

MINIMUM DATA SETS - NATIONAL SURVEY 1999 – 2000 document:

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1	Inpatient	page 2
2	Day Care	page 5
3	Home Care	page 7
4	Hospital Support	page 9
5	Bereavement Support	page 11
6	Outpatients	page 12
7	All patients	page 13

Questionnaires were sent in April 2000 to all the known services providing palliative care in the UK asking about service provision for the year April 1999 to March 2000. These services were listed in the 2000 Directory of Hospice and Palliative Care Services published by the Hospice Information Service. Some services had indicated they would provide a joint response which accounts for the discrepancy between the number of services listed in the Directory and the number of questionnaires. Joint responses were considered to be one service for the purposes of analysis. Data was returned during the summer of 2000. Responses to any questions where data was deemed to be grossly inaccurate were subject to checking. 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 'don't know' was more than 10% of the total. In the subsequent analyses, 'don't knows' were omitted.

Individual reports were sent at end of August to all services providing a response, in order for the services to compare themselves with national and regional averages, maxima and minima. In these reports mean values are given as the average of each of the individual means. These differ in some cases from the means quoted in the present paper which are calculated from the overall totals from all the services responding. When preparing the present report some further answers were rejected as being unreliable. The present report considers data from services providing a palliative care service to adults, and does not include specialist units (eg for HIV/AIDS or children)

### *Response rate*

The response rate to all parts of the questionnaire was higher than that previously obtained. Comparing with figures of two years ago, for the inpatient units there were at least 7% more responses to each of the questions, for home care the figure was 8%, day care at least 10% , and for hospital support there were between 4% and 8%.

## 1. INPATIENT UNITS

The data were analysed from those services which provided a palliative care inpatient service, primarily to adults in a dedicated palliative care unit. Palliative care beds within the general wards of hospitals and services with 2 or less beds were also excluded. Taking into account joint returns from some services, there were 187 units with a total of 2975 beds, the bed numbers being those quoted in the 2000 Directory of Hospice and Palliative Care Services. The units varied in size from 3 to 63 beds (although a joint return gave data for a total of 66 beds) with a mean of 15.2, the most common size being 10 beds. There was 70% response rate to the survey although the response to most of the questions was slightly lower than this. Where data for an incomplete year was provided, this was ignored.

### *Patient profile*

About 60% of the total number of services gave details of new patients, and this showed that about a third of patients were aged under 65, with only 0.22% under 25. This number is less than that recorded in 1998/9 when 0.8% were under 16. Of the older patients, 8% were over 84 compared with only 7% in 1998/9. The sexes were almost equally divided with 50.6% female. Excluding the 236 patients with a 'not known' diagnosis, 4.4% patients had a non-cancer diagnosis, including 62 patients (0.3%) with HIV/AIDS

The patients were admitted from a variety of locations, the majority (73%) from the patient's own home, but almost a quarter from hospital.

	<b>Findings</b>		<b>Services responding / Beds</b>	<b>Patients in those services</b>
New patients	Mean/service	229	127 / 2094	29041
Age	<25	0.22%	111 / 1754	23927
	<65	32%		
	65-74	31%		
	75 - 84	29%		
	>84	8%		
Diagnosis	Cancer diagnosis	95.6%	104 / 1681	22885
	Range	74%-100%		
	HIV/AIDS	0.3%		
Location before first admission	Home	73%	113 / 1774	24462
	Hospital	25%		

### *Analysis of inpatient stays*

Day cases were recorded by 21% of those responding, totalling 2% of total admissions. **Twenty nine percent of admissions were repeat admissions and half the admissions ended in death.** By far the majority of discharges (85%) were to a patient's own home, with 5% to hospital, and others to nursing/residential homes, or other types of care.

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. **The average was 13.4 days**, varying between 6 and 50 days. There is a correlation between length of stay and size of unit,  $r=0.22$   $p<0.01$ , ( $r=0.34$  if the 12 bedded unit having a great number of long stay patients is excluded) **the larger units having a longer length of stay.** The variation in mean length of care for different sizes of units is shown in the table below.

	<b>Beds</b>	<b>3-10</b>	<b>11-15</b>	<b>16-20</b>	<b>21-25</b>	<b>&gt;25</b>	<b>Mean</b>
No of responses	40	27	22	16	12		
Mean length of stay (days) (omitting outlier)	11.8	13.7	14.0 (12.2)	14.5	15.4		13.4 (13.0)

Almost half the services gave a breakdown of the length of stay and this showed just over 41% admissions were for one week or less, while 17% were for more than 3 weeks. Day cases were excluded from the calculations, so it seems likely that the 2.7% of patients with a length of stay of less than one day died on the day of admission. Seven units recorded having a total of 41 patients staying in those units for the whole period of the survey, but 37 of these were in three units.

	<b>Findings</b>	<b>Services supplying data / Beds</b>	<b>Patients in those services</b>	
Admissions ended	Mean/service	314	129 / 2068	40246
Day case	Day case Range	2% 0%-61%	108 / 1691	32323
Admission type	Repeat admission	29%	108 / 1691	33326
At end of admission	Deaths Discharge to own home Discharge to hospital	50% 42% 2.4%	120 / 1850	36329
Mean length of Admission (days)	Mean Mode Range	13.4 13 6-50	117 / 1892	
Length of admission	< 1 day 1-7 days 8-14 days 15-21 days >21 days	2.7% 38% 27% 15% 17%	110 / 1664	32297

### **Bed use**

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, ward closures, or because too recently occupied, are considered unavailable. The variations found were between 97% and 43% with a mean of 75%

The mean value of throughput (admissions per bed per year) was calculated as 22.4 admissions per bed. The mean turnover interval (unoccupied beds/number of stays) when a bed is kept empty between patients was found to be 4.5 days, varying between 28.4 days and 0.5 days.

	<b>Findings</b>	<b>Services supplying data / Beds</b>	
Bed Occupancy	Mean Range	75% 97.1% - 42.6%	83 / 1307
Throughput	Mean	22.4 admissions/bed	108 / 1696

	Range	42.1 - 7.4	
Turnover interval	Mean	4.5 days	90 / 1403
	Range	28.4 - 0.5	

*National estimates*

From the data supplied it is possible to make estimates of palliative care provision nationally, although this makes the assumption that those services which did not respond have similar ways of working to those which did respond. There was a variation in response rates from different sizes of unit, the lowest being 56% of the units with 16-20 beds. 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 121 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 but it can be seen that the differences are less than 1% from the estimates using the overall totals, although in each case they are lower.

Size – beds	3-10	11-15	16-20	21-25	>25	Overall Totals	Weighted Totals
Units responding	42	28	22	15	14	121	
<b>Total units</b>	<b>66</b>	<b>37</b>	<b>39</b>	<b>25</b>	<b>20</b>	<b>187</b>	
Beds in responding units	330	366	390	339	502	1927	
<b>Total beds</b>	<b>500</b>	<b>483</b>	<b>690</b>	<b>577</b>	<b>725</b>	<b>2975</b>	
Response rate units	64%	76%	56%	60%	70%	65%	
Response rate beds	66%	76%	57%	59%	69%	65%	
New admissions	5569	5689	5604	4282	5759	26903	
<b>Estimated total new admissions</b>	<b>8438</b>	<b>7508</b>	<b>9915</b>	<b>7288</b>	<b>8317</b>	<b>41534</b>	41466
Deaths	3521	3857	3973	3160	4424	18935	
<b>Estimated total deaths</b>	<b>5335</b>	<b>5090</b>	<b>7029</b>	<b>5379</b>	<b>6389</b>	<b>29233</b>	29222
Discharges (not deaths)	4431	4655	3778	2806	3135	18805	
<b>Estimated total discharges</b>	<b>6714</b>	<b>6143</b>	<b>6684</b>	<b>4776</b>	<b>4528</b>	<b>29032</b>	28844
Deaths/discharges	0.79	0.83	1.05	1.13	1.41	1.01	1.01
New admissions/(d+d)	0.70	0.67	0.72	0.72	0.76	0.71	0.71
Deaths/d+d	0.44	0.45	0.51	0.53	0.59	0.50	0.50
Deaths/new admissions	0.63	0.68	0.71	0.74	0.77	0.70	0.70

It is noticeable that the smaller units discharge a larger percentage of their patients than do the larger units, which is consistent with the finding that the larger units have a longer mean length of stay. The deaths/new admissions ratio is 70%. This means that about 30% of patients do not die in a palliative care inpatient unit on the first or any subsequent admission.

*Comparisons with previous years*

Comparing the estimates with those of the previous surveys of 1994/5 and 1998/9, using similar weighted estimates, it is seen that there are more admissions but a similar number of new admissions. This is consistent with a lower death rate per admission. (In a previous report it was noted that the 1997/8 estimated admission figures may be lower than the actual figures because of a low response rate from the larger units, which is not currently the case).

Estimates	New admissions	Total stays	New admissions/ Deaths Total stays	Discharges	Deaths/ Discharges
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1994/5	41600	54000	0.77	29000	25000	1.16
1997/8	39000	56000	0.70	29000	27000	1.06
1999/2000	41000	58000	0.71	29000	29000	1.01

## 2. DAY CARE

Questionnaires were sent to all the known services providing palliative day care in the UK asking about service provision for the year April 1999 to March 2000. Of 228 forms sent there were 165 replies giving at least some information (72% response rate). (Some services had indicated they would provide a joint response which accounts for the discrepancy between the number of services listed in Directory 2000 and the number of forms sent)

### *Patient profile*

Almost all the respondents gave the number of their new patients, and this showed a mean of 81 patients per service ranging from 14 to over 500. About 60% of the total number of services were able to give details of age and diagnosis. A third of the patients were under 65 and of 10813 patients only 24 (0.2%) were under 24. Excluding patients with a 'not known' diagnosis, 95% had a diagnosis of cancer. There were 14 patients (0.1%) with HIV/AIDS. However 23 (16%) of the 139 services responding had less than 1% non-cancer patients, while 29 (21%) had over 10% ranging to 31%

	<b>Findings</b>		<b>Services responding</b>	<b>Patients</b>
New patients	Mean per service Range	81 14 - 533	164	13319
Total patients	Mean per service Range	126 23-384	149	18806
New patients/total patients	Mean Range	0.62 0.01-1	148	11620/18734
Caseload	Mean Range	48 0-204	148	11620/18734
Age	16-24 <65 65-84 >84	0.2% 35% 59% 6%	140	10813 56% female
Diagnosis	Non Cancer Range	5% 0-31%	139	10829

### *Deaths and discharges*

Data from the 146 services which were able to give details of discharges from day care showed that 45% of the discharges were recorded as deaths. No information is available on the reason for discharge and many of those discharged from day care may have been referred to an inpatient unit and died shortly after referral.

### *Caseload*

The caseload is the average daily number of patients registered as day care patients who have not been discharged or died. The caseload at the beginning of the year can be calculated from the difference between the new patients to total patients and the mean per service was 48 patients, ranging from 0 to 204. The ratio of new patients to total patients was 65% with a range of 1% to 100%.

The ratio of deaths and discharges compared with new patients showed there were 12% more discharges than new patients, implying a decreasing caseload overall. Individual services

varied from a increase of 80% to an decrease 150%. However examination of the data showed that for 21 of these service the 'total number of patients seen' was in fact less than the total number of discharges, implying that some 'tidying up of the books' was taking place. Calculations of caseload from the given data must therefore be somewhat approximate.

Another measure of caseload can be calculated from the mean length of time that patients are registered as receiving day care. This was found to be about 5 months (see below). The caseload each day can be calculated as the number of new patients in the year times the fraction of the year they are receiving care..

Let t = total patients, n = new patients, d = length of care in days

Caseload at beginning of year = t-n

Average daily caseload =  $nd/365$

Hence, if caseload remains constant throughout year  $d = 365(t-n)/n$

Using this calculation, the average length of time of care is calculated to be about 7 months

It would therefore appear that the actual caseload may well be less than that found by simply subtracting new patients from total patients

#### *Length of care*

The length of time patients were under the care of the day centre prior to discharge was given by 120 services but only for 107 of these did the patients totals agree within 10% of the given total number of discharges. Discounting services where there were anomalies, of almost 10,000 patients there were 22% who attended day care for more than 6 months while 62% attended for 3 months or less. The mean length of care recorded was about 5 months, ranging from two weeks to 18 months. However, a considerable number of services reported having patients registered for the full year (April to March). Of 119 services recording such patients, 20% of the 15000 patients seen during the year were registered for the whole of this period. Some services recorded having nearly 80% of their patients in this category.

#### *Day care use*

Reports from 64% of the total number of units showed that the average number of sessions per unit per year was 227, about 4.5 per week, ranging from about one per fortnight to 11 or 12 per week. (Some services provide day care on more than one site). A session is defined as the time that one centre is open on one day. There is an average of 14 places per session, ranging from 6 to 40. The mean attendance rate is 67% ranging from 25% to 134%. Seven units reported an occupancy rate of over 100%. The survey specified that counts should be of attendances and places available for patients only (including 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.

	<b>Findings</b>		<b>Services respondin g</b>	<b>Patients</b>
Deaths and discharges	Deaths	45%	146	13028 patients
	Deaths+discharges/ new patients	1.12		11644 new patients
	Range	0.2-2.5		
Length of care	<3 months	62%	107	9765 patients
	>6 months	22%		

Mean length of care	146 days Range	15-558	96	9362
Long term patients (registered for whole year)	2999 long term patients Range	0-79%	119	15293 total patients
Day care places	Average per unit Range Places/session Range Occupancy Range	227 29-566 14 6-40 67% 25-134%	146	33211 sessions 469274 places 314189 attendances

### *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 228 day care services in the country.

	<b>New patients</b>	<b>Total patients</b>	<b>Places/week</b>	<b>Attendances</b>
Services responding	164 (72%)	149 (65%)	146 (64%)	146 (64%)
Patients	13319	18806	469274 / 50	314189 / 50
<b>National estimates</b>	<b>18 500</b>	<b>29 000</b>	<b>14 600</b>	<b>9 800</b>

### **3. HOME CARE**

Questionnaires were sent to 330 services, eliciting 172 replies giving at least some information (52% response rate).

#### *Patient profile*

Just over half the total number of services recorded a total of 60,076 new patients and about 40% responded to questions on age and diagnosis. A third of the patients were under 65 and 248 (0.6%) of these were aged between 16 and 24. Excluding patients with a 'not known' diagnosis, only 3.7% had a non-cancer diagnosis, including 37 patients (less than 1%) with HIV/AIDS. However 36 (27%) of the 132 services responding had less than 1% non-cancer patients, while 15 had over 10% ranging to almost 30%

	<b>Findings</b>		<b>Services respondin g</b>	<b>Patients</b>
New patients	Mean per service Range	351 14-1673	171	60076
Total patients	Mean per service Range	470 19-1879	151	71029
New patients/total patients	Mean Range	0.72 0.24-1	149	49618 new patients 68944 total patients
Age	16-24 <65 65-84 >84	0.6% 36% 56% 8%	134	45721

Diagnosis	Non Cancer Range	3.7% 0-29%	132	43481
Referral time	At diagnosis	19%	68	20558
Reason for referral	Pain/symptom control Psychological support Multiple reasons	29% 28% 26%	49	13480

### Referrals and visits

Only a small number of services (less than 20%) reported on referrals and they recorded that 19% of their patients were referred at the time of diagnosis. Almost a third of patients were referred with pain or symptom control as the main reason, slightly fewer were referred for psychological or emotional support. A quarter of patients had multiple reasons for referral.

About 43% of services gave details of visits. **The average number of visits received by each patient was calculated using the total number of visits made by the service divided by the number of new patients registered during the year, and was found to be 8.9. This covers wide variations (between 1.3 and 38, with 75% between 4 and 15) and reflects both different ways of working and different ways of recording.**

On telephone enquiry it transpired that two services which recorded less than one visit per patient were counting all the patients who were registered with them, but some of these patients only received various aids and support services and not actual nursing care; their records did not allow them to distinguish between the two. These returns have been ignored in the subsequent calculations. **Most visits (83%) were by a clinical nurse specialist and only 1% were recorded as being by a doctor.**

### Deaths and discharges

Services reported on the numbers of deaths and discharges. There is some variation in the way services record these: some of the discharges may be to inpatient units (where the patient may well die) and other patients are discharged because they no longer need the service (although possibly may be referred again in the future). Of the 49989 deaths and discharges reported by 42% of services, 62% were deaths.

### Length of care:

A mean length of care was given by 89 services and the average reported was 107 days (3.5 months). There were 93 units who reported having patients who were registered for the whole of the period of the survey. This ranged from 1% to 52% of the total number of patients each service cared for, with a mean of 12%.

	Findings		Services respondin g	Patients
Total visits	Average/patient Range	8.9 1.3-38	143	51669 patients 437890 visits
Visits by profession	By CNS By other nurse By doctor	83% 7% 1%	122	351198
Phone calls	Average/patient Range	5.95 0-31	76	41014 patients 244195 calls
Deaths and discharges	Deaths Deaths+discharges/ new patients Range	62% 1.05 0.2-3.3	137	49989 patients 47419 new patients

Caseload (start of year)	Mean	130	149	49618 new patients
	Range	0-562		68944 total patients
Length of care	<2 weeks	21%	99	23933
	<3 months	64%		
	>6 months	19%		
Mean length of care	<b>107 days</b>		<b>89</b>	
	Range	7-281		
Long term patients (registered for whole year)	5810 long term	12%	93	48548 total patients
	Range	1-52%		

#### *Caseload.*

The caseload of each team at the beginning of the year can be measured by taking the difference between the total number of patients seen and the number of new patients seen in the year. The average caseload for the 149 teams which responded was 130. The change in caseload over the year was measured by comparing the numbers of deaths and discharges with the number new patients. Overall there were 5% more deaths and discharges than new patients (and therefore a corresponding drop in caseload) but the reports from the 137 teams which responded showed variations from an increase of 45% to a decrease of 230%, although 75% of services had a range between +/- 30%.

The 5% decrease in caseload contrasts strongly with the findings of 5 years ago when an increase of caseload of the order of 30 or 40% was estimated. It was stated then that those figures seemed to be unreliable, possibly due to under-reporting of deaths and discharges. (Unpublished figures from 1998/9 indicated almost no change in caseload from the beginning to the end of the year). However it is thought that the present figures may still have some inaccuracies. A measure of caseload can be gained by looking at the mean length of time patients are under the care of the home care service. The total number of new patients seen by all services multiplied by the fraction of the year they are under care (107/365) gives an indication of a national caseload at any one time of 34000. This can be compared with a national caseload of 43000 found by multiplying the average caseload at the beginning of the year (130) by the number of services (330). However it should be noted that, because of varying response rates, if the caseload at the beginning of the year is calculated using national estimates, the caseload is found to be 39000. An overall drop of 5% by the end of the year gives 37000. This suggests the true caseload may be somewhere between 35000 and 40000.

#### *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 330 services in the country.

<b>New patients</b>	<b>Total patients</b>	<b>Deaths &amp; discharges</b>	<b>Daily caseload</b>
116000	155000	120000	35000 - 40000

## **4. HOSPITAL SUPPORT**

Questionnaires were sent to 328 services and there were 143 replies giving at least some information (44% response rate)

#### *Patient profile*

Just over 40% of the total number of services recorded a total of 50,080 patients and about a third responded to questions on age and diagnosis. A third of the patients were under 65, 6% were aged between 16 and 24 and 9% aged 85 years and over. Excluding patients with a 'not known' diagnosis,

only 5% had a non-cancer diagnosis. However 24 of the services responding (19%) saw only patients with cancer.

	Findings		Services responding	Patients
New patients	Mean per service Range	373 1-1455	134	50080
Total patients	Mean per service Range	430 1-1480	125	53752
New patients/total patients	Mean Range	0.85 0.38-1	116	41817new 49289 total
Age	16-24 <65 65-84 >84	6% 35% 56% 9%	91	31590
Diagnosis	Non Cancer Range	5% 0-29%	125	45695
Referral time	At diagnosis	42%	68	22009
Reason for referral	Pain/symptom control Psychological support Multiple reasons Discharge planning Other	31% 29% 20% 7% 13%	73	26606

#### *Referrals and contacts*

Almost half of the patients seen by the 20% of services which reported were referred at the time of diagnosis. About 30% were referred for symptom control, a similar number for psychological reasons and about 20% for multiple reasons. Each patient received an average of 3.6 contacts, with a range from 1 to 13 although 80% of teams recorded between 2 and 6.5 contacts. **Only 12% of contacts were recorded as being by a doctor, and 82% by clinical nurse specialist.** Social workers, other nurses and other medical professionals made the other contacts.

The length of time patients were under the care of the support service was recorded by about 15% of services, rather more than the 10% returning data in 1997/8, but the findings were similar, showing 90% of patients had contact for less than a month. Rather more contacts were 'once only' (30% compared with 23%).

	<b>Findings</b>		<b>Services responding</b>	<b>Patients</b>
Total contacts	Average/patient Range	3.6 1-13	82	35071 patients 124531 contacts
Contacts by profession	By CNS By other nurse By doctor	82% 3% 12%	70	110821
Deaths and discharges	Deaths Range	32% 0-1	100	35009 patients
Caseload	Mean Range	64 0-556	116	41817 new 49289 total
Length of care	1 contact <1 month	30% 90%	58	19586
Mean length of care	Range	20 days 4-91	48	

*National estimates*

Assuming that the data collected were typical of all services in the country then as many as 140,000 patients a year may have contact with hospital support services. The estimated figure in 1997/8 was 100,000. The number of new patients seen by a hospital support team in the course of the year is estimated to be 120,000. The current estimate may be too high, as it may be that the larger teams are able to have more facilities for data collection and return than smaller teams. The number of services eligible to return data has only increased by 2, but the average number of new patients seen by each service has increased by more than 10%. This may be because some services have increased the number of team members. In January 1998 the proportion of services describing themselves as 'teams' rather than 'hospital support nurses' was 57% whereas in 2000 the figure was 64%.

## 5. BEREAVEMENT SERVICES

The overall response rate from the 356 services listed in the Hospice Directory was 167 (47%). There were 141 services who gave full details of both clients and total face-to-face contacts. There were 24 of these services who recorded a mean of less than one contact/client and it would seem that many services are recording as 'clients' many who only receive telephone contact. Overall for the 141 services there was a mean of 2 contacts per client, but the mean for each of the services was over 3. If only those services where the contact to client ratio was greater than 1 are considered, the mean number of contacts per client rises to 3.5.

The type of contact was given by 130 services and 70% of contacts were either in the home, or as individual counselling. 21% of contacts occurred in a group setting, 3% being in a group with no staff present. The main staff member for each of the contacts was given by 28% of all services and this showed that half of all contacts were either with a Clinical Nurse Specialist and a volunteer while rather more than a third were either with a Social Worker or Counsellor. Less than half of respondents recorded telephone calls, but they received or made an average of 1.8 calls per client.

	<b>Findings</b>		<b>Services responding</b>	<b>Clients</b>
Total number of clients	Mean per service Range	222 2-3849	151	34013
Total contacts	Mean per service	469	148	69469 contacts
Contacts/client	Mean per service Range	2.8 1-13.8	117	22158
Contacts/client	Overall contacts/client Mean per service Range	2.11 3.08 0.05-13.8	141	32152 clients 67873 contacts
Contact type	Individual / at home Group with staff Self help group Other	70% 18% 3% 9%	130	63517
Staff type	CNS Volunteer Social Worker/Counsellor	25% 25% 37%	102	46180
Telephone calls	Mean per service Range	1.8 0-8.3	79	20832 clients 31255 calls

## 6. OUTPATIENTS

Questionnaires were sent to all the known services providing palliative home care in the UK asking about service provision for the year April 1999 to March 2000. Of 254 forms sent there were 104 replies giving at least some information (41% response rate).

### *Patient profile*

Just over half of the patients seen at out patient clinics were seen for the first time during the year. Nearly half the patients were under 65 and 6% were 85 or over. There was a big discrepancy between the sexes: only 40% were male. This was particularly marked in the age range 25 to 64 where there were twice as many females as males. Excluding patients with a 'not known' diagnosis, data from 65 services showed 7% of patients with a non-cancer diagnosis although almost a third of the services had no such patients, while 8 services had over 25% noncancer patients.

### *Clinics and attendances*

Clinics were attended on average 3.9 times per patient but there were wide variations up to 31 times. At each clinic there was an average of 3.5 patients, ranging from 1 to 17.5. According to the data, 5 services had only one patient at each of their clinics, a total of 1344 clinics. Almost half the clinics were held by doctors, nearly a third by nurses or professions allied to medicine, 9% by social workers and 15% described as 'other'. It is not clear who is providing these 'other' clinics, except that in one case all 375 outpatient clinics held were described as 'lymphoedema clinics' (and each clinic had only one patient attending)

	<b>Findings</b>		<b>Services responding</b>	<b>Patients</b>
New patients/total patients	Mean Range	0.53 0.17-1	93	8927 new 16890 total
Age	Under 24 <65 65-84 >84	0.4% 44% 50% 6%	76	7426 60% female
Diagnosis	<b>Non Cancer Range</b>	<b>7% 0-79%</b>	65	5899
Clinic attendances	Attendances/patient Range	3.9 1-31	81	13345 total patients
Clinic size	Attendances/clinic Range	3.5 1-17.5	73	51681 attendances 14923 clinics
Clinic type	<b>Consultant Other doctor</b> CNS PAMS Social Worker/Counsellor Other	<b>36% 10%</b> 16% 14% 9% 15%	65	12705 clinics



## 7. ALL PATIENTS

All services surveyed for the year 1999-2000 were sent this part of the questionnaire, so a total of 601 forms were sent and elicited a 49% response.

### *Ethnicity*

About a quarter of the total number of services gave useful information on ethnicity. Ignoring those responses where the number of 'not knowns' was greater than 10% of the total, it was found that 97.0% of patients described themselves as white, 1.16% as black (African, Caribbean or other), 1.03% as Indian, Pakistani or Bangladeshi and 0.12% as Chinese. (cf 1997/8 97.13% white)

### *Diagnosis*

Most of the returns were able to give a breakdown into cancer and non-cancer patients, 4.8% being noncancer. (cf 1997/8 6.3%) About 80% of returns were further able to breakdown the diagnoses. Of the cancer patients, about a quarter were respiratory and intrathoracic, and slightly less were digestive. Of the noncancer patients, diseases of the nervous system accounted for 18% and heart and stroke 12%. The diagnosis was not specified for well over half of the noncancer patients.

	<b>Findings</b>		<b>Services responding</b>	<b>Patients</b>	
Ethnicity	White	97%	154	48001	
	Black	1.16%			
	Indian/Pakistani/Bangladeshi	1.03%			
	Chinese/Other	0.82%			
Diagnosis	Cancer 95.2%	Respiratory	21%	243	96898
		Digestive	26%		
		Breast	12%		
		Head & neck	6%		
		Genital M&F	12%		
		Urinary	6%		
		Lymph	5%		
	Noncancer 4.8%	Other cancer	12%		
		HIV/AIDS	3%		
		MND/MS/Spinal	19%		
		Heart/stroke	13%		
		Respiratory	7%		
		Other non ca	58%		
		Referrals	GP		
Hospital doctor	39%				
District Nurse	9%				
Palliative care service	10%				
Living alone	Living alone	26%	83	25100	
Main carer	Spouse	51%	114	39447	
	Daughter	13%			
	Son	8%			
	Other relative	7%			
	Other	18%			
	No main carer	3%			

Place of death	Home	29%	220	50539
	Palliative care unit	35%		
	Hospital	31%		
	Other	5%		

### *Referrals, Carers*

First referrals were made most commonly by a hospital doctor (39%) and 35% from primary health care. 10% of referrals were from another palliative care service. The main carer was most frequently the spouse (51%), while other relatives did most of the caring for 28% patients. However 3% of patients had no main carer. Just over a quarter of patients lived alone.

### *Place of death*

Of the 50539 patients whose place of death was known, their place of death was pretty equally divided between palliative care unit, home and hospital, slightly more being in a palliative care unit. However the place of death of 7% of the patients who were known to have died was not known.