

*National Survey
of
Patient Activity Data
for
Specialist Palliative
Care Services*

*MDS Full Report for the year
2006 - 2007*

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INTRODUCTION

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, NCPC) 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 and end of life care strategy and service planning
- Commissioning of services
- Development of national policy

Specifically for the year 2007/8 this data forms a vital part in England of the NHS Operating Framework: PCT baseline review of services for end of life care as it provides part of the information for the service mapping aspect. NCPC also provides other forms of information and data for this process through its dementia work, workforce survey of specialist palliative care and population based needs assessment. For further information visit the relevant part of the website (www.ncpc.org.uk). Subscribers receive this information free as part of their subscription.

Extract from NHS Operating Framework 2007-8: PCT Baseline Review of Services for End of Life

What services are we providing for patients / families / carers as they approach the end of life? Are these services available to all patients?

For example:

- Specialist palliative care in-patient services in voluntary hospices and NHS managed units - bed numbers
- Hospital specialist palliative care support teams
- Community specialist palliative care teams
- Specialist palliative care day therapy/out patients

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 2006/07 and is therefore the twelfth since the introduction of the MDS.

Over the last two years we have attempted to report more accurately the level of activity in the different countries; this process will continue as the response rate from Wales and Northern Ireland improves. Country analysis will therefore be an important part of this and future reports.

During these twelve 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 new funding mechanisms are introduced, 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 main changes have involved removing some items that have not been found to be useful, but including work done over the telephone, contacts with carers and contacts made with patients in day care, as well as ad hoc outpatient contacts. The new questionnaires were piloted at various sites around

the country for a three month period. Adjustments were then made to the questionnaires and the final version was launched in June 2007. A series of Guides has been produced which detail question-by-question exactly what data is to be collected. These Guides are intended to be 'user-friendly' and will be updated if any difficulties of interpretation are found when the new datasets are in use.

Services will start collecting data in April 2008 and the first national collection of data will be in Spring 2009. The new forms and Guides are available on NCPC's website at www.ncpc.org.uk and electronic submission has been made easier to help services provide the information this way.

The Survey for 2006/07

The Survey is of all hospice and specialist palliative care services located in England, Northern Ireland and Wales that are listed in the 2007 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 2007. 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 2007. Responders can submit electronically, online or by email attachment, and only about 22% were received on paper. Electronic submission cuts down considerably on data input time, prevents input errors and leaves more time for checking and querying.

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 late July 2007 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, or, in the case of Wales and Northern Ireland, for the whole country. 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 this report some further responses to particular questions were rejected as being unreliable, and some amended data was included.

RESPONSE RATE

The overall response rate reached 80% for the first time this year, continuing the trend of increasing response rates (see Section 8). Table 1 shows the

response rate for the different parts of the questionnaire and it is seen that the response rates varied from 59% to 87%. Chart 1 compares the response rates for England, N Ireland and Wales with the overall response rate.

	Number of services				Overall Response
	England	N Ireland	Wales	Total	
In-patient	167	5	17	189	84%
Day Care	189	6	16	213	87%
Home Care	245	11	22	278	73%
Hospital Support	243	15	23	281	61%
Bereavement Support	260	8	19	287	63%
Out-patient	274	18	21	313	59%
All patients	441	22	40	503	72%
OVERALL RESPONSE				503	80%

Table 1 Response rate to survey

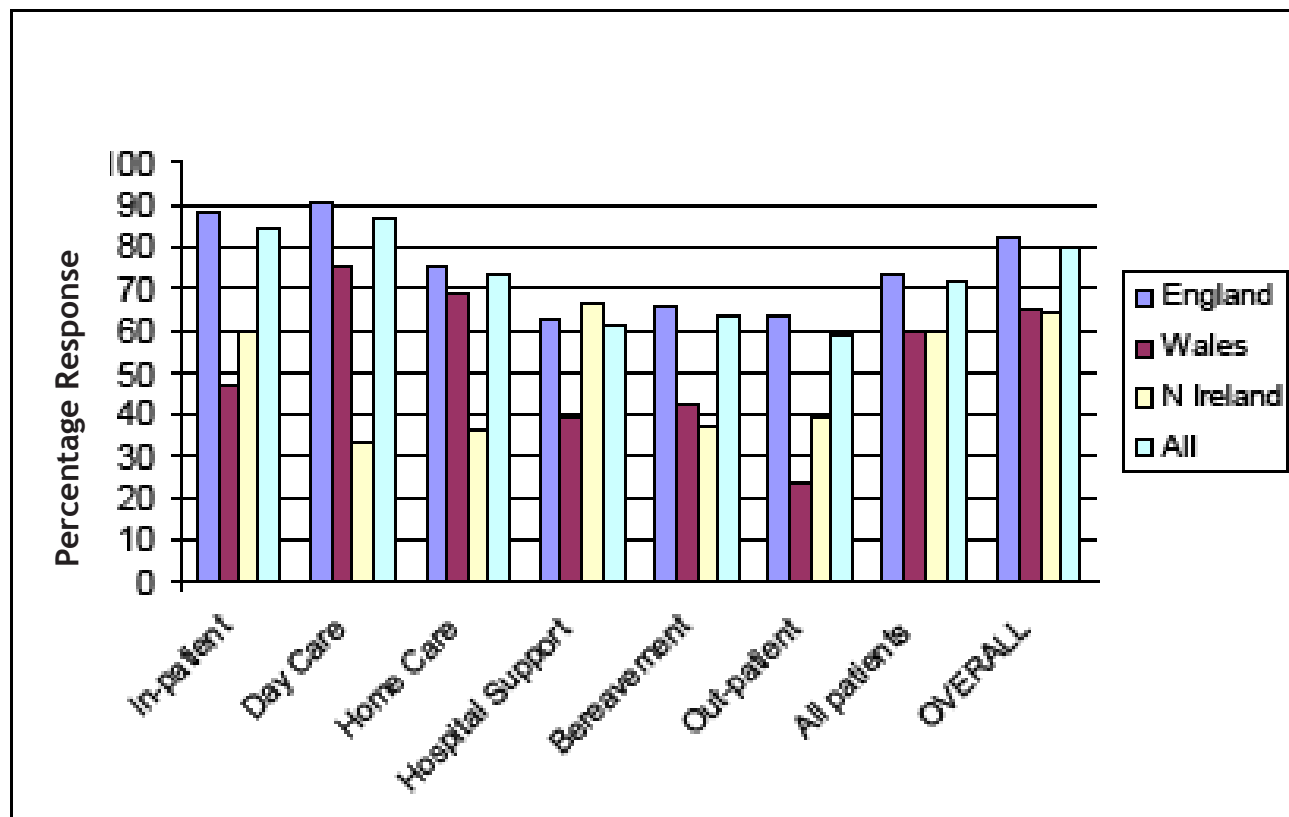


Chart 1 Response rates by country 2006/07

1. INPATIENT SERVICES

Data was collected from those services which provided a specialist palliative care inpatient service during 2006 to 2007, primarily to adults in a dedicated specialist palliative care unit in England, Wales or Northern Ireland. Designated specialist 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 189 units with 2782 beds, the bed numbers (unless advised otherwise) being those quoted in the 2007 Directory of Hospice and Palliative Care Services. The units varied in size from 2 to 48 beds, (there were 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 158 units, an 84% response rate, although some respondents did not answer all the questions. The response rate to individual questions does therefore vary from 84% and there was a

slight drop from the 87% response rate of the previous year. The response rate from independent units was 86%, while for the NHS units it was 78%.

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 0.4% under 25. Ten per cent were over 84. Excluding the patients with a 'not known' diagnosis, 7.2% patients had a diagnosis other than cancer. This included 67 patients (0.2%) with HIV/AIDS. The range of percentages of non-cancer patients in the different units ranged from 0% to 38%. A total of 28 units (20% of responding units) had over 10% non-cancer patients while 9 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.

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	256	155 / 2,405 (82% response)	34,660 new patients 39,707 total patients
	New patients as % of all patients	87%		
	Range of above	48%-100%		
Age of patients	Under 25	0.4%	151 / 2,321	33,391
	Under 65	32%		
	65 to 74	28%		
	75 to 84	30%		
	Over 84	10%		
Diagnosis	Cancer	92.8%	142 / 2,218	31,506
	Non-cancer	7.2%		
	HIV/AIDS	0.1%		
	Range of % of non-cancer in each unit	0-38%		
Location before first admission	Home	69%	144 / 2,265	32,813
	Hospital	28%		

Table 2 Inpatient services - new patients

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 8% with three outliers of 14%, 39% and 74%. If these latter three are ignored the overall percentage of day case admissions drops from 1.9% to 0.5%. More than a quarter of admissions were repeat admissions with a range between 0% and 59% apart from the unit with a large number of day cases where there were 75% repeat admissions. Just over half the admissions ended in death with a range from 9% to 94%. By far the majority of discharges (85%) were to a

patient's own home, with 5% to hospital, and others to care homes both nursing and personal care homes, or other types of care.

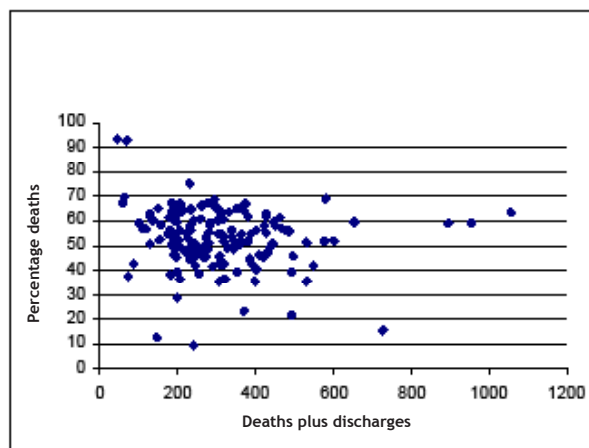


Chart 2 Inpatient deaths as a percentage of deaths plus discharges

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	304	158 / 2,440 (83% response)	48,027
	Range of admissions per unit	47 to 1055		
Day cases	Day cases as % of admissions	1.9%	139 / 2,226	43,119
	Range of % per unit	0% to 79%		
Admission type	Repeat admissions as % of all admissions	26%	148 / 2,303	45,296
	Range of % per unit	0% to 75%		
Admission outcome	Deaths	52.2%	148 / 2,334	45,826
	Range of % per unit	9% to 94%		
	Discharge to own home	41%		
	Discharge to hospital	3%		
Mean length of stay	Mean	12.9 days	145 / 2,254	43,472
	Range of above	6 to 47		
	Median of means	12.05 days		
Length of stay	Under 1 day	2.9%	145 / 2,254	43,472
	1 to 7 days	41.3%		
	8 to 14 days	25.8%		
	15 to 21 days	13.3%		
	Over 21 days	16.6%		

Table 3 Analysis of admissions and outcomes

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