

Palliative care information development

**Progress report on the
National Minimum Data Set
for Palliative Care**

The Australian Institute of Health and Welfare is an independent health and welfare statistics and information agency. The Institute's mission is to inform community discussion and decision making through national leadership in the development and provision of authoritative and timely information on the health and welfare of Australians.

Palliative care information development

**Progress report on the
National Minimum Data Set
for Palliative Care**

**Clara Jellie
and
Janis Shaw**

December 1999

Australian Institute of Health and Welfare
Canberra

AIHW cat. no. HSE 8

© Australian Institute of Health and Welfare 1999

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced without prior written permission from the Australian Institute of Health and Welfare. Requests and enquiries concerning reproduction and rights should be directed to the Head, Communication and Public Affairs, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

A complete list of the Institute's publications is available from the Publications Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601, or via the Institute's web site (<http://www.aihw.gov.au>).

ISBN 1 74024 036 7

Suggested citation

Jellie C & Shaw J 1999. Palliative care information development: progress report on the National Minimum Data Set for Palliative Care. AIHW cat. no. HSE 8. Canberra: Australian Institute of Health and Welfare.

Australian Institute of Health and Welfare

Board Chair
Professor Janice Reid

Director
Dr Richard Madden

Any enquiries about or comments on this publication should be directed to:

Ms Clara Jellie
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601

Phone: (02) 6244 1180

Published by the Australian Institute of Health and Welfare

Printed by Elect Printing; Acrobat conversion by Green Words & Images

Contents

Abbreviations	vii
1 Introduction	1
1.1 Aims of this report.....	1
2 Palliative care in Australia	2
2.1 What is palliative care?	2
2.2 The increase in palliative care.....	2
2.3 Palliative care services in Australia	3
2.4 Implications for data collection	5
3 Existing palliative care data	6
3.1 National Hospital Morbidity Database	6
3.2 National Public Hospital Establishments Database	16
3.3 Private Health Establishments Collection.....	17
3.4 National Census of Palliative Care Services	18
3.5 Other data developments	20
3.6 Issues in data development.....	22
4 Performance indicators for palliative care	26
4.1 Issues in developing performance information	26
4.2 Future development of performance indicators	27
5 Development of the National Minimum Data Set for Palliative Care	29
5.1 Initial development of the NMDS—palliative care	29
5.2 Recent development of the NMDS—palliative care	31
6 Future directions	33
6.1 Proposed data developments.....	33
6.2 Work program.....	35
Appendix A	37
Performance indicators proposed by Palliative Care Australia	37
Appendix B	38
Data requirements for palliative care performance indicators	38

Appendix C	41
Data elements recommended by the Victorian Department of Human Services for inclusion in the National Minimum Data Set—palliative care.....	41
Appendix D	42
The Australian Institute of Health and Welfare	42
Structures and data development processes for national health information	43
References	45

Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AN-SNAP	Australian National Sub-Acute and Non-Acute Patient Classification
CNMDSA	Community Nursing Minimum Data Set Australia
HACC	Home and Community Care
HIV/AIDS	Human immunodeficiency virus/Acquired immune deficiency syndrome
ICD-9-CM	International Classification of Diseases, 9th edition, Clinical Modification
ICD-10-AM	International Classification of Diseases, 10th edition, Australian Modification
NCSIMG	National Community Services Information Management Group
NHIMG	National Health Information Management Group
NMDS	National Minimum Data Set
PCA	Palliative Care Australia
RUG-ADL	Resource Utilisation Groups Activities of Daily Living

1 Introduction

The need for high-quality information on health services is recognised as a basic requirement in the development and evaluation of health policy initiatives and interventions. In relation to palliative care, data are needed to inform evaluation of the *National Strategy for Palliative Care in Australia 1998–2003* that has been released by the Commonwealth Department of Health and Aged Care (DHFS 1998a). The strategy recognises the fundamental differences in the nature of palliative care in comparison to acute health care, and aims to:

- support the integration of palliative care services within the health services sector;
- ensure that services are accessible to all Australians;
- ensure that available services are of high quality; and
- ensure that adequate education and information is available to all (including specialised programs for those working within palliative care services).

The need for national data relating to palliative care is also highlighted in the context of current efforts to develop performance indicators for palliative care. These are proposed for reporting at a number of levels: high-level indicators as required by the current Australian Health Care Agreements for funding accountability, and other national indicators to assist in monitoring the development and delivery of palliative care services. These indicators will also facilitate improvements at the local service level.

Consequently, there is an urgent need for the development of a National Minimum Data Set for palliative care (NMDS—palliative care) to provide descriptive information in relation to palliative care and to underpin the reporting of performance indicators. The development of a NMDS—palliative care would signify an agreement among all States and Territories to collect a specified core data set according to nationally agreed definitions. Recommendations to develop such a NMDS have been supported by Palliative Care Australia (PCA—the peak non-government organisation representing palliative care service providers), State and Territory health authorities, and the Commonwealth Department of Health and Aged Care.

1.1 Aims of this report

The aims of this report are:

- to describe the palliative care service delivery environment and implications for the development of the NMDS—palliative care;
- to provide an assessment of existing data collections relating to palliative care;
- to describe performance indicator data requirements and data development processes; and
- to provide information on work undertaken to date in developing the NMDS—palliative care, and to make recommendations for the future development of palliative care data.

2 Palliative care in Australia

2.1 What is palliative care?

Palliative care is

...the active total care of people whose disease is not responsive to curative treatment. Care is delivered by coordinated medical, nursing and allied health services which are provided, where possible, in the environment of the person's choice. Control of pain, of other symptoms and provision of psychological, social, emotional and spiritual support is paramount. (DHFS 1998a, p. 2)

While the term 'palliative care' has often been used to refer to the care received by people in the terminal phase of their disease, in current models of palliative care the term is used more broadly to refer to the total care of people with life-threatening disease whose death may not be imminent (Higginson 1993; Kasap and Associates 1996). It should be noted that palliative care does not preclude interventions such as chemotherapy or radiotherapy, where these treatments are undertaken to provide symptomatic relief.

While providing palliation of symptoms and other support to the dying has always been regarded as fundamental to good medical care, it is only in recent decades that care for people with terminal illnesses has been viewed as a specialised area of medical and nursing practice. Common symptoms experienced by palliative care patients, for which patients may benefit from the care of staff with specialised training, include pain, shortness of breath, eating problems, nausea/vomiting, constipation, confusion and psychological disturbances (including anxiety and depression) (Chan and Woodruff 1991).

Patients may also benefit from care delivered by a range of allied health and other professionals. These include physiotherapists, social workers, occupational therapists, clinical pharmacists, psychologists/counsellors, nutritionists and pastoral care workers. The use of volunteers (particularly for respite care) and bereavement counsellors (for the family and carers following the death of the patient) is also common in a comprehensive model of palliative care.

2.2 The increase in palliative care

The relatively rapid rise of palliative care services in Australia and elsewhere has been likened to a social movement (Maddocks 1990). In South Australia, it was found that the proportion of cancer deaths that occurred in major metropolitan public acute hospitals had declined from 40% to 28% between 1981 and 1990. In this same period, the proportion of cancer patients dying in designated hospice/palliative care admitted patient settings increased from 5% to 20%. The proportion of cancer patients dying at home, in nursing homes, and in other hospitals (other metropolitan and non-metropolitan hospitals), however, remained unchanged (Hunt et al. 1993).

Similar findings emerged in another Australian study based in a large metropolitan public acute hospital. The records of 110 patients who had received treatment for incurable disseminated cancer were retrospectively analysed. It was reported that 75% of these patients died in hospital, 6% at home, and 19% in an admitted patient hospice. Following the establishment of a palliative care service for cancer and other patients in the hospital, 45% of patients died in hospital, 24% at home and 31% within an admitted patient hospice (Woodruff et al. 1991). Outcomes such as these indicate the increased use of palliative care services within the Australian healthcare system.

The increased usage of palliative care services has been attributed to a number of factors. Among these are:

- the increasing number of people dying of cancer (and expected increases in cancer deaths as our population continues to age);
- the lack of coordinated care and other care that addresses the special needs of the dying as a result of the structure of health services and the emphasis on service delivery provided in large hospitals; and
- the need for improved understanding and management of pain and other symptoms (DHFS 1998b; Higginson 1993; Kasap and Associates 1996; Maddocks 1990).

2.3 Palliative care services in Australia

Funding was first provided to States and Territories specifically for the development of palliative care service delivery in 1988. The aim of this funding was to enable dying patients to remain at home through the course of their illness in a familiar environment, as well as to minimise hospital stays (DHFS 1998b). Before these initiatives, care to the terminally ill was largely delivered by charitable organisations and volunteers (Kasap and Associates 1996).

Services that are now available to the dying include designated facilities that deliver palliative care exclusively, with a range of trained medical, allied health and other professionals at hand, and other service providers who may have a broader client base. These latter service providers include general practitioners, community/district nurses and domiciliary care support. The full scope of services currently involved in the delivery of palliative care is described in the *Report to the Palliative Care Program Review: Stage One* (Kasap and Associates 1996). The mix of services involved in the delivery of palliative care is regarded as an important feature of good palliative care, as it supports a range of options for palliative care patients and their families (such as supporting families to care for the patient at home).

In the current healthcare environment, designated palliative care programs (i.e. programs that exclusively deliver care to palliative care patients) are delivered by a range of services in a variety of settings including hospital settings and hospices, homes and residential institutions. The types of services delivered include admitted patient services, outpatient care, home-based care (provided in the setting in which the patient is living), respite care and bereavement care for the family/carer following the death of the patient. The mix of typical services and their service settings is presented in Table 2.1.

Table 2.1: Palliative care services by type of service and service delivery setting

Service setting	Patient clinical care			Respite/day care	Bereavement care
	Admitted patient care	Outpatient care	Home-based care		
Hospital	✓	✓			
Hospice	✓	✓		✓	✓
Home/community			✓	✓	✓
Residential institution (e.g. nursing home)			✓		

While this table broadly represents the range of palliative care services provided and their usual settings, there may be exceptions to this classification table. For example, not all hospices provide respite/day care, while some hospitals do provide such programs. Activities not directly related to patient care (such as conducting educational sessions with other health professionals or community members) are not considered in this matrix.

The way in which services are delivered varies greatly. Hospital-based services may be organised as a dedicated palliative care ward or unit within the hospital, or may be organised as beds distributed throughout the hospital with care delivered by a palliative care consultancy team. Under a consultancy model, specialised staff deliver care in consultation with the referring medical team and assist in referring patients to appropriate community-based palliative care services.

In some instances, services may provide care for specific groups of palliative care patients only, such as cancer patients, HIV/AIDS patients or children requiring palliative care.

Principles of palliative care service delivery

With the development of these services, there has also been work undertaken to articulate the underlying principles of palliative care and to develop standards for care (PCA 1998b; DHFS 1998a). Agreed characteristics of the optimal palliative care service include:

- recognition of the patient, family and carers as all requiring care;
- responsiveness to the needs and preferences of the patient and family (e.g. the service is able to provide support for a patient and their family when the patient chooses to die at home);
- provision of multidisciplinary care, including specialised medical and nursing staff, allied health professionals, and counselling or other professionals who are able to assist the patient and their family in their emotional and spiritual needs when required;
- provision of holistic care and continuing support through all stages of palliative care from the initial stable phase (where maintaining pain and other symptom control is the primary goal) to bereavement care (where the family is supported to cope with the death of the patient); and
- commitment by palliative care services and professionals to quality improvement and the ongoing evaluation of services.

2.4 Implications for data collection

Under present funding arrangements, States and Territories determine the nature and location of palliative care services delivered within their jurisdictions (DHFS 1997). As a result, the structure of programs that deliver palliative care services varies greatly across jurisdictions, particularly with respect to the relative balance between admitted patient and home-based palliative care services, and the extent to which palliative care services are integrated with other health services. Thus, there is a need to develop data on the provision of designated palliative care services that extends across both the admitted patient and community health service sectors in order to obtain comprehensive data that are comparable across jurisdictions.

Long-term data development efforts will also need to assess the extent to which data on palliative care can be obtained from non-specialised services such as general practitioners and community nurses.

3 Existing palliative care data

National data collections relating to palliative care at present are fragmented. Four data collections, however, provide a range of useful data on the provision of palliative care in Australia. Summary data from these collections are provided below and some additional potential sources of data are also described.

3.1 National Hospital Morbidity Database

The National Hospital Morbidity Database is a patient-level data set that is collected on admitted patients in public and private hospitals (including hospices) in Australia and collated by the Australian Institute of Health and Welfare. The only exceptions are public hospitals not within the jurisdiction of a State or Territory health authority or the Department of Veterans' Affairs. Data are not complete for a small number public and private hospitals in some jurisdictions, although coverage of these hospitals is improving.

All data collected on admitted patients are agreed as part of the NMDS—institutional health care and data definitions are compiled in the *National Health Data Dictionary* (National Health Data Committee 1999). Data are validated in conjunction with the States/Territories and Department of Veterans' Affairs, and a summary of the data is reported annually in *Australian Hospital Statistics* (AIHW 1999a).

Data in this database include administrative data, demographic information on patients, and clinical information including diagnoses and procedures performed. Data provided to this data set are based on episodes of care, that is, a single phase of treatment for an admitted patient. Each phase of care is classified as either a palliative, acute, rehabilitation, non-acute or other episode of care. Unqualified neonates (i.e. most healthy newborn babies) are also identified separately. Where a patient receives only one type of care in a hospital, the episode of care length will be equivalent to the hospital stay length. Where patients receive different types of care (for example, in the case of a patient who is admitted for active cancer treatment as an acute patient, but who may be reclassified as a palliative care patient), the patient will be statistically separated from the hospital and transferred into a second phase (or episode) of care. The collection of morbidity data is separation-based (i.e. all data are reported at the completion of each episode of care) and each admission or re-admission generates a separate patient record.

Episode of care types are able to be identified through the collection of the data element *type of episode of care*, which enables palliative care separations data to be distinguished from data for other episodes of care. The episode of care 'flag' is needed to undertake analyses because palliative care patients cannot be distinguished by diagnosis or other clinical characteristics. This data item, however, has not been supplied by the Australian Capital Territory for any hospital, and is not complete for private hospitals in Victoria, Tasmania and the Northern Territory. Other notes on the data and data quality may be found in *Australian Hospital Statistics 1997–98* (AIHW 1999a).

Table 3.1: Separations by type of episode of care and hospital sector, States and Territories, 1997–98

	NSW	Vic	Qld	WA	SA	Tas ^(a)	ACT	NT ^(b)	Total
Type of episode of care	Public hospitals								
Acute care	1,223,555	902,306	659,290	338,500	342,226	78,140	n.a.	51,782	3,595,799
Rehabilitation	28,626	17,993	19,212	3,025	2,681	766	n.a.	179	72,482
Palliative care	8,581	2,644	1,852	369	957	480	n.a.	24	14,907
Non-acute care	7,630	5,904	4,317	1,188	918	761	n.a.	400	21,118
Other care	4,145	0	674	82	0	230	n.a.	13	5,144
Not reported	260	0	0	3,199	0	12	57,175	2	60,648
<i>Total</i>	<i>1,272,797</i>	<i>928,847</i>	<i>685,345</i>	<i>346,363</i>	<i>346,782</i>	<i>80,389</i>	<i>57,175</i>	<i>52,400</i>	<i>3,770,098</i>
	Private hospitals								
Acute care	520,157	477,194	379,431	158,934	146,147	1,136	n.a.	n.a.	1,682,999
Rehabilitation	11,446	6,867	5,705	220	812	n.a.	n.a.	n.a.	25,050
Palliative care	503	n.a.	930	1,172	312	n.a.	n.a.	n.a.	2,917
Non-acute care	1,794	140	771	21	149	n.a.	n.a.	n.a.	2,875
Other care	10,237	0	1,241	11	0	1	n.a.	n.a.	11,490
Not reported	214	0	0	0	0	49,860	17,571	n.a.	67,645
<i>Total</i>	<i>544,351</i>	<i>484,201</i>	<i>388,078</i>	<i>160,358</i>	<i>147,420</i>	<i>50,997</i>	<i>17,571</i>	<i>n.a.</i>	<i>1,792,976</i>
	All hospitals								
Acute care	1,743,712	1,379,500	1,038,721	497,434	488,373	79,276	n.a.	51,782	5,278,798
Rehabilitation	40,072	24,860	24,917	3,245	3,493	766	n.a.	179	97,532
Palliative care	9,084	2,644	2,782	1,541	1,269	480	n.a.	24	17,824
Non-acute care	9,424	6,044	5,088	1,209	1,067	761	n.a.	400	23,993
Other care	14,382	0	1,915	93	0	231	n.a.	13	16,634
Not reported	474	0	0	3,199	0	49,872	74,746	2	128,293
Total separations	1,817,148	1,413,048	1,073,423	506,721	494,202	131,386	74,746	52,400	5,563,074

(a) Data has been adapted from that published in *Australian Hospital Statistics 1997–98* (AIHW 1999a): some separations from psychiatric hospitals that were reported as *palliative care* have been re-coded to *non-acute care*.

(b) For the Northern Territory, *acute care* includes *other care*, and *psychiatric care* has been included in *non-acute care*.

n.a. Not available.

There were 5,563,074 hospital separations from public and private hospitals in 1997–98 (Table 3.1). Of these, 17,824 (0.3%) separations were palliative care separations (see exclusions described on page 6). The vast majority of separations were acute care separations (95%), with much smaller proportions of rehabilitation, non-acute and other patients. Table 3.1 also shows that 84% of palliative care separations were from public hospitals, and the remaining 16% were from private hospitals.

Table 3.2: Palliative care separations and patient days by patient accommodation status, public and private hospitals, Australia, 1997–98^(a)

Accommodation status	Sameday separations	Non-sameday separations	Total separations	Patient days
Public patient	2,254	10,991	13,245	167,876
Private patient	389	2,357	2,746	37,298
Department of Veterans' Affairs patient	60	1,629	1,689	29,649
Other ^(b)	3	57	60	750
Unknown/missing	0	84	84	1,877
Total	2,706	15,118	17,824	237,450

(a) Excludes the Australian Capital Territory.

(b) Includes patients who do not meet the criteria for the other categories (such as compensable patients, patients with Defence Force personnel entitlements and patients who are not eligible under Medicare).

Table 3.2 provides further information on the accommodation status (i.e. public, private, Department of Veterans' Affairs or other) of admitted palliative care patients. A majority of patients were treated as public patients (74% of separations), and a majority of hospital separations involved a stay of at least one night (85%). Palliative care separations accounted for 237,450 patient days, indicating that the average length of stay was 13.3 days (compared to 4.0 days for all other patient separations).

Table 3.3: Palliative care separations by age group and sex, public and private hospitals, Australia, 1997–98^(a)

Age group	Males	Females	Total separations	Per cent total separations	Average length of stay (days)
<1	2	2	4	0.0	5.5
1–4	29	9	38	0.2	2.9
5–14	8	12	20	0.1	1.5
15–24	28	44	72	0.4	10.7
25–34	125	116	241	1.4	13.5
35–44	304	413	717	4.0	15.0
45–54	814	790	1,604	9.0	12.0
55–64	1,840	1,311	3,151	17.7	10.9
65–74	3,106	2,188	5,294	29.7	13.8
75–84	2,548	2,381	4,929	27.7	14.4
85+	897	857	1,754	9.8	14.1
Total	9,701	8,123	17,824	100.0	13.3

(a) Excludes the Australian Capital Territory.

Males accounted for 54% of the palliative care separations, and females the remaining 46% (Table 3.3). Over one-third of palliative care separations were patients aged 75 years or over. Approximately two-thirds of all palliative care separations were patients aged 65 years or over.

Table 3.4: Palliative care separations by Indigenous status, public and private hospitals, 1997–98^(a)

Indigenous status	Separations	Per cent separations	Patient days
Aboriginal/Torres Strait Islander	208	1.2	2,354
Not Aboriginal/Torres Strait Islander	16,863	94.6	227,232
Not reported	753	4.2	7,864
Total	17,824	100.0	237,450

(a) Excludes the Australian Capital Territory.

Table 3.5: Palliative care separations by selected country/region of birth, public and private hospitals, 1997–98^(a)

Country/region of birth	Separations	Per cent separations	Patient days
Oceania			
Australia ^(b)	12,119	68.0	166,749
New Zealand	175	1.0	2,068
Other Oceania	42	0.2	644
<i>Total Oceania</i>	<i>12,336</i>	<i>69.2</i>	<i>169,461</i>
Europe and the former USSR			
England	1,167	6.5	14,766
Scotland	305	1.7	3,737
Ireland, Republic of	230	1.3	1,716
Greece	225	1.3	2,864
Italy	481	2.7	5,566
Germany	241	1.4	2,509
Netherlands	187	1.0	2,264
Poland	173	1.0	2,602
Europe and the former USSR (other)	1,303	7.3	15,324
<i>Total Europe and the former USSR</i>	<i>4,312</i>	<i>24.2</i>	<i>51,348</i>
Middle East and North Africa	252	1.4	2,912
Southeast Asia	200	1.1	2,951
Northeast Asia	153	0.9	1,879
Southern Asia	87	0.5	1,179
Northern America	48	0.3	615
South America, Central America and the Caribbean	55	0.3	774
Africa (excluding North Africa)	61	0.3	657
Not reported/inadequately described	320	1.8	5,674
Total	17,824	100.0	237,450

(a) Excludes the Australian Capital Territory.

(b) Includes Australian External Territories.

Tables 3.4 and 3.5 provide information on the Indigenous status and the country of birth of palliative care patients. There were 208 separations (1.2%) for patients reported as Aboriginal and/or Torres Strait Islander. This information was not reported for 4.2% of separations. A majority of palliative care patients were Australian-born (68%; 12,119 separations). People born in Europe and the former USSR accounted for a further 24% of separations, with England being the most common country of birth outside Australia (7%; 1,167 separations).

Table 3.6 provides information on the geographic location (rural, remote or metropolitan) of the usual residence of palliative care patients at the time of their hospital admission. Approximately 75% of patients usually resided in metropolitan areas, a further 23% in rural areas and 2% in remote areas. This pattern broadly approximates the population distribution in Australia. It should be noted that this table does not show the geographic location of the hospital to which the patient was admitted, and so does not provide information on availability and access to services in rural and remote areas.

Table 3.6: Palliative care separations and patient days by area of usual residence of patient, public and private hospitals, Australia, 1997–98^(a)

Area of usual residence	Separations	Per cent separations	Patient days	Per cent patient days	Average length of stay (days)
Capital cities	12,581	70.6	175,099	73.7	13.9
Other metropolitan centres	852	4.8	10,818	4.6	12.7
<i>Total metropolitan</i>	<i>13,433</i>	<i>75.4</i>	<i>185,917</i>	<i>78.3</i>	<i>13.8</i>
Large rural centres	1,300	7.3	14,349	6.0	11.0
Small rural centres	953	5.3	11,178	4.7	11.7
Other rural areas	1,822	10.2	22,264	9.4	12.2
<i>Total rural</i>	<i>4,075</i>	<i>22.9</i>	<i>47,791</i>	<i>20.1</i>	<i>11.7</i>
Remote centres	133	0.7	1,214	0.5	9.1
Other remote areas	162	0.9	2,404	1.0	14.8
<i>Total remote</i>	<i>295</i>	<i>1.7</i>	<i>3,618</i>	<i>1.5</i>	<i>12.3</i>
Not recorded	21	0.1	124	0.1	5.9
Total	17,824	100.0	237,450	100.0	13.3

(a) Excludes the Australian Capital Territory.

The following tables present information on the diagnoses (classified according to ICD-9-CM (National Coding Centre 1996)) reported for palliative care patients. The principal diagnosis is 'the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of care in hospital' (National Health Data Committee 1999, p. 115). The principal diagnosis is usually a disease, injury or poisoning, but can also be a specific treatment for an already diagnosed condition (e.g. dialysis for renal disease), or other reason for hospitalisation. In addition to the principal diagnosis, additional diagnoses (which include comorbidities and complications) can be recorded for each separation. On average, identified palliative care patients had 5.0 diagnoses reported (including the principal diagnosis), compared to 2.8 diagnoses for all other patients (Table 3.7).

Table 3.7: Palliative care separations and all other separations by number of diagnoses reported^(a) and hospital sector, 1997–98

Hospital sector	Palliative care separations^(b)		All other separations	
	Number	Per cent	Number	Per cent
Public hospitals				
No diagnosis codes reported	46	0.3	982	0.0
One diagnosis code only	911	6.1	1,087,468	29.0
Two diagnosis codes only	2,053	13.8	1,019,800	27.2
Three diagnosis codes only	2,109	14.1	571,181	15.2
Four diagnosis codes only	2,142	14.4	356,615	9.5
Five or more diagnosis codes	7,646	51.3	719,145	19.2
Mean diagnosis codes per separation ^(c)	5.0	..	3.0	..
<i>Total public hospital separations</i>	<i>14,907</i>	<i>100.0</i>	<i>3,755,191</i>	<i>100.0</i>
Private hospitals				
No diagnosis codes reported	0	0.0	503	0.0
One diagnosis code only	135	4.6	656,520	36.7
Two diagnosis codes only	437	15.0	513,728	28.7
Three diagnosis codes only	472	16.2	282,532	15.8
Four diagnosis codes only	460	15.8	147,222	8.2
Five or more diagnosis codes	1,413	48.4	189,554	10.6
Mean diagnosis codes per separation ^(c)	4.8	..	2.4	..
<i>Total private hospital separations</i>	<i>2,917</i>	<i>100.0</i>	<i>1,790,059</i>	<i>100.0</i>
All hospitals				
No diagnosis codes reported	46	0.3	1,485	0.0
One diagnosis code only	1,046	5.9	1,743,988	31.5
Two diagnosis codes only	2,490	14.0	1,533,528	27.7
Three diagnosis codes only	2,581	14.5	853,713	15.4
Four diagnosis codes only	2,602	14.6	503,837	9.1
Five or more diagnosis codes	9,059	50.8	908,699	16.4
Mean diagnosis codes per separation ^(c)	5.0	..	2.8	..
Total separations	17,824	100.0	5,545,250	100.0

(a) Codes reporting external causes of injury and poisoning were not included.

(b) Excludes the Australian Capital Territory.

(c) Does not include separations for which no diagnosis codes were recorded.

Note: The AIHW requested up to 31 diagnosis codes to be reported.

.. Not applicable.

Table 3.8 shows that the most common principal diagnosis group recorded for palliative care separations (70%) was neoplasm (of which a vast majority is cancer). By contrast, neoplasm was recorded as a principal diagnosis in only 7% of all hospital separations. The group *other reasons for contact with health services* (9%) was the second most common principal diagnosis group of codes for palliative care patients. This category includes admissions that arise from circumstances other than a disease or injury that would be coded to categories 001–999. For palliative care patients, the most common codes indicated: admission for administrative purposes, chemotherapy, admission to hospital where there is no household member able to render care to the patient, admission for a rehabilitation procedure, admission for a person awaiting admission to an adequate facility elsewhere, respite care, and admission for aftercare following surgery. The other disease chapters accounted for much smaller proportions of palliative care separations (0.03–3.32%).

HIV/AIDS was reported as the principal diagnosis for 16 palliative care separations, and as an additional diagnosis for 206 separations.

The majority of palliative care separations for neoplasms were classified as ‘malignant neoplasm of other and unspecified sites’, then ‘malignant neoplasm of the digestive organs and peritoneum’ and ‘malignant neoplasm of the respiratory and intrathoracic organs’ (Table 3.9). At the more detailed 3-digit disease groupings level, the most common diagnoses (for those with cancer) were: malignant neoplasm of the trachea, bronchus and lung; secondary malignant neoplasm of other unspecified sites; secondary malignant neoplasm of the respiratory and digestive systems; malignant neoplasm of the prostate; malignant neoplasm of the female breast; and malignant neoplasm of the colon. Only a very small proportion of palliative care separations with a principal diagnosis of neoplasm had benign tumours (codes 210–229; 0.2%).

The National Hospital Morbidity Database also contains information on all procedures (also classified according to ICD-9-CM (National Coding Centre 1996)) that are performed during each hospital admission. A reported procedure is one that ‘is surgical in nature; carries a procedural risk; carries an anaesthetic risk; requires specialised training; or requires special facilities or equipment only available in an acute care setting’ (National Health Data Committee 1999, p. 318). The principal procedure is that procedure performed in the treatment of the principal diagnosis. However, when no procedure was performed to treat the principal diagnosis, then other procedures can be recorded (further details may be found in National Health Data Committee 1999). Procedures are not necessarily performed during all hospital admissions. For palliative care patients, 54.9% (9,786) of separations did not report a procedure. For separations where procedures were reported, the most common principal procedures were: social work assessment and management (9.5%; 1,688 separations); diagnostic physical therapy (4.3%; 766 separations); injection or infusion of other therapeutic or prophylactic substances (3.8%; 673 separations); other rehabilitation therapy (3.7%; 668 separations); and transfusion of blood and blood components (3.5%; 627 separations).

Table 3.8: Separations, patient days and average length of stay by principal diagnosis in ICD-9-CM chapter groupings, palliative care patients, public and private hospitals, 1997–98^(a)

Principal diagnosis		Separations	Per cent separations	Patient days	Per cent patient days	Average length of stay (days)
001–139	Infectious and parasitic diseases	110	0.6	1,420	0.6	12.9
140–239	Neoplasms	12,465	69.9	185,213	78.0	14.9
240–279	Endocrine, nutritional and metabolic diseases, and immunity disorders	152	0.9	1,586	0.7	10.4
280–289	Diseases of the blood and blood-forming organs	300	1.7	1,419	0.6	4.7
290–319	Mental disorders	223	1.3	4,903	2.1	22.0
320–389	Diseases of the nervous system and sense organs	398	2.2	5,111	2.2	12.8
390–459	Diseases of the circulatory system	572	3.2	5,664	2.4	9.9
460–519	Diseases of the respiratory system	591	3.3	7,014	3.0	11.9
520–579	Diseases of the digestive system	466	2.6	4,748	2.0	10.2
580–629	Diseases of the genitourinary system	199	1.1	2,135	0.9	10.7
630–677	Complications of pregnancy, childbirth, and the puerperium	5	0.0	26	0.0	5.2
680–709	Diseases of the skin and subcutaneous tissue	40	0.2	627	0.3	15.7
710–739	Diseases of the musculoskeletal system and connective tissue	167	0.9	2,109	0.9	12.6
740–779	Congenital anomalies/certain conditions originating in the perinatal period	18	0.1	151	0.1	8.4
780–799	Symptoms, signs and ill-defined conditions	360	2.0	3,520	1.5	9.8
800–999	Injury and poisoning	121	0.7	1,831	0.8	15.1
V01–V82	Other reasons for contact with health services	1,591	8.9	9,443	4.0	5.9
	Not reported	46	0.3	530	0.2	11.5
Total		17,824	100.0	237,450	100.0	13.3

(a) Excludes the Australian Capital Territory.

Table 3.9: Separations, patient days and average length of stay for separations with a principal diagnosis of neoplasm, palliative care patients, public and private hospitals, 1997–98^(a)

Principal diagnosis		Separations	Per cent separations	Patient days	Per cent patient days	Average length of stay (days)
ICD-9-CM disease groupings						
140–149	Malignant neoplasm of lip, oral cavity, and pharynx	249	2.0	4,029	2.2	16.2
150–159	Malignant neoplasm of digestive organs and peritoneum	2,673	21.4	36,380	19.6	13.6
160–165	Malignant neoplasm of respiratory and intrathoracic organs	2,176	17.5	30,979	16.7	14.2
170–176	Malignant neoplasm of bone, connective tissue, skin, and breast	1,030	8.3	14,431	7.8	14.0
179–189	Malignant neoplasm of genitourinary organs	1,522	12.2	27,052	14.6	17.8
190–199	Malignant neoplasm of other and unspecified sites	3,990	32.0	61,945	33.4	15.5
200–208	Malignant neoplasm of lymphatic and haematopoietic tissue	750	6.0	9,293	5.0	12.4
210–229	Benign neoplasms	22	0.2	273	0.1	12.4
230–234	Carcinoma in situ	7	0.1	135	0.1	19.3
235–238	Neoplasms of uncertain behaviour	38	0.3	487	0.3	12.8
239	Neoplasms of unspecified nature	8	0.1	209	0.1	26.1
Total		12,465	100.0	185,213	100.0	14.9
3-digit ICD-9-CM disease groupings with the highest number of separations						
162	Malignant neoplasm of trachea, bronchus and lung	1,986	15.9	28,363	15.3	14.3
198	Secondary malignant neoplasm of other unspecified sites	1,550	12.4	27,336	14.8	17.6
197	Secondary malignant neoplasm of respiratory and digestive systems	1,429	11.5	16,726	9.0	11.7
185	Malignant neoplasm of prostate	694	5.6	13,432	7.3	19.4
174	Malignant neoplasm of female breast	679	5.4	8,520	4.6	12.5
153	Malignant neoplasm of colon	546	4.4	7,737	4.2	14.2
157	Malignant neoplasm of the pancreas	539	4.3	6,511	3.5	12.1
154	Malignant neoplasm of the rectum, rectosigmoid junction, and anus	515	4.1	8,749	4.7	17.0

(a) Excludes the Australian Capital Territory.

The following tables (Tables 3.10 and 3.11) provide information on the modes of admission to and discharge from hospital. The majority of patient admissions (67%) were new admissions (rather than transfers from other hospitals or patients already in hospital and being statistically re-admitted). A further 24% of separations were for patients admitted to hospital via transfer from another hospital. For palliative care patients, 48% of separations ended with the patient's death, and 43% of separations were coded as 'other' (which includes discharge home or to the patient's usual residence), which compares with 1% deaths and 93% coded as 'other' for all other patients. Referral data and information on non-hospital aftercare provided in the home are not available.

Table 3.10: Mode of admission, palliative care patients, public and private hospitals, Australia, 1997–98^(a)

Mode of admission	Separations	Per cent separations
Admitted patient transferred from another hospital	4,326	24.3
Statistical admission—type change ^(b)	1,515	8.5
Statistical admission from leave	1	0.0
Other	11,955	67.1
Not recorded	27	0.2
Total	17,824	100.0

(a) Excludes the Australian Capital Territory.

(b) A *statistical admission—type change* occurs for patients whose hospital stay has been divided into separate episodes of care. Discharge and admission between the episodes of different types within the same hospital stay is said to be statistical.

Table 3.11: Mode of separation, palliative care patients, public and private hospitals, Australia, 1997–98^(a)

Mode of separation	Separations	Per cent separations
Discharge/transfer to an(other) acute hospital	796	4.5
Discharge/transfer to a nursing home	418	2.3
Discharge/transfer to other health care accommodation	64	0.4
Statistical discharge—type change ^(b)	228	1.3
Left against medical advice/discharge at own risk	24	0.1
Statistical discharge from leave	167	0.9
Died	8,486	47.6
Other (includes discharge to usual residence)	7,640	42.9
Not recorded	1	0.0
Total	17,824	100.0

(a) Excludes the Australian Capital Territory.

(b) A *statistical admission—type change* occurs for patients whose hospital stay has been divided into separate episodes of care. Discharge and admission between the episodes of different types within the same hospital stay is said to be statistical.

Other variables reported to this data set that are not analysed in this report include: additional procedures, compensable status, insurance status, diagnosis-related groups and the State or Territory of the hospital the patient was treated in. A full listing of data elements reported to this

data set is available through the Knowledgebase—Australia’s Health and Community Services Data Registry (AIHW 1999b).

Limitations of data

- While palliative care episodes can be identified through the *type of episode of care* data item, this item has not been provided by one jurisdiction (the Australian Capital Territory). It is anticipated, however, that this field will be provided by all jurisdictions from 1998–99, which will enable complete national admitted palliative care patient data to be compiled.
- The extent to which statistical discharging has been implemented may have varied, particularly in the private sector. This may result in an underestimation of palliative care episodes (e.g. following acute episodes).
- This data collection relates to admitted patients only and does not include information on patients cared for in their homes, in residential facilities (e.g. nursing homes), or by community-based services. Data from services providing residential respite care are also not included.
- All data in this database are based on separations and not individual patients. Hence, a patient entering hospital three times in a year will generate three records. Similarly, a patient who enters hospital for acute care and then receives palliative care will generate two records. Therefore, data on the number of individuals being cared for is not available, nor are there any data to describe an individual’s passage through the health system. The database does, however, provide a good measure of the total volume of palliative care provided to all patients.

3.2 National Public Hospital Establishments Database

This database provides hospital-level data on all Australian public hospitals. Data collected includes aggregate information on hospital activity (including admitted patient and non-admitted patient services), staffing levels, expenditure data and services provided (including the number of beds). All data are collected under the NMDS—institutional health care and all definitions are outlined in the *National Health Data Dictionary* (National Health Data Committee 1999). This database is collated and released annually by the Australian Institute of Health and Welfare (AIHW). *Australian Hospital Statistics 1997–98* (AIHW 1999a) provides the most recent summary data.

The National Public Hospital Establishments Database collects information on the specialised services provided by public hospitals. In 1997–98, 111 of the 734 public acute hospitals reported having a ‘hospice care unit’. These units are defined as a ‘facility dedicated to the provision of palliative care to terminally ill patients’ (National Health Data Committee 1999, p. 177).

Information is also collected from each hospital on the hospital establishment type (e.g. public acute care hospital, Veterans Affairs’ hospital or public psychiatric hospital). Public hospices are identified separately within this classification. However, in 1997–98, no hospitals were reported to the National Public Hospital Establishments Database as being a free-standing hospice. This is because most hospices, while located in free-standing buildings, are administered by larger organisational units (such as a public acute hospital).

Limitations of data

- Data are for public hospitals only.

- Similarly, data relates to institutional health services only—data relating to publicly funded community-based health service agencies are not collated nationally.
- Hospitals report as a single organisational unit, therefore it is not possible to identify resources and activity being directed specifically towards palliative care as palliative care services (either an identified ward or identified beds, or a palliative care consultative program) may be one of many services provided by a hospital.
- Similarly, hospitals are required to report only if they have a dedicated palliative care ward. Hospitals that provide designated palliative care services but do not have a dedicated ward (e.g. hospitals that provide palliative care through a consultative program) may not be captured in these figures.

3.3 Private Health Establishments Collection

The Private Health Establishments Collection is a national census of private hospitals conducted annually by the Australian Bureau of Statistics (ABS). Data are collected and reported for private acute and psychiatric hospitals and free-standing day facilities. Data collected on these hospitals includes information on available facilities, aggregate activity levels, aggregate patient (clinical and demographic) data, staffing and annual expenditure. The most recent data are summarised in *Private Hospitals Australia, 1997–98* (ABS 1999).

The data items and their definitions are consistent with those in the *National Health Data Dictionary*, which forms the basis of other data collections discussed above. Additional items (not based on *National Health Data Dictionary* items) are included in consultation with central health authorities and private hospital associations. All data are validated in collaboration with the private hospitals concerned and missing data are estimated by the private hospital or imputed by the ABS.

In 1997–98, 18 private hospitals (out of the 294 total private acute hospitals providing overnight care) reported providing specialised palliative care services. Of these hospitals, 10 had a unit dedicated to the provision of palliative care and 9 provided palliative care in the general hospital setting (one hospital provided hospice/palliative care services in both a dedicated unit and in the general hospital setting). In total, these services provided, on average, 177 beds for palliative care in 1997–98, and reported 4,994 separations and 46,568 patient days (Table 3.12). The average length of stay for each separation was 9.3 days.

Table 3.12: Palliative care specialised services, private hospitals, 1997–98

Hospice/palliative care setting	Number of hospitals^(a)	Average available beds	Number of separations	Number of patient days
Provided in a unit dedicated to this purpose	10	148	4,550	39,205
Provided in the general hospital setting ^(b)	9	29	444	7,363
Total	18	177	4,994	46,568

(a) One hospital provided services in both settings—this hospital has been counted only once in the total.

(b) Includes one hospital that recorded no corresponding activity.

Source: ABS unpublished data from Private Health Establishments Collection 1997–98.

Limitations of data

- Data are for private hospitals only.

- Data relate to admitted patient care only, and do not include information on private palliative care services for non-admitted patients.
- As for the National Hospital Morbidity Database, all patient-level data are separation-based, and therefore do not provide information on the number of patients who received care.

3.4 National Census of Palliative Care Services

This paper-based survey has been undertaken annually by Palliative Care Australia (formerly the Australian Association for Hospice and Palliative Care). The most recent National Census of Palliative Care Services for which data are available (PCA 1997) was open to any organisation/agency that identified themselves as being providers of palliative care (including both admitted patient and non-admitted patient services). This survey received data from 171 services representing 76.7% of services known to PCA. These services delivered 321 programs—a breakdown of participating services and their programs is provided in Table 3.13.

Table 3.13: Palliative care programs provided by palliative care services reporting to the National Census of Palliative Care Services, 1997

Program type	Number of programs	Per cent of services providing program type
Home care/community	119	69.6
Admitted patient	64	37.4
Hospital consultancy	57	33.3
Coordinated care	30	17.5
Outpatient clinic	27	15.8
Day care centre	14	8.2
Volunteer only	10	5.8
Total	321	

Source: PCA 1997.

This survey estimated that there were 21,741 patients cared for between July 1996 and June 1997. This estimate is based on the number of deaths of patients of palliative care services recorded by the service that was caring for the patient at the time, with an adjustment for the services that did not participate in the census. Based on information provided to this survey, PCA estimated that palliative care patients had, on average, three episodes of care in palliative care (admitted patient or non-admitted patient) programs per patient in 1996–97.

Table 3.14: Summary of patient-related events on census day for all programs reporting to the National Census of Palliative Care Services, 1997

Patient-related events	Number of patients	Number of programs reporting
Patients registered	12,526	264
New referrals received	368	250
Patients accepted	340	240
New patients seen	344	242
Planned admissions	122	218
Unplanned admissions	63	219
Patients seen for care	2,745	248
Phone consultations	1,898	245
Consultations without a referral	641	230
Discharges	106	106
Deaths	65	221

Source: PCA 1997.

The survey also collected patient activity data based on census day (12 November 1997) activities. A summary of patient-related activities is provided in Table 3.14.

Sixty-three per cent of the services participating in the national census were able to provide information on expenditure. For services that were able to report financial data (52.7% of responding services), \$101 million was spent on palliative care services, with an average expenditure per program of \$947,295 (Table 3.15). The major funding sources for these programs, as reported to the national census, were the State/Territory and Commonwealth Governments through the Palliative Care Program and Medicare Incentives Package.

Table 3.15: Annual expenditure for palliative care programs in Australia as reported to the National Census of Palliative Care Services, 1997

Program type	Expenditure (\$'000)	Number of programs^(a)	Per cent of program type	Average expenditure per program (\$'000)
Home care/community	37,716	48	40.3	786
Admitted patient	37,581	20	31.2	1,879
Hospital consultancy	2,934	10	17.5	293
Coordinated care	1,155	8	26.6	144
Outpatient clinic	35	1	3.7	35
Day care centre	416	2	14.2	208
Volunteer only	524	6	60.0	87
Not reported by program	20,999	n.a.	n.a.	n.a.
Total	101,361	107 services	62.6% of services	947 per service

(a) Not all services were able to provide a breakdown of data by program type.

n.a. Not available.

Source: Adapted from PCA 1997.

Limitations of data

- Coverage of palliative care services in the national census is not complete. All palliative care services known to PCA were invited to participate, and 76.7% of these services responded. As the characteristics of the non-respondent (and unidentified) services are not known, the bias of survey respondents is also unknown.
- Data are submitted on a standard form although reporting against nationally agreed data definitions is not required. Therefore, it is difficult to assess the comparability of data provided. PCA do, however, audit a sample of returns (which includes services that provided incomplete data) to check the methods of calculation.

3.5 Other data developments

This section briefly considers other relevant national data sources, including potential data sources. These are developing data sets that may provide useful data relating to palliative care in the future, but for which national data are not currently available.

Australian National Sub-Acute and Non-Acute Patient Classification

The Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP) has been developed by the Centre for Health Service Development at the University of Wollongong for rehabilitation, psychogeriatric, geriatric evaluation and management, maintenance care and palliative care patients (Eagar et al. 1997). Within each of these case types, a number of classes (i.e. groups of patients who are similar in terms of level of resource utilisation, morbidity profile and/or type of intervention received) were identified. This type of classification can be used for service funding (when combined with cost weights) and other purposes and, if implemented, could provide some data on palliative care patients. For palliative care patients, 33 classes were identified (11 classes for overnight palliative care patients and 22 classes for ambulatory palliative care patients).

In order to classify all palliative care patients to a specific class, a number of data elements are required. For overnight care patients, the following information is required:

- phase of care (stable, unstable, deteriorating, terminal care or bereaved);
- RUG-ADL (Resource Utilisation Groups Activities of Daily Living) score (which provides a measure of nursing dependency); and
- age of the patient.

For ambulatory palliative care patients, the following information (in addition to the above) is required:

- whether the patient is receiving medical care only;
- whether the care provided is bereavement care (for the family and carers) only;
- whether the patient is receiving therapies only;
- whether the patient is receiving multidisciplinary care or only nursing care; and
- symptom severity as measured by the Severity Score index developed by Palliative Care Australia (Smith & Firms 1994).

The AN-SNAP has not been implemented nationally and, at this stage, there are no nationally available data.

National Community Based Health Services Codeset

The National Community Based Health Services Codeset project has been managed by NSW Health with the involvement of all States and Territories, under the auspices of the National Health Information Management Group. This project has developed a draft codeset, based on numerous classification schemes, and is designed for use in community-based health services.

The project commenced with the development of the Community Health Information Model and the companion function model, which formed the underlying data model for the codeset and related information system. The codeset that was subsequently developed is a hierarchical classification system for each of the following core concepts: issues, activities, events, clients, service providers, physical resources, locations, programs and outcomes. Version 1.0 of the codeset has recently been finalised by the AIHW and NSW Health and will be added to the Knowledgebase—Australia's Health and Community Services Data Registry in the near future.

The development of the codeset has been supported by a consortium including New South Wales, Queensland, South Australia and the Australian Capital Territory. The aim of developing the codeset has been to provide a framework from which uniform community-based services data could be derived, including data relating to home- and community-based palliative care. In recent months, work has been conducted to refine the data set for inclusion in the Knowledgebase—Australia's Health and Community Services Data Registry (AIHW 1999b).

Community Nursing Minimum Data Set Australia

The Community Nursing Minimum Data Set Australia (CNMDSA), which has been developed by the Australian Council of Community Nursing Services, is not a compulsory data collection among community nursing services, although it has been adopted by a number of community nursing agencies as the basis of their information systems. Version 1.0 was released in 1991, and version 2.0 (including new data elements and updated data elements) was released in 1997.

The data elements included in this data set relate to:

- services provided (e.g. *agency identifier, date of first delivery of services and source of referral*);
- demographic characteristics of patients (e.g. *date of birth, area of residence, language spoken at home*); and
- clinical items (e.g. *nursing diagnosis, goal of care and dependency in activities of daily living*).

The full listing of data elements is available in the CNMDSA, *version 2.0: Data Dictionary and Guidelines* (Australian Council of Community Nursing Services 1997).

To some extent, the further development of the CNMDSA has been overtaken by the development of the Home and Community Care (HACC) National Minimum Data Set (Ryan et al. 1998). The HACC NMDS, which has been developed under the auspices of the National Community Services Information Management Group, is agreed for collection from 1 July 2000, and collection will be required by all community nursing services that receive HACC Program funding. It is anticipated that these two data sets will converge as further development of each occurs.

Palliative care demonstration and development projects

There is a large body of research and information available about palliative care that has been funded through project grants from the Commonwealth under the National Palliative Care Program (see DHFS 1998c for a listing of funded projects). Most of these projects were concerned with the development of educational resources and service delivery models in local areas, while those that did relate to information development primarily focussed on:

- investigating unmet needs in relation to palliative care and documenting needs in specific population groups (such as people from non-English-speaking backgrounds);
- evaluating specific services and patients' experiences of these services in order to improve service delivery;
- developing and validating instruments that may assist evaluation of palliative care service outcomes and clinical management of patients (e.g. scales for the measurement of pain, psychological distress and quality of life); and
- developing systems to collect data across services to support the integration and coordination of local area service delivery.

These projects have provided a range of useful data for health policy makers and palliative care service providers, and represent potential sources of national data that may be available in the future.

3.6 Issues in data development

Data development processes

The data sets described above vary in the extent to which they have achieved (or may achieve) nationally complete and consistent data. Those data collections that are agreed by all States and Territories through National Health Information Agreement processes (Appendix D), or are obtained through legislative powers (such as ABS data collections), facilitate the collection of consistent data to describe palliative care with national coverage.

Under the National Health Information Agreement, States and Territories are committed to working with the AIHW, the ABS and others to develop, collate and report national health information. The Agreement is managed by the National Health Information Management Group (NHIMG) which also oversees the National Health Information Work Program. The NHIMG is assisted by the National Health Data Committee which has the major role in reviewing and advising on proposals for data standards and definitions for national health data. Agreed definitions are published in the *National Health Data Dictionary* (National Health Data Committee 1999). Agreement to *collect* data elements, however, can only be made by the NHIMG as part of an agreed national minimum data set. Decisions to collect particular data elements are consensus-based and are made after considering issues such as:

- the value of national information to policy makers and others;
- the ability for existing information systems to report data (e.g. if data are already collected in a consistent manner, then information systems may be easily modified to extract the information on an annual basis);
- the burden of data collection on service providers and jurisdictions. Most data currently agreed for collection is administrative-type data that would be collected by the service in the normal course of service delivery (e.g. date of birth of patient). Non-administrative data (e.g. patient satisfaction data) require greater resources for collection and may not provide meaningful data at a national level.

Further information on the Agreement and related data development structures is provided in Appendix D.

At present, data collections relating to admitted patients in institutional settings are well developed and agreed, in part because of the existing information systems in these settings. The collection of data on palliative care patients in admitted patient settings is, therefore, a convenient

starting point for developing palliative care data. Data that become available as a result of emerging data sets (e.g. clinical data collected as part of AN-SNAP) may also inform data definitions, and subsequently be developed for collection and reporting at the national level.

A greater degree of effort will be required to collect national data from community-based services providing non-admitted patient care where information systems may be less well developed. Efforts to develop data collection agreements from these services will need to commence with a scoping study to assess the capacity of these services to provide data against nationally agreed definitions.

Data collection and reporting methods

The existing data sets described above also vary in the modes of collection, i.e. electronic collection and supply of data versus paper-based collection. Supply of data in these ways is largely related to the nature of underlying information systems used across the institutional and community-based services sectors.

In terms of the collection of data, the advantage of electronic systems is that administrative data can be routinely extracted from patient management or business management systems with little burden on clinical or administrative staff. For large data sets (such as patient-based data sets), paper-based reporting systems would be unacceptable. Paper-based collection methods, however, may be suitable for organisation-level data (such as expenditure, staffing and aggregate patient-activity data). Therefore, the development of data for collection in community-based services needs to be informed by information on the capacity of these services to routinely extract data from information systems.

Record linkage

There is increasing work being undertaken in the area of record (or data) linkage to provide information on the range of services accessed by an individual (and thereby develop a profile of clients) and to estimate the number of individuals being served by a service or a group of services. Record linkage is the matching of data records relating to a particular individual within a database or between databases. In Australia, these techniques have been used to link a number of data sets in Western Australia (described in Holman et al. 1999) to explore issues such as hospitalisation patterns over the last year of life, estimation of the incidence of hospital admissions for illicit drug problems, and to investigate suicide rates among admitted psychiatric patients (Brameld et al. 1998; Lawrence et al. 1999; Patterson et al. 1999). Data linkage has also been explored in relation to HACC services, national labourforce databases, assessment of integrated service delivery models and is being considered for use in linking Medicare and Pharmaceutical Benefits Scheme data with other data sets (Bentley et al. 1998).

Data linkage undertaken for statistical or research purposes differs from linkage undertaken for clinical or administrative purposes as it does not attempt to identify the individual, but makes use of a derived linkage key to undertake probabilistic matching of records that are likely to belong to the same individual.¹ It should be noted that statistical record linkage tolerates some degree of

¹ A derived linkage key is used where individuals within a database are not identified by a unique client identifier or the same identifier is not used across the databases to be linked. A derived linkage key is one that can be derived from standard data held within the database (such as name and date of birth) that, in specific combinations, is likely to be unique to individuals. For example, in the HACC NMDS a derived linkage key composed of: 2nd, 3rd and 5th characters of surname, 2nd and 3rd characters of first given name, sex and date of birth has been proposed. After testing, this data linkage key was found to produce an acceptable level of duplication and error, while also being acceptable to service providers and clients. It was

error in matching records that would not be acceptable if linkage was for administrative or clinical purposes, as a small proportion of errors should not greatly affect the value of the linked information for statistical purposes.

In palliative care, record linkage has significant potential in evaluating and monitoring service delivery. Clients frequently receive care from more than one service—particularly where both admitted patient and non-admitted patient services are provided over the course of the illness and/or the patient has multiple admissions to a service that is not able to report linked separations. Record linkage may provide the means of generating a profile of patients receiving palliative care in terms of the number of individuals receiving care and the number and type of services received. Record linkage is of particular relevance in palliative care, which has a substantial requirement for coordinated care. The success of record linkage activities, however, is dependent on the identification of a suitable data linkage key with an acceptable error and duplication rate.

Privacy considerations must also be considered and addressed. Any usage of record linkage will balance palliative care service and policy needs for data in this area against the rights to privacy of the individuals being treated.

Therefore, applied under properly agreed protocols, record linkage offers an opportunity to overcome limitations in existing national data sets, such as the National Hospital Morbidity Database, which is separation-based and not patient-based.² In the future, record linkage may also be used to link data that is obtained from community-based services with hospital-based data.

Conclusion

There are a range of data available that describe people receiving palliative care and palliative care services. None of these data sets, however, are complete. These data sets are compiled in two major ways: survey data on a sample of palliative care patients (or services), and data sets that are based on administrative data on all palliative care patients and/or services. Clearly, the major advantage of data sets based on administrative data is that coverage is complete (that is, all patients or services are included rather than a sample). Secondly, as data collection is built into the information systems used within these services, the collection of these data can be less of a burden to service providers than the collation of survey data. The major limitation of this method is in the type of data collected which is limited to administrative-type data and would not include data such as patient satisfaction-type information.

The use of administrative-type data sets for palliative care, particularly at the patient level, also capitalises on existing data collection agreements that apply to all hospital (i.e. admitted patient) separations. Much work, however, is required to establish equivalent data agreements that apply to community-based palliative care services. Recent work and planned directions for the progress of this work are outlined in later chapters (see Chapters 5 and 6).

Further investigation of the feasibility of record linkage using palliative care separation records could also be considered. This would enhance the value of data reported in the future under the NMDS—palliative care, but could only be used where data on all patients was being collected.

also considered that this data linkage key adequately addressed privacy concerns (that is, the data linkage key was not based on data that was unreasonable to collect, nor was it likely to identify individuals).

² There is some limited capacity to link separation records belonging to the one patient within the National Hospital Morbidity Database. In some jurisdictions, patient identifiers are reported the same for each admission for the patients in question to different extents. For example, in Queensland, patient identifiers are the same within an establishment within a reporting year, but may differ from year to year.

It is clear also that the development of national data to describe palliative care should also proceed within the framework and structures established under the National Health Information Agreement. This process offers a framework within which the collection of nationally consistent data is agreed by States and Territories, and provides ongoing opportunities to review the data collected in terms of data quality and relevance of the information that is being collected.

4 Performance indicators for palliative care

In addition to the reporting of descriptive information in the health sector, there is an increasing requirement for health sector performance information across a range of health services. This has occurred as a result of the need to inform quality assurance activities and a shift in interest from describing the inputs and outputs of the health system to a concern with describing the quality and outcomes of care (National Health Ministers' Benchmarking Working Group 1998). In palliative care, an additional imperative for developing performance indicators is to support the shift of palliative care from being a specialised service funded by special grants to that of being a service that is funded through mainstream funding mechanisms alongside other health services (DHFS 1998b). This will require development of the infrastructure for ongoing performance monitoring, including a national minimum data set.

As a first step towards developing performance indicators for palliative care, the Commonwealth Department of Health and Aged Care sponsored a Palliative Care Performance Indicators Workshop in February 1998. Participants included policy makers, service administrators, clinicians and non-government organisations. Participants in the workshop drew on their experience in the palliative care field and the work of the Standards and Quality Committee of PCA to develop a range of draft performance indicators (PCA 1998a). The full proceedings and outcomes of this workshop are reported in *Performance Indicator Development in Palliative Care: Work in Progress* (DHFS 1998d).

Further work has occurred to review these performance indicators for use by States and Territories for national reporting, although no agreement to report against performance indicators has been made. Development of performance indicators has also been undertaken by PCA's Standards and Quality Committee (see Appendix A), and by the Victorian Department of Human Services which has developed clinical performance indicators to comply with central health authority reporting requirements (see Appendix C) (PCA 1998a; Victorian Government Department of Human Services 1998).

These performance indicators raise a number of issues that will need to be resolved in relation to the development and collection of national palliative care data. These are outlined below.

4.1 Issues in developing performance information

Coverage of palliative care services

In order to fully derive performance indicator information, data will be required both from institutional palliative care services and non-institutional services (i.e. those services providing home- and other community-based care) at both the organisation and patient level. At present, data collections that operate through the NMDS—institutional health care (see Chapter 3) represent admitted patient services only (although data on the total number of non-admitted patient services conducted by these services are collected). Community-based palliative care services are not required to collect data based on nationally agreed definitions nor to report data for collation nationally. Thus, it is necessary to investigate the feasibility of collecting data from community-based palliative care services in order to improve the coverage of services contributing data to performance indicator calculations.

Performance indicator data requirements

The first step in producing performance indicator information is to identify the specific data elements from which the indicators are to be derived. Table B1 (Appendix B) includes information on the range of data that would be required in order to report against the types of performance indicators that were developed at the Palliative Care Performance Indicators Workshop. At present, none of the performance indicators proposed can be derived for the palliative care sector in total, nor for admitted patient services alone (where some data are available). The majority of data elements of interest for these performance indicators are yet to be developed.

A number of these data elements relate to aspects of care that are not routinely collected and reported as part of a nationally agreed minimum data set. For example, patient satisfaction with palliative care services and knowledge of after-hours services would not usually be recorded within the patient record, whereas date of birth, sex and information on the source of referral are routinely collected by health facilities. The collection of additional data may have resource implications for services that would be required to collect data of this type. Additionally, the development of these data items would demand considerable effort in terms of identifying a suitable instrument or codeset to record this data, and development of guidelines about when and how this information should be recorded. Therefore, the additional burden of collection of items needs to be considered in light of the value of the performance indicator reported at the national level.

Level of data

The collection of palliative care data to derive performance indicators can occur at two levels: the patient (or person) level or the organisation (or service) level. This can have resource implications for the collection of national data, as one requires reporting of information on each patient or client of the service while the other requires reporting only once by each service on operational details (such as staffing numbers or expenditure data). Patient-level data may also be aggregated and reported at the organisation level (such as the total number of separations from a service).

It should be noted that in the existing national admitted patient data collection (the National Hospital Morbidity Database) patient-level data are collected on each patient treated, but is reported for each episode of care at separation (see Section 3.1 for further explanation). Consequently, data on the number of discrete patients are not available, and performance indicators that are based on the number (or proportion) of patients or carers would need to be estimated, based on the number (or proportion) of separations, until such time that unique patient identifiers become available or data linkage techniques are applied to resolve this problem.

4.2 Future development of performance indicators

Further work to develop national performance indicators is being undertaken by the Palliative Care Intergovernmental Forum, which has been convened by the Commonwealth Department of Health and Aged Care to advise on issues relating to implementation of the *National Strategy for Palliative Care in Australia 1998–2003*.

These performance indicators will include a small number of indicators for inclusion in the Australian Health Care Agreements, plus a larger suite of indicators for national reporting under the National Strategy for Palliative Care. Where possible, these performance indicators will draw on data available through the developing NMDS, but where this is not possible, the Intergovernmental Forum may consider alternative data collection strategies (e.g. sample surveys).

5 Development of the National Minimum Data Set for Palliative Care

Previous and current efforts to develop an agreed National Minimum Data Set for Palliative Care (NMDS—palliative care) have occurred within the processes established by the National Health Information Agreement. As discussed in Chapter 3, the Agreement establishes mechanisms for developing and collecting national data. Data development work undertaken within this framework must firstly be agreed at a conceptual level by the National Health Data Committee (all agreed data definitions are published in the *National Health Data Dictionary* (National Health Data Committee 1999)), and may then be agreed for collection by the NHIMG. Further details on the role of the AIHW and the National Health Information Agreement may be found at Appendix D.

5.1 Initial development of the NMDS—palliative care

In 1995–1996 the Victorian Department of Human Services undertook initial work (jointly funded by the Commonwealth and Victorian Governments) to develop an NMDS—palliative care for national application (Victorian Government Department of Human Services 1997). This work was directed by the need for palliative care services to establish a place within the mainstream health system and move away from grant-based funding. It was recognised that national data (collected across all services settings and reported as a single national minimum data set for palliative care) could be used to describe the extent of palliative care and could support benchmarking activities within palliative care services (Kasap and Associates 1996).

This activity was placed on the National Health Information Work Program, and the development of national data definitions was endorsed by the Australian Health Ministers' Advisory Council. The project was overseen by a steering committee comprising representatives of most States and Territories (excluding the Northern Territory), PCA, the AIHW, and a service provider representative.

Palliative care data model

The first stage of this project involved collecting information about data already collected within States/Territories. This was followed by a data-modelling workshop (in July 1995) that included steering committee members and their nominees. This modelling exercise defined the data entities relevant to palliative care and their relationships, and formed a basis for proposing data elements relating to each entity that, as a whole, would describe palliative care. The key data model elements were:

- client characteristics
- relationships to others (mainly family) and their status as carers
- provider characteristics
- contacts/services—whether planned or actual
- the goal of the contact/service (Victorian Government Department of Human Services 1997).

The resulting proposed data set for palliative care included demographic, clinical and administrative data on all patients receiving designated palliative care services. Where possible,

these definitions were based on definitions in the *National Health Data Dictionary* (National Health Data Committee 1999) and other data collections.

Pilot testing

The second stage of this project involved pilot testing all data definitions. The purpose of the pilot test was to test the usage of data definitions and not to assess the extent to which services could routinely extract this data from their information systems for national reporting. Eleven services, distributed across Australia (excluding the Australian Capital Territory and the Northern Territory) participated in the pilot project. Participating services provided a mix of admitted-patient, home- or community-based, and palliative care consultancy services.

All data were collected via the use of three forms—one containing data items to be collected at first contact, one containing information to be collected at each contact, and the third containing data items collected at separation.³ Recommended NMDS items (incorporating changes recommended as a result of the pilot test) and their collection points are summarised in Appendix C.

For reporting purposes, in this data set the episode of care would commence at first admission or contact with a palliative care service to death. It would continue beyond the patient's death in instances where the family/carers receive bereavement services, which is consistent with current philosophical approaches to palliative care. While this is an optimal conceptual model to follow, work was required to assess the feasibility of data collection, particularly the ability of service agencies to routinely extract this data from their information systems. This was not assessed within the pilot study.

In October 1997 this NMDS was considered by the National Health Data Committee. The data set, however, was not agreed to by the States and Territories for collection. Concerns included the lack of adequate identification of the scope of services involved in the collection and the lack of an implementation strategy across all service settings (i.e. covering admitted patients in acute hospitals, admitted patients and non-admitted patients in hospices and community-based services). There was also concern that there was some conflict with data requirements as agreed under the NMDS—institutional health care, and it was considered that further work was required on some data definitions.

5.2 Recent development of the NMDS—palliative care

In 1998, the AIHW continued the work of the Victorian Department of Human Services in the development of the NMDS—palliative care for endorsement by the National Health Data Committee and the NHIMG. Following from the previous project, this data set will provide descriptive information on patients receiving palliative care and the services involved. This data set, however, will also allow the derivation of a small number of national performance indicators that are required under the *National Strategy for Palliative Care in Australia 1998–2003* and the current Australian Health Care Agreements.

Recent developmental work on the NMDS—palliative care has recognised existing differences in the capacity for data to be provided on admitted patients versus home- or other community-based patients, and the subsequent need to consider different data requirements in each sector. This

³ For data collected at each contact, this applied to: each contact from designated palliative care (medical or nursing) staff or other disciplines in hospitals with non-identified palliative care beds; only contacts other than medical or nursing in hospitals and hospices with identified palliative care beds; and each contact in community- or home-based services (Victorian Government Department of Human Services 1997).

work has also been driven by a concern to use existing data collection agreements and data sets (in particular, admitted patient data currently provided to the National Hospital Morbidity Database under agreements relating to the NMDS—institutional health care). As a result, two separate data sets will be developed—one for collection from admitted patients and the other for collection from home and other community-based services. It is anticipated, however, that there will be a large degree of overlap between these data sets where equivalent data elements can be reported (e.g. date of birth, sex, principal diagnosis) although there may be differences in the codeset used to report these data, recognising the different capacity to report data across these sectors. For example, principal diagnosis for all admitted patients is presently coded to ICD-9-CM or ICD-10-AM; however, a simplified coding scheme that is able to be mapped to ICD codes may be required for community-based services.

The initial focus of this work has been on development of the NMDS—institutional palliative care, which is described below. It is proposed that developmental work on data definitions for use in community settings is undertaken in future stages of the project. Data elements for collection at the organisation level may also be developed. More detailed information on these activities is provided in the following chapter.

Ethics approval for this work was granted on 29 October 1998 by the AIHW Ethics Committee.

Development of institutional palliative care data

Initial efforts to develop the NMDS—palliative care have focussed on the development of existing data provided to the National Hospital Morbidity Database on admitted patients. As described previously, existing data supplied to this database includes demographic, administrative and clinical information for all patient separations. Palliative care patients are identified in this database by the variable *type of episode of care* (that distinguishes palliative care episodes from acute, rehabilitation, non-acute, newborn and other episodes of care).

Table 5.1: NMDS—institutional palliative care data elements for admitted patients, showing status of elements with respect to the NMDS—institutional health care

Data element	NMDS— institutional health care ^(a)
Person identifier	✓
Establishment identifier	✓
Type of episode of care	✓
Area of usual residence	✓
Date of birth	✓
Country of birth	✓
Sex	✓
Indigenous status	✓
Admission date	✓
Previous specialised treatment	X
Mode of admission	✓
Principal diagnosis	✓
Additional diagnosis	✓
Separation date	✓
Mode of separation	✓

(a) Indicates those items that are currently collected for the National Hospital Morbidity Database.

The data elements presented in Table 5.1 have been endorsed by the NHIMG as the NMDS—institutional palliative care for collection from 1 July 2000. The agreed data element definitions may be found in the latest version of the *National Health Data Dictionary* (National Health Data Committee 1999). Further work to develop the data set is being undertaken by the Palliative Care Data Working Group, which is a working group of the Palliative Care Intergovernmental Forum that has been established to further develop all aspects of the NMDS—palliative care. In particular, referral information is to be developed as a priority during 2000.

The Palliative Care Data Working Group is now developing a proposal for a NMDS—palliative care for collection in community-based palliative care services. This work includes development of the scope, content and data definitions of this data set and is further outlined in Chapter 6.

6 Future directions

6.1 Proposed data developments

Future activities to develop national palliative care data will concentrate on three major activities. These are summarised below.

Development of community palliative care data

This activity will see the development of an appropriate data set for collection in community-based palliative care agencies and investigation of the potential for these agencies to report these data. Where possible, this data set would mirror data collection agreements in admitted patient settings through the collection of equivalent data elements. While this work is in very early stages, candidate data elements that are presently being considered are outlined in Table 6.1. Final agreement to include each of these data elements in the NMDS—community palliative care would depend on the development of a suitable definition, the ability of the States and Territories to apply the data definition and the perceived relevance of the data element. Issues that have already been identified in relation to each of the candidate data elements are also summarised.

Further development of institutional palliative care data

As mentioned in the previous chapter, agreed admitted patient data will be further developed to include other relevant concepts (such as *source of referral* and *referral destination*).

Assessment of the need for organisation level data

The need for organisation-level data from designated palliative care services will be assessed. These data could complement the patient-level data collection and could provide information on aspects of service delivery that are not captured through the patient-level data set. This may include data such as staffing levels (including use of volunteers), the range of services provided, and the reporting of aggregate activity data not available through the patient-level data (including educational activities, bereavement care activities for families following the death of the patient and inter-agency activities).

Table 6.1: Data elements under consideration for inclusion in the NMDS—community palliative care

Data element	Status of data elements in the NMDS— institutional palliative care	Comments
Person identifier	✓	Use <i>National Health Data Dictionary</i> definition.
Establishment identifier	✓	Use <i>National Health Data Dictionary</i> definition.
Area of usual residence	✓	Use <i>National Health Data Dictionary</i> definition.
Date of birth	✓	Use <i>National Health Data Dictionary</i> definition.
Country of birth	✓	Use <i>National Health Data Dictionary</i> definition.
Sex	✓	Use <i>National Health Data Dictionary</i> definition.
Indigenous status	✓	Use <i>National Health Data Dictionary</i> definition.
Service contact date	✓	Use <i>National Health Data Dictionary</i> definition.
Previous specialised treatment	✓	Use <i>National Health Data Dictionary</i> definition. There may be some problems in collecting this item in both community and institutional settings. It will be necessary to check the data quality of this item once data are received, and review this item in the future.
Source of referral	X	It is important that this item (once developed) meets the information needs of palliative care service providers and policy makers and can be applied in both institutional and community-based services. This item may also need to meet the information needs of other data collections.
Referral destination	X	As above.
Principal diagnosis	✓	There is an interest in including diagnosis information in community-based palliative care services. Issues in relation to this data element include: (a) Community-based services do not have the coding expertise or resources to code to ICD-10, but recognise that mappability to ICD is desirable. (b) There may be more interest in collecting information on the underlying disease rather than the principal diagnosis (i.e. the disease that is responsible for the episode of care). This data element would need to be developed and would need to be applicable in both institutional and community-based settings. (c) There is a need for the data elements in the community and institutional NMDSs to be broadly equivalent (i.e. it would not be desirable to have 'principal diagnosis' reported for admitted patients and 'underlying palliative care diagnosis' reported for non-admitted patients). (d) There may be a need to develop an additional data element that would provide information on the reason for the palliative care service contact (e.g. pain management, monitoring, management of other symptoms, personal care).
Separation date	X	There will be a need to develop an equivalent item for use by community-based agencies to record the date of final separation. At present, the concept of 'separation' relates only to admitted patients. Therefore, there may be a need to broaden this concept, or to develop equivalent terminology that applies to community-based services. Further work will need to be undertaken in consultation with other collection developments.
Mode of separation	✓	There will be a need to develop an equivalent item for use by community-based agencies to record the mode of final separation. In many (but not all) cases this will be 'death'.

(continued)

Table 6.1 (continued): Data elements under consideration for inclusion in the NMDS—community palliative care

Data element	Status of data elements in the NMDS— institutional palliative care	Comments
Preferred language	X	This item may provide useful information on the language background of patients/clients, but will require further assessment. Issues to be considered are: (a) coding burden on staff; (b) this item is not currently included in the institutional NMDS but could be considered for inclusion in both datasets; (c) whether a data element that measures the need for an interpreter provides more useful information for service planning (see below).
Interpreter required	X	As above. There is currently no data element that reports the need for an interpreter in the <i>National Health Data Dictionary</i> , although this data element does exist in the <i>National Community Services Data Dictionary</i> .
Date of first contact/ Date of registration	X	This data element relates to <i>service contact date</i> . There may be a need to develop a data element to record one (or both) of these data elements. These items are used in Victoria to report against agreed clinical performance indicators. It will be necessary to collect information from other jurisdictions on how community-based palliative care services intake operates in their State/Territory. Further work will need to be undertaken in consultation with other collection developments.
Performance status	X	There is interest in collecting information on the dependency of each patient. This will involve identification of an appropriate physical functioning scale.
Contact recipient type	X	This would distinguish between contacts with patients and/or family members.
Contact setting	X	
Principal nature of the service provided	X	
Site of death	X	
Date of last contact with related person(s)	X	This is a useful indicator of bereavement care. There may be some technical issues to resolve with this data element relating to reporting periods.

6.2 Work program

This section briefly describes the major activities that will be undertaken to achieve these goals.

Consultation with States and Territories

It is proposed that the major mechanism for consultation with States and Territories would be through the Palliative Care Intergovernmental Forum Data Working Group. This group has been formed to provide detailed advice on the development of the NMDS—palliative care and other related data development activities. This group reports regularly to, and is informed by the work of, the Palliative Care Intergovernmental Forum, which will decide on national performance indicators.

In the first instance, the Working Group was convened as a subgroup of the existing Intergovernmental Forum membership and included representatives from the Tasmanian, Victorian, Queensland and New South Wales central health authorities, AIHW and the Commonwealth Department of Health and Aged Care. The first meeting of this Working Group was held in July 1999. More recently, however, the membership of this group has been expanded to include representatives of all State and Territory health authorities in order to streamline consultation processes that need to occur in relation to the NMDS.

Scoping study

There may be a need for the Palliative Care Intergovernmental Forum Data Working Group to survey all designated palliative care programs in order to scope existing palliative care services and provide information on the capacity of each of these services to report patient- and establishment- (or organisation-) level data. Such a survey may also provide initial data on the number of designated palliative care programs, service characteristics and information on regions served and/or special population groups served. This information will form the basis of all work to develop the NMDS—palliative care.

Data collection agreements

The outcomes of all work advised on by the Working Group will be referred to the Palliative Care Intergovernmental Forum, which will provide an auspice for recommendations submitted to the National Health Data Committee and National Health Information Management Group for agreement.

It is anticipated that agreement on an initial patient-level data set for collection by palliative care services providing community-based care will be achieved for collection from 1 July 2001. This will complement the data collection agreements that apply to palliative care patients seen in admitted patient settings that are agreed for collection from 1 July 2000.

Appendix A

Performance indicators proposed by Palliative Care Australia

Table A1: Palliative care performance indicators as proposed by Palliative Care Australia

PCA Performance indicator	
1.1	Interdisciplinary assessment and planning of care: percentage of patient healthcare records in which family participation is documented.
1.2	Service contacts with family: percentage of service contacts that are with the patient/client and related person(s) or related person(s) only.
2.1	Place of death while receiving palliative care: percentage of palliative care deaths that occur at home.
2.2	A comprehensive patient-centred assessment is completed on admission: percentage of patient healthcare records in which a comprehensive assessment is documented.
2.3	Pain assessment: percentage of patients presenting for pain in which a pain assessment tool is utilised.
2.4	Pain management: percentage of patients admitted with pain who have a pain assessment on admission and repeated within 24 hours.
2.5	Pain control (outcome): percentage of patients who achieve a 50% reduction in pain value (score) within a specified timeframe (either 24, 48 or 72 hours as indicated by the service).
3.1	Interdisciplinary team: the number of disciplines represented on staff.
3.2a	Percentage of services using shared patient records.
3.2b	Proportion of patients for whom a shared record exists.
4.1	Ratio of volunteer coordinator hours to volunteer hours provided to the service.
4.2	Proportion of volunteer services with a designated budget.
5.1	Total annual hours education provided to formal (i.e. professional and volunteer) and informal (i.e. family or significant others) carers.
5.2	Total annual hours of community education provided.
6.1	Proportion of palliative care services accredited with the Australian Council on Healthcare Standards using palliative care guidelines.
6.2	Palliative care services have at least one appropriate benchmarking partner: percentage of palliative care services reporting an appropriate benchmarking partner.
6.3	Level of satisfaction with the care provided by the palliative care service.
7.1	Palliative care services apply a bereavement risk assessment to all primary carers: percentage of bereaved carers who are assessed using an assessment tool.
7.2	Bereavement services with a funded coordinator: percentage of palliative care services with a funded designated bereavement coordinator.
8.1	Proportion of palliative care services which provide 24-hour (indirect or direct) access.

Source: PCA 1998a.

Appendix B

Data requirements for palliative care performance indicators

Table B1: Palliative care performance indicators identified at the Performance Indicators Workshop, February 1998, and data requirements

Type of performance indicator	Level of data required	Data development requirements
Integrated care	Organisation	Development of a shared record indicator and a single intake assessment indicator.
	Patient	Development of a shared record indicator.
Bereavement risk assessment services	Organisation	Development of a bereavement service indicator and/or a bereavement risk assessment service indicator.
	Patient	Development of a data element to collect the date of first (or each) carer risk assessment and the outcome of the carer risk assessment. Agreement on outcome scales of risk assessment contacts would be required.
Source of referral	Patient	Requires data on the source of referral for each patient. A draft <i>source of referral</i> data element has been developed, but was not accepted by the National Health Data Committee at their meeting in October 1998. Further development work is continuing on this item.
Length of time between referral and death	Patient	Requires development of data elements that record the date of first referral to a palliative care service and the date of death of the patient. This indicator may only be possible with the introduction of unique patient identifiers for use across services
Service response time	Patient	Development of data elements that record the date of first referral to a palliative care service and either the date of first administrative contact with the patient or the date of the first clinical contact with the patient.
Coverage of palliative care	Patient	Requires identification of the number of people who would be eligible for palliative care (which is not able to be derived through health services data alone). Also requires identification of the number of people receiving these services. Could not be achieved in the short term using administrative data because of the need for unique patient identifiers (or data linkage) so that patients are counted only once. Derivation of this indicator could be undertaken as a research project similar to that by Hunt & McCaul (1996) who identified the proportion of patients who had died of cancer in 1990 and who had received hospice care in South Australia.
24-hour access to services	Organisation	Development of a 24-hour access indicator. These indicators would apply to services providing home- and other community-based care only.
	Patient	Development of data elements that record the extent of the patient and carer's knowledge of the service's after-hours arrangements, the date of each after-hours clinical contact and the mode of contact (e.g. telephone contact, face-to-face visit).
Access to preferred site of care	Patient	Development of data elements that record the patient's preferred site of care and the days spent in the service's care and the type of care. It should be noted that preferred site of care may change throughout the course of the illness (see, for example, Hinton 1994) and that, currently, total admitted patient days are not able to be collected for each patient (only admitted patient days per episode of care—see section 3.1 for further information on episodes of care). Data for this indicator will not be able to be collected until the introduction of unique patient identifiers (or data linkage) to track patterns of admission for individual patients and would depend on the establishment of data collection agreements applying to community-based palliative care services for the measurement of time spent in home-based care.

(continued)

Table B1 (continued): Palliative care performance indicators identified at the Performance Indicators Workshop, February 1998, and data requirements

Type of performance indicator	Level of data required	Data development requirements
Palliative care expenditure	Organisation	Development of a data element that records total palliative care expenditure for each service (and expenditure for particular program areas), and development of a methodology to identify expenditure at the unit/ward level of hospitals.
Satisfaction with care	Patient	Development of a data element to record patient satisfaction with the palliative care service and with the after-hours service arrangements. This would require agreement of a suitable client satisfaction scale.
Interdisciplinary care planning	Patient	Development of a data element that records the date of the first care planning meeting. The definition of this item would specify that care planning meetings must be interdisciplinary and involve family members/carers.
Pain assessment	Patient	Development of data elements that record the date of the first patient assessment and the date of the first clinical contact with the patient. Also requires agreement on a suitable pain assessment scale.
Availability of staff debriefing	Organisation	Requires development of a staff counselling service indicator.

Appendix C

Data elements recommended by the Victorian Department of Human Services for inclusion in the National Minimum Data Set—palliative care

Table C1: Data elements recommended by the Victorian Department of Human Services for inclusion in the NMDS—palliative care

Data element
Agency identifier
Patient/client identifier
Date of birth
Country of birth
Sex
Aboriginality
Preferred language
Area of usual residence
Source of referral to palliative care
Date of first contact
Performance status
Principal palliative care diagnosis
Date of each contact
Contact recipient type
Contact setting
Principal nature of the service provided
Date of separation
Mode of separation
Site of death
Date of last contact with related person(s)

Appendix D

The Australian Institute of Health and Welfare

The AIHW is a statutory authority of the Australian Government established by the *Australian Institute of Health and Welfare Act 1987*. This legislation:

- authorises the Institute to undertake data collection (with agreement of the Australian Bureau of Statistics);
- authorises arrangements with other bodies for performance of functions on behalf of the Institute;
- provides confidentiality protection for individual persons and organisations;
- enables research access (subject to confidentiality constraints).

The mission of the Institute is to inform community discussion and decision making through national leadership in the development and provision of authoritative information and analysis on the health and welfare of Australians.

What is national health information and why is it needed?

National health information is information that is either national in coverage or has relevance nationally and relates to:

- the health of the population;
- the determinants of the population's health, including external factors (physical, biological, social, cultural and economic) and those internal to individuals (e.g. knowledge, behaviour, disease risk factors);
- health interventions or health services, including those provided directly to individuals and those provided to communities, covering information on the nature of interventions, management, resourcing, accessibility, use and effectiveness; and
- the relationships among these elements.

Health information is needed by consumers and providers of health services, the health industry, governments and the community to enable informed decision-making. Consumers need information to guide their decisions to seek care, modify their behaviour, choose between different treatment options and understand the care they are receiving. Providers of health services need information about the needs of the populations they serve, the effectiveness of their interventions and for whom they are effective, and the acceptability of these interventions to consumers. Providers also require nationally consistent information to be able to compare the effectiveness and efficiency of their operations with those of their peers. The health industry and governments need information to make decisions about how to provide services equitably, efficiently and effectively, and to monitor health service financing, performance and health outcomes.

Structures and data development processes for national health information

Australia has a well-established infrastructure to develop and provide national health information.

National Health Information Agreement

The foundation of the framework is the National Health Information Agreement. The Agreement, signed by the Commonwealth, State and Territory health authorities, the Australian Bureau of Statistics and the AIHW, came into effect in 1993, and has been recently extended to 2003. One of its objectives is to provide cooperative national structures and mechanisms to improve the collection, quality and dissemination of national health information. The National Health Information Management Group (NHIMG) and the National Health Data Committee (both established under the National Health Information Agreement), in consultation with other national working groups, provide the mechanism for State and Territory endorsement of data standards and collections.

National Health Information Management Group

The NHIMG is responsible for:

- overseeing the direction, development, review and implementation of the National Health Information Agreement and the agreed work program;
- making recommendations to the Australian Health Ministers' Advisory Council on national health information priorities, work programs, funding implications and other policy issues;
- negotiating with other groups and individuals for the collection and dissemination of information which will enhance the provision of health care;
- overseeing the role and function of the National Health Data Committee; and
- overseeing the review and maintenance of the *National Health Data Dictionary*.

National Health Data Committee

The National Health Data Committee coordinates national information development and endorses all definitions proposed for inclusion in the *National Health Data Dictionary* before submission to the National Health Information Management Group. Other responsibilities include:

- reviewing and endorsing national minimum data sets in the health field;
- promoting and facilitating the sharing of information about developments in national health information; and
- taking a pro-active role in health information development that is consistent with identified National Health Information Priority Areas.

National Health Data Dictionary

The *National Health Data Dictionary*, which has been produced each year since 1991, is a compilation of data items and definitions that is intended to facilitate the collection of uniform data in order to more accurately describe and compare health services in Australia. Originally it covered only the National Minimum Data Set—institutional health care. However, since the implementation of the National Health Information Agreement in 1993, it has become the vehicle for all national data definitions developed through the National Health Data Committee.

Coverage has extended beyond institutional health care, drawing on data development projects in the National Health Information Work Program. Consequently, in recent versions, several data elements for population health and non-institutional health care are included (National Health Data Committee 1999). Given the continuing policy interests in non-institutional health care, including continuity of care issues, further expansion of the Dictionary's coverage over the next few years is anticipated.

National Minimum Data Sets

An NMDS in the health field is a minimum set of data elements agreed by the NHIMG for mandatory collection and reporting at a national level. One NMDS may include data elements that are also included in another NMDS. An NMDS is contingent upon a national agreement to collect uniform data and to supply it as part of the national collection, but does not preclude agencies and service providers from collecting additional data to meet their own specific needs.

Existing NMDSs include: institutional health care, hospital waiting times, institutional mental health care, community mental health care, health labour force and the perinatal collection.

References

- Australian Bureau of Statistics (ABS) 1999. *Private hospitals Australia, 1997–98*. Cat. No. 4390.0. Canberra: ABS.
- Australian Council of Community Nursing Services 1997. *Community Nursing Minimum Data Set Australia, version 2.0: data dictionary and guidelines*. Melbourne: ACCNS.
- Australian Institute of Health and Welfare (AIHW) 1999a. *Australian hospital statistics 1997–98*. Health Services Series. Canberra: AIHW.
- Australian Institute of Health and Welfare (AIHW) 1999b. *The Knowledgebase—Australia’s Health and Community Services Data Registry*. <http://www.aihw.gov.au>.
- Bentley R, Abraham B, Gibson D & Wordsworth T 1998. Record linkage at the AIHW [Internal report]. Canberra: AIHW.
- Brameld KJ, Holman CDJ, Bass AJ, Codde JP & Rouse I 1998. Hospitalisation of the elderly during the last year of life: an application of record linkage in Western Australia, 1985–1994. *Journal of Epidemiology and Community Health* 52: 740–744.
- Chan A & Woodruff RK 1991. Palliative care in a general teaching hospital, 1. Assessment of needs. *Medical Journal of Australia* 155: 597–599.
- Commonwealth Department of Health and Family Services (DHFS) 1997. *Commonwealth response to recommendations contained in Stage 1 report to the ‘Palliative Care Program Review 1996’*. Canberra: AGPS.
- Commonwealth Department of Health and Family Services (DHFS) 1998a. *A national strategy for palliative care in Australia 1998–2003*. Canberra: AGPS.
- Commonwealth Department of Health and Family Services (DHFS) 1998b. *Background for a national strategy for palliative care in Australia*. Canberra: AGPS.
- Commonwealth Department of Health and Family Services (DHFS) 1998c. *National compendium of palliative care projects*. Canberra: AGPS.
- Commonwealth Department of Health and Family Services (DHFS) 1998d. *Performance indicator development in palliative care: work in progress*. Canberra: AGPS.
- Eagar et al. 1997. *The Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP): report of the National Sub-Acute and Non-Acute Casemix Classification Study*. Wollongong: Centre for Health Services Development, University of Wollongong.
- Higginson I 1993. Palliative care: a review of past changes and future trends. *Journal of Public Health Medicine* 15: 3–8.
- Hinton J 1994. Which patients with terminal cancer are admitted from home care? *Palliative Medicine* 8: 197–210.
- Holman CDJ, Bass AJ, Rouse IL & Hobbs MST 1999. Population-based linkage of health records in Western Australia: development of a health services research linked database. *Australian and New Zealand Journal of Public Health* 23: 453–459.
- Hunt R, Bonett A & Roder D 1993. Trends in the terminal care of cancer patients: South Australia, 1981–1990. *Australian and New Zealand Journal of Medicine* 23: 245–251.
- Hunt R & McCaul K 1996. A population-based study of the coverage of cancer patients by hospice services. *Palliative Medicine* 10: 5–12.
- Kasap and Associates 1996. *Report to the Palliative Care Program Review: stage one*. Canberra: AGPS.

- Lawrence DM, Holman CDJ, Jablensky AV & Fuller SA 1999. Suicide rates in psychiatric in-patients: an application of record linkage to mental health research. *Australian and New Zealand Journal of Public Health* 23: 468–470.
- Maddocks I 1990. Changing concepts in palliative care. *Medical Journal of Australia* 152: 535–539.
- National Coding Centre 1996. The Australian version of the International Classification of Diseases, 9th revision, clinical modifications (ICD-9-CM). Sydney: University of Sydney.
- National Health Data Committee 1999. National health data dictionary. Version 8.0. Canberra: Australian Institute of Health and Welfare.
- National Health Ministers' Benchmarking Working Group 1998. Second national report on health sector performance indicators by the National Health Ministers' Benchmarking Working Group, June 1998: a report to the Australian Health Ministers' Conference. Canberra: DHFS.
- Palliative Care Australia (PCA) 1997. State of the nation 1997: report of National Census of Palliative Care Services. Canberra: PCA.
- Palliative Care Australia (PCA) 1998a. Resource manual for palliative care performance indicators in Australia. Canberra: PCA.
- Palliative Care Australia (PCA) 1998b. Standards for palliative care provisions. 2nd ed. Canberra: PCA.
- Patterson KM, Holman CDJ, Hulse GK & Unwin E 1999. First-time hospital admissions with illicit drug problems in Indigenous and non-Indigenous Western Australians: an application of record linkage to public health surveillance. *Australian and New Zealand Journal of Public Health* 23: 460–463.
- Ryan T, Holmes B & Gibson D 1998. Home and Community Care (HACC) Program National Minimum Data Set Project: final report (prepared for Commonwealth and State/Territory Government Home and Community Care Officials). Canberra: AIHW.
- Smith M & Firms P 1994. Palliative care casemix classification: testing a model in a variety of palliative care settings: preliminary results. In: Conference proceedings from the 6th National Casemix Conference. Canberra: Commonwealth Department of Human Services and Health.
- Victorian Government Department of Human Services 1997. Palliative Care National Minimum Data Set Pilot Study. Service Development Series no. 4. Melbourne: Victorian Government Department of Human Services.
- Victorian Government Department of Human Services 1998. Palliative care agencies minimum data set and clinical performance indicators: data specifications. Melbourne: Victorian Government Department of Human Services.
- Woodruff RK, Jordan L, Eicke JP & Chan A 1991. Palliative care in a general teaching hospital, 2. Establishment of a service. *Medical Journal of Australia* 155: 662–665.