

National Survey
of
Patient Activity Data
for Specialist Palliative
Care Services

MDS Full Report for the year
2005–2006

CONTENTS

Introduction	page 3
Chapter 1 – Inpatient services	page 6
Chapter 2 – Day care services	page 14
Chapter 3 – Home care services	page 19
Chapter 4 – Hospital support services	page 26
Chapter 5 – Bereavement support services	page 30
Chapter 6 – Out-patient services	page 32
Chapter 7 – All patients	page 34

LIST OF TABLES AND CHARTS

		Page
Table 1	Response Rates to survey	5
Table 2	New patients – inpatient service	6
Table 3	Analysis of admissions and outcomes	8
Table 4	Length of stay by size of unit	9
Table 5	Bed usage	11
Table 6	Nurse Staffing – inpatient unit	11
Table 7	National estimates – inpatient units	12
Table 8	National estimates 2001/2 – 2005/6	13
Table 9	New patients – day care	14
Table 10	Patient care	16
Table 11	Day care provision	17
Table 12	National estimates – day care	18
Table 13	New patients – home care	20
Table 14	Palliative care in the community	22
Table 15	Home care service provision	24
Table 16	National estimates – home care	25
Table 17	New patients – hospital support	26
Table 18	Patient care in hospital	28
Table 19	Bereavement services	31
Table 20	Outpatient services	32
Table 21	Patient profile – all patients	38

Chart 1	Percentage response rate	5
Chart 2	Inpatient deaths as percentage of deaths plus discharges	7
Chart 3	Length of stay in an inpatient unit	9
Chart 4	Mean length of stay by size of unit	10
Chart 5	Home Care visits by profession	21
Chart 6	Workload of hospital based specialist palliative care nurses	29
Chart 7	Proportion of patients of different ages and gender	34
Chart 8	Proportion of cancer and non-cancer diagnoses	35
Chart 9	Cancer diagnosis by type	36

The Minimum Data Set for Specialist Palliative Care Services

The Minimum Data Set (MDS) was developed in 1995 by the National Council for Hospice and Specialist Palliative Care Services (now the National Council for Palliative Care) in association with the Hospice Information Service at St. Christopher's Hospice, London. In 1996 its use was commended to the NHS by the Department of Health in Executive Letter 96(85).

The aim of the MDS is to provide good quality, comprehensive data about hospice and specialist palliative care services on a continuing basis. This data is therefore useful on a variety of levels to inform:

- Service management
- Service monitoring and audit
- Development of local palliative care strategy and service planning
- Commissioning of services
- Development of national policy

Each data item in the MDS has been identified as meeting one or more of the following purposes:

- For national statistics
- For commissioner/provider agreements
- For local service management

National collections of the data intended for national statistics have been made for each year from 1995/96. This report is for the year 2005/06 and is therefore the eleventh since the introduction of the MDS.

During these eleven years the commissioning, provision and delivery of specialist palliative care services have changed greatly. It is important the MDS changes to reflect this so that it is still appropriate to meet the original aims and inform all involved in specialist palliative care. To this end in 2005/6 The National Council for Palliative Care (NCPC) has been working in partnership with Marie Curie Palliative Care Institute Liverpool (MCPCIL) to review the minimum data set questionnaires through a series of workshops and pilot projects.

Review of the Minimum Data Set

This review has given us the opportunity to examine whether data items are still relevant and appropriate. In particular it is hoped that the information gathered will correlate with that required by the Department of Health when Payment by Results is introduced in 2008 and that the data will support the changes that have occurred in specialist palliative care services and new areas of NCPC's policy work. The first stage of this process was a series of workshops to review each dataset, involving leading national figures from the services concerned and people who are experienced in collecting, submitting or using the data.

The second stage is currently underway. Questionnaires have been sent to pilot sites throughout the country. At the end of a three month period the returns will be analysed and comments noted. It is hoped that the final format of the questionnaires will be available in Spring 2007 with a start date for the collection using the new format of Spring 2008 for the 2008/9 data. Providers are assured there will be enough notice given of any changes in data requirements.

The Survey for 2005/06

The Survey is of all hospice and specialist palliative care services located in England, Northern Ireland and Wales that are listed in the 2006 Directory of Hospice and Palliative Care Services published by Hospice Information. Not included in the survey are services for children, and specialist services such as those for HIV/AIDs or those provided by 'site specific' cancer specialist nurses such as breast care nurses, or chemotherapy nurses. Services in Scotland are no longer included in the annual surveys, because they fall within the remit of the Scottish Partnership for Palliative Care rather than that of the NCPC.

Questionnaires were circulated to all listed services in April 2006. Some services had indicated that they would provide a joint response. This accounts for the difference between the number of services listed in the Directory and the number of questionnaires circulated. Joint responses were considered to be one service for the purpose of analysis. Data was returned during the summer of 2006. Responses to any questions where data appeared to be grossly inaccurate were

subject to checking or rejection. Where the aggregate data for individual parts of questions differed by more than 10% from the stated total, this was rejected, as was data where 'not known' was more than 10% of the total. In the subsequent analyses, all calculations have ignored 'not known' figures.

In August 2006 individual reports were sent to all services providing a response to the questionnaire. This was to enable services to compare their data with national means, maxima and minima, and to provide an opportunity for them to send corrected or amended data where necessary. Means for their local cancer network were also provided. In these individual reports mean values are given as the average of each of the individual means. These differ in some cases from the means quoted in this present report which are calculated from the overall totals from all the services responding. When preparing the report some further responses to particular questions were rejected as being unreliable, and some amended data was included.

Response rate

The overall response rate from services providing at least a minimum of data was 75%, considerably higher than the previous year. Table 1 and Chart 1 show the percentage response rates for the individual parts of the survey, and it can be seen that for inpatient care, day care and homecare the response rates have improved considerably over the last 5 years, while the rate for hospital support services has risen a full 10% this year over the previous year. For the first time, responders were able to

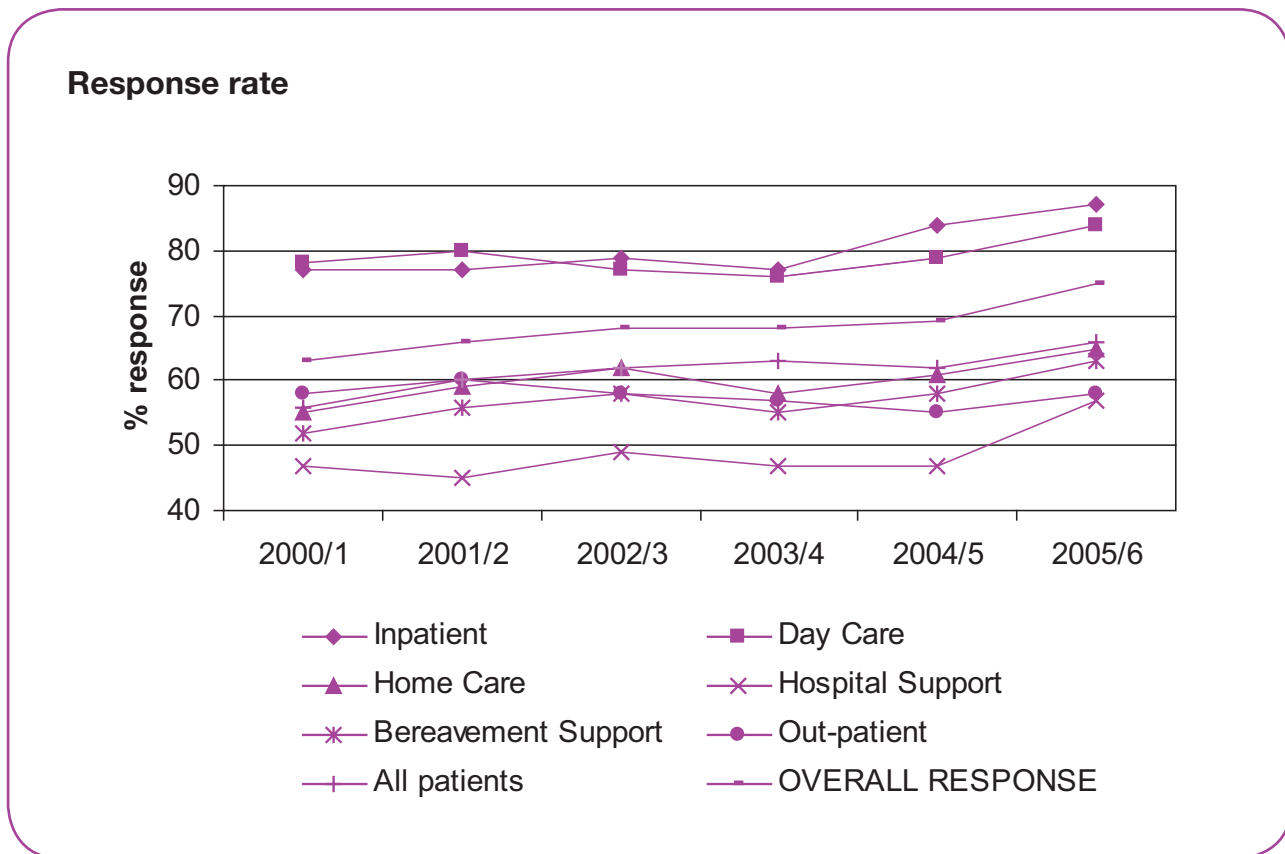
TABLE 1 Response Rates to each Section of the Questionnaire

SERVICES	% response					
	2000/01	2001/02	2002/3	2003/4	2004/5	2005/6
Inpatient	77	77	79	77	84	87
Day Care	78	80	77	76	79	84
Home Care	55	59	62	58	61	65
Hospital Support	47	45	49	47	47	57
Bereavement Support	52	56	58	55	58	63
Out-patient	58	60	58	57	55	58
All patients	56	60	62	63	62	66
OVERALL RESPONSE	63	66	68	68	69	75

submit electronically via email or through the website: about 45% in total (30% online and 15% by email). This will be encouraged further in subsequent years

with improvements to the online forms, both for ease of use by responders and for considerable reduction in the time taken to collate the information.

Chart 1 There is an improved response rate over the last six years



1. INPATIENT UNITS

Data was collected from those services which provided a specialist palliative care inpatient service during 2005 to 2006, primarily to adults in a dedicated palliative care unit in England, Wales and Northern Ireland. Designated palliative care wards within general hospitals were included, but beds within the general wards of hospitals were excluded. Taking into account joint returns from some services, there were 187 units with 2774 beds, the bed numbers (unless advised otherwise) being those quoted in the 2006 Directory of Hospice and Palliative Care Services.

The units varied in size from 2 to 61 beds including two joint returns which gave data for a total of 56 and 59 beds) with a mean of 14, the most common size being 10 beds.

Data was received from 162 units, an 87% response rate, although some respondents did not answer all the questions. The response rate to individual questions does therefore vary from 87%. The response rate from independent units was 89%, while for the NHS units it was 80%, an increase of 15% over the previous year.

Table 2 New Patients – inpatient service

Data Item	Analysis	Results	Number of responding units / beds in those units	Number of new patients in responding units
No. of patients	Mean number of total patients per unit	242	156 / 2,359 (83% response)	33,026 new patients 37,753 total patients
	New patients as % of all patients	87%		
	Range of above	39% – 100%		
Age of patients	Under 25	0.2%	147 / 2,242	31,603
	Under 65	32%		
	65 to 74	28%		
	75 to 84	30%		
	Over 84	10%		
Diagnosis	Cancer	93.9%	143 / 2,203	30,662
	Non-cancer	6.1%		
	HIV/AIDS	0.1%		
	Range of % of non-cancer in each unit	0 – 25%		
Location before first admission	Home	69%	149 / 2,278	32,055
	Hospital	28%		

Patient profile

Most of the returns gave details of new patients, and this showed that about a third of patients were aged under 65, with only 0.2% under 25. Of the older patients, 10% were over 84. Excluding the patients with a 'not known' diagnosis, 6.1% patients had a diagnosis other than cancer. This included 36 patients (0.1%) with HIV/AIDS. The range of percentages of non-cancer patients in the different units ranged from 0% to 25%. A total of 23 units (16% of responding units) had over 10% non-cancer patients while 7 units had cancer patients only.

The patients were admitted from a variety of locations. The majority (69%) were from the patient's own home and 28% from hospital.

Analysis of inpatient stays

Most of the responding units gave the numbers of inpatient stays. About a fifth of the respondents recorded some day case patients. The percentage of day case admissions ranged from 0% to 15% with an outlier of 79%. If this latter is ignored then the overall percentage of day case admissions drops from 2.2% to 0.5%. More than a quarter of admissions were repeat admissions with a range between 0% and 63% apart from the unit with a large number of day cases where there were 77% repeat admissions. Just over half the admissions ended in death with a range from 92% to 22% with an outlier of 14% in the unit with a large number of day cases. By far the majority of discharges (87%) were to a patient's own home, with 5% to hospital, and others to nursing/residential homes, or other types of care.

Chart 2 This shows that almost all units have a death rate less than 70% of their admissions

Inpatient deaths as a percentage of deaths plus discharges

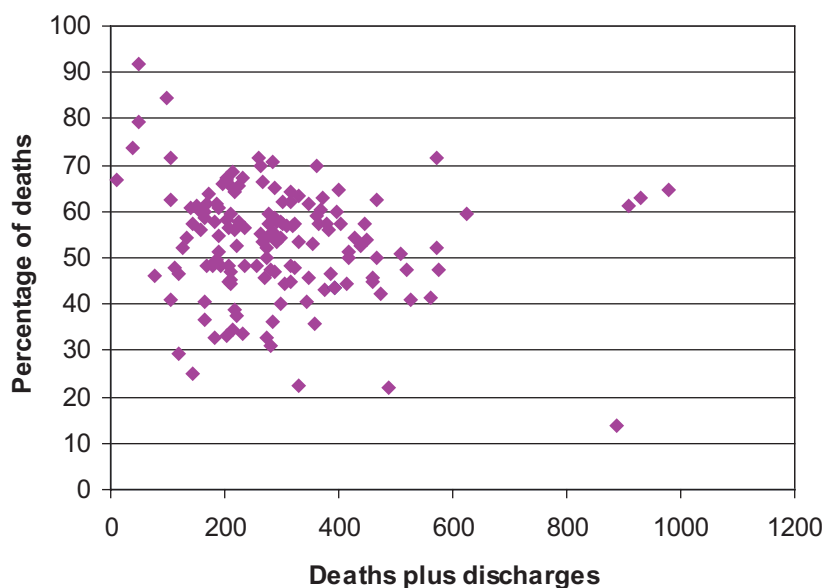


TABLE 3 Analysis of admissions and outcomes

Data item	Analysis	Results	Number of responding units/ beds in those units	Number of admissions to responding units
Admissions ended	Mean number of admissions ended per unit	295	159 / 2,426 (85%)	46,853
	Range of admissions per unit	6 to 978		
Day cases	Day cases as % of admissions	2.2%	137 / 2,136	41,667
	Range of % per unit	0% to 79%		
Admission type	Repeat admissions as % of all admissions	28%	137 / 2,136	41,667
	Range of % per unit	0% to 77%		
Admission outcome	Deaths	52.3%	147 / 2,239	43,510
	Range of % per unit	14% to 92%		
	Discharge to own home	41%		
	Discharge to hospital	2.5%		
Mean length of stay	Mean	13.1 days	149 / 2,294	44,327
	Range of above	6.4 to 34		
	Median of means	12.7 days		
Length of stay	Under 1 day	2.7%	143 / 2,163	41,354
	1 to 7 days	41.4%		
	8 to 14 days	25.7%		
	15 to 21 days	13.6%		
	Over 21 days	16.5%		

Services were asked to calculate the mean length of stay from the number of nights spent in the unit, including home leave of up to three nights, plus Saturday, Sunday and Bank Holidays. As it has been noted in the past that values of the mean length of stay have contained inaccuracies, checks were made on the accuracy of reports by comparing a theoretical maximum and minimum value, calculated from the given ranges of length of stay, with the stated value. Values falling

outside these theoretical values were excluded.

The average length of stay was 13.1 days (median 12.7 days). The range was between 6.4 and 34. Consistent with the findings of previous surveys, the larger units tend to have a longer length of stay. The variation in mean length of care for different sizes of units is shown in Table 4. The longer average length of stay in the very smallest units was less than that in

Chart 3 Two thirds of patients stay less than two weeks in an inpatient unit

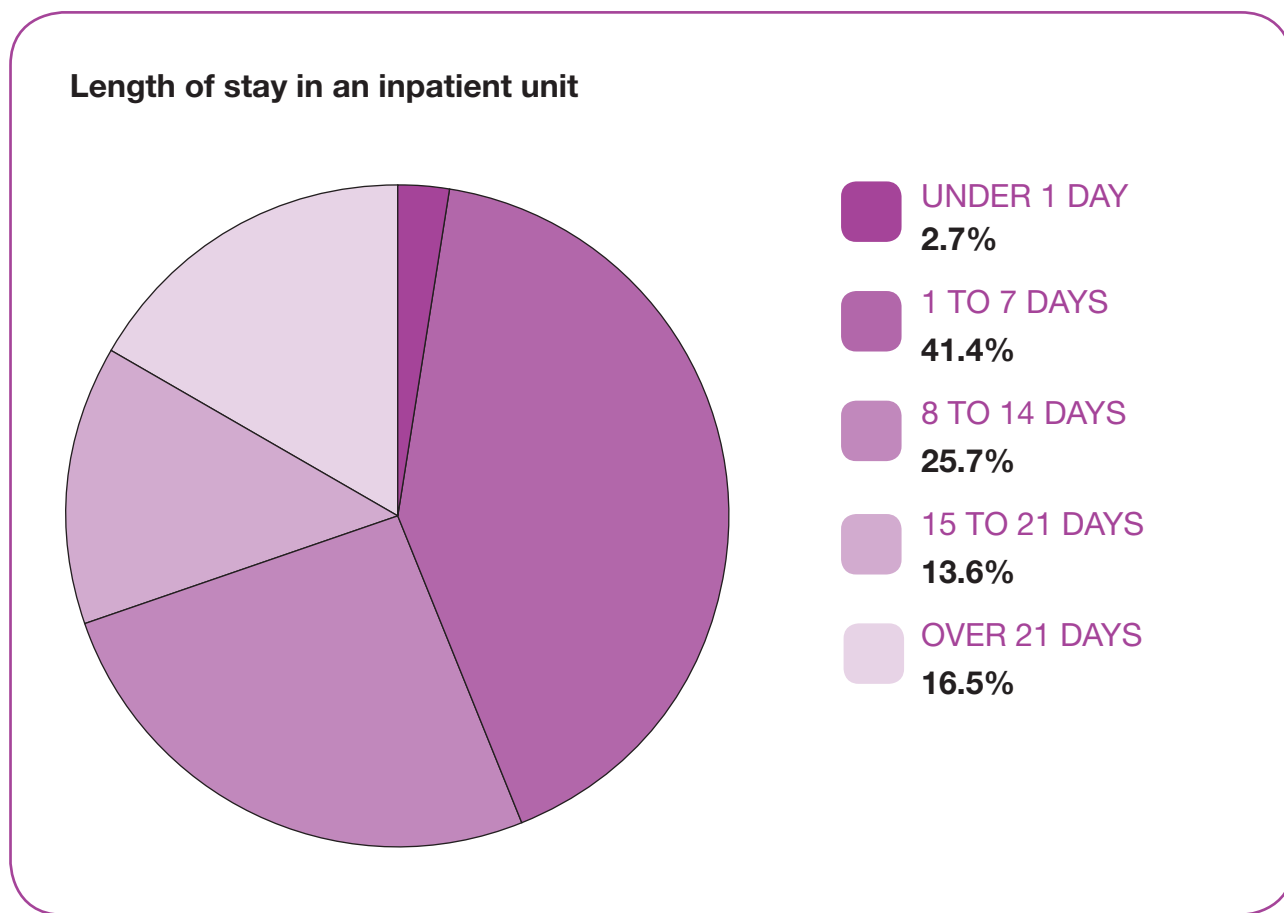


TABLE 4 Length of stay by size of unit

Size of unit by number of beds	2 – 6	7 – 10	11 – 15	16 – 20	21 – 25	Over 25	All units
Number of responding units	15	38	35	34	13	14	149
Mean length of stay in days	13.2	10.8	12.4	14.7	14.2	15.6	13.1

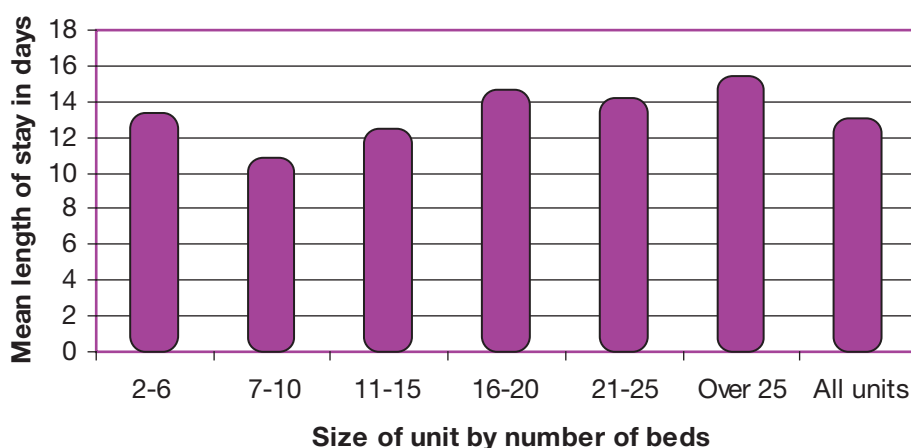
the next group if data from the smallest (2 bedded) unit was ignored. The average length of stay in the NHS units (20% of responders) was 12.2 days and for independent units 13.3 days.

Most of the returns gave a further analysis of their admissions and outcomes. Excluding day case patients, this showed 44% of admissions were for one week or less, while 17% were for more than

3 weeks. As day case patients should have been excluded from the returns sent (amendments were made where it seemed obvious that they had not been excluded) those 2.7% of patients with a length of stay of less than one day may be presumed to have died on the day of admission. Nine units recorded having a total of 22 patients staying in those units for the whole period of the survey.

Chart 4 There are longer lengths of stay in larger units

Mean length of stay by size of inpatient unit



Bed usage

Services were asked to calculate the bed occupancy rate from a midnight count of the number of beds actually occupied (or reserved for a patient temporarily away), as a percentage of available beds, the latter being those which are occupied, reserved, or available for use the following day. Beds kept empty because of staff shortages, or ward closures, are considered unavailable. Beds kept empty for other reasons, such as a recent death, are considered available. Two thirds of the total number of inpatient services sent usable data. The mean bed occupancy overall was 74.0%. The variations in occupancy were between 52% (with an outlier of 36%) and 94%. Two units recorded a higher bed occupancy than this, one a very small unit with long stay patients, and one a service which had almost a quarter of beds designated 'reserved'. The numbers of reserved beds

varied considerably, suggesting different ways of counting. There was a mean of 1.7% reserved beds but almost half the units (51) recorded no reserved beds while others recorded up to 25%. Reserved status should only be used where a patient is temporarily away, and not where a new patient is to be admitted the following day. It was impracticable to check the validity of this in all cases, but it is known that there has been misinterpretation of this in the past.

The mean value of throughput (admissions per bed per year, including any beds designated for day patients) was calculated as 21.1 admissions per available bed, ranging from 6 to 41 with an outlier of 50 in a unit with a very large number of day case beds.

The mean turnover interval when a bed is empty between admissions is defined as the number of unoccupied bed days

TABLE 5 Bed usage

Data item	Analysis	Results	Number of responding units / beds in those units	Number of admissions to responding units
% Bed Occupancy	Mean per unit	74.0%	125 / 1,865 (67%)	37,431
	Range of above	36.3% to 98.7%		
Throughput (Admissions per bed per year)	Mean per unit	21.1		
	Range of above	4 to 50		
Turnover interval between admissions	Mean per unit	4.5 days		
	Range of means per unit	0.17 to 21 days		

divided by the number of completed stays (including day case admissions). This was found to be 4.5 days, varying between 0.17 days and 14 days with an outlier of 21 days. Of the four units with a turnover interval of less than one day, one had a high number of reserved beds, and another had a large number of day cases.

Staffing

Services were asked to report their nurse staffing complement on 31 March 2006. Over two thirds of the total number of services responded. For all grades of nurses the full complement was 1.9 nurses per bed but 5.4% of these posts were not filled at the time. There were on average 0.94 grade D or E nurses per bed.

TABLE 6 Nurse Staffing – inpatient unit

Data item	Analysis	Results	Number of responding units / beds in those units	Number of admissions to responding units
Nurse Staffing	Mean number of nurses per bed (all grades, all posts)	1.84	130 / 1,930 (70%)	36,830
	Mean % vacancies	5.4%		
	Range of means of nurses per bed (all grades, all posts)	0.25 to 5.1		
	Mean number of Grade D or E nurses per bed (all posts)	0.94		
	Range of means of grade D or E nurses per bed	0 to 2.75		

National estimates

From the data supplied it is possible to make estimates of palliative care activity nationally in terms of admission, deaths and discharges. However, in order to do that it is necessary to make the

assumption that those services which did not respond have similar ways of working to those which did respond. Considering only those units which answered all the relevant parts of the questionnaire there was a variation in response rates

TABLE 7 National estimates – England, Wales and N Ireland Inpatient units

Size of Unit In beds	2 to 10 beds	11 to 15 beds	16 to 20 beds	21 to 25 beds	Over 25 beds	Overall totals	Weighted totals
No. of Units	73	41	40	16	17	187	
Responding Units	52	35	33	10	13	143	
Total beds	546	530	717	363	620	2,774	
No. of beds in Units responding	416	458	586	222	500	2,182	
Response Rate for Units	71%	85%	83%	71%	76%	76%	
Response Rate for beds	76%	86%	82%	61%	81%	79%	
New Patient admissions – responding units	6,590	7,460	7,988	2,758	5,881	30,677	
New Patient admissions – national estimates	8,649	8,633	9,774	4,485	7,292	39,000	38,833
Deaths in responding units	4,520	5,253	5,928	2,024	4,413	22,138	
Deaths – national estimates	5,933	6,079	7,253	3,291	5,472	28,144	28,028
Discharges in responding units	4,472	5,615	4,999	1,790	3,429	20,314	
Discharges – national estimates	5,870	6,498	6,117	2,925	4,252	25,825	25,661
Ratio of Deaths to Discharges	1.01	0.94	1.19	1.13	1.29	1.09	1.09
Ratio of New Patient Admissions to Deaths + Discharges	0.73	0.69	0.73	0.72	0.75	0.72	0.72
Ratio of Deaths to Deaths + Discharges	0.50	0.48	0.54	0.53	0.56	0.52	0.52
Ratio of Deaths to New Patient Admissions	0.69	0.70	0.74	0.73	0.75	0.72	0.72

from different sizes of unit, between 63% and 85% with an overall rate of 76%. To minimise the error in making estimates, groups of differently sized units were considered separately. The Table below gives details of admissions, deaths and discharges from those 143 units which responded to all the relevant parts of the survey. The weighted totals are those calculated by adding together the estimates from the different groups.

However these differed by less than 1% from the overall totals.

The numbers of deaths and discharges are broadly similar, with slightly more deaths than discharges, the ratio being 1.09. The ratio of deaths to new patient admissions is 0.72. This means that about 28% of patients do not die in a palliative care inpatient unit on the first or any subsequent admission.

TABLE 8 National Estimates – England, Wales and N Ireland Inpatient data 2001/2 to 2005/6

Year	New patient admissions	Total patient admissions	Ratio of new to total admissions	Deaths	Discharges	Ratio of deaths to discharges
2001/02	36,500	52,000	0.70	26,000	26,000	1.01
2002/03	37,000	51,000	0.72	25,500	25,500	1.00
2003/04	38,000	52,000	0.73	27,000	25,000	1.09
2004/05	38,000	52,000	0.72	27,000	25,500	1.06
2005/06	39,000	54,000	0.72	28,000	25,500	1.09

2. DAY CARE

Questionnaires were sent to all the known services providing specialist palliative day care in England, Wales and Northern Ireland asking about service provision for the year April 2005 to March 2006. Of 216 forms sent there were 182 replies giving at least some information (84% response rate)

Patient profile

Almost all the respondents provided the number of their new patients. This showed that the mean number of patients per service was 89 with a range from 5 to 500. The number of new patients was 61% of the total number of patients attending day care. This total included patients already receiving day care at the start of

the accounting period, together with any re-referrals of patients discharged in the previous year.

More than three-quarters of the total number of services were able to provide details of age and diagnosis. Over a third of the patients were under 65 and of 15,000 patients there were 88 who were under 25. More females than males attended day care (56% female and 44% male). Excluding patients with a 'not known' diagnosis, 91% had a diagnosis of cancer. There were only 18 patients with HIV/AIDS. Of the 161 services responding, 34 (21%) had over 15% non-cancer patients (ranging up to 45%). There were 17 services which recorded no non-cancer patients, and a further 7 had less than

TABLE 9 New Patients – Day Care

Data Item	Analysis	Results	Number of responding units	No. of patients in responding units
Number of patients	Mean number of new patients per unit	89	180 (83%)	15,952
	Range of above	5 to 500		
	Mean total number of patients per unit	148	172 (80%)	15,596 new patients 25,479 total patients
	Range of above	25 to 749		
	New patients as % of total patients	61%		
	Range per unit	18% to 100%		
Age of patients	Under 25	0.4%	162 (78%)	13,969 56% female
	Under 65	35%		
	65 to 84	56%		
	Over 84	9%		
Diagnosis	Cancer	90.7%	162 (75%)	13,590
	Non-cancer	9.3%		
	Range of % non-cancer	0 to 45%		

2%. However some of these had patients where the diagnosis was 'unknown' or 'unrecorded'.

Deaths and discharges

Data from the 173 services which were able to provide details of discharges from day care showed that 40% of the discharges were recorded as deaths. No information is available on the reason for discharge and many of those counted as discharged from day care may have been referred to an inpatient unit and died shortly after referral. Some services would record this as a death.

The data on deaths, discharges, new patients and total patients shows some anomalies. It could be expected that, for most services, the number of deaths and discharges should be approximately the same as the number of new patients. This would imply a workload which did not alter greatly throughout the year. However if service provision altered, with more sessions held or more places available, then the number of new patients might exceed the number of deaths and discharges, but this is likely only to apply to a very few units. Alternatively, deaths and discharges might exceed the number of new patients as it is known that some services count as discharged any patient who is admitted to an inpatient facility, but the patient may later return to day care and subsequently be counted again in the discharges.

It might be supposed that large variations in the figures would only occur in a few cases, but, in only 28% of responses were the number of deaths and discharges within 10% of new patients, with 26%

having a much lower ratio, and 46% much higher, up to more than four times the number of new patients. The higher number of discharges is possibly accounted for by re-referrals but there is no obvious explanation for the many units having a lower number, although it has been suggested that the counting or discounting of patients attending day care whilst an inpatient may account for some anomalies. Taking together the data from all 168 services which replied, there were 18% more deaths and discharges than new patients.

Length of care

The length of time patients were under the care of the day centre prior to discharge was given by 63% of total number of services. Of 14,515 patients there were 21% who attended day care for more than 6 months while 59% attended for 3 months or less. The mean length of care recorded was about 5 months, ranging from just over one month to 16 months. Calculations were made after eliminating any figures thought to be unsound after comparing with data given for the numbers of patients receiving care over the given periods. However, in view of the number of long term patients (see below) there is still some risk of inaccuracy.

A considerable number of services (137) reported having patients registered for the full year (April to March). Data from these services showed 14% of a total of about 20,000 patients were attending day care for the whole of this period. Three services recorded over half (up to 87%) of their patients in this category.

TABLE 10 Patient care

Data Item	Analysis	Results	Number of services responding	Numbers in responding services
Deaths and discharges	Deaths as % of deaths and discharges	40%	173 (80%)	18,253 deaths and discharges 15,480 new patients
	Deaths + discharges as % of new patients	118%		
	Range of above	20% to 430%		
Length of care	Less than 3 months	59%	136 (63%)	14,515 patients
	More than 6 months	21%		
Average length of care	Mean of service averages	174 days	113 (52%)	12,027 deaths and discharges
	Median of averages	164 days		
	Range	39 to 481 days		
Long term patients (registered for whole year)	% of total number of patients	14%	137 (63%)	20,436 total patients 2,858 long term patients
	Range	0.2 to 87%		

Caseload

The caseload is the average daily number of patients registered as day care patients. It can be calculated from the number of deaths and discharges in the year multiplied by the fraction of the year during which they received care. In view of the anomalies in the numbers of deaths and discharges compared with the number of new patients as described above, only very approximate figures can be found. However, using the data shown in Table 10, where the mean length of care was found to be 174 days, the average caseload was 46 patients, although the median was smaller at 38 patients.

If there are no re-referrals, then another measure of caseload is the difference between the total number of patients seen and the number of new patients. Using this measure, the average caseload is

58 patients, with a median of 48. These higher figures suggest that there may be a significant number of re-referrals, as well as long-term patients who are registered for the whole of the year.

Day care use

A day care session is defined as the time that one centre is open on one day. Reports from 81% of the total number of units showed that the average number of sessions per unit per year was 205, about 4 per week, ranging from about one per week to about 14 per week. (Some services provide day care on more than one site.) There is an average of 14.6 places per session, ranging from 6 to 30. The mean attendance rate is 62% ranging from 28% to 99%. The survey specified that counts should be of attendances and places available only for patients (including

TABLE 11 Day care provision

Data Item	Analysis	Results	Number of services responding	Numbers in responding services
Caseload	Mean for these services, based on mean length of care	46	118 (55%)	12,555 deaths and discharges
	Median based on length of care	38		
	Mean for these services based on difference between new and total number of patients	58		
	Median based on new and total patients	48		
Day care places	Mean no. of sessions per year per unit	205	165 (81%)	35,663 sessions 522,387 places 321,689 attendances
	Range of number of sessions	51 to 701		
	Mean number of places per session	14.6		
	Range of number of places	6 to 30		
	% use of available places	62%		
	Range of % use of available places	28 to 99%		

any specifically for inpatients) and not for relatives or carers, but it is thought that some of these may be included in counts, as well as some who attend the centre for a specific clinic rather than for the general day centre activities. Another potential source of error is the counting of booked attendances rather than actual attendances. In the present case, these non-attendances should not have been counted, but as there is a workload attached to them, in the following up of these patients, it may be considered necessary to count these in the future, as long as there is consistency in counting across all the services.

National Estimates

If the assumption is made that units who did not respond to the survey have similar work patterns and size to those who did respond, then overall estimates can be made of the service provided by all the 216 day care services in the England, Wales and Northern Ireland. From the discussion above, it will be appreciated that the number of patients receiving care at any one time, the national caseload, can be only estimated very approximately as somewhere between 8,000 and 12,000 patients.

TABLE 12 National estimates for England, Wales and N Ireland – day care

	New patients	Total patients	Day care places per week	Attendances per week
2001/2	18,000	28,500	12,600	8,200
2002/3	20,000	31,500	13,600	8,400
2003/4	20,000	32,500	13,700	8,600
2004/5	20,000	32,000	12,800	8,000
2005/6	20,000	32,000	13,000	8,000

There is a major caveat to this section of the report, relating to the definition of home care services. At present, it is not possible to distinguish between the primarily advisory services delivered by community specialist palliative care teams and other more sustained care provided in the patient's home. As these services differ in purpose, staffing and mode of delivery, this severely limits the usefulness of this data. Our wish to remedy this is hampered by a lack of clear or agreed definitions, but nevertheless in future years we will attempt to find a way of disaggregating these different types of service.

Data was sought from all the palliative care services known to be providing care in the community, primarily to adults, in England, Wales and Northern Ireland during 2005 to 2006. There were 192 replies from the 295 questionnaires sent, a 65% response rate, although not all returns provided all the data requested.

Patient profile

Table 13 shows that on average, each service cared for over 400 new patients, varying between 0 and 1600 patients. These patients comprised rather more than two thirds of the total number cared for. This total includes those already receiving care at the start of the year, any re-referrals of those who had received care in a previous year and been discharged, as well as new patients. A third of these new patients were under 65 and 0.4% were under 25, with 12% aged 85 or over.

Excluding patients with a 'not known' diagnosis, there were 6.2% with a non-cancer diagnosis, including 77 patients (0.1%) with HIV/AIDS. However, 16 services (9%) saw only cancer patients, while 30 services had between 10% and 36% non-cancer patients (with two outliers of 46% and 64%).

Referrals and visits

About a third of services reported on referrals and they recorded that 23% of their patients were referred at the time of diagnosis. More than one reason for referral could be given. Pain or symptom control was a presenting problem in 60% of referrals and 40% required psychological or emotional support. Other reasons for referral were carer support, social problems and assessment for admission.

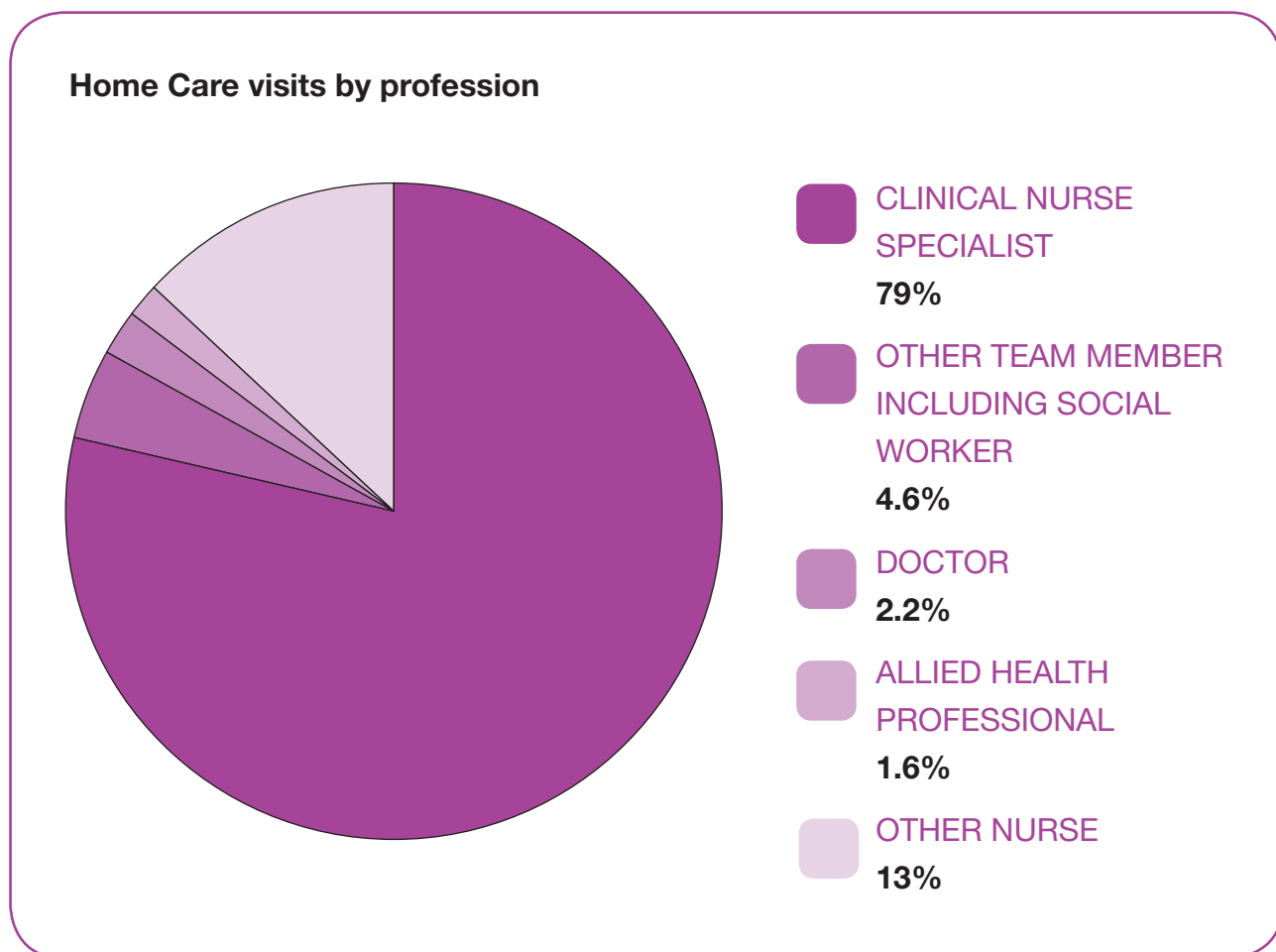
The average number of visits received by each patient during the year was calculated using the total number of visits made by the service divided by the total number of patients seen by the same service in the year. This was found to be 4.9 visits. This covers wide variations, between 1 and 19 with two outliers of 43 and 29. Some of the lowest values were where the visits were almost all made by a doctor. The high average number of visits may be where the service is providing more 'hands-on' nursing rather than an advisory role.

In fact each patient may receive rather more visits than the number found by

TABLE 13 New patients – home care

Data items	Analysis	Results	Number of services responding	Numbers in responding services
Number of patients	Mean number of new patients per service	407	177 (60%)	72,041 new 108,182 total
	Range of above	0 to 1,1608		
	Median number per service	343		
	Mean total number of patients per service	611		
	Range of above	1 to 2,890		
	Median number per service	470		
	New patients as % of total patients for all services	67%		
	Range of above percentages	0 to100%		
Age of new patients	Under 25	0.4%	171 (58%)	69,727 48.9% female
	Under 65	31%		
	65 to 84	57%		
	Over 84	12%		
Diagnosis	Cancer	93.8%	173 (59%)	71,367
	Non-cancer	6.2%		
	Range of % of non-cancer	0 to 64%		
Referral time	At diagnosis	23%	94 (32%)	32,249
Reason for referral	Pain or symptom control	60%	113 (38%)	44,014
	Psychological support	40%		
	Carer support	9%		
	Assessment for admission	4%		
	Social or financial reasons	6%		

Chart 5 More than three quarters of home care visits are made by Clinical Nurse Specialists



this calculation. If the calculations are based on the numbers of deaths and discharges (visits per completed episode) this gives an average of 6.5 visits for each episode. Most visits (79%) were by a clinical nurse specialist and 2% were recorded as being by a doctor. However this may be artificially low due to lack of recording, as it is known that some services sent in returns which excluded the visits made by a doctor. Other visits were made by allied health professionals, social workers and other nurses. However there was a relatively large percentage (2.7%) classified as ‘other’. Who these

‘other’ are is not known, but they may include for example aromatherapists and reflexologists.

Deaths and discharges

Services reported on the numbers of deaths and discharges. There is some variation in the way services record these: some services automatically discharge any patient who is admitted to an inpatient unit, but the patient may return home and be re-referred, whereas other services will not discharge the patient at every admission. 26% of services recorded more discharges than deaths, although overall

TABLE 14 Palliative care in the community

Data Item	Analysis	Results	Number of services responding	Numbers in responding services
Total visits	Average no. of visits per patient	4.9	161 (55%)	93,808 total patients 459,784 visits
	Range of visits per patient per service	1 to 43		
Visits by profession	% by CNS	79%	152 (52%)	425,648
	% by other nurse	13%		
	% by doctor	1.7%		
	% by AHP	2.2%		
Phone calls	Average per patient	8	103 (35%)	70,988 patients 586,340 calls
	Range	0.2 to 31		
Deaths and discharges	Deaths as percentage of deaths + discharges	62%	173 (59%)	76,833 deaths and discharges 71,247 new patients
	Deaths + discharges as % of new patients	108%		
	Range	22 to 266%		
Home deaths	Home deaths as percent of new patients	29%	151 (51%)	62,092 new patients 18,239 home deaths
	Range of above	0 to 92%		
Length of care	Less than 2 weeks	25%	124 (42%)	53,111
	Less than 3 months	67%		
	Over 6 months	17%		
Average length of care	Mean of service averages	105 days	100 (34%)	
	Range of service averages	7 to 260 days		
	Median of service averages	97 days		
Long term patients (registered for whole year)	Long term patients as percentage of total patients	10% total	98 (33%)	66,585 total patients 6,469 long term
	Range	0.1 to 59%		

deaths accounted for 62% of the patients no longer receiving care. Over 80% of respondents gave the place of death of their patients. Home deaths accounted for 29% of new patients, ranging from 0% to 92%. The proportions occurring in hospital and hospice and other places cannot accurately be determined as many teams will record a discharge if their patients are admitted to an inpatient facility.

As in the case of day care services, it might be expected that in the majority of cases the number of deaths and discharges would be approximately the same as the number of new patients. This assumes that there are only a small number of re-referrals of patients who had previously been discharged within the same or previous year, and that the staffing provision does not alter. However, the number of deaths and discharges varied from less than a quarter to more than two and a half times the number of new patients. Overall there were 8% more deaths and discharges than new patients.

Those services which count a discharge each time a patient is admitted to an inpatient facility will record a proportionally higher number of discharges than those services which keep such patients on their books and not count them as discharged until they die or no longer need the service. Where the number of discharges is proportionally small there is no immediately obvious explanation, apart from poor record keeping. In fact about 24% of respondents reported deaths and discharges of less than 90% of new patients. Further work needs to be done on this.

Length of care

A mean length of care was given by 100 services. This excludes those services where there seemed to be some discrepancy between the reported lengths of care for the given time periods and the quoted mean. Both the average and the median length of care were about 100 days (rather more than 3 months) ranging between 7 and 260 days. About two thirds of patients were looked after for less than 3 months. There were 98 units who reported having patients who were registered for the whole of the period of the survey. This ranged from less than 0.1% to 59% of the total number of patients each service cared for, with a mean of 10%.

Staffing

More than half the total number of services recorded their staffing complement in terms of whole time equivalent (WTE) staff. It was found that of 167 services, 22 did not include any Clinical Nurse Specialists in the team, and 5 services reported only the work of auxiliaries or allied health professionals. Over two thirds of the teams had no doctor, but 12 of these teams had a social worker working with the nurses. Over half of the teams apparently comprised nurses only, 5 of these being a single nurse working alone. Overall, the composition of the home care services was about three fifths Clinical Nurse Specialists, one fifth other nurses, and 5% doctors. Social workers, other allied health professionals and administrative staff accounted for the other members of the teams.

TABLE 15 Home care service provision

Data Item	Analysis	Results	Number of services responding	Numbers in responding services
Staffing – overall composition of home care services	Clinical Nurse Specialist	64%	167 (57%)	1,382 total WTE staff
	Other nurses	10%		
	Nursing auxiliaries	9%		
	Doctors	5%		
	Social workers	4%		
	Other professionals	4%		
	Others	4%		
Staffing	Mean number of CNS per service	5.3	167 (57%)	882 WTE nurses
	Range of above	0 – 28		
	Median	4.5		
Caseload	Average per registered nurse	26	85 (29%)	600 Nurses 522 CNS 45,266 deaths and discharges
	Average per CNS	28		
	Range per CNS per service	1.1 to 173		
Caseload per team	Average per team	144	98 (33%)	48,214 deaths and discharges
	Median of team means	129		

Caseload

The caseload for each team is considered to be the number of patients they care for at any one time. This can be calculated from the number of deaths and discharges multiplied by the fraction of the year they are under the care of the team.

As discussed above, there seem to be discrepancies in the recording of deaths and discharges as compared with new patients. However, if the combined data from all the services who responded to all the relevant parts of the questionnaire is used, this should minimise the discrepancy. For these 98 teams, where the mean length of care was 105 days,

the average caseload was 144 patients per team. However the median of the caseloads from each team was only 129. Using this data, the national caseload, that is the number of patient receiving palliative care in the community at any one time from all 295 community palliative care teams, can be calculated to be somewhere between 38,000 and 42,000.

The average caseload per Clinical Nurse Specialist was 28, although there was a wide variation between the different services, where each nurse had between 1.1 and 59 patients (with one outlier of 173) at any one time. For all registered nurses the average was 26 patients. The

accuracy of the data may be questioned in respect of the very small caseloads. It may be that the staffing has not been accurately represented: nurses may have duties apart from their work in the community, or it may be that numbers of nurses rather than whole time equivalents have been given in error.

National Estimates

If the assumption is made that the teams who did not respond to the survey have similar work patterns and size as those who did respond, then national estimates can be made of the service provided by all the 295 services in the England, Wales and Northern Ireland. Median rather than mean values have been used in the calculations.

TABLE 16 National Estimates – home care

Year	New patients	Total patients	Deaths and discharges	Home deaths calculated as % of new patients	Caseload at any one time	WTE Clinical Nurse Specialists
2001/02	95,000	138,000	95,000	29,000	27,000 to 42,000	1,100
2002/03	92,000	130,000	97,000	27,000	35,000 to 40,000	1,100
2003/04	96,000	134,000	105,000	27,000	34,000 to 43,000	1,200
2004/05	100,000	140,000	109,000	28,000	38,000 to 41,000	1,390
2005/06	101,000	139,000	109,000	29,000	38,000 to 42,000	1,330

4. HOSPITAL SUPPORT

Questionnaires were sent to 288 services providing specialist palliative care to adults within the hospital setting in England, Wales and Northern Ireland in 2005 to 2006. This did not include palliative care services provided by specialists such as chemotherapy nurses, or site specific cancer services such as breast care nurses. There were 163 replies providing at least some information. (One form had

to be rejected entirely because it included all the cancer patients in the particular hospital, rather than just those patients requiring palliative care.) Although the response rate of 57% is the lowest return rate of all the questionnaires, it is 10% higher than in the previous year, which indicates a growing recognition of the importance of data collection.

TABLE 17 New patients – hospital support

Data Item	Analysis	Results	Numbers of services responding	Numbers in responding services
Number of patients	Mean number of new patients per service	406	157 (54%)	63,682
	Range of number per service	1 to 1,249		
	Median number per service	387		
	Mean total number of patients per service	513	149 (52%)	76,509
	Range of number per service	1 to 2,328		
	Median number per service	450		
	New patients as % of all patients	80%	144 (50%)	59,522 new patients 74,341 total patients
	Range of % per service	10% to 100%		
Age of new patients	Under 24	0.6%	132 (46%)	55,682
	Under 65	32%		
	65 to 84	54%		
	Over 84	14%		
Diagnosis	Cancer	86.9%	136 (475)	54,802
	Non-cancer	13.1%		
	Range of % of non-cancer	0 to 84%		
Referral	% referred at time of diagnosis	34%	83 (29%)	33,090

Patient profile

The total number of patients seen included new patients and those currently registered at the start of the year, as well as re-referrals of those who were first registered in a previous year, or re-referred after discharge in the present year. New patients comprised 80% of the total. Almost a third of the new patients were aged under 65, 0.6% were aged between 16 and 24 and 14% aged 85 years and over.

Excluding patients with a 'not known' diagnosis, there were 13% with a non-cancer diagnosis. This ranged from 0% to 37%, with one service having 84% of its patients with a non-cancer diagnosis. Sixteen of the services responding (12%) saw only patients with cancer.

Referrals and contacts

Over a third of the patients were first seen at the time of diagnosis. This may have been by teams some of whose work is in oncology clinics. Each patient received an average of 4.1 contacts during the year, with a range from 1 to 11.4 and one outlier of 42.2 contacts per patient. Of these contacts 15% were by a doctor and 77% by a clinical nurse specialist. Social workers, other nurses and other medical professionals made the other contacts. It is known that some services are sending in reports which include only the work of part of the team (usually the clinical nurse specialist) and the doctor's work is not included, although efforts are being made to rectify this omission.

The length of time patients were under the care of the support service was one of the items of data requested. Over a fifth

of patients were seen only once and over 90% had died or were discharged within one month, but 1% remained under care for over 6 months, with three services reported having over 10% of their patients in this category. The data does not give information as to whether these patients were actively receiving care or whether they simply remained registered with the service until they died. Services were asked to give the mean length of care, the median of which was found to be 10 days although they were wide variations from 2 days to 5 months. If the five services with a stated mean length of care greater than 60 days are ignored, then the mean drops from 20 to 12 and the median from 10 to 9.5.

Staffing

The average team size reported by almost half of the total number of services was 2.6 Clinical Nurse Specialists working with 0.70 doctors and 0.57 other staff, including social workers, therapists and chaplains. Nearly a fifth of the services (24 out of 134) did not include a doctor. However, it is thought that there are some services which have some medical input, but this has not been included in the data sent because the form has been completed by the nursing staff who did not have access to the relevant data.

The actual caseload of the team at any one time cannot be accurately calculated from the data collected since it is not known how many re-referrals there are, but a measure of the workload of the team was calculated as a ratio of number of new patients compared with the number of Clinical Nurse Specialists in the team. Using data from almost half the total

TABLE 18 Patient care in hospital

Data Item	Analysis	Results	Number of services responding	Numbers in responding services
Total contacts	Mean no. of contacts per patient in year	4.1	109 (38%)	56,766 total patients 234,124 contacts
	Range of above	1 – 42.2		
Contacts by profession	% by CNS	77%	98 (34%)	201,260 contacts
	% by other nurse	3.6%		
	% by doctor	16%		
Length of care	One contact	21%	85 (29%)	38,635
	Less than one month	92%		
	Median of stated mean lengths of care	9.9 days	64 (22%)	
	Mean of stated means	19.7 days		
	Range of mean length of care per service	2 – 155		
Staffing average team size	Number of CNS	2.6	134 (47%)	515 WTE staff
	Range per service	0 – 9.6		
	Doctors	0.70		
	Social workers	0.13		
	Other staff	0.44		
Workload	Mean number of new patients per CNS	164	126 (44%)	54,672 patients 333.7 CNS
	Range of number of new patients per CNS	17 – 475		

number of services the overall figure was 164 new patients per CNS ranging from 17 to 398 with one team having more than 475 new patients per CNS. Chart 6 shows that the workload of a CNS working in a team which sees a large number of patients will tend to be higher than that of a CNS working in a team which sees a smaller number of patients.

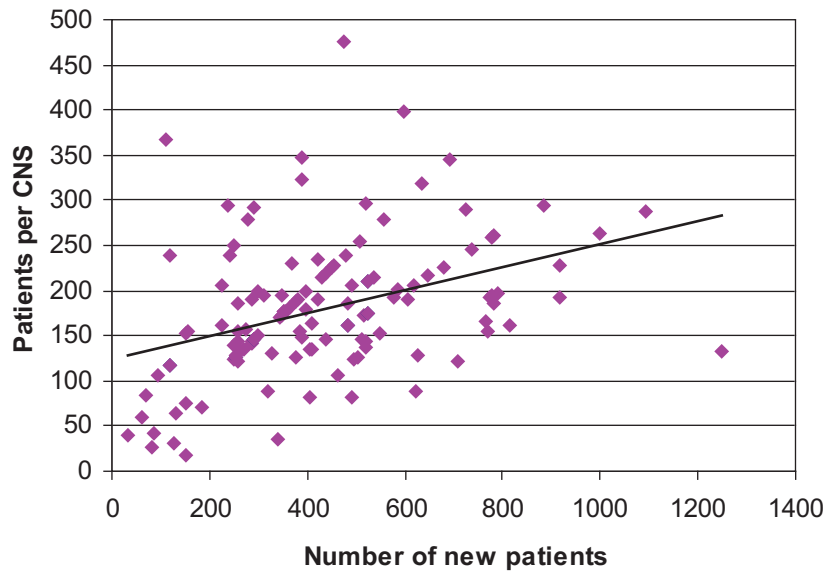
National estimates

Assuming that the data collected were typical of all services in the country then,

using median values, it can be estimated that about 130,000 patients may have contact with hospital support services in the course of a year, with 110,000 patients being seen for the first time during that year (England, Wales and Northern Ireland). These figures are slightly smaller than those found in previous years but are likely to be more accurate as a larger percentage of teams have responded. A much smaller estimate of the number of new patients can be obtained from the workload calculated above. The mean

Chart 6 The trendline shows that the number of patients per nurse increases with the number of new patients cared for by the team

Workload of hospital based specialist palliative care nurses



number of new patients per CNS as reported by 127 services with a total of 334.7 CNS was found to be 163. If each of the other services which did not send in a return (161) each had a minimum of

1 CNS, then an estimate of the number of new patients is 81,000. A true figure of about 100,000 new patients per year would therefore seem to be a reasonable estimate.

5. BEREAVEMENT SERVICES

The 2006 Hospice Directory listed 276 bereavement services associated directly with specialist palliative care providers in England, Wales and Northern Ireland, who were all asked whether they provided a bereavement service. This was intended to elicit those services which provided a more extensive service than a simple follow up call, memorial service, or referral to another organisation. Data was received from 174 services, a 63% response rate, but analysis showed that not all the bereavement services listed were comprehensive.

A bereavement client is defined as one who receives face to face contact after the death of a patient. There were 143 services who gave full details of both clients and total face-to-face contacts.

The mean for contacts per client was found to be 3.6 ranging from 1 to 26. Of these, there were 19 (7%) who recorded a mean of only one contact per client.

The type of contact was given by just over half the number of services and 69% of contacts were either in the home, or as individual counselling. A quarter of contacts occurred in a group setting with less than 1% being in a group with no staff present. The main staff member for each of the contacts was given by 45% of all services and this showed that half of all contacts were with a social worker or counsellor, while 10% were with a Clinical Nurse Specialist or other nurse. More than half of the respondents recorded telephone calls; they received or made an average of 2.8 calls per client.

TABLE 19 Bereavement services

Data Item	Analysis	Results	Number of responding services	Numbers in responding services
Number of clients	Mean number of clients per service	170	164 (59%)	27,882 clients
	Range of means per service	1 to 1,312		
Number of contacts	Mean number of contacts per service	609	167 (61%)	101,648 contacts
	Range of means per service	1 to 4,4480		
Contacts per client	Mean number of contacts per client	3.6	158 (57%)	26,944 clients 97,939 contacts
	Range of contacts per client per service	1 to 26		
Contact type	Individual contact or at home as % of total contacts	69%	152 (55%)	92,604 contacts
	Group with staff	22%		
	Self help group	<1%		
	Other	6%		
Staff type for each contact	Social Worker or Counsellor	50%	125 (45%)	78,544 contacts
	Clinical Nurse Specialist	6%		
	Volunteer	35%		
Telephone calls	Mean number of calls per client	2.8	102 (37%)	18,359 clients 51,200 calls
	Range of means per service	0.1 to 25		

6. OUTPATIENTS

Questionnaires were sent to all the specialist palliative care services in England, Wales and Northern Ireland which were known to provide outpatient

clinics. An outpatient clinic may be held regularly or occasionally and be attended by one or more patients (usually by appointment). It may be held in a hospital

TABLE 20 Outpatient services

Data Item	Analysis	Results	Number of services responding	Numbers in responding services
Number of patients	New patients as % of all patients	52%	166 (53%)	15,762 new patients 33,137 total patients
	Range of above	11% to 100%		
Age of patients	Under 24	0.9%	155 (49%)	14,833 61% female
	Under 65	48%		
	65 to 84	47%		
	Over 84	5%		
Diagnosis	Cancer	85.9%	123 (39%)	11,577
	Non Cancer	14.1%		
	Range of % of non-cancer	0 to 72%		
Patient attendances	Mean number of attendances per patient	3.0	157 (50%)	30,989 total patients 93,001 attendances
	Range of means per service (note 2 below)	1 – 14		
Clinic size	Mean number of attendances per clinic	3.4	146 (46%)	87,497 attendances 25,989 clinics
	Range of above	0.4 – 15.9		
Clinic type	Medical Consultant led	36%	138 (44%)	23,253 clinics
	Nurse led	5%		
	Lymphoedema only	31%		
	Breathlessness only	2%		
	Other	25%		
Clinic attendances	Medical Consultant led	31%	148 (47%)	83,161 attendances
	Nurse led	4.5%		
	Lymphoedema only	42%		
	Breathlessness only	1%		
	Other	21%		

or a palliative care unit or another setting. Of 314 forms sent, there were 181 replies giving at least some information, a 58% response rate.

Patient profile

Rather less than half the patients attending out patient clinics were seen for the first time during the year. Almost half were aged under 65 and 5% were 85 or over. There was a big discrepancy between the sexes; overall 61% were female and in the age range 25 to 64 there were 66% females. Excluding patients with a 'not known' diagnosis, data from over a third of the total number of services showed 14% of patients with a non-cancer diagnosis, although 21% of the services had no such patients. The range of non-cancer patients varied up to 72%. It may be noted that of all the different types of palliative care surveyed, inpatient, home care, day care and hospital support, the outpatient service apparently had the highest percentage of non-cancer patients at 14.1% followed by hospital support services at 13.1%.

Clinics and attendances

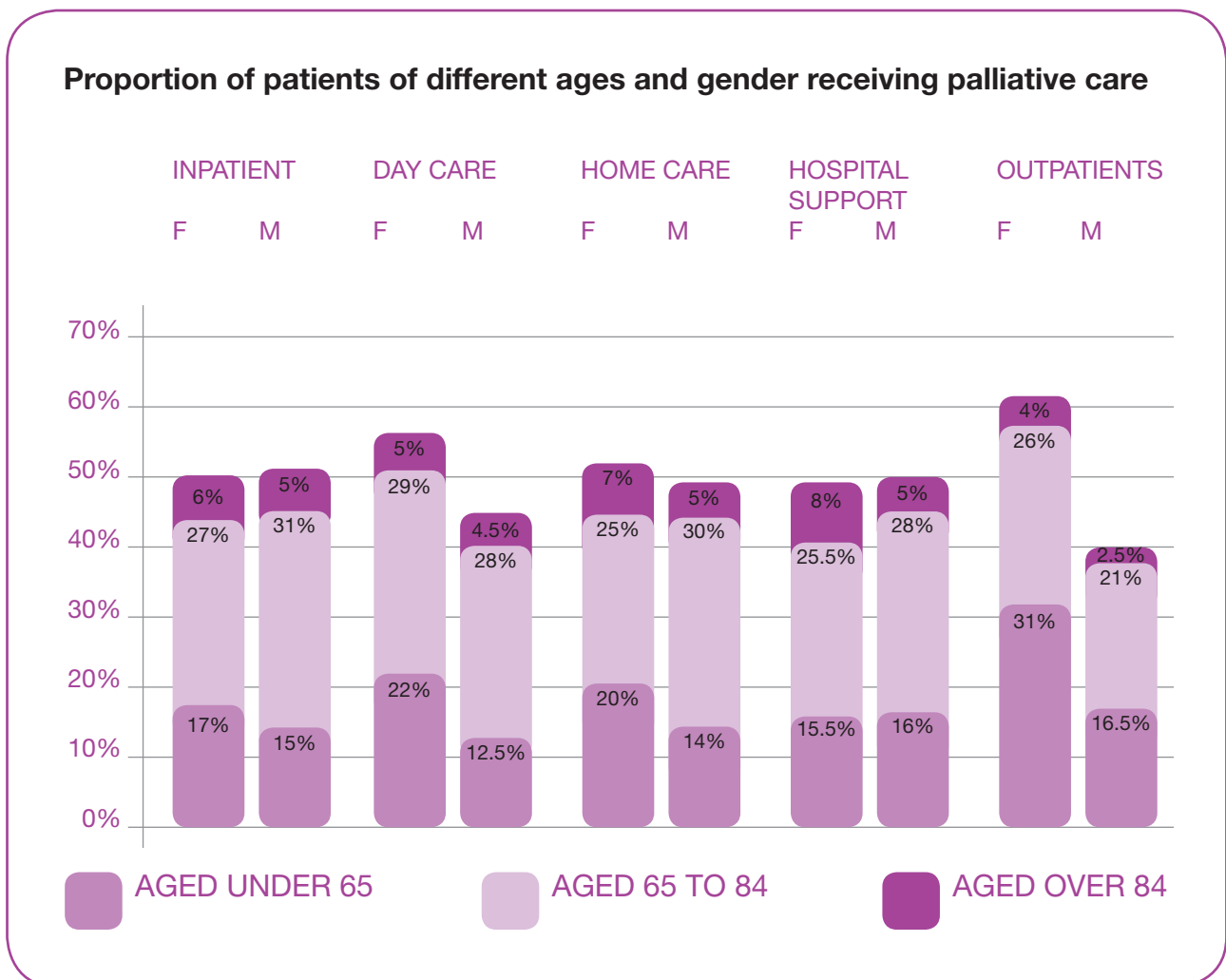
Patients attended clinics on average 3.0 times but there were wide variations, from 1 up to 14 times. At each clinic there was an average of 3.4 patients, with service averages ranging from less than 1 to 16. In the three cases where the average attendance was less than 1, this was because sometimes a clinic was scheduled but no-one actually attended. About a third of clinics had an average of less than 2 patients per clinic. Medical Consultants held about a third of clinics. Over 40% of the attendances were at specialist lymphoedema clinics but only 1% of attendances were at specialist breathlessness clinics. This will reflect the fact that lymphoedema clinic attendances will often be for ongoing treatment extending for a lengthy period of time. Attendances at 'other' clinics ranged from 0 to over 4000. Enquiry revealed that some of the higher numbers reflected the number of patients receiving complementary therapies. It is likely that some services have included these in their counts while others have not.

7. ALL PATIENTS

This section of the questionnaire was devised to find out more information about the patients who were receiving palliative care from any of the foregoing services: inpatient care, hospital support services, community care, day care or outpatient care (but not bereavement care). Where one service provides more than one type of care, it was hoped that the responses to this part of the questionnaire would avoid

double counting of patients receiving more than one type of care. However double counting of patients who receive the different types of care from different service providers cannot be avoided, since at present patients do not have a unique identifier. Because there is undoubtedly some double counting, the report gives percentages rather than absolute figures, and it is recognised that these will not

Chart 7 Age of patients receiving palliative care



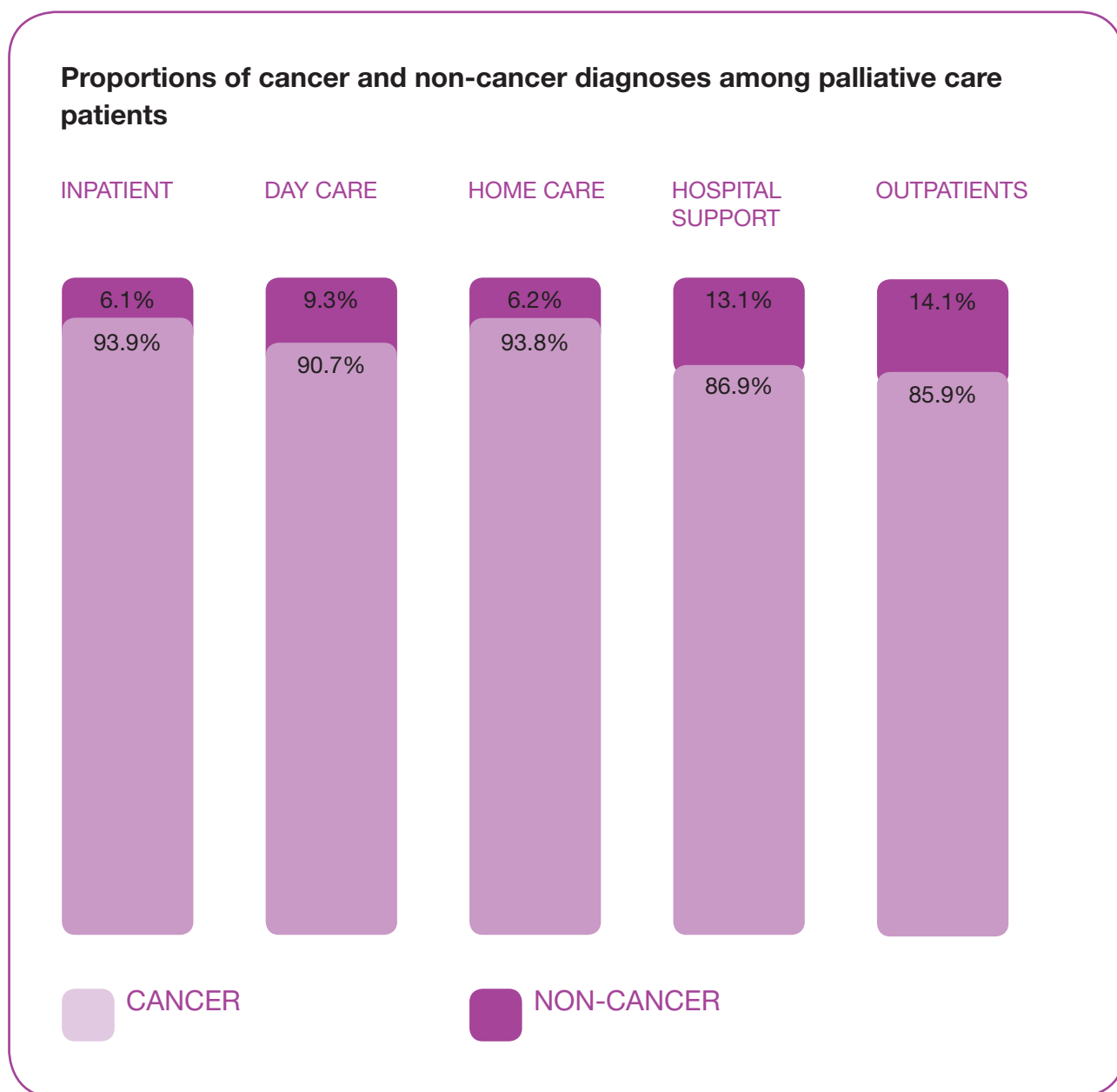
necessarily give a completely accurate picture.

All 513 palliative care services were sent this part of the questionnaire and 340 (66%) responded. This is only 88% of the 388 who returned some data, as 48 of these did not return this section.

Age and gender

Data from the returns of the individual services was used in Chart 7 to compare the different services with regard to age and gender of patients cared for. The proportion of elderly patients is largest for the hospital based services, while outpatients have the largest proportion of female patients.

Chart 8 Outpatient services and hospital based services have the highest proportion of non-cancer patients.



Ethnicity

Palliative care services are expected to categorise their patients according to the 17 ethnic groupings used by the Department of Health and 54% of respondents were able to do this, an increase of 10% over the previous year.

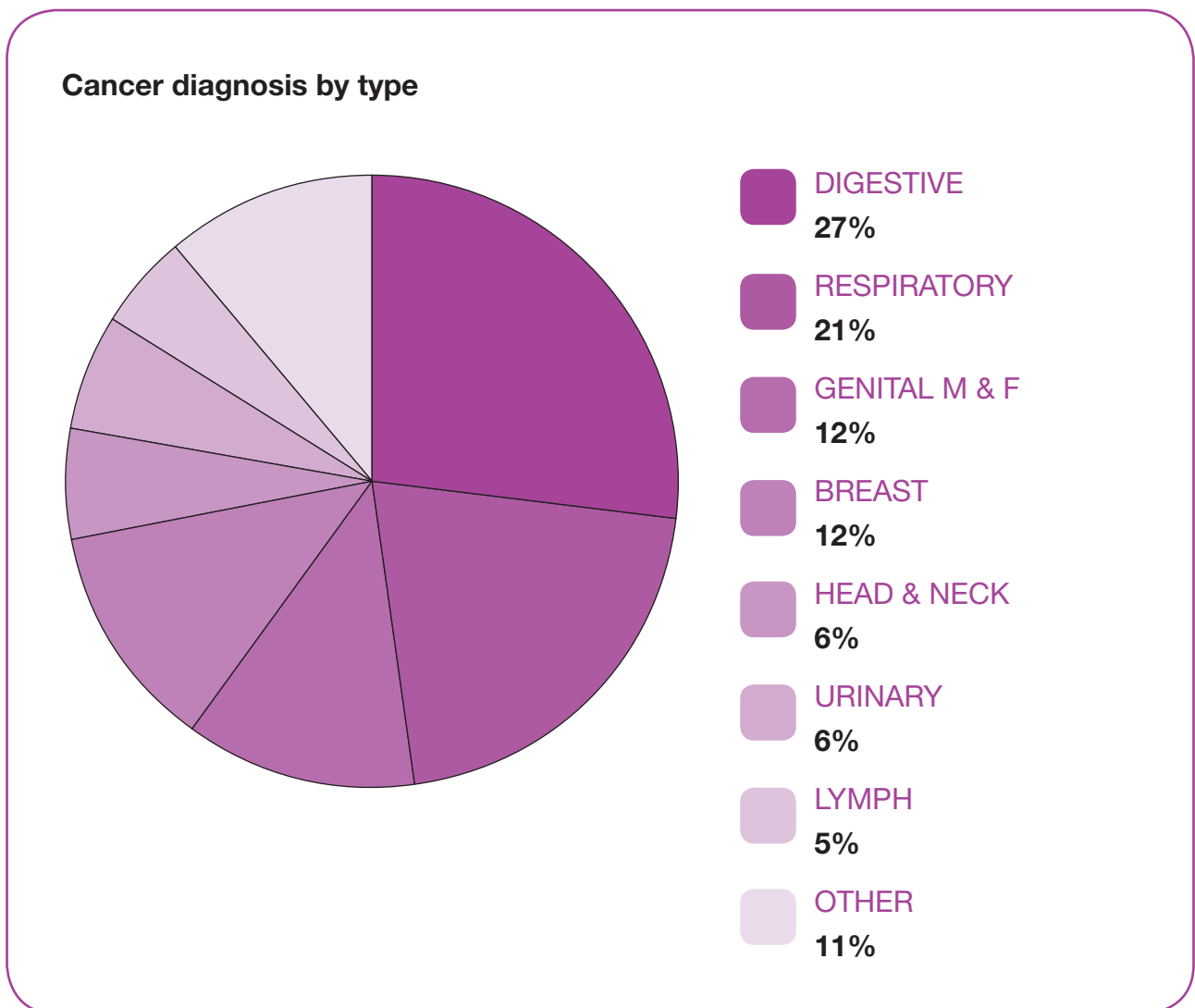
It was found that 4.9% of patients described themselves as non-white, comprising 1.82% black (African, Caribbean or other), 1.22% Indian, Pakistani or Bangladeshi, 0.29% as

mixed race, with 1.59% of other ethnicity including Chinese. Where services recorded more than 10% of their patients' ethnicity as 'not known' or 'not stated' these services were not included in order to avoid any selective counting.

Diagnosis

There is some evidence that a sizable proportion of respondents were using a computerised reporting system which recorded as 'other non-cancer' a combination of non-specified diagnosis

Chart 9 Cancers of the digestive system are the most common among those cared for by palliative care services



(cancer or non-cancer) and 'unknown/not recorded'. This gave an artificially high number of 'non-cancer' diagnoses. Using the data as given gave the percentage of non-cancer patients as 11.4% but eliminating 30 sets of data thought not to correspond with data for the individual services reduced this value to 10.8%, but this may be a little high. The services which see the most patients are home care and hospital support which both see about 100,000 new patients per year. Most inpatients, outpatients and day care patients will probably also receive either or both of these services. Given that hospital support see about 13% non-cancer and home care about 6%, an overall mean of about 9% or 10% would seem reasonable. Chart 8 shows the percentage of non-cancer patients for each of the different types of service.

Chart 9 reports only those whose type of cancer was given. About half were cancers of the respiratory, intrathorax and digestive systems. Breast cancer accounted for 12%. Table 21 shows some of the diseases of the non-cancer patients with a specified diagnosis. Diseases of the nervous system accounted for a third and heart and stroke a similar proportion. The figures given however do not necessarily include all the most common categories of disease found in palliative care; for instance chronic renal disease has not been included in the above listings.

Referrals, Carers

First referrals were made most commonly by a hospital doctor (37%). A quarter were from primary health care and 15% were from another palliative care service. The main carer was most frequently the

spouse (51%), while other relatives did most of the caring for 34% patients and 5% of patients had no main carer.

The category 'other' may include those patients in residential or care homes, but also it was felt that in some cases this category was used rather than 'not known', borne out by the fact that the 20% with the highest number had virtually no 'unknown'. Over a quarter of patients lived alone.

Place of death

Of the 75,000 deaths where the place of death was given, there were rather more in hospital than at home or in a palliative care unit: 36%, 27% and 31% respectively. How representative this is of all palliative care patients may be questioned. The respondents do not necessarily mirror the proportions of the different types of palliative care service; the response rates varied from 57% for the hospital based services to 87% for the inpatient services. Also it should be noted that the total number of deaths for which the place of death was given was only 62% of the total number of new patients given in this section, which suggests that many patients have been 'lost' as the majority of palliative care patients may be expected to die.

The total number of deaths in an inpatient palliative care unit was estimated to be 28,000 (see Section 1 above) of which 94% had cancer, so the estimated number of cancer deaths in an inpatient unit is 26,000. In England, Wales and Northern Ireland there were 138,350 deaths from cancer in 2004 (Cancer Research UK). From the estimates found from the

TABLE 21 Patient profile – all patients

Data item	Analysis	Results	Number of services responding	Number of new patients in responding units	
Ethnicity	White	95.1%	183 (36%)	70,726	
	Mixed race	0.29%			
	Black	1.82%			
	Indian/Pakistani/Bangladeshi	1.22%			
	Chinese/Other Asian/other	1.59%			
Diagnosis	Cancer (specified type)	Respiratory	21%	246 (48%)	97,908
		Digestive	27%		
		Breast	12%		
		Head & neck	6%		
		Genital M&F	12%		
		Urinary	6%		
		Lymph	5%		
		Other	11%		
	Non cancer (specified diagnosis)	HIV/AIDS	1.7%	202 (39%)	4,882
		MND/MS/Spinal	42%		
		Heart/stroke	30%		
Respiratory		26%			
Referrals	From GP or district nurse	25%	254 (50%)	111,655	
	From hospital doctor	37%			
	From other palliative care service	17%			
Living alone	Living alone	27%	146 (28%)	56,826	
Main carer	Spouse	51%	141 (27%)	56,303	
	Daughter	16%			
	Son	9%			
	Other relative	9%			
	Other	8%			
	No main carer	5%			
Place of death of patients cared for by palliative care service*	Home	27%	265 (52%)	74,679 deaths	
	Palliative care unit	31%			
	Hospital	36%			
	Other	6%			

*These figures should be treated with caution – see above

inpatient unit returns it can be inferred that about 19% of all cancer deaths occur in a palliative care unit. This is much lower than 31% found above. The explanation could be that only two thirds of all the patients dying of cancer are cared for by a palliative care service, or alternatively that there is selective recording, such that there is a larger proportion of data from the inpatient units. The true answer probably lies somewhere in between. It may be noted that estimates from the home care palliative care data suggest that about 101,000 new patients are cared for each year, of whom 94% have cancer. This is approximately 69% of the number of patients dying of cancer.

Validity of questionnaire

The validity of some of the data in this section may be questioned because there appears to be some double counting of patients even when they receive the different types of palliative care within the same organisation. It is inevitable that there is double counting where patients are cared for by different organisations during their period of care. It is also noted that there were low response rates with less than half the total number of services providing usable data for almost every question. This problem is being addressed in the MDS review.

Ann Eve, NCPC's MDS Manager, was the author of the MDS Full Report for the year 2005/06.

The National Council for Palliative Care (NCPC) is the umbrella organisation for all those involved in providing, commissioning and using hospice and palliative care services in England, Wales & Northern Ireland. It promotes the extension and improvement of palliative care services regardless of diagnosis in all health and social care settings and across all sectors to government, press and national and local policy makers.

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