National Survey of Patient Activity Data for Specialist Palliative Care Services

About the National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland.

Our vision is that everyone who has palliative care needs or is approaching the end of life, dying or bereaved should receive the high quality care and support they need, where and when they need it. We promote the extension and improvement of palliative care services for all people with life threatening and life-limiting conditions and promote palliative care in health and social care settings across all sectors to government, national and local policy makers. For further information or to subscribe to NCPC visit www.ncpc.org.uk

About The National End of Life Care Intelligence Network

The National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN) to improve the collection and analysis of national data about end of life care for adults in England.

This is with the aim of helping the NHS and its partners commission and deliver high quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. Established in 2010, NEoLCIN plays a vital role in supporting the comprehensive implementation of the strategy. On 1st April 2013 NEoLCIN became part of Public Health England, an executive agency of the Department of Health.

The NEoLCIN website is www.endoflifecare-intelligence.org.uk
Public Health England’s website is www.gov.uk/phe

About Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 220 member organisations that provide hospice care across the UK, so that they can deliver the highest quality care to people with terminal or life-limiting conditions and support their families.

Hospice UK supports the breadth, dynamism and flexibility of modern hospice care, by: influencing Government and decision makers; improving quality of care through the sharing of good practice; and providing resources, training, education and grant programmes.

We work collaboratively with our members to support their vital work and to create a stronger voice for hospice care in the UK. We also support the development of hospice and palliative care worldwide. Hospice UK’s website is www.hospiceuk.org

MDS Bereavement Support Trend Report 2014/15

Contents

Key findings .................................................................................................................................................. 4
Definition ..................................................................................................................................................... 4
Response rate ................................................................................................................................................ 5
Number of service users .............................................................................................................................. 6
Age of service users ........................................................................................................................................ 7
Sex .................................................................................................................................................................. 8
Ethnicity ........................................................................................................................................................ 9
Contacts ......................................................................................................................................................... 9
Length of support .......................................................................................................................................... 10
VOICES data ................................................................................................................................................. 11

• Note on figures: where possible, the number of organisations providing each data item in each year is
given on each graph. Different organisations return MDS data from year to year, and so any historical
trends presented here are subject to the caveat that the profile of services responding may be
different from year to year.

• Some data cleansing has been undertaken on historical data and the methodology used to assess
numbers of ‘not stated’ or ‘not recorded’ figures has been altered; consequently there are some
changes to figures that appear in previous reports.

• Not all services report on all items of data; consequently the total number of people accessing a
service varies from section to section of the report. Throughout the report, where services have
provided clearly anomalous data, they have been excluded from the analysis. All tables referenced are
available in the accompanying annex document.

• To help interpret graphs that show quartiles, it may be useful to think of it as: 25% of services are
below the blue line, 25% of services are above the red line, and 50% of services sit between the blue
and red lines.
Definition
A Bereavement Support service is provided to relatives, partners and carers of a deceased person and may include individual counselling, home visits, and group activities. Although similar emotional and psychosocial support is often provided to carers of people who are close to death, this dataset records after the death.

Bereavement Support services are organised with varying degrees of formality. Some are provided quite informally or integrated into the general pattern of services, while others have routine referral, assessment and discharge procedures. Services are encouraged to develop procedures to ensure that this important aspect of their workload is recorded.

Key findings
- Women continue to be more likely to access Bereavement Support than men, as far as can be assessed from incomplete demographic data.
- Incomplete data capture by respondents on age and ethnicity makes it difficult to assess any other characteristics of people who access Bereavement Support.
- Data from VOICES suggests that in fact, the likelihood someone will access bereavement support may be partially dependent on place of death, or rather that bereavement support is more likely to be offered in some settings than others.
Response rate

106 of 244 Bereavement Support services returned MDS data in 2013/14 representing a 43.4% response rate, down from 47% in the previous MDS reporting year.

This is consistently the section of the MDS with the poorest response rate, due to a number of possible factors:

- We believe the data is often held separately to patient data and so the form may not reach the person who should complete the return when it is often sent to a contact who is better able to complete the forms for other settings;
- The data asked for is not useful data for the sector so services see limited value in returning it;
- Bereavement services in hospitals are held on our database but may not provide the kind of support we ask about here. If they provide logistical support around funeral arrangements and signpost on to counselling services not specifically associated with specialist palliative care then the majority of their work is not captured by the MDS form and so they may not return it.

Work was undertaken to review the data captured on the Bereavement Support form in 2015, working alongside the Association of Bereavement Support Co-ordinators to ensure a new form would capture as much useful information as possible. Rollout of the new form is on hold until such time as the plans for a new national dataset are finalised. In 2016/17, work will be undertaken to try and improve the Bereavement Support response rate by contacting services for specific bereavement contacts.

Table 7a: response rates by type of organisation and type of management

<table>
<thead>
<tr>
<th>Year</th>
<th>Hospice</th>
<th>Hospital</th>
<th>Clinic</th>
<th>Community</th>
<th>Health Centre</th>
<th>Total services responding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Managed by NHS</td>
<td>Managed by Independent</td>
<td>Management not recorded</td>
<td>Managed by NHS</td>
<td>Managed by Independent</td>
<td>Management not recorded</td>
</tr>
<tr>
<td>2008/09</td>
<td>18</td>
<td>83</td>
<td>21</td>
<td>11</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>2009/10</td>
<td>16</td>
<td>90</td>
<td>15</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2010/11</td>
<td>16</td>
<td>93</td>
<td>16</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2011/12</td>
<td>13</td>
<td>109</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2012/13</td>
<td>9</td>
<td>106</td>
<td>10</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>2013/14</td>
<td>9</td>
<td>93</td>
<td>11</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2014/15</td>
<td>6</td>
<td>88</td>
<td>1</td>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Number of service users

There has been a decrease over time in the mean number of people seen per service, which is likely to be due to the decrease in response rates, particularly from larger services (as shown by the variation in the 3rd quartile of the data).

Figure 7.1: changes in the range of size of Bereavement Support services over time (Table 70)
**Age of service users**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not known</td>
<td>72.9%</td>
<td>55.8%</td>
<td>48.5%</td>
<td>46.4%</td>
<td>47.4%</td>
<td>33.5%</td>
<td>35.7%</td>
</tr>
<tr>
<td>85+</td>
<td>1.4%</td>
<td>2.6%</td>
<td>3.5%</td>
<td>2.9%</td>
<td>2.5%</td>
<td>3.2%</td>
<td>3.0%</td>
</tr>
<tr>
<td>75-84</td>
<td>4.0%</td>
<td>7.2%</td>
<td>8.6%</td>
<td>8.5%</td>
<td>7.3%</td>
<td>8.2%</td>
<td>7.6%</td>
</tr>
<tr>
<td>65-74</td>
<td>5.3%</td>
<td>8.7%</td>
<td>11.0%</td>
<td>10.7%</td>
<td>10.1%</td>
<td>12.5%</td>
<td>12.0%</td>
</tr>
<tr>
<td>25-64</td>
<td>12.4%</td>
<td>20.5%</td>
<td>22.3%</td>
<td>24.7%</td>
<td>25.3%</td>
<td>32.9%</td>
<td>33.2%</td>
</tr>
<tr>
<td>Under 25</td>
<td>4.0%</td>
<td>5.2%</td>
<td>6.1%</td>
<td>6.8%</td>
<td>7.4%</td>
<td>9.7%</td>
<td>8.6%</td>
</tr>
</tbody>
</table>

*Figure 7.2: proportion of different age groups accessing Bereavement Support services (Table 71)*

Bereavement Support is consistently the service with the greatest proportion of unrecorded demographic data, making it very difficult to assess trends in access over time by different age groups.
A clear majority of Bereavement Support clients are female and this has been true for all years of data collection. Data quality for this item has improved significantly in the last two years.

*Figure 7.3: proportion of men and women accessing Bereavement Support services (Table 72)*

Ethnicity

As Bereavement Support is the setting with by far the highest proportion of unrecorded ethnicity at 48.4%, it has commensurately low levels of recorded access for people of BAME origin. It is difficult to compare provision with prospective need, although we will look further into how this may be done using census data on the BAME population aged over 65 as a proxy measure for need.

Contacts

The range of services provided is consistent over time, with an increase in the proportion of individual support.

Figure 7.4: types of contacts recorded by Bereavement Support services (Table 75)

The range of services provided is consistent over time, with an increase in the proportion of individual support.

Length of support

Figure 7.5: length of support recorded by Bereavement Support services (Table 76)

There is a large amount of variation in the recorded length of support data, reflecting both the data quality of submissions received and the changes in services responding from year to year. Consequently, it is difficult to make any judgements about trends in this area, although it can be said that reasonably few people require support for over a year.
**VOICES data**

Data from VOICES\(^1\) suggests that in fact, the likelihood someone will access bereavement support may be partially dependent on place of death, or rather that bereavement support is more likely to be offered in some settings than others.

![Figure 7.6: VOICES data across all settings: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)](image)

For example, looking at overall statistics from VOICES for the past four years, around two thirds of bereaved people say they did not access bereavement support and would not have wanted to, while 18% of people say they would have liked to access bereavement support but did not. Around 14% of people both wanted to and were able to access some form of bereavement support. Yet breaking this down to setting level, these percentages vary significantly.

---

\(^1\) National survey of the bereaved (VOICES), ONS 2013.

Figure 7.7: VOICES data in each setting for 2014: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

The proportion of unmet need is greatest in a hospital setting, the setting in which the MDS received the fewest returns on bereavement services. The proportion of unmet need is smallest in the hospice setting but still present.

The National Council for Palliative Care
4th Floor
34-44 Britannia Street
London
WC1X 9JG
Tel: 020 7697 1520
Fax: 020 7697 1530
enquiries@ncpc.org.uk
www.ncpc.org.uk
Registered Charity no. 1005671
A company limited by guarantee no. 2644430
July 2016