

State of
The Nation
1998

Report of National Census
of Palliative Care Services

November 1998

Report of National Census of Palliative Care Services for 1998 conducted by
Palliative Care Australia.

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Acknowledgement

Palliative Care Australia Inc gratefully acknowledges the financial assistance of the
Commonwealth Department of Health and Aged Care. However, the views expressed are
those of Palliative Care Australia Inc and may not represent the views of the Commonwealth.

October 1999

CONTENTS

| | |
|---|-----|
| CONTENTS | i |
| LIST OF TABLES | iii |
| FOREWORD | iv |
| INTRODUCTION | 1 |
| Definition Of Terms | |
| Limitations Of The Census Data | |
| Sampling | |
| Design | |
| Instrument | |
| Procedure | |
| Data Entry And Analysis | |
| Ethical Considerations | |
| Organisation Of This report | |
| Exclusion Of Data | |
| SECTION 1 DISTRIBUTION OF CENSUS AND REPNSE | 5 |
| 1.1 Distribution | |
| 1.2 Response | |
| SECTION 2 SERVICE AND PROGRAM DESCRIPTION | 7 |
| 2.1 Services And Programs | |
| 2.2 Access To Senior Clinical Practitioners - Palliative Medicine Specialists | |
| 2.3 Access To Senior Clinical Practitioners - Senior Nursing Practitioners | |
| 2.4 Specified Palliative Care Nursing In Community Based Programs | |
| 2.5 Availability Of Palliative Care Beds | |
| SECTION 3 STAFF WORKING IN PALLIATIVE CARE SERVICES | 13 |
| 3.1 Category & Number Of Staff | |
| 3.2 Palliative Care Teams | |
| SECTION 4 CENSUS DAY 18 NOVEMBER 1998 | 18 |
| 4.1 Patient Activity Data | |
| 4.3 Characteristics Of The Palliative Population: Census Day | |
| 4.4 Age Distribution | |
| 4.5 Long-Term Community Patients | |

| | |
|---|----|
| SECTION 5 ANNUAL DATA | 27 |
| 5.1 People Who Died While Receiving Palliative Care | |
| 5.2 Place Of Death | |
| 5.3 Palliative Care Casemix: Diagnosis | |
| 5.4 Length Of Registration With Palliative Services | |
| 5.5 Access Issues In Data Of Sections 4-5 | |
| SECTION 6 PERFORMANCE INDICATORS | 33 |
| 6.1 Palliative Care Performance Indicator 3.1: The number of disciplines available in the interdisciplinary team of the service | |
| 6.2 Palliative Care Performance Indicator 3.2a and 3.2b: Shared patient records | |
| 6.3 Palliative Care Performance Indicator 4.1 and 4.2: Volunteer Services | |
| 6.4 Palliative Care Performance Indicator 5.1 and 5.2: Education | |
| 6.5 Palliative Care Performance Indicator 6.2: Benchmarking | |
| 6.6 Palliative Care Performance Indicator 7.1: Bereavement Risk Assessment | |
| 6.7 Palliative Care Performance Indicator 8.1: Proportion of palliative care services which provide 24 hour access | |
| SECTION 7 BEREAVEMENT SUPPORT | 38 |
| 7.1 BEREAVEMENT PROGRAM CASELOAD | |
| CONCLUSION AND RECOMMENDATIONS | 40 |
| APPENDIX ONE | 41 |
| CENSUS QUESTIONS | |

LIST OF TABLES

- Table 1.1: Distribution of Palliative Care Providers*
Table 1.2: Distribution of Responses to Census 1998
Table 2.1: Programs Provided by Palliative Care Services
Table 2.3: Medical Supervision of Hospitalised Patients
Table 2.4: Access To PMS By Program and Location
Table 2.5: Access To Senior Nursing Practitioners By Program And Location
Table 2.6 : Provision of Specific Palliative Care Nursing and Access To Senior Nursing Practitioners Within Community Palliative Care Programs
Table 2.7: Palliative Care Beds by Type, State and Location
Table 3.1: Distribution of Clinical Personnel by State
Table 3.2: Palliative Care Staffing By Category And Location
Table 3.3: Suggested classification of Palliative Care Teams:
Table 4.1: Patients Registered on Census Day by State and Location
*Table 4.2: Adjusted Registrations * on Census Day: Relation to Population Aged 55+ Years*
Table 4.3: Patients in Hospice Inpatient or Hospital Consultancy Programs: Census Day
Table 4.4: Patients In Community Based Programs: Census Day

4.2 UTILISATION DATA : CENSUS DAY

- Table 4.5 : Clinical Activities By State : Census Day*
Table 4.6: Patients of Hospice Inpatient and Hospital Consultancy Programs by Sex And Principal Diagnosis
Table 4.7: Comparison of Major Diagnoses: Palliative Care Inpatients and Australian Cancer Deaths
Table 4.8: Patients Of Community Based Programs By Sex And Principal Diagnosis
Table 5.1: Annual Deaths, PC Services 1997-1998
*Table 5.2: Proportion Of Home Deaths Identified In Annual Data * 1997-1998*
Table 5.4: Annual Deaths 1997-98 : Principal Diagnosis
Table 5.5: Comparison Of Principal Diagnoses: Palliative Care Deaths (1997-98) and Australian Cancer Deaths (n=2196)
Table 6.1: Interdisciplinary Teams
Table 6.2: Shared Clinical Records
Table 6.3: Volunteer Services
Table 6.4 : Volunteers Hours Of Service (One Week)
Table 6.5: Education Hours Provided (One Week)
Table 6.6: Access To Palliative Care Team Member(s)
Table 7.1: Bereavement Support Distribution of Services and Trained Staff
Table 7.2: Duration Of Bereavement Support in 84 Programs With Defined Policy
Table 7.3: Bereavement Support Programs Distribution of Annual Caseload and Activity

FOREWORD

Palliative Care Australia is the national peak body for palliative care in Australia. Our goal is to work toward the relief of pain and suffering of dying people in Australia and the provision of the care they need. Palliative Care Australia is an advocate for ALL Australians who need palliative care.

Palliative Care Australia defines palliative care as "... specialised health care of dying people, which aims to maximise quality of life, and assist families and carers during, and after death."

Therefore, the primary objectives of palliative care are to enable people facing death:

- to be as free as possible from unnecessary suffering (physical, emotional, or spiritual);
- to maintain their dignity and their independence throughout the experience;
- to be cared for in the environment of choice;
- to have their grief needs recognised and responded to; and
- to be assured that their family's needs are also being met.

This document represents the second Census of palliative care in Australia. The Census was conducted in November 1998 and describes who receives palliative care, where they live, and who provides it, and how much is provided.

The findings will assist Palliative Care Australia, Australian Governments, and the Community to be better informed about palliative care. Palliative Care Australia intends that this report will be used as the most reliable and comprehensive information available about palliative care provision in Australia.

Palliative Care Australia acknowledges and is appreciative of the considerable contribution palliative care services throughout Australia have made by completing a comprehensive survey document. In particular, we are appreciative of the amount of manual collation of data undertaken by individuals in the absence of appropriate technological information systems.

Palliative Care Australia would also like to acknowledge the work of the Census Working Party: Dr Peter Whan, Dr Bruce Stafford, Ms Tonia Barnes and Ms Ellen Nightingale (Convenor). The data has been given considerable meaning and has been turned into useful information through the skill, insight and curiosity of Dr Tony Ireland who has performed the data analysis and has written the bulk of this report.

Palliative Care Australia is confident that the State of the Nation 1998 will be used extensively to assist with planning of palliative care service provision, so that ALL Australians have access to palliative care if they need it and want it.



Ellen Nightingale
President

INTRODUCTION

As part of its strategy to be better informed about palliative care in Australia, PCA conducted its second census of patient services in November 1998.

The aim of this census was to:

- quantify the type and amount of palliative care provision by palliative care services;
- quantify the type and amount of palliative care programs provided by palliative care services;
- describe the age, sex, and primary disease of people receiving palliative care;
- quantify the amount and sources of funding used by palliative care services; and
- collect data on selected palliative care performance indicators.

The Census collected five types of information:

1. descriptive data about palliative care services
2. data about what was happening in a palliative care service over a 24 hour period in order to get a picture of what happens on a typical day in palliative care throughout Australia
3. data about 12 months of service provision
4. unidentified data about age, sex and diagnosis of palliative care patients, Census day
5. palliative care performance indicator data pertaining to the week prior to Census day.

The Census Questionnaire (Appendix One) was divided into sections and broadly sought information about:

- identification and service profile
- staffing
- census day and annual data
- consultation service data
- performance indicators for palliative care
- bereavement program and
- annual financial data.

DEFINITION OF TERMS

For the purposes of the Census, the following definitions were used:

Palliative Care Program - describes the type of service delivery, for example inpatient palliative care is described as an inpatient program. A program may be independent or part of an umbrella organisation.

Palliative Care Service - is an organisation providing palliative care through one or more programs.

Occasion of Service - represents the number of times a patient receives care from a program. An admission to a hospice is one such occasion of service and may last for several days, whereas an occasion of service from an outpatient program refers to a single appointment.

LIMITATIONS OF THE CENSUS DATA

The methods of collection and reporting of data continue to be manual and developmental in most palliative care services. Thus a number of points should be kept in mind when reading this report.

1. Methods of record keeping vary considerably across programs, services and states, making some data difficult to retrieve for some respondents.
2. The difficulty associated with determining accurately the number of patients receiving palliative care.
3. Data is gathered on a self-reported basis, and no formal means of verification is in place.

SAMPLING

Participation in the census was open to any individuals and organisations who identified themselves as being providers of palliative care. Notification of the Census was placed in the Palliative Care News, the official newsletter of the PCA.

DESIGN

A descriptive cross-sectional survey design was used to capture as much data as possible in order to describe the work of palliative care services in Australia and meet the objectives of the census. The survey took data from two contexts. Firstly, the activities of a single day, Census Day which was 18 November 1998 were recorded. Secondly, service provision was described using annual data, giving a broader picture incorporating the normal fluctuations of activity over one year.

INSTRUMENT

The questionnaire was developed specifically for the purposes of the census and is in its third phase of development. The first phase involved a group of expert palliative care practitioners and administrators constructing a set of questions that would capture, as far as possible, information on the organisation of palliative care services in Australia through the range of palliative care programs in metropolitan and rural areas. The analysis of the pilot census identified that the items concerning events of census day and the annual data were valid and required only minor refinement. It was also identified that the issues of staffing and bereavement programs required further attention to develop valid questions. The continued refinement of the questionnaire was planned to occur over a period of three years.

The second phase of development involved separating areas of the questionnaire. The two sections for Census day and annual data were refined in terms of order and some wording. The issue of bereavement services was dealt with by giving respondents the opportunity to describe the services they provide.

The third phase of development has made a further attempt to gather information about staffing and has asked for new information about limited details about people accessing palliative care. Some questions have been deleted to make the size of the questionnaire manageable. Further, details about the bereavement program are also reduced because the phase two questionnaire was exploratory and has been followed up with a separate project.

PROCEDURE

In August 1998 a letter was sent to all palliative care services on the PCA Directory database announcing the Census, outlining its objectives and asking that someone be nominated to coordinate data collection and take responsibility for completing the questionnaire and returning it.

In October 1998 another letter was sent to service providers enclosing the Census questionnaire and a reply paid return envelope. A total of 304 Questionnaires were distributed.

DATA ENTRY AND ANALYSIS

All surveys were checked for completeness by a member of the Census Working Party and respondents were contacted for clarification as necessary. However follow-up for clarification was limited because of resource constraints.

Services where palliative care was provided but not specifically funded were excluded from the survey, eg a private hospital providing care for patients requiring palliative care. Also services which provided palliative care through specific palliative care nursing specialists, eg some domiciliary nursing services, were excluded where data could not be provided specifically for palliative care patients.

Data were analysed using descriptive statistics entered into Excel.

ETHICAL CONSIDERATIONS

Participation in the Census was voluntary. The name of the service and the person who completed the questionnaire were identified to facilitate clarification and judge the representativeness of the data. Strict measures were used to ensure the confidentiality of the data including storage in a locked area and limiting access to raw data to members of the Working Party, and PCA staff. Care has been taken to present the data in a grouped form only and ensure that no service is identifiable.

ORGANISATION OF THIS REPORT

This report is organised into seven sections, each section detailing findings and following the order of the questions where possible making comparison with 1997 Census data.

Finally, conclusions will be drawn about the State of the Nation for palliative care and recommendations will be made.

EXCLUSION OF DATA

Details of funding and expenditure were requested from services. However, the response was even less than in 1997, and was incomplete. Recommendations about how this information can be gathered will be made.

SECTION 1 Distribution of Census and Response

1.1 DISTRIBUTION

The 1998 Census was distributed to 304 services identified in the Register of Palliative Care Services held by Palliative Care Australia. Of these 304 entries, forty provided only non-clinical services; eight additional entries separately identified the inpatient and domiciliary programs of the one service. There were thus 254 services identified through the Register as probable clinical providers of Palliative Care. The distribution of these providers is shown in Table 1.1.

Table 1.1: Distribution of Palliative Care Providers

| State | Metropolitan | Non-Metropolitan | Total |
|---------------------|--------------|------------------|-------|
| New South Wales/ACT | 41 | 44 | 85 |
| Northern Territory | 2 | 4 | 6 |
| Queensland | 12 | 31 | 43 |
| South Australia | 18 | 12 | 30 |
| Tasmania | 5 | 7 | 12 |
| Western Australia | 9 | 19 | 30 |
| Victoria | 21 | 29 | 50 |
| Totals | 108 | 146 | 254 |

In metropolitan and major regional centres there is often a fluid interface between specialist Palliative Care providers and generalist units in the provision of multi-faceted services to registered palliative care patients. In many regional and rural areas, close interaction with generalist services is essential. These interfaces and interactions are particularly complex in the provision of domiciliary services. The precise definition, and identification of the resources being applied to the palliative care caseload is not simple. Data items of Census 1998 will partly clarify these difficulties. Some of the 254 listed services report access to expert personnel and physical resources appropriate for palliative care services. Other hospital and community programs are clearly generalist, yet identify some resources and/or programs dedicated to Palliative Care. A further group of generalist services cares for "palliative patients" with consultative support, either immediate or remote, from expert personnel. In yet other instances, the data reported to Census 1998 do not permit confident classification.

1.2 RESPONSE

From the 254 probable provider services identified in Table 1.2, there were 187 (171 in 1997) returns, a crude response rate of 73.6%. Table 2 shows the geographic distribution of these responses. Response rates of close to 80% were achieved from most capital cities, and from regional/rural services in New South Wales, Victoria and South Australia. Of the 176 providers across Australia most likely to be specialised and exclusive Palliative Care Units, 135 returns (77%) were received.

Table 1.2: Distribution of Responses to Census 1998

| State | Metropolitan | Regional* | Rural | Total | Total 1997 |
|----------------------|--------------|-----------|-------|-------|------------|
| New South Wales /ACT | 30 | 20 | 17 | 67 | 55 |
| Northern Territory | 2 | 1 | 2 | 5 | 3 |
| Queensland | 8 | 16 | 1 | 25 | 29 |
| South Australia | 8 | 2 | 10 | 20 | 19 |
| Tasmania | 4 | 2 | 2 | 8 | 7 |
| Western Australia | 9 | 6 | 7 | 22 | 18 |
| Victoria | 17 | 9 | 14 | 40 | 40 |
| Totals | 78 | 56 | 53 | 187 | 171 |

* Non-metropolitan centre of population > 20 000.

SECTION 2 Service and Program Description

2.1 SERVICES AND PROGRAMS

Data items in this section (Q2 -Q10) sought the following information:

- Programs provided by each service - Community, inpatient, consultative (hospital), outpatient clinic, day centre
- Beds available to inpatient programs - number and classification
- Components of community (domiciliary) programs
- Access to senior Palliative Care practitioners within identified programs

There were 187 responses to this section, although not all respondents provided complete data for all questions. Table 2.1 displays the distribution of the 375 (311 in 1997) separate programs of care provided across Australia.

Table 2.1: Programs Provided by Palliative Care Services

| Number of Services | | Number of Programs | | | | | |
|--------------------|---------|--------------------|-----------|--------------|------------|-----|-------|
| State | Service | Community | Inpatient | Consultative | Outpatient | Day | Total |
| NSW/ACT | 67 | 55 | 28 | 38 | 16 | 12 | 149 |
| Northern Territory | 5 | 4 | 3 | 1 | 0 | 0 | 7 |
| Queensland | 25 | 17 | 16 | 10 | 7 | 3 | 53 |
| South Australia | 20 | 18 | 12 | 11 | 3 | 1 | 45 |
| Tasmania | 8 | 6 | 2 | 3 | 1 | 0 | 12 |
| Western Australia | 22 | 13 | 17 | 5 | 2 | 2 | 29 |
| Victoria | 40 | 33 | 13 | 17 | 6 | 0 | 69 |
| Totals 1998 | 187 | 146 | 91 | 85 | 35 | 18 | 375 |
| Totals 1997 | 171 | 149* | 64 | 57 | 27 | 14 | 311 |

*Coordinated Care Programs were reported separately in 1997, and have been added to the community program statistics here.

Overall 146 of 187 services (78%) provide some form of community based program. This percentage is essentially similar in all States with the exception of Western Australia where one service (Silver Chain) provides an almost exclusive metropolitan coverage. Approximately half of the services (91 of 187) provide an inpatient program; these vary from large stand-alone Hospices to single beds in district hospitals with no regular Palliative care staffing. Further details of inpatient facilities are shown in Table 2.7.

Consultancy programs within acute general hospitals are provided by 85 services (46%) with considerable variations in reported rates across the States and especially in rural areas (see Table 2.2). Interpretation of these apparent differences is difficult. In many instances, especially in the country, the service already maintains an inpatient program within the local hospital, making a separate consultancy program redundant.

Outpatient clinics and day-centres were a rarity except in metropolitan Sydney and in regional centres of Queensland.

Table 2.2: Location of Major Programs

| State | Metropolitan | | | | Region/Rural | | | |
|--------------|--------------|-----|-----|-----|--------------|-----|-----|-----|
| | Ser | Com | Inp | Con | Ser | Com | Inp | Con |
| NSW/ACT | 30 | 22 | 12 | 17 | 37 | 34 | 16 | 20 |
| N/Territory | 2 | 1 | 2 | 1 | 3 | 3 | 1 | 0 |
| Queensland | 8 | 5 | 5 | 3 | 17 | 12 | 11 | 7 |
| South Aust | 8 | 7 | 3 | 2 | 12 | 11 | 9 | 9 |
| Tasmania | 4 | 2 | 1 | 1 | 4 | 4 | 1 | 2 |
| Western Aust | 9 | 2 | 6 | 4 | 13 | 11 | 11 | 1 |
| Victoria | 17 | 10 | 6 | 5 | 23 | 23 | 7 | 12 |
| TOTALS | 78 | 49 | 35 | 33 | 109 | 98 | 56 | 51 |

Abbreviations: Ser = Number of services: Com = Community: Inp = Inpatient: Con = Consultancy

2.2 ACCESS TO SENIOR CLINICAL PRACTITIONERS - PALLIATIVE MEDICINE SPECIALISTS

Fifty-four of the 78 metropolitan services replied to Question 8, describing the likely status of medical supervision "if a patient of your service requires hospital admission". A Palliative Medicine Specialist (PMS) was nominated in 42 instances and another seven services nominated access to PMS as consultants to the admitting doctor. Thus 49 of 54 (91%) of metropolitan palliative care services provide direct or indirect access to a PMS when patients require hospital admission. Only three services (6%) nominated general practitioners as the supervising doctors in this situation.

Of the 56 regional services, 54 provided data for Question 8. Direct care by a PMS was nominated by 20 services and consultant access was nominated by a further 9 services. Direct or indirect access was thus indicated for 54% of these services, of which a further 28% nominated care by general practitioners.

Of the 53 rural services, 48 provided data, with only five having direct PMS access and a further eleven by consultation, to a total of 33%. General Practitioner care was nominated by 27 rural services (56%). These data are summarised in Table 2.3.

Table 2.3: Medical Supervision of Hospitalised Patients

| Doctor | Metropolitan | Regional | Rural |
|----------------------|--------------|----------|-------|
| PMS - Direct | 78* | 37 | 10 |
| PMS - Consultant | 13 | 17 | 23 |
| Other Specialist | 4 | 18 | 11 |
| General Practitioner | 5 | 28 | 56 |

* All values are percentages

Replies to other questions in the Census suggest that non-responders to Question 8 may be less likely to provide access to PMS services, but the trend is not strong. At Question 10, 47 metropolitan services reported inpatient and/or hospital consultancy programs, with 42 (89%) having direct PMS access. For the 40 regional services which reported inpatient and/or consultancy programs, 63% stated direct PMS access, while for 37 rural services the corresponding rate was 49%.

With respect to community programs, 71% of 49 metropolitan services, 66% of 47 regional services and 55% of 51 rural services reported access to PMS. A greater proportion of this access was indirect (telephone only) outside the capital cities. Data from Question 10 with respect to PMS access is summarised in Table 2.4.

Table 2.4: Access To PMS by Program and Location

| Program | Metropolitan (N=78) | | Region (N=56) | | Rural (N=53) | |
|---------------------------|---------------------|----------|----------------|---------|--------------|---------|
| | SER# | PMS(D) | SER | PMS(D) | SER | PMS(D) |
| Inpatient/ Consultancy | 47 | 42 (42)* | 40 | 25 (23) | 37 | 18 (12) |
| Community | 49 | 35 (33) | 47 | 31 (22) | 51 | 28 (20) |

Services which reported inpatient and/or hospital consultancy programs (Question 10)

*Numbers in parentheses indicate direct access

2.3 ACCESS TO SENIOR CLINICAL PRACTITIONERS - SENIOR NURSING PRACTITIONERS

Question 10 also reported access to Clinical Nurse Consultants (CNC) and Clinical Nurse Specialists (CNS).

Of 47 metropolitan services reporting inpatient and/or hospital consultancy programs, 36 provided direct or indirect access to CNC (77%) within these programs, compared with 25 of 40 regional services (63%) and 27 of 37 rural services (73%). CNC access within community based programs was provided in 86% of reporting metropolitan services, 89% of regional and 55% of rural services. Nearly 90% of CNC access was direct, with no appreciable variation across programs or locations.

Direct and/or indirect access to CNS services was reported by 33 of the 47 metropolitan services with inpatient or hospital consultancy programs, a rate of 70%. Corresponding values for regional and rural services were 65% and 70% respectively. CNS access within community based programs was reported by 74% of metropolitan, 72% of regional and 61% of rural services. Data describing access to senior nursing practitioners are summarised in Table 2.5.

Table 2.5: Access To Senior Nursing Practitioners By Program And Location

| Program | Metropolitan (N=78) | | | Regional (N=56) | | | Rural (N=53) | | |
|---------------------------|-------------------------|-----|-----|--------------------|-----|-----|-----------------|-----|-----|
| | SER* | CNC | CNS | SER* | CNC | CNS | SER* | CNC | CNS |
| Inpatient/ Consultancy | 47 | 37 | 33 | 40 | 25 | 26 | 37 | 27 | 26 |
| Community | 49 | 42 | 36 | 47 | 42 | 34 | 51 | 28 | 31 |

* SER = Services reporting data for this item

2.4 SPECIFIED PALLIATIVE CARE NURSING IN COMMUNITY BASED PROGRAMS

Question 9 reported further details of community based programs. Of the 49 Metropolitan community programs, 40 reported Palliative Care Nursing as a specific element of that program. Of 47 community based programs in regional centres 37 reported PC specific nursing as did 44 of the 51 rural community programs. Table 2.6 incorporates data from Question 9 and Question 10 to again describe availability of senior nursing personnel to these specialised nursing programs. The data of Table 2.6, with some minor variations, reinforces the pattern of Table 2.5. A lesser availability of senior nursing personnel to rural programs is evident, even for programs which purport to deliver specific expertise in palliative care. The proportion of PC Nursing programs unsupported by senior personnel was higher in New South Wales than in the other states.

Table 2.6: Provision of Specific Palliative Care Nursing and Access To Senior Nursing Practitioners Within Community Palliative Care Programs

| | METROPOLITAN (N=49) | REGIONAL (N=47) | RURAL (N=51) | TOTAL (N=147) |
|--------------------------|------------------------|--------------------|-----------------|------------------|
| PC NURSING | 40 | 37 | 44 | 121 |
| CNC (DIRECT) | 29 | 30 | 19 | 78 |
| CNS (direct)* | 2 | 3 | 13 | 18 |
| INDIRECT ONLY (CNC/S) | 4 | 2 | 3 | 9 |
| NIL CNC/CNS | 5 | 2 | 9 | 16 |

* No CNC available: CNS is most senior practitioner

2.5 AVAILABILITY OF PALLIATIVE CARE BEDS

The distribution of beds available for inpatient programs is shown in Table 2.7. The total number of beds reported to Census 1998 was 702 (762 in 1997). Given that 23 per cent of "probable clinical PC providers" did not reply to the Census, the actual number would be substantially higher, probably between 900 and 1000. The total of 226 reported beds in Stand-alone Hospices unit represents only nine units; data from some "flagship" Hospices are missing from or incomplete in this Census.

Of the 211 non-metropolitan beds, 38 were reported for rural services, all within local acute hospitals. Twenty-two of these 38 beds had at least partially dedicated palliative care staffing. No beds were reported from rural services in Queensland, Tasmania or Northern Territory.

Table 2.7: Palliative Care Beds by Type, State and Location

| STATE | LOC | SOH | DAH | DNH | NDAH | NDNH | TOTAL |
|----------------------|-----|-----|-----|-----|------|------|-------|
| New South Wales /ACT | M | 131 | 49 | 93 | 0 | 0 | 273 |
| | R/R | 0 | 52 | 18 | 8 | 0 | 78 |
| Northern Territory | M | 0 | 1 | 2 | 0 | 0 | 3 |
| | R/R | 0 | 0 | 0 | 0 | 0 | 0 |
| Queensland | M | 0 | 16 | 28 | 0 | 12 | 56 |
| | R/R | 17 | 37 | 0 | 6 | 0 | 60 |
| South Australia | M | 16 | 10 | 12 | 4 | 0 | 42 |
| | R/R | 0 | 14 | 0 | 3 | 0 | 17 |
| Tasmania | M | 0 | 0 | 0 | 0 | 0 | 0 |
| | R/R | 0 | 0 | 0 | 0 | 0 | 0 |
| Western Australia | M | 46 | 22 | 0 | 0 | 0 | 68 |
| | R/R | 8 | 16 | 0 | 3 | 1 | 27 |
| Victoria | M | 8 | 41 | 0 | 0 | 0 | 49 |
| | R/R | 0 | 24 | 0 | 4 | 0 | 28 |
| TOTALS | M | 201 | 139 | 135 | 4 | 12 | 491 |
| | R/R | 25 | 143 | 18 | 24 | 1 | 211 |

LEGEND: SOH = Dedicated PC beds in acute hospital
 DAH = Dedicated PC beds in acute hospital
 DNH = Dedicated beds in non-acute hospital or nursing home
 NDH = Non-dedicated beds in acute hospital
 NDNH = Non-dedicated beds in non-acute hospital or nursing home

SECTION 3 Staff Working in Palliative Care Services

3.1 CATEGORY & NUMBER OF STAFF

Details of personnel employed by palliative care services were reported in Question 11. 180 services provided data. Staff were identified as full-time equivalents (FTE) and by professional category. The distribution of palliative care clinicians as FTE within each State is shown in Table 3.1.

Table 3.1: Distribution of Clinical Personnel by State

| | NSW | NT | QLD | SA | TAS | WA | VIC | TOTAL |
|--------------------------------|-------|-----|------|------|------|------|------|-------|
| Palliative Medicine Specialist | 29.9* | 1.0 | 12.2 | 5.6 | 0 | 5.1 | 17.5 | 71.3 |
| Clinical Nurse Consultant | 57.9 | 4.0 | 16.5 | 9.8 | 8.6 | 7.3 | 31.7 | 135.8 |
| Clinical Nurse Specialist | 60.4 | 5.0 | 45.9 | 23.7 | 8.4 | 29.8 | 71.3 | 244.5 |
| Registered Nurse | 187.8 | 0 | 72.7 | 46.8 | 15.8 | 80.6 | 83.5 | 487.2 |
| Other Nursing | 114.5 | 0 | 41.6 | 15.5 | 5.0 | 47.1 | 19.7 | 243.4 |
| Other Medical officer | 18.4 | 0 | 5.2 | 4.0 | 0 | 10.6 | 9.9 | 48.1 |
| Pharmacist | 8.6 | 0 | 2.8 | 2.0 | 0 | 1.1 | 1.6 | 16.1 |
| Social Worker | 20.5 | 1.0 | 7.5 | 9.2 | 4.8 | 4.4 | 15.9 | 63.3 |
| Pastoral Care | 16.2 | 0.8 | 11.6 | 6.0 | 0 | 17.6 | 15.2 | 67.4 |
| Bereavement Coord. | 15.1 | 0 | 3.0 | 5.4 | 0 | 5.2 | 6.4 | 35.1 |
| Volunteer Coord. | 20.3 | 0 | 6.5 | 1.4 | 3.0 | 4.1 | 10.7 | 46.0 |
| Occupational Therapist | 10.7 | 0.5 | 2.5 | 3.0 | 0 | 3.4 | 4.6 | 24.7 |
| Physiotherapist | 9.6 | 0 | 4.7 | 3.0 | 2.0 | 2.5 | 4.8 | 26.6 |

* All values represent Full-Time equivalents (FTE)

In the data returns for Question 11 there were some obvious anomalies which have been addressed in Table 3.1. Some services quoted very high staff numbers for some categories (particularly medical staff and registered nurses) quite out of proportion to values quoted by comparable services. It was evident that these services were quoting the entire establishment for their hospital or community nursing service, and equally obvious that the entire establishment was not dedicated to palliative care. Reasonable estimates, based upon peer group values, of the dedicated palliative care resources have been substituted in these instances.

Interpretation of staffing data is also made in the context of an almost 30% non-response rate, which includes some substantial providers. Several metropolitan services, particularly in Hobart, Melbourne and Adelaide, employ a number of Palliative Medicine Specialists, but have not reported here. There are also differing specifications for some nursing classifications across States.

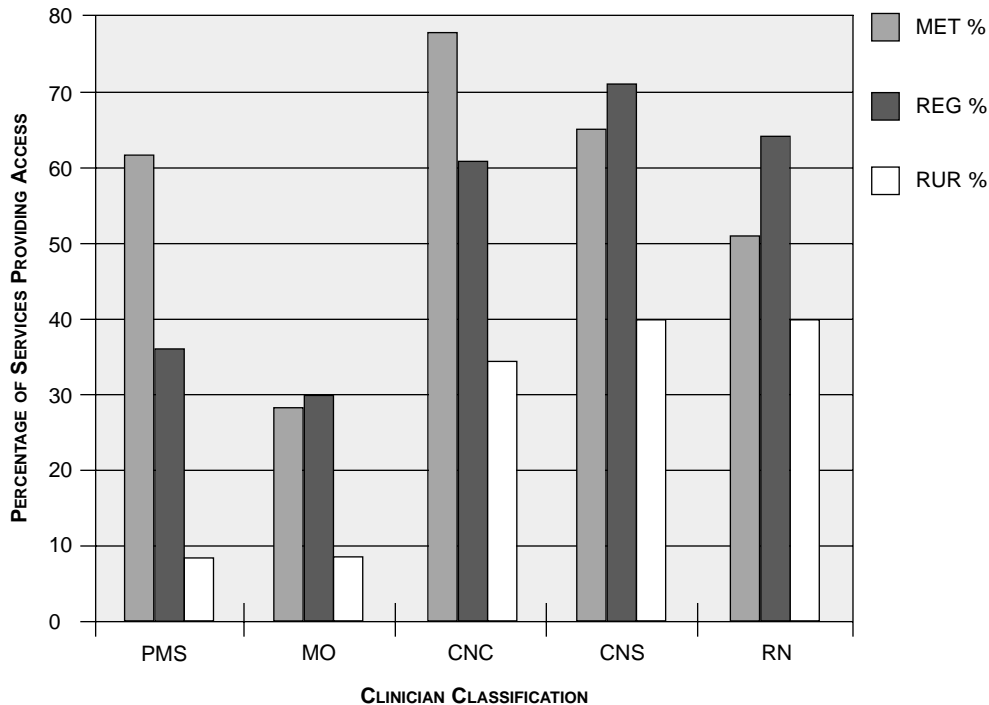
Given these disclaimers, the data of Table 3.1 show a reasonably consistent distribution both in relation to age-weighted State populations and the representation of the professions within each State. The 71.3 FTE positions for Palliative Medicine Specialists include a number of fractional positions and represent a minimum of 90 appointments. Similarly the 135.8 FTE positions for Clinical Nurse Consultants represent at least 146 positions and there are a minimum of 259 separate appointments as Clinical Nurse Specialist. Almost exactly half of the reported senior nursing workforce (50% for CNC and 48% for CNS) is deployed in community based programs. In contrast nearly three-quarters of FTE for Registered Nurses are reported from inpatient programs, heavily concentrated within the major Hospices. The collation for Table 3.1 in respect of Registered Nurses has attempted to exclude those many nurses employed by generalist community services who provide valuable assistance to palliative patients, but are not primarily employed as palliative care practitioners. As already noted, the boundaries between specialised palliative care and other care systems are often fluid.

Table 3.2 shows the number of services in the various locations which provide access to each of the designated categories of clinical staff. Table 3.2 indicates only that there is access to a (full-time or part-time) person(s) of the stated category; it does not quantify the numbers of FTE of any staff category which are available.

Table 3.2: Palliative Care Staffing By Category And Location

| Category | Metrop SER* | (N=78) (%) | Regional SER | (N=56) (%) | Rural SER | (N=53) (%) | Totals SER | (N=187) (%) |
|--------------------------------|----------------|---------------|-----------------|---------------|--------------|---------------|---------------|----------------|
| Palliative Medicine Specialist | 48 | 62 | 20 | 36 | 4 | 8 | 72 | 39 |
| Clinical Nurse Consultant | 61 | 78 | 34 | 61 | 18 | 34 | 113 | 60 |
| Clinical Nurse Specialist | 51 | 65 | 40 | 71 | 21 | 40 | 112 | 60 |
| Registered Nurse | 40 | 51 | 36 | 64 | 21 | 40 | 97 | 52 |
| Other Medical Officer | 22 | 28 | 17 | 30 | 4 | 8 | 43 | 23 |
| Pharmacist | 15 | 19 | 10 | 18 | 4 | 8 | 29 | 16 |
| Social Worker | 40 | 51 | 19 | 34 | 6 | 11 | 65 | 35 |
| Pastoral Care | 27 | 35 | 15 | 27 | 4 | 8 | 46 | 25 |
| Bereavement Coord. | 26 | 33 | 12 | 21 | 7 | 13 | 45 | 24 |
| Volunteer Coord. | 29 | 37 | 28 | 50 | 8 | 15 | 65 | 35 |
| Occupational Therapist | 21 | 27 | 7 | 13 | 3 | 6 | 31 | 17 |
| Physiotherapist | 20 | 26 | 5 | 9 | 4 | 8 | 29 | 16 |

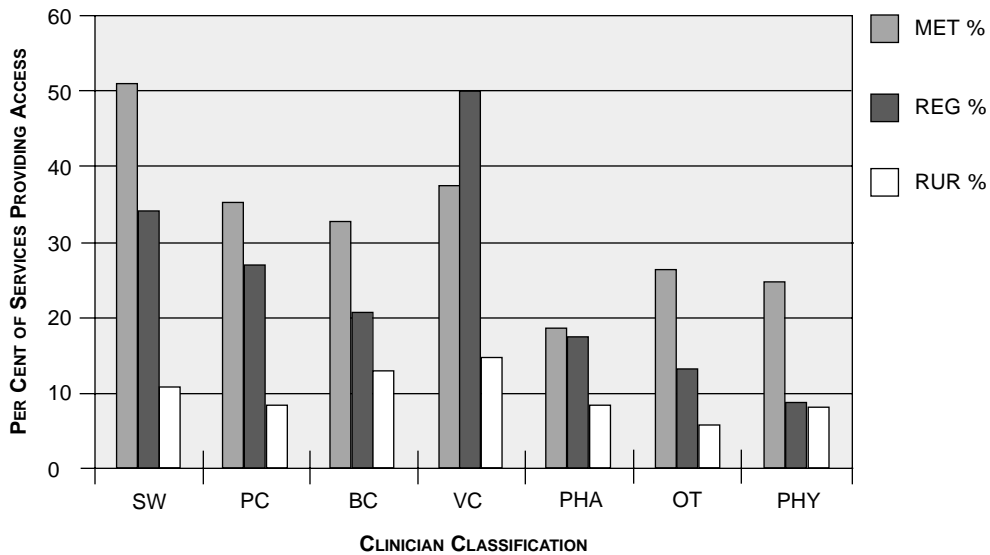
*SER = PC Services with reported establishment

Figure 3.1: Access to Medical and Nursing PC Services by Location

The data of Table 3.2 and Figure 3.1 illustrate the differences in rates of access to senior medical and nursing expertise according to location. Over 60% of metropolitan services report the presence of a PMS, nearly 80% have some CNC establishment and 65% provide access to CNS. The percentages of regional centres reporting access to PMS and CNC are lower (36 and 61 respectively) while the value in respect of CNS access is just above 70%. Among rural services only 8% report PMS access, with 34% reporting CNC access and 40% in respect of CNS. It is clear that most direct clinical services in rural areas are provided by nursing personnel, either Clinical Nurse Specialists or Registered Nurses, with very limited access to specialised medical support.

Parallel trends are shown for the Allied Health components of Palliative Care, as illustrated in Figure 3.2. Social Workers are employed by half of the reporting metropolitan services, while one-third report the presence of Pastoral Care staff and/or Bereavement Coordinators. The presence of these three classifications is less by a factor of one-third in regional services, and found in only one out of ten rural services. Half of the regional services provide a Coordinator of Volunteers, slightly more than in the city, but only 15% of rural services report this position. Access to Occupational Therapy, Physiotherapy or Pharmacy services is reported by approximately one quarter of metropolitan services and by about one in eight services in regional centres. Formal support from these practitioners is almost negligible in rural locations.

Figure 3.2: Access to Allied Health Services by Location



3.2 PALLIATIVE CARE TEAMS

The provision of comprehensive, and ideally holistic patient care is central to the palliative philosophy. A team based approach to care delivery which utilises the skills of multiple healthcare disciplines is the logical application of this philosophy. It is usually accepted that holistic palliative care stands upon the foundation of accurate diagnosis and effective control of physical symptoms. It is equally accepted that a wide range of social, cultural, emotional, spiritual and behavioural concerns, of both the sick person and their designated family may require the attention of appropriately trained personnel.

A Proposed Classification of PC Teams:

The following classification of PC Teams, in accord with Standard 3 of the Standards for Provision of Palliative Care (PCA, 1998) thus recognises primarily those services which include at least a doctor and nurse. Teams are arbitrarily graded A to D to reflect the seniority and presumed expertise of the doctor / nurse partnership plus the completeness of the allied health and volunteer complement. A fifth classification (E) has been allocated to teams which comprise a CNC and comprehensive allied health services but no formal medical input. The possibility of such units accessing medical support from outside the establishment of the PC service itself can be inferred from the data of Section 5.

Table 3.3: Suggested classification of Palliative Care Teams:

| | MEDICAL | NURSING | AHS (1) | AHS(2) |
|-----|-----------|------------|-----------------|----------------------|
| A * | PMS # | CNC | One of SW,PC,BC | One of OT,PHY,PHA* |
| B | PMS or MO | CNC or CNS | One of SW,PC,BC | One of Any Other |
| C | PMS or MO | CNC or CNS | One of SW,PC,BC | |
| D | PMS or MO | CNC or CNS | | |
| E | --- | CNC or CNS | One of SW,PC,BC | One of OT,PHY,PHA,VC |

All abbreviations as for Table 3.1

Table 3.4 displays the results by location where this classification is applied to the data of Question 11.

Table 3.4: Distribution of Palliative Care Teams by Class and Location

| Class | Metropolitan | Regional | Rural | Totals |
|--------|--------------|----------|-------|--------|
| A | 34 | 13 | 1 | 48 |
| B | 4 | 2 | 2 | 8 |
| C | 2 | 8 | 3 | 13 |
| D | 6 | 3 | 0 | 9 |
| E | 5 | 5 | 2 | 12 |
| TOTALS | 51 | 31 | 8 | 90 |

Exactly 50% of the 180 services who reported staffing data presented a definable multi-disciplinary Palliative Care Team. Two thirds of metropolitan services provided legitimate team-based care by these criteria, and two-thirds of these teams were classification "A". Slightly more than half of the regional services contained teams with 40% of these teams being classification "A". Only one "A" team was included in the eight definable teams (15%) reported by rural services.

SECTION 4 Census Day 18 November 1998

4.1 PATIENT ACTIVITY DATA

Questions 14-23 requested details of new referrals, occasions of service including consultations, discharges and deaths in respect of a single 24-hour period. Services were also asked to state the total numbers of patients registered within their various programs on census day. Questions 24 and 25 sought additional details of age, gender, diagnosis and date of admission for all patients registered in community and inpatient programs on census day.

A total of 184 services provided partial or complete data for Questions 14-23 and 169 services completed the additional details of Questions 24 and 25. It was evident that only a small minority of services had administrative or data processing support systems for the collation and transcribing of these routine but substantial statistical returns. A wide variety of methods for data collection and collation was in evidence. Despite the conscientious effort and sheer clerical labour required to answer Questions 24 and 25 by such a high proportion of services, there were numerous inconsistencies in data returned in these sections.

The data presented in Tables 4.1- 4.4 are the result of matching responses to Questions 14, 1-4 and Questions 24-25 for each participating service. The data in Questions 24-25, which provide diagnostic and demographic details for individual (anonymous) patients, determined the minimum number of registrations for the given service or program. Higher numbers in Question 14 were accepted provided they were not incompatible with local demographics or the data from services known to be comparable.

It was not possible to consistently identify palliative care patients within the caseloads of domiciliary nursing and allied health services in Adelaide. This difficulty, together with deficiencies in data from some other sectors of the palliative network prevented even a reliable estimate of the palliative population for that city. In the ensuing tables the data for South Australia- Metropolitan reflects the National experience.

Table 4.1: Patients Registered on Census Day by State and Location

| State | Metropolitan | Regional | Rural | Totals |
|---------------------|--------------|----------|-------|--------|
| New South Wales/ACT | 2583 | 1398 | 318 | 4299 |
| Northern Territory | 63 | 1 | 9 | 73 |
| Queensland | 538 | 467 | 9 | 1012 |
| South Australia | 635 | 13 | 249 | 897 |
| Tasmania | 136 | 96 | 20 | 252 |
| Victoria | 1223 | 340 | 213 | 1776 |
| Western Australia | 624 | 68 | 72 | 764 |
| TOTALS | 5802 | 2383 | 888 | 9073 |

Of the 9073 reported registrations, 7027 were in community programs, and 1167 were inpatients of either palliative care units or consultancy programs in general hospitals (Question 14: parts 2-4). The remaining 879 registrations were identified in outpatient or day-hospital programs. There were 12 526 patients registered for Census day in 1997 in Australia. In both 1997 and 1998 data patients could be simultaneously registered in more than one program. The data samples for the two census years are also not identical.

Apparent geographical differences in the data of Table 4.1 must also be viewed with great caution. It must be noted that only three-quarters of identified PC providers responded to Census 1998 and that the response rate varied with location (Table 1.2).

An attempt is made in Table 4.2 to standardise the registration data. Patient numbers from each location are inflated by an appropriate factor to reflect a response from 100% of the PC services of that location. The values thus obtained are then related to the local population of persons aged 55 years and over. This age specification, which captures 85% of PC caseload, seems the most relevant choice for a single denominator.

Table 4.2: Adjusted Registrations * on Census Day: Relation to Population Aged 55+ Years

| State | Metropolitan | R: 1000 # | REG / RUR | R: 1000 |
|---------------------|--------------|-----------|-----------|---------|
| New South Wales/ACT | 3530 | 4.2 | 2041 | 3.5 |
| Northern Territory | 63 | 8.3 | 13 | 1.5 |
| Queensland | 807 | 2.8 | 864 | 2.2 |
| South Australia | 817 | 3.3 | 257 | 2.6 |
| Tasmania | 170 | 3.9 | 203 | 3.3 |
| Victoria | 1511 | 2.2 | 697 | 2.2 |
| Western Australia | 763 | 3.1 | 166 | 2.0 |
| TOTALS | 7661 | 3.26 | 4241 | 2.75 |

* Registrations from Table 4.1, proportionally adjusted to include non-responding services in each location
Registrations per 1000 of local population aged 55+ years.

Interpretations of the above Table must still be constrained, firstly by the small numbers in several of the individual cells. It has also been assumed that average patient numbers in non-responding services are equal to those represented in Table 4.1. The relatively low returns from Victoria in this section, and elsewhere in the census, are more likely to reflect the non-response of several major services than a state-wide deficiency in PC service.

Given these reservations, the national picture - 11 902 patients registered on Census Day, and slightly higher rates of service delivery to metropolitan areas - could closely approximate the real-life situation across Australia. It is noted that patients may be simultaneously registered with more than one program: the number of individual patients receiving palliative care on any one day is likely to be lower than the number of registrations. Further details and parallel calculations with respect to the community based and inpatient programs are provided in Table 4.3 and 4.4.

Table 4.3: Patients in Hospice Inpatient or Hospital Consultancy Programs: Census Day

| State | Metropolitan | Regional | Rural | Totals |
|---------------------|--------------|----------|-------|--------|
| New South Wales/ACT | 379 | 120 | 13 | 512 |
| Northern Territory | 5 | - | 7 | 12 |
| Queensland | 109 | 67 | 2 | 178 |
| South Australia | 68 | 3 | 14 | 85 |
| Tasmania | 29 | 15 | 1 | 45 |
| Victoria | 171 | 42 | 21 | 234 |
| Western Australia | 90 | 7 | 4 | 101 |
| TOTALS | 851 | 254 | 62 | 1167 |

Adjustment of the data in Table 4.3 using the calculations described for Table 4.2, yields a high estimate of 1460 inpatients - 1030 in the capital cities and 430 in regional/rural areas. This represents 44 inpatients per 100 000 persons aged 55+ years for the capital cities, and 28 per 100 000 in regional / rural areas - a much wider discrepancy than shown for total registrations in Table 4.2. Approximately two-thirds of these inpatients are accommodated in dedicated hospice beds (Question 14).

Table 4.4: Patients In Community Based Programs: Census Day

| State | Metropolitan | Regional | Rural | Totals |
|---------------------|--------------|----------|-------|--------|
| New South Wales/ACT | 1945 | 1172 | 284 | 3401 |
| Northern Territory | 58 | - | 2 | 60 |
| Queensland | 425 | 205 | 5 | 635 |
| South Australia | 488 | 10 | 235 | 895 |
| Tasmania | 107 | 75 | 19 | 201 |
| Victoria | 908 | 293 | 187 | 1388 |
| Western Australia | 503 | 58 | 48 | 609 |
| TOTALS | 4434 | 1813 | 780 | 7027 |

Adjustment of the data in Table 4.4 using the calculations described for Table 4.2, yields an estimated total of 9300 registrations in community programs - 5950 in the capital cities and 3350 in regional / rural areas. This represents 253 patients per 100 000 persons aged 55+ years for the capital cities, and 217 per 100 000 in regional / rural areas.

4.2 UTILISATION DATA: CENSUS DAY

The data of Table 4.5 describe the elements of PC service delivery on Census day. Across Australia there were 273 reported new referrals. Several individual services, other than hospital consultancy programs, reported new referrals exceeding one quarter of total registrations on Census Day.

Table 4.5: Clinical Activities By State: Census Day

| Service | NSW | NT | Qld | SA | Tas | VIC | WA | Total '98 | Total '97 |
|------------------------|------|----|-----|-----|-----|-----|-----|-----------|-----------|
| New referrals | 116 | 3 | 47 | 41 | 0 | 40 | 26 | 273 | 368 |
| Direct contacts | 1271 | 19 | 293 | 433 | 23 | 565 | 361 | 2955 | 2745 |
| Telephone contacts | 860 | 2 | 180 | 165 | 27 | 530 | 271 | 2025 | 1898 |
| Informal consultations | 160 | 0 | 70 | 32 | 8 | 415 | 64 | 750 | 641 |
| Discharges | 18 | 0 | 24 | 18 | 2 | 7 | 8 | 77 | 106 |
| Deaths | 30 | 0 | 15 | 12 | 0 | 15 | 8 | 80 | 65 |

There were 2955 face-to-face patient contacts, either in homes, hospices or hospitals. 2025 telephone contacts with or about patients, and 749 formal or informal ("corridor") consultations with non-palliative care providers were reported. Eighty patients died in the 24 hours of the Census period (31 at home) and 77 were discharged alive from PC programs. A one-day mortality rate of approximately 1% implies a caseload turnover of about 15 weeks, which is in reasonable accord with general PC experience.

4.3 CHARACTERISTICS OF THE PALLIATIVE POPULATION: CENSUS DAY.

The responses to Questions 24 and 25 provided more detailed diagnostic and demographic descriptions of the PC population. In response to Question 24, 110 services identified a total of 1002 inpatients, either in hospice inpatient or hospital consultancy programs. This represents a substantial sample of 1167 inpatients identified in Question 14.

Table 4.6: Patients of Hospice Inpatient and Hospital Consultancy Programs by Sex And Principal Diagnosis

| DIAGNOSIS | MALES | FEMALES | TOTALS |
|-----------------|-------|---------|--------|
| Lung | 109 | 55 | 164 |
| Breast | 1 | 99 | 100 |
| Prostate | 68 | - | 68 |
| Colorectal | 50 | 51 | 101 |
| Haematological | 23 | 25 | 48 |
| Pancreas | 17 | 17 | 34 |
| Unknown Primary | 28 | 33 | 61 |
| Other Cancer | 127 | 142 | 269 |
| Non-Cancer | 57 | 41 | 98 |
| No Data | 30 | 29 | 59 |
| TOTALS | 510 | 492 | 1002* |

*165 fewer patients identified in Question 24 than in Question 14

Of the 943 inpatients with diagnostic data, 98 (10.4%) had principal diagnoses other than cancer and 42 of 480 males (8.8%) and 41 of 463 females (8.9%) presented a variety of system failure and degenerative conditions. Fifteen males (3.1%) were diagnosed HIV/AIDS.

Table 4.7: Comparison of Major Diagnoses: Palliative Care Inpatients and Australian Cancer Deaths

| Diagnosis | Males | | Females | |
|-----------------|-------------------|------------|----------|----------|
| | ABS 1996 * | CEN 1998 # | ABS 1996 | CEN 1998 |
| Lung | 26.8 [•] | 25.8 | 14.2 | 13.0 |
| Breast | - | - | 17.4 | 23.6 |
| Prostate | 13.6 | 16.1 | - | - |
| Colorectal | 9.5 | 11.9 | 11.1 | 12.1 |
| Haematological | 9.5 | 5.5 | 10.1 | 5.9 |
| Pancreas | 4.0 | 4.0 | 5.5 | 4.0 |
| Unknown Primary | 9.6 | 6.6 | 10.1 | 7.8 |

* Proportion of Cancer deaths Australia 1996: Causes of Death (ABS 3303.0)

Proportion of cancer diagnoses: inpatient sample Census 1998

• All values are percentages

The two series of data listed in Table 4.7 are not strictly comparable. The ABS data describe the entire population of cancer deaths for a complete 12-month period, while the 1002 patients identified in the census are a vertical sample of patients treated on a single day. With these limitations, some of the apparent differences between the two series deserve comment. The over-representation in the PC data of patients with breast cancer, and to a lesser extent prostate cancer is not unexpected. These cancers are often chronic illnesses with bone pain a prominent feature. Problems with pain control, mobility and recovery from fractures mean that these patients are likely to accumulate in the inpatient beds of PC services. On the other hand, patients with advanced leukaemia or lymphoma, often present with acute problems of septicaemia, bleeding or profound anaemia, for which treatment in acute general hospitals is often preferred.

The relatively low proportion of PC inpatients with metastatic cancer of undiagnosed primary origin is probably an artifact of the data. The number of PC patients simply listed as "Liver cancer" far exceeded the expected rates for primary hepatocellular disease; these were classified as "Other Cancer" rather than "Unknown Primary". It is of interest that, despite recent developments of accurate, non-invasive diagnostic procedures, approximately 10% of cancer patients still die without definitive diagnosis.

Table 4.8: Patients Of Community Based Programs By Sex And Principal Diagnosis

| DIAGNOSIS | MALES | FEMALES | TOTALS |
|-----------------|-------|---------|--------|
| Lung | 441 | 211 | 652 |
| Breast | 2 | 541 | 543 |
| Prostate | 351 | - | 351 |
| Colorectal | 213 | 209 | 422 |
| Haematological | 190 | 175 | 365 |
| Pancreas | 72 | 75 | 147 |
| Gynaecological | - | 193 | 193 |
| HIV / AIDS | 45 | 3 | 48 |
| Unknown Primary | 71 | 80 | 151 |
| Other Cancer | 752 | 544 | 1296 |
| Non-Cancer | 221 | 201 | 422 |
| TOTALS | 2358 | 2232 | 4590* |

* Fewer more patients identified in Question 25 than in Question 14

The data of Table 4.8 are accumulated from 124 community programs who responded to Question 25. A non-cancer diagnosis was reported for 9.4% of males and for 9% of females.

Table 4.9: Comparison of Major Diagnoses: Palliative Care Community Patients and Australian Cancer Deaths

| Diagnosis | Males | | Females | |
|-----------------|-------------------|------------|----------|----------|
| | ABS 1996 * | CEN 1998 # | ABS 1996 | CEN 1998 |
| Lung | 26.8 [•] | 22.0 | 14.2 | 10.8 |
| Breast | - | - | 17.4 | 27.7 |
| Prostate | 13.6 | 17.5 | - | - |
| Colorectal | 9.5 | 10.6 | 11.1 | 10.7 |
| Haematological | 9.5 | 9.5 | 10.1 | 9.0 |
| Pancreas | 4.0 | 3.6 | 5.5 | 3.8 |
| Unknown Primary | 9.6 | 3.5 | 10.1 | 4.1 |

* Proportion of Cancer deaths Australia 1996: Causes of Death (ABS 3303.0)

Proportion of cancer diagnoses: inpatient sample Census 1998

• All values are percentages

Table 4.9 compares the diagnostic profile of 4590 identified community patients with Australian cancer mortality data. The same disclaimers apply as for Table 4.7. The apparent over-representation of breast and prostate cancer is even more pronounced for community patients, reflecting the chronic course of many of these cancers, even when metastatic. By contrast, the "palliative phase" of advanced lung cancer is usually brief and relatively few of these patients will be captured in a vertical sample.

In comparison with the data of Table 4.8, the proportions of community patients with haematological malignancies closely match those of the national population. The previous comment regarding patients with an "unknown primary" diagnosis remains valid.

4.4 AGE DISTRIBUTION

In Table 4.10 the age distributions for males and females in three samples of the PC population are compared with the age profiles for Australians who died from cancer in 1996.

Table 4.10: Age Distribution of Palliative Care Patients: Comparison with Australian Cancer Deaths

| Sample | N | Males | | | Females | | |
|---------------|-------|--------|-------|--------|---------|-------|--------|
| | | <55yrs | 55-74 | 75+yrs | <55yrs | 55-74 | 75+yrs |
| ABS 96 | 34668 | 10.9* | 49.8 | 39.3 | 15.3# | 41.6 | 43.1 |
| INPAT 98 | 1002 | 16.6 | 49.0 | 34.5 | 19.7 | 44.1 | 36.3 |
| COMM 98 | 4590 | 14.4 | 52.9 | 32.7 | 22.5 | 45.4 | 32.2 |
| PC Dths 97-98 | 2196 | 13.6 | 51.8 | 34.6 | 14.1 | 48.2 | 37.7 |

* % of all males in sample

% of all females in sample

4.5 LONG -TERM COMMUNITY PATIENTS

Tables 4.11 and 4.12 describe the numbers of patients within each state and each major diagnostic group who were registered with PC community programs for periods exceeding six months. Date of registration was provided for 4397 of the 4590 community patients identified in response to Question 25.

Across Australia, 28.5% of the patients thus identified had been registered for more than six months on Census Day and more than half of these (15.3%) had been registered for more than one year. A handful of patients had been registered for more than five years.

The percentages of patients from each of the major diagnostic groups which had been registered for longer than six months are shown in Table 4.11. Only 20.1% of patients with lung cancer (17.7% of males) had reached this milestone compared with 39.7% of females with breast cancer. Of the 541 females with breast cancer in this particular sample, 118 (22%) had been receiving PC support for more than one year. These data give some verification for the differing diagnostic relativities shown in Table 4.9.

Table 4.11: Prolonged Registration With PC Community Program: By Sex And Diagnosis

| DIAGNOSIS | MALES | | | FEMALES | | | TOTALS | | |
|------------|-------|-------|------|---------|-------|------|--------|-------|------|
| | N | 6/12+ | % | N | 6/12+ | % | N | 6/12+ | % |
| Lung | 441 | 78 | 17.7 | 211 | 53 | 25.1 | 652 | 131 | 20.1 |
| Breast | 2 | - | - | 541 | 215 | 39.7 | 541 | 215 | 39.7 |
| Prostate | 351 | 106 | 30.2 | - | - | - | 351 | 106 | 30.2 |
| Colon | 213 | 77 | 36.2 | 209 | 75 | 35.9 | 422 | 152 | 36.0 |
| Haem | 190 | 63 | 33.5 | 175 | 71 | 40.6 | 365 | 134 | 36.7 |
| Other | 841 | 161 | 19.9 | 801 | 205 | 25.6 | 1642 | 372 | 22.7 |
| Non-Cancer | 221 | 95 | 43.0 | 201 | 55 | 27.4 | 422 | 150 | 35.6 |
| Totals | 2259 | 580 | 25.7 | 2138 | 674 | 31.5 | 4397 | 1254 | 28.5 |

SECTION 5 Annual Data

In Questions 39 to 44 of the Census, services were asked to provide a numerical summary of annual activity. Annual admissions to community, inpatient and hospital consultancy programs were requested, as well as the grand total for the whole service in respect of financial year 1997-1998. Numbers of discharges and deaths were likewise requested for each program and for the whole service and at Question 44 a classification of place of death was sought for all deaths registered during the year.

Analysis of these data was a frustrating task. Many services who, elsewhere in the Census, had identified activity within a certain program, failed to provide meaningful data in this section. In some instances total "admissions" for the service were listed, without detail of the component programs, or conversely the service reported nil total admissions but then identified activity within one or more programs. Some services with mixed palliative and general roles appeared to report on their entire caseload, as the numbers of patients involved exceeded expected cancer deaths for the given catchment population.

In assessing the responses to Questions 39 to 44, data which were not corroborated by other elements of the Census have been excluded, or modified to reflect the lowest number of the given activities that could be substantiated with certainty from other descriptors. The summary data presented in Tables 5.1 to 5.5 therefore represent a significant under-reporting of annual caseloads and activities, and interpretation even of these data must be cautious.

In Section 2, 146 community programs, 91 hospice inpatient and 84 consultancy programs were identified. In this Section annual data were accepted, by the above criteria, for 94 services in respect of community programs; a total of 18567 admissions was described. There were 9694 admissions through 45 hospice inpatient programs and 5895 admissions identified by 26 hospital consultancy programs. Although the numbers of programs contributing to these totals are relatively small, they include a high proportion of units with heavy caseloads. The admission totals quoted above probably represent about two-thirds of the actual caseloads.

5.1 PEOPLE WHO DIED WHILE RECEIVING PALLIATIVE CARE

The data for annual deaths appeared more internally consistent than some other data elements in this Section. Data from 159 of the 187 responding services contribute to Table 5.1. Mortality figures are probably the most reliable indicator of Palliative Care caseload, since duplication of patient data between programs is least likely to occur in respect of deaths. The 12 456 annual deaths reported by metropolitan palliative care services represent 5.3 deaths per 1000 persons aged 55+ years. The 7027 deaths reported by regional and rural PC services represent 4.6 deaths per 1000 persons aged 55+ years.

Table 5.1: Annual Deaths, PC Services 1997-1998

| State | Metropolitan | Regional/Rural | Totals |
|---------------------|--------------|----------------|--------------|
| New South Wales/ACT | 4763 | 3609 | 8372 |
| Northern Territory | 117 | 12 | 129 |
| Queensland | 1393 | 1010 | 2403 |
| South Australia | 1294 | 517 | 1811 |
| Tasmania | 290 | 449 | 739 |
| Victoria | 2860 | 1205 | 4065 |
| Western Australia | 1739 | 225 | 1964 |
| TOTALS | 12456 | 7027 | 19483 |

Adjustment of the sectional sub-totals in Table 5.1 to reflect a 100 % response from the services of each location (see Table 4.2) would produce a national total of 24 390 annual deaths. Rates per 1000 persons aged 55+ years range from 5.2 (VIC) to 7.4 (NSW) in the capital cities and from 3.2 (WA) to 6.9 (NSW) in regional and rural Australia.

Given that 9-10% of deaths within PC services are attributable to non-malignant diagnoses (Table 5.4), there would be some 21 950 deaths from cancer in the "adjusted" total of 23 700, or 62 per cent of the projected cancer deaths across Australia for 1997-1998. With due acknowledgment of the approximations involved in this calculation, it is probable that almost two-thirds of cancer patients who require and will accept palliative care are now receiving this service.

5.2 PLACE OF DEATH

Dying at home is the stated preference of many palliative care patients, at least in the earlier stages of their final illness. A number of factors may arise to make ongoing home-based care impractical for individual patients. The proportion of patients supported at home until death remains however an important performance indicator for many community palliative care programs.

Table 5.2: Proportion Of Home Deaths Identified In Annual Data * 1997-1998

| State | Metropolitan | | | Regional / Rural | | | Totals | | |
|---------|--------------|------|------|------------------|------|------|--------|------|------|
| | DTHS | HOME | % | DTHS | HOME | % | DTHS | HOME | % |
| NSW/ACT | 2941 | 633 | 21.5 | 3609 | 1238 | 34.3 | 6550 | 1871 | 28.6 |
| NT | 117 | 51 | 43.6 | 9. | 7 | 78 | 126 | 58 | 46.0 |
| Qld | 846 | 427 | 50.5 | 744 | 400 | 53.8 | 1590 | 827 | 52.0 |
| SA | 1001 | 147 | 14.7 | 443 | 102 | 23.0 | 1444 | 249 | 17.2 |
| Tas | 290 | 66 | 22.8 | 449 | 180 | 40.1 | 739 | 246 | 33.3 |
| VIC | 2381 | 976 | 41.0 | 646 | 270 | 41.8 | 3027 | 1246 | 41.2 |
| WA | 1713 | 763 | 44.5 | 217 | 107 | 49.3 | 1930 | 870 | 45.1 |
| TOTALS | 9289 | 3063 | 33.0 | 6117 | 2304 | 37.7 | 15406 | 5367 | 34.8 |

* Place of death identified for 15406 of 21874 deaths 1997-1998 (Questions 43,44)

The data of table 5.2 show that death at home occurs in approximately one-third of reported cases. The proportion is slightly higher in non-metropolitan areas. There are considerable apparent differences between the States. The comparatively low figures for South Australia are consistent with previous reports (Hunt et al., Aust NZ J Med 1993) from that State. High rates of deaths at home may sometimes reflect lack of other options for end-of-life care, but reported numbers of PC beds were not notably low in Queensland or Western Australia (Table 2.7) where nearly half the reported deaths were at home.

Table 5.3: Place Of Death: Registered PC Patients Australia 1997-1998 and 1996-1997

| Place | 1997 - 1998 | | 1996 - 1997 | |
|--|-------------|-------|-------------|-------|
| | Deaths | % | Deaths | % |
| Home | 5367 | 34.8 | 4603 | 27.5 |
| Palliative Care Inpatient Unit | 4606 | 29.9 | 7482 | 49.85 |
| General Hospital: Palliative Care Consultant | 3790 | 24.6 | 2126 | 12.7 |
| General Hospital: Nil Palliative Care | 709 | 4.6 | - | - |
| Nursing Home | 493 | 3.2 | - | - |
| Other/Unknown | 411 | 3.0 | 3508 | 20.9 |
| Totals | 15406 | 100.0 | 16719 | 100 |

*Deaths not attributed to program type in 1996 - 1997

The locations of death for PC patients are shown in Table 5.3. It is significant that more than one third (34.8%) of patients died at home, an increase of 7.3% from the 1997 Census. It also compares favourably with UK statistics where a rate of 26.6% was reported. Nearly 30% of deaths were in specialised Hospice inpatient units and a further one-quarter took place in general hospitals where PC practitioners provided at least a consultative service. Nearly 12% of palliative care patients died in a situation where ongoing PC support was not obviously accessible. Many residents of nursing homes do receive skilled palliation, often with direct involvement of local PC practitioners, but the extent of unmet need in this situation requires further clarification.

5.3 PALLIATIVE CARE CASEMIX: DIAGNOSIS

Table 5.4: Annual Deaths 1997-98: Principal Diagnosis

| Diagnosis | Males | Females | Totals |
|-----------------|-------|---------|--------|
| Lung | 295 | 118 | 413 |
| Breast | - | 140 | 140 |
| Prostate | 133 | - | 133 |
| Colon | 98 | 98 | 196 |
| Haematological | 72 | 64 | 136 |
| Pancreas | 47 | 51 | 98 |
| Unknown Primary | 56 | 49 | 105 |
| Other Cancer | 402 | 275 | 677 |
| Non-Cancer | 106 | 92 | 198 |
| TOTALS | 1209 | 887 | 2196 |

Nineteen services were able to provide details of individual patients who had died under their care during financial year 1997-1998 (Optional Question). The 2196 patients identified in these reports are described in Table 5.4. The preponderance of male patients (55%) matches the proportion of males in cancer mortality data. The relative proportions of the most common malignancies in this small sample and the Australian population of cancer deaths (1996) are compared in Table 5.5. Apart from the time difference of 18 months, these data series are directly comparable. If the previous observations concerning haematological and "unknown primary" cancers (Table 4.8) are again accepted, the distributions of diagnoses in the palliative care sample closely matches the profile for national cancer deaths.

Table 5.5: Comparison Of Principal Diagnoses: Palliative Care Deaths (1997-98) and Australian Cancer Deaths (n=2196)

| Diagnosis | Males | | Females | |
|-----------------|------------|------------|----------|----------|
| | ABS 1996 * | CEN 1998 # | ABS 1996 | CEN 1998 |
| Lung | 26.8 • | 26.8 | 14.2 | 14.8 |
| Breast | - | - | 17.4 | 17.6 |
| Prostate | 13.6 | 12.1 | - | - |
| Colon | 9.5 | 8.9 | 11.1 | 12.3 |
| Haematological | 9.5 | 6.5 | 10.1 | 8.1 |
| Pancreas | 4.0 | 4.3 | 5.5 | 6.4 |
| Unknown Primary | 9.6 | 5.1 | 10.1 | 6.2 |

* Proportion of Cancer deaths Australia 1996: Causes of Death (ABS 3303.0)

Proportion of cancer diagnoses: sample of 2196 PC deaths 1997-98 (Question 44)

• All values are percentages

5.4 LENGTH OF REGISTRATION WITH PALLIATIVE SERVICES

At Question 40, services were asked to report their total days of patient service for the past year and also the days of service within their community and inpatient programs respectively. A total of 44 services identified a grand total of 489 650 patient days in respect of their overall service for twelve months.

Fifty three (53) services provided data for their community programs. Of these, 44 provided data for both patient numbers and days of service. Eleven of these reports were discarded because the mean period of registration was less than 15 days - not compatible with bona fide community experience. The 33 remaining programs with acceptable matching data reported a total of 246 443 days of service for 3355 patients, an average of 73.5 days per registration. This figure underestimates the true "length of stay" since a proportion of the reported service episodes were still current and incomplete at Census day. The 19 services which provided individual data for deceased patients (Question 44) reported an average of 102 days from date of admission to death.

Thirty six (36) services provided matched data of patient numbers and occupied bed days in respect of their inpatient programs. A total of 9172 patient episodes consumed 113 133 bed days for an average of 12.3 days per episode. Once again, these data would be reporting a proportion of incomplete episodes, and the true value is likely to be some 15 per cent longer at approximately 14 days.

5.5 ACCESS ISSUES IN DATA OF SECTIONS 4 - 5

It would appear, on the evidence of Tables 4.7, 4.9 and 5.5 that referral of cancer patients to palliative care is without major bias in respect of tumour type. The overall ratio of males to females very closely matches that found in national cancer mortality data. It does appear (Table 4.11) that cancer patients aged 75+ years are under-represented in PC populations, by factors of 10-15% for males and almost 20% for females. This may be because a greater number of patients in this age group live in aged care facilities.

Population-based rates of admission to PC services in regional and rural locations are 30-35% lower than in the capital cities (Table 5.1). Palliative care services in regional, and particularly in rural locations, are less likely to provide access to specialist PC doctors and allied health personnel than are metropolitan services (Table 3.2).

SECTION 6 Performance Indicators

In June 1998 the Standards and Quality Committee of PCA published definitions for 20 performance indicators. These indicators reflected the eight Standards for Provision of Palliative Care (PCA, 1998) and also the "Continuum of Care" which is central to the Accreditation process (EQulP) of the Australian Council of Healthcare Standards. Of the twenty PCA indicators, Census 1998 selected nine items, addressing the six most quantifiable Standards. Given the short interval between publication of the Indicators and Census day, data availability was also a consideration in selecting indicators for the Census. The rationale for each indicator is briefly explained to provide context for this report. Full description of the palliative care performance indicators are published in "The Resource Manual for Palliative Care Performance Indicators" (PCA, 1998).

6.1 PALLIATIVE CARE PERFORMANCE INDICATOR 3.1: THE NUMBER OF DISCIPLINES AVAILABLE IN THE INTERDISCIPLINARY TEAM OF THE SERVICE.

This indicator is seeking to determine the scope of interdisciplinary teams within Australian palliative care services.

Of the 187 identified services 133 reported some form of interdisciplinary team structure of which 75 (40%) were Level 1 as defined below. Elsewhere in the census (Question 11 and Table 3.3) teams comprising doctor, nurse and specific other disciplines were reported by 69 services (37%). "Partial teams" - level 2 and level 3 - were reported by 58 services (31%) whereas only 21 such combinations (11%) are shown in Table 3.3. This difference was greatest in respect of rural services which reported 16 (level 2 or level 3) "partial teams" but only two of comparable status at Table 3.3.

Table 6.1: Interdisciplinary Teams

| Team | Metropolitan (N=80) | Region (N=54) | Rural (N=53) | Totals (N=187) |
|------------|------------------------|------------------|-----------------|-------------------|
| Level 1 | 42 | 21 | 12 | 75 |
| Level 2 | 14 | 9 | 7 | 30 |
| Level 3 | 12 | 7 | 9 | 28 |
| Levels 1-3 | 68 | 37 | 28 | 133 |
| Level 4 | 8 | 15 | 23 | 46 |
| Nil data | 4 | 2 | 2 | 8 |
| TOTALS | 80 | 54 | 53 | 187 |

Legend: Level 1 = Doctor + Nurse + Allied Health (unspecified)
 Level 2 = Doctor + Nurse
 Level 3 = Nurse + Allied Health (unspecified)
 Level 4 = Single discipline only

Different data specifications may partly explain these apparent discrepancies. The data analysed for Table 3.3 identified, by discipline and FTE, personnel actually employed by each PC service. The data for Table 6.1 was drawn from Question 31 which nominated categories of personnel available to each service. It is quite possible that services would identify access to personnel, particularly doctors and some allied health disciplines, who were not part of their formal establishment and budget.

6.2 PALLIATIVE CARE PERFORMANCE INDICATOR 3.2A AND 3.2B: SHARED PATIENT RECORDS

Shared patient records are desirable to reduce duplication of effort on the part of the patient and the services involved, improves communication between services and will contribute to the development of a more integrated approach to care. A shared record is a health record used by more than one service provider which facilitates the collection, storage and retrieval of information about a patient, promotes continuity of care, reduces repetition of assessment and documentation, and allows for access by nominates service providers.

The sharing of clinical records between multiple service providers was reported by 56% of services with no appreciable geographical variation. Of these services, 84% of metropolitan services identified that individual records were shared, compared with 72% of regional and rural services.

Table 6.2: Shared Clinical Records

| Team | Metropolitan (N=80) | Region (N=54) | Rural (N=53) | Totals (N=187) |
|------------------|------------------------|------------------|-----------------|-------------------|
| Services with SR | 47 | 24 | 33 | 104 |
| Total records | 2431 | 1030 | 549 | 4010 |
| Shared records | 2036 | 746 | 389 | 3171 |

6.3 PALLIATIVE CARE PERFORMANCE INDICATOR 4.1 AND 4.2: VOLUNTEER SERVICES

Volunteers are seen as integral in service provision, therefore, it is essential that efficiencies are addressed, and that an operating budget exists for volunteer services in order to provide services to the community and maintain standards.

A total of 146 services (78%) reported the use of Volunteers. There was a higher rate of Volunteer use in regional and rural locations (83%) than in the capital cities (71%). The position of Volunteer Coordinator was reported by 98 services - 67% of the 146 services using Volunteers. Again there is an apparent discrepancy with the data of Table 3.3 where only 65 services report a position of Volunteer Coordinator. However, still fewer services (48) report any specific budget for Volunteer services. Among metropolitan Volunteer services, 42% were funded, compared with 30% of regional and 24% of rural Volunteers. It is evident that many Volunteer Coordinators are themselves unpaid Volunteers; those services with a defined budget for volunteer activities do not always use this money for the salary of a Coordinator.

Table 6.3: Volunteer Services

| Vol | Vol Coord | BUDG | Metropolitan (N=80) | Regional (N=54) | Rural (N=53) | Totals (N=187) |
|--------|-----------|------|---------------------|-----------------|--------------|----------------|
| Yes | Yes | Yes | 19 | 12 | 11 | 42 |
| Yes | Yes | No | 15 | 23 | 18 | 56 |
| Yes | No | Yes | 5 | 1 | 0 | 6 |
| Yes | No | No | 18 | 8 | 16 | 42 |
| No | No | No | 23 | 10 | 8 | 41 |
| TOTALS | | | 80 | 54 | 53 | 187 |

As shown in Table 6.4, Volunteers provided more than 5000 hours of service in the week preceding the census, on average 48.5 hours per week for metropolitan services, 45.5 hours per week for regional services and 10.4 hours per week for rural services.

Table 6.4 : Volunteers Hours Of Service (One Week)

| | Metropolitan (N=80) | Region (N=54) | Rural (N=53) | Totals (N=187) |
|--------------------------|---------------------|---------------|--------------|----------------|
| Services with Volunteers | 57 | 44 | 45 | 146 |
| 40+Hours, past week | 16 | 11 | 4 | 31 |
| Total hours, past week | 2750 | 2004 | 457 | 5211 |

6.4 PALLIATIVE CARE PERFORMANCE INDICATOR 5.1 AND 5.2: EDUCATION

Palliative care services have an important role in providing education to Specialist Palliative Care Health Provider, Generalist Health Care Service Providers, Volunteers, and to family members providing care. Education promotes quality of care and has a positive impact on professional attitudes towards death and dying. Further, ensuring appropriate and equitable access to palliative care services is dependent upon the level of community awareness. Community education is also important in changing community attitudes to death and dying.

As shown in Table 6.5, 60 services reported no education for carers in the week preceding Census, or failed to report this question. The remaining 127 services provided 1992 hours of teaching, with a good proportional distribution of hours in regional and rural areas. Twelve services reported more than 40 hours of care education in the week, with the highest value being 316 hours by the collective PC agencies of a regional Health Service.

Table 6.5: Education Hours Provided (One Week)

| Education For | Hours | Metropolitan (N=80) | Region (N=54) | Rural (N=53) | Totals (N=187) |
|---------------|-------|---------------------|---------------|--------------|----------------|
| Carers | NIL | 19 | 16 | 25 | 60 |
| | 1-9 | 40 | 29 | 22 | 91 |
| | 10-39 | 13 | 5 | 6 | 24 |
| | 40+ | 8 | 4 | 0 | 12 |
| | TOTAL | 1063 | 731 | 198 | 1992 |
| Community | NIL | 54 | 29 | 31 | 114 |
| | 1-4 | 15 | 18 | 18 | 51 |
| | 5+ | 11 | 7 | 4 | 22 |
| | TOTAL | 259 | 123 | 69 | 451 |

Community education is a way of improving care outcomes through enhanced participation of the diverse local organisations, with special regard for relevant ethnic or cultural groups. Access to palliative services is also enhanced in an appropriately informed community. Sixty-seven services reported a total of 451 hours of community-directed education in the week preceding the Census.

6.5 PALLIATIVE CARE PERFORMANCE INDICATOR 6.2: BENCHMARKING

Benchmarking provides opportunities for comparing quality of service and participating in the development of best practice standards. It involves the comparison of performance data between services with matching programs, resources, locations and caseload demographics. The diversity of palliative care services across Australia makes the choice of appropriate partners difficult. Only 19 services reported the existence of a benchmarking partner(s) at the time of the Census. It is intended that the profiles of service characteristics constructed through this Census will permit a more meaningful classification of PC services and identification of many more potential benchmarking partners

6.6 PALLIATIVE CARE PERFORMANCE INDICATOR 7.1: BEREAVEMENT RISK ASSESSMENT

The utilisation of risk assessment tools to identify those at risk, will prompt referral to available services and will be informative for health care planners. The presence of predictors for dysfunctional grieving is now well recognised. A number of assessment tools are in use to identify these risk factors in the immediate associates of palliative care patients. The resources of expert bereavement counsellors can thus be directed towards clients with high potential needs.

In the Census 73 services (39%) reported the use of some form of bereavement risk assessment. There were 33 reports from metropolitan services, 20 from regional and 20 from rural services, a very even distribution.

6.7 PALLIATIVE CARE PERFORMANCE INDICATOR 8.1: PROPORTION OF PALLIATIVE CARE SERVICES WHICH PROVIDE 24 HOUR ACCESS.

Patients and families should have access to information and assistance on a 24hour, 7 day basis. Services were asked to indicate the lowest level of access they provided across a 24-hour period and whether this standard of access was maintained for each of the seven days. Access was defined only as direct (face-to face) or indirect (telephone only).

Table 6.6: Access To Palliative Care Team Member(s)

| 24 Hours | 7 DAY | Metropolitan | Regional | Rural | Totals |
|----------|-------|--------------|----------|-------|--------|
| Direct | YES | 26 | 29 | 23 | 78 |
| Direct | NO | 3 | 6 | 4 | 13 |
| Indirect | YES | 35 | 8 | 16 | 59 |
| Indirect | NO | 2 | 1 | 4 | 7 |
| Nil | n/a | 10 | 6 | 6 | 22 |
| Totals | | 76 | 50 | 53 | 179 |

Of the 179 services who responded to this question, 78 (44%) stated they provided continuous, direct access to some member of their team. Continuous, direct access was provided by 51% of regional and rural services who answered this question compared with 34% of metropolitan responders. A further 59 services (33%) provided a seven-day service, but only by telephone access and 46% of metropolitan services described this level of access, compared with 23% outside the capital cities. Thirteen others provided direct round-the-clock access but not for the full week. Twenty-nine services (16%) described a lesser level of access; seventeen of these were in country areas. These data are summarised in Table 6.6. A total of 137 (76.5%) provided direct or indirect 24 hour, 7 day access to information and assistance.

SECTION 7 Bereavement Support

Data describing the nature and extent of Bereavement support and follow-up programs were provided by 161 services in Questions 45-49. In this section the absence of reply to direct yes/no questions was taken to mean a negative answer. A total of 155 services (83% of the 187 Census respondents) stated that they provided some formal bereavement program. Metropolitan services were less likely (76%) to have bereavement programs than were regional (82%) or rural services (94%).

Ninety percent (139 of 155) of the identified bereavement programs were provided by staff members and/or volunteers who had received specific education in grief and loss issues. In Question 11, only 45 services reported the formal, salaried position of Bereavement Coordinator with less than half of these positions in regional and rural locations.

Table 7.1: Bereavement Support Distribution of Services and Trained Staff

| | Metropolitan (N=80) | Region (N=54) | Rural (N=53) | Totals (N=187) |
|-------------------------|------------------------|------------------|-----------------|-------------------|
| Programs identified | 61 | 44 | 50 | 155 |
| Access to trained staff | 54 | 42 | 43 | 139 |

The duration of routine bereavement follow-up and support was reported in Question 46. Of the 155 services who identified a bereavement program, 84 reported policies which limit the period of routine support, but only 59 were able to state specific end-points. Three quarters of the identified time limits were 12 months or more, with the longest being 24 months. Fourteen programs reported time limits of between two and six months.

Table 7.2: Duration Of Bereavement Support in 84 Programs With Defined Policy

| Time Limit | Metropolitan (N=36) | Region (N=22) | Rural (N=26) | Totals (N=84) |
|------------|------------------------|------------------|-----------------|------------------|
| >12months | 3 | 1 | 4 | 8 |
| 12 months | 17 | 11 | 9 | 37 |
| 2-6 months | 6 | 2 | 6 | 14 |
| Nil stated | 10 | 8 | 7 | 25 |
| TOTALS | 36 | 22 | 26 | 84 |

7.1 BEREAVEMENT PROGRAM CASELOAD

Basic caseload details were supplied by 119 of the 155 services who reported bereavement programs. In the twelve months to 30 June 1998, a total of 17238 families received support, as displayed in Table 7.3. The 12096 families seen by 42 metropolitan programs represents 78 % of reported annual deaths (Table 5.1) while the 5142 families seen by 38 regional and 39 rural programs was equivalent to 66% of reported deaths. Fifteen of the 119 programs returning bereavement caseload data reported no specifically trained personnel, but these programs were collectively responsible for only 242 families.

Table 7.3: Bereavement Support Programs Distribution of Annual Caseload and Activity

| | Metropolitan (N=80) | Region (N=54) | Rural (N=53) | Totals (N=187) |
|------------------------|------------------------|------------------|-----------------|-------------------|
| Programs identified | 61 | 44 | 50 | 155 |
| Caseload data reported | 42 | 38 | 39 | 119 |
| Families supported | 12096 | 3893 | 1249 | 17238 |
| Contacts data reported | 40 | 32 | 33 | 105 |
| Total contacts | 27263 | 14189 | 3849 | 45301 |
| <2 contacts : Family | 18 | 4 | 9 | 31 |
| >5 contacts : Family | 8 | 11 | 6 | 25 |
| Mean contacts : family | 2.25 | 3.65 | 3.08 | 2.63 |

There were 45301 occasions of service - whether direct or telephone contact was not specified - reported by the 105 programs responding to Question 49. As suggested by the summary in the second part of Table 7.3, there were widely different intensities of support provided by different programs. Eighteen of 40 (45%) metropolitan programs reported fewer than two contacts per registered family across the year. Only 20% of country programs reported involvement at this level. An average exceeding 5 contacts per registered family was reported by 34% of regional programs and by 20% of metropolitan and rural programs. Average number of contacts per registered family for individual programs ranged from less than one (5 programs) to more than ten (3 programs) with the highest being 20.3. Numbers of contacts in respect of individual client families were not recorded, but the range would obviously have been much wider again.

CONCLUSION AND RECOMMENDATIONS

This report presents a comprehensive view of palliative care service provision throughout Australia. At the present time inclusion in this sample is largely self determined by the individual services, and does not reflect any other kind of endorsement of participants as palliative care service providers. A response rate of just less than 75%, still provides a sample size which makes generalisations credible, though as stated throughout the report, interpretation must be made with certain caveats in mind.

This is the second comprehensive Census conducted by Palliative Care Australia, and an enormous amount of data has been reported, and interpreted. The main conclusions to be drawn from this census are:

- there appears to have been an increase of people who die receiving palliative care from 56% in 1997 to 62% in 1998;
- there are still significant differences access to any kind of palliative care service between people who live in metropolitan centres in Australia in comparison to regional and rural areas;
- more than one third of Australians who die receiving palliative care services die at home.

Comparisons between 1997 and 1998 data have not been possible in many instances because of differences in data collection and analysis. A significant amount of the content of this census is new, especially data relating to staff and to patient diagnosis, age, and length of stay in services. This has provided a large amount of information, and comparisons have been made with other population based statistics. However, trends in the palliative care context cannot be made at this stage.

The major concern for PCA relates to identifying definitively which services should be contributing to this census information, and how to increase the overall response rate. In addition, the level of verification of the data provided at service level needs to be increased, and responsibility for this taken at the highest administrative level. This may make it possible to also collect financial information.

Aside from these issues, it is acknowledged that many palliative care services are collecting data in very tedious and rudimentary way, which makes the task of completing census information onerous, and PCA is appreciative of the effort made by so many palliative care providers.

The Census working party recommends that the next Census to be conducted

- 1 is a much briefer document
- 2 records only minimal annual statistics on patient activity
- 3 records the performance indicators as reported in this report
- 4 requests detailed financial information
- 5 that the census return is verified at the service director/chief executive level of the service.

Further, PCA will explore ways in which it is possible for palliative care services to more easily respond to requests for information. This information is useful at many levels within the Australian health care system, and does help PCA in its advocacy role. Reliable information helps to identify the gaps in equity and access Australians experience when they require the expertise and skills of palliative care practitioners wherever they live.

APPENDIX ONE

CENSUS QUESTIONS

Variables and other details of questions are not included in this list.

| Question No. | Identification and Service Profile |
|---------------------|--|
| 1 | What is the name of your service? |
| 2a | Are you reporting for all palliative care services within your Area Health Service (or equivalent)? |
| 2b | What other services provide palliative care within your Area? |
| 3 | What is the post code of your service's street address? |
| 4 | What is the name, position, and contact numbers of the contact person for this census? |
| 5 | Where are your patients mainly located? |
| 6 | What programs does your service provide? |
| 7 | Describe the type and capacity of your inpatient program? |
| 8 | If a patient registered with your service requires admission to a hospital for palliative care will the nominated Medical Practitioner be: |
| 9 | Describe the components of your community-based services. |
| 10 | Indicate the availability of services by senior clinical staff to the various localities across your service. |
| Staffing | |
| 11 | This table seeks information about the staffing establishment of your service as at 1700hrs today. |
| 12 | Establishment positions gained between 01/07/97 and 30/06/08. |
| 13 | Establishment positions lost between 01/07/97 and 30/06/08. |

Census Day

| | |
|----|---|
| 14 | How many patients were registered to receive care with your service at 1700 hours today? |
| 15 | How many new referrals were received by your service in the past 24 hours? |
| 16 | How many admissions were made to your service in the past 24 hours? |
| 17 | In the past 24 hours, how many patients were seen by your service? |
| 18 | In the past 24 hours, how many telephone consultations were made with registered patients or family carers? |
| 19 | What was the total number of kilometres travelled by staff in the past 24 hours? |
| 20 | How many corridor or telephone consultations without referral were made in the past 24 hours? |
| 21 | How many discharges (other than deaths) were made from your program in the past 24 hours? |
| 22 | How many deaths occurred in the care of your service in the past 24 hours? |
| 23 | Indicate place of death for all deaths identified in question 22. |
| 24 | Census of Inpatients: list all registered patients of your palliative care service who are known to be inpatients at 1700 hours today. |
| 25 | Census of Community Patients: list all registered patients of your palliative care service who are known to be receiving home care at 1700 hours today. |

Consultation to Other Health Care Facilities

| | |
|----|--|
| 26 | How many new referrals were received in other health care facilities in the past week? |
| 27 | How many patients were seen in other health care facilities in the past week? |
| 28 | What type of facilities did you provide services for in past week? |
| 29 | What types of consultations were provided? |
| 30 | How was your service reimbursed for consultations provided to other facilities? |

Performance Indicators for Palliative Care

| | |
|----|--|
| 31 | Performance Indicator 3.1: Interdisciplinary Team |
| 32 | Performance Indicator 3.2a and 3.2b: Shared Records |
| 33 | Performance Indicator 4.1 and 4.2: Volunteer Services |
| 34 | Performance Indicator 5.1: Education for Carers |
| 35 | Performance Indicator 5.2: Community Education |
| 36 | Performance Indicator 6.2: Benchmarking |
| 37 | Performance Indicator 7.2: Bereavement Risk Assessment |
| 38 | Performance Indicator 8.1: Access |

Annual Data

| | |
|----|--|
| 39 | What was the total number of admissions to your services for the period? |
| 40 | How many days of patient care (or occupied bed days did your service have for the period? |
| 41 | What was the total number of consultations provided during this period? |
| 42 | How many discharges (other than deaths) were there in your service in this period? |
| 43 | How many deaths were there in your service in this period? |
| 44 | Indicate place of death for all deaths identified in question 43. Optional question: Description of annual patient population is data is readily available. |

Bereavement support and follow-up program

| | |
|----|---|
| 45 | Does your service provide bereavement support and follow-up? |
| 46 | Does your service have a policy which limits the period of routine bereavement support? |
| 47 | Is your bereavement support service provided by staff and volunteers who have received specific education in bereavement support, grief and loss? |
| 48 | How many families received bereavement support for the period 010797 to 300698? |
| 49 | How many contacts (telephone, appointment or visit) were made for bereavement support by your service for the period 010797 to 300698? |

Annual Financial Data

| | |
|----|---|
| 50 | How is your funding organised? |
| 51 | What was the percentage of public and private patients admitted to your service in this period? |
| 52 | If you answered 'don't know' for Q50, please let us know the reason. |
| 53 | Where did the funds for this period come from? |
| 54 | What is the total expenditure for your service for this period? |
| 55 | What proportion of your budget is spent on each program? |
| 56 | Are these figures.... Recorded (actual financial data) or calculated as a proportion of budget? |

