia

The Client Management Engine (CME) system, which is used throughout South Australia, manages service provision, care planning, regular appointments scheduling and equipment loan. It is used to capture, in part, domiciliary care, country mental health, palliative care, bereavement care, aged care, HACC, community health services, informal client activity, each with differing data attributes.

An important flexible feature of CME is that there can be different episodes of care which capture different data. The palliative care episode specifically captures data for Department of Health funded palliative care activity. It is possible that sites undertake palliative care related activity but if it is not provided under palliative care

specific funding it may be recorded under a different episode of care type (i.e. domiciliary care, general community service), thus different information is collected. The activity may or may not even be clearly identifiable as palliative care related.

The South Australian Department of Health receives two types of palliative care related records via a standard six-monthly export from the relevant health service sites. One type of record is the palliative care details provided for clients and the other record type is the bereavement care details provided for clients.

The export is obtained via an export facility in CME that creates text files which are emailed to the Department of Health for incorporating into Microsoft Access databases. From this data, summary bulletins are produced which are sent back to the health service sites and regions for their information and to identify data input completeness/errors.

Only palliative care related details for activity/services provided by Department of Health funded palliative care positions/staff are recorded.

Information currently collected

As outlined above, the South Australian Palliative Care Minimum Data Set (MDS) is reported to the South Australian Department of Health. A list of the South Australian MDS data items is included in Appendix G.

Tasmania

Current system

Currently in Tasmania each community-based service collects data on a spreadsheet and forwards it to the area manager for correlation and analysis. A number of data items are forwarded through a performance reporting mechanism to the Tasmanian Department of Health and Human Services.

Current data collection systems in Tasmania include Acute Care Homer system, Microsoft Access and Excel database, and Microsoft Word documents.

Proposed system

Tasmania has developed a new community-based information system using an electronic health record for community clients. This is currently being trialled at two sites. Community nurses, home care and allied health workers who work out of community health centres are participating in these pilots.

Palliative care providers will report palliative care-specific information as well. Palliative Care has completed an analysis into determining how compatible the new system is to palliative care and what areas need further development. The new system is expected to be implemented across the state later this year.

Information currently collected

Tasmania currently collects aggregated data on a monthly basis with regard to admissions, deaths, direct and indirect contacts of palliative care clients. An activity summary report for Tasmania is included in Appendix G.

Victoria

Victoria has an established minimum data set (MDS) for community-based palliative care data collection. The MDS includes patient demographics, palliative care contacts, inpatient episodes and performance indicators, although reporting of the performance indicators is not compulsory at this stage. Most client information systems used in Victoria are able to meet the MDS as well as HACC reporting requirements. All Victorian regions except one submit the minimum set of data from their area to the Department of Human Services on a quarterly basis.

The Department aggregates the data using the Victorian Palliative Care Reporting System, which is a Microsoft Access database system.

State-level reports on the MDS are produced by the Department and made available to the regions. This allows the regions to view their own statistics and compare their region with the rest of the state. It also allows services to compare their service with the rest of their region.

Information currently collected

All community-based palliative care service providers in Victoria are required to provide individual data in order to compile a minimum data set (MDS). Some also provide performance indicator information for the performance indicators data set (PIDS). The MDS allows for the collection of common, client-specific data to enable the community-based palliative care agency to accurately identify and describe the clients who receive care from the centre and the services provided to those clients. It also enables the aggregation of regional and state-wide information. Collection of the MDS allows the Department of Human Services to establish a clear picture of clients accessing community-based palliative care agencies and to monitor activity and demand over time. The MDS and PIDS are reported to the Department on a quarterly basis. The Victorian MDS list of data items is included in Appendix G.

Western Australia

The Western Australian Department of Health has negotiated a statewide license for the Palliative Care Information System (PalCIS) to facilitate clinical management and generate summary activity reports. Rural sites using the Western Australian Rural Palliative Care Database will over time be upgraded to PalCIS and some staff are currently being trained with special funding from the Australian Department of Health and Ageing. The PalCIS software will also be piloted at selected metropolitan sites.

The major provider of community-based palliative care services within Western Australia is Silver Chain's Hospice Care Service, which comprises interdisciplinary teams. Silver Chain uses a computer software system called ComCare in the metropolitan area.

Information currently collected

All palliative care services funded by the Western Australian Department of Health provide monthly reports of aggregated data. The information reported includes the type of services provided and the time devoted to the provision of services. The type of services reported by palliative care services are Counseling, Night Registered Nurse, Night Personal Care, In Home Nursing, Nursing Support and Personal Care.

Other information reported by service providers are number of clients admitted to service, number of clients discharged, number of deaths and place of death. An example of a metropolitan Silver Chain report is included in Appendix G.

3.2 Mapping of data items

The project team undertook a mapping exercise in order to determine what information states and territories were currently collecting about community-based palliative care funded services. Those jurisdictions that currently have a system set up for patient-level, unit record data reporting (Victoria, South Australia and the Northern Territory) were included in the mapping, as was New South Wales which, while at this stage receiving aggregate data only, has a mandatory core data set of clearly categorised data items. The original mapping exercise produced a core set of data items that were fairly commonly reported in the four states and territories. That core data set was then presented to service providers as a suggested set of candidate items, and comments were invited (see Chapter 4 for details on the feedback received).

On top of the suggested core data set a number of new data items were suggested during consultation. Some of these were taken up by the project team and have been included in the suggested or recommended 'extra' data items in Chapter 6. In Table 1, the data items included in the original core data set plus a number of these 'extra' items are mapped against the same or similar patient-level items reported in the four states and territories.

Table 2 shows a similar mapping exercise, but it provides the names of the items currently collected by the four states and territories. A set of tables that present the original, more extensive mapping of all the data items reported at patient level across these four states and territories is included in Appendix D.

Table 1: Patient-level data reported at state/territory level, mapped to the draft core data set suggested to service providers during consultation

Data item	NSW	Vic	SA	NT
Agency identifier	Y *	Y	Y	Y
Australian state/territory identifier	n.a	n.a	Y	Y
Carer—co—residency	n.a	n.a	n.a	n.a
Contact recipient type	n.a	Y	n.a	n.a
Country of birth	n.a	Y	Y	Y
Date of birth	Y	Y	Y	Y
Date of commencement of service episode	n.a	n.a	n.a	n.a
Discipline of service provider	Y *	Y	Y	Y
Indigenous status	Y	Y	Y	Y
Informal carer availability	n.a	Y	n.a	n.a
Living arrangements	n.a	Y	n.a	n.a
Main language other than English spoken at home	n.a	Y	Y	Y
Mode of contact	n.a	Y	Y	n.a
Mode of separation	n.a	Y	Y	Y
Person identifier	Y *	Y	Y	Y
Phase of care	n.a	n.a	n.a	n.a
Postcode—Australian	Y	Y	Y	Y
Principal diagnosis	n.a	Y	Y	Y
Referral date	n.a	n.a	Y	Y
Referral source	Y	Y	Y	Y
Relationship of carer to care recipient	n.a	n.a	n.a	Y
Separation date	n.a	Y	Y	Y
Service contact date	Y *	Y	Y	Y
Service delivery setting	Y *	Y	Y	Y
Sex	Y	Y	Y	Y
Site of death	n.a	Y	Y	Y
Type of assistance received	Y *	Y	Y	Y

* = compulsory data item collected by DOHRS in NSW.

n.a = not applicable

Table 2: Most common data items, mapped against patient-level data items reported in four states/territories

Common data items	SA (MDS)	Vic (MDS)	NT	(NSW) DOHRS * = required for reporting	NSW AN-SNAP used in CHIME
Agency identifier	Unit ID	Agency identifier	Work unit	Local clinic name Establishment identifier *	Provider unit code Facility code
Australian state/territory ID			State		Usual state
Country of birth	Country of birth	Country of birth	Country of birth		Country of birth
Date of birth	Date of birth	Date of birth	Date of birth	Date of birth	Date of birth
Date of commencement of service event		Date of admission	Case date and time	Episode begin date	Episode begin date
Discipline of service provider	Discipline of provider	Discipline of service provider	Providers (full details on separate screen)	Provider type code *	Provider type
Indigenous status	ATSI status	Indigenous status	Indigenous status	Aboriginal and Torres Strait Islander status	Indigenous status
Living arrangements		Living arrangements			
Main language spoken at home	Language (main preferred language spoken)	Preferred language	Main language spoken at home		Preferred language
Mode of contact	Mode	Mode of contact		Mode of service delivery type code *	
Mode of separation	Reason for separation	Mode of separation from palliative care	Case closure outcome		Reason for episode end
Patient/client identifier	Client number	Patient/client identifier	Client ID	Person identifier*	Medical record number
Postcode	SLA/postcode	Postcode of usual residence	Suburb/postcode	Postcode	Usual postcode
Principal diagnosis	Diagnosis	Principal palliative care diagnosis	Diagnosis – event summary		Diagnosis
Referral date	Date of referral		Referral date		Referral date

(continued)

Table 2 (continued): Most common data items, mapped against patient-level data items reported in four states/territories

Common data items	SA (MDS)	Vic (MDS)	NT	(NSW) DOHRS * = required for reporting	NSW AN-SNAP used in CHIME
Referral source	Referral source	Source of referral to palliative care Referring agency	Referral source	Source of referral	
Separation date	Separation date	Date of separation	Case closure		Episode end date
Service activity type	Procedure	Principal nature of service provided	Event type Service provided	Service type code *	Main intervention Episode type
Service contact date	Contact date	Date of each contact	Event date and time	Date of service event *	Care date
Service delivery setting	Details for site of contact	Contact setting	Venue	Setting type code *	
Sex	Gender	Sex	Sex	Sex	Sex
Assessment e.g. Activities of Daily Living		Performance status	Status of client		AN-SNAP class Resource utilisation group activities of daily living-scale (RUG-ADL)
Setting/site of death	Site of death	Site of death	Site of death		

3.3 Other possible sources of palliative care data

Some other sources of information that have relevance to palliative care and that are potentially sources of information about palliative care provision have been included in this section. A number of these collections reference palliative care in their own data collections. For example, the Home and Community Care data collection mentions palliative care as a source of referral and the Cancer (Clinical) Data Set Specification identifies, among others, palliative care as an intention of treatment.

At a later stage in the development of a palliative care data collection, there is the potential to use data linkage between a community-based palliative care data collection and a number of the aged and community care programs through the inclusion of a common data linkage key.

Aged and Community Care programs

A range of Australian and state/territory government programs provide services to Australians in need of assistance. In some instances these services are provided to clients of palliative care services. Palliative care data can be collected from funded palliative care services, however this may not provide the true picture of the needs and services accessed by these clients. Data linkage with the programs described below could be one way of more accurately describing many of the services accessed by clients of palliative care-funded agencies.

Home and Community Care (HACC) program

The Home and Community Care (HACC) program is jointly funded by the Australian government and the state and territory governments. The program provides services to frail or disabled older people and their carers (approximately 80% of the HACC client population) and to younger people (aged under 70) with a disability and their carers (the remaining 20%) (AIHW 2003 a).

Community Aged Care Package (CACP) program

The Community Aged Care Package (CACP) program is an Australian government-funded program, and was established in 1992. It provides assistance to enable frail or disabled older people with complex care needs to continue living in the community. Younger people with disabilities may also access a care package where there are no appropriate care options available in an area.

National Respite for Carers program

Carer respite centres provide a coordinated system of respite assistance to carers. At least one Carer Respite Centre has been established in every HACC region across Australia to provide a single point of access to all respite services in their region. The centres focus on the needs of carers and assist them, through the coordination of service provision, to access the respite services which best suit them. Carers can also purchase respite services when the most appropriate type of service is not readily available.

Cancer (Clinical) Data Set Specification

A data set specification (DSS) is a core set of data definitions that makes up a data collection. A DSS can be either optional or mandatory. The Cancer (Clinical) Data Set Specification is an optional data collection.

The clinical cancer data collection underpins the evaluation of cancer treatment services and this can occur at a number of levels: the individual clinician, the health care institution, at state or territory level and ultimately at a national level. One of the data items included in this data set is 'Intention of treatment for cancer'. This item mentions palliative care as one of the intentions of treatment. Information from this or other data items may in the future be able to contribute to a broad picture of palliative care service provision in Australia.

Schedule of Pharmaceutical Benefits (PBS) Palliative Care Benefits—Therapeutic Index

A number of preparations which may be prescribed for patients receiving palliative care are now available under the Schedule of Pharmaceutical Benefits (PBS). These benefits were introduced in early 2004, and the resulting PBS information is another potential source of data that may contribute to the picture of palliative care in Australia.

The schedule lists drugs available for palliative care of patients with active, progressive and far advanced diseases for whom the prognosis is limited and the focus of care is quality of life. The listed palliative care medicines need authority approval. Approved prescribers can request an initial authority to provide for a maximum of four months' therapy. If the patient needs repeats (one- and three-month repeats) the prescriber will need to confirm that a palliative care physician or palliative care service has been consulted regarding the care of the patient. If this consultation has not occurred, the continuing authority is approved only for one month's supply (Health Insurance Commission 2004).

Linking data

Data linkage with data from some of these programs may be an option in the medium term. For example, the inclusion of the data element 'Letters of name' in a palliative care data set would establish the potential to identify clients receiving HACC services as well as any other programs that collect data using the same 'Letters of name' data item.

Department of Veterans' Affairs (DVA)

The Department of Veterans' Affairs (DVA) exists to serve Australia's veteran and defence force communities, war widows and widowers, widows and dependants, through programs of care, rehabilitation, compensation, income support, commemoration and defence support services (DVA 2004).

The Department has provision to fund palliative care services.

To be eligible to receive health care and related services, an entitled person must hold a Repatriation Health Card for accepted condition(s). Therefore specific palliative diagnosis or data may not be obtained.

In terms of community nursing palliative care provision, currently DVA collects data in relation to treatment and services received by veterans (and for which DVA pays) from agencies that provide palliative care community nursing services. DVA's data collections also include comprehensive data on service provision by general practitioners (local medical officers—LMOs), medical specialists, hospitals, pharmacists, and allied health providers, which may assist in identifying services that may be related to palliative care. The data, however, may not necessarily indicate whether a client is receiving palliative care as they are receiving care for

their accepted condition. Services related to palliative care, however, can be identified from hospital and community nursing data directly, i.e. from the item number within the schedule of fees (community nursing) and from the episode of care data (hospitals).

The information provided by the various disciplines, i.e. community nursing agencies, LMOs, allied health and so on, is sourced, in the main, from the Health Insurance Commission (for LMO, hospital, community nursing, pharmacy and allied health services) along with associated payment data. Some service data are collected directly by DVA, e.g. community nursing minimum data set data. The operational data collected by DVA is made available for reporting and analysis through DVA's Departmental Management Information System (DMIS) – a system that includes a corporate data warehouse, data marts and data cubes with a particular business focus, e.g. community nursing, hospitals. DVA uses the Cognos suite of Business Intelligence products to provide end users in DVA with access to the data.

Data in the DMIS data marts are currently focused on the reporting and analysis needs of particular business areas, e.g. community nursing, private hospitals, medical & allied health, pharmacy, but data can be linked across the data marts or, externally, using data extracts from DMIS with other products such as Microsoft Access.

Analysis of the data in this manner could provide a view of the range of palliative services a particular client has received. DVA intends to do further work on integrating the data views in DMIS data marts in 2004–2005 to simplify the linking and comparison of data originally sourced for different business streams. The result of this work will allow for the possibility of more easily linking data about those DVA clients receiving palliative care community nursing with information about other services received by those clients, such as hospital, pharmaceutical and general practitioner services.

As indicated above, for those veterans who do not receive palliative care-specific community nursing, a palliative care flag does not at this time exist in DVA records. Therefore, information about palliative care provision currently through DVA data would rely on a level of derivation from the actual services provided, possible in other settings, such as hospital. The extent of information available from DVA's data warehouse would have to be analysed before a definitive assessment could be made on the extent to which identification of palliative care could be derived if it was not directly identified.

General practice data

Bettering the Evaluation and Care of Health program

The Bettering the Evaluation and Care of Health (BEACH) program is a continuous study of general practice activity. It also investigates changes in morbidity and management demonstrated over the five years since the program began in March 1998.

A random sample of general practitioners (GPs) who claimed at least 375 general practice Medicare items of service in the previous three months is regularly drawn from the Health Insurance Commission data by the General Practice Branch of the Australian Department of Health and Ageing (DoHA). GPs are approached by letter and followed up by telephone recruitment. Participating GPs complete details about 100 consecutive patient encounters on structured paper encounter forms that provide

information about themselves and their practice. In the 2002–2003 BEACH data year, a random sample of 1,008 GPs from across Australia provided details of 100,800 GP–patient encounters. Results are reported in terms of GP and patient characteristics, patient reasons for encounter, problems managed and management techniques used (Britt et al. 2003).

At present there are no questions in the BEACH data collection that refer to palliative care. There is the option of including one or more questions on palliative care provision by GPs in the survey. However, researchers involved in the study have advised that this would not provide reliable information, because the proportion of encounters with palliative care patients by the average GP is very low. This means that the chance that one of the 100 patient encounters includes an encounter with a palliative care patient is also very low. As a result, the sample size would be too small to be representative of GP activity in the area of palliative care. In other words, the number of positive responses to a palliative care question from the sample of GPs involved in the questionnaire would be very small and would not provide an accurate picture.

Health Insurance Commission data

There is currently no way of identifying what items are specifically claimed for palliative care through the Medical Benefits Schedule (MBS). Also, there are no specialty codes for palliative care specialists in the MBS. This means that any palliative care-related medical consultation claimed through Medicare is not flagged as such.

As the MBS is updated with new items twice a year (in May and November), it may be possible to add specific MBS items to the Schedule that will allow for the identification of claims related to palliative care.

4. Consultation with service providers

An important aspect of the project was consultation with palliative care service providers. Service providers are involved in the provision of care on a daily basis, and are also generally responsible for collecting and recording the information. They are often responsible for inputting the information into an IT system. They have a 'coalface' understanding of the day-to-day issues faced by staff in their service, and as a result, they have valuable experience to share.

This chapter contains an outline of the feedback received from service providers during the project team's consultation round. It should be noted that, while the project team has done its best to paint an accurate picture of that feedback, it is not possible to reflect every comment made by all who participated in those consultations.

This chapter is the main avenue for presenting the comments provided by the participants. However, the input by providers has influenced the content of this entire report, particularly the chapters on options and recommendations. Many participants have also provided much-needed information to the project team, such as examples of forms and details about their IT systems. This too has assisted in shaping other chapters in this report.

4.1 Approach

During this project, a range of consultation methods has ensured that input from service providers was obtained:

1. The PaLcID Working Group (the group responsible for providing expert advice to the project team) included two service providers.
2. In some states and territories, the project team conducted consultation workshops with a group of providers, mostly an existing group already used to meeting on a regular basis. While these groups were usually not fully representative of all providers in their state/territory, they tended to consist of a broad range of providers from a variety of organisations.
3. In those states and territories where such a group meeting was not possible, the team conducted more ad hoc meetings with individual providers.
4. The team made a number of field visits, aimed at gaining a better understanding of the day-to-day running of a service involved in the provision of palliative care, as well as the 'typical' information flow in such a service.
5. Meetings with Palliative Care Australia representatives were also held.

4.2 Background/discussion paper

All service providers involved in the consultation process were sent a background/discussion paper about one week before the project team visit. (One exception to this was Victoria, where consultation took a somewhat different approach and differed in timing.) The paper provided background information about the project and a broad outline of a possible approach to palliative care data collection. Also included in the paper was a set of possible data items for collection. These items were presented as an early draft set, and providers were strongly encouraged to make comments. The last section of the paper outlined some thoughts on the need for data to reflect something about the quality of care, or to give an indication of whether the 'palliative approach' was used in the provision of care. Participants were sent a feedback sheet beforehand for their comments on the draft data items and the quality of care indicator question.

Five questions for discussion were outlined in the paper, and these were workshopped/discussed during the meetings. The questions were:

1. How is the collection of information important for a service that provides palliative care?
2. What are some of the difficulties experienced by staff who collect and/or input the information?
3. What would you like to know about palliative care provision in your state/territory and across Australia? In other words, if you were given a state/territory or national report, what would you like to see reported in it?
4. Do you have any comments on the suggested data items in Section 7 (refer to your feedback sheet) that you would like to bring up for discussion today?
5. What information could be included to reflect the quality of the service provided (see section 8 and your feedback sheet)?

4.3 Outcomes of the consultation

The project team's meetings with providers across all the states and territories produced quite a large quantity of feedback, both through written comments and through discussion. While the states and territories, and individual service providers, may have some of their own specific issues, much of the feedback can be condensed into a number of common themes. These themes are outlined further below.

While acknowledging that not all providers will agree with the following statement, the gist of much of the feedback from providers could be described as follows:

(1) The collection of data is important and has many benefits, but (2) the time and cost involved needs to be in proportion to the benefits, and (3) the resulting information needs to be of good quality, otherwise it is not worth doing. By and large (4) the suggested set of data items are already currently being collected by services, or are able to be collected, and most would be worth including in a future state/territory/national data collection.

The four main messages in this statement are further explored below.

(1) 'The collection of data is important and has many benefits'

In relation to this message (1), the following themes emerged:

- a. Provides feedback to staff about the types of clients and the services provided, e.g. diagnosis, cultural diversity, geographical patterns, proportion of phone calls versus face-to-face contact.
- b. Information supports service planning, e.g. staff composition, rostering, education initiatives.
- c. Information can assist in keeping the service relevant, e.g. ensuring the service is culturally appropriate.
- d. May support funding bids, or assist in maintaining funding.
- e. Outcomes: does the service make a difference? Quality of care: benchmarking, supporting best practice.

(2) 'The time and cost involved needs to be in proportion to the benefits'

In relation to this message (2), the following themes emerged:

- a. Software/hardware systems, including:
 - user-friendliness: some IT systems are not user-friendly
 - speed: some IT systems are too slow (at times due to geographical distance)
 - duplication of effort: recording information on paper forms at the client's home, then inputting into the system elsewhere
 - inputting contact data: some providers believe that the reporting of daily contact data should not be a requirement in a national palliative care data collection
 - many agencies cannot afford to pay an administrative assistant to input the data
 - training: staff need good, ongoing training in using the software
 - reports: extracting reports needs to be easy, and the reports need to provide relevant and useful information
 - small services in rural and remote areas tend to have less access to clinical IT systems, or cannot afford to install software.
- b. Incompatibility of data collection requirements:
 - difficulty of inputting data into two or more different systems
 - having to run reports for a number of programs (in some cases seven or more).
- c. Cost – any new and ongoing data collection requires a lot of resources:
 - services that have no system need to purchase one
 - staff need to be trained properly (initially and ongoing)
 - changes need to be made to existing systems, and systems need maintenance
 - often hard copy forms need to be changed and reprinted

In relation to (a), software/hardware systems, it is worth noting that many of the points made are information management and IT problems faced by providers, whether or not a data collection is implemented.

Also noteworthy is that, while the introduction of new IT systems is often costly and time consuming, new technology also presents an opportunity to reduce costs in the longer term, and to improve efficiency, quality and safety.

(3) 'The resulting information needs to be of good quality'

In relation to this message (3), the following themes emerged:

- a. Staff training:
 - staff need good training in how to collect and enter the information
 - staff need clear guidelines so that definitions and rules are applied consistently.
- b. Time lapse between service delivery and data entry:
 - sometimes this time lapse is very long, especially in rural/remote areas, and may result in poor quality of 'contact data'.
- c. Utility of data at the service level:
 - the information needs to have practical utility for staff, i.e. support client care
 - the information also should provide statistics that support service planning.
- d. Staff attitudes to data collection:
 - all staff need to input data consistently, otherwise the information is useless
 - some staff have not been used to collecting data, and are only likely to change if the service has a culture that supports data collection and good data collection practices
 - the varying levels of computer literacy affect staff attitudes.
- e. Client privacy:
 - asking many questions at a time of need is intrusive and gets in the way
 - importance of collecting information in a face-to-face setting (not by telephone).

(4) 'The suggested set of data items'

This section provides information on the feedback received on the suggested set of data items, and providers' suggestions for other data items to be collected at the state/territory or national level.

Participants in the consultation meetings were sent a feedback sheet as part of the background/discussion paper (see Appendix E), which included a table listing the data items from the suggested draft core data set. Participants were asked to indicate whether the data items listed (or similar items) were being collected by their service, or could be collected in the foreseeable future, and whether they believed the item would be a desirable part of a state/territory or national data collection.

It should be noted that the responses received are not necessarily representative of all palliative care service providers, as the providers involved in the consultation did not represent all providers in their state/territory. However, the participants did consist of a cross-section of the palliative care service provider community.

Column 2 in the feedback sheet asked for participants to indicate whether a particular data item was, in their opinion, desirable for inclusion in a

state/territory/national data collection. When examining the feedback participants had given in column 2, it became clear that unfortunately this column had been interpreted differently. Some people ticked each item they thought desirable, while others only ticked the column for those items they were unable to collect, but felt were desirable in a state/territory/national collection. This has meant that the feedback received on this question is inconsistent and could not be analysed in the way planned by the project team. However, despite some confusion in the way this question was meant to be answered, responses do give some indication of the participating providers' views on the desirability of candidate data items.

In the main part of the background/discussion paper, the candidate data items were presented in a table that divided the set into three main sections (see Table 3).

Table 3: Candidate data items as presented to the service providers in the background/discussion paper

Information about each client	Information about each time a service is provided	Information about each episode
Patient/client identifier	Service contact date	Date of commencement of service episode
Date of birth	Service delivery setting (e.g. home, public hospital (possibly with sub-codes))	Source of referral (e.g. GP, self)
Sex	Service type (e.g. assessment, clinical care, bereavement counselling)	Referral date
Indigenous status	Discipline of service provider (e.g. nurse, allied health practitioner)	Assessment results (e.g. RUG-ADL or palliative care phase)
Country of birth	Mode of contact (e.g. face-to-face, phone)	Mode of separation (e.g. died, discharged/transfer to an acute hospital)
Main language spoken at home		Separation date
Principal diagnosis		Setting/site of death (e.g. home, hospital palliative care bed)
Postcode (of usual residence)		
State/territory ID		

Data item: 'Assessment results'

As mentioned earlier, the main feedback from providers on the suggested data set was that the majority of candidate data items are already currently collected (or at least items similar to those listed), or are able to be collected by services. Of all the data items outlined in the table above, there was only one data item that overall did not receive favourable feedback in terms of ability to collect, and it also received mixed feedback from providers on whether this type of data item would be desirable in a national data collection. This was the 'Assessment' item, which in the table is suggested as involving the collection of information about RUG-ADL scores and/or palliative care phase.

The majority of providers did not tick this item as being easily collectable. However, it should be noted that the example of RUG-ADL may have influenced the response. While some providers in some states/territories use the RUG-ADL assessment instrument, many use different activities of daily living (ADL) assessment instruments. Those using different instruments may well currently collect data on their assessment results, and may be able to report these results. Whether a data element could be created that accommodates the range of assessment instruments used by providers is unclear and, as this is beyond the scope of this project, would require a separate investigation.

The suggestion of collecting ‘palliative care phase’ also received a mixed response. Some of the reasons for this seem to be:

- Palliative care phase is changeable, and recording the phase as part of a data collection is seen by some providers as not meaningful.
- While some providers record palliative care phase at the time of assessment only, others record the phase change, e.g. for the AN-SNAP classification, and are required to record this each time such a change occurs for a patient. In other words, current practices across the country vary.
- Some feedback suggests that there is an interest in collecting palliative care phase at the time of first assessment or referral. This information, together with the time of referral to death, could give an indication of the stage at which patients tend to get referred.

Other information of interest to providers

In several states and territories, providers were asked to answer the following question, which was outlined in the provider background/ discussion paper:

What would you like to know about palliative care provision in your state/territory and across Australia? In other words, if you were given a state/territory or national report, what would you like to see reported in it?

Many of the responses on what information is desired by providers were already covered by the suggested candidate items. In other words, a substantial proportion of the information that providers would like to find out about could be included in a national report if it were based on the candidate data items presented in the section above. However, a number of other suggestions were also made. Tables 4 and 5 present lists of suggestions made by providers, drawn from both their written comments and from comments made during the consultation meetings. Some of these responses express a desire for additional data items (see Table 4). The specific data items suggested by providers were considered by the project team, and some have been included in the core data set recommended in Chapter 6. Other responses were not as specific, and refer to an interest in a particular topic. Table 5 presents those suggestions for information reporting that could be based on the suggested set of candidate items (left column), and a range of other topics of interest raised by providers (right column). Some of the topics listed in the right column could or need to be collected at an agency level (i.e. not for each patient), and some of these suggestions have been incorporated in the agency-level data items suggested in Chapter 6.

Table 4: Additional data items suggested

Additional data items suggested by providers

- Availability of carer
 - Date of first contact
 - Date of first service provision
 - Date of diagnosis
 - Cause of death
 - Preferred site of death
 - Time spent on each service event
 - Travel time
 - Referral to bereavement counselling
-

Table 5: Topics of interest

Some desired information that could be analysed from the suggested set of candidate items	Some other topics of interest raised by providers
<ul style="list-style-type: none"> • Demographics, who are we seeing • Numbers • Diagnosis • Age • Sex • Place of death • Length of stay/episode • *Access by Aboriginal and Torres Strait Islander people • *Access by people from culturally and linguistically diverse backgrounds • Time from referral to death • Rural/metropolitan/remote spread • Type of service provision • Timing of referrals for particular diagnoses • Trends • How long client is likely to receive services (informs resource needs) • How compares to other states? • Distribution of patients receiving palliative care services across the state and nationally to identify areas of need • Impact of diagnostic group on service provision, e.g. cancer vs non-cancer • Inclusion of bereavement follow-up, identifying end-of-life referrals/non-malignant long-term symptom treatment, what are the resource-intensive areas in palliative care, i.e. end stage cardiac failure/geriatrics? • *Identify palliative care patients in nursing homes 	<ul style="list-style-type: none"> • Extent/outcomes/focus • *Who doesn't/can't access palliative care services and why • Service availability • GP management, multidisciplinary team management • Tertiary/secondary or primary level of palliative care service • Main care setting during palliative illness • Satisfaction levels of patients and families • Differences in methodology, support • Time—hours of service • *Ability to link data • Time from diagnosis to referral • Size of area serviced by the agency • Referral destination of patients if discharged • Actual funding of average episode of care • What are others doing which could improve our service? • All service providers—inpatient and outpatient • *Incidence, prevalence • *Location of service, hospital community residential care, CACP, EACH • Service complexity, i.e. GPs, HACC service involvement, multidisciplinary approach • Compliance with the National Palliative Standards Service, e.g. 24-hour access • *Population data, including problems of care of patients not referred, cancer/non-cancer referrals • Days in hospital in last 6 months, 1 month • Emergency department presentations in last month • Who is seeing patient (i.e. nursing/social worker/occupational therapist/medical/physio) • Capture the intensity of services provision (i.e. intensive palliative care provided to patients with motor neurone disease) • Staffing profiles of different services, i.e. are there any allied health/bereavement/volunteer services? • How the services support their staff • Education • *Access to service—no. of deaths per area (of cause amenable to palliative care) and no. of services provided would tell whether access to services is similar across regions • Information to support benchmarking • *Population data: acuity and dependency levels of the aged

* These suggestions would or may require data from other sources, e.g. ABS population data, residential aged care, AIHW National Cancer Statistics Clearing House, AIHW National Mortality Database, CACP, HACC, EACH.

4.4 Providers' suggestions on quality of care indicators

On the feedback sheet, providers were asked what information they thought could be included in a national data collection to reflect the quality of the service provided.

Some of the suggestions, while important aspects of service provision, were not suitable in terms of a data collection. Other suggestions were suitable, but were controversial and attracted a range of opinions. Many service providers agreed that identifying appropriate measures of quality of care and outcomes of care is a difficult task. Some of the suggestions put forward, both on the feedback sheets and during discussion, are outlined in the table below.

Table 6: Some suggestions from service providers on quality of care/performance indicators

Potential quality of care information
<ul style="list-style-type: none"> • Palliative care phase/SNAP. • Days spent in hospital. • Number of unplanned admissions to hospital may be useful (define 'unplanned') • Family satisfaction; whether a client/carer satisfaction survey tool was utilised and if so, whether the outcome was positive/negative level of satisfaction • Service providers' perception of overall outcome of episode of care from referral to separation surveying the provider on what they would have done differently for the client • Whether the variety of services offered meets the identified community needs • Quality should be measured by how well we (service providers) meet clients' stated goals • Information on breaks in episodes of care (similar to DVA MDS) and what these specifically were for, i.e. dates, site (home/hospice/hospital), reason (respite/pain/symptoms/other) • Models of care • Symptom assessment, management, evaluation; changes/scores at each visit • Admission/discharge waiting times • Follow-up of bereavement • What are the clients goals? • 'Expectations survey', followed up by satisfaction survey • Casemix • Data that reflect what we are unable to get to, e.g. lack of staff (social work) to fulfil work required • Data that are reflective of what we do (through appropriate assessment tools) • Client choice of site of death • Care plans—algorithms (development of same) • Consistency • Pain management time scale • Holistic assessment scales • Family needs assessment • Bereavement risk assessment • Time between referral and first contact measured against (RUG) score (Very difficult due to many variables, e.g. referral to first assessment may be delayed at patient's wish) • Response time to and outcome of interventions

(continued)

Table 6 (continued): Some suggestions from service providers on quality of care / performance indicators

Potential quality of care information
<ul style="list-style-type: none">• Ease of access to appropriate services/supports for patient/family/carers• Bereavement contact• Access to appropriate medications regardless of cost• Some measurement of the acuity of care• Type of care planning and how this was developed, e.g. was it developed in a holistic way with input from the patient and family?• Equity of service availability (however there are many variables affecting this such as high patient expectations, service provider over-committing their time these variables are hard to measure in a data collection)• Agency-level data could provide information that compares demographics and acuity of care• Reliance on GPs providing after-hours service to the palliative care client.• Agency-level data should include a description of the nurse/patient ratios in order to make comparisons with other organisations• Out-of-hours reflection• Time spent with carers• Time cared for in the community until hospital admission and/or death• High-level information regarding collaboration between funded services• Percentage of coverage• Support for carer, i.e. equipment availability, carer satisfaction, contacts provided, bereavement follow-up, availability of respite• Diagnosis

For further exploration of performance indicator information, see Chapter 5, Section 5.6.

4.5 Lessons from the consultation feedback

Below are some important lessons to be learnt from the consultation with service providers:

1. It is important to service providers that any state/territory or national data collection describes what they do.
2. Service providers need to receive timely feedback on what they report. In other words, they need to 'get something back' for their effort, which allows them to compare their service's report with a broader report (e.g. area health service, state/territory, national).
3. Many service providers are keen to compare their service with others, but this is only worthwhile if this compares like with like. This means that any data collection needs to allow analysis by categories of similar services.
4. The likely improvements in IT systems will hopefully, at least in the medium to long term, support service providers in their patient care and overall reduce the duplication of effort. For some providers this improvement is already occurring.

However, in the short term, the developments in the area of IT may, for some service providers, increase the time and effort required.

5. Many service providers are very interested in collecting and analysing data, but may not have the skills and/or appropriate system to do so. If provided with good training in how to collect and enter the information, and how to extract the reports in which they have an interest, many are potentially enthusiastic 'collaborators' in the quest for information about palliative care provision.
6. Some individual services have developed their own information systems, sometimes without being aware of similar efforts by other services or of suitable systems already developed. It would be beneficial for providers who are considering the development of new systems to consult with other service providers in the sector who have already gone through the experience. It may also benefit smaller services to band together with other services to reduce development and maintenance costs or to consider purchasing existing systems that have proven to be useful and reliable.

5. Feasibility and performance monitoring

One of the main aims of the Palliative Care Information Development project was to explore the feasibility of a future national palliative care data collection. During the project, five topics emerged that required exploration in order to determine what type of data collection is feasible in the area of palliative care. These are purpose; scope; data items for collection; collection mechanisms; and timeframe. These are discussed in Sections 5.1 to 5.5.

Section 5.6 presents some thoughts on the demand for performance measuring through state/territory and national data collection, and some potential performance areas/measures that may be considered for a national community-based palliative care data collection are presented and discussed.

5.1 Purpose

5.1.1 Current commitment to data collection

In 2003, the Palliative Care Intergovernmental Forum (PCIF) agreed that the overall aim of palliative care information development is the 'collection of meaningful data at both a national and jurisdictional level to inform policy and planning for palliative care in Australia'. The members also agreed to a set of information development principles. The third principle reads 'It is important to have access to data at the jurisdictional and national level for analysis for policy and planning purposes at each of those levels'. (The PCIF Information Development Principles can be found in Appendix A of this report.)

As outlined in Chapter 3, several states and territories already have set up a data collection, or are in the process of setting up a system that will allow the collection of palliative care data. Victoria and South Australia have already implemented a statewide data collection of palliative care specific funded community-based services. In the Northern Territory an information system has been set up that is able to collect data from palliative care services, and some service providers are inputting data currently using that system. Tasmania is in the process of setting up a statewide information system that will allow data collection and reporting by palliative care services. New South Wales has a central database that holds activity data reported by public palliative care services. Some aggregated data are reported in the other three states and territories, though these are not always comprehensive in terms of data and/or participating agencies.

The information outlined above suggests that there is a belief at the state and territory level that information about (funded) palliative care activity is required.

5.1.2 Benefits of state/territory and national data collections

Collecting data from those service providers that receive palliative care-specific funding has a number of benefits. This type of data collection can potentially assist with:

- knowing how many and which patients receive palliative care services;
- planning of palliative care services;
- allocating resources across palliative care-specific funded services;
- evaluation, e.g. efficiency, effectiveness, responsiveness;
- describing resources, e.g. number and location of services;
- supporting research carried out by universities and others; and
- supporting appropriate education campaigns, e.g. through targeting particular cultural or linguistic groups, or particular health professionals.

This type of data collection may also enable services to compare themselves with other, similar services (a desire expressed by many service providers during consultation).

5.2 Scope

When considering what a national palliative care data collection should look like, there are several issues of scope to be considered. What settings should be in or out of scope? Should it comprise only specialist or also non-specialist services? Should it just cover government or also non-government agencies? Should funding be the determining factor? Also, should palliative care for special needs groups be included, and how could partnerships (e.g. with GPs, volunteers) be embraced in a collection? In this section each of these issues is discussed.

5.2.1 Settings

Palliative care service provision in Australia occurs across three settings:

- community settings, which include the patient's private home and community living environments such as an aged or supported care facility;
- designated palliative care beds in hospices, which may include various configurations, e.g. beds in a rural community hospital, designated beds in a teaching hospital or a purpose-built hospice;
- acute hospitals, which involves patients identified as needing palliative care while in an acute hospital (PCA 2003, p. 17).

Community-based and admitted patient settings

As patients frequently move between these three settings, and in some instances the same staff are even engaged across settings, ideally a palliative care data collection should be patient-centered and should provide information about patients and services across settings. However, the reality of palliative care service provision in Australia is that it is administered by a large range of organisations, including government and non-government, many with their own specific IT system. Also, hospital IT systems are set up to report data for the respective state or territory and national admitted patient morbidity data collections. In practice this means that data about admitted patients and their care are entered into the hospital's IT system, and data related to community-based palliative care patients or their care are entered into other IT systems, and/or recorded on paper forms and files. This results in separate data collections. Without a unique patient identifier or reliable record linkage key across settings and agencies, patients across such separate data collections cannot be tracked.

Another limitation of the admitted patient palliative care NMDS, is that the data quality is somewhat questionable. Through the NMDS, information is collected about those patients for whom the data item 'Type of episode of care' is coded as palliative care. There are varying practices both across and within states and territories regarding the identification of palliative care episodes. It is likely that some episodes of care or portions of episodes of care, although palliative in nature, will not be reported as palliative. This may be because patients who undergo an acute phase of care in hospital, followed by a palliative phase of care (without being physically discharged from the hospital), may not have a statistical separation between the phases. A new care type would therefore not be recorded for the second phase.

The limitations outlined above mean that any new national data collection for palliative care will need to be, at least initially, limited to community-based settings. However, in future it is likely that opportunities will come up to bring together data across settings. Examples include the development of unique patient identifiers, record linkage (the Western Australian linked database is a current example), *HealthConnect*, and IT systems currently under development or being trialled that function across inpatient and community settings (e.g. projects underway in the South East and South West Area Health Services in Sydney).

Outpatient care

At the time of writing, information about the provision of hospital outpatient care is not collected on a national basis, although in recent years some work aimed at developing an Outpatient Care National Minimum Data Set has been undertaken. The absence of data in this area means that information about patients who receive hospital outpatient services with a palliative care intent is not captured. These services include, but are not limited to, radiotherapy and chemotherapy.

As with admitted patient data, the development of unique patient identifiers or the use of a reliable record linkage key may in future provide the opportunity to merge any data across outpatient and community-based settings. This would assist in providing a more complete picture of palliative care provision in Australia.

While hospital outpatient care is out of scope for a community-based national palliative care data collection, ambulatory care/outreach services provided by hospitals should be included in such a collection, where this care is funded by palliative care-specific funding (see Section 5.2.3).

Residential aged care

As outlined at the start of this section, community settings include both home settings and aged or supported care facilities. In recent years, high-level care residential aged care facilities (nursing homes) have increased as sites of death, both due to shorter lengths of stay in hospital beds and due to an increased number of beds in nursing homes (Palliative Care Unit, The Flinders University of South Australia 1996). As a result, nursing home staff are increasingly involved in palliative care provision for residents. As residential aged care facilities collect data for the Residential Aged Care Services (RACS) data collection, capturing data about palliative care provided by nursing home staff would be best done through that collection. Currently, that data collection does not include a data item that indicates whether a resident is deemed to be receiving palliative care. For this information to be captured, further work would need to be done in terms of how to define palliative care intent in the nursing home environment, and who would be responsible for determining at what point a resident is deemed to be in need of palliative care.

At the time of writing, a project is underway to develop guidelines for palliative care in residential aged care and an education and training program for residential aged care staff. Outcomes from this project may be able to support any future development of information on palliative care in residential aged care. More information about the Australian Palliative Residential Aged Care project can be found at www.apracproject.org.au.

Conclusion

The scope of a national palliative care data collection will need to be community-based palliative care. This includes palliative care provided by agencies based in the community as well as ambulatory care/outreach services provided by hospitals. In relation to nursing homes, it is suggested that information is collected about consultative visits by community-based palliative care service providers, and that the possibilities for collecting data about palliative care provision by nursing home staff through the RACS data collection be investigated.

5.2.2 Specialist and non-specialist services

Palliative Care Australia (PCA 2003) offers the following definitions.

A palliative care provider is defined as:

a medical, nursing or allied health professional who provides primary care with a palliative approach to patients with a life-limiting illness.

A specialist palliative care provider is defined as:

a medical, nursing or allied health professional, recognised as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available), who provides primary or consultative care to patients with a life-limiting illness.

A specialist palliative care service is defined as:

a service provided by a cohesive interdisciplinary network of specialist palliative care providers.

Setting up a national data collection with a scope based on the first definition, i.e. a very broad definition of palliative care provision, is at this stage not feasible. Such a set of data would need to be collected from not only specialist providers, but also all

GPs, generalist community nurses, and allied health providers, and would require extensive linkage of records. Current information systems do not allow for such broad data collection on one area, such as palliative care, within community-based health services. As outlined in the section on IT systems in this report, there are promising developments in the IT and communication technology area, but they will not allow for this type of collection for some time.

Some of the stakeholders consulted have indicated that the scope of a national data collection should be specialist palliative care service provision. Such a scope could be based on the above two definitions of a specialist palliative care provider and service. While this would be feasible, there are many voices against confining a data collection to specialist services only. As the national palliative care strategy states: 'Much of the care is delivered by local providers who know the person and family – particularly general practitioners and community nurses – with support from specialist services where it is needed.' (DHAC 2000, p.2)

The main argument against a specialist collection is that, while specialist palliative care is an important part of palliative care provision in Australia, it does not encompass all palliative care.

Conclusion

The scope of a national palliative care data collection should not be based on whether services are specialist palliative care services or not.

5.2.3 Funding

As mentioned in Section 5.1, there is recognition by all states and territories of the need for data on palliative care provision in the community. Data collection developments in all states and territories are based on data collection from funded agencies with an emphasis on the need for monitoring and evaluation (see also Section 5.3).

Provided that all states and territories could agree on a core set of standardised items that they either are already collecting or would like to collect, and provided that coverage is complete in each jurisdiction, a national data collection could be a by-product of those jurisdictional collections. The scope of such a national collection would be determined by the scope of the state or territory collections, i.e. funded agencies.

It should be noted that there are two issues that need to be considered here.

First, in some states and territories there are inherent difficulties with tracing funding from its source to particular agencies. For example, in some states there are two funding streams. Where the funding is allocated directly from the state department to the agency, it is usually able to be traced. However, for funding that is allocated by the state to the area level, and then distributed by the area to the various agencies, tracing may be more difficult. In those states where this is an issue, this will need to be resolved, and this will require time.

Second, it is unlikely that all community-based agencies within scope but with multiple funding sources will be able to trace the palliative care-specific funding to particular patients, staff or service events. This means that agencies included in the collection would need to provide data about all palliative care provided, even though some of this care may have also attracted funding from other sources (e.g. other type of state funding, donations, etc). This situation can be clarified to some extent by a

parallel agency level data collection that includes information about funding sources. For more information about the suggestion for an agency-level data collection, refer to Section 6.1 in Chapter 6. In relation to this issue, it is also suggested that only agencies with a minimum level of palliative care-specific funding should be in scope. This minimum level would need to be defined.

Conclusion

The scope of a national palliative care data collection should be those agencies receiving palliative care-specific funding.

5.2.4 Special needs groups

Clients in receipt of palliative care who have special needs include Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, children and young people, and people with HIV/AIDS.

It is imperative that any palliative care data collection include data items identifying Aboriginal and Torres Strait Islander peoples, as well as people from culturally and linguistically diverse groups, as this will allow valuable analysis on these population groups to be carried out, which may in turn support strategies that promote access.

Children who are dying, and their families, often have different needs from adults. One reason for this is that the duration of the child's illness is usually longer than that of an adult, and tends to include periods requiring intensive support. Also, specific expertise is required to provide bereavement counselling and support (PCA 2003). In some states, specialist paediatric palliative care services provide care and consultative services, e.g. in Victoria (Victorian Paediatric Palliative Care Program) and New South Wales (Children's Hospital at Westmead). These specialist paediatric services should be included in a community-based palliative care data collection, as the data would form an important part of the picture of the full range of services provided by palliative care funded agencies. Similarly, in order to create a full picture, those agencies specifically involved in and funded to provide palliative care to patients with HIV/AIDS and their families should also be included in a community-based palliative care data collection.

It should be pointed out, however, that many Aboriginal and Torres Strait Islander people are more likely to receive non-specialist palliative care, as a large proportion of this population lives in rural and remote areas, where specialist palliative care may not be available. This should be acknowledged in any future data analysis reports.

Conclusion

The scope of a national data collection should include those services specifically funded to provide specialist palliative care for HIV/AIDS patients and their families, and specialist paediatric palliative care. A national data collection should also include data items identifying Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.

5.2.5 Partnerships

While some metropolitan palliative care services employ a range of staff able to provide multidisciplinary care, many smaller agencies, particularly in rural areas, do

not have the capacity to provide that range of care. Whether large or small, metropolitan or rural, good palliative care provision is about creating networks. Establishing partnerships with the patients and their families, volunteers, GPs and other health care professionals enables the provision of integrated and seamless care for people who are dying (DHAC 2000, p. 26).

Agencies participating in a state/territory or national data collection can reasonably be expected to provide data about the care provided by their own staff. They cannot, however, be expected to provide data about the services provided to their clients by *other* service providers, such as GPs, nursing staff from other agencies, or allied health staff from other agencies. Similarly, sometimes volunteers are coordinated by other agencies, and data about their involvement is not necessarily available to the agency participating in the data collection. Information about the agency's partnerships in care would be more easily and more accurately captured through an agency data collection. Such a collection would give an agency a chance to provide data on the links it has forged with the other providers, communities and volunteers in the community, without the difficulties of collecting such information in relation to each patient.

Conclusion

The scope of a national data collection should include partnerships with other providers, communities and volunteers, but this should be captured at an agency level rather than at a patient level.

5.3 Data items for collection

There are two main points to consider in deciding what data to collect. These are usefulness/desirability and ease of collection. A tension exists between these two variables. For example, a data set that is easily collectable might not be comprehensive or informative enough. On the other hand, if a data set is too large and a number of data items are difficult to collect, it becomes too time consuming and too costly. This tension was often reinforced during consultation with providers. Detailed information and discussion of the collectability and desirability of specific data items are presented in Chapters 4 and 6.

5.4 Collection mechanisms

The question of how data are able to be collected and transferred is another important factor in determining the feasibility of a national data collection for palliative care. Consideration needs to be given to the large range of IT systems in use both within and across states and territories, the training required by agency staff, and the need for the transfer of data from the state/territory level to a national repository. Detailed information and discussion of data collection and transmission systems are presented in Chapters 2 and 6.

5.5 Timeframe

The significant question of when a national data collection could be implemented needs to be addressed before feasibility can be determined. Although in some states and territories service providers are already collecting relevant data, other jurisdictions do not yet have such a collection. Furthermore, even where data are reported, there are issues to be resolved in terms of collection on a national basis. These issues include:

- **Definitional issues.** In order to collect meaningful information across Australia, data need to be consistent and comparable. This means that state and territory collections, and therefore all service providers involved in the collection, need to use the same:
 - concept definitions – some draft concept definitions are presented in Chapter 6 of this report, but further work in this area will be required;
 - data definitions – data will need to be defined in the same way, include the same data domain (i.e. have the same code list, or at least be able to be mapped to a common code list) and will need to be collected using the same rules.
- **Issues of scope.** Once the desired scope of the national data collection is determined, each state and territory would need to put a system in place that ensures all agencies within the scope report the data.
- **Resource issues.** In those states and territories where a reporting mechanism is not yet in place, resources will be needed to ensure that data can be collected correctly at the agency level (system and training issues), and transferred to the state/territory level, in some cases via a regional database. Where the state/territory does not yet have a data repository, this needs to be set up. In the states and territories where a reporting mechanism is in place, or will be in place soon, extra resources would be needed to make adjustments to systems, and staff training would need to be resourced. In all states and territories, a system for reporting data from the state/territory level to a national repository would also be required (see Chapter 6, Section 6.3).

5.6 Evaluation and performance indicators

5.6.1 Evaluation of health service provision

Data on health service provision can assist in providing information that supports the evaluation of how well the health system is performing, and there is a demand for data that can support such evaluation at a number of different levels. In this section, the demand at three levels (the national, state/territory and agency level) is discussed. The discussions on national and state/territory levels include a description of some significant documents and developments in this area.

National level

National Health Performance Committee

In 2001, the National Health Performance Committee (NHPC) published the National Health Performance Framework (the framework) Report (NHPC 2001). That report describes a national health performance framework which is intended to support performance measurements at all levels of the health system. The aim of measuring performance is to achieve improvements in the health system. This is reflected in the overall vision of the NHPC: 'a health system that searches for, compares, and learns from the best and improves performance through the adoption of benchmarking practices across all levels of the system'. The Committee's mission is to 'foster the use of benchmarking based on national performance measures and indicators to improve the quality of care of health services'.

Before the 2001 framework was developed, reports on performance focused on indicators relating mostly to institutional care and acute care settings. The framework was developed to also accommodate indicators for services such as community health, general practice and public health (NHPC 2001, p. v). This shift towards the inclusion of community health means that indicators for areas like community-based palliative care are now more easily accommodated in the framework.

Australian Health Care Agreements

The Australian Health Care Agreements between the Australian Government and the states and territories 2003–2008 outline the need for and commitment to the provision of performance information. This includes a commitment to 'co-operate through the AHMAC agreed governance arrangements for information management and information technology to continue the development of comparable performance indicators on efficiency, quality, appropriateness, accessibility and equity of services, and on performance indicators with a particular focus on health outputs and outcomes at the national level'. In the agreements, indicators of access and quality of palliative care services are specifically mentioned.

In the light of the Agreements, any newly developed national data collection for palliative care will need to incorporate data items that are capable of supporting performance measurement.

At the current time, four indicators have been agreed by the states and territories and the Australian Government, and will be pilot tested during 2004 (see Section 5.6.2).

The National Palliative Care Strategy

The National Palliative Care Strategy is a framework for palliative care service development. It outlines a number of strategies aimed at achieving three goals (DHAC 2000). Three of these strategies are relevant to the area of performance measurement and are part of a set of strategies aimed at achieving Strategy Goal 2: 'to support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia':

Strategy 2.3.2:

Implement an agreed national reporting framework, through a collaborative process involving the Australian, state and territory governments and service providers, to inform the Australian community of palliative care services.

Strategy 2.3.4:

Develop performance indicators for palliative care service provision, as agreed under the Australian Health Care Agreements.

Strategy 2.3.5:

Report on and monitor against service benchmarks, performance indicators and agreed data items.

As with the National Health Performance Framework, these strategies are not designed to be an aim in themselves, but seek to achieve improvements in the health system.

Palliative Care Australia

In its resource manual for palliative care performance indicators in Australia, Palliative Care Australia points out that, while the process of accreditation is important and necessary, the use of indicators is also crucial in producing evidence on performance and determining where change is required (PCA 1998).

State and territory level

There is recognition in each state and territory of the need for and value of evaluation of service delivery.

So far, Victoria is the only state in Australia that has developed and implemented a set of performance indicators for palliative care services, although reporting against these indicators is not mandatory at this stage.

Two states are in the process of developing performance indicators for palliative care service provision, for use at the jurisdictional level.

Queensland Health has developed a Statewide and Non-government Health Services Performance Framework to monitor service delivery, consumer involvement, quality improvement activities and management. A proportion of Queensland's palliative care-funded services will be expected to report against this framework.

New South Wales is also in the process of introducing performance indicators in the area of community health. A small set of performance indicators is being developed for New South Wales Health funded palliative care services (inpatient and community). These will eventually feed into higher level community health performance indicators.

In all other states and territories where strategic plans are in place, those plans recognise the need for and value of evaluation of service delivery at a state/territory and national level. Plans include the Australian Capital Territory Palliative Care Strategic Plan (currently under revision), Tasmanian Palliative Care Plan, Palliative Care: The Plan for Western Australia and the South Australian Strategic Plan.

In the Northern Territory, where a strategic plan is currently under development, the selection of an appropriate information system to facilitate evaluation of palliative care services is recognised as an important aspect of the plan's development.

Agency level

Managers of palliative care services involved in the consultation process overwhelmingly expressed the need for and importance of monitoring performance of their service through good quality data. Many were keen to generate and examine

regular reports on their service's performance. Many also expressed a strong interest in the ability to compare their service's data with state/territory and national level reports, provided they could compare themselves with similar agencies, i.e. compare like with like.

5.6.2 Developing indicators

While there is a demand for performance information at the levels described above, finding appropriate measures for the area of palliative care is not easy. In recent years, a number of projects have been undertaken in Australia in the area of performance indicators for palliative care. Amongst them is the previously mentioned resource manual for palliative care indicators in Australia, which was the outcome of a project carried out by Palliative Care Australia in 1998. In 2002, South Eastern Sydney Area Health Service produced its report on the development of national high level performance indicators for palliative care (South Eastern Sydney Area Health Service 2002). This work was built on further by the AIHW, resulting in the draft Palliative Care Performance Indicator Data Dictionary Version 1.0 (AIHW 2002).

In 2002, four high-level performance indicators were endorsed by the Palliative Care Intergovernmental Forum for trial. These are to be trialled during 2004 and centre around the proportion of:

- reporting regions that have a written plan for palliative care which incorporates palliative care elements;
- palliative care agencies within their 'setting of care' that have quality improvement mechanisms in place;
- palliative care agencies, within their service setting, that actively collect feedback from patients/consumers and staff (within the workforce) relating to services and service delivery; and
- palliative care agencies within their 'setting of care' that have formal working partnerships with other palliative care providers.

During this project's consultative meetings, the project team found that there is a recognition amongst palliative care service providers that identifying appropriate measures of quality of care and outcomes of care is a difficult task. Even amongst palliative care researchers there does not appear to be consensus yet on what are desirable and meaningful measures, particularly for measuring effectiveness or outcomes. While it is possible to describe what quality service delivery should look like, or what the ideal outcomes may be for patients and their families, translating this into 'measures' using numbers in a data set, and applying these for evaluation purposes, is a big leap.

Dimensions of the National Health Performance Framework

One tool designed to assist with the development of performance indicators is the Health System Performance tier of the earlier mentioned National Health Performance Framework (NHPF). The Health System Performance tier is the most relevant to palliative care service delivery, and includes nine dimensions: effective, appropriate, efficient, responsive, accessible, safe, continuous, capable and sustainable. For this tier, the following questions are posed: 'How well is the health system performing in delivering quality health actions to improve the health of all

Australians? Is it the same for everyone?' As equity is integral to all three tiers, the second question, 'Is it the same for everyone?' is asked across the whole framework. Quality is integral to the health system performance tier of the framework, and the nine dimensions all contribute to the assessment of the quality of the system. Both quality and equity are therefore not included as separate dimensions (NHPC 2001). A depiction of the NHPF is included in Appendix F.

Performance monitoring in a national community-based palliative care data collection

Some potential performance areas/measures that may be considered for a national community-based palliative care data collection are discussed in this section. They are presented by NHPF dimension (Health System Performance tier) in Table 7 and in the text below. Some measures are suited to measurement at the patient level, others can only be evaluated at the agency level (for definitions of 'patient level information' and 'agency information', refer to the Glossary). The potential measures discussed below have either come up during consultation, or were included in the report on the development of national high level performance indicators for palliative care (South Eastern Sydney Area Health Service 2002).

It should be noted that, while some of these measures are recommended as possible indicators in conjunction with a potential national data collection (see Chapter 6), the measures are not all recommended by the project team. Rather, they are presented as a resource for further discussion and exploration.

Table 7: Some potential performance areas for a national community-based data collection

NHPF dimension	Indicator area	Level at which collected	
Effective	Quality of life	Patient level	
	Satisfaction with the service	Patient level	
	Ability of the carer to move on	Patient level	
	Symptom control	Patient level	
	Setting of death	Patient level	
Appropriate	Whether the agency is accredited	Agency level	
	Whether interpreter services are available to clients	Agency level	
	Palliative care approach: Multidisciplinary approach to care Multidisciplinary approach to assessment Case conferencing Coordination with other providers and volunteers in the community	Agency level	
	Patient held home records	Patient or agency level	
	Coordination with other providers	Patient level	
	Efficient	Coordination with other providers and volunteers in the community	Agency level
		Number of clients and quantity/type of care provided by size of population denominator by model of care	Patient level
Casemix classifications, e.g. AN-SNAP		Patient level	
Responsive	Agency's involvement in education	Agency level	
	Agency's use of satisfaction surveys	Agency level	
	Time from referral to first contact	Patient level	
	Time from first contact to assessment	Patient level	
Accessible	Access for clients to 24-hour support	Agency level	
	Availability of interpreter services	Agency level	
	Whether the agency has a waiting list	Agency level	
	Whether the agency provides consultation in a residential aged care facility	Agency level	
	Whether the agency provides consultation to Aboriginal Community Controlled Health Services	Agency level	
Safe	No obvious indicators		
Continuous	Partnerships with other providers and volunteers in the community	Agency level	
	Multidisciplinary assessments	Agency level	
	Multidisciplinary care plans	Agency level	
	Patient-held home records	Patient level	
	Multidisciplinary case conferences with the patient and their carer	Patient level	
Capable	Accreditation information	Agency level	
	Specialised palliative care education undergone by staff	Agency level	
Sustainable	The agency's staffing profile	Agency level	
	The number of training places	Agency level	

1. Effective: care/intervention/action achieves the desired result in an appropriate timeframe.

While this is a very important dimension, it is probably the most difficult dimension to measure in the area of palliative care. Some measures possibly appropriate for reporting in this dimension are: quality of life, for both the patient and their family; the patient's and the family's level of satisfaction with the care received; the ability of the family to move on; patient symptom control; and, controversially, whether the patient died at home. These measures of effectiveness would all need to be collected at the patient level. The table below outlines some of the arguments for and against each measure.

Table 8: Effectiveness/outcome measures

Potential performance measure (effectiveness)	Arguments against	Arguments in support
Quality of life, e.g. survey outcome	Self-appraisal is subjective; patients and their families are likely to adjust their expectations, therefore results are not reliable or meaningful. Not routinely collected in current IT systems	Possible to measure and is meaningful if combined with other measures, e.g. combined with symptom status, Karnofsky score, functional status and general health perceptions (Wilson & Cleary 1995; Bakken et al 1997).
Satisfaction with the service, e.g. satisfaction survey score	Not meaningful, as these are often given to families 2 to 3 months after the patient's death; often the family is still in a 'fog' and will give high scores, not representative of their experience.	Can be quite meaningful if provided to the patient and family within a few weeks of referral, and to the family again 1 year after the patient's death.
Ability of the carer to move on, e.g. 6–12 months after patient's death	Logistical difficulties of how to measure this on a state/territory/national basis	Need to look beyond the patient's death: this is one of the important outcomes of palliative care. May be possible using data linkage.
Symptom control, e.g. outcome of symptom assessment, or PCA Problem Severity Scale	Appropriate for use by the service, but not at the state/territory/national level. Difficulty of different assessment tools used nationally	This is possible to measure and meaningful if combined with other measures (see comments on 'Quality of life').
Setting of death, i.e. whether the patient died at home	Highly controversial: not uncommon for patient to receive care at home for months, but be admitted to hospital in the last few days.	Should not be applied to individual patients or services, but has validity in a larger data set, e.g. to evaluate national trends. In 'real life', many service providers tend to 'judge' their service according to this measurement Routinely collected data item

2. Appropriate: relevant to the client's needs and based on established standards.

Some measures possibly suitable for reporting in this dimension at the agency level are whether the agency is accredited (and perhaps in future: whether it applies the PCA standards, currently under revision, to service provision); and whether interpreter services are available to clients. At the patient or agency level indicators on whether the agency provides care according to the 'palliative care approach' would fit into this dimension, e.g. use of the multi disciplinary approach to care and

to assessment, case conferencing, coordination with other providers and volunteers in the community, or information on patient-held home records. Patient-level information on the coordination with other providers could possibly be measured in a way similar to the SNAP model of care, which has three main categories, indicating whether the agency is the main provider, whether it is a shared care arrangement or whether the agency's main role is consultation/liaison.

3. Efficient: achieve desired results with most cost effective use of resources.

Some measures possibly suitable for reporting in this dimension at the agency level are those indicating the agency's coordination with other providers and volunteers in the community. At the patient level, a possible indicator fitting into this dimension is the number of clients and quantity/type of care provided by size of population denominator by model of care. While such an indicator has potential, it would need further exploration, in particular on the classification and definitions of model of care, and the calculation of the population denominator.

Casemix classifications are also possible tools that could be used to indicate efficiency. Casemix classifications have been successfully implemented in inpatient settings, including for palliative care through the AN-SNAP classification. Data used in relation to palliative care provision in the AN-SNAP casemix classification include the Resource Utilisation Groups Activities of Daily Living (RUG-ADL) scale, Palliative Care Phase change, and the PCA Problem Severity Scale. However, the use of the AN-SNAP classification in community-based palliative care settings is less reliable, as the patient's need for the agency's services is highly dependent on the community resources available, i.e. the level of involvement by other service providers, the availability of a carer, and other volunteer involvement. Also, recording the occurrence of a phase change within the required time span (72 hours), and carrying out the assessment at that time, is often not possible in the community setting, particularly for services that use the consultative model.

4. Responsive: provides respect for persons and is client orientated.

Possibly suitable data for reporting against this dimension at the agency level would be information on the agency's involvement in education, including the education of other professionals, volunteers or community members. Two measures quite suitable for reporting in this dimension at the patient level, and generally supported by service providers, are the time from referral to first contact, and the time from first contact to assessment.

5. Accessible: ability of people to obtain health care at the right place and right time irrespective of income, cultural background or physical location.

Measures possibly suitable for reporting in this dimension at the agency level include information on access for patients to 24-hour support (this could be stratified by telephone support or face-to-face support), availability of interpreter services, whether the agency has a waiting list, whether the agency provides consultation in a residential aged care facility and whether the agency provides consultation to Aboriginal Community Controlled Health Services.

At the patient level, as an example, a data collection could provide data on patients with a diagnosis other than cancer. Provided that agreement could be reached on an acceptable way to calculate a population denominator, such data may give an indication of access to funded palliative care services by people who died with a principle diagnosis other than cancer.

However, due to the nature and organisation of palliative care service provision, and the differences in definition of what palliative care is, 'access to palliative care' is difficult, if not impossible, to measure. While a national palliative care collection of palliative care-specific funded services could provide data on access to those services, it does not provide information on access to other, primary care, providers. Further discussion on this topic is provided in Section 5.2.

6. Safe: the avoidance or reduction to acceptable levels of actual or potential harm from health care management or the environment in which health care is delivered

There are no obvious examples of any indicators related to this dimension.

7. Continuous: ability to provide uninterrupted, coordinated care/intervention/action across programs, practitioners, organisations and levels over time

Any measures related to coordinated care will fit into this dimension. At the agency level, information on the agency's partnerships with other providers and volunteers in the community, or on the practice of carrying out multi-disciplinary assessments or preparing multi disciplinary care plans, could provide measures of continuous care.

At the patient level, measures possibly suitable for reporting in this dimension include information on patient-held home records, or data on whether any multidisciplinary case conferences were held with the patient and their carer.

8. Capable: an individual's or service's capacity to provide a health care/service/intervention based on skills and knowledge

Only agency-level information would be suitable to report on for this dimension. Information on whether an agency is accredited with the Australian Council for Health Care Standards or equivalent recognised body would be appropriate for reporting against this dimension, as would be information on specialised palliative care education undergone by staff.

9. Sustainable: providing an infrastructure such as workforce, facilities and equipment, being innovative and responding to emerging needs (research, monitoring)

Two measures possibly suitable for reporting in this dimension at the agency level include the agency's staffing profile and the number of training places, including placements under the Program of Experience in the Palliative Approach.

6. A national community-based palliative care data collection

This chapter provides the proposed characteristics of a national palliative care data collection, deemed to be feasible by the project team. As well as a description of the proposed characteristics, a recommended draft core data set and draft definitions are presented (with the relevant national data standards where available included in Appendix H). The last section outlines the recommended strategies for data collection and transfer.

6.1 Proposed characteristics of a national data collection

Scope

Section 5.2 in Chapter 5 provides background information and discussion regarding issues of scope. The proposed characteristics outlined below are based on the arguments outlined in that section.

It is proposed that a national palliative care data collection:

- be a requirement of those service providers who provide community-based palliative care and who receive palliative care-specific funding;
- include agencies based in the community and hospitals providing ambulatory care/outreach services;
- include both government and non-government agencies;
- include agencies funded to provide community-based palliative care for special needs groups;
- require the collection of data identifying Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds; and
- require the collection of data on networks/partnerships in care.

Level

Information reported by agencies may include those data collected at the patient level and data that provide information at the agency level. In this report, patient-level information is information collected about each patient, and the services provided to each patient. Agency-level information is information about the agency, e.g. its policies, its staffing profile, or its target group. Examples of some other agency-level data collections are the National Public Hospital Establishments database, the National Minimum Data Set for Community Mental Health Establishments and the agency collection in the Supported Accommodation Assistance Program.

Some examples of the kind of data that could potentially be collected through a palliative care data collection about agencies are:

- the agency's staffing profile;
- provision or access to a 24-hour helpline;
- information about the agency's policies on care plans, case conferencing, etc.;
- partnerships with other providers, community groups, and volunteers;
- the agency's involvement with education activities;
- whether the agency is accredited;
- policy on the use of client satisfaction surveys;
- information about the agency's other funding sources;
- the agency's special target group(s), if any; and
- the agency's model(s) of care.

Advantages of an agency-level collection

An agency-level data collection provides a way to gain information about an agency's service provision without the agency needing to collect that particular type of information about each patient. Furthermore, it can assist in putting the patient-level data from each agency into context, which allows for analysis by different types of agencies. For example, it allows grouping of agencies with particular target groups, or of those agencies that have a consultative model only. Agency-level data may also provide data that support performance indicators (see Section 5.3 in Chapter 5) and, if based on properly defined data elements, is less time consuming for agency staff than survey-type collections.

Other characteristics

It is proposed that a national community-based data collection should:

- be a 'by-product' of palliative care data collections at the state and territory level;
- where possible, be a by-product at the service level as well, i.e. collect information that service providers already want or need to collect about their clients and service provision;
- use national data standards where available (those outlined in the *National Health Data Dictionary* and the *National Community Services Data Dictionary*);
- produce data that is consistent and comparable across services and all states and territories;
- provide basic but useful information, e.g. number of patients cared for, patient demographics, types of services provided; and
- include information that supports performance indicators, e.g. gives an indication of the quality of the care, a reflection of whether the palliative care approach is used by the service, or an indication of client outcomes (see also Section 5.6 in Chapter 5).

Timing

The project team believes that the type of data collection described in this chapter could be set up in the medium term (say in the order of two to four years), and suggests that it is implemented in stages, i.e. some states and territories earlier than others.

The implementation of a national community-based data collection across all states and territories, particularly the patient-level aspect of it, is not recommended in the

short term, say within one or two years. This is because some states and territories will require more lead time, due to the need to further develop information systems. As well as resources and time, those systems need input in terms of agreement on data items for collection, and on definitions and code sets for these data items. Also, before implementing a national data collection, many states and territories will need time to set up a database of all agencies considered within scope. This will involve the need to reach final and detailed agreement on scope across the states and territories.

6.2 Recommended data set and draft definitions

This section presents a set of candidate data items and broad concepts, or object classes, for a community-based palliative care data set, and a glossary of terms. The data items and definitions are designed to reflect information collected by service providers in their day-to-day practice. Once the scope of a community-based national palliative care data collection has been decided, concept definitions better targeted to the scope of the collection can be developed.

The data items and object classes specified in this metadata set provide a framework for describing how a palliative care service operates and are a first step towards consistency of data between palliative care services across states and territories.

6.2.1 Selecting the data items

The suggested draft core data set presented in this section was developed according to a number of guiding principles. First, it was considered important that the data items be useful and meaningful to the day-to-day care of clients and to the management of the service. Second, the data set uses national standards wherever relevant. Third, there is a need to be mindful of palliative care services' other reporting requirements and to be consistent with those requirements where possible. Figure 1 outlines the data items that were supported for collection by the majority of participants at the consultative meetings. The data items are listed according to their relevant object classes.

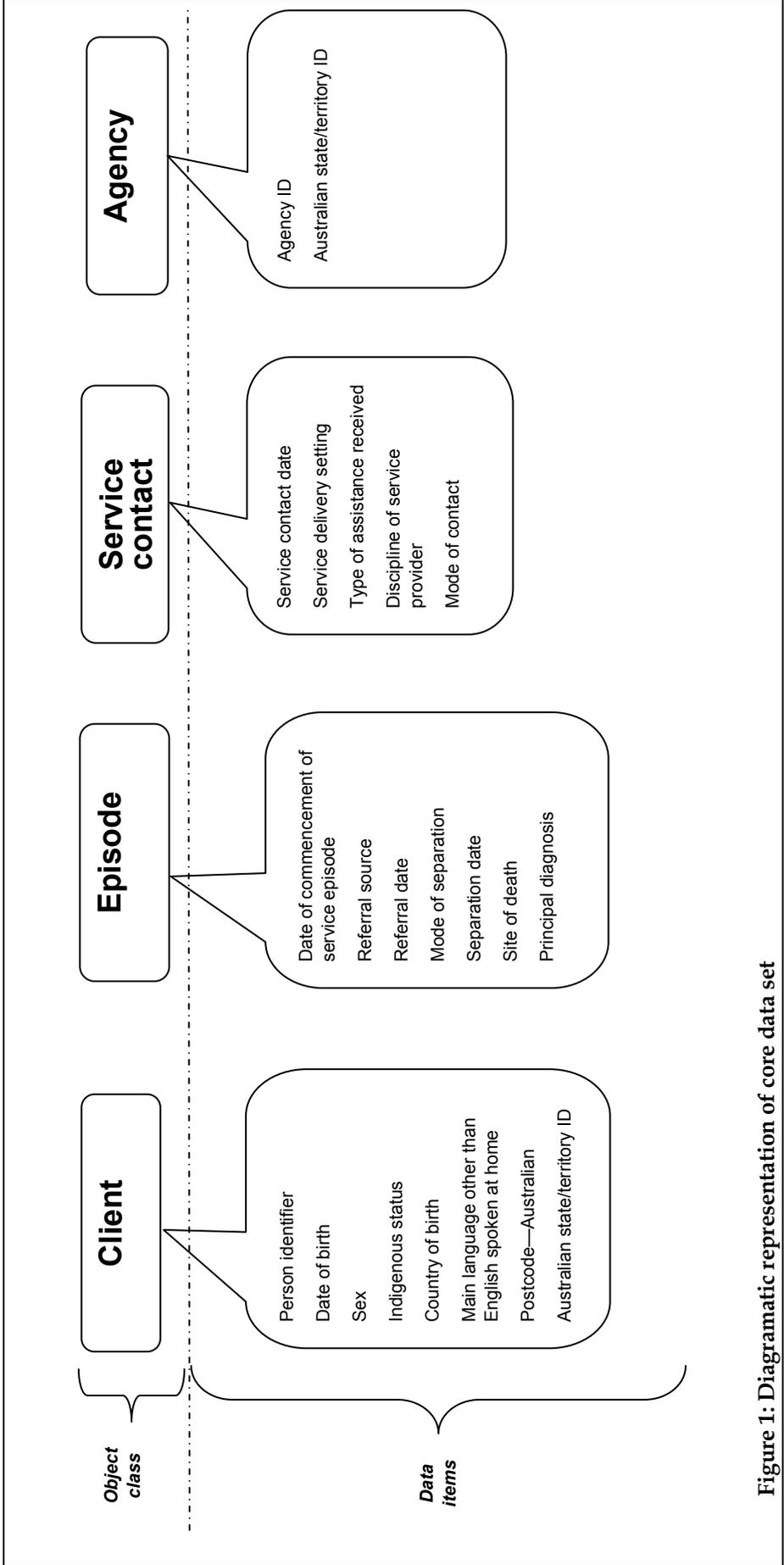


Figure 1: Diagrammatic representation of core data set

6.2.2 Object classes

Any national data collection has a number of core concepts or object classes that clearly represent the entity or 'thing' being described by data elements. It is crucial that these object classes are clearly defined in accordance with national data standards to facilitate comparison across the palliative care sector and between palliative care and other related sectors. The object classes for the core data set have been listed in Table 9. The definitions of the object classes have been based on national data standards included in either the *National Health Data Dictionary* (NHDD) or the *National Community Services Data Dictionary* (NCSDD).

This list of object classes is in the initial stages of development and can be added to depending on the type of data set that is finally agreed.

Table 9: Object classes applicable to palliative care

Object Class	Draft definition
Agency *	An organisation or organisational sub-unit that is responsible for the provision of palliative care services to clients
Client *	A person, group or organisation eligible to receive palliative care services either directly or indirectly (i.e. through partner organisations) from an agency
Service contact *	A contact between a patient/client and an ambulatory care health unit (including outpatient and community health units) which results in a dated entry being made in the patient/client record
Service episode *	A period of time during which a client receives palliative care services from an agency

Note: Refer to Appendix H for national data standards and draft definitions.
* = national data standard or based on a national data standard.

6.2.3 Glossary of terms

Table 10 contains a glossary of terms that are important to meaningful communication in the community-based palliative care sector. These terms are likely to be used in various areas of the data specifications and their meaning within this context needs to be clearly understood by all users of the data set.

Family

The glossary of terms in Table 10 includes definitions for two terms related to the patient's family: 'Family' and 'Support network'. The definition for family is a national data standard, included in the NCSDD. The term 'Support network' and its draft definition have been included to reflect what in palliative care circles is often referred to as 'the family'. It should be noted that in the Australian Aboriginal and Torres Strait Islander kinship system the term 'family' has a different meaning from both these terms. It relates to the person's extended family or kinship group, as recognised by the Aboriginal and Torres Strait Islander community to which the person belongs (New South Wales Attorney General's Department 2002).

Table 10: Glossary of terms applicable to palliative care

Name	(Draft) definition
Family *	Two or more people related by blood, marriage, adoption or fostering and who may or may not live together. They may form the central core of support networks for individuals.
Informal carer *	A carer includes any person, such as a family member, friend or neighbour, who is giving regular, ongoing assistance to another person without payment for the care given. The definition excludes formal care services such as homecare, care provided by volunteers or foster care that is arranged by formal services. It also excludes unregistered child carers who are receiving payment for their services. Where a potential carer is not prepared to undertake the caring role, the carer is considered to be not available.
Volunteer *	A person who willingly gives unpaid help in the form of time, service or skills through an organisation or group. The reimbursement of expenses in full or part (for example, token payments) or small gifts (for example, sports club T-shirts or caps) is not regarded as payment of salary, and people who receive these are still considered to be voluntary workers. People who receive payment in kind for the work they do (e.g. receiving farm produce as payment for work done on a farm, rather than cash) are not considered to be volunteers. An organisation or group is any body with a formal structure. It may be as large as a national charity or as small as a local book club. Purely ad hoc, informal and temporary gatherings of people do not constitute an organisation. Persons on community service orders and other similar work programs are not considered volunteers.
Palliative care phase	A stage of change or development for a person and their family facing the problems associated with life-threatening illness.
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Interdisciplinary palliative care team	A team consisting of members who contribute from their particular expertise and who work interdependently, together providing a broad spectrum of knowledge, skill and creative problem-solving to deliver palliative care.
Support network	The people who are closest to the patient in knowledge, care and affection. They may include the biological family, the family of acquisition (related by marriage or de-facto relationship) and friends. [Definition based on text in the National Palliative Care Strategy (DHAC 2000:5)]

Note: Refer to Appendix H for national data standards and draft definitions.

* = national data standard or based on a national data standard.

6.2.4 Data items

Core data items

The data items listed below as a core data set for palliative care are recommended as a result of the mapping process and consultative meetings with service providers and other stakeholders. Where possible they have been based on current national data standards and existing data collections. Where an existing standard or data item was not applicable or did not exist, a new draft item was developed and included in this report. These items were presented for comment to the consultative meetings conducted in each state and territory. One item, 'Assessment results', has been removed from the original list. This item was excluded from the suggested core data set based on the feedback received in that there is considerable variation between states and territories with regard to the method of assessment used. Information obtained through the use of this data item would not be comparable in a data collection. Although the results of assessment may be important information for national reporting analysis, inclusion in the data set is unlikely, in itself, to generate the standardisation in clinical practice necessary to produce comparable data.

Table 11: Core data items

Australian state/territory identifier *	Principal diagnosis *
Agency identifier *	Postcode—Australian *
Country of birth *	Referral date *
Date of birth *	Referral source *
Date of commencement of service episode	Separation date *
Discipline of service provider (draft)	Service contact date *
Indigenous status *	Service delivery setting *
Main language other than English spoken at home *	Site of death (draft)
Mode of contact (draft)	Sex *
Mode of separation *	Type of assistance received (draft)
Person identifier *	

Note: Refer to Appendix H for national data standards and draft definitions.

* = national data standard or based on a national data standard.

Data items strongly recommended for inclusion

Following consultations with states and territories and stakeholders, an additional list of data items was developed that was thought to provide important information not included in the first list. Most of these items were suggested by the service providers as being important to include in a state/territory or national collection about the activities of palliative care services. These items (listed in Table 12) are strongly recommended for inclusion in a palliative care data set. The items are not necessarily reported in the states or territories, however, a palliative care data set would be strengthened by their inclusion. Once again, national data standards have been referenced (all four already exist as a national data standard). The project team recommends that a palliative care data set should be a combination of the core data set and these items recommended for inclusion.

Table 12: Items strongly recommended

Carer availability *	Living arrangements*
Carer co-residency *	Relationship of carer to care recipient *

Note: Refer to Appendix H for national data standards and draft definitions.

* = national data standard or based on a national data standard.

Optional items

These items have been included in this report as they support the information to be obtained from a palliative care data set though, they are not routinely collected. They are of interest to a palliative care data collection according to feedback from the consultation process. The recommendation here is that these items should be considered for a data set at a later date.

Table 13: Optional items

Assessment date *	Date of first delivery of service *
Case management plan indicator *	Date of last contact *
Contact recipient type (draft)	Letters of name (draft)
Date of diagnosis *	Phase of care (draft)
Date of first contact *	

Notes: Refer to Appendix H for national data standards and draft definitions.

* = national data standard or based on a national data standard.

Commonality with other national data collections

Almost all the data items recommended in this chapter are national data standards, i.e. they are included in either the NHDD or the NCSDD. However, this does not mean that these items are defined in exactly the same way in other major national community health or community services data collections or even that the same data items are collected in those data sets (e.g. the Home And Community Care MDS, the Alcohol and Other Drugs Treatment Services NMDS). Some data items obviously are of interest to some community-based collections but are inappropriate for others. However, there are a number of data items that are of interest across a fairly wide range of programs and that could be collected in a more comparable format.

It has been suggested during this project's consultation that ideally there should be a standard core set of data items that is collected across all community health services. The project team supports this approach, as it would improve efficiency of data collection and comparability across data sets. While each data collection will always have a requirement for its own specialist data items, collection of an agreed core data set across national community health data collections consistent with national standards would significantly relieve the burden on those involved in collecting, reporting and analysing multiple community health data sets.

6.3 Strategies for data collection and transfer

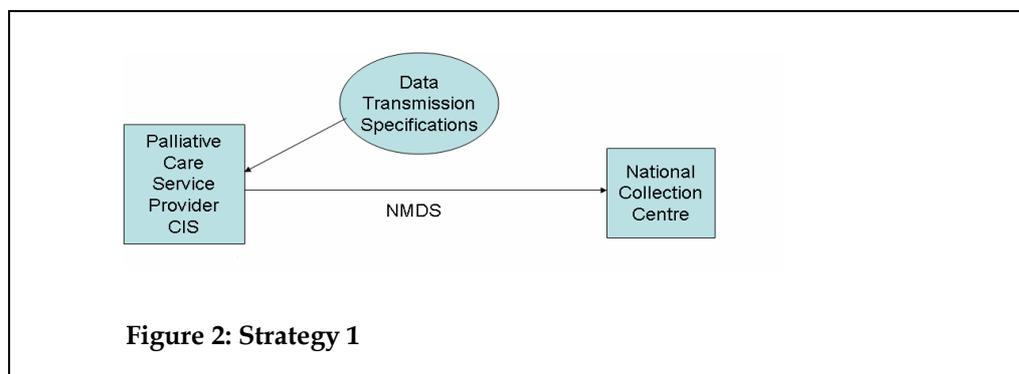
The following four strategies for the collecting and reporting of the proposed national data collection are considered below:

- Strategy 1: Data are received by a national collection centre directly from community-based palliative care service providers in conformance with transmission specifications provided to them.
- Strategy 2: A Client Information System is provided for community-based palliative care service providers that would automatically meet the collection's reporting requirements.
- Strategy 3: Data are received by a national collection centre directly from central state, territory or regional locations in conformance with transmission specifications provided to them.
- Strategy 4: A data collection and reporting system is provided for state, territory or regional centres that would automatically meet the collection's reporting requirements and provide feedback in the form of reports about the data it holds.

6.3.1 Strategy 1

For this strategy, a set of data transmission specifications would be developed for all community-based palliative care service providers. The specifications would define how the data included in the data collection should be transmitted to a national collection centre and cover such things as:

- transmission medium, e.g. electronic mail, computer disk, etc.;
- format, e.g. comma separated variable (csv) files, XML, etc.;
- order of data items within the data file;
- mandatory data items;
- allowable values; and
- other rules applying to the data.

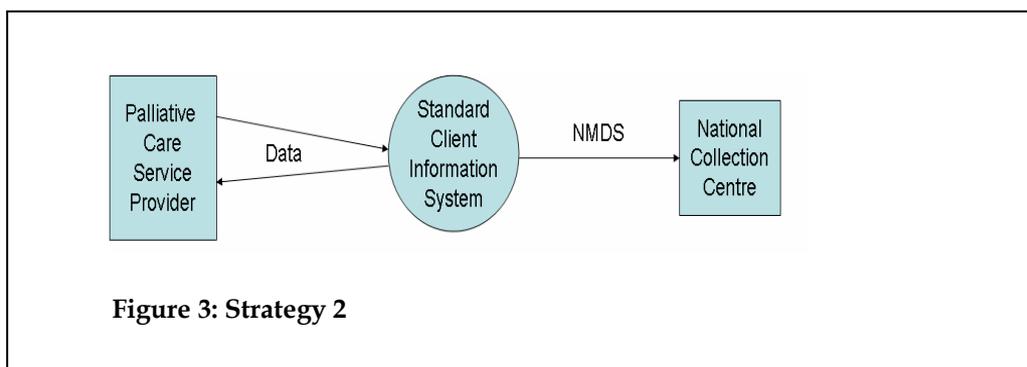


This strategy would suit those services that do not report to their state, territory or region or where their state, territory or region is not participating in the national collection.

The strategy is non-intrusive, allowing service providers to use their current client information systems from which the data would be collected as a by-product of the running of the business. However, some client information systems may need to be modified if they do not already meet the collection's reporting requirement.

6.3.2 Strategy 2

For this strategy, a standard client information system would be developed for use by all community-based palliative care providers and a mechanism for reporting the national data collection would be built in to the system.



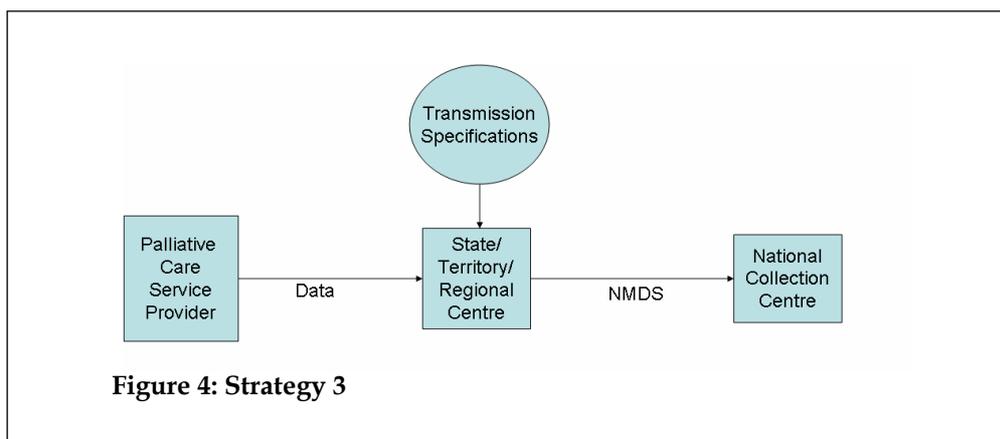
Although this strategy would facilitate standard collection of palliative care data across the nation, it is not recommended that a standard client information system be developed for the following reasons:

- states, territories and service providers have already invested considerable resources in developing and implementing their own current client information systems.
- the system would be complex and costly to develop as it needs to cater not only to a wide variety of palliative care models, but also to other non-palliative care models of health provision.
- it would be costly and resource intensive to install in all sites and to train all provider staff in its use.
- to develop the system would require considerable input and liaison with all service providers to ensure that it has minimal impact on the collection and reporting workload at the source level.
- it would be unreasonable to expect to develop a system that was considered acceptable and practical in terms of usability and functionality by all community-based palliative care providers across Australia and at the same time be cost effective and cost efficient.

6.3.3 Strategy 3

For strategy 3 a set of data transmission specifications (the same as the specifications described in strategy 1) would be developed for use at the state, territory or regional centre level.

Data would be received at a regional centre or at the state/territory department and then forwarded to a national collection centre in accordance with the transmission specifications.



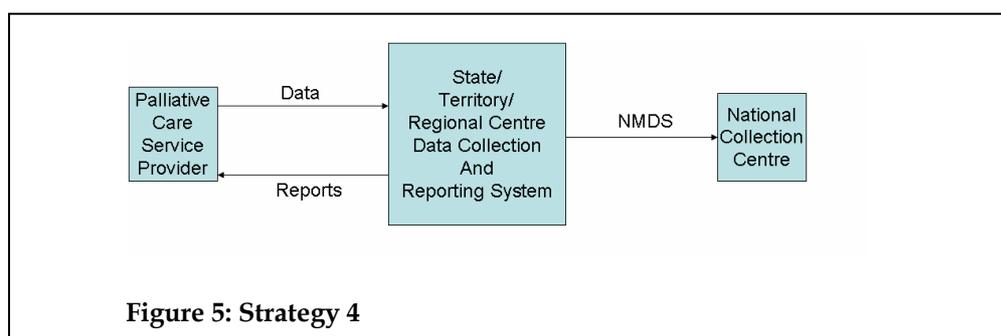
This strategy takes into consideration the reporting of community-based palliative care data that currently occurs between providers and regional centres or state/territory departments, especially where there are already data collation and reporting systems in place.

Although service provider client information systems may still need to change if they do not currently meet the reporting requirements, with this strategy the onus of producing the data set in the required format is with health regions and state/territory departments where resources are more likely to be available for the task.

6.3.4 Strategy 4

This strategy involves the development of a data collection and reporting system that would be used at a regional centre or at the state/territory level.

Data from service providers would be loaded into this system from which the data collection could be exported to a national collection centre. Analytical and other reports about the data would be available for all stakeholders.



The following paragraphs provide further details about the proposed data collection and reporting system.

Specification outline

The proposed data collection and reporting system would need to:

- be developed using platform-independent computer technologies so that it can be deployed on a variety of platforms across the state and territory health departments or regional centres;
- employ security measures to ensure data are protected from misuse and unauthorised access;
- be able to import data from a variety of sources such as XML and text files;
- export data in XML format;
- allow users to interrogate and report on the data it contains;
- provide some standard reports; and
- be extensible to facilitate any future changes to the system.

The standard reports produced by the proposed data collection and reporting system at the regional centre and state/territory levels will not only provide them with the palliative care information they need to manage their palliative care programs, but should also be distributed to the service providers. This gives the palliative care service providers something in return for their cooperation and efforts in collecting data for a national collection.

Information and communication technology

To ensure that the proposed data collection and reporting system is easily deployed on the variety of computer platforms in the regional centres and state/territory departments, it should be developed using appropriate tools.

Developing the proposed system as a Java application would facilitate deployment across all computing platforms.

For the transmission of data to and from the data collection and reporting system it would be preferable to use XML technology because:

- XML is a widely accepted standard that can be implemented by a large body of languages and application interfaces;
- using XML to encapsulate structured data helps to ensure data quality as data are passed between different computing systems; and
- XML offers flexibility along the system development path.

The data import process in the data collection and reporting system should allow the upload of data in the preferred XML format. However, as it is unrealistic to expect that data will be extracted in XML format from the various client information systems in use in the palliative care sector, the system should also allow data to be imported from basic text files such as comma separated variable (csv) files.

Security and privacy

Where data are communicated between systems, appropriate encryption mechanisms such as Secure Sockets Layer protocol should be used.

Authentication and encryption should be used to prevent misuse and to ensure only authorised users have access to the data.

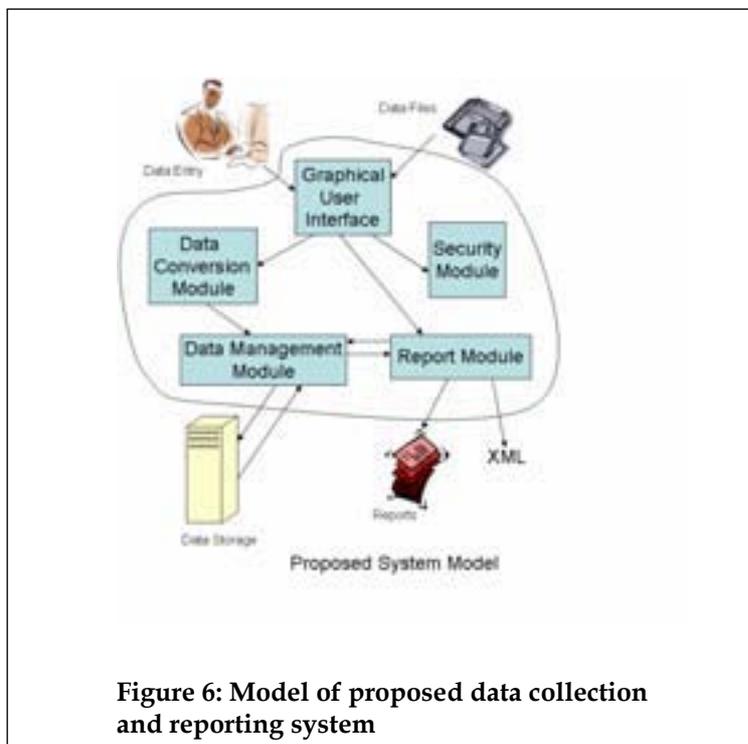
Export data should be de-identified to ensure the privacy of clients is maintained in accordance with the *Privacy Act 1988*.

Proposed design

Figure 6 depicts a possible realisation of the proposed data collection and reporting system.

The functionality to be provided by each module within the logical model is as follows:

- graphical user interface – handles the loading and display of information;
- security module – handles security measures including authentication and encryption;
- data conversion module – transforms data received in formats such as XML, csv and fixed length for handling by the data management module;
- data management module – provides validation of data and communication with the chosen data storage entity;
- reporting module – formats data reports for the user and creates XML documents.



Without going to tender for the development of this system, it is only possible to give a rough estimate of how long and how much it would cost to develop.

It is expected that a competent software designer/developer would take about three months to develop a system of this size and complexity at a cost of between \$30,000 and \$50,000.

Engaging a company that has already developed systems of this nature would mean less development time and better support for the product. It does not necessarily mean though that the system would cost any less.

Use at provider level

The preferred method for collecting data at the service provider level is as a by-product of their patient management or clinical information systems.

For those services currently without any or with inadequate computer systems it would be preferable if they purchased existing client information systems tailored to palliative care and that conform to the proposed national data collection. However, if services cannot afford the cost of specialised clinical information systems, it would be possible and perhaps beneficial for them to deploy the proposed data collection and reporting system in their service.

In order to make the proposed system more suitable for their purposes and to assist the service providers in the day-to-day running of their business, it may be useful to add data items further to the proposed national set. Also, a form interface would need to be included to allow for entry of information. There would need to be limits on features included in the system for its use at the provider level to prevent it from becoming unmanageable.

Implementation

Training of staff in the use of the new system would need to be held in every regional centre or state/territory department that chooses to adopt the proposed data collection and reporting system.

System and user documentation would need to be developed for distribution with the proposed system.

Testing of the system would require cooperation between service providers, regional centres or state/territory departments and the national collection centre.

Maintenance of the system would be an ongoing commitment for the central collection authority.

6.3.5 Analysis of strategies

Of the four strategies proposed for collecting the national data collection only strategy 2, which suggests developing a standard client information system for use by all community-based palliative care providers, is not recommended.

The other three strategies are all feasible and cater for the different circumstances of data collection and reporting that currently exist in the palliative care sector.

Strategies 1 and 3 are similar and the same data transmission specification for the national data collection could be developed for use in both scenarios.

Strategy 4 is a more expensive proposal as it involves the cost of developing a system. However, after the initial development cost, ongoing maintenance costs should be minimal. This strategy also provides a return on investment by delivering standard reports on palliative care information that are available from the service provider level through the regional level to the national level. It is understood that some, if not all, state and territory departments are more interested in a system that collects and reports on data from a broad range of (community) health services and may not be best served by this proposed system, which is narrowly focused on palliative care.

Strategies 1, 3 and 4 may involve changes to the service provider client information systems so that they can produce the required data for the data collection. The potential for changing these systems is discussed in the next section.

6.3.6 Changing current client information systems

From various discussions during state visits it became clear that a lot of the client information systems used to collect community palliative care data from publicly funded palliative care services could be modified, if necessary, to conform to a nationally consistent set of palliative care data, i.e. building in new or changed data items.

This is especially true of the smaller, locally developed client information systems that are particularly palliative care focused. Changing larger software vendor systems, especially where palliative care data are only a small part of the overall system, may be more costly as the provider base is larger and the systems more complex.

It has been suggested during consultation that there may be resistance from some non-government organisations to the requirement to change their client information systems.

Resource issues

The main concern with making modifications to current client information systems is the need for additional resources to fund the software development and testing, and the staff time required to test the system and to undergo training.

The costs involved in modifying systems would vary greatly in line with the types of changes required as well as the ownership, complexity and user base of each client information system.

Costs that may be incurred are:

- re-design and printing of paper forms where new data items are required;
- coding of client information systems to include new data items;
- modification of code in client information systems to change allowable values for existing data items where they do not conform to the national data collection;
- addition of code in client information systems to export all the data specified in the national data collection; and
- training of staff in any changes to their client information systems.

HealthConnect

If and when CIS vendors change their products to integrate with *HealthConnect*, it would be cost effective to introduce any changes required for the palliative care national data collection at the same time.

However this would mean that palliative care data items and definitions would need to be agreed nationally in time for vendors to include them when they enable the interface with *HealthConnect* in their products.

7. Options and recommendations for future national data collection

A number of options for future national data collection were considered during this project. Three approaches for advancing palliative care information development are recommended by the project team, and these are outlined in detail in Section 7.1. Section 7.2 describes two other options considered but not recommended. It also contains a recommendation that any future work in the area of palliative care information development include further exploration of other sources of data relevant to palliative care provision, in particular those outlined in Chapter 3, Section 3.3.

7.1 A way forward

As discussed in Chapters 5 and 6, the project team believes that the development and implementation of a national data collection for palliative care is feasible, provided it has certain attributes. The differences between the states and territories in terms of the current stage of data collection as well as the differences in, or lack of, data item definitions and codes mean that a short timeline for setting up a national data collection is not realistic. Therefore, the project team recommends against trying to establish a fully implemented national minimum data set, i.e. a mandated national data collection for all states and territories, within the next two years. Rather, the team suggests a phased approach through a collaborative process, involving the development of national data items and their definitions, and the gradual involvement of states and territories in actual collection as they are ready to participate.

The project team recommends three approaches as a way forward for national information development and data collection. It is suggested that they are implemented successively. However, each approach may also be carried out on its own. They are outlined below, in sequential order.

7.1.1 A palliative care data set specification

The first approach, which the project team believes is suitable for the immediate future and which offers ‘a way forward’ without the need to commit to a mandated national data collection, is the development of a palliative care data set specification (DSS). A data set specification could be described as a core set of data items, and definitions for these items, that has been agreed by stakeholders as an important set of core items to be collected by providers in relation to particular types of patients/clients and their care, and that has been endorsed by the National Health Information Group (NHIG) for inclusion in the *National Health Data Dictionary* (NHDD). A crucial feature of a DSS is that there does not need to be any obligation to collect or report it, i.e. the collecting or reporting of all or any of the DSS data items can be mandatory or optional.

One example of a DSS is the Cancer (Clinical) Data Set Specification, which has recently been endorsed by NHIG for inclusion in the NHDD. The Cancer DSS

consists of a set of 42 data items, developed and agreed to by the members of the National Cancer Control Initiative. Some of the data items in this DSS are already included in the current version of the NHDD (i.e. a national standard exists); others have been newly drafted and will expand the coverage of the NHDD. The Cancer DSS will provide guidance to all providers/treatment facilities involved in the treatment of cancer patients, on what information should be collected and recorded at a minimum about those patients and their care.

Advantages of a DSS

Some of the advantages of the development of a palliative care DSS are:

- It would provide a standardised approach to the collection of data items by agencies involved in the provision of palliative care.
- It would provide an opportunity for all jurisdictions to contribute meaningfully to a nationally agreed set of data items.
- It would form the groundwork for a national (community-based) palliative care data collection, as well as for any new or re-designed state/territory collections.
- It could include recommended data items for community-based settings only, but could also include data items recommended for inpatient settings, in particular for hospices/designated palliative care units.
- It could include agency data items as well as patient-level data items (see also Chapter 6 and Section 7.1.2 below).
- Even if no mandated community-based data collection were instigated at any time, a data set specification would give guidance to services on what data should be collected as a minimum; it would also provide guidance to software developers involved in developing systems for agencies that provide palliative care.
- If built in to systems used by most providers (various settings, specialist and non-specialist services, GPs), an agreed data set specification would eventually enable consistent data to be extracted and reported across a broad spectrum of providers (provided that detailed pilot testing is carried out).

A DSS for palliative care should have input from palliative care clinicians, palliative care researchers, palliative care policy experts and data management/health information experts. This range of expertise is imperative to producing a DSS that reflects true palliative care practice and that is useful from both a clinical and a policy perspective.

As mentioned above, the development of a DSS could include the development of both patient-level and agency data items. Once developed and agreed, a set of agency data items could possibly be collected earlier, as outlined in Section 7.1.2 below.

It is recommended, should the option of developing a DSS be adopted, that the patient-level data items outlined in Chapter 6 be used as a starting point for work on a DSS.

Implications of this approach (DSS)

DSS development program

The implementation of Approach 1, the development and endorsement of a Palliative Care DSS, would involve carrying out a number of steps. The major steps involved are outlined below:

1. Development of draft data specifications and draft definitions for the relevant object classes and concepts underpinning the DSS. Data items could cover both patient-level and agency items.
2. Consultation with stakeholders, including palliative care service providers, state/territory and Australian Government policy staff, data management/health information experts, other relevant data working groups and palliative care researchers. The consultation phase would include submitting the draft definitions to the Health Data Standards Committee (HDSC) for its input.
3. Incorporating the outcomes of the consultation into the draft data specifications, and reaching agreement by the states and territories on the draft definitions to allow pilot testing.
4. Pilot testing the data items (patient-level and/or agency items), including testing of data collection, transmission systems and data analysis.
5. Incorporating outcomes from the pilot test into the data specifications.
6. Submitting the DSS to the Palliative Care Information Forum for endorsement.
7. Further consultation with other relevant data working groups potentially affected by proposed changes to existing data standards arising from the palliative care DSS development.
8. Submitting the DSS to the HDSC, with the view to obtaining that committee's recommendation for endorsement.
9. Submitting the DSS to the National Health Information Group (NHIG) for endorsement.

While the program outlined above includes a specific consultative phase, consultation should be an ongoing activity throughout the development period and during each step.

Timeline

It is envisaged that the development of a DSS for palliative care would take approximately 12 months (six months for steps 1 to 3, and six months for steps 4 to 6), and the endorsement phase approximately 3 months, depending on the relevant committee's meeting schedule at that time and the extent of consultation required with other data working groups. The total timeframe is therefore expected to be around 15 months. Figure 7 at the end of Section 7.1.2 provides a graphic representation of the major steps involved in the development of a DSS for palliative care, presented against the suggested timeline.

7.1.2. A national agency data collection

As outlined in Section 6.1, in this report agency-level information is information about the agency, e.g. its policies, its staffing profile or its target group. This is

different from patient-level information, which is information collected about each patient, and about the services provided to that patient.

In relation to the development and collection of agency data, the project team makes the following recommendations:

1. That, should the development of a palliative care data set specification (DSS) be undertaken, a set of agency - level data items is developed as part of that DSS.
2. That a set of agreed agency data are collected nationally before the implementation of any national patient-level data collection.
3. That a national agency data collection would, at least initially, consist of only a modest number of data items (possibly no more than 10). It is suggested that these data items would include items which support the calculation of the three already agreed performance indicators that are based on agency information. It is also suggested that the set include data items that support stratification by level of service.
4. That the agency data are collected annually.
5. That agency data are collected as part of a future mandated national community-based palliative care data collection.

As part of this approach, the project team suggests that agency data be collected earlier than patient-level data. The early collection of agency data items would:

- provide a way to gain information about an agency's service provision without the agency needing to collect that particular information about each patient;
- provide data that support performance indicators (PIs) (see Section 5.6), including three agency-level PIs from the four already agreed PIs outlined in Section 5.6.2;
- be less time consuming than survey-type collections, if based on properly defined data items;
- be complementary to accreditation developments;
- provide early data on palliative care provision in Australia against an agreed scope; and
- assist in establishing a database of agencies that are within scope; such a database will be necessary if a patient-level data collection is to be implemented in the future.

In addition, an agency data collection is likely to be an important adjunct to a future patient-level data collection, as it can assist in putting the patient-level items into context. In particular, it could allow analysis by different types of agencies, e.g. agencies' target group, funding arrangements or model of care. During this project's consultation, a number of service providers across the country have indicated that they see benchmarking as important, but that it is crucial that similar services are compared, i.e. the need to compare like with like.

Implications of this approach (an agency data collection)

Many of the major steps involved in the development, endorsement and implementation of an agency palliative care data collection are the same as those outlined in the work program for a DSS. The extra steps involved in carrying out this approach are:

- developing a data collection instrument. It is recommended that this be an especially designed Excel spreadsheet, rather than a questionnaire, to reduce the burden on service providers and to facilitate the task of collating and analysing the data;
- developing a 'Guidelines document' for service providers, based on the data specifications but providing detailed, plain English advice on the definitions and other reporting specifications for those reporting the data;
- establishing a database of agencies that are within scope; such a database will be necessary for the implementation of an agency data collection. Such a database would also be necessary if a patient-level data collection were implemented in the future;
- developing a business case for the implementation of a national agency data collection, and submitting it to the Statistical Information Management Committee (SIMC), with the view to obtaining that committee's recommendation for endorsement;
- securing endorsement from the PCIF and the NHIG to implement the data collection, which would involve the submission of the data items and the business case to both these groups;
- the actual implementation of the data collection; and
- ensuring that a mechanism is set up for reporting back to service providers.

Data development and implementation program

The development and implementation of a national agency collection specifically, whether a patient-level data collection were developed in parallel or not, would require the following major steps:

1. development of data specifications and draft definitions for the relevant object classes and concepts underpinning the data collection;
2. consultation with stakeholders, including palliative care service providers, state/territory and Australian Government policy staff, data management/health information experts, other relevant data working groups and palliative care researchers. The consultation phase would include submitting the draft definitions to the Health Data Standards Committee (HDSC) for its input;
3. incorporating the outcomes of the consultation into the draft data specifications and reaching agreement by the states and territories on the draft definitions to allow pilot testing;
4. establishing a database of agencies that are within scope in each state and territory;
5. designing an Excel spreadsheet for easy data collection, transmission and collation/analysis of data;
6. developing a 'Guidelines document' for service providers, based on the data specifications but providing detailed, plain English advice on the definitions and other reporting specifications for those reporting the data;
7. pilot testing the agency data items, including testing of data collection using the Excel spreadsheet, the Guidelines document, transmission and collation/analysis;
8. incorporating outcomes from the pilot test into the data specifications;

9. developing a business case for the implementation of a national agency data collection;
10. submitting the final agency draft definitions and the business case for implementation of the collection to the PCIF for endorsement;
11. further consultation with other relevant data working groups potentially affected by proposed changes to existing data standards arising from the palliative care DSS development;
12. submitting the final agency draft definitions to the HDSC, with the view to obtaining that committee's recommendation for endorsement;
13. submitting the business case to the Statistical Information Management Committee (SIMC), with the view to obtaining that committee's recommendation for endorsement;
14. submitting the final agency draft definitions and the business case for implementation of the collection to the NHIG for endorsement;
15. implementation of the agency data collection. This would include giving notice to service providers of the first data collection date, sending the pre-designed spreadsheets and the Guidelines document to the participating service providers, establishing a helpline, collating and analysing the data (either at the state/territory level and/or at the national level), following up the non-respondents, preparing and producing a data analysis report, and ensuring that a mechanism is set up for reporting back to service providers.

As with the DSS development program, while the program outlined above includes a specific consultation phase, consultation should be an ongoing activity throughout the development period and during each step.

Timeline

It is envisaged that the development of a national agency data collection alone (i.e. without developing patient-level items at the same time) would take between 6 and 8 months (steps 1 to 8) and the endorsement phase approximately 3 months (depending on the relevant committee's meeting schedule and the extent of consultation required with other data working groups). The implementation phase, including the preparation of the data analysis report, is likely to take 4 to 6 months. The total timeframe is therefore expected to be somewhere between 13 and 17 months. Figure 8 at the end of this section provides a graphic representation of the major steps involved in the development and implementation of a palliative care agency data collection, presented against the suggested time line.

Should a decision be made to develop a palliative care DSS (including patient-level and agency data items) and also implement an agency data collection, as recommended by the project team, the total timeframe would be in the vicinity of 20 to 22 months. Figure 9 provides a graphic representation of the timeline and the major steps involved in the recommended approach, i.e. the development of a DSS together with the implementation of an agency data collection.

7.1.3 A national mandated community-based palliative care data collection

This option, a national mandated palliative care data collection, was considered in detail by the project team, because an assessment of its feasibility was an important part of the project.

The outcome of this assessment is that a national mandated palliative care data collection is deemed feasible by the project team, provided it has certain characteristics, and provided implementation (at least at the patient level) across all states and territories is not attempted in the short term, say within one or two years.

A detailed description of a data collection considered viable by the project team is provided in Chapter 6, and some of the important characteristics are also outlined below.

The project team recommends that this type of data collection be set up in the medium term (say in the order of two to four years), and implemented in stages, i.e. some states and territories earlier than others. This timeframe allows for the collection of an agreed set of data by 2008, which marks the end of the current Australian Health Care Agreements.

Two important reasons why it is desirable to hold off in the short term on implementation of a mandated data collection are:

1. Some states and territories require more lead time, due to the need to further develop information systems. As well as resources and time, those systems need input in terms of agreement on data items for collection, and on definitions and code sets for these data items. This crucial input could be obtained through implementing a DSS (see Section 7.1.1).
2. Before implementing a national data collection, many states and territories will need time to set up a database of all agencies considered within scope. This will involve the need to reach final and detailed agreement on scope across the states and territories.

Recommended features of a national data collection

Some of the main recommended features of a future national data collection for palliative care are outlined below. Further detail is provided in Chapter 6 of this report.

- It is recommended that a national mandated palliative care data collection:
 - be a requirement of those service providers that provide community-based palliative care and who receive palliative care-specific funding;
 - include consultative visits to residents of residential aged care facilities by community-based palliative care service providers;
 - have a patient-level and an agency component;
 - be a 'by-product' of state/territory data collections;
 - include the core data set items outlined in Chapter 6, including basic socio-demographic information and activity and service episode data items, subject to pilot testing;
 - include data items that can support a number of performance indicators;
 - specify the rules governing the transmission of data to a national collection repository.

- In relation to this type of national data collection, it is recommended that investigation is undertaken into the amount of interest within the palliative care sector in developing a data collection and reporting computer system for use by those regions, states or territories where no system is yet in place. Such a system would facilitate the collection of data from service providers and the transmission of those data to a national collection repository. This type of system should also be set up to provide standard and ad hoc reports about the information it contains for use by all stakeholders. Due to the constant change in the systems being used within the sector, this investigation should be carried out closer to the implementation of the data collection.

Implications of developing a national mandated data collection

Many of the major steps involved in the development, endorsement and implementation of a palliative care data collection are the same as those outlined in the work program for a DSS (Section 7.1.1). The extra steps involved here are:

- developing a data collection instrument for the agency part of the collection. It is recommended that this be a specially designed Excel spreadsheet, rather than a questionnaire, to reduce the burden on service providers and to facilitate the task of collating and analysing the data;
- developing a 'Guidelines document' for service providers, based on the data specifications but providing detailed, plain English advice on the definitions (agency and patient-level) and other reporting specifications for those reporting the data;
- establishing a database of agencies that are within scope; such a database is necessary for the implementation of both the agency and the patient-level component of the data collection;
- developing a business case for the implementation of the national data collection, and submitting it to the Statistical Information Management Committee (SIMC), with the view to obtaining that committee's recommendation for endorsement;
- securing endorsement from the PCIF and the NHIG to implement the data collection, which would involve the submission of the data items and a business case to both these committees;
- the actual implementation of the data collection;
- ensuring that a mechanism is set up for reporting back to service providers.

Data development and implementation program

The development and implementation of a national collection, at both the patient level and agency level, would require the following major steps:

1. development of draft data specifications and draft definitions for the relevant object classes and concepts underpinning the data collection;
2. consultation with stakeholders, including palliative care service providers, state/territory and Australian Government policy staff, data management/health information experts and palliative care researchers. The

- consultation phase would include submitting the draft definitions to the Health Data Standards Committee (HDSC) for its input;
3. incorporating the outcomes of the consultation into the draft data specifications and reaching agreement by the states and territories on the draft definitions to allow pilot testing;
 4. establishing a database of agencies that are within scope in each state and territory;
 5. designing an Excel spreadsheet for easy data collection of the agency data, transmission and collation/analysis of data;
 6. developing a 'Guidelines document' for service providers, based on the data dictionary but providing detailed, plain English advice on the definitions and other reporting specifications for those reporting the data;
 7. pilot testing the data items, including testing of data collection, the Guidelines document, transmission and collation/analysis;
 8. incorporating outcomes from the pilot test into the data specifications;
 9. developing a business case for the implementation of the agency data collection;
 10. submitting the final draft definitions and the business case for implementation of the collection to the PCIF for endorsement;
 11. submitting the final draft definitions to the HDSC, with the view to obtaining that committee's recommendation for endorsement;
 12. submitting the business case for the implementation of a national agency data collection to the Statistical Information Management Committee (SIMC), with the view to obtaining that committee's recommendation for endorsement;
 13. submitting the final draft definitions for the full collection and the business case for implementation of the agency collection to the National Health Information Group (NHIG) for endorsement;
 14. implementation of the agency data collection. As outlined earlier, the project team suggests that agency data could be collected earlier than patient-level data. Implementation of the agency collection would include giving notice to service providers of the first data collection date, sending the pre-designed spreadsheets and the Guidelines document to the participating service providers, establishing a helpline, collating and analysing the data (either at the state/territory level and/or at the national level), following up the non-respondents, preparing and producing a data analysis report, and ensuring that a mechanism is set up for reporting back to service providers;
 15. developing a business case for the implementation of the patient-level data collection;
 16. submitting the business case for implementation of the patient-level collection to the PCIF for endorsement;
 17. submitting the business case for the implementation of a patient-level national data collection to SIMC and to NHIG for endorsement;
 18. implementation of the patient-level collection. It is envisaged that patient-level data would be a 'by-product' of state/territory data collections, and would be implemented in stages, i.e. some states and territories earlier than others. The specifics of the actual implementation of a patient-level data collection will need to be agreed closer to the time. However, one crucial aspect of the

implementation would be the development, in conjunction with the states and territories, of a communication and training strategy. Also of high importance is the need to ensure that a mechanism is set up for reporting back to service providers;

As with the data development programs for the first two approaches, consultation should be carried out during each step as well as during the specific consultation phase(s).

Timeline

It is envisaged that the development of a national data collection, including the development of both patient-level and agency items, would take the estimated 12 months for developing a DSS, plus approximately 3 months for the endorsement phase (depending on the relevant committee's meeting schedule).

There would then be two implementation phases:

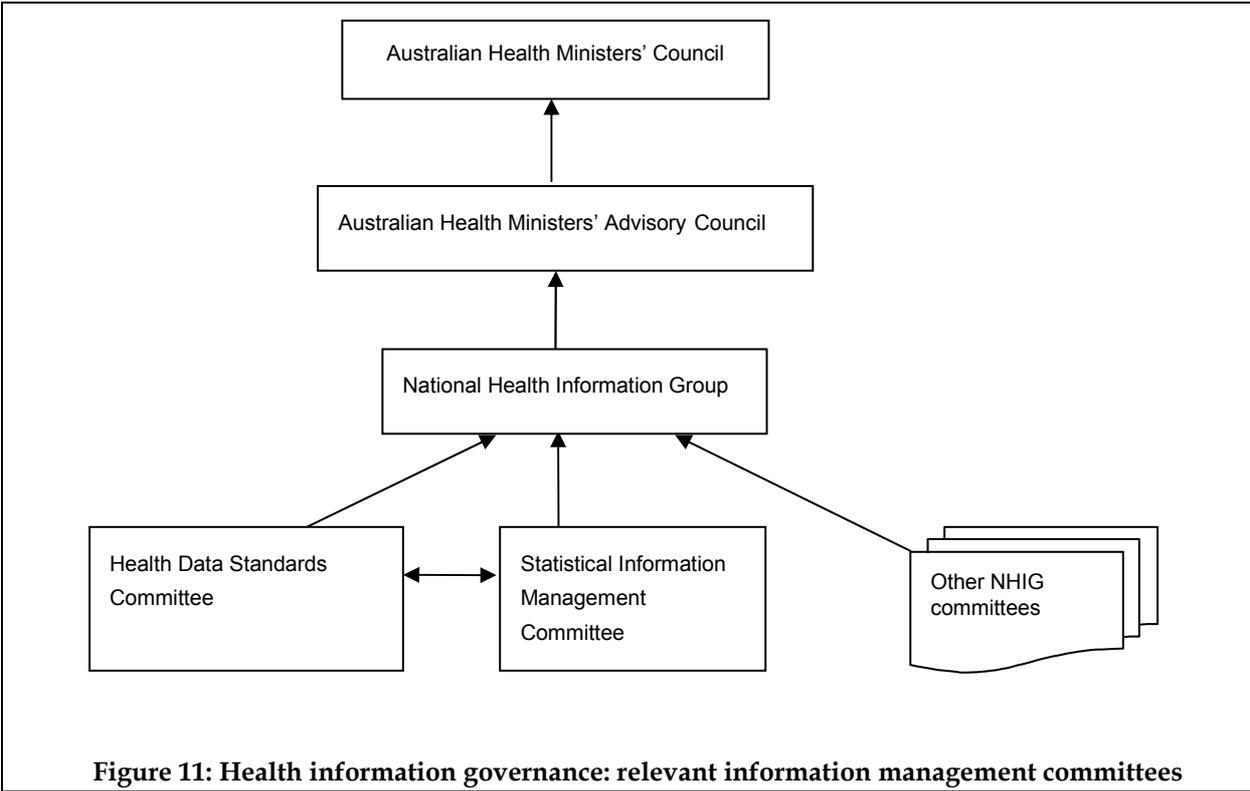
1. the implementation and analysis/reporting of the agency collection, estimated at 4 to 6 months; this timeframe would allow for the first collection of data by the end of 2006 (see also Figures 8 and 9 in Section 7.1.2);
2. the implementation phase for the patient-level collection. The recommendation is that this is implemented in stages, with the states and territories participating as they are ready, perhaps over a period of 2 years from the time of endorsement of the DSS. This timeframe would allow for the first collection of patient-level data by the end of the current Australian Health Care Agreements, i.e. 2008. However, this process would need to be negotiated on a state-by-state basis due to the current developments in client information systems. Figure 10 provides a simple graphic representation of the implementation of a palliative care patient-level data collection, presented against the suggested time-line.

<i>Total time: approx. 2 years</i>	
<i>3 months</i>	<i>21 months</i>
Develop a business case and submit to the PCIF, SIMC and NHIG for endorsement	Implementation of the patient-level national community-based data collection in stages Suggested period is for 2006–2008, with full implementation by the end of 2008
<p>Figure 10: Flow chart – business case development and implementation phase of a patient-level community-based national data collection</p>	

7.1.4 National information governance arrangements

Health information governance arrangements

Any palliative care data development and implementation needs to go through the AHMAC agreed information management and information technology arrangements. This section describes some of the relevant committees and their respective roles. The following diagram outlines their relationship to each other.



National committees

The National Health Information Group (NHIG), the Statistical Information Management Committee (SIMC) and the Health Data Standards Committee (HDSC) are all national committees under the auspice of the Australian Health Ministers' Advisory Council (AHMAC) which reports to the Australian Health Ministers' Council (AHMC). These committees have a mission of promoting national consistency in health information. Membership includes representation from the health authorities of all states and territories and the Australian Government as well as from organisations such as the AIHW and ABS, and other agencies which have a role or interest in health information standards or collections.

National Health Information Group (NHIG)

The role of the NHIG is to advise the AHMAC on national priorities and planning and management requirements in health information management and technology (IM&T) and to manage and allocate resources to health IM&T projects and working groups. Some aspects of the NHIG functions and responsibilities are currently under review in the light of proposals to establish a new entity, which would have

responsibility for managing some aspects of national priorities in health IM&T. The Chair of SIMC is a member of the NHIG and the chair of the HDSC is an observer.

Statistical Information Management Committee (SIMC)

The SIMC is a standing committee of the NHIG. It advises the NHIG on national health statistics, develops and coordinates implementation of national minimum data sets, develops the National Health Information Development Plan and oversees the direction, development, review and implementation of the National Health Information Agreement and agreed work program.

Health Data Standards Committee (HDSC)

The HDSC is also a standing committee of the NHIG. The HDSC is responsible for maintaining the development and revision of the *National Health Data Dictionary* and for reviewing and making recommendations for NHIG endorsement of national minimum data sets, data set specifications and new data standards in the health field.

Community services information governance arrangements

The two groups responsible for information management in the area of community services are described below.

National Community Services Information Management Group (NCSIMG)

The NCSIMG is responsible for the overall management of the National Community Services Information Agreement (NCSIA) and the Work Program. The NCSIA is a multilateral agreement between government community services and statistical agencies and provides the framework for a cooperative approach to national community service information development. The Agreement, by facilitating more reliable, timely and consistent national information, will contribute to the efficient provision of more appropriate and improved services and outcomes for the Australian community.

For the purposes of the Agreement, the scope of community service is: aged care (including residential and community care); disability services; child care (including preschools); family support services; child welfare (including juvenile justice); supported accommodation assistance; and emergency relief and crisis services.

National Community Services Data Committee

The National Community Services Data Committee (NCSDC) is a standing committee of the NCSIMG. The NCSDC is responsible for developing and maintaining the *National Community Services Data Dictionary* and promoting national data consistency in the community services field.

7.2 Other options considered

Other data sources

A number of other sources of data relevant to palliative care provision are outlined in Chapter 3, Section 3.3. These include aged and community care program data (e.g. HACC), the Cancer (Clinical) Data Set Specification, data collected by the

Department of Veterans' Affairs and Health Insurance Commission data, including Medical Benefits Schedule (MBS) and Pharmaceutical Benefits Schedule data.

Some of these sources may in future be able to contribute to the broader picture of palliative care provision in Australia. It is recommended that any future work in the area of palliative care information development keep abreast of these and other relevant sources, and further explore their potential.

Two other options for palliative care data collection

Two other options for future data collection that were considered by the project team, but that are not recommended, are outlined below.

A state/territory-based analysis and data quality report

The project team considered this option as a first step towards the production of palliative care data as well as an intermediate step towards developing nationally consistent and comparable data. It would involve the production of a report on community-based data from each state/territory, which could be done within a fairly short time-frame.

Such a report could have the following features:

- chapter by chapter analysis of data by state and territory. Data from the states and territories would not be added together to form a national picture, as this can only be done once some differences are resolved;
- the data would be reported in aggregate form by all states and territories, i.e. in aggregated tables rather than unit record data;
- as many common or similar data items as possible could be reported;
- some states and territories would be in a position to provide data currently already available;
- some states and territories may be interested in expanding on currently available data, or running a pilot test in one or more areas of their state/territory;
- data could relate to a three or six month period; which would not need to fall within the same dates for all states and territories;
- the report would be used to further explore data issues and limitations, as well as commonalities between the data.

The process of producing the data could in itself be a step towards more consistent data collection across the states and territories.

However, the project team does not recommend this option as a first choice. It is suggested that the development of a DSS, i.e. taking steps towards agreement of nationally consistent data definitions, in the short term would be more constructive and lead on to nationally comparable information more quickly.

A snapshot collection

During consultation carried out as part of this project, it was suggested by some that a national data collection should take the form of a 'snapshot' collection rather than an ongoing data collection. The suggestion was that each agency could be required to collect (detailed) data on the activities of its staff during a reference period, e.g. one week, including direct care provided to patients, but also indirect care activities.

Presented below is a list of some of the advantages and disadvantages of a snapshot collection.

Advantages of a snapshot collection

- Is overall less labour intensive than an ongoing data collection, particularly a collection that includes activity data (i.e. information about each service contact).
- May enable agencies to collect more detailed information, e.g the amount of time staff are involved in particular activities.

Disadvantages of a snapshot collection

- Information collected is not likely to be truly representative; the types of patients seen or care provided may differ from week to week or month to month; this is particularly true for smaller rural services, where the workload may wax and wane, or where travel patterns may be changeable.
- Data collected has no other use for the agency, i.e. does not support service provision.
- If the collection and reporting of information is not built in to the routine of staff, it is likely to be seen as an extra burden during the reference period, particularly if it is a mandated national collection. This could adversely affect the response rate and/or the quality of the data.

The project team does not recommend this option as a first choice, as it believes that the disadvantages outweigh the advantages, at least for a mandated national data collection. It is suggested that a snapshot collection may be useful for individual agencies to undertake, particularly if it includes information on staff time spent on certain activities. Such information could give the agency a detailed insight into the time spent by staff on particular tasks. This information could inform any policy changes made by the agency.

Appendix

Appendix A: Palliative Care Intergovernmental Forum—Information Development Principles

AIM:

Collection of meaningful data at both a national and jurisdiction level to inform policy and planning for palliative care in Australia.

PRINCIPLES:

- Palliative care is delivered across settings of care and involves a multidisciplinary approach, and carer and volunteer involvement.
- Good quality data across these settings of care are required to inform decisions about policy and planning for palliative care in Australia.
- It is important to have access to data at the jurisdictional and national level for analysis for policy and planning purposes at each of those levels.
- While elements of palliative care require specialist care providers, palliative care is also provided by other generalist health providers and in other specialist settings (renal, oncology, paediatric, cardiac, etc.). As with chronic disease management, this presents inherent difficulties in data collection.
- It is important, both to reduce burden on providers and to reduce cost to the health system, that any developments in the data collection for palliative care are cognisant of existing collections.

Appendix B: PalCID Working Group members

Membership of the Palliative Care Information Development (PalCID) Working Group during the Palliative Care Information Development project (phase 1)

Kim White, NSW Health

Maureen Frances, NSW Health

Jenny Trewartha, Calvary Health Care Bethlehem, Victoria

Sue Cornes, Queensland Health

Clory Carrello, WA Department of Health

Meryl Horsell, SA Department of Health

Julie Gardner, SA Department of Health

Maribeth Harris, Tasmanian Department of Health and Human Services

Paul Adams, ACT Health

Sonia Hogan, ACT Health

Meribeth Fletcher, NT Department of Health and Community Services

Meredith Neilson, NT Department of Health and Community Services

Rita Evans, Australian Government Department of Health and Ageing

Mick O'Hara, Consultant to the Palliative Care Section, Department of Health and Ageing

Mieke Van Doeland, AIHW

Robyn Kingham Edwards, AIHW

Kay Grzadka, AIHW

Appendix C: Data collection systems

Australian Capital Territory

Organisational structure

ACT Health is responsible for providing the people of the Australian Capital Territory with the best health care possible through the implementation of the ACT Health Action Plan 2002, and aims to be recognised for delivering the best health care and health-related services in Australia.

ACT Health incorporates The Canberra Hospital, Calvary Public Hospital, Community Health, Mental Health, Population Health and the Department of Health.

Information systems

Community-based palliative care for the ACT is based at the ACT Hospice, Clare Holland House, which is operated by but not located with the Calvary Hospital.

Data are collected on paper forms and statistical data are stored in Microsoft Excel spreadsheets or a Microsoft Access database.

New South Wales

Organisational structure

New South Wales Health is responsible for providing health care for the people of New South Wales.

It is made up of:

- NSW Department of Health
- Area Health Services
- Children's Hospital at Westmead
- Corrections Health Service
- Ambulance Service of New South Wales.

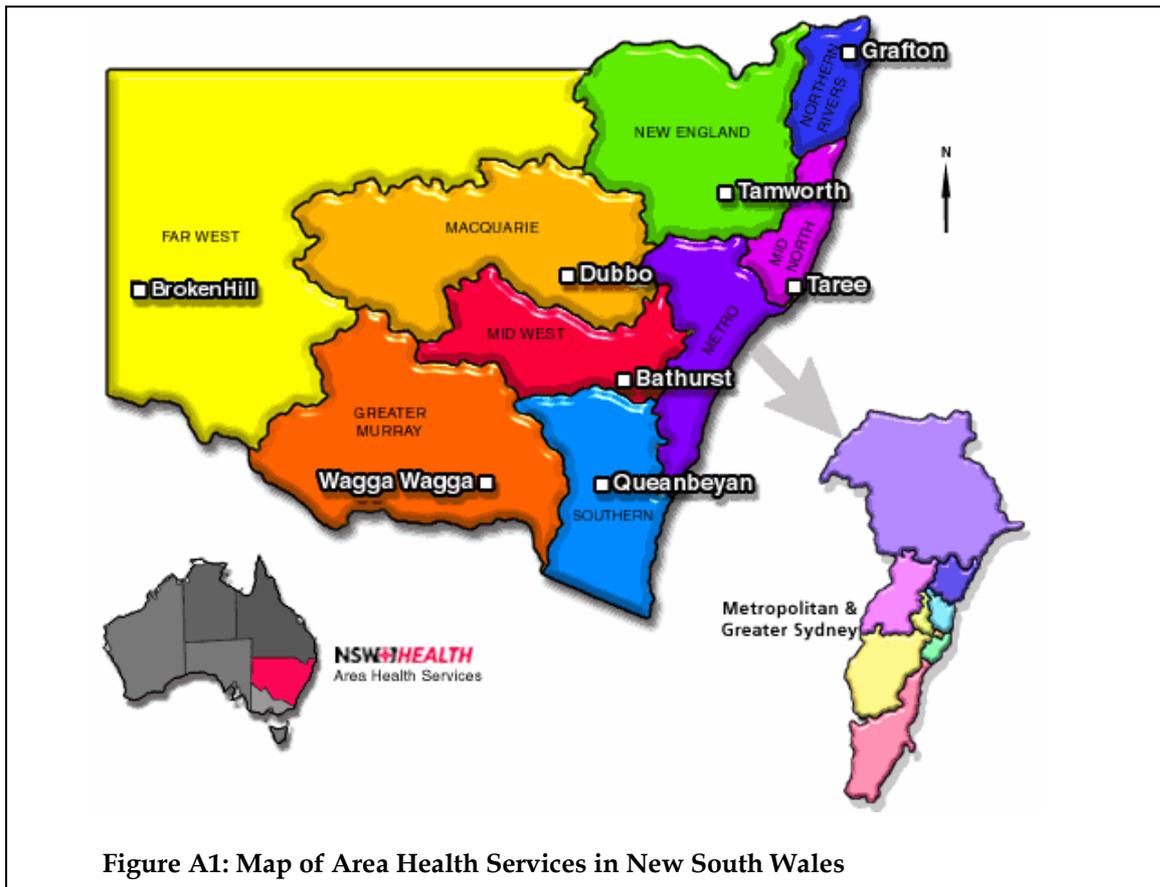
New South Wales has nine metropolitan and eight rural Area Health Services (AHS) not including the Children's Hospital at Westmead:

Metropolitan

- Central Coast AHS
- Hunter AHS
- Illawarra AHS
- Northern Sydney AHS
- South Eastern Sydney AHS
- South Western Sydney AHS
- Wentworth AHS
- Western Sydney AHS
- Central Sydney AHS

Rural

- Far West AHS
- Greater Murray AHS
- Macquarie AHS
- Mid North Coast AHS
- Mid Western AHS
- New England AHS
- Northern Rivers AHS
- Southern AHS



Information systems

New South Wales public hospitals currently use one of four different patient administration systems:

- HOSPAS (a legacy patient administration system approaching the end of its useful life)
- WinPAS (a PC-based adaptation of HOSPAS)
- CERNER PAS
- IPMS.

For community-based health services, the state government is in the process of a state-wide implementation of CHIME, which includes the AN-SNAP classification.

Table A1 lists the information systems currently used by Palliative Care Services within the New South Wales Area Health Services for the collection of patient data.

Table A1: Information systems used by NSW Palliative Care Services

AREA HEALTH SERVICE (AHS)	COLLECTION INSTRUMENT
Metropolitan	
Central Coast AHS	Roll-out of CERNER Millennium PAS (CHIME has commenced. (CHIME will be implemented if it can integrate with the existing system.)
Central Sydney AHS	CRS-based database. CRS/CERNER used to provide CHIME-type information.
Hunter AHS	CHIME is being introduced for community-based services. PalData (MS Access/SQL system) used for inpatient and outreach palliative care services.
Illawarra AHS	CHIME is being introduced for community-based services.
Northern Sydney AHS	Several systems ranging from paper-based through Excel to HOSPAS and SNAP.
South Eastern Sydney AHS	Southern Sector uses SNAPShot and HOSPAS for inpatients. HOSPAS will be replaced by CERNER PAS. A paper-based system is used for community clients with statistics recorded using MS Excel. Northern Sector uses PCS.
South Western Sydney AHS	CHIME is being introduced for community-based services.
Wentworth AHS	Range from paper-based through Excel to CHIME, which has been partially rolled out.
Western Sydney AHS	SNAP for inpatients, Palliative Care Information System (PCIS) for community-based palliative care clients.
Rural	
Far West AHS	WinPAS in inpatient. Paper based for community clients.
Greater Murray AHS	PalCIS SNAPShot Excel Bereavement program
Macquarie AHS	Paper based AN-SNAP Pat-Reg (MS Access database) FISCH CHIME in 3-5 years

Table A1 (continued): Information systems used by NSW Palliative Care Services

AREA HEALTH SERVICE (AHS)	COLLECTION INSTRUMENT
Mid North Coast AHS	Community Health Application (CHAPP).
Mid Western AHS	CHIME is in the implementation phase. In the meantime SNAPShot is being used.
New England AHS	CHIME within 12 months for community based Services. CHIS for community HOSPAS and SNAP for hospitals
Northern Rivers AHS	Cerner Millenium PAS and SNAP for inpatients. Paper based system for community clients. CHIME is being introduced for community-based services.
Southern AHS	SNAPShot for community-based services with CHIME pilot in one divisional area. SNAPShot for designated inpatient SNAP units. WinPAS for remaining inpatient facilities.

CERNER HNA Millennium Patient Administration System

South Western Sydney Area Health Service (SWSAHS) is the lead agency for the implementation of the Cerner HNA Millennium suite of software products within the NSW health system.

In a 21-month period SWSAHS implemented the replacement system across five major hospital campuses (1,700 beds and 4,000 users) and is currently implementing the system into a number of community-based health centres to support the processing of client administrative data for community-based services associated with SWSAHS.

The system captures both inpatient and non-inpatient services and the overall information architecture supports the introduction of a unique patient identifier across organisational and legislative boundaries.

It implements the foundation components for the introduction of a State and national electronic health record system.

CHIME

The Community Health Information Management Enterprise (CHIME) software allows remote entry of community service information.

CHIME records service episode data, demographic data, procedures and interventions.

The original code set used in CHIME is being redeveloped to comply with Classification and Terminology for Community Health.

In CHIME clients can be identified according to what palliative care phase they are in. A subset of ICD-10-AM codes is used for palliative care patients.

Palliative Care Information System (PalCIS)

PalCIS is a patient registration and clinical information system designed by Unique Database Solutions for use exclusively with palliative care.

The PalCIS database records demographic details, diagnoses and other data.

PalCIS may be used by multidisciplinary services operating from multiple sites.

The data exportation, importation and merging tools allow data for single or multiple patients to be shared between sites and services using securely encrypted files.

The PalCIS database is portable via the use of an integrated palm pilot allowing recording of information at the point of care.

PalCIS is used at Griffith, within the Greater Murray Area Health Service of New South Wales.

Palliative Care Systems (PCS)

The Palliative Care Systems (PCS) was developed by South Eastern Sydney Area Health Service, having gained approval via the Chronic and Complex Care Programs of the NSW Department of Health. PCS is a Microsoft SQL Server based database with a web browser interface. The database is therefore accessible from any PC on the NSW Department of Health HealthNet that has proxy access to South East Health. (This includes South Western Area Health Service, Greater Murray Area Health Service, Western Sydney Area Health Service, Children's Hospital at Westmead and Mid Western Area Health Service.)

The database uses a unique patient identifier and has fields that can incorporate the New South Wales state unique patient identifier project. It records demographic details, ICD-10 diagnoses, SNAP data, referral data, progress letters and allied health data (physiotherapy, occupational therapy, social work, volunteers and bereavement).

Even though the current database has a reporting facility, the database can also be accessed by Microsoft Access using an ODBC connection which is then able to produce Health Information Exchange applicable reports, SNAP applicable reports and any other ad hoc reports required by palliative care services.

PCS uses up-to-date data fields and definitions including ICD-10, *National Health Data Dictionary* version 10, Australian Community Base Health Services code set version 1.7H and the NSW SNAP Data Dictionary version 2.01.

SNAPShot

The Centre for Health Service Development (CHSD), University of Wollongong, developed the SNAPware software for use in the 1996 National Sub-Acute and Non-Acute Casemix Classification Study. The SNAPware software has been subsequently developed into a system called SNAPShot, which is currently being used by palliative care services within six Area Health Services in New South Wales.

Northern Territory

Organisational structure

The Department of Health and Community Services is responsible for the health and wellbeing of people throughout the Northern Territory. The Building Healthier Communities Framework provides direction and a commitment to ensure all Territorians have long and healthy lives, and to ensure that health and community services are responsive, accountable and effective. The Department provides a comprehensive range of health and community services to Territorians.

Territory Palliative Care is nested within the Acute Care section of the Department. Territory Palliative Care consists of two specialist consultative teams, one based in Darwin for the Top End of the Northern Territory and one in Alice Springs for Central Australia. Palliative care service delivery involves a number of key stakeholders from within the Department of Health and Community Services and non-government organisations.

Information systems

CCIS is the Northern Territory Community Care Information System, which was implemented in 1998–1999 in all community-based centres throughout the NT. It is a case managed system. The palliative care teams register information on CCIS including client details (including Indigenous status, Preferred language, Relationships and Phone contacts), Referrals, Cases and Service events, Diagnosis, registration of Equipment and Care phase to name a few. CCIS is a multidiscipline program across the different community services and can be customised to address different program requirements for data entry and reporting.

CareSys is the hospital information system used in all Territory hospitals. CareSys is an episode-based system which records attendance to hospital services including casualty, outpatients clinics, theatre and the general wards with access to pathology and X-ray results. Each client's demographic information is registered on a client master index, which is shared with the CCIS.

CCIS and CareSys are Jade Co-ordinated Care products.

Queensland

Organisational structure

The Queensland Department of Health aims to provide and be recognised for providing Queenslanders with the best health and health-related services in the nation.

There are three zones and 38 Health Districts in Queensland as follows:

Northern

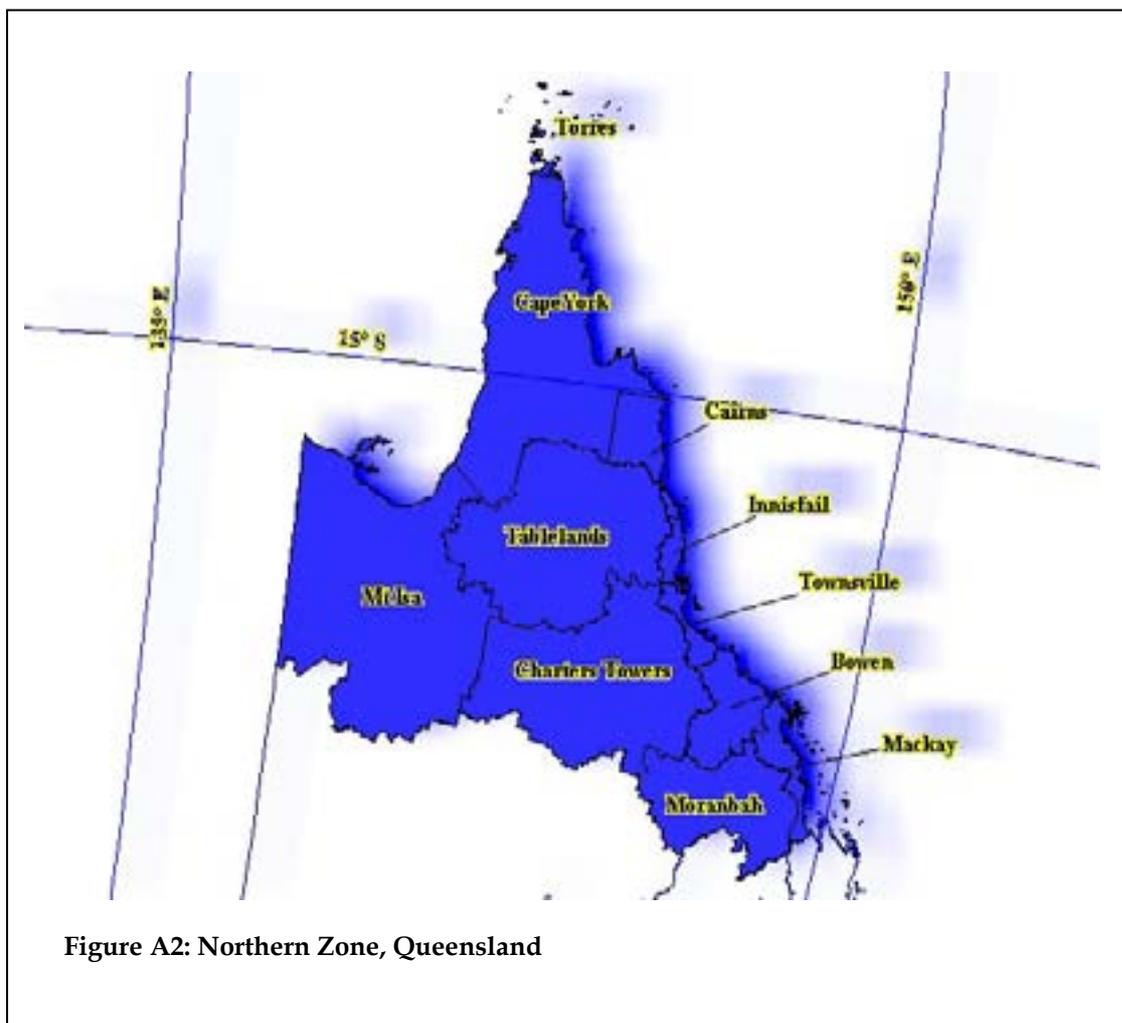
- Bowen
- Cairns
- Cape York
- Charters Towers
- Innisfail
- Mackay
- Moranbah
- Mt Isa
- Tablelands
- Torres Strait and Northern Peninsula
- Townsville

Central

- Banana
- Bundaberg
- Central Highlands
- Central West
- Fraser Coast
- Gladstone
- Gympie
- North Burnett
- Redcliffe-Caboolture
- Rockhampton
- Royal Brisbane and Women's Hospital
- Royal Children's Hospital
- South Burnett
- Sunshine Coast
- Prince Charles Hospital

Southern

- Bayside
- Charleville
- Gold Coast
- Logan–Beaudesert
- Mater
- Northern Downs
- Princess Alexandra Hospital
- Queen Elizabeth II Jubilee Hospital
- Roma
- Southern Downs
- Toowoomba
- West Moreton



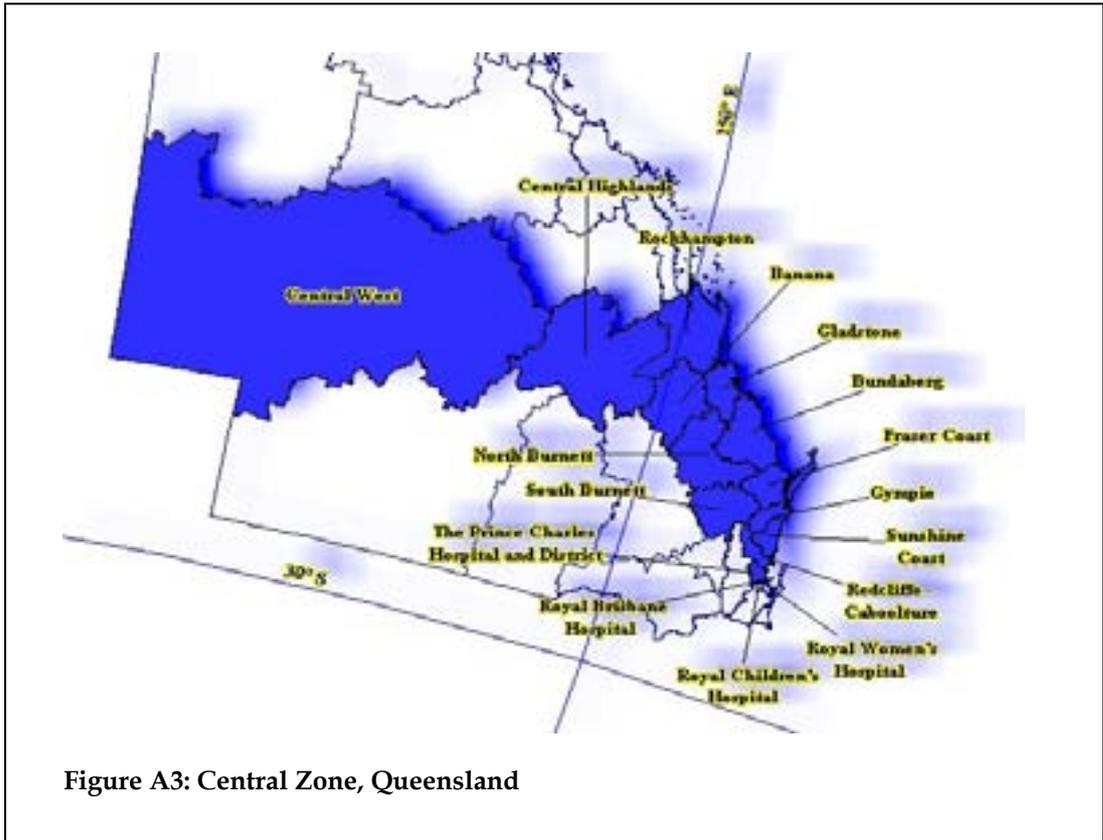




Figure A4: Southern Zone, Queensland

Information systems

At the time of writing it remains unclear what Information Systems are being used by most services involved in the provision of palliative care in Queensland.

Some services have indicated that they record their data in either Microsoft Access databases Microsoft Excel spreadsheets. Some information systems reported by Queensland service providers to the project team are IBA, Palliative Care Database and Cecil Program.

Queensland Health has one corporate system for admitted patients, HBCIS, which is used in all public hospitals.

CHIME is currently being trialled in one District and is only intended for Queensland Health community-based services.

South Australia

Organisational structure

The Department of Health is responsible for the policy administration and operation of public health, hospitals, family and community services, disability services, ageing and housing in South Australia.

There are five specialist adult palliative care services within metropolitan Adelaide and 12 regional sites that provide Department of Health funded palliative care related data to the Department of Health. Paediatric palliative care is coordinated through the Women's and Children's Hospital.

Metropolitan

- Central Adelaide Palliative Service (based at the Royal Adelaide Hospital)
- North Eastern Palliative Care Service based at Modbury Public Hospital
- Lyell McEwin Palliative Care Service (based at Lyell McEwin Health Service)
- Southern Adelaide Palliative Service (based at Repatriation General Hospital)
- Western Palliative Care Service (based at The Queen Elizabeth Hospital)

Regional

- Barossa
- Clare/Lower North
- Gawler
- Murray Mallee
- Northern Yorke Peninsula
- Port Augusta
- Port Lincoln
- Port Pirie
- Riverland
- South East
- Southern Flerieu
- Whyalla

Information systems

Client Management Engine (CME) software is used widely throughout South Australia, primarily in the non-acute/community-based sector but is also used by Allied Health in three of the metropolitan teaching hospitals.

Only two of the 27 palliative care sites in South Australia do not use CME.

Client Management Engine (CME)

CME is a Visual FoxPro application which is currently being migrated to a SQL backend. It is supported on terminal servers, client server as well as stand-alone machines.

Reports are mainly created external to the application using third-party products such as Crystal Reports and Microsoft Access.

The CME system manages service provision, care planning, regular appointments scheduling and equipment loan. It is used to capture, in part, Domiciliary Care, Country Mental Health, Palliative Care, Bereavement Care, Aged Care, HACC, Community Health Services and Informal Client activity, each with differing data attributes.

An important flexible feature of CME is that there can be different episodes of care which capture different data.

The palliative care episode specifically captures data for Department of Health funded palliative care activity. It is possible that sites provide palliative care related activity but if it is unfunded it may be recorded under a different episode of care type (i.e. domiciliary care, general community service), thus different information is collected. The activity may or may not even be clearly identifiable as palliative care related.

Tasmania

Organisational structure

The Department of Health and Human Services brings together a wide range of services for the people of Tasmania – providing health care services in hospitals and the community, offering a range of support services, promoting better health, maintaining services for elderly people and those with disabilities, and providing housing programs.

There are three Health Regions within Tasmania:

- South;
- North; and
- North West.

Information systems

Three specialist community teams based in Hobart, Launceston and Burnie provide palliative care data to the Department.

Currently data collection is through four types of systems:

- Paradox;
- Acute care Homer system;
- Microsoft Access database; and
- Electronic word documents.

CCHP

A new purpose-built community-based system called Community Client Health Profile (CCHP) is being developed for community nurses and allied health persons who work out of community health centres.

It is intended for roll-out to all regions, including district hospitals and multi-purpose centres, later this year.

The new system has the capacity to interface with the acute care systems and the unique patient identifier system.

A palliative care version of CCHP, including an interface to CCHP, is being developed in 2004–2005 for use by palliative care clinicians.

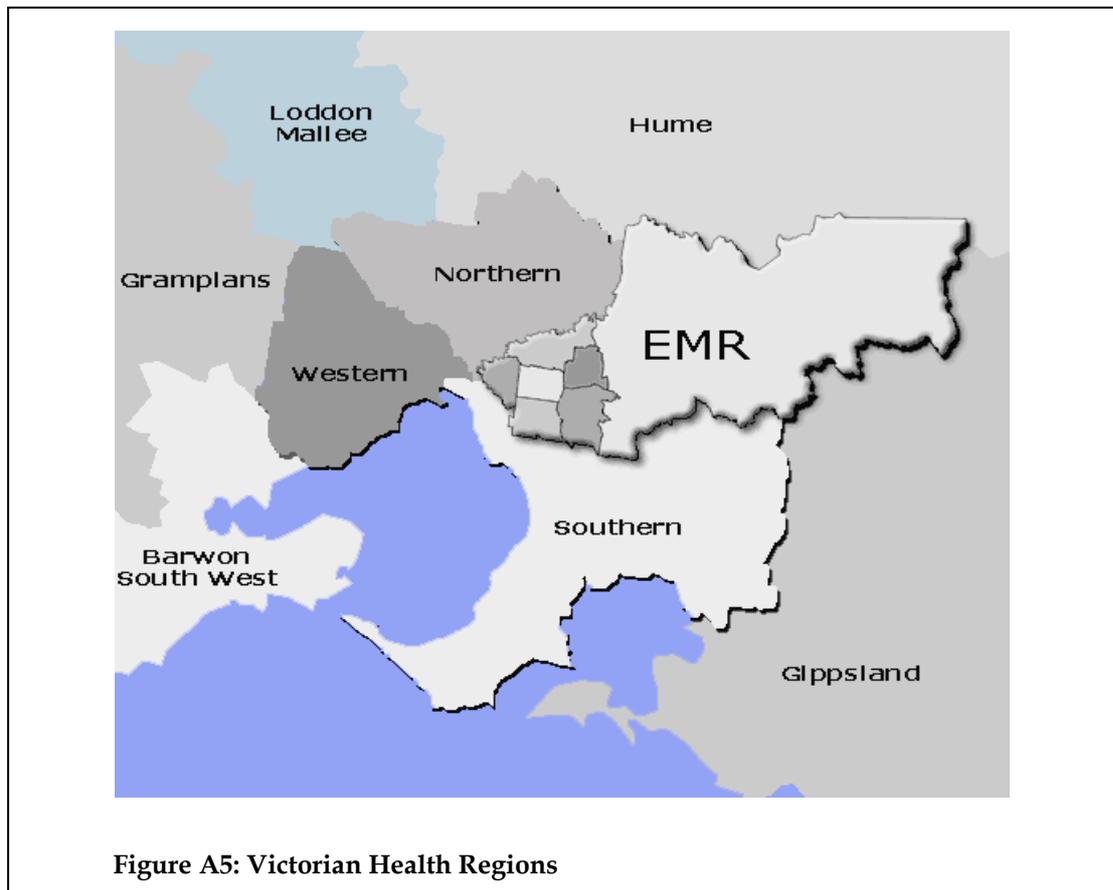
Victoria

Organisational structure

The Department of Human Services is responsible for enhancing and protecting the health and wellbeing of all Victorians.

There are eight divisions within the department and nine rural and metropolitan regions. The regions are as follows:

- Barwon-South Western Region;
- Eastern Metropolitan Region (EMR);
- Gippsland Region;
- Grampians Region;
- Hume Region;
- Loddon Mallee Region;
- Northern Region;
- Southern Region; and
- Western Region.



Information systems

Instruments used to collect information about the provision of palliative care services vary both within and across regions in Victoria.

Close to fifty percent of palliative care services in Victoria use the BDNH software.

The following table lists the information systems used within each Victorian Health Region.

Table A2: Information systems used in Victorian Health Regions

HEALTH REGION	COLLECTION INSTRUMENT
Barwon-South Western	BDNH PJB
Eastern Metropolitan	Own system developed on site
Gippsland	Mostly unknown but BDNH and PJB probably used in some services
Grampians	All BDNH
Hume	All BDNH except for one unknown
Loddon Mallee	BDNH PJB
Northern	Jade IBA Eclipse
Southern	BDNH One service has its own software developed on site
Western	IBA Eclipse but may be changing or have changed to BDNH

BDNH

BDNH is a Microsoft Access program that was originally developed for district nurses in Ballarat.

The software has since been modified to allow entry of occasions of palliative care service.

The database holds data such as patient demographics and occasions of service and meets the VicPCRS Minimum Data Set as well as HACC reporting requirements.

The software can produce a large number of reports about the data.

PJB

PJB Data Manager is a client server product developed by PJB Software Australia Pty Ltd that may be networked or used in a stand-alone environment. It comes with the Microsoft Data Engine (MSDE), a database fully compatible with MS SQL Server.

PJB complies with reporting requirements for the Victorian and national HACC Minimum Data Sets and supports the DVA Minimum Data Set for Community Nursing Services.

PJB's Client Assessment Form is based on the standard DVA Clinical Pathways Generic Assessment.

JADE

Jade Co-ordinated Care is a web-enabled client information system developed by the Jadecare Software Corporation.

Jade collects client or patient information and tracks service events and multiple service providers over time.

Jade allows staff in varying locations to share information about clients while on the road and automates the production of statutory national reporting.

IBA Eclipse

The IBA Eclipse software was developed by IBA Health Australia but the company now markets different products to fill that niche.

Western Australia

Organisational structure

The Department of Health manages a comprehensive range of health and health-related services to all Western Australians.

There are four metropolitan health services and seven rural health regions within the state.

The services/regions are as follows:

Metropolitan (M)

- East Metropolitan Health Service;
- North Metropolitan Area Health Service;
- South Metropolitan Health Service; and
- Women's and Children's Health Service.

Country (C)

- Goldfields and South East Health Region;
- Great Southern Health Region;
- Kimberley Health Region;
- Midwest and Murchison Health Region;
- Pilbara and Gascoyne Health Region;
- South West Health Service; and
- Wheatbelt Health Region.

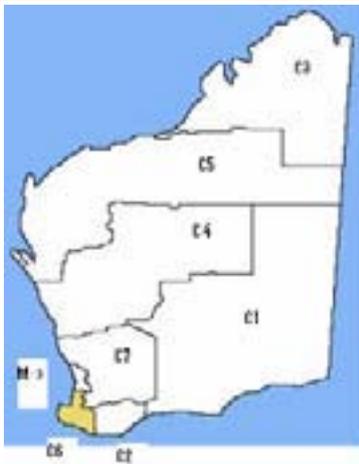


Figure A6: Western Australian Health Services/Regions

Information systems

The Department of Health negotiated a statewide license for the Palliative Care Information System (PalCIS) to facilitate clinical management and generate summary activity reports.

Rural sites using the Western Australian Rural Palliative Care Database are to be upgraded to PalCIS. The PalCIS software will also be piloted at selected metropolitan sites.

ComCare

A major provider of community-based palliative care services within Western Australia is Silver Chain's Hospice Care Service, which comprises interdisciplinary teams that use a software package called ComCare.

ComCare is a Client Management application developed using Microsoft standards.

ComCare is currently being redeveloped to take advantage of mobile phones and networks to allow entry and retrieval of up-to-date information from any location (see Section 2.2.1).

Palliative Care Information System (PalCIS)

PalCIS is a patient registration and clinical information system designed by Unique Database Solutions for use exclusively with palliative care.

The forerunner to PalCIS is the Western Australia Rural Palliative Care Database (WARP CD), which is currently in use at eight sites in Western Australia. That situation is changing though with the Western Australian government rolling out PalCIS across regional areas and training users under an Australian Government-funded project (this may take some time).

The PalCIS database records demographic details, diagnoses and other data.

PalCIS may be used by multidisciplinary services operating from multiple sites.

The data exportation, importation and merging tools allow data for single or multiple patients to be shared between sites and services using securely encrypted files.

The PalCIS database is portable via the use of an integrated palm pilot allowing recording of information at the point of care.

Appendix D: Mapping exercise

Additional recommended data items

The table below lists additional data items that are recommended for inclusion in the data set specification mapped to data items in existing state and territory data collections. The data items are not routinely reported to the states and territories as can be seen by the limited number that has been mapped. It was indicated during consultations that these items could be beneficial to a national palliative care data set.

Table A3: Additional recommended data items

Draft items desirable/not common	SA Dept of Health DRAFT PALLIATIVE CARE MINIMUM DATASET	Vic DD (PALLPAT) & Vic DD (PALLCONT)	NT	DOHRS (NSW) * = required for reporting	NSW SNAP data collection—palliative care case type not reported—used in CHIME
Contact recipient type		Contact recipient type			
Informal carer (concept)					
Informal carer availability		Carer availability			
Relationship of carer to care recipient			Relationship of carer to care recipient		
Carer co-residency					

Data items not common across the four states and territories included in the mapping.

The items listed below are included in data reported for state and territory data collections but were not common to all states and territories or to any national health data standards.

SA Department of Health DRAFT PALLIATIVE CARE MINIMUM DATASET

Northern Territory (CCIS)

(Data elements that can be recorded in CCIS for palliative care)

Contact method	Referral in outcome
Epidemiological district	Referral In reason
Referral destination	Service sub-type
Palliative care phase start date	Referral out reason
Palliative care phase end date	Alert type and description
Palliative care phase	Bereavement activity
Case outcome	Progress notes
Palliative care issues	Phone contact details
Palliative care issues severity	Primary reason for phone call
Palliative care issues frequency	Phone start date time
Palliative care issues status	Phone end date time
Case review type	Phone contact outcome
Case review date	Phone contact relationship
Equipment prescription	Case providers and their role
Equipment items including—type, Model, P number	Involved persons
Equipment approver	Involved providers
Equipment approval date and outcome	Diary entry—date, time, type
Equipment order details including supplier, order type, order/IR no., order date, company, freight and freight no., and expected delivery date.	Able to create word documents associated with events
Equipment funding details including funding source, value, cost code and notes	CCIS has the ability to create care plans, however none set up for palliative care at present
Admitted non-palliative care bedcard consults	Number of clients receiving only bereavement care
Bereavement activity	Number of face-to-face bereavement contacts (paid staff only)
Diagnosis of new registered clients	Number of face-to-face client contacts
Discipline of provider (paid staff only)	Number of new registered clients with cancer diagnosis
Face to face contacts	Number of separations/discharges from the service
Group contacts	Out patient debarment (OPD) (clinic and ad hoc)
Length of contact (direct client time only)	Total number of registered clients for the reporting period
Length of contact (direct contact time only)	Volunteer activity
Length of stay as a registered client	

Vic DD (PALLPAT) and Vic DD (PALLCONT)

Community resources	Service purchased with unassigned bed fund
Date of last contact with related person(s)	Service status of related person(s)
Income source	Transfer destination
Mode of separation with related person(s)	Unassigned bed fund

NSW SNAP data collection—palliative care case type not reported—used in CHIME

Accommodation type	Palliative care phase begin date
Assessment only	Palliative care phase end date
Assessment type	Palliative care phase of care
Case type	Palliative care problem severity score
Leave days	Reason for episode start
Length of stay—ambulatory episodes	Reason for palliative care phase end
Length of stay—palliative care phase	Same day care date
Model of care	Sole practitioner intervention
Palliative care phase	

DOHRS (NSW)

Division/department	Institution type
Facility of Medical Record Number (MRN)	Medical officer code/staff ID

Appendix E: Service provider feedback sheet

Name: _____

Service represented: _____

(If you are happy for us to contact you for clarification, please provide a contact phone number: _____)

I. Early draft set of data items: please indicate whether the data items listed below (or similar items) are being collected by your service at this point in time, or could be collected in the foreseeable future, and whether you believe the item would be a desirable part of a state/territory or national data collection. Comments on individual items are welcome, also from those participants who are not service providers.

Data item	Able to collect (please tick)	Desirable (please tick)	Comments
Patient/client identifier			
Date of Birth			
Sex			
Indigenous Status			
Country of Birth			
Main language spoken at home			
Principal diagnosis			
Postcode (of usual residence)			
State/Territory ID			
Service contact date			
Service delivery setting			

Appendix E (continued): Service provider feedback sheet

Service type			
Discipline of service provider			
Mode of contact			
Date of commencement of service episode			
Source of referral			
Referral date			
Assessment results (eg RUG/ADL or PC phase)			
Mode of separation			
Separation date			
Setting/Site of death			

II. Quality (Section 8)

Please describe below what type of information you believe could indicate the quality of the services provided, through a state/territory or national data collection:

THANK YOU FOR YOUR INPUT—please contact the project team by phone or e-mail if you have any further comment.

Appendix F: National Health Performance Framework

Health Status and Outcomes				
How healthy are Australians? Is it the same for everyone? Where is the most opportunity for improvement?				
Health Conditions	Human Function	Life Expectancy and Wellbeing	Deaths	
Prevalence of disease, disorder, injury or trauma or other health-related states.	Alterations to body, structure or function (impairment), activities (activity limitation) and participation (restrictions in participation).	Broad measures of physical, mental, and social wellbeing of individuals and other derived indicators such as Disability Adjusted Life Expectancy (DALE).	Age and/or condition specific mortality rates.	
Determinants of Health				
Are the factors determining health changing for the better? Is it the same for everyone? Where and for whom are they changing?				
Environmental Factors	Socioeconomic Factors	Community Capacity	Health Behaviours	Person-related Factors
Physical, chemical and biological factors such as air, water, food and soil quality resulting from chemical pollution and waste disposal.	Socioeconomic factors such as education, employment, per capita expenditure on health, and average weekly earnings.	Characteristics of communities and families such as population density, age distribution, health literacy, housing, community support services and transport.	Attitudes, beliefs knowledge and behaviours e.g. patterns of eating, physical activity, excess alcohol consumption and smoking.	Genetic related susceptibility to disease and other factors such as blood pressure, cholesterol levels and body weight.
Health System Performance				
How well is the health system performing in delivering quality health actions to improve the health of all Australians? Is it the same for everyone?				
Effective		Appropriate		Efficient
Care, intervention or action achieves desired outcome.		Care/intervention/action provided is relevant to the client's needs and based on established standards.		Achieving desired results with most cost effective use of resources.
Responsive		Accessible		Safe
Service provides respect for persons and is client orientated and includes respect for dignity, confidentiality, participation in choices, promptness, quality of amenities, access to social support networks, and choice of provider.		Ability of people to obtain health care at the right place and right time irrespective of income, physical location and cultural background.		The avoidance or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered.
Continuous		Capable		Sustainable
Ability to provide uninterrupted, coordinated care or service across programs, practitioners, organisations and levels over time.		An individual's or service's capacity to provide a health service based on skills and knowledge.		System or organisation's capacity to provide infrastructure such as workforce, facilities and equipment, and be innovative and respond to emerging needs (research, monitoring).

Appendix G: Reporting requirements and sample reports provided by some states and territories.

Australian Capital Territory:	
Clare Holland House – Outpatient Occasions of Service – Nov 2003	116
New South Wales:	
Department of Health Reporting System (DOHRS)	118
Northern Territory:	
Community Care Information System (CCIS) reports	120
South Australia:	
Minimum Data Set	124
Tasmania:	
Community, Population & Rural Health Division – Activity Summary Report	130
Victorian	
Palliative Care Reporting System	131
Western Australia:	
Silver Chain example report	138

Australian Capital Territory: Clare Holland House – Outpatient Occasions of Service – Nov 2003

Service Provider	Type of Service												Total Occasions of Service	Total Hours	
	Community Home Visits	Outpatient Clinics		Visits Conducted at Other Service Centres					Phone						
		Hospice/consult Rm	TCH	Calv	JJH	TCH	NCP	NH	Occ of Service >20mins	Phone Checks & Calls					
Director of Palliative Care	New														
	F/up														
Palliative Care Specialists	New														
	F/up														
Home Based Palliative Care Nurses	New														
	F/up														
After hours phone consults from community	New														
Taken at hospice	F/up														
Day Centre	New														
	F/up														
Art Classes	New														
	F/up														
Physiotherapist	New														
	F/up														
Hospice Bereavement Counsellor	New														
	F/up														
Occupational Therapist	New														
	F/up														
Pastoral Care	New														
	F/up														
Community Breaav/Social W/kr	New														

	Type of Service											Total Occasions of Service	Total Hours		
	Service Provider	Community Home Visits	Outpatient Clinics		Visits Conducted at Other Service Centres						Phone				
			Hospice/consult Rm	TCH	Calv	JH	TCH	NCP	NH	Occ of Service >20mins	Phone Checks & Calls				
														F/up	
Total															

New South Wales: Department of Health Reporting System (DOHRS)

Draft Core Data Set

	Column Name	Description	Data type
1	* Establishment identifier	The establishment where the service was provided.	Char(4)
2	* Person identifier	Medical Record Number or local identifier	Char(10)
2a	Facility of MRN	Code of the facility issuing the MRN	Char(4)
3	Sex	Sex of the patient receiving the service.	Char(1)
4	Date of Birth	Date of birth of the patient receiving the service.	Datemmdd yyyy
5	Aboriginal and Torres Strait Islander status	Aboriginal and Torres Strait Islander status of the patient receiving the service.	Char(1)
6	DVA file number	DVA file number found on the DVA card of the patient receiving the service.	
7	DVA card type	DVA card type of the patient receiving the service.	Char(20)
8	Postcode	Postcode of the home address of the patient receiving the service.	Numeric(4)
9	Suburb	Suburb of the home address of the patient receiving the service.	Char(20)
10	Address	The street address of the patient receiving the service.	Char(200)
11	Local clinic name	The name of the clinic where the service was delivered	Char(100)
12	Division/ department	The name of the division or department of the hospital or health service to which the local clinic reports.	Char(20)
13	* Service Type code	A list of 'service types' has been developed for WebDOHRS, based upon the Tier 2 list in NHDD9 with additions from the CHIME codeset. A numeric code set has also been developed for WebDOHRS.	Numeric(3)
14	Medical officer code/ staff ID	Local code for the medical officer or other member of staff delivering the service.	Char(20)
15	* Provider type code	A list of 'provider types' has been developed for WebDOHRS.	Numeric(2)
16	* Payment status code	A list of 'payment status types' has been developed for WebDOHRS. A numeric code set has also been developed for WebDOHRS.	Numeric(2)
17	* Procedure type code	A list of 'procedure types' has been developed for WebDOHRS based upon procedures commonly performed in a non-admitted setting. A numeric code set has also been developed for WebDOHRS.	Numeric(3)

18	* Setting type code	A list of 'setting types' has been developed for WebDOHRS. A numeric code set has also been developed for WebDOHRS.	Numeric(1)
19	* Mode of service delivery type code	A list of 'mode of service delivery types' has been developed for WebDOHRS. A numeric code set has also been developed for WebDOHRS.	Numeric(1)
20	Institution type	To be derived by rules to be supplied to vendors	
21	Source of referral	To be used to identify and delete 'consultation & liaison' services	
22	* Date of service event	Date of service delivery.	Datemmdd yyyy

Variables marked ' * ' are required for WebDOHRS reporting.

Northern Territory: Community Care Information System (CCIS) reports

Operational reports

This type of report is used to assist with client management and the daily operation of the Work Unit. They generally provide details of the client including client name and some other identifiers. They are directly available for users in CCIS from two main sources:

- a) Search screens e.g. individual provider case history search: Reports from the search screens are defined by the search criteria entered. They are common queries and allow the user to view the data and then access the particular client record(s). They can also be printed immediately using the “Print” button.
- b) Reports menu: Reports from the Reports menu are secured to specified users and/or services. They have been defined by the operational areas in conjunction with the CCIS Business Analysts. These reports require parameters to be set to define the range of client information to be included in the report, e.g. work unit name, service type, date range. These reports can be printed immediately or can be scheduled.

Examples of current operational reports

There are many Operational reports available in CCIS. The following are currently available to Palliative Care:

- *Current Cases For A Work Unit With No Service History.*
All open cases that have only a referral recorded and no services.
- *Deceased clients with current cases.*
List of all clients that have current cases and a date of death recorded in CCIS occurring within the report period.
- *Work Unit Case List.*
List of current cases for a work unit in all or selected service types.
- *Current cases by Location.*
Lists the location and case managers for current cases for a Work Unit.
- *Bereavement list for a Work Unit.*
Lists the Bereavement members with or without a case for Palliative care clients who have been recorded as deceased.
- *Palliative Care 1800 Calls.*
Lists the Palliative Care “Phone Contact” events.
- *Equipment item funding sources.*
Used by any work unit that uses the Equipment functionality in CCIS and lists the funding sources for all equipment on issue to individual clients. Particular funding source or equipment type can be specified in the parameters.

- *Referrals received for a work unit: Further action required.*
Lists all the referrals received for a work unit where some action remains outstanding. E.g. waiting for the acceptance of the referral by Palliative Care.
- *Client by current care phase.*
Lists the care phase for current client cases. The report can be ordered by care phase or the care phase start date. This report can be run for an individual case manager.
- *Involved provider current case list.*
Lists all open cases where an individual or work unit provider has been recorded as an involved provider in a case for the specific service type.
- *Issues for a Work unit.*
Lists identified issues for a work unit for a specific service type.
- *Event history results search.*
 - *From Person/Client Search* – lists all the events for the client based on the search criteria and the user security access. This includes all service events from all cases, diary items, casual service events, referrals etc.
 - *From Individual Provider* – lists all events for the provider based on the search criteria and the user security access. This includes all service events from all cases, casual service events, referrals etc., whether the provider has been the item provider or an involved provider.
 - *From Work Unit* – lists all events for the work unit based on the search criteria and the user security access. This includes all service events from all cases, casual service events, referrals etc.
- *Service event summary report.*
Prints all details from the client's service event including client identifying information, event date, venue and status, event items, their results and provider, related issues, name of associated documents and event notes.

Management reports

These reports are either statistical / trend analysis reports or meet national reporting requirements e.g. minimum data sets. In general, a data extract is taken from CCIS (& other DHCS systems) and converted into the required format in the SHILO data warehouse by the Corporate Information Systems (CIS) area.

Examples of current Management Reports

Activity and Throughput

- *Events*
Count Events for a Work Unit by Service Sub Type and Event Type (excluding 'Diary' and 'Person History') per calendar year. Grouped according to month of event start date.
- *Events - Total and Percentage*
Count Events for a Work Unit by Service Sub Type and Event Type (excluding 'Diary' and 'Person History') per calendar year. Type % is the proportion of events for each Event Type within a Subtype. % of Total Events is the proportion of all Events allocated to each Subtype.
- *Anonymous Enquiries*
Count Events (where event type = Anonymous Enquiry) for a Work Unit by calendar year, Contact Method and Service Provided.
- *Referral In*
Count Referrals In for a Work Unit by Referral Source, Referral Reason and Referral Outcome by calendar year.
- *Referral In - Total and Percentage*
Count Referrals In for a Work Unit by Referral Reason and Referral Outcome per calendar year. Outcome % is the proportion of Events for each Outcome within a Referral Reason. % of Total Referrals is the proportion of all Referrals allocated to each Referral Reason.
- *Referral Out*
Count Referrals Out for a Work Unit by Referral Destination, Referral Reason and Referral Outcome by calendar year
- *Closed Cases*
Count Cases (where a case has been closed) for a Work Unit by Service Sub Type. Grouped according to month of case end date
- *New Cases*
Count Cases (where a case has been opened) for a Work Unit by Service Sub Type. Grouped according to month of case start date.
- *Current Cases*
Count Cases (where a case has not been closed) for a Work Unit by Service Sub Type. Includes all Cases which started in any time period but have not yet been closed. Number of cases is current as at the first day of the month.

- *Current Cases (Graph)*
Count Cases (where a case has not been closed) for a Work Unit by Service Sub Type. Includes all Cases which started in any time period but have not yet been closed. Number of cases is current as at the first day of the month.
- *Case Outcomes*
Count Cases (where case has been closed) for a Work Unit by Service Subtype, by Case Outcome and Status of Client at time of case closure by calendar year.

Demographics

- *Case Demographics.*
Count Cases (where a case is current) for a Work Unit by 5 year age groupings, sex and full categories of indigenous status.
- *Case Demographics – Summarised Indigenous Status.*
Count Cases (where a case is current) for a Work Unit by 5 year age groupings, sex and summarised categories of indigenous status.
- *Case Demographics – 5 Years & Under.*
Count Cases (where a case is current) for a Work Unit by indigenous status and 1 year age groupings for 0 - 5 years.
- *Person Demographics (may not have a case, i.e. just casual event).*
Count Persons who had an Event for a Work Unit (excluding 'Diary' and 'Person History') by 5 year age groupings, sex and indigenous status, by calendar year.
- *Clients Utilising the Service (District specific, not work unit).*
Count Persons who had an Event for Alice Springs Urban and Darwin Urban Administrative Districts (CCIS Data) compared with population in equivalent Epidemiological District (ABS population data) by 5 year age groupings, by indigenous status and calendar year.
- *Estimated Resident Population.*
Alice Springs Urban and Darwin Urban Epidemiological Districts Calendar Year.

Access & Equity

- *Relationship between Usual Residence of client and locality of service utilisation outlet.*
Count Event Persons for a Work Unit (excluding 'Diary Entry' and 'Person History') by usual residence of Client and calendar year.

South Australia: Minimum Data Set

Minimum Department of Health Data Requirements

- The Department of Health receives two types of palliative care related records via a standard 6 monthly export from the relevant health service sites.
- The export is obtained via an export facility in CME that creates text (txt) files that are then e-mailed to the Department of Health for incorporating into MS Access databases. From this data, summary bulletins are produced which are sent back to the health service sites and regions for their information and to identify data input completeness/errors.
- One type of record is the palliative care details provided for clients and the other record type is the bereavement care details provided for clients (see attachment 1 for data fields)
- *Only palliative care related details for activity/services provided by Department of Health funded palliative care positions/staff are recorded.*
- Information other than listed on attachment 1 may be recorded for palliative care related activity (see attachment 3) but completeness of recording is not monitored by the Department of Health. These data *do not* form part of the standard export sent to the Department of Health.

CME System Brief

- CME (Client Management Engine) is a Visual FoxPro compiled application which is currently being migrated to a SQL backend.
- It is in wide usage throughout South Australia primarily in the non-acute/community based sector but is also used by Allied Health in 3 of the metropolitan teaching hospitals.
- CME is supported on terminal server via Network Computers and Personal Computers, client server both fat and thin client (LAN is preferable, WAN is slow unless bandwidth is optimised) as well as on stand-alone machines. Users of Novell networks can experience issues accessing FoxPro applications if they run Windows XP (a known Novell problem).
- The system uses a 'toolbox' feature to allow a high degree of user configurability. Due to this feature, reports are mainly externally created via third party products such as Crystal Reports and Microsoft Access.

ATTACHMENT 1: DEPARTMENT OF HEALTH REQUIRED DATA FIELDS – FUNDED PALLIATIVE CARE RELATED ACTIVITY

Palliative care records (see attachment 2 for code values)

FIELD	A/N/D	LEN	DESC
UnitId	N	4	Health site unit id generally matches the MMSS codes
ClientNo	N	6	Client identifier. Unique within unit id
Sex	N	1	Client sex
BirthDate	D	10	Client date of birth (dd/mm/yyyy)
AgeEst	A	1	Flag indicating if estimate date of birth/age is input
Indigenous	N	1	Client indigenous status
Country	N	4	Client country of birth (from ABS SACC 1998 list)
Language	N	1	Client main/preferred language spoken
Sla	N	4	Client statistical area of residence (from ABS codes)
Refdate	D	10	Client referral date for episode of care (dd/mm/yyyy)
Refsource	N	5	Source referring client
Diagnos	A/N	4	Diagnosis group of disease (ICD10 derived groups)
SepDate	D	10	Date client separated from service (dd/mm/yyyy)
SepMode	N	1	Reason for client separation
SiteDied	N	1	Location of client death
EpisodeNo	N	6	Episode number identifying unique episode activity
ContactNo	N	6	Contact number identifying unique contact activity
ContDate	D	10	Date of client contact (dd/mm/yyyy)
Time	N	2	Length of client contact in minutes (10, 15, 30, etc)
Mode	N	1	Mode of contact with client
Procedure	N	7	Service provided to/for client (HACC derived list)
DisciplineCode	N	2	Discipline of worker providing service to/for client

Bereavement care records

FIELD	A/N/D	LEN	DESC
UnitId	N	4	Health site unit id generally matches the MMSS codes
ClientNo	N	6	Client identifier. Unique within unit id
Sla	N	4	Client statistical area of residence (from ABS codes)
Refdate	D	10	Client referral date for episode of care (dd/mm/yyyy)
SepDate	D	10	Date client separated from service (dd/mm/yyyy)
SepMode	N	1	Reason for client separation
EpisodeNo	N	6	Episode number identifying unique episode activity
ContactNo	N	6	Contact number identifying unique contact activity
ContDate	D	10	Date of client contact (dd/mm/yyyy)
Time	N	2	Length of client contact in minutes (10, 15, 30, etc)
Mode	N	1	Mode of contact with client
Procedure	N	7	Service provided to/for client (HACC derived list)
DisciplineCode	N	2	Discipline of worker providing service to/for client

ATTACHMENT 2: CODE LISTS — DEPARTMENT OF HEALTH REQUIRED DATA FIELDS

FIELD NAME	CODE	VALUE
SEX	1	Male
	2	Female
	9	Unknown/Not Stated
INDIGENOUS	1	Aboriginal not Torres Strait Islander
	2	Torres Strait Islander not Aboriginal
	3	Aboriginal and Torres Strait Islander
	4	Non-indigenous
	5	Unknown/Not Stated
COUNTRY	1101	Australia
	1102	Norfolk Island
	1103	Australian External Territories, not elsewhere class
	Plus more	
LANGUAGE	01	Danish
	02	English
	03	Gaelic (Scotland)
	Plus more	
SLA	0070	Adelaide C
	2604	Holdfast Bay C - South
	5683	Playford C - Elizabeth
	Plus more	
REFSOURCE	01	Self
	02	Family, significant other, friend
	03	GP/Medical practitioner – community based
	Plus more	
DIAGNOS	01	Lung cancer
	02	Breast cancer
	03	Colo-rectal cancer
	Plus more	
SEPMODE	01	Discharged or case closure
	02	Discharge/transfer to another hospital
	03	Discharge/transfer to residential care agency
	04	Discharge/transfer to other pall care agency
	05	Statistical discharge type change
	06	Died
SITEDIED	09	Other
	01	Home
	02	Hospital Public (pall care bed)
	03	Hospital Public (other bed)
	04	Hospital private

FIELD NAME	CODE	VALUE
	05	Residential care agency – High
	06	Residential care agency – Low
	07	Mary Potter Hospice
	08	Phillip Kennedy Centre
	09	Other
MODE	1	Face-to-face
	2	Telephone
	3	Written
	9	Unknown/not applicable
PROCEDURE	01.0000	Assessment
	02.0000	Review
	05.1000	Bereavement Counselling (centre based)
	Plus more	
DISCIPLINECODE	14	Medical Officer
	25	Respite Worker
	4	Community Health Nurse
	Plus more	

ATTACHMENT 3: OTHER DATA FIELDS – PALLIATIVE CARE RELATED ACTIVITY

The following data items are collected for palliative care related activity but do not form part of the standard data extract sent to the Department of Health. The completeness of non-mandatory items would be questionable. However, those mandatory items listed below that are not currently included in the data received by the Department of Health could be considered if there is value in the aggregation of that information.

Data Item	Status	Description
CLIENT		
Title	Non-mandatory	Patient/Bereaved Title
Surname	Mandatory	Family name of patient/bereaved
Given Names	Mandatory	Given names patient/bereaved
Age	System Generated	Calculated from Date of Birth
Address	Mandatory	Current residential address
Suburb/Town	Mandatory	Current residential suburb
Postcode	System Generated	Current residential postcode
Postal Address	Non-mandatory	Postal address
Postal Suburb/Town	Non-mandatory	Postal Suburb
Postal Postcode	Non-mandatory	Postal Postcode
Address History	Non-mandatory	Date of change of address
Client Links	Non-mandatory	Patient relationship to link
Other UR/s	Non-mandatory	Hospital UR numbers
Phone Home	Non-mandatory	Current residence phone no.
Phone Work	Non-mandatory	Work number where applicable
Phone Mobile	Non-mandatory	Mobile number where applicable
Needs Interpreter	Non-mandatory	Check box for interpreter service
Comments	Non-mandatory	Additional patient information
Last Contact	System Generated	Date last contact made
REFERRAL ITEMS		
Response	Non-mandatory	Urgency of referral
Referring Person	Non-mandatory	Name of person referring patient
Referral Reason	Non-mandatory	Reason for referral
Patient Location	Non-mandatory	Location at time of referral
Patient Location (ward)	Non-mandatory	Description of patient location
ICD9	Non-mandatory	Disease related to Pall Care
Date of Main Diagnosis	Non-mandatory	Date diagnosis made
Case Manager	Non-mandatory	Designated case manager
Health Fund	Non-mandatory	Current health fund

Ambulance Cover	Non-mandatory	Check box re eligibility
Pension Status	Non-mandatory	Nature of pension received
Medicare Number	Non-mandatory	Medicare number assigned
Religious Affiliation	Non-mandatory	Religious affiliation as stated
Marital Status	Non-mandatory	Marital status at time of referral
Living Arrangement	Non-mandatory	Usual living arrangement
Carer Availability	Non-mandatory	Willingness of carer role
Primary Carer Surname	Non-mandatory	Family name of carer
Primary Carer Names	Non-mandatory	Given names of carer
Primary Carer Relationship	Non-mandatory	Relationship to patient
Primary Carer Address	Non-mandatory	Carer residential address
Primary Carer Postcode	Non-mandatory	Carer residential postcode
Primary Carer Telephone	Non-mandatory	Usual contact number of carer
Other Carer Surname	Non-mandatory	Additional carer family name
Other Carer Given Names	Non-mandatory	Additional carer given names
Other Carer Relationship	Non-mandatory	Relationship to the patient
Other Carer Address	Non-mandatory	Additional carer resident address
Other Carer Postcode	Non-mandatory	Additional carer resident postcode
Other Carer Telephone	Non-mandatory	Usual contact number
Community Resources used	Non-mandatory	Resources currently used
Community Resource Details	Non-mandatory	Details of resources in use
GP / Specialist	Non-mandatory	Full contact details for GP/Spec
SEPARATION DETAILS		
Details of site of death	Non-mandatory	Additional site of death information
BEREAVED DETAILS		
Bereavement follow-up	Non-mandatory	Risk need for bereavement follow-up
Review date	Non-mandatory	Date prompt for client review
CONTACT ITEMS		
Worker ID	Mandatory	ID allocated to team member

Tasmania: Community, Population & Rural Health Division—Activity Summary Report

CODE	ACTIVITY MEASURE	2002-03 Totals Year End Averages	APR-04	MAY-04	Financial Year to Date	Data Projected to end 2003-04	Target at end 2003-04	COMMENTS
PC	Community Activity Data - Statewide							
	Direct Client Contacts After Hours - South							
	Direct Client Contacts After Hours - North							
	Direct Client Contacts After Hours - NW							
	Total: Direct Client Contacts							
	Indirect Service Contacts After Hours - South							
	Indirect Service Contacts After Hours - North							
	Indirect Service Contacts After Hours - NW							
	Total: Indirect Client Contacts							
PC	Whittle (Inpatient - Hobart)							
	Deaths							
	Discharges							
	Total: Separations							
	Average Length of Stay [Days]							
	Occupancy [%]							
PC	Philip Oakden House (Inpatient - Launceston)							
	Deaths							
	Discharges							
	Total: Separations							
	Average Length of Stay [Days]							
	Occupancy [%]							

List of data items from the
User manual
Victorian Palliative Care Reporting System
(VicPCRS)
Minimum Data Set (MDS)
Performance Indicators Data Set (PIDS)
February 2004¹

Published by the Metropolitan Health and Aged Care Services
Division Victorian Government Department of Human Services,
Melbourne, Victoria

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Services web site at:

www.health.vic.gov.au/palliativecare/pcrsmanual

Authorised by the State Government of Victoria, 555 Collins Street,
Melbourne.

(040406)

¹ See References: (Victorian Government Department of Human Services, 2004)

PALLPAT

The purpose of the PALLPAT dataset is to record information about the community-based palliative care patient/client. The information collected in PALLPAT is primarily demographic data.

The table below summarises the data items to be collected, the field names to be used, the format and length of the data and a representational layout.

PALLPAT.TXT

Item No.	Item Description	Field Name	Data type	Representation al form	Max length	Representational layout	Required for	Reported in
PAT 1	Agency identifier	AgencyID	Numeric	Code	5	NNNNN	MDS, PIDS	MDS, PIDS
PAT 2	Patient/client identifier	PatID	Alpha	Code	10	AAAAAAAAAA	MDS, PIDS	MDS
PAT 3	Date of birth	DOB	Numeric	Date	10	DD/MM/YYYY	MDS	MDS
PAT 4	Sex	Sex	Numeric	Code	1	N	MDS	MDS
PAT 5	Country of birth	CBirth	Numeric	Code	4	NNNN	MDS	MDS
PAT 6	Indigenous status	IndStat	Numeric	Code	1	N	MDS	MDS
PAT 7	Preferred language	PrefLang	Numeric	Code	2	NN	MDS	MDS
PAT 8	Postcode of usual residence	PCode	Numeric	Code	4	NNNN	MDS	MDS
PAT 9	Source of referral to palliative care	RefSrc	Numeric	Code	2	NN	MDS	MDS
PAT 10	Referring agency	RefAgID	Numeric	Code	5	NNNNN	MDS	MDS
PAT 11	Date of admission	DateAdm	Numeric	Date	10	DD/MM/YYYY	MDS, PIDS	MDS
PAT 12	Principle palliative care diagnosis	PrinDiag	Numeric	Code	1	N	MDS	MDS
PAT 13	Date of separation	DateSep	Numeric	Date	10	DD/MM/YYYY	MDS, PIDS	MDS
PAT 14	Mode of separation	SepMod	Numeric	Code	2	NN	MDS, PIDS	MDS
PAT 15	Transfer destination	TranDes	Alpha	Code	5	AAAAA	MDS	MDS
PAT 16	Site of death	SiteDeath	Numeric	Code	2	NN	MDS	MDS
PAT 17	Date of last contact with related person(s)	LastDate	Numeric	Date	10	DD/MM/YYYY	MDS	MDS
PAT 18	Mode of separation with related person(s)	RelMod	Numeric	Code	1	N	MDS	MDS
PAT 19	Insurance status	InsStat	Numeric	Code	1	N	MDS	MDS
PAT 20	DVA file number	DVANum	Alpha	Identification No.	9	AAAAAAAAA	MDS	MDS ***

Item No.	Item Description	Field Name	Data type	Representation al form	Max length	Representational layout	Required for	Reported in
PAT 21	Income source	IncSrc	Numeric	Code	1	N	MDS	MDS
PAT 22	Performance status	PerStat	Numeric	Code	2	NN	MDS	MDS ***
PAT 23	Carer availability	CarAv	Numeric	Code	2 ²	NN ³	MDS, PIDS	MDS
PAT 24	Living arrangements	LivArr	Numeric	Code	1	N	MDS	MDS
PAT 25.01	Community resource – none	ComRes01	Numeric	Code	1	N	MDS	MDS ***
PAT 25.02	Community resource – Meals on Wheels	ComRes02	Numeric	Code	1	N	MDS	MDS ***
PAT 25.03	Community resource – home help	ComRes03	Numeric	Code	1	N	MDS	MDS ***
PAT 25.04	Community resource – church group	ComRes04	Numeric	Code	1	N	MDS	MDS ***
PAT 25.05	Community resource – social worker	ComRes05	Numeric	Code	1	N	MDS	MDS ***
PAT 25.06	Community resource – community health centre	ComRes06	Numeric	Code	1	N	MDS	MDS ***
PAT 25.07	Community resource – day centre	ComRes07	Numeric	Code	1	N	MDS	MDS ***
PAT 25.08	Community resource – transport	ComRes08	Numeric	Code	1	N	MDS	MDS ***
PAT 25.09	Community resource – nurse consultant	ComRes09	Numeric	Code	1	N	MDS	MDS ***
PAT 25.10	Community resource – interpreter	ComRes10	Numeric	Code	1	N	MDS	MDS ***
PAT 25.11	Community resource – clergy	ComRes11	Numeric	Code	1	N	MDS	MDS ***
PAT 25.12	Community resource – handyman services	ComRes12	Numeric	Code	1	N	MDS	MDS ***
PAT 25.13	Community resource – district nursing services	ComRes13	Numeric	Code	1	N	MDS	MDS ***
PAT 25.14	Community resource – private services	ComRes14	Numeric	Code	1	N	MDS	MDS ***
PAT 25.15	Community resource – other	ComRes15	Numeric	Code	1	N	MDS	MDS ***

*** Collection of this data item is optional.

² Updated 26 February 2003

³ Updated 26 February 2003

PALLCONT

PALLCONT is to be collected for each contact between a staff member employed by the community palliative care service (including contracted staff) and the primary patient/client and/or related person(s).

PALLCONT.TXT

Item No.	Item Description	Field Name	Data type	Representational form	Max length	Representational layout	Required for	Reported in
CON 1	Agency identifier	AgencyID	Numeric	Code	5	NNNNN	MDS, PIDS	MDS, PIDS
CON 2	Patient/client identifier	PatID	Alpha	Code	10	AAAAAAAAAAA	MDS, PIDS	MDS
CON 3	Unassigned bed fund	UnBedF	Numeric	Code	1	N	MDS	MDS
CON 4	Service purchased with unassigned bed fund	UBedSer	Numeric	Code	1	N	MDS	MDS
CON 5	Date of each contact	ConDate	Numeric	Date	10	DD/MM/YYYY	MDS	MDS
CON 6	Contact recipient type	ConRec	Numeric	Code	1	N	MDS	MDS
CON 7	Contact setting	ConSet	Numeric	Code	2	NN	MDS	MDS
CON 8	Mode of contact	ConMod	Numeric	Code	2	NN	MDS	MDS
CON 9.1	Principal service – clinical consultancy and/or care	PriServ1	Numeric	Code	1	N	MDS	MDS
CON 9.2	Principal service – personal care	PriServ2	Numeric	Code	1	N	MDS	MDS
CON 9.3	Principal service – spiritual and/or emotional support and/or counselling	PriServ3	Numeric	Code	1	N	MDS	MDS
CON 9.4	Principal service – home care and/or support	PriServ4	Numeric	Code	1	N	MDS	MDS
CON 9.5	Principal service – education	PriServ5	Numeric	Code	1	N	MDS	MDS
CON 9.6	Principal service – case management and/or care coordination	PriServ6	Numeric	Code	1	N	MDS	MDS
CON 10	Discipline of service provider	SerDis	Numeric	Code	1	N	MDS	MDS

PALLINPE

The following items are to be collected by the funded community base palliative care agency each time a palliative care patient/client is admitted to any agency as an inpatient whilst the patient is a client of a community-based palliative care agency/ service. These items are to be collected irrespective of whether the client is an inpatient for the purposes of palliative care or for any other purpose. Other than the agency and patient identifiers, this information can be obtained from the inpatient facility's medical records department or from the relevant ward.

The community-based palliative care should endeavour to establish relationships with relevant inpatient facilities to facilitate the timely transfer of this information, however, it is recognised that the transfer of this data is the responsibility of the inpatient facility.

PALLINPE.TXT

Item No.	Item Description	Field Name	Data type	Representational form	Max length	Representational layout	Required for	Reported in
INP 1	Agency identifier	AgencyID	Numeric	Code	5	NNNNN	MDS, PIDS	MDS, PIDS
INP 2	Patient/client identifier	PatID	Alpha	Code	10	AAAAAAAAAAA	MDS, PIDS	MDS
INP 3	Hospital identifier	HOSPCODE	Alpha	Code	4	AAAAA	MDS	MDS
INP 4	Hospital UR number	URNO	Alpha	Code	10	AAAAAAAAAAA	MDS	MDS ###
INP 5	Date of admission to inpatient facility	ADMDATE	Numeric	Date	10	DD/MM/YYYY	MDS	MDS
INP 6	Date of discharge from inpatient facility	SEPDATE	Numeric	Code	10	DD/MM/YYYY	MDS	MDS
INP 7	Care type	CARE	Numeric	Code	1	N	MDS	MDS ###
INP 8	RUG-ADL score on admission	RUGADLAD	Numeric	Code	2	NN	MDS	MDS ***

Collection of this data item is desirable but not mandatory.

*** Collection of this data item is optional.

CALCULATION OF PERFORMANCE INDICATORS

The following items are required to be collected in order to calculate and report the performance indicators described in Section F. The items should be collected, where possible, at the same time as the Minimum Data Set items. However, several items require collection from referral of the patient/client to the service and following the discharge of the patient/client.

DATA ITEMS REQUIRED FOR CALCULATION OF PERFORMANCE INDICATORS

Item No.	Item description	Field name	Data type	Representational form	Max length	Representational layout	Required for	Reported in
CI 1	Agency identifier	AgencyID	Numeric	Code	5	NNNNN	MDS, PIDS	MDS, PIDS
CI 2	Patient/client identifier	PatID	Alpha	Code	10	AAAAAAAAAA	MDS, PIDS	MDS
CI 3.1	Reporting start date	RepPerS	Numeric	Date	10	DD/MM/YYYY	PIDS	PIDS
CI 3.2	Reporting finish date	RepPerF	Numeric	Date	10	DD/MM/YYYY	PIDS	PIDS
CI 4	Date referral received		Numeric	Date	10	DD/MM/YYYY	PIDS	PIDS
CI 5	Date of first contact	DateFCon	Numeric	Date	10	DD/MM/YYYY	PIDS	PIDS
CI 6	Date of completion of palliative care assessment		Numeric	Date	10	DD/MM/YYYY	PIDS	
CI 7	Date of documented discussion of palliative care patient at team meeting		Numeric	Date	10	DD/MM/YYYY	PIDS	
CI 8	Date general practitioner notified of client admission		Numeric	Date	10	DD/MM/YYYY	PIDS	***
CI 9	Patient/family provided with information about 24 hour service		Numeric	Code	1	N	PIDS	
CI 10	Family asked to complete satisfaction survey		Numeric	Code	1	N	PIDS	
CI 11	Date of bereavement risk assessment		Numeric	Date	10	DD/MM/YYYY	PIDS	

*** Collection of this data item is optional.

Performance indicators

The following items are the performance indicators to be reported to the Department. The performance indicators are to be preceded by the agency identifier and the reporting period. Note that only the numerator is required to be reported by the agency/ service. The Department will derive the denominator from the reported data.

Note that the field names described in the following sections must be used and reported exactly in the format and order described in the relevant section. No field may be omitted.

PALLCLIN.TXT

Item No.	Item description	Field name	Data type	Representational form	Max length	Representational layout	Required for	Reported in
CI 1	Agency identifier	AgencyID	Numeric	Code	5	NNNNN	MDS, PIDS	MDS, PIDS
CI 3.1	Reporting start date	RepPerS	Numeric	Date	10	DD/MM/YYYY	PIDS	PIDS
CI 3.2	Reporting finish date	RepPerF	Numeric	Date	10	DD/MM/YYYY	PIDS	PIDS
Perf Ind 1	Appropriateness of referral	AppRef	Numeric	Quantitative value	4	NNNN	PIDS	PIDS ***
Perf Ind 2	Entry to palliative care system	RefResp	Numeric	Quantitative value	4	NNNN	PIDS	PIDS ***
Perf Ind 3	Assessment	AssResp	Numeric	Quantitative value	4	NNNN	PIDS	PIDS
Perf Ind 4	Care planning	DocPlan	Numeric	Quantitative value	4	NNNN	PIDS	PIDS
Perf Ind 5a & 5b	Implementation of care	GPNote	Numeric	Quantitative value	4	NNNN	PIDS	PIDS
Perf Ind 6a	Evaluation	FamSat	Numeric	Quantitative value	4	NNNN	PIDS	***
Perf Ind 6b	Evaluation	BrvRisk	Numeric	Quantitative value	4	NNNN	PIDS	***

*** Performance indicators are not yet required to be reported.

Western Australia: Silver Chain example report



REPORT

Reporting\CR03_04

18 November 2003

REPORT ON In Home Palliative care – Metropolitan Area (Service 1) FOR OCTOBER 2003

Client Movements October 2003

The number of admissions, discharges and deaths are shown in Table 1 below.

Admissions, Discharges and Deaths

	Clinical	Bereaved
Clients Admitted to Service		
Clients Discharged		
Number of Deaths		
Place of Death - Home		
Hospice (Cottage 12, Murdoch 12)		
Private Hospital		
Public Hospital		

Care Provided

The following figures represent home nursing hours, nursing support hours, night service hours, personal care hours and travel hours provided by the Hospice Care Service to clients with a terminal illness requiring palliative care within the metropolitan area during October 2002.

Counselling hours relate to “bereavement” clients, i.e. those clients who require support pre- and/or post-death of a palliative client.

These figures do NOT include activity by Doctors, Volunteers, Grief Counsellors, or Chaplains. The inclusion of this data would increase the volume of care.

Out of Home care is integral to a “Best Practice” community-based palliative care model and contributes to both the effectiveness and efficiency of the service

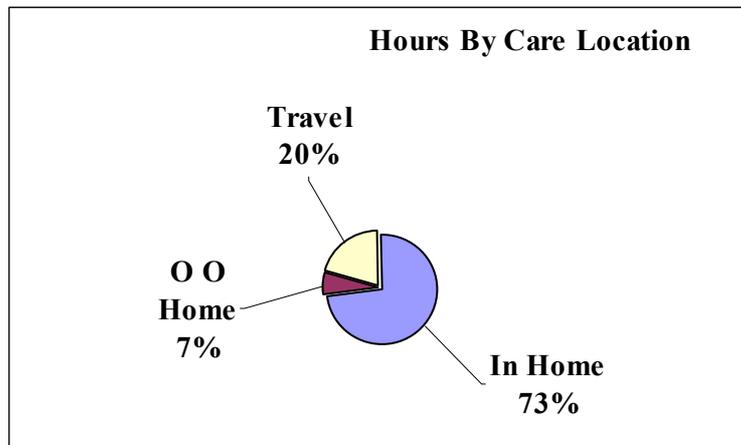
**Summary of Clients, Hours, Occasions of Service and Days of Delivered Care for
October 2003**

Service	Provider Type	Clients	Hours	Occasions	Travel Hours	Location of Care	Days of Delivered Care
In Home Nursing	RN						
RN Night Service	RN						
Personal Care	CA						
PC Night Service	CA						
Counselling : Face to Face	RN						
Counselling : Phone	RN						
Nursing Support: -	RN						
Clinical Meetings**	RN						
RN Client Coordn	RN						
Totals:	RN						
Totals:	CA						
<i>Grand Totals:</i>	<i>All</i>						

** NOT shown on spreadsheet, not postcode related.

Location of care

Figure 1: Proportion of Nursing and Personal Care Hours Spent in Various Care Locations



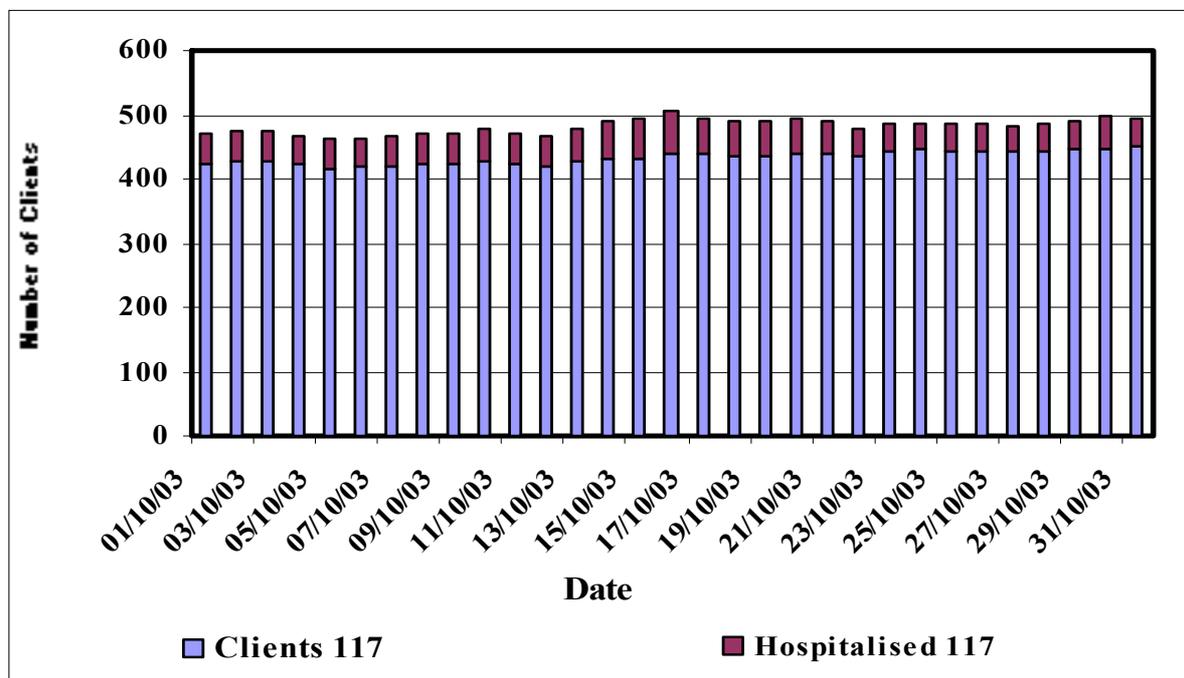
Days of Care – Clinical Clients

Days of Care (i.e. number of clients by number of days each client had an open service delivery record) during October 2003

	Total days	Average days
ALL Clinical Clients		
ALL Clinical Clients In Hospital		
ALL Clinical Clients At Home		

The number of clinical clients in the service each day during October 2003 is as shown in figure 2 below.

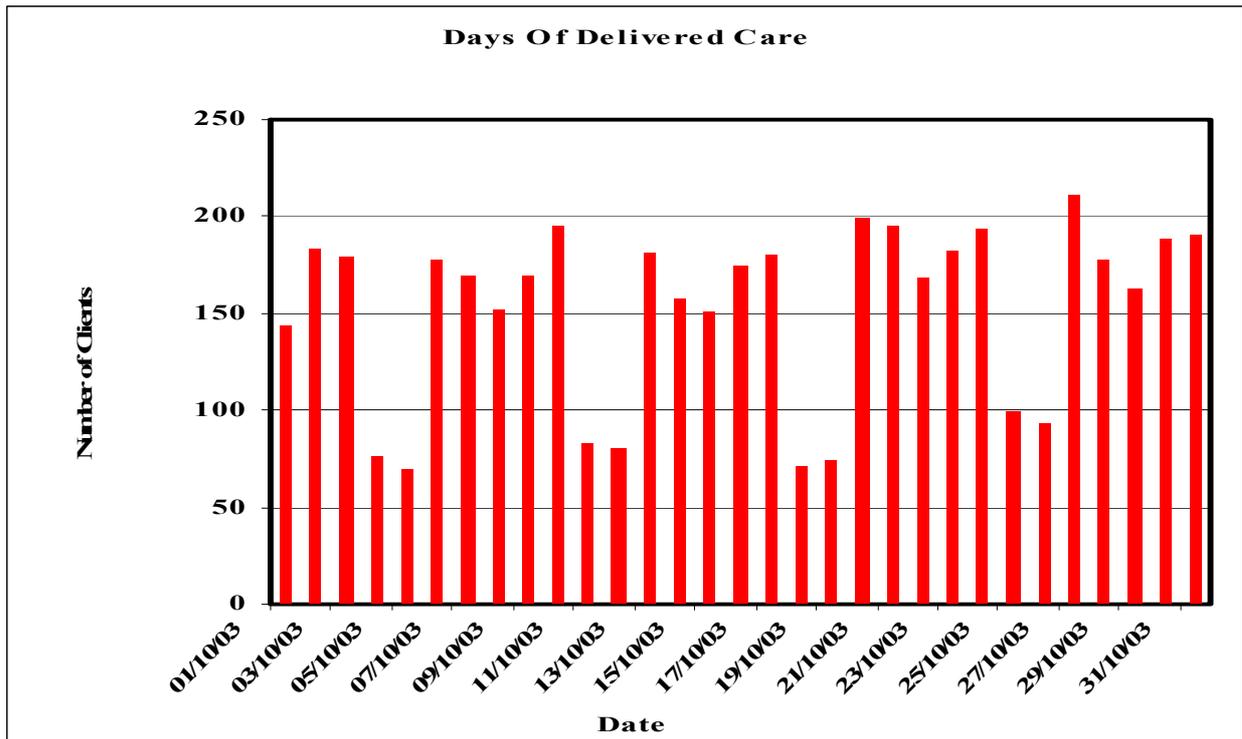
Figure 2: Days of Care: Current CLINICAL Clients Each Day during October 2003



Days of Delivered Care – All Clients Table 4: Days of Delivered Care Provided During October 2003

	Total	Average per day
Days of Delivered Care: CLINICAL		
Days of Delivered Care: BEREAVED		
TOTAL Days of Delivered Care		

Figure 3: Days of Delivered Care (ie number of days on which CLINICAL + BEREAVED clients received face-to face visit by nursing or personal care staff) during October 2003



S. Stowell
 Reporting Officer – Information
 SS.SS CR03_04\Hospice\Service1

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Draft data elements

Below are the data items discussed in the body of the report. Please note that some attributes in the following data items have been left blank because the information is either unavailable or in the case of draft items is yet to be developed.

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Agency identifier

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000541	<i>Version number:</i>	2
<i>Metadata type:</i>	DATA ELEMENT CONCEPT		
<i>Definition:</i>	The unique identifier for the establishment, which provides care or services.		
<i>Context:</i>	This element identifies the agency in which the provision of the service event occurred.		

Representational attributes

<i>Data type:</i>		<i>Field size minimum:</i>	
<i>Representational form:</i>		<i>Field size maximum:</i>	
<i>Representational layout:</i>			
<i>Data domain:</i>			
<i>Guide for use:</i>			
<i>Verification rules:</i>			
<i>Collection methods:</i>			

Relational attributes

<i>Related metadata:</i>	relates to the data element concept Agency, version 1
<i>Information Model link:</i>	Party characteristic/Agency characteristic

Administrative attributes

<i>Registration authority:</i>	NCSIMG	
<i>Administrative status:</i>	CURRENT	<i>Effective date:</i> 01/07/2000
<i>Source organisation:</i>	National Health Data Committee	
<i>Source document:</i>	National Health Data Dictionary	
<i>Comments:</i>	Desirable components of a unique agency identifier include Australian state/territory identifier, Establishment sector, and Agency number. Currently, there is no uniform method throughout community services for the identification of agencies. However, adoption of consistent practices for allocating unique agency identifiers has the potential to enhance data comparability and utility.	

Agency identifier

(continued)

It is important to note that if agencies are to communicate confidentially between one another, a unique agency identity needs to be established. The use of this item will lead to reduced duplication in reporting client activity and will enable linkage of services to one episode of care or service event.

Australian state/territory identifier

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002025	<i>Version number:</i>	4
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	An identifier of the Australian State or Territory.		
<i>Context:</i>	This is a geographic indicator which is used for analysis of the distribution of clients or patients, agencies or establishments and services.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	1	New South Wales	
	2	Victoria	
	3	Queensland	
	4	South Australia	
	5	Western Australia	
	6	Tasmania	
	7	Northern Territory	
	8	Australian Capital Territory	
	9	Other territories (Cocos (Keeling) Islands, Christmas Island and Jervis Bay Territory)	

Guide for use: When used specifically in the collection of address information for a client, the following local implementation rules may be applied: NULL may be used to signify an unknown address State; and Code 0 may be used to signify an overseas address.

The order presented here is the standard for the ABS. Other organisations (including the AIHW) publish data in State order based on population (that is, Western Australia before South Australia and Australian Capital Territory before Northern Territory).

Irrespective of how the information is coded, conversion of the codes to the ABS standard must be possible.

DSS - Health care client identification:

When used specifically in the collection of address information for a client, the following local implementation rules may be applied:

- NULL may be used to signify an unknown address State; and
- Code 0 may be used to signify an overseas address.

Australian state/territory identifier

(continued)

NMDS - Residential mental health care:

This is the State or Territory of the establishment.

Verification rules:

Collection methods:

Relational attributes

Related metadata:

is composed of Establishment identifier, version 4

relates to the NCSDD data element Geographic indicator, version 2

relates to the NHDD data element Address type, version 1

relates to the NHDD data element Australian postcode, version 1

relates to the NHDD data element Postal delivery point identifier, version 2

relates to the NHDD data element Suburb/town/locality name, version 2

supersedes the NCSDD data element State/territory identifier, version 1

supersedes the NHDD data element State/territory identifier, version 3

Information Model link:

Location/Address

Administrative attributes

Registration authority:

NCSIMG & NHIMG

Administrative status:

CURRENT

Effective date: 01/07/2003

Source organisation:

Australian Institute of Health and Welfare,
Australian Bureau of Statistics,
Health Data Standards Committee,
National Community Services Data Committee.

Source document:

Australian Bureau of Statistics 2001. Australian Standard Geographical Classification (ASGC). Cat. no. 1216.0. Canberra: ABS.

Reference through:

<http://www.abs.gov.au/Ausstats/abs@.nsf/StatsLibrary>

Comments:

This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary.

Country of birth

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002004	<i>Version number:</i>	4
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The country in which the person was born.		
<i>Context:</i>	Country of birth is important in the study of access to services by different population sub-groups. Country of birth is the most easily collected and consistently reported of a range of possible data items that may indicate cultural or language diversity. Country of birth may be used in conjunction with other data elements such as Period of residence in Australia, etc., to derive more sophisticated measures of access to (or need for) services by different population sub-groups.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	4
<i>Representational layout:</i>	NNNN	<i>Field size maximum:</i>	4
<i>Data domain:</i>	Standard Australian Classification of Countries 1998 (SACC). Australian Bureau of Statistics Cat. no. 1269.0 Reference through http://www.abs.gov.au/Ausstats/abs@.nsf/StatsLibrary Select ABS classifications		
<i>Guide for use:</i>	The Standard Australian Classification of Countries 1998 (SACC) is a 4-digit, three-level hierarchical structure specifying major group, minor group and country. A country, even if it comprises other discrete political entities such as states, is treated as a single unit for all data domain purposes. Parts of a political entity are not included in different groups. Thus, Hawaii is included in Northern America (as part of the identified country United States of America), despite being geographically close to and having similar social and cultural characteristics as the units classified to Polynesia.		
<i>Verification rules:</i>	NHDD specific: DSS - Health Care client identification: County of birth for newborn babies should be 'Australia'.		
<i>Collection methods:</i>	Note that the Standard Australian Classification of Countries (SACC) is mappable to but not identical to Australian Standard Classification of Countries for Social Statistics (ASCCSS)		

Country of birth

(continued)

Some data collections ask respondents to specify their country of birth. In others, a pre-determined set of countries is specified as part of the question, usually accompanied by an 'other (please specify)' category.

Recommended questions are:

In which country were you/was the person/was (name) born?

Australia

Other (please specify)

Alternatively, a list of countries may be used based on, for example common Census responses.

In which country were you/was the person/was (name) born?

Australia

England

New Zealand

Italy

Viet Nam

Scotland

Greece

Germany

Philippines

India

Netherlands

Other (please specify)

In either case coding of data should conform to the SACC.

Sometimes respondents are simply asked to specify whether they were born in either 'English speaking' or 'non-English speaking' countries but this question is of limited use and this method of collection is not recommended.

Relational attributes

Related metadata:

supersedes the NCSDD data element Country of birth, version 2

Country of birth

(continued)

Information Model link: supersedes the NHDD data element Country of birth, version 3
Party characteristic/Person characteristic/Social-cultural characteristic

Administrative attributes

Registration authority: NCSIMG & NHIMG

Administrative status: CURRENT *Effective date:* 02/09/2003

Source organisation: Australian Bureau of Statistics,
Health Data Standards Committee,
National Community Services Data Committee.

Source document: Australian Bureau of Statistics 1998. Standard Australian Classification of Countries 1998 (SACC). Cat. no. 1269.0. Canberra: ABS.

Reference through:
<<http://www.abs.gov.au/Ausstats/abs@.nsf/StatsLibrary>>

Comments: This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary.
This data element is consistent with that used in the Australian Census of Population and Housing and is recommended for use whenever there is a requirement for comparison with Census data.
The Standard Australian Classification of Countries (SACC) supersedes the Australian Standard Classification of Countries for Social Statistics (ASCCSS).

Date of birth

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002005	<i>Version number:</i>	5
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The date of birth of the person.		
<i>Context:</i>	Required for a range of clinical and administrative purposes. Date of birth enables derivation of age for use in demographic analyses, assists in the unique identification of clients if other identifying information is missing or in question, and may be required for the derivation of other data elements (e.g. Diagnosis related group for admitted patients).		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	DATE	<i>Field size minimum:</i>	8
<i>Representational layout:</i>	DDMMYYYY	<i>Field size maximum:</i>	8
<i>Data domain:</i>	Valid date.		
<i>Guide for use:</i>	<p>If date of birth is not known or cannot be obtained, provision should be made to collect or estimate age. Collected or estimated age would usually be in years for adults and to the nearest three months (or less) for children aged less than two years. Additionally, an estimated date flag should be reported in conjunction with all estimated dates of birth.</p> <p>For data collections concerned with children's services, it is suggested that the estimated Date of birth of children aged under 2 years should be reported to the nearest 3 month period, i.e. 0101, 0104, 0107, 0110 of the estimated year of birth. For example, a child who is thought to be aged 18 months in October of one year would have his/her estimated Date of birth reported as 0104 of the previous year. Again, an estimated date flag should be reported in conjunction with all estimated dates of birth.</p>		

Verification rules:

<i>Collection methods:</i>	<p>Information on Date of birth can be collected using the one question: What is your/(the person's) date of birth?</p> <p>In self-reported data collections, it is recommended that the following response format is used: Date of birth: __ / __ / ____</p> <p>This enables easy conversion to the preferred representational layout (DDMMYYYY).</p>
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Date of birth

(continued)

Estimated dates of birth should be identified by an appropriate estimated date flag to prevent inappropriate use of Date of birth data for record identification and/or the derivation of other data elements that require accurate date of birth information.

NHDD specific:

NMDS - Perinatal:

Data collection systems must be able to differentiate between the date of birth of the mother and the baby(s). This is important in the Perinatal data collection as the date of birth of the baby is used to determine the antenatal length of stay and the postnatal length of stay.

Relational attributes

Related metadata:

is qualified by NHDD Estimated date flag, version 1

is used in the calculation of NHDD Length of stay (antenatal), version 1

is used in the calculation of NHDD Length of stay (postnatal), version 1

is used in the derivation of NHDD Diagnosis related group, version 1
supersedes the NCSDD data element Date of birth, version 1
supersedes the NHDD data element Date of birth, version 4

Information Model link:

Party characteristic/Person characteristic/Demographic characteristic

Administrative attributes

Registration authority:

NCSIMG & NHIMG

Administrative status:

CURRENT

Effective date: 02/09/2003

Source organisation:

National Health Data Committee,
National Community Services Data Committee.

Source document:

NHDC 2003. National Health Data Dictionary, Version 12. Cat. no. HWI 43. Canberra: AIHW

Comments:

This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary. Privacy issues need to be taken account in asking persons their date of birth.

Date of birth

(continued)

Wherever possible and wherever appropriate, Date of birth should be used rather than Age because the actual date of birth allows more precise calculation of age.

When Date of birth is estimated or default value, national health and community services collections typically use 0101 or 0107 or 3006 as the estimate or default for DDMM.

It is suggested that different rules for reporting data may apply when estimating the Date of birth of children aged under 2 years because of the rapid growth and development of children within this age group which means that a child's development can vary considerably over the course of a year.

Thus, more specific reporting of estimated age is suggested.

NHDD specific:

DSS Health care client identification:

Any new information collection systems should allow for 0000YYYY. (Refer to Standards Australia AS5017-2002 Health Care Client Identification).

DSS Cardiovascular disease (clinical)

Age is an important non-modifiable risk factor for cardiovascular conditions.

The prevalence of cardiovascular conditions increases dramatically with age. For example, more than 60% of people aged 75 and over had a cardiovascular condition in 1995 compared with less than 9% of those aged under 35.

Aboriginal and Torres Strait Islander peoples are more likely to have cardiovascular conditions than other Australians across almost all age groups.

For example, in the 25 - 44 age group, 23% of Indigenous Australians reported cardiovascular conditions compared with 16% among other Australians (Heart, Stroke and Vascular Diseases: Australian Facts 2001).

Indigenous status

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002009	<i>Version number:</i>	5
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	Indigenous status is a measure of whether a person identifies as being of Aboriginal or Torres Strait Islander origin. This is in accord with the first two of three components of the Commonwealth definition. See Comments for the Commonwealth definition.		
<i>Context:</i>	Australia's Aboriginal and Torres Strait Islander peoples occupy a unique place in Australian society and culture. In the current climate of reconciliation, accurate and consistent statistics about Aboriginal and Torres Strait Islander peoples are needed in order to plan, promote and deliver essential services, to monitor changes in wellbeing and to account for government expenditure in this area. The purpose of this data element is to provide information about people who identify as being of Aboriginal or Torres Strait Islander origin. Agencies or establishments wishing to determine the eligibility of individuals for particular benefits, services or rights will need to make their own judgments about the suitability of the standard measure for these purposes, having regard to the specific eligibility criteria for the program concerned.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	1	Aboriginal but not Torres Strait Islander origin	
	2	Torres Strait Islander but not Aboriginal origin	
	3	Both Aboriginal and Torres Strait Islander origin	
	4	Neither Aboriginal nor Torres Strait Islander origin	
	9	Not stated/inadequately described	

<i>Guide for use:</i>	<p>This data element is based on the ABS Standard for Indigenous Status. For detailed advice on its use and application please refer to the ABS Website as indicated below under Source document.</p> <p>The classification for 'Indigenous Status' has a hierarchical structure comprising two levels. There are four categories at the detailed level of the classification which are grouped into two categories at the broad level. There is one supplementary category for 'not stated' responses. The classification is as follows:</p>
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Indigenous status

(continued)

Indigenous:

- Aboriginal but not Torres Strait Islander Origin
- Torres Strait Islander but not Aboriginal Origin
- Both Aboriginal and Torres Strait Islander Origin

Non-indigenous:

- Neither Aboriginal nor Torres Strait Islander Origin

Not stated/ inadequately described:

This category is not to be available as a valid answer to the questions but is intended for use:

- primarily when importing data from other data collections that do not contain mappable data;
- where an answer was refused;
- where the question was not able to be asked prior to completion of assistance because the client was unable to communicate or a person who knows the client was not available.

Only in the last two situations may the tick boxes on the questionnaire be left blank.

Verification rules:

Collection methods:

The standard question for Indigenous Status is as follows:

[Are you] [Is the person] [Is (name)] of Aboriginal or Torres Strait Islander origin?

(For persons of both Aboriginal and Torres Strait Islander origin, mark both 'Yes' boxes.)

No.....

Yes, Aboriginal.....

Yes, Torres Strait Islander.....

This question is recommended for self-enumerated or interview-based collections. It can also be used in circumstances where a close relative, friend, or another member of the household is answering on behalf of the subject.

When someone is not present, the person answering for them should be in a position to do so, i.e. this person must know well the person about whom the question is being asked and feel confident to provide accurate information about them. However, it is strongly recommended that this question be asked directly wherever possible.

This question must always be asked regardless of data collectors' perceptions based on appearance or other factors.

Indigenous status

(continued)

The Indigenous status question allows for more than one response. The procedure for coding multiple responses is as follows:

If the respondent marks 'No' and either 'Aboriginal' or 'Torres Strait Islander', then the response should be coded to either Aboriginal or Torres Strait Islander as indicated (i.e. disregard the 'No' response).

If the respondent marks both the 'Aboriginal' and 'Torres Strait Islander' boxes, then their response should be coded to 'Both Aboriginal and Torres Strait Islander Origin'.

If the respondent marks all three boxes ('No', 'Aboriginal' and 'Torres Strait Islander'), then the response should be coded to 'Both Aboriginal and Torres Strait Islander Origin' (i.e. disregard the 'No' response).

This approach may be problematical in some data collections, for example when data are collected by interview or using screen based data capture systems. An additional response category

Yes, both Aboriginal and Torres Strait Islander.

May be included if this better suits the data collection practices of the agency or establishment concerned.

Relational attributes

<i>Related metadata:</i>	supersedes the NCSDD data element Indigenous status, version 2
	supersedes the NHDD data element Indigenous status, version 4
<i>Information Model link:</i>	Party characteristic/Person characteristic/Social-cultural characteristic

Administrative attributes

<i>Registration authority:</i>	NCSIMG & NHIMG	
<i>Administrative status:</i>	CURRENT	<i>Effective date:</i> 02/09/2003
<i>Source organisation:</i>	Australian Bureau of Statistics National Health Data Committee and National Community Services Data Committee	
<i>Source document:</i>	The ABS standards for the collection of Indigenous status appear on the ABS Website. http://www.abs.gov.au/Ausstats/abs@.nsf/StatsLibrary , select: Other ABS Statistical Standards/Standards for Social, Labour and Demographic Variables/Demographic Variables/Cultural Diversity Variables/Indigenous Status.	

Indigenous status

(continued)

Comments:

This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary.

The following definition, commonly known as 'The Commonwealth Definition', was given in a High Court judgement in the case of *Commonwealth v Tasmania* (1983) 46 ALR 625.

'An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives'.

There are three components to the Commonwealth definition:

- descent;
- self-identification; and
- community acceptance.

In practice, it is not feasible to collect information on the community acceptance part of this definition in general purpose statistical and administrative collections and therefore standard questions on Indigenous status relate to descent and self-identification only.

Mode of separation

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000096	<i>Version number:</i>	3
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	Status at separation of person (discharge/transfer/death) and place to which person is released (where applicable).		
<i>Context:</i>	Required for outcome analyses, for analyses of intersectoral patient flows and to assist in the continuity of care and classification of episodes into diagnosis related groups.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	1	Discharge/transfer to an(other) acute hospital	
	2	Discharge/transfer to a nursing home	
	3	Discharge/transfer to an(other) psychiatric hospital	
	4	Discharge/transfer to other health care accommodation (includes mothercraft hospitals and hostels recognised by the Commonwealth Department of Health and Family Services, unless this is the usual place of residence)	
	5	Statistical discharge - type change	
	6	Left against medical advice/discharge at own risk	
	7	Statistical discharge from leave	
	8	Died	
	9	Other (includes discharge to usual residence/own accommodation/welfare institution (includes prisons, hostels and group homes providing Primarily welfare services))	

Guide for use: For Code 4 - In jurisdictions where mothercraft facilities are considered to be acute hospitals, patients separated to a mothercraft facility should have a mode of separation of Code 1.

Verification rules:

Collection methods:

Mode of separation

(continued)

Relational attributes

Related metadata: is supplemented by the data element Source of referral to acute hospital or private psychiatric hospital, version 3
is supplemented by the data element Source of referral to public psychiatric hospital, version 3
is used in the derivation of Diagnosis related group, version 1

Information Model link: Event/Health and welfare service event/Exit / leave from service event

Administrative attributes

Registration authority: NHIMG

Administrative status: CURRENT *Effective date:* 01/07/2000

Source organisation: National Health Data Committee

Source document:

Comments: The terminology of the modes relating to statistical separation have been modified to be consistent with the changes to data element Type of episode of care and other data elements related to admissions and separations.

Main language other than English spoken at home

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002012	<i>Version number:</i>	3
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The language reported by a person as the main language other than English spoken by that person in his/her home (or most recent private residential setting occupied by the person) on a regular basis, to communicate with other residents of the home or setting and regular visitors.		
<i>Context:</i>	<p>This data element is important in identifying those people most likely to suffer disadvantage in terms of their ability to access services due to language and/or cultural difficulties. In conjunction with Indigenous status, Proficiency in spoken English and Country of birth, this data element forms the minimum core set of cultural and language indicators recommended by the Australian Bureau of Statistics (ABS).</p> <p>Data on main language other than English spoken at home are regarded as an indicator of 'active' ethnicity and also as useful for the study of inter-generational language retention. The availability of such data may help providers of health and community services to effectively target the geographic areas or population groups that need those services. It may be used for the investigation and development of language services such as interpreter/translation services.</p>		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	4
<i>Representational layout:</i>	NNNN	<i>Field size maximum:</i>	4
<i>Data domain:</i>	Valid codes from ABS Australian Standard Classification of Languages, 1997 (ABS Cat. no. 1267.0)		
<i>Guide for use:</i>	The Australian Standard Classification of Languages (ASCL) has a three-level hierarchical structure. The most detailed level of the classification consists of base units (languages) which are represented by four-digit codes. The second level of the classification comprises narrow groups of languages (the Narrow Group level), identified by the first two digits. The most general level of the classification consists of broad groups of languages (the Broad Group level) and is identified by the first digit. The classification includes Indigenous Australian languages and sign languages.		

Main language other than English spoken at home

(continued)

For example, the Lithuanian language has a code of 3102. In this case 3 denotes that it is an Eastern European language, while 31 denotes that it is a Baltic language.

The Pintupi Aboriginal language has a code of 8217. In this case 8 denotes that it is an Australian Indigenous language and 82 denotes that the language is Central Aboriginal.

Language data may be output at the Broad Group level, Narrow Group level or base level of the classification. If necessary significant Languages within a Narrow Group can be presented separately while the remaining Languages in the Narrow Group are aggregated. The same principle can be adopted to highlight significant Narrow Groups within a Broad Group.

Note that the code 9900 should be used where language is Not stated/inadequately described. Code 9900 is not for use on primary collection forms. It is primarily for use in administrative collections when transferring data from data sets where the item has not been collected.

Persons not in private residential settings should respond for 'at home' as the most recent private residential setting in which that person has resided.

The reference in the title to 'at home' may cause offence to homeless persons and should be shortened to 'Main language other than English spoken' where applicable.

Verification rules:

Collection methods:

Data collected at the 4 digit level (specific language) will provide more detailed information than that collected at the 2 digit level. It is recommended that data be collected at the 4 digit level however where this is not possible data should be collected at the 2 digit level.

Recommended question:

Do you/Does the person/Does (name) speak a language other than English at home?

(If more than one language, indicate the one that is spoken most often.)

No (English only) ____

Yes, Italian ____

Yes, Greek ____

Yes, Cantonese ____

Main language other than English spoken at home

(continued)

Yes, Mandarin ____

Yes, Arabic ____

Yes, Vietnamese ____

Yes, German ____

Yes, Spanish

Yes, Tagalog (Filipino) ____

Yes, Other (please specify) _____

This list reflects the 9 most common languages spoken in Australia.

Languages may be added or deleted from the above short list to reflect characteristics of the population of interest.

Alternatively a tick box for 'English' and an 'Other - please specify' response category could be used.

Relational attributes

Related metadata:

relates to the NHDD data element Country of birth, version 4

relates to the NHDD data element Proficiency in spoken English, version 2

supersedes the NCSDD data element Main language other than English spoken at home, version 2

supersedes the NHDD data element Main language other than English spoken at home, version 1

Information Model link:

Party characteristic/Person characteristic/Social-cultural characteristic

Administrative attributes

Registration authority:

NCSIMG & NHIMG

Administrative status:

CURRENT

Effective date: 02/09/2003

Source organisation:

Australian Bureau of Statistics

National Health Data Committee and National Community Services Data Committee

Main language other than English spoken at home

(continued)

Source document:

Australian Bureau of Statistics 1997. Australian Standard Classification of Language (ASCL), 1997. Cat. no. 1267.0. Canberra: ABS. Reference through:

[http:// www.abs.gov.au/Ausstats/abs@nsf/StatsLibrary](http://www.abs.gov.au/Ausstats/abs@nsf/StatsLibrary)

Australian Bureau of Statistics 1999. Standards for Statistics on Cultural and Language Diversity 1999. Cat. no. 1289.0. Canberra: ABS. Reference through:

[http:// www.abs.gov.au/Ausstats/abs@nsf/StatsLibrary](http://www.abs.gov.au/Ausstats/abs@nsf/StatsLibrary) select Other ABS Statistical Standards

Comments:

This data element is consistent with that used in the Australian Census of Population and Housing and is recommended for use whenever there is a requirement for comparison with Census data.

Person identifier

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002020	<i>Version number:</i>	2
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	Person identifier unique within an establishment or agency.		
<i>Context:</i>	This item could be used for editing at the agency, establishment or collection authority level and, potentially, for episode linkage. There is no intention that this item would be available beyond collection authority level.		

Representational attributes

<i>Data type:</i>	Alphanumeric		
<i>Representational form:</i>	IDENTIFICATION	<i>Field size minimum:</i>	6
	NUMBER		
<i>Representational layout:</i>	AN(20)	<i>Field size maximum:</i>	20
<i>Data domain:</i>	Valid person identification number.		
<i>Guide for use:</i>	Individual agencies, establishments or collection authorities may use their own alphabetic, numeric or alphanumeric coding systems.		
<i>Verification rules:</i>	Field cannot be blank.		
<i>Collection methods:</i>			

Relational attributes

<i>Related metadata:</i>	is qualified by NHDD Person identifier type - health care, version 1 relates to the NCSDD data concept Agency, version 1 relates to the NHDD data element Establishment identifier, version 4 supersedes the NHDD data element Person identifier, version 1		
<i>Information Model link:</i>	Party role/Person role/Recipient role		

Administrative attributes

<i>Registration authority:</i>	NCSIMG & NHIMG		
<i>Administrative status:</i>	CURRENT	<i>Effective date:</i>	02/09/2003
<i>Source organisation:</i>	National Health Data Committee and National Community Services Data Committee		
<i>Source document:</i>			
<i>Comments:</i>	This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary.		

Postcode — Australian

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002021	<i>Version number:</i>	3
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The numeric descriptor for a postal delivery area, aligned with locality, suburb or place for the address of a party (person or organisation), as defined by Australia Post.		
<i>Context:</i>	Postcode is an important part of a person's or organisation's postal address and facilitates written communication. It is one of a number of geographic identifiers that can be used to determine a geographic location. Postcode may assist with uniquely identifying a person or organisation.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	4
<i>Representational layout:</i>	NNNN	<i>Field size maximum:</i>	4
<i>Data domain:</i>	Valid Australia Post postal code.		
<i>Guide for use:</i>	The postcode book is updated more than once annually as postcodes are a dynamic entity and are constantly changing.		
<i>Verification rules:</i>			
<i>Collection methods:</i>	May be collected as part of Address line or separately. Postal addresses may be different from where a person actually resides, or a service is actually located. Leave Postcode - Australian blank for: Any overseas address Unknown address No fixed address.		

Relational attributes

<i>Related metadata:</i>	relates to the NCSDD data concept Address, version 1
	relates to the NCSDD data concept Agency, version 1
	relates to the NCSDD data concept Geographic indicator, version 2
	relates to the NHDD data element Address type, version 1
	relates to the NHDD data element Australian state/territory identifier, version 4
	relates to the NHDD data element Labour force status, version 3

Postcode — Australian

(continued)

relates to the NHDD data element Postal delivery point identifier, version 2

relates to the NHDD data element Suburb/town/locality name, version 2

supersedes the NCSDD data element Postcode, version 2

supersedes the NHDD data element Australian postcode, version 1

Information Model link: Location/ Address

Administrative attributes

Registration authority: NCSIMG & NHIMG

Administrative status: CURRENT **Effective date:** 02/09/2003

Source organisation: Standards Australia
National Health Data Committee and National Community Services Data Committee

Source document: Standards Australia 2002. Australian Standard AS5017-2002 Health Care Client Identification. Sydney: Standards Australia.
Australia Post Postcode book. Reference through:
<<http://www1.auspost.com.au/postcodes/>>

Comments: This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary. Postcode — Australian may be used in the analysis of data on a geographical basis, which involves a conversion from postcodes to the ABS postal areas. This conversion results in some inaccuracy of information. However, in some data sets postcode is the only geographic identifier, therefore the use of other more accurate indicators (e.g. Statistical Local Area) is not always possible. When dealing with aggregate data, postal areas, converted from postcodes, can be mapped to ASGC codes using an ABS concordance, for example to determine SLAs. It should be noted that such concordances should not be used to determine the SLA of any individual's postcode. Where individual street addresses are available, these can be mapped to ASGC codes (eg SLAs) using the ABS National Localities Index (NLI). Refer to ABS Catalogue No. 1252.0 for full details of the NLI.

NHDD specific:

DSS Cardiovascular disease (clinical):

Postcode — Australian

(continued)

Postcode-Australian can also be used in association with the Australian Bureau of Statistics Socio-Economic Indexes for Areas (SEIFA) index (Australian Bureau of Statistics Socio-Economic Indexes for Areas (SEIFA), Australia - CD-ROM Latest Issue: Aug 1996 was released on 30/10/1998) to derive socio-economic disadvantage, which is associated with cardiovascular risk.

People from lower socio-economic groups are more likely to die from cardiovascular disease than those from higher socio-economic groups. In 1997, people aged 25 - 64 living in the most disadvantaged group of the population died from cardiovascular disease at around twice the rate of those living in the least disadvantaged group (Australian Institute of Health and Welfare (AIHW) 2001. Heart, stroke and vascular diseases- Australian facts 2001.).

This difference in death rates has existed since at least the 1970s.

Principal diagnosis

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000136	<i>Version number:</i>	3
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care, and episode of residential care or an attendance at the health care establishment.		
<i>Context:</i>	Health services: the principal diagnosis is one of the most valuable health data elements. It is used for epidemiological research, casemix studies and planning purposes. Admitted patients: The principal diagnosis is a major determinant in the classification of Australian Refined Diagnosis Related Groups and Major Diagnostic Categories.		

Representational attributes

<i>Data type:</i>	Alphanumeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	3
<i>Representational layout:</i>	ANN.NN	<i>Field size maximum:</i>	6
<i>Data domain:</i>	Current edition of ICD-10-AM		
<i>Guide for use:</i>	<p>The principal diagnosis must be determined in accordance with the Australian Coding Standards. Each episode of admitted patient care must have a principal diagnosis and may have additional diagnoses. The diagnosis can include a disease, condition, injury, poisoning, sign, symptom, abnormal finding, complaint, or other factor influencing health status. The first edition of ICD-10-AM, the Australian modification of ICD-10, was published by the National Centre for Classification in Health in 1998 and implemented from July 1998. The second edition was published for use from July 2000 and the third edition for use from July 2002.</p> <p>For the National Minimum Data Set for Community Mental Health Care and the National Minimum Data Set for Residential Mental Health Care, codes can be used from ICD-10-AM or from The ICD-10-AM Mental Health Manual: An Integrated Classification and Diagnostic Tool for Community-Based Mental Health Services, published by the National Centre for Classification in Health in 2002.</p>		
<i>Verification rules:</i>	<p>As a minimum requirement the Principal diagnosis code must be a valid code from the current edition of ICD-10-AM.</p> <p>For episodes of admitted patient care, some diagnosis codes are too imprecise or inappropriate to be acceptable as a principal diagnosis and will group to 951Z, 955Z and 956Z in the Australian Refined Diagnosis Related Groups, Version 4.</p>		

Principal diagnosis

(continued)

Diagnosis codes starting with a V, W, X or Y, describing the circumstances that cause an injury, rather than the nature of the injury, cannot be used as principal diagnosis. Diagnosis codes which are morphology codes cannot be used as principal diagnosis.

Collection methods:

The principal diagnosis should be recorded and coded upon separation, for each episode of patient care. The principal diagnosis is derived from and must be substantiated by clinical documentation.

Admitted patients: where the principal diagnosis is recorded prior to discharge (as in the annual census of public psychiatric hospital patients), it is the current provisional principal diagnosis. Only use the admission diagnosis when no other diagnostic information is available. The current provisional diagnosis may be the same as the admission diagnosis.

Residents: The principal diagnosis should be recorded and coded upon the end of an episode of residential care (i.e. annually for continuing residential care).

Relational attributes

Related metadata:

is an alternative to Bodily location of main injury, version 1

is used as an alternative to Nature of main injury - non-admitted patient, version 1

is used in the derivation of Major diagnostic category, version 1

relates to the data element Additional diagnosis, version 4

relates to the data element Diagnosis onset type, version 1

relates to the data element Diagnosis related group, version 1

relates to the data element External cause - admitted patient, version 4

relates to the data element External cause - human intent, version 4

relates to the data element External cause - non-admitted patient, version 4

relates to the data element Procedure, version 5

supersedes previous data element Principal diagnosis - ICD-9-CM code, version 2

Information Model link:

Party Characteristics/State of health and wellbeing/Component health and wellbeing/Health status/Physical wellbeing

Principal diagnosis

(continued)

Administrative attributes

Registration authority: NHIMG

Administrative status: CURRENT *Effective date:* 14/11/2003

Source organisation: Health Data Standards Committee.
National Centre for Classification in Health.
National Data Standard for Injury Surveillance Advisory Group.

Source document: Current edition of International Statistical Classification of Diseases and Related Health Problems - Tenth Revision - Australian Modification. National Centre for Classification in Health, Sydney.

Comments:

Referral date

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000515	<i>Version number:</i>	2
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The date on which an agency receives a client referral from another party.		
<i>Context:</i>	Many providers collect the date of referral because it has administrative importance. It can be used in the calculation of response times and for performance indicators that measure the provision of service. Can also be used to measure work-load (ie the number of referrals coming to a particular agency). This may be measured for particular clients or particular types of services.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	DATE	<i>Field size minimum:</i>	8
<i>Representational layout:</i>	DDMMYYYY	<i>Field size maximum:</i>	8
<i>Data domain:</i>	Valid dates		
<i>Guide for use:</i>	This data element should always be recorded as an 8 digit valid date comprising day, month and year. Year should always be recorded in its full 4 digit format. For days and months with a numeric value of less than 10, zeros should be used to ensure that the date contains the required 8 digits. For example if an agency receives a client referral on July 1 2000 the Referral date should be recorded as 01072000 as specified in the representational layout.		
<i>Verification rules:</i>			
<i>Collection methods:</i>	Can be collected at initial referral of a client to an agency or at each referral, although this should be done consistently within a collection. Individual collections will also need to determine what constitutes a referral for their purposes (eg Is it only formal referrals that are considered, or are self-referral counted as a referral also etc).		

Relational attributes

<i>Related metadata:</i>	is used in conjunction with Referral source, version 2 relates to the data element concept Agency, version 1 relates to the data element concept Client, version 1 supersedes previous data element Date of referral, version 1
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Referral date

(continued)

Information Model link: Event/Health and welfare Service event/Referral event

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT *Effective date:* 01/07/2000

Source organisation: National Health Data Committee

Source document: National Health Data Dictionary

Comments:

Referral source

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000536	<i>Version number:</i>	2
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The party (person or agency) responsible for the referral of a client to a community service agency.		
<i>Context:</i>	Source of referral is important in assisting in the analyses of inter-service client flow and for community service planning.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N(.N)	<i>Field size maximum:</i>	3
<i>Data domain:</i>	1	Agency	
	1.1	Health agency	
	1.2	Community services agency	
	1.3	Educational agency	
	1.4	Legal agency	
	1.5	Employment/ job placement agency	
	1.6	Other agency	
	2	Non-agency	
	2.1	Self	
	2.2	Family	
	2.3	Friends	
	2.4	General Medical Practitioner	
	2.5	Other party	
	9	Not stated/inadequately described	

<i>Guide for use:</i>	<p>Individual data collections use specific categories relevant to their particular information needs. These categories should be mappable to the above generic domain at the 1- or 2-digit level.</p> <p>The separation of agency from non-agency for source of referral is a significant distinction. For instance, it is important to differentiate between a referral from a private practising general medical practitioner and a referral from a health agency, such as a health clinic in a hospital.</p> <p>Examples:</p>
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Referral source

(continued)

- Aged care assessment team would map to category 1.1
- Residential aged care factor to category 1.1
- Community nursing service to category 1.1
- School/other education institution to category 1.3
- General Practitioner to category 2.4
- Police/legal unit to category 1.4 etc

Verification rules:

Collection methods:

Individual collections may like to expand categories further for example, by distinguishing between immediate family and non-immediate family. In addition, this item may be collected at the point of initial contact with an agency, or for other contact points as well, for the agency as a whole, or for different services provided by that agency.

Relational attributes

Related metadata:

is used in conjunction with Referral date, version 2
relates to the data element concept Agency, version 1
relates to the data element concept Client, version 1
relates to the data element concept Family, version 2
supersedes previous data element Source of referral, version 1

Information Model link:

Event/Health and welfare Service event/Referral event

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT *Effective date:* 01/07/2000

Source organisation: Australian Institute of Health and Welfare

Source document: Supported Accommodation Assistance Program (SAAP) National Data Collection Agency 2001. National Data Collection Data Dictionary. Version 2. Unpublished.

Comments:

Relationship of carer to care recipient

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000585	<i>Version number:</i>	1
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The relationship of the carer to the person for whom they care.		
<i>Context:</i>	Resource and service planning: Information about this relationship assists in the establishment of a profile of informal caring relationships and the assistance provided (such as by the HACC program) to maintain and support those relationships. As such it increases knowledge about the dynamics of caring and provides an insight into the gender and inter-generational patterns of informal care giving in the community.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	1	Spouse/partner	
	2	Parent	
	3	Child	
	4	Child-in-law	
	5	Other relative	
	6	Friend/neighbour	
	9	Not stated/inadequately described	

Guide for use: This data element should always be used to record the relationship of the carer to the person for whom they care, regardless of whether the client of the agency is the carer or the person for whom they care.

For example, if a woman were caring for her frail aged mother-in-law, the agency would record that the carer is the daughter-in-law of the care recipient (ie code 4). Similarly, if a man were caring for his disabled son, then the agency would record that the carer is the father of the care recipient (ie code 2).

Relationship of carer to care recipient

(continued)

If a person has more than one carer (eg a spouse and a son), the coding response to Relationship of carer to care recipient should relate to the carer who provides the most significant care and assistance related to the person's capacity to remain living at home. The expressed views of the client and/ or their carer or significant other should be used as the basis for determining which carer should be considered to be the primary or principal carer in this regard. Code 1 includes defacto and same sex partnerships.

Verification rules:

Collection methods:

To obtain greater detailed information about carers data can be collected using other elements such as 'Age' and 'Sex' etc.

Relational attributes

Related metadata:

relates to the data element concept Informal carer, version 2

Information Model link:

Party role/Person role/Carer role

Administrative attributes

Registration authority:

NCSIMG

Administrative status:

CURRENT

Effective date: 01/07/2000

Source organisation:

Australian Institute of Health and Welfare

Source document:

Home and Community Care (HACC) Data Dictionary Version 1.0, 1998

Comments:

There is inconsistency between the definition of 'Informal carer' with the ABS definition of 'Principal carer'.

Separation date

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000043	<i>Version number:</i>	5
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	Date on which an admitted patient completes an episode of care.		
<i>Context:</i>	Required to identify the period in which an admitted patient hospital stay or episode occurred and for derivation of length of stay.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	DATE	<i>Field size minimum:</i>	8
<i>Representational layout:</i>	DDMMYYYY	<i>Field size maximum:</i>	8
<i>Data domain:</i>	Valid dates		
<i>Guide for use:</i>			
<i>Verification rules:</i>	For the provision of state and territory hospital data to Commonwealth agencies this field must: - be <= last day of financial year - be >= first day of financial year - be >= Admission date		

Collection methods:

Relational attributes

<i>Related metadata:</i>	is used in the calculation of Length of stay (including leave days), version 1 is used in the calculation of Length of stay (postnatal), version 1 supersedes previous data element Discharge date, version 4
<i>Information Model link:</i>	Event/Health and welfare service event/Exit/leave from service event

Administrative attributes

<i>Registration authority:</i>	NHIMG		
<i>Administrative status:</i>	CURRENT	<i>Effective date:</i>	01/07/1999
<i>Source organisation:</i>	National Health Data Committee		
<i>Source document:</i>			

Separation date

(continued)

Comments:

There may be variations amongst jurisdictions with respect to the recording of separation date. This most often occurs for patients who are statistically separated after a period of leave (and who do not return for further hospital care). In this case, some jurisdictions may record the separation date as the date of statistical separation (and record intervening days as leave days) while other jurisdictions may retrospectively separate patients on the first day of leave. Despite the variations in recording of separation date for this group of patients, the current practices provide for the accurate recording of length of stay.

Service contact date

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000402	<i>Version number:</i>	1
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The date of each service contact between a health service provider and patient/client.		
<i>Context:</i>	The service contact is required for clinical audit and other quality assurance purposes NMDs Community mental health care Collection of the date of each service contact with health service providers allows a description or profile of service utilisation by a person or persons during an episode of care.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	DATE	<i>Field size minimum:</i>	8
<i>Representational layout:</i>	DDMMYYYY	<i>Field size maximum:</i>	8
<i>Data domain:</i>	Valid date		
<i>Guide for use:</i>	Requires services to record the date of each service contact, including the same date where multiple visits are made on one day (except where the visits may be regarded as a continuation of the one service contact). Where an individual patient/client participates in a group activity, a service contact date is recorded if the person's participation in the group activity results in a dated entry being made in the patient's/client's record.		
<i>Verification rules:</i>			
<i>Collection methods:</i>	For collection from community based (ambulatory and non-residential) agencies.		

Relational attributes

<i>Related metadata:</i>	is used in the derivation of Number of service contact dates, version 2 relates to the data element concept Service contact, version 1		
<i>Information Model link:</i>	Event/Health and welfare service event/Service provision event		

Service contact date

(continued)

Administrative attributes

Registration authority: NHIMG

Administrative status: CURRENT *Effective date:* 01/07/1999

Source organisation:

Source document:

Comments:

NMDS Community mental health care:

The National Health Data Committee acknowledges that information about group sessions or activities that do not result in a dated entry being made in each individual participant's patient/client record is not obtained via this data element.

Service delivery setting

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000539	<i>Version number:</i>	3
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	The type of physical setting in which a service activity is actually provided or could be provided to a client, irrespective of whether or not this is the same as the usual location of the service providing agency.		
<i>Context:</i>	This element is used, in conjunction with other data elements about service provision, to obtain a more detailed appraisal of service availability and how services are provided. At the broadest level, this data element should provide a measure of the extent to which services are provided to clients in their own homes, in community settings or centre-based facilities, residential care facilities or other settings.		

Representational attributes

<i>Data type:</i>	Alphanumeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	2
<i>Representational layout:</i>	AN.N.NN	<i>Field size maximum:</i>	7
<i>Data domain:</i>	A data domain appropriate for a particular collection should be mappable to the service settings classification in the National Classifications of Community Services Version 2. Reference through: http://www.aihw.gov.au/publications/hwi/nccsv2/index.html		
<i>Guide for use:</i>	Service delivery settings should be collected according to the lower level of coding in the NCCS V2. To meet program or service specific needs, the categories used in individual data collections may be more detailed than those in the settings classification of the NCCS, but they should always be mappable to categories in the NCCS V2.		
<i>Verification rules:</i>			
<i>Collection methods:</i>			

Service delivery setting

(continued)

Relational attributes

Related metadata: relates to the data element concept Agency, version 1
relates to the data element concept Client, version 1
relates to the data element concept Household, version 2
supersedes previous data element Service delivery setting, version 2

Information Model link: Location/Setting/Service delivery setting

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT *Effective date:* 02/09/2003

Source organisation: Australian Institute of Health and Welfare

Source document: Australian Institute of Health and Welfare 2003. National Classifications of Community Services, Version 2.0. AIHW Cat. no. HWI 40. Canberra: AIHW.

Reference through:
<http://www.aihw.gov.au/publications/hwi/nccsv2/index.html>

Comments: Categories used in individual community services data collections such as the Home and Community Care (HACC), Commonwealth state/territory Disability Agreement (CSTDA) and the Supported Accommodation Assistance Program (SAAP) have been mapped to the settings classification in the National Classifications of Community Services.

Sex

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002024	<i>Version number:</i>	4
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	Sex is the biological distinction between male and female. Where there is an inconsistency between anatomical and chromosomal characteristics, sex is based on anatomical characteristics.		
<i>Context:</i>	Sex is a core data element in a wide range of social, labour and demographic statistics.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	1	Male	
	2	Female	
	3	Intersex or indeterminate	
	9	Not stated/inadequately described	
<i>Guide for use:</i>	Code 3 Intersex or indeterminate, refers to a person, who because of a genetic condition, was born with reproductive organs or sex chromosomes that are not exclusively male or female or whose sex has not yet been determined for whatever reason.		
<i>Verification rules:</i>	Code 3 Intersex or indeterminate, should be confirmed if reported for people aged 90 days or greater. Diagnosis and procedure codes should be checked against the national ICD-10-AM sex edits, unless the person is undergoing, or has undergone a sex change as detailed in Collection methods or has a genetic condition resulting in a conflict between sex and ICD-10-AM code.		
<i>Collection methods:</i>	Operationally, sex is the distinction between male and female, as reported by a person or as determined by an interviewer. When collecting data on sex by personal interview, asking the sex of the respondent is usually unnecessary and may be inappropriate, or even offensive. It is usually a simple matter to infer the sex of the respondent through observation, or from other cues such as the relationship of the person(s) accompanying the respondent, or first name. The interviewer may ask whether persons not present at the interview are male or female.		

Sex

(continued)

A person's sex may change during their lifetime as a result of procedures known alternatively as Sex change, Gender reassignment, Transsexual surgery, Transgender reassignment or Sexual reassignment. Throughout this process, which may be over a considerable period of time, Sex could be recorded as either Male or Female.

In data collections that use the ICD-10-AM classification, where sex change is the reason for admission, diagnoses should include the appropriate ICD-10-AM code(s) that clearly identify that the person is undergoing such a process. This code(s) would also be applicable after the person has completed such a process, if they have a procedure involving an organ(s) specific to their previous sex (e.g. where the patient has prostate or ovarian cancer).

Code 3 Intersex or indeterminate, is normally used for babies for whom sex has not been determined for whatever reason; should not generally be used on data collection forms completed by the respondent; and should only be used if the person or respondent volunteers that the person is intersex or where it otherwise becomes clear during the collection process that the individual is neither male nor female.

Code 9 Not stated/inadequately described, is not to be used on primary collection forms. It is primarily for use in administrative collections when transferring data from data sets where the item has not been collected.

Relational attributes

<i>Related metadata:</i>	is used in the derivation of NHDD Diagnosis related group, version 1 supersedes the NCSDD data element Sex, version 2 supersedes the NHDD data element Sex, version 3
<i>Information Model link:</i>	Party characteristic/Person characteristic/Demographic characteristic

Administrative attributes

<i>Registration authority:</i>	NCSIMG & NHIMG	
<i>Administrative status:</i>	CURRENT	<i>Effective date:</i> 02/09/2003
<i>Source organisation:</i>	Australian Bureau of Statistics	
<i>Source document:</i>	The ABS standards for the collection of Sex appear on the ABS Website.	

Sex

(continued)

<http://www.abs.gov.au/Ausstats/abs@.nsf/StatsLibrary>, select: Other ABS Statistical Standards/Standards for Social, Labour and Demographic Variables/Demographic Variables/Sex.

Comments:

This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary.

The definition for Intersex in Guide for use is sourced from the ACT Legislation (Gay, Lesbian and Transgender) Amendment Act 2003.

DSS - Diabetes (clinical):

Referring to the National Diabetes Register Statistical profile (December 2000), the sex ratio varied with age. For ages less than 25 years, numbers of males and females were similar. At ages 25-44 years, females strongly outnumbered males, reflecting the effect of gestational diabetes in women from this group.

For older age groups (45-74 years), males strongly outnumber females and in the group of 75 and over, the ratio of males to females was reversed, with a substantially lower proportion of males in the population in this age group due to the higher female life expectancy. (AIHW National Mortality Database 1997/98; National Diabetes Register; Statistical Profile, December 2000)

Carer co-residency

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000553	<i>Version number:</i>	1
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	Whether or not a carer lives with the person for whom they care.		
<i>Context:</i>	Personal and social support: This item helps to establish a profile of the characteristics of informal carers and as such increases knowledge about the dynamics and patterning of the provision of informal care. In particular, whether the carer lives with the person for whom they care or not is one indication of the level of informal support available to clients and of the intensity of care provided by the carer.		

Representational attributes

<i>Data type:</i>	Alphabetic		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	1	Co-resident carer	
	2	Non-resident carer	
	9	Not stated/inadequately described	

Guide for use: A co-resident carer is a person who provides care and assistance on a regular and sustained basis to a person who lives in the same household. A non-resident or visiting carer is a person who provides care and assistance on a regular and sustained basis to someone who lives in a different household.

Usually used to record residency status of the person who provides most care to the person. If a client has both a co-resident (eg. a spouse) and a visiting carer (eg. a daughter or son), the coding response should be related to the carer who provides the most significant care and assistance related to the client's capacity to remain living at home. The expressed views of the client and/or their carer(s) or significant other should be used as the basis for determining this.

Verification rules:

Collection methods: This item can be collected when either the carer or the person being cared for is the client of an agency.

Agencies may be required to collect this item at the beginning of each service episode. Agencies should also assess the currency of this information at subsequent assessments or re-assessments.

Carer co-residency

(continued)

Some agencies may record this information historically so that they can track changes over time. Historical recording refers to the practice of maintaining a record of changes over time where each change is accompanied by the appropriate date.

Relational attributes

Related metadata: relates to the data element concept Informal carer, version 2
Information Model link: Party characteristic/Person characteristic/Accommodation/living characteristic

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT *Effective date:* 01/07/2000

Source organisation: Australian Institute of Health and Welfare

Source document: Home and Community Care (HACC) Data Dictionary Version 1.0, 1998

Comments: There is inconsistency between this definition of 'Carer co-residency', and the ABS definition of 'Principal carer', 1993 Disability, Ageing and Carers Survey and, 'Primary carer' used in the 1998 survey. The ABS definitions require that the carer has or will provide care for a certain amount of time and that they provide certain types of care. This may not be appropriate for community services agencies wishing to obtain information about a person's carer regardless of the amount of time that care is for or the types of care provided.

This type of information can of course be collected separately, but for most collections it is not needed and would place a burden on service providers.

Informal carer availability

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002003	<i>Version number:</i>	4
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	<p>Whether someone, such as a family member, friend or neighbour, has been identified as providing regular and sustained informal care and assistance to the person requiring care.</p> <p>Carers include those people who receive a pension or benefit for their caring role but does not include paid or volunteer carers organised by formal services.</p>		
<i>Context:</i>	<p>Ageing, disability and health</p> <p>Recent years have witnessed a growing recognition of the critical role that informal support networks play in caring for frail older people and people with disabilities within the community. Not only are informal carers responsible for maintaining people with often high levels of functional dependence within the community, but the absence of an informal carer is a significant risk factor contributing to institutionalisation. Increasing interest in the needs of carers and the role they play has prompted greater interest in collecting more reliable and detailed information about carers and the relationship between informal care and the provision of and need for formal services.</p>		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	1	Has a carer	
	2	Has no carer	
	9	Not stated/inadequately described	

Guide for use: This data element is purely descriptive of a client's circumstances. It is not intended to reflect whether the carer is considered by the service provider to be capable of undertaking the caring role.

In line with this, the expressed views of the client and/or their carer should be used as the basis for determining whether the client is recorded as having a carer or not.

Informal carer availability

(continued)

A carer is someone who provides a significant amount of care and/or assistance to the person on a regular and sustained basis. Excluded from the definition of carers are paid workers or volunteers organised by formal services (including paid staff in funded group houses).

When asking a client about the availability of a carer, it is important for agencies or establishments to recognise that a carer does not always live with the person for whom they care. That is, a person providing significant care and assistance to the client does not have to live with the client in order to be called a carer.

The availability of a carer should also be distinguished from living with someone else. Although in many instances a co-resident will also be a carer, this is not necessarily the case. The data element Living arrangement is designed to record information about person(s) with whom the client may live.

Verification rules:

Collection methods:

Agencies or establishments and service providers may collect this item at the beginning of each service episode and also assess this information at subsequent assessments or re-assessments.

Some agencies, establishments/providers may record this information historically so that they can track changes over time. Historical recording refers to the practice of maintaining a record of changes over time where each change is accompanied by the appropriate date.

Relational attributes

Related metadata:

is used in conjunction with NHDD Service contact date, version 1

relates to the NCSDD data concept Family, version 2

relates to the NCSDD data concept Volunteer, version 2

relates to the NCSDD data element Activity - level of difficulty, version 2

relates to the NCSDD data element Carer co-residency, version 1

relates to the NCSDD data element Relationship of carer to care recipient, version 1

relates to the NHDD data element Formal community support access status, version 1

relates to the NHDD data element Living arrangement, version 1

supersedes the NCSDD data element Carer availability, version 1

Informal carer availability

(continued)

supersedes the NHDD data element Carer availability, version 3

Information Model link: Party role/Person role/Carer role

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT *Effective date:* 02/09/2003

Source organisation: Australian Institute of Health and Welfare
National Health Data Committee and National Community Services Data Committee

Source document:

Comments:

This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary.

This definition of 'Informal carer availability' is not the same as the ABS definition of 'Principal carer', 1993 Disability, Ageing and Carers Survey and 'Primary carer' used in the 1998 survey. The ABS definitions require that the carer has or will provide care for a certain amount of time and that they provide certain types of care. This may not be appropriate for agencies or establishments wishing to obtain information about a person's carer regardless of the amount of time that care is for or the types of care provided.

Information such as the amount of time for which care is provided can of course be collected separately but, if it were not needed, it would place a burden on service providers.

NHDD specific DSS Cardiovascular disease (clinical):

Informal carers are now present in 1 in 20 households in Australia (Schofield HL, Herrman HE, Bloch S, Howe A and Singh B. ANZ J PubH. 1997) and are acknowledged as having a very important role in the care of stroke survivors (Stroke Australia Task Force. National Stroke Strategy. NSF; 1997) and in those with end-stage renal disease.

Absence of a carer may also preclude certain treatment approaches (for example, home dialysis for end-stage renal disease). Social isolation has also been shown to have a negative impact on prognosis in males with known coronary artery disease with several studies suggesting increased mortality rates in those living alone or with no confidant.

Living arrangement

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000527	<i>Version number:</i>	3
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	Whether a person usually resides alone or with others.		
<i>Context:</i>	It is important to record the type of living arrangement for a person in order to develop a sense of the level of support, both physically and emotionally, to which a person may have access.		

Representational attributes

<i>Data type:</i>	Numeric		
<i>Representational form:</i>	CODE	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	1	Lives alone	
	2	Lives with family	
	3	Lives with others	
	9	Not stated/inadequately described	

<i>Guide for use:</i>	<p>Code 2 Lives with family: If the person's household includes both family and non-family members, the person should be recorded as living with family.</p> <p>'Living with family' should be considered to include de facto and same sex relationships.</p> <p>On occasion, difficulties can arise in deciding the living arrangement of a person due to their type of accommodation (e.g. boarding houses, hostels, group homes, retirement villages, residential aged care facilities). In these circumstances the person should be regarded as living alone, except in those instances in which they are sharing their own private space/room within the premises with a significant other (e.g. partner, sibling, close friend).</p>		
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Verification rules:

<i>Collection methods:</i>	Generally this item is collected for the person's usual living arrangement, but may also, if required, be collected for a person's main living arrangement or living arrangement at a particular time reference point.
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Related metadata:

relates to the data element concept Dwelling, version 1
relates to the data element concept Family, version 2
relates to the data element concept Household, version 2
supersedes previous data element Living arrangements, version 2

Information Model link: Party characteristic/Person characteristic/Accommodation/living characteristic

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT **Effective date:** 09/02/2003

Source organisation: Commonwealth and state/territory Home and Community Care
Officials
National Health Data Committee and National Community Services
Data Committee

Source document: Commonwealth Department of Health and Family Services 1998.
Home and Community Care Data Dictionary. Version 1.0. Canberra:
DHFS.

Comments:

Contact recipient type (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type: DATA ELEMENT

Definition: Identification of the recipient/s of the contact.

Context: Service planning and monitoring.

Representational attributes

Data type: Numeric

Representational form: Code *Field size minimum:* 1

Representational layout: N *Field size maximum:* 1

Data domain:

1. Patient/client only
2. Patient/client and related person(s)
3. Related person(s) only
4. Other professional/service provider
5. Other recipient

Guide for use: Only one option may be selected. If more than one contact has taken place (but at the same time) they are to be recorded as separate contacts. Contact recipient type and Service delivery setting are closely related items.

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document: Victorian Palliative Care Reporting System (VicPCRS)

Comments:

Date of commencement of service episode (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type: DATA ELEMENT

Definition: The day on which the delivery of a service episode commences.

Context: Hospital non-admitted patient care and public health care.

Representational attributes

Data type: Numeric

Representational form: DATE *Field size minimum:* 8

Representational layout: DDMMYYYY *Field size maximum:* 8

Data domain: Valid dates

Guide for use:

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document:

Comments:

Discipline of service provider (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type: DATA ELEMENT

Definition: The identified discipline of the person providing the service to the patient/client.

Context:

Representational attributes

Data type: Numeric

Representational form: Code *Field size minimum:* 1

Representational layout: NN *Field size maximum:* 2

Data domain:

1	Nurse
2	Medical officer
3	Allied health practitioner
4	Chaplain or pastoral carer
5	Counsellor or bereavement counsellor
6	Complementary therapist
7	Volunteer
8	Other

Guide for use: Allied health practitioner includes physiotherapist, occupational therapist, speech pathologist, social worker, dietician and community development coordinator.

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document: Victorian Palliative Care Reporting System

Comments:

Mode of contact (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type: DATA ELEMENT

Definition:

Context: The type of contact

Representational attributes

Data type: Numeric

Representational form: Code *Field size minimum:* 1

Representational layout: NN *Field size maximum:* 1

Data domain:

1	Face to face – during office hours
2	Face to face – after office hours
3	Telephone – during office hours
4	Telephone – after office hours
5	Written
6	Group
7	Other

Guide for use:

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document: Victorian Palliative Care Reporting System.

Comments:

Phase of care (DRAFT)

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	002004	<i>Version number:</i>	4
<i>Metadata type:</i>	DATA ELEMENT		
<i>Definition:</i>	Describes the person's stage of illness in terms of 5 phases.		
<i>Context:</i>	Clients of a Palliative care service.		

Representational attributes

<i>Data type:</i>	Alphanumeric		
<i>Representational form:</i>	Code	<i>Field size minimum:</i>	1
<i>Representational layout:</i>	N	<i>Field size maximum:</i>	1
<i>Data domain:</i>	<ol style="list-style-type: none">1. Stable phase2. Unstable phase3. Deteriorating phase4. Terminal care phase5. Bereaved phase		

<i>Guide for use:</i>	<p>Record the phase at episode start. The Palliative care team should then review the patient/client at each visit and record phase changes if and when they occur during the episode.</p> <ol style="list-style-type: none">1. Stable phase All clients not classified as unstable, deteriorating, or terminal.2. Unstable phase The person experiences the development of a new problem or a rapid increase in the severity of existing problems, either of which require an urgent change in management or emergency treatment.3. Deteriorating phase4. Terminal care phase: Death is likely in a matter of days and no acute intervention is planned or required.5. Record only one bereavement phase per patient – not one for each carer/family member.
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Verification rules:

Collection methods:

Relational attributes

Related metadata: relates to data element concept Palliative care phase

Information Model link:

Phase of care (DRAFT)

(continued)

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document:

The Australian National Sub-Acute and Non-Acute Patient
Classification (AN-SNAP)

Comments:

Site of death (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type: DATA ELEMENT

Definition: The place where the patient/client died.

Context:

Representational attributes

Data type: Numeric

Representational form: Code *Field size minimum:* 1

Representational layout: NN *Field size maximum:* 1

Data domain:

1. Home – not including nursing home, hostel or community hospice
2. Public hospital – identified palliative care bed
3. Public hospital – non-identified bed
4. Private hospital-publicly funded bed, identified palliative care bed
5. Private hospital-publicly funded bed-not identified bed
6. Private hospital-other
7. Residential care-identified home, hostel or Supported Residential Services
8. Residential care-identified palliative care (includes hospice bed facilities, not identified as a public or private hospital)
9. Other

Guide for use:

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Site of death (DRAFT)

(continued)

Source organisation: Victorian Palliative Care Reporting System

Source document:

Comments:

Type of assistance received (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type: DATA ELEMENT

Definition: The primary type of assistance that the person receives from the agency during a service delivery event.

Context:

Representational attributes

Data type: Numeric

Representational form: Code *Field size minimum:* 1

Representational layout: NN *Field size maximum:* 2

Data domain:

1	Domestic assistance
2	Social support
3	Nursing care
4	Allied health care
5	Personal care
6	Centre-based day care
7	Meals
8	Other food services
9	Respite care
10	Assessment
11	Case management
12	Case planning/review and coordination
13	Home maintenance
14	Home modification
15	Provision of goods and equipment
16	Formal linen service
17	Transport
18	Counselling/support, information and advocacy

Guide for use: Only one option may be selected. If more than one activity has taken place (but at the same time) they are to be recorded as separate contacts.

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Type of assistance received (DRAFT)

(continued)

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document:

Home and Community Care Data Dictionary

Comments:

Object classes

The following object classes are suggested for inclusion in a community-based palliative care data collection. Some object classes are already national standards that have been included in either the NHDD or the NCSDD while others are newly suggested object classes specifically for a palliative care data set. It is envisaged that each of the object classes will be associated with a group of data elements that will describe each of the object classes. Please note that some attributes in the following data items have been left blank because the information is either unavailable or in the case of draft items is yet to be developed.

Agency 205
Client 208
Service contact 210
Service episode 212

Agency

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000544	<i>Version number:</i>	1
<i>Metadata type:</i>	DATA ELEMENT CONCEPT		
<i>Definition:</i>	An organisation or organisational sub-unit that is responsible for the provision of assistance to clients.		
<i>Context:</i>	<p>Defining agency is extremely important for data collection, as it is the level at which most data are collected in the community services area.</p> <p>An agency may or may not directly provide the services to clients, but is responsible for their provision, whether directly, administratively or via allocation of funds.</p> <p>Sometimes agencies may contract out or broker the assistance required by their clients to other service providers. Although the agency may not directly provide the assistance in these cases, the agency paying for the assistance to clients is considered responsible for that assistance and should be able to report on those clients and the assistance they receive.</p> <p>Regardless of the way in which an organisation is funded, an agency is the level of the organisation responsible for service provision to clients. In some instances one organisation will have more than one or many agencies.</p>		

Representational attributes

<i>Data type:</i>		<i>Field size minimum:</i>	
<i>Representational form:</i>		<i>Field size maximum:</i>	
<i>Representational layout:</i>			
<i>Data domain:</i>			
<i>Guide for use:</i>	<p>Different collections define agency differently according to their context and varying need for information on the different levels of organisations providing community services. Individual data collections will therefore need to further specify what an agency is for their collection purposes.</p> <p>Agencies may be government or non-government organisations.</p> <p>In the SAAP National Data Collection, SAAP agencies are defined as 'The body or establishment which receives a specified amount of money (SAAP funds) to provide a SAAP service. The agency is the level at which data are collected'.</p>		

Agency

(continued)

In the HACC Data Dictionary however, a HACC agency is defined as 'A HACC funded organisation or organisational sub-unit that is responsible for the direct provision of HACC funded assistance to clients'.

In Children's Services, agency most closely corresponds to the definition of Service Provider 'The entity (individual, agency, organisation, body or enterprise) that provides the service(s)'.

At this point in time the NCSDD definition of agency is of necessity quite broad. As agency is generally the level at which the responsibility for service provision lies and at which data are collected. As there are different needs for data collection in different areas, a more precise definition would be too narrow to encompass all community services data collections.

Verification rules:

Collection methods:

Relational attributes

Related metadata:

relates to the data element Assessment date, version 1

relates to the data element Assistance - reason not provided, version 1

relates to the data element Assistance received date, version 1

relates to the data element Assistance request date, version 1

relates to the data element Assistance request reason, version 1

relates to the data element Case management plan indicator, version 1

relates to the data element Client, version 1

relates to the data element concept Agency identifier, version 2

relates to the data element Eligibility status, version 2

relates to the data element Landlord type, version 1

relates to the data element Postcode - Australian, version 3

relates to the data element Referral date, version 2

relates to the data element Referral source, version 2

relates to the data element Service activity type requested, version 2

relates to the data element Service activity type, version 2

relates to the data element Service delivery setting, version 3

relates to the data element Service episode, version 1

relates to the data element Service event, version 1

relates to the data element Service operation days, version 1

Agency

(continued)

relates to the data element Service operation hours, version 1
relates to the data element Service operation weeks, version 1
supersedes previous data element Unique agency identifier, version 1

Information Model link: Party/Agency

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT *Effective date:* 01/07/2000

Source organisation: Australian Institute of Health and Welfare

Source document: Home and Community Care (HACC) Data Dictionary Version 1.0, 1998

Comments:

Client

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000555	<i>Version number:</i>	1
<i>Metadata type:</i>	DATA ELEMENT CONCEPT		
<i>Definition:</i>	A person, group or organisation eligible to receive services either directly or indirectly (ie through partner organisations) from an agency.		
<i>Context:</i>	<p>Community service agencies may provide assistance to individual persons, groups of persons (eg support groups) or to other organisations. All of these maybe considered clients of an agency. Specific data collections may circumscribe the Type of clients that are included in the collection. For example, at the current stage of development of the HACC MDS, HACC funded agencies are only required to report on clients who are individual persons. Future developments may extend the coverage of the HACC MDS collection to include organisational or group clients.</p> <p>The definition of a 'client' may also be circumscribed by the definition of 'assistance'. What is included as 'assistance' may depend on what activities are considered significant enough to warrant separate recording and reporting of the nature and/or amount of the assistance provided to a person. For example, an agency worker answering a telephone call from an anonymous member of the public seeking some basic information (eg a phone number for someone) would not usually consider that this interaction constituted assistance of sufficient significance to warrant recording that person as a 'client'.</p> <p>Furthermore, what constitutes 'assistance' may be influenced by the type of assistance the agency was established to provide. In the above example, the agency in question was funded specifically to provide telephone advice, and referral information, to members of the public or specific sub-groups of the public. The agency may have a policy that all persons telephoning the agency for information are classified as clients, albeit anonymous clients.</p> <p>The level of support or the amount of support given to a person by an agency can also be used to define them as a client or not. For example in the SAAP National Data Collection clients are defined by either taking up an amount of time of an agency; being accommodated by an agency; or by entering an ongoing support relationship with an agency.</p>		

Representational attributes

<i>Data type:</i>	
<i>Representational form:</i>	<i>Field size minimum:</i>

Client

(continued)

Representational layout:

Field size maximum:

Data domain:

Guide for use:

Verification rules:

Collection methods:

Relational attributes

Related metadata:

relates to the data element Assessment date, version 1
relates to the data element Assistance received date, version 1
relates to the data element Assistance request reason, version 1
relates to the data element Case management plan indicator, version 1
relates to the data element concept Agency, version 1
relates to the data element concept Assistance received, version 1
relates to the data element Goods and equipment received, version 1
relates to the data element Name suffix, version 2
relates to the data element Name title, version 2
relates to the data element Referral date, version 2
relates to the data element Referral source, version 2
relates to the data element Service activity type, version 2
relates to the data element Service delivery setting, version 3
relates to the data element Service episode, version 1
relates to the data element Service event, version 1

Information Model link:

Party role/Person role/Recipient role

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT

Effective date: 01/07/2000

Source organisation: Australian Institute of Health and Welfare

Source document:

Comments:

Service contact

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000401	<i>Version number:</i>	1
<i>Metadata type:</i>	DATA ELEMENT CONCEPT		
<i>Definition:</i>	A contact between a patient/client and an ambulatory care health unit (including outpatient and community health units) which results in a dated entry being made in the patient/client record.		
<i>Context:</i>	Identifies service delivery at the patient level for mental health services (including consultation/liaison, mobile and outreach services). A service contact can include either face-to-face, telephone or video link service delivery modes. Service contacts would either be with a client, carer or family member or another professional or mental health worker involved in providing care and do not include contacts of an administrative nature (e.g. telephone contact to schedule an appointment) except where a matter would need to be noted on a patient's record. Service contacts may be differentiated from administrative and other types of contacts by the need to record data in the client record. However, there may be instances where notes are made in the client record that have not been prompted by a service contact with a patient/client (e.g. noting receipt of test results that require no further action). These instances would not be regarded as a service contact.		

Representational attributes

<i>Data type:</i>		<i>Field size minimum:</i>	
<i>Representational form:</i>		<i>Field size maximum:</i>	
<i>Representational layout:</i>			
<i>Data domain:</i>			
<i>Guide for use:</i>			
<i>Verification rules:</i>			
<i>Collection methods:</i>			

Relational attributes

<i>Related metadata:</i>	relates to the data element Service contact date, version 1
<i>Information Model link:</i>	Event/Health and welfare service event/Service provision event

Service contact

(continued)

Administrative attributes

Registration authority: NHIMG

Administrative status: CURRENT

Effective date: 14/11/2003

Source organisation:

Source document:

Comments:

The proposed definition is not able to measure case complexity or level of resource usage with each service contact alone. This limitation also applies to the concept of occasions of service (in admitted patient care) and hospital separations.

The National Health Data Committee also acknowledges that information about group sessions or activities that do not result in a dated entry being made in each individual participant's patient/client record is not currently covered by this data element concept.

Service episode

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000590	<i>Version number:</i>	1
<i>Metadata type:</i>	DATA ELEMENT CONCEPT		
<i>Definition:</i>	A period of time during which a client receives assistance from an agency.		
<i>Context:</i>	Service provision and planning: The concept of a Service episode (and associated data elements) is necessary for the analysis, of the length of provision of assistance to clients. In conjunction with information about the amount and type of assistance received by clients, information about the length of Service episode also gives some indication of the intensity of assistance provided by agencies. A client's Service episode always begins and ends with dates that mark the first and last time that the person received assistance from the agency. That is, a Service episode will always begin and end with Service event (see data element concept Service event). The pathway or process followed by a person entering or exiting from a Service episode varies from one agency to another and from one type of assistance to another. It cannot be assumed, for example, that every client has undergone an assessment (or the same type of assessment) before entering a Service episode. At times, a client may receive services from an agency on the basis of a referral from an established source with which the agency has well-developed referral protocols. At other times, a client who has been previously assisted by the agency may begin to receive services again without undergoing the same level of assessment on entry into a subsequent Service episode. The definition of Service episode has not assumed that any standard sequence of events applies to all Service episodes for all clients across all types of agencies and across all programs. Rather, the definition of a Service episode allows for the receipt of any of the types of assistance to serve as a trigger for the beginning of a Service episode. That is, the service activity associated with the beginning of a Service episode (ie the first Service event) will vary across agencies.		

Service episode

(continued)

While agency policies and practices will impact upon the determination of a Service episode to some extent (e.g. different policies for taking clients 'off the books') the basic feature across agencies remain the first and the last Service events received by a client within a period of receipt of assistance. Establishing greater consistency in the determination of Service episodes would require a national cross-program approach to standardising entry and exit procedures across the community service sector.

Representational attributes

Data type:

Representational form:

Field size minimum:

Representational layout:

Field size maximum:

Data domain:

Guide for use:

Verification rules:

Collection methods:

Relational attributes

Related metadata:

relates to the data element concept Agency, version 1

relates to the data element concept Client, version 1

relates to the data element concept Service event, version 1

Information Model link:

Event/Health and welfare Service event/Service provision event

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT

Effective date: 01/07/2000

Source organisation: Australian Institute of Health and Welfare

Source document: Home and Community Care (HACC) Data Dictionary Version 1.0, 1998

Comments:

Glossary of terms

The following glossary of terms is suggested for inclusion in a community-based palliative care data collection. Some terms are already national data standards that have been included in either the NHDD or the NCSDD; others are new terms specifically for a palliative care data set. Please note that some attributes in the following data items have been left blank because the information is either unavailable or in the case of draft items is yet to be developed.

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Interdisciplinary team (DRAFT) 223
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Support network (DRAFT) 225

Family

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000517	<i>Version number:</i>	2
<i>Metadata type:</i>	DATA ELEMENT CONCEPT		
<i>Definition:</i>	Two or more people related by blood, marriage (including step-relations), adoption or fostering and who may or may not live together. They may form the central core of support networks for individuals.		
<i>Context:</i>	<p>The 'household family' has been traditionally viewed as a building block of society and it is the predominant unit reported statistically and historically. However, the 'household family', since it is tied to the idea of co-residence, forms only a snapshot in time and refers only to related people who live in the same household at a point in time. Related persons who leave the central household live in other households may still participate in the lives of other family members they do not live with in a variety of ways, including financial, material, physical, emotional, legal and spiritual. For instance, frail older people may receive help from their adult children even though they do not live in the same household.</p> <p>Data on families are essential elements for the study of the well being of family groups and in this way for the study of the well being of individuals. They are a tool for assessing the type of and level of support to which a person has access.</p> <p>By defining the extended family as the central support network for individual, support which would not have been defined as accessible to the individual using the 'Household family' definition becomes apparent. It is important to recognise the 'family beyond the household' when examining types and levels of support available to individuals.</p>		

Representational attributes

<i>Data type:</i>		
<i>Representational form:</i>		<i>Field size minimum:</i>
<i>Representational layout:</i>		<i>Field size maximum:</i>
<i>Data domain:</i>		
<i>Guide for use:</i>		
<i>Verification rules:</i>		
<i>Collection methods:</i>		

Family

(continued)

Relational attributes

<i>Related metadata:</i>	relates to the data element concept Agency, version 1
	relates to the data element concept Household family, version 1
	relates to the data element concept Informal carer, version 2
	relates to the data element concept Target group, version 1
	relates to the data element Environmental factors, version 2
	relates to the data element Family name, version 2
	relates to the data element Given name(s), version 2
	relates to the data element Household family type, version 3
	relates to the data element Household type, version 3
	relates to the data element Informal carer availability, version 4
	relates to the data element Labour force status, version 3
	relates to the data element Living arrangement, version 3
	relates to the data element Mother's original family name, version 2
	relates to the data element Referral source, version 2
	relates to the data element Relationship in household, version 3
	relates to the data element Status in employment, version 2
	supersedes previous data element Family, version 1
<i>Information Model link:</i>	Party/Party group/Family

Administrative attributes

<i>Registration authority:</i>	NCSIMG	
<i>Administrative status:</i>	CURRENT	<i>Effective date:</i> 01/07/2000
<i>Source organisation:</i>	Australian Institute of Family Studies	
<i>Source document:</i>	McDonald, P. 1995. Families in Australia: A Socio-Demographic Perspective. Melbourne: Australian Institute of Family Studies.	
<i>Comments:</i>	This definition differs from the ABS standard. This is necessary because the ABS standard is based on household collection, which is not suitable, in many community services' areas. The community service definition needs to be broader to incorporate families that exist outside of households.	

Informal carer

Identifying and definitional attributes

Knowledgebase ID: 000508

Version number: 2

Metadata type: DATA ELEMENT CONCEPT

Definition: A carer includes any person, such as a family member, friend or neighbour, who is giving regular, ongoing assistance to another person without payment for the care given.

The definition excludes formal care services such as homecare, care provided by volunteers or foster care that is arranged by formal services. It also excludes unregistered child carers who are receiving payment for their services. Where a potential carer is not prepared to undertake the caring role, the carer is considered to be not available.

Context: Care and support networks where the carers are unpaid (other than pension or benefit) play a critical role in community services provision, especially in caring for frail aged and younger people with disabilities within the community.

Information about carers is therefore of fundamental importance in assessing the ongoing needs of clients and their carers, and in service planning. The presence of a carer is often a key indicator of a person's ability to remain at home, especially if the person requires assistance. The absence of a carer, where a vulnerable client lives alone, is an indicator of client risk. Information on client living arrangement and informal carer availability provides an indicator of the potential in-home support and the extent to which the burden of care is absorbed by the informal caring system. The stability or otherwise of the carer's availability may be significant in the capacity of the client continuing to remain at home.

Existing carer definitions (eg. for purposes of establishing eligibility for Domiciliary Nursing Care Benefits (DNCB/Carer Allowance; Carer's Pension/Carer Payment) definitions used in ABS population, surveys of disability, ageing and carers) vary in context and purpose.

Representational attributes

Data type:

Representational form:

Field size minimum:

Representational layout:

Field size maximum:

Data domain:

Guide for use:

Verification rules:

Collection methods:

Informal carer

(continued)

Relational attributes

Related metadata: relates to the data element Activity - level of difficulty, version 1
relates to the data element Carer co-residency, version 1
relates to the data element concept Family, version 2
relates to the data element concept Volunteer, version 2
relates to the data element Relationship of carer to care recipient, version 1

Information Model link: Party role/Person role/Carer role

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT *Effective date:* 01/07/2000

Source organisation: Australian Institute of Health and Welfare

Source document: Home and Community Care (HACC) Data Dictionary Version 1.0, 1998

Comments:

Volunteer

Identifying and definitional attributes

<i>Knowledgebase ID:</i>	000608	<i>Version number:</i>	2
<i>Metadata type:</i>	DATA ELEMENT CONCEPT		
<i>Definition:</i>	<p>A person who willingly gives unpaid help in the form of time, service or skills through an organisation or group.</p> <p>The reimbursement of expenses in full or part (for example, token payments) or small gifts (for example, sports club T-shirts or caps) is not regarded as payment of salary, and people who receive these are still considered to be voluntary workers.</p> <p>People who receive payment in kind for the work they do (for example, receiving farm produce as payment for work done on a farm, rather than cash) are not considered to be volunteers.</p> <p>An organisation or group is any body with a formal structure. It may be as large as a national charity or as small as a local book club. Purely ad hoc, informal and temporary gatherings of people do not constitute an organisation.</p> <p>Persons on Community Service Orders and other similar work programs are not considered volunteers.</p>		
<i>Context:</i>	Voluntary work is an important contribution to national life. It meets needs within the community at the same time as it develops and reinforces social networks and cohesion.		

Representational attributes

<i>Data type:</i>		<i>Field size minimum:</i>	
<i>Representational form:</i>		<i>Field size maximum:</i>	
<i>Representational layout:</i>			
<i>Data domain:</i>			
<i>Guide for use:</i>			
<i>Verification rules:</i>			
<i>Collection methods:</i>			

Volunteer

(continued)

Relational attributes

Related metadata: relates to the data element concept Informal carer, version 2
relates to the data element Full-time equivalent volunteer/unpaid staff, version 1
relates to the data element Hours per week - volunteer/unpaid staff, version 1
relates to the data element Informal carer availability, version 4
supersedes previous data element Volunteer, version 1

Information Model link: Party role/Agency role/Service provider role (agency)

Administrative attributes

Registration authority: NCSIMG

Administrative status: CURRENT *Effective date:* 02/09/2003

Source organisation: Australian Bureau of Statistics.
Australian Institute of Health and Welfare

Source document: Australian Bureau of Statistics 2000. Voluntary Work, Australia. Cat. no. 4441.0.Canberra: ABS.

Comments:

Palliative care (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number: 1

Metadata type:

DATA ELEMENT CONCEPT

Definition:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Context:

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Representational attributes

Data type:

Representational form:

Field size minimum:

Representational layout:

Field size maximum:

Data domain:

Guide for use:

Verification rules:

Collection methods:

Palliative care (DRAFT)

(continued)

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document:

World Health Organisation Definition of Palliative Care 2002

Interdisciplinary team (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type:

DATA ELEMENT CONCEPT

Definition:

A team consisting of members who contribute from their particular expertise and who work interdependently, together providing a broad spectrum of knowledge, skill and creative problem solving to deliver palliative care.

Context:

Representational attributes

Data type:

Representational form:

Field size minimum:

Representational layout:

Field size maximum:

Data domain:

Guide for use:

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document:

Comments:

Palliative care phase (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type:

DATA ELEMENT CONCEPT

Definition:

A stage of change or development for a person and their family facing the problems associated with life-threatening illness.

Context:

Required to classify palliative care episodes of care.

Representational attributes

Data type:

Representational form:

Field size minimum:

Representational layout:

Field size maximum:

Data domain:

Guide for use:

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Source document:

Comments:

Support network (DRAFT)

Identifying and definitional attributes

Knowledgebase ID:

Version number:

Metadata type:

DATA ELEMENT CONCEPT

Definition:

The people who are closest to the patient in knowledge, care and affection. They may include the biological family, the family of acquisition (related by marriage or de-facto relationship) and friends.

Context:

Palliative care service provision

Representational attributes

Data type:

Representational form:

Field size minimum:

Representational layout:

Field size maximum:

Data domain:

Guide for use:

Verification rules:

Collection methods:

Relational attributes

Related metadata:

Information Model link:

Administrative attributes

Registration authority:

Administrative status:

Effective date:

Source organisation:

Australian Institute of Health and Welfare

Source document:

Resource manual for palliative care performance indicators in Australia.

Comments:

Glossary⁴

Agency information/ data	Information that is collected about each agency, e.g. staffing profile or target group. It does not refer to aggregated information about patients.
Client information system (CIS) (health sector)	A computer application that has been purpose built for the management of health service clients. Such a system may or may not cater solely for palliative care clients.
Community-based palliative care	Palliative care delivered in community-based settings, which include the person's private home or a community-living environment such as an aged or supported care facility' (PCA 2003).
Data item	The basic unit of identifiable and definable information, e.g. date of birth or site of death. The term 'data item' is used throughout this report as it is a commonly used term and is used interchangeably with the term 'data element'. It should be noted that the nationally and internationally preferable term is 'data element'.
Data set specification (DSS)	An agreed core set of data items and attributes, the collection of which may be optional or mandatory.
National health data standard	A specification for the definition and representation of a data item which has been endorsed by the National Health Information Group (NHIG) as a health data standard for Australia and hence is included in the <i>National Health Data Dictionary</i> .
National minimum data set (NMDS) (health sector)	An agreed core set of data items and their attributes, the collection of which is

⁴ The descriptions in this glossary are not nationally endorsed definitions, and are intended for use in the context of this report only. For some terms internationally agreed definitions have been used as a basis, but as these are highly technical they have been adjusted (ISO/IEC 2003).

	mandatory and endorsed for national collection by the NHIG under the National Health Information Agreement. A NMDS is a special type of data set specification.
Object class	A class of persons, places, events or things that needs to be described.
Palliative care	An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' (WHO 2003)
Patient-level information/data	Information collected about each patient and reported as either aggregated or unit record data.
Performance indicator	A measure that quantifies the level of performance for a particular aspect of (health) service provision.

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