National Survey of Patient Activity Data for Specialist Palliative Care Services

Minimum Data Set (MDS)
Inpatient Services Trend Report for 2014-15
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

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• 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.
Key findings

- The number of people accessing Inpatient services is increasing over time, even given variation in the number of services returning data to the MDS.
- The number of people of 85+ years who access Inpatient care is rising – from 10% in 2008 to 14% in 2014, still well below the proportion of 85 year olds dying in 2014 (39%).
- The proportion of people accessing Inpatient services who have a diagnosis other than cancer - especially chronic respiratory disease - is also increasing but people with cancer still account for a disproportionately high amount of Inpatient care.
- A higher proportion of Inpatient stays ended in death in 2014/15 (59%) than in 2008/09 (50%) with fewer being discharged home.
- 30% of patients are now being admitted to hospice inpatient beds from hospital – whereas in 2008 it was only 20%.

Definition

An inpatient is a person who is admitted and occupies a bed in the unit, not necessarily overnight. There are several types of inpatient admission:

- An ordinary inpatient is admitted with the intention of staying one or more nights in the unit
- A day case inpatient is admitted with a view to discharge the same day i.e. they do not stay overnight in the unit
- A regular inpatient is admitted as part of a planned series of short stays, usually of one day or one night each e.g. for pain control adjustment or respite care. A series of day admissions differs from Day Care in that a person occupies a bed while in the unit
- An ordinary inpatient who does not actually occupy a bed for one night is still counted as an ordinary inpatient e.g. an urgent admission who dies the same day
- Someone admitted as a day case who for any reason stays overnight becomes an ordinary inpatient, as does any regular inpatient who overstays the planned period of admission

Response rate

128 of 182 Inpatient services returned MDS data in 2014/15 representing a 70.3% response rate, down from 71.3% in the previous MDS reporting year.

Table 2a: Inpatients response rates by type of organisation and type of management

<table>
<thead>
<tr>
<th>Year</th>
<th>Hospice</th>
<th>Hospitals*</th>
<th>Trusts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Managed by NHS</td>
<td>Managed by Independent</td>
<td>Managed by NHS</td>
</tr>
<tr>
<td>2008/09</td>
<td>20</td>
<td>99</td>
<td>17</td>
</tr>
<tr>
<td>2009/10</td>
<td>17</td>
<td>106</td>
<td>16</td>
</tr>
<tr>
<td>2010/11</td>
<td>17</td>
<td>111</td>
<td>14</td>
</tr>
<tr>
<td>2011/12</td>
<td>16</td>
<td>110</td>
<td>13</td>
</tr>
<tr>
<td>2012/13</td>
<td>12</td>
<td>116</td>
<td>13</td>
</tr>
<tr>
<td>2013/14</td>
<td>12</td>
<td>104</td>
<td>12</td>
</tr>
<tr>
<td>2014/15</td>
<td>14</td>
<td>101</td>
<td>12</td>
</tr>
</tbody>
</table>

*It should be noted that even where responses appear to be from hospitals, it may be that the data return is carried out by a hospital on behalf of a hospice Inpatient unit.

Number of people seen

In total, 36,164 people were seen by 128 responding Inpatient services in 2014/15.

29,000 people were seen by independent hospices, and 7,164 were seen in NHS-managed units.

On average, each unit saw 283 people over the course of the reporting year.
Figure 2.1: changes in the range of size of Inpatient units over time (Table 12)

The mean number of people per unit accessing each Inpatient service is increasing over time, although the total reported number of patients varies from year to year due to varying response rates.
Age of patients

The proportion of people aged over 85 who access Inpatient services has increased over time, while the proportion of those aged 25-64 has decreased. However, as compared with the ages of those who died in 2014, older people are still accessing Inpatient care less than might be expected, while younger people have disproportionately high access. Please see the Summary Report for 2014-15 for further discussion on this.

*ONS data includes all deaths registered in 2014 in England and Wales excluding those from accidental causes, childbirth-related conditions and those of anyone aged under 14 years old.

Figure 2.2: proportion of different age groups accessing Inpatient care (Table 13)

Sex
The split in the sex of people accessing Inpatient services remains stable in each year, and is roughly equally split between men and women.

Diagnoses
The mean proportion of people accessing Inpatient services who have a cancer diagnosis has changed from 86.5 % in 2008/09 to 79.6 % in 2014/15. However, people with cancer are still over-represented in the data from Inpatient units compared with the proportion of people who die from cancer each year. ONS data for 2014 shows that, of people who died in a hospice, 88.9% died from a form of cancer – yet only 29.3% of all deaths registered in 2014 were due to cancer (31.4% once those under 14 and those due to external causes and childbirth are excluded).

*ONS data includes all deaths registered in 2014 in England and Wales excluding those from accidental causes, childbirth-related conditions and those of anyone aged under 14 years old.

Figure 2.3: proportion of people with different categories of primary diagnosis accessing Inpatient care (Table 15)

Data quality and reporting continues to be an issue; the increase in unrecorded diagnoses in 2014/15 is solely due to several services using SystmOne, a database that makes the extraction of diagnosis data in line with the MDS coding very difficult.
**Diagnosis breakdown: cancer**

There has been very little change in the proportions of people diagnosed with different cancers recorded by Inpatient services over the past 6 years, and the representation of each type of cancer seen by Inpatient services largely maps onto those recorded in the ONS death data for England and Wales.

**Diagnosis breakdown: diagnoses other than cancer**

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>All other non-cancer diagnoses</td>
<td>27.2%</td>
<td>26.8%</td>
<td>31.1%</td>
<td>25.4%</td>
<td>25.5%</td>
<td>28.4%</td>
<td>32.3%</td>
<td>26.7%</td>
</tr>
<tr>
<td>Chronic renal disease</td>
<td>3.7%</td>
<td>5.2%</td>
<td>5.4%</td>
<td>5.2%</td>
<td>4.5%</td>
<td>4.1%</td>
<td>4.4%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Chronic respiratory disorder</td>
<td>13.4%</td>
<td>18.6%</td>
<td>17.1%</td>
<td>20.2%</td>
<td>21.0%</td>
<td>22.5%</td>
<td>20.6%</td>
<td>9.6%</td>
</tr>
<tr>
<td>Other heart and circulatory conditions</td>
<td>7.2%</td>
<td>8.8%</td>
<td>7.2%</td>
<td>6.2%</td>
<td>6.7%</td>
<td>6.5%</td>
<td>6.4%</td>
<td>41.0%</td>
</tr>
<tr>
<td>Heart failure</td>
<td>8.0%</td>
<td>8.4%</td>
<td>9.5%</td>
<td>11.1%</td>
<td>10.6%</td>
<td>10.3%</td>
<td>10.9%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Dementia and Alzheimers</td>
<td>1.4%</td>
<td>3.7%</td>
<td>2.1%</td>
<td>3.3%</td>
<td>3.5%</td>
<td>3.8%</td>
<td>5.0%</td>
<td>16.1%</td>
</tr>
<tr>
<td>Neurological disorders excluding dementia</td>
<td>13.4%</td>
<td>14.5%</td>
<td>14.0%</td>
<td>14.9%</td>
<td>14.3%</td>
<td>12.6%</td>
<td>9.9%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Motor Neurone Disease</td>
<td>12.7%</td>
<td>14.0%</td>
<td>13.2%</td>
<td>11.9%</td>
<td>11.5%</td>
<td>11.4%</td>
<td>9.7%</td>
<td>0.6%</td>
</tr>
<tr>
<td>HIV or AIDS</td>
<td>0.2%</td>
<td>0.4%</td>
<td>0.4%</td>
<td>0.2%</td>
<td>0.5%</td>
<td>0.3%</td>
<td>0.5%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

*ONS data includes all deaths registered in 2014 in England and Wales excluding those from accidental causes, childbirth-related conditions and those of anyone aged under 14 years old.

**Figure 2.4: proportion of people with diagnoses other than cancer accessing Inpatient care (Table 17)**

*MDS Inpatient services trend report: 2014-2015*
Ethnicity

Since 2008/09, there has been very little change in the recorded proportion of BAME people who access Inpatient palliative care services.

Breaking the BAME data down further, it can be seen that a large proportion of people are being recorded as ‘Other’. Without consistently recorded ethnicity data, understanding issues about lack of access based on ethnicity will continue to be difficult. As ethnicity is not captured on death certificates, 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.

Figure 2.5: proportions of people accessing Inpatient care reported as white, BAME and not recorded (Table 18)
**Location at end of stay**

The proportion of Inpatient stays that end with death has risen by 8.9% from 2008/09 to 2014/15, while discharges to home have dropped by 5.6%.

![Figure 2.6: proportions of location of people at the end of completed Inpatient stays (Table 20)](image)

No one service is responsible for the trend in increasing numbers of Inpatient stays ending in death, therefore it is likely to reflect a change across the sector. However, it is unclear from the data available what the causes for that change might be. For example, it may be due to a change in how severe someone’s condition is by the time they are referred to an Inpatient unit with more people being able to have their symptoms managed at home and so being able to avoid an Inpatient referral altogether, or it may reflect difficulties in discharging before someone’s condition deteriorates too far to discharge. Further investigation is needed to understand what is driving this trend.
**Length of stay**
Length of stay data varies very little from year to year; the majority of people stay on an Inpatient unit for under two weeks, with around a quarter of people staying between 1 to 4 days.

Mean length of stay across all units remains steady at around 14.1 days in 2014/15.

**Location prior to admission**
A lower proportion of people are admitted to Inpatient units from their homes now than in 2008/09 although this is still by far the largest category. The proportion of people admitted from Acute Hospitals has increased which may reflect a change in service patterns that requires further investigation.

![Figure 2.7: location of person prior to admission to Inpatient unit (Table 22)](image-url)

*Figure 2.7: location of person prior to admission to Inpatient unit (Table 22)*

**MDS Inpatient services trend report: 2014-2015**
Bed availability

Available beds are all beds 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.

Bed availability is typically between 92% and 95%. In 2014/15, bed availability stood at 93.7%.

The mean available number of beds per unit was 16.3 in 2014/15, up from 14.5 in 2008/09 (Table 24), but this masks a large range in the size of units. The smallest Inpatient unit reporting in 2014/15 has 3 beds, while the largest has 51 beds.

Bed occupancy

Bed occupancy is calculated from a midnight count of the number of beds actually occupied (or reserved for someone temporarily away) as a percentage of available beds.

- An occupied bed has someone in it, alive or dead.
- A reserved bed is being kept for a patient temporarily away. This category should not be used for a bed which is being kept empty because of a planned admission or because someone has recently died.
- An unoccupied bed is a bed which is empty whatever the reason, except for those few (if any) beds being kept because a patient has temporarily gone home.

The average national occupancy rate (occupied bed days plus reserved bed days, divided by available bed days) for Inpatient units was 78.6% in 2014/15.
Looking at the historical occupancy rate, most services cluster around the mean. The majority of services report occupancy rates of between 71-90%. The lowest occupancy rate reported in 2014/15 was 44%, and the highest was 98%.
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