SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 1: Variation in the proportion of all people who died who were aged 75 years and older by CCG (2015)
Introduction

The proportion of people who die aged 75 years and older varies from about half to just over three-quarters. This means that CCGs face quite different challenges in terms of palliative and end of life care dependent on the age profile of their population. For those CCGs in the middle of the range the differences between them is widening. CCGs with large elderly populations need to particularly focus on the provision of good end of life care in care homes and in the community and look at the quality of care for elderly patients dying in hospitals.

Trends and magnitude of variation

In 2015 the value for England was 69.2% with a variation between 51.7% and 77.8% by CCG. The box plot shows the distribution of CCG values for the period 2006 to 2015 calendar years. The 75th to 25th percentile gap widened significantly. The CCG median increased significantly from 65.9% in 2006 to 68.9% in 2015.

Local considerations

Commissioners and providers are advised to consider how the age profile at death impacts on need for care including cause of death (maps 4 to 9) and place of death (maps 11, 20, 23 and 24). Maps 24 to 29 give insight into the geographical variation in the role played by care homes at the end of life, especially for older people, many with multimorbidity. In addition, commissioners should review community based social care services.
SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 2: Variation in the proportion of adults who are aged 65 years or older and who are living alone by lower tier local authority (2011)

Equal-sized quintiles by value

- Highest 40.97 - 45.02 (6)
- 36.91 - 40.96 (16)
- 32.86 - 36.90 (61)
- 28.80 - 32.85 (161)
- Lowest 24.74 - 28.79 (80)
- No data (2)

Significance level compared with England

- Significantly higher than England (99.8%) (97)
- Significantly higher than England (95.0%) (10)
- Not significantly different from England (44)
- Significantly lower than England (95.0%) (11)
- Significantly lower than England (99.8%) (162)
- No data (2)
Introduction

This indicator gives insight into the local authority areas with the highest proportion of people aged 65 years or older who are living alone showing that this ranges from a quarter to almost a half. The most recent data is from the 2011 Census. Understanding how many elderly people live alone is important as they may have greater need for social care as well as healthcare as they approach the end of life. Living alone not only presents care challenges but also loneliness which impacts on people’s wellbeing especially at the end of their life. A number of recent research reports identify loneliness as a major factor for older people.\textsuperscript{1, 2, 3}

Interestingly, it is parts of London and the north-west and East that have among the highest proportions of people aged 65 or older who are living alone but there are small pockets throughout the country and this emphasises the need to understand local data.

Magnitude of variation

In 2011 the value in England was 31.5\% with a variation between 24.7\% and 45.0\% by local authority which is a 1.8-fold difference. The box plot shows the distribution of local authority values for the 2011 calendar year and a local authority median of 30.5\%.

Local considerations

Commissioners and providers should review this map and underlying data to examine the relationship between living alone and care home and nursing home bed rates (maps 26 and 27). They should also consider their local community health and social care service provision and the opportunities presented by social prescribing.\textsuperscript{4}
SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 3: Variation in the proportion of the population aged 16 years or older who are unpaid carers by CCG (2011)

Equal-sized quintiles by value

<table>
<thead>
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<th></th>
<th>Highest</th>
<th>13.94 - 15.51</th>
<th>(29)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>12.37</td>
<td>12.93</td>
<td>(95)</td>
</tr>
<tr>
<td></td>
<td>10.79</td>
<td>12.36</td>
<td>(53)</td>
</tr>
<tr>
<td></td>
<td>9.22</td>
<td>10.78</td>
<td>(20)</td>
</tr>
<tr>
<td>Lowest</td>
<td>7.63</td>
<td>9.21</td>
<td>(12)</td>
</tr>
</tbody>
</table>

Significance level compared with England

- Significantly higher than England (99.8%) (109)
- Significantly higher than England (95.0%) (5)
- Not significantly different from England (19)
- Significantly lower than England (95.0%) (2)
- Significantly lower than England (99.8%) (74)
Variation in the proportion of the population aged 16 years or older who are unpaid carers by CCG (2011)

Magnitude of variation

In 2011 the England value was 12.4% with a variation between 7.6% and 15.5% by CCG, which is a 2.0-fold difference. The box plot shows the distribution of CCG values for the 2011 calendar year and a local authority median of 12.7%.

Local considerations

Commissioners and providers should review this map and underlying data in combination data on the proportion of people who died at home (map 23). They should also look at their local policies, plans and budgets to support carers including service provision of bereavement services and the referral of carers for carer’s assessments3.

Introduction

The data in this indicator comes from the 2011 Census. While it does not relate directly to end of life care it gives an indication of the variation in the proportion of adult carers engaged in unpaid caring. Much of this care will be at home and for frail elderly people at the end of their life. While many of these unpaid carers and those they are caring for receive support from the NHS and social care it is important to ensure the carers, themselves, receive adequate support and care.

Seventy per cent of carers come into contact with health professionals yet health professionals only identify one in 10 carers and GPs identify 7%1. Sixty-six per cent of carers feel that healthcare staff do not help to signpost them to relevant information or support, and when information is given, it tends to come from charities and support groups2.
SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 4: Variation in the proportion of all people who died with an underlying cause of cancer by CCG (2015)

Equal-sized quintiles by value

- Highest 29.85 - 31.58 (18)
- 28.12 - 29.84 (53)
- 26.38 - 28.11 (91)
- 24.65 - 26.37 (44)
- Lowest 22.90 - 24.64 (3)

Significance level compared with England

- Significantly higher than England (99.8%) (5)
- Significantly higher than England (95.0%) (13)
- Not significantly different from England (172)
- Significantly lower than England (95.0%) (17)
- Significantly lower than England (99.8%) (2)
Introduction

Cancer is the disease group that accounts for the greatest proportion of deaths in England. Patients dying of cancer often have a more predictable end of life trajectory than patients with other conditions, which can facilitate end of life planning. Cancer site-specific NICE guidance\(^1\) emphasises the importance of involving specialist palliative care in decision making for patients with advanced cancer. However, there are documented inequalities in access to specialist palliative care advice\(^2\)\(^3\). A lower proportion of cancer patients die in hospital compared to patients from other major disease groups. There has been a decline in the proportion of cancer patients dying in hospital over the past decade, with a reciprocal increase in deaths at home and in care homes (figure 11 in the Introduction). Cancer patients still make up the majority of patients who die in hospice inpatient units (map 21), and hospices support many more people with cancer to die at home.

Trends and magnitude of variation

One in 4 deaths (27.4%) in England in 2015 had cancer as an underlying cause, with a variation of between 1 in 5 (22.9%) and 1 in 3 deaths (31.6%) by CCG, a 1.4-fold difference. The CCG median was 27.5% in 2015, there has been no significant change in the CCG median between 2006 and 2015.

Local considerations

Commissioners and providers should review this map and underlying data in combination with maps 18, 20 and 21, the End of life care profiles\(^4\) on place of death and underlying cause of death and local data on provision of general and specialist palliative care services including out of hours.
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Map 5: Variation in the proportion of all people who died with an underlying or contributory cause of dementia by CCG (2015)
**Introduction**

People with dementia tend to have a prolonged period of dependency for months to years, with high care needs and an unpredictable end of life trajectory. Dementia policy and guidelines recommend offering early and ongoing opportunities for advance care planning for people living with dementia and those involved in their care, and offering flexible palliative care that takes into account the unpredictable disease progression\(^1\)\(^2\). People with dementia are more likely to die in nursing homes than patients dying of other disease groups\(^3\), and particularly benefit from being cared for in a familiar environment. NICE guideline NG97 makes recommendations on how to assess the balance of benefits and harms before admitting patients with severe dementia to hospital\(^4\). The Nuffield Council on Bioethics highlight the ethical considerations in care\(^4\).

**Trends and magnitude of variation**

On average 1 in 6 deaths (17.5%) in England had dementia as an underlying or contributory cause, with a variation of between 1 in 8 (12.3%) and 1 in 4 (23.8%) by CCG, a 1.9-fold difference. The median by CCG increased significantly from 8.2% in 2006 to 17.2% in 2015 as did all the measures of the range of values. The increasing median is in part due to the aging population, although improved diagnosis and recording of dementia is likely to have contributed.

**Local considerations**

This map should be reviewed in combination with data on deaths aged 75 years (map 1) and data on care homes (maps 24 to 29). Other resources include: the End of life care profiles\(^5\), Dementia profiles\(^3\), and local data on primary care assessments of the palliative care needs of people in the later stages of dementia (NICE QS1)\(^6\).
SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 6: Variation in the proportion of all people who died with an underlying cause of chronic heart disease by CCG (2015)

Equal-sized quintiles by value

- Highest: 18.96 - 21.68 (2)
- 16.22 - 18.95 (4)
- 13.49 - 16.21 (11)
- 10.75 - 13.48 (99)
- Lowest: 8.00 - 10.74 (93)

Significance level compared with England

- Significantly higher than England (99.8%) (17)
- Significantly higher than England (95.0%) (12)
- Not significantly different from England (142)
- Significantly lower than England (95.0%) (24)
- Significantly lower than England (99.8%) (14)
Introduction

One in 10 people in England die from chronic heart disease (CHD), including end stage heart failure, and these patients may have a high symptom burden towards the end of life. Those with CHD often have an unpredictable disease trajectory, which can make end of life planning difficult. They tend not to consider that their condition may be life-limiting despite their considerable symptom burden\(^1\). Patients with CHD can benefit considerably from generalist and specialist palliative care\(^2\)\(^3\)\(^4\)\(^5\), and this can reduce hospitalisation near the end of life\(^6\). NICE draft heart failure guidelines recommend assessing palliative care needs of patients with heart failure when symptoms are worsening despite optimal specialist treatment, rather than on the basis of prognostic risk tools\(^7\). It is also important that healthcare professionals initiate advance care planning discussions around deactivation of implantable cardiac defibrillators (ICDs) at an appropriate time\(^8\).

Trends and magnitude of variation

One in 10 deaths (11.2 %) in England had CHD as an underlying cause in 2015, with a variation of between 1 in 13 (8.0%) and 1 in 5 (21.7 %) by CCG, a 2.7-fold difference. There has been a significant decrease in the median by CCG from 12.6% in 2006 to 11.0% in 2015 and a narrowing in the 75\(^{th}\) to 25\(^{th}\) percentile range.

Local considerations

Commissioners and providers should review this map and underlying data in combination with data on place of death (maps 11, 20, 23 and 24) and local data on integrated heart failure/palliative care services and access to palliative care services for patients with CHD. PHE produces resources to support local planning\(^9\).
SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 7: Variation in the proportion of all people who died with an underlying or contributory cause of chronic obstructive pulmonary disease (COPD) by CCG (2015)

Equal-sized quintiles by value

- Highest: 15.81 - 18.13 (6)
- 13.49 - 15.80 (26)
- 11.16 - 13.48 (54)
- 8.84 - 11.15 (80)
- Lowest: 6.51 - 8.83 (43)

Significance level compared with England

- Significantly higher than England (99.8%) (39)
- Significantly higher than England (95.0%) (19)
- Not significantly different from England (93)
- Significantly lower than England (95.0%) (21)
- Significantly lower than England (99.8%) (37)
Introduction

One in 10 people die in England with a mention of COPD as either the underlying or a contributory cause to their death. They often have an unpredictable disease trajectory, which can make end of life planning difficult. Patients with end-stage COPD have a very high symptom burden, with physical and psychosocial needs\(^1\), and patients with advanced COPD benefit from generalist and specialist palliative care\(^2,3,4,5\).

The majority of patients with COPD die in hospital, with only a small reduction in hospital deaths over the past decade. Comorbidities and deprivation increase the chances of a hospital death\(^6\).

Trends and magnitude of variation

One in 10 deaths (10.7%) in England had COPD as an underlying or contributory cause in 2015, with a variation of between 1 in 15 (6.5%) and 1 in 6 (18.1%) by CCG, a 2.8-fold difference. There has been a small but statistically significant increase in the median value by CCG over the past decade (from 8.0% in 2006 to 10.7% in 2015), and all the measures of the range of CCG values widened.

Local considerations

Commissioners and providers should review this map and underlying data in combination with the place of death maps (11, 20, 22, 23 and 24). They should also look at local data on integrated COPD/palliative care services and access to palliative care services for patients with COPD. PHE’s INHALE profile\(^7\) provides data on prevalence and quality of care for patients with COPD.
SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 8: Variation in the proportion of people who died with an underlying cause of stroke by CCG (2015)

Equal-sized quintiles by value

- Highest: 9.57 - 10.86 (1)
- 8.26 - 9.56 (8)
- 6.96 - 8.25 (54)
- 5.66 - 6.95 (115)
- Lowest: 4.34 - 5.65 (31)

Significance level compared with England

- Significantly higher than England (99.8%) (11)
- Significantly higher than England (95.0%) (13)
- Not significantly different from England (161)
- Significantly lower than England (95.0%) (18)
- Significantly lower than England (99.8%) (6)
Introduction

National guidelines recognise that high quality end of life care is a core activity for all multi-disciplinary stroke teams. Acute stroke patients have a high prevalence of palliative care needs. Patients who survive acute stroke with life-limiting disability have a variable and often unpredictable period of dependency and high care needs before dying, often in a care home. However, a low proportion of people with stroke are identified for end of life care in hospital and community settings. Guidelines recommend that commissioners ensure they include the whole stroke pathway from prevention to palliative care.

Trends and magnitude of variation

One in 15 deaths (6.6%) in England had stroke as the underlying cause in 2015, with a variation of between 1 in 23 (4.3%) and 1 in 9 (10.9%) by CCG, a 2.5-fold difference. The median value by CCG decreased significantly from 8.7% in 2006 to 6.5% in 2015, and two measures of the variation in values across CCGs (95th to 5th percentile and 75th to 25th percentile) narrowed. This is likely to reflect reductions in mortality from stroke due to public health campaigns leading to earlier recognition, diagnosis and treatment in hospital.

Local considerations

Commissioners and providers should review this map and underlying data in combination with maps 1, 10, 15 to 18 and 25, and local data on palliative care and rehabilitation services for stroke patients. Indicators on stroke prevalence, treatment and hospital admissions are available in the Cardiovascular disease profiles. Data is also available on brain imaging for stroke patients.
SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 9: Variation in the proportion of all people who died with an underlying cause of liver disease by CCG (2015)

Equal-sized quintiles by value

- Highest: 3.86 - 4.52 (6)
- 3.19 - 3.85 (26)
- 2.52 - 3.18 (60)
- 1.85 - 2.51 (92)
- Lowest: 1.17 - 1.84 (25)

Significance level compared with England

- Significantly higher than England (99.8%) (14)
- Significantly higher than England (95.0%) (21)
- Not significantly different from England (148)
- Significantly lower than England (95.0%) (21)
- Significantly lower than England (99.8%) (5)
Introduction

Deaths from liver disease as the underlying cause continue to increase in England, whereas they are decreasing in many other European countries\(^1\).

Palliative and end of life care for patients with liver disease can be particularly challenging as most people who die from liver disease are young (71% are under 75 years), the prognosis in advanced liver disease can be very uncertain, there is a high symptom burden, and patients may face barriers to accessing care\(^2\). A high proportion (59.2%) of deaths from liver disease occurs in hospital, and patients with liver disease have a large number of hospital admissions in the last year of life. Patients with advanced liver disease may benefit from integration of active medical management of acute crises and palliative and supportive care\(^2\)\(^3\).

Trend and magnitude of variation

One in 40 deaths (2.4%) in England had liver disease as the underlying cause in 2015, with a variation of between 1 in 85 (1.2%) to 1 in 22 (4.5%) by CCG, a 3.9-fold difference. There was a significant increase in the median value by CCG from 2.0% in 2006 to 2.4% in 2015.

Local considerations

Commissioners and providers should review this map and underlying data in combination with hospital maps (11 to 18), the 2\(^{nd}\) Atlas of variation in risk factors and healthcare for liver disease in England\(^1\), Liver disease profiles\(^4\) and local data on the integration of palliative and social care services into local liver networks.
SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 10: Variation in the percentage change in the annual number of people dying between 2014 and 2030 by lower-tier local authority

Equal-sized quintiles of geographies

- Highest 27.05 - 36.22 (25)
- 17.86 - 27.04 (62)
- 8.68 - 17.85 (117)
- -0.50 - 8.67 (88)
- Lowest -9.70 - -0.51 (32)
- No data (2)

Significance level compared with England

- Significantly higher than England (99.8%) (67)
- Significantly higher than England (95.0%) (45)
- Not significantly different from England (146)
- Significantly lower than England (95.0%) (18)
- Significantly lower than England (99.8%) (48)
- No data (2)
ATLAS OF VARIATION FOR PALLIATIVE AND END OF LIFE CARE IN ENGLAND

Variation in the percentage change in the annual number of people dying between 2014 and 2030 by lower-tier local authority

Introduction

A recent article describing the need for palliative and end of life care across care settings predicted that at least 42% more people will need palliative care in England and Wales by 2040\(^1\).

This map shows the variation in projected percentage change in numbers of deaths between 2014 and 2030 by lower tier local authority. At a national level, the number of deaths are projected to increase over this period partly due to the ‘baby boomer’ population ageing. However, as can been seen from the data presented the percentage increase in numbers is not uniform. The actual numbers, which are important for service planning and commissioning are shown in Appendix 2 – projected deaths for 2030 at local authority level.

Magnitude of variation

The map, column chart and box plot display the projected percentage change in number of deaths between 2014 and 2030, for which local authority values ranged from -9.7% to 36.2%. The percentage change for England was 9.6% and the local authority median was 11.3%.

Local considerations

Commissioners and providers should review this map and the data provided alongside Appendix 1 – number of deaths and crude death rate by CCG (2016) and Appendix 2 – projected deaths for 2030 at lower tier local authority level.