



## **Briefing on key findings from an analysis of member hospice Minimum Data Set returns, 2004-2008**

Over the past few months, Help the Hospices has been analysing the data from member hospice MDS returns for the five year period 2004 – 2008. This exercise is an important element in delivering on our strategic objective to help build the evidence base for hospice care.

This briefing provides an early summary of the key findings, and gives an outline of the next steps that will be taken to progress this work. A summary of some of the headline data is included as an appendix to this briefing.

### **About the Minimum Data Set**

The Minimum Data Set was established in 1995 by the National Council for Palliative Care to obtain comprehensive high quality annual data from specialist palliative care providers in England, Wales and Northern Ireland. Questionnaires are sent annually to providers of specialist palliative care. Up to and including the 2008 data collection, the questionnaires were divided in to seven sections – inpatient, day care, home care, hospital support, bereavement support, outpatients, and all patients.

Each year, NCPC produces a Full Report on that year's findings providing statistics on the services provided and activities of specialist palliative care providers in that year.

### **About our analysis**

Help the Hospices has undertaken a secondary analysis of the MDS data from member hospices in England, Wales and Northern Ireland covering the five year period from 2004 to 2008 in order to obtain better information on trends among member hospices.

### **Limitations of the analysis**

There are limitations to the analysis which must be taken in to account when reading the final report. Principal among these is the issue of response rates. Although on the whole, there are an increasing number of hospices completing the MDS returns, response rates for individual sections do vary considerably. Small increases may therefore simply be the result of different response rates.

In addition, the MDS survey does not include all Help the Hospices member hospices. Scottish hospices do not complete the MDS returns.

The surveys from 2004-2007 did not differentiate between general home care services and Hospice at Home services. The 2008 survey did include a separate Hospice at Home section, but this means that it is not yet possible to examine trends specifically in Hospice at Home services.

The 2009 survey was significantly different to previous years, meaning that future analysis of trends will be more difficult.

A full account of the limitations of the study will be included in the final report to be circulated.

## **Debunking the 4% myth**

It is often stated, by Government and others that '*only 4% of deaths occur in hospices*'. This, of course, is quite true when you look only at the exact place of death recorded on the death certificate (which is where that particular figure comes from).

From our analysis, when you look at the number of deaths occurring where the patient was being supported by hospice care, the figure is much higher at 8.72% of all deaths in England and Wales in 2008.

When you focus down on cancer deaths only (given that cancer continues to be the primary diagnosis of the majority of users of hospice care), the figure is even higher. The number of cancer deaths occurring where the patient was being supported by hospice care stood at 26.87% in 2008.

## **Where hospice patients die**

Governments around the UK have a policy priority to support more people in or near to their own home. In England and Wales, almost 70% of deaths occur in hospital settings. The English NHS is now able to select a specific measure of the proportion of people dying in their own homes as one of the optional indicators for the Vital Signs.

Our analysis shows that the proportion of hospice deaths occurring in a hospice inpatient unit has fallen over the past five years, from 41% of all hospice deaths in 2004 to 36% in 2008.

At the same time, the proportion of hospice deaths occurring in a patients own home has increased from 28.8% in 2004 to 32.8% in 2008.

This seems to suggest that patients supported by a hospice have a greater likelihood of subsequently dying in their own home, although further research is needed to establish whether hospice patients are more likely to die in their own preferred place of death.

## **The changing nature of hospice service users**

There have been questions posed in the past about whether hospices are reaching out to the oldest old. The analysis shows that while the majority (92%) of hospice patients and service users are aged under 84, there has been an increase over the past five years in the proportion of people over the age of 84 being supported by hospice care. All services now show an increase over the five year period in the proportion of people aged over 84 being supported. The service with the highest proportion of people aged over 84 being supported is home care, which has also shown the biggest increase over the five year period.

A large majority of patients being supported by hospice care have a primary diagnosis of cancer. The service with the highest proportion of people with a cancer diagnosis was inpatient care (an average of 91.53% over the five year period). However, the proportion of patients with a cancer diagnosis is observed to be changing. On average, the proportion

of hospice patients and service users with a primary cancer diagnosis has fallen by between 2.5% and 5% over the five year period.

## **Growth in the care provided by hospices**

The total number of people using each type of hospice service covered by the MDS surveys has increased over the past five years. The largest increase was observed in the number of people using home care services (up 58% between 2004 and 2008). The smallest increase was observed in the number of people using day care services (up 3.5% between 2004 and 2008).

## **Signposting future research needs**

While this secondary analysis of the hospice MDS data provides some valuable and useful information on trends in hospice care provision, it also highlights areas in which further research is needed.

For example, the analysis clearly demonstrates that the majority of hospice patients and service users are of a White British ethnicity. It also suggests that the proportion of non-white hospice patients and service users is increasing, but the limitations of the MDS data, and the large number of returns where ethnicity data was not collected, mean that it is impossible to draw any conclusions on the diversity of hospice patients and service users from the analysis.

## **Next steps**

A full write up of the analysis of the MDS data will be produced in the coming weeks, which will be circulated to member hospices via Executive News Online, and made available on the Help the Hospices website. That report will provide more detailed analysis of the data, and much more information on the trends in each of the service areas covered by the MDS surveys in the period 2004-2008.

We will also be exploring ways in which to promote the findings with government at national, regional and local level, with the academic community, and with other stakeholders. More information to follow in due course.

## **Acknowledgements**

The secondary analysis of the hospice MDS data was undertaken by Lauren Limb. Help the Hospices expresses its thanks to the National Council for Palliative Care for sharing the data with us. We also extend our thanks to Sheila Payne, Professor of Hospice Studies at Lancaster University, for her advice and guidance.

## **For more information**

If you have any specific questions about the analysis, or want more information on the findings, or the next steps that we will take, please contact Jonathan Ellis, Director of Public Policy & Parliamentary Affairs by emailing [j.ellis@helpthehospices.org.uk](mailto:j.ellis@helpthehospices.org.uk), or by calling 020 7520 8894.

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## **Appendix: Headline findings from the analysis of hospice MDS returns.**

### **Use of hospice care services**

- Almost 9% of deaths in England and Wales in 2008 involved hospice care
- The number of patients and their families using hospice services is increasing.
- Almost 100,000 patients and their families used hospice services in 2008 – an increase of 15% since 2004.
- 25,000 family members in the UK received bereavement support from hospices in 2008

### **Hospice care at home**

- Hospices are caring for an increasing number of patients in their own home. In 2008 over 73,000 patients were cared for in their own home by hospices – an increase of 58% in the last five years.
- Hospices are providing more home care visits. There were 350,000 home care visits in 2008 – an increase of 49% in the last five years.
- The majority of home care visits are carried out by a palliative care nurse specialist

### **Hospice beds**

- A typical in-patient will stay in the hospice between one to seven days
- 40% of hospice inpatients have their care transferred their own home
- 72% of hospice inpatients were in their own home prior to admission
- 25% of hospice inpatients were in a NHS hospital prior to admission

### **Out-patient clinics and day care**

- A typical day care patient will attend the hospice for over 6 months
- Hospices are offering an increasing amount of outpatient clinics for people with terminal illness. Outpatient clinics have increased by nearly 40% in the last five years, seeing more people for specialist support for pain and symptom control.

### **Support for families**

- Hospice support for bereaved people has increased. In the last five years, the number of support sessions for families has risen by 40%.
- An average hospice in England, Wales and Northern Ireland will see about 260 people for bereavement support each year. This support most commonly takes the form of individual counselling and is on the increase.
- Around a third of those undertaking this work are paid-for counsellors and a third are fully trained volunteers. The number of trained volunteers supporting this area is increasing.