

Protecting and improving the nation's health

The role of care homes in end of life care

Briefing 1 - Care home bed provision and potential end of life care need in people aged 75 or older in England

National End of Life Care Intelligence Network (NEoLCIN)

Introduction

This is the first of two briefings produced by the National End of Life Care Intelligence Network to describe the actual and potential role of care homes in provision of end of life care for people aged 75 years or over.

Care homes are becoming an increasingly important place for end of life care (EoLC) as the population ages because the weeks, months, and sometimes years before death are marked, for many, by physical and mental decline, frailty and increasing need for support and care. It is also recognised that for many people the acute hospital setting may not be the best place to provide end of life care.

In 2015, 493,498 people died in England of whom 111,738 (23%) died in a care home. The number of deaths in care homes has increased from 87,751 (20%) in 2011. Care homes are a major provider of end of life care.

105,099 permanent care home residents (all ages) died in 2015, 71% (74,634) of these died in a care home and 29% (30,465) died elsewhere, predominantly in hospital.

Key findings:

People aged 75 years or older account for 8% of the population of 54,786,327 (2015).

69% of deaths are in people aged 75 years or older (2015).

The population aged 75 years or older has increased from 4.1 million (2011) to 4.4 million (2015).

The number of deaths in people aged 75 years or older has increased by 13% (2011-2015).

In 2015/16 there were 462,035 care home beds in 16,765 care homes.

Care homes providing nursing care account for almost half of all care home beds (49%; 224,853 beds).

The number of beds in care homes has decreased (466,317 in 2012 to 462,035 in 2016). Nursing home beds have increased from 216,726 beds in 2012 to 224,853 in 2016.

PHE publications gateway number: 2017275

Published: September 2017

One third of people who died in care homes normally lived in their own home but were transferred to a care home, often via an acute admission to hospital, for their final care. In this briefing they are referred to as temporary residents.

Adding together deaths in care homes with permanent residents who die elsewhere, there are at least 142,203 people (29% of all deaths) in 2015 who were cared for in a care home shortly before death. This underestimates the end of life care role of care homes as there are temporary residents of care homes who died in hospital and are not included in this total.

This briefing focuses on people aged 75 or older because the majority of all deaths (69% in 2015) occur in this age group. The vast majority of people who die in a care home 102,953 (92%) were aged 75 or older. Of all those aged 75 or older at death 30% died in a care home and 38% have been cared for in a care home before death.

This briefing describes the variation in potential need for care home places and in particular for end of life care across England by Clinical Commissioning Groups (CCGs) and explores variation in capacity. It also highlights changes in care home bed capacity over recent years.

This is the first of a pair of briefings on the role of care homes in end of life care provision. The second one examines place and cause of death for permanent and temporary residents of care homes. These new briefings are part of a wider collection of products on the role of care homes in end of life care. These include:

- briefing 1 Care home bed provision and potential end of life care need in people aged 75 or older in England
- briefing 2 Place and cause of death for permanent and temporary residents of care homes
- three new indicators for local authorities and clinical commissioning groups which are included in the End of Life Care Profiles – care home bed rate, nursing home bed rate, temporary resident care home deaths
- a summary infographic on the data presented in these two data briefings
- results of a national survey of support to adult care homes in England: A specialist palliative care provider perspective
- care home briefing 1 and 2 slide set
- webinar recording and slide set 'A focus on end of life care in care homes'

For a wide range of other products on EoLC visit the National End of Life Care Intelligence Network website.

Methodology

Three data sources were used: ONS mid-year population estimates for CCGs 2011-2015, registered deaths (ONS mortality) 2011-2015, and a snapshot of care home bed availability from the Care Quality Commission (CQC) 2012-2016.

Eight indicators were identified and values calculated at CCG level. Five year data periods are used to ensure sufficient numbers for breakdown by CCGs. The 209 CCGs were ranked by and divided into five equal quintile groups of the values of the distributions which means that there are unequal numbers of CCGs in each group.

Two new exploratory measures have been developed - care home bed rate and nursing home bed rate. These rates show the number of care home beds (nursing and residential) or nursing home beds per 100 persons aged 75 years or older. More detailed data definitions can be found in the End of Life Care Profiles.

Results

End of life care need in older persons and care home capacity in 2015/16

In 2015 341,470 people aged 75 years and older died. Nearly a third of these, 102,953 (30%), died in a care home. However, a further 25,429 were resident in a care home but were transferred to hospital shortly before death and died there. Therefore at least 38% of people aged 75 and older were cared for in a care home before death. For the same period, 158,854 people aged 75 and older (including 23,056) transferred from care homes) died in hospital, 63, 865 died (19%) in their own home and 12,018 died (3.5%) in a hospice.

During a similar time period, 2015/16, there were 462,035 beds in 16,765 care homes registered in England.

Care home bed provision and potential end of life care need in people aged 75 or older in England. Of these:

- 224,853 beds were in 4,643 nursing homes
- 237,182 beds were in 12,122 residential homes

Trends in end of life care in care homes

To contextualise changes in end of life care need in the care home setting over the past five years we have presented data for the ageing population, trends in deaths in older persons, and nursing and residential care bed numbers (Figure 1).

- More older people the population aged 75 years or older increased from 4,137,496 in 2011 to 4,425,817 in 2015 (+7%)
- More deaths in older people deaths in people aged 75 years or older increased from 303,196 in 2011, to 341,470 in 2015 (+13%)
- More deaths in care homes deaths of people aged 75 or older in care homes increased from 80,647 in 2011 to 102,953 in 2015 (+28%)
- A higher proportion of deaths in people aged 75 years or older in care homes increased from 27% in 2011 to 30% in 2015
- Overall number of care home beds has decreased beds in care homes decreased from 466,317 in 2012 to 462,035 in 2016 (-1%)
- Nursing home beds have increased beds in nursing homes increased from 216,726 beds in 2012 to 224,853 in 2016 (+4%)
- Residential care home beds have decreased beds in residential homes decreased from 249,591 in 2012 to 237,182 in 2016, (-5%)

Since 2012 there are 1,045 fewer care homes in England, providing 4,282 fewer care beds. However, since 2012 there are 8,127 extra nursing home beds. Almost half (49%) of care home beds at 31 March 2016 were in homes registered to provide nursing care (2012, 46%). These changes are illustrated in Figure 1 below.



Figure 1: Number of beds in nursing and residential care homes, and proportion of all care home beds that are in care homes registered to provide nursing care, England 2012-2016

Note: The last 5 annual data points differ according to data set: population (ONS mid-year estimates for CCGs), 2011 to 2015; deaths (ONS mortality) 2011 to 2015, care home beds (CQC) 2012 to 2016.

Care home bed rates

From 2012 to 2016 the 'care home bed rate' reduced from 11.3 per 100 people aged 75 years or older in 2012 to 10.4 in 2016 (-7%). This is because over this period the number of care home beds have reduced by 4,282 but the population of people aged 75 or older has increased by 288,321.

Almost half of care beds (49%) are now in nursing homes. The number of beds in nursing homes has increased by 8,127 between 2012 and 2016. The nursing home bed rate in 2012 was 5.2 and in 2016 5.1 nursing home beds per 100 people aged 75 years or older. The nursing home bed rate has seen little change because despite the number of nursing home beds increasing in this period the population of people aged 75 or older has increased by 7%. The care home bed rate for residential homes also fell from 6.0 per 100 people aged 75 years and over in 2012 to 5.4 in 2016 (-11%). For this indicator the number of residential beds fell by 12,409 while the population aged 75 years or older increased by of 288,321.

Table 1 below shows that there was a difference between the care home bed rates, nursing home bed rates and residential home bed rates in London and elsewhere. In London the percentage reductions in the indicators between 2012 and 2016 were greater than in other parts of England. More detail on variation by CCGs is given below.

Table 1: Change in care home bed rate (care homes, nursing homes and residential homes), England, 2012-2016

Care home bed rate	2012	2016	Rate change	% change
Beds per 100 population aged 75 or older				
England				
Care homes	11.3	10.4	-0.8	-7.4
Nursing homes	5.2	5.1	-0.2	-3.0
Residential homes	6.0	5.4	-0.7	-11.2
London				
Care homes	9.1	8.0	-1.1	-12.1
Nursing homes	4.8	4.5	-0.3	-6.5
Residential homes	4.3	3.5	-0.8	-18.5
Elsewhere- not London				
Care homes	11.5	10.7	-0.8	-6.9
Nursing homes	5.3	5.1	-0.1	-2.6
Residential homes	6.2	5.6	-0.7	-10.6

Sources: Population; ONS Mid-Year Population estimates for CCGs; Deaths, ONS Mortality data; Care home beds; Care Quality Commission.

Note: The latest four years of data cover slightly different time periods as follows - ONS Mid-Year Population estimates for CCGs, 2011 to 2015; ONS Mortality data, 2011 to 2015; Care Quality Commission care home beds, 2012 to 2016.

Care homes and end of life care: A focus on variation

This section describes the eight indicators selected to demonstrate the degree of variation across CCGs in England. Maps 1 and 2, show potential need for care home places. Map 1 shows the variation in absolute numbers of people living who are aged 75 or older by CCG. These absolute numbers are useful for planning. Map 2 shows the variation in the proportion of the living population who are aged 75 or older. This map clearly shows that some CCG populations have a much greater proportion of elderly people than others and therefore will need to think about the distribution of health and social care budgets between population segments.

Maps 3 and 4 show need for end of life care tailored to older people aged 75 years or older, some of which could be provided in a care home setting. Map 3 shows variation in the absolute numbers of deaths in people aged 75 or older by CCG, this is useful for planning the resources needed. Map 4 shows the variation in proportion of deaths in people aged 75 years or older by CCG this helps to consider the balance between the needs of younger or older people nearing the end of life in terms of service design and resources needed.

Maps 5 and 6 give more insight into variation by CCGs, the role care homes play in providing end of life care and how the age distribution of the care home populations can vary. Map 5 shows variation in the proportion of all people who died age 75 years or older who died in a care home by CCG. This gives an indication of the magnitude of support from specialist and generalist EoLC which may be needed by care homes to provide optimal care. This may include direct advice and training of care home staff. At a local CCG level it is worth comparing deaths in care homes (all ages) with deaths at other locations such as own home, hospital and hospice. Map 6 shows variation in the proportion of people who died in a care home who were aged 75 years or older at death by CCG. The variation across England emphasises that the age profile of the care home population especially close to end of life varies and should be considered in planning.

Map 7 and 8 show the experimental indicators to allow comparison of care home bed provision rates. Map 7 shows variation in care home bed rate, i.e. the number of care home beds per 100 head of population aged 75 years or older by CCG. Map 8 shows variation in the nursing home bed rate, i.e. the number of nursing home beds per 100 head of population aged 75 years or older by CCG.

These maps and the underlying CCG data should be used at a local level to understand the role care homes and nursing homes in particular play in providing end of life care. This may be especially relevant in areas of low provision per 100 population aged 75 years or older and high proportion of deaths in hospital.

All eight indicators and their corresponding maps help to highlight potential variation in care home need, end of life care need and capacity for people aged 75 years or older across England.

Local stakeholders can interrogate the data further and create a more detailed understanding of their local circumstances using the End of Life Care Profiles.

Measures of potential need for care homes places and end of life care for people aged 75 years or older

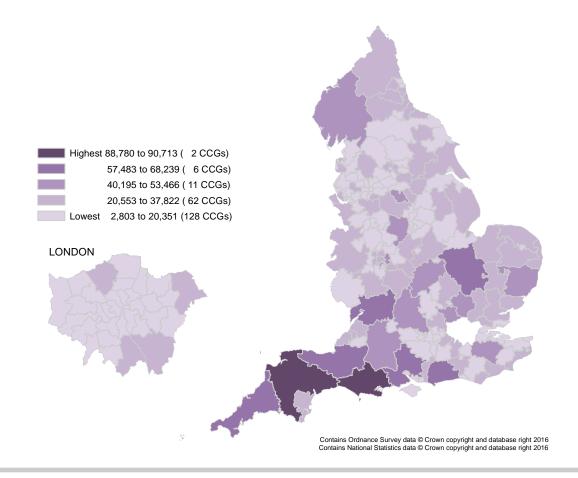
Map 1: Variation in absolute numbers of people living who are aged 75 years or older by CCG

The variation between CCGs in the size of the population aged 75 or older is illustrated in Map 1. In 2015 in England there were 4,425,817 people aged 75 or older. CCGs vary widely in population size and age structure so the number of people aged 75 or older varies.

The fifth of CCGs which had the smallest numbers had 11,681 or less and the fifth with the highest numbers had 27,204 people or more people aged 75 or older. (The minimum was 2,803, the maximum was 90,713).

The map shows the distribution of numbers split into fifths and from this there are two CCGs had over 88,780 and in comparison over a half of all CCGs had less than 20,351. The vast majority of CCGs have less than 40,000 people aged 75 years or older.

Map 1: Variation in absolute numbers of population aged 75 or older by CCG, 2015



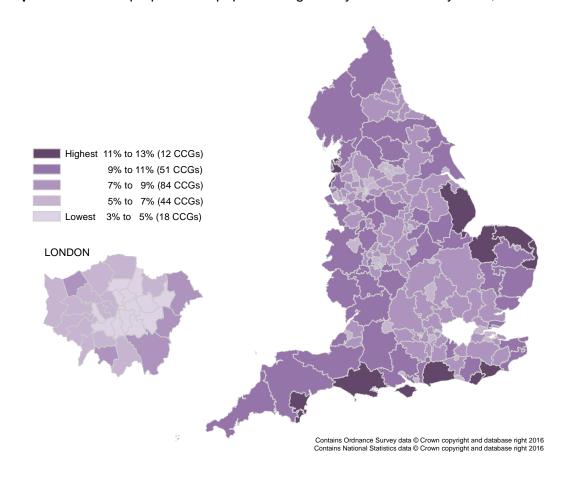
Map 2: Variation in the proportion of the living population who are aged 75 or older

The variation between CCGs in the proportion of their populations aged 75 or older is illustrated in Map 2. In 2015 8.1% of the population in England were aged 75 or older compared with 7.8% in 2011.

The fifth of CCGs with the lowest proportion had 6% or less and the fifth with the highest had 10% or more of the population aged 75 or older. (The minimum was 3%, the maximum was 13%).

When the distribution is divided into five equal ranges as shown in the map, 12 CCGs in the highest group have 11% or more of the population aged 75 or older. In the lowest group 18 CCGs have 5% or less of the population aged 75 or older.

Map 2: Variation in proportion of population aged 75 years or older by CCG, 2015



Indicators of potential need for end of life care for people aged 75 years or older

Not everyone who dies will need specialist palliative care and not everyone who dies will need end of life care as some people die unexpectedly. However, the majority of older people will experience several years of decline in physical and mental health function and will need increasing care and support. The needs of older adults in terms of specialist and generalist end of life care are less well understood than, for example, those of cancer patients. However, it is clear that at present very few have formal planning for end of life care. Advance Care Planning can help people, their families and health professionals achieve end of life care that the older person hopes for including place of care and place of death. Older people are likely to need a combination of support from health and social care services and possibly from family and voluntary organisations too. This section shows variation by CCGs in absolute numbers of deaths in people who died aged 75 years or older and in the proportion of deaths which occur in this age group. The absolute numbers are useful for service planning. The proportion gives insight into the balance of types of end of life care, support and of investment which will be required between population groups in a given area.

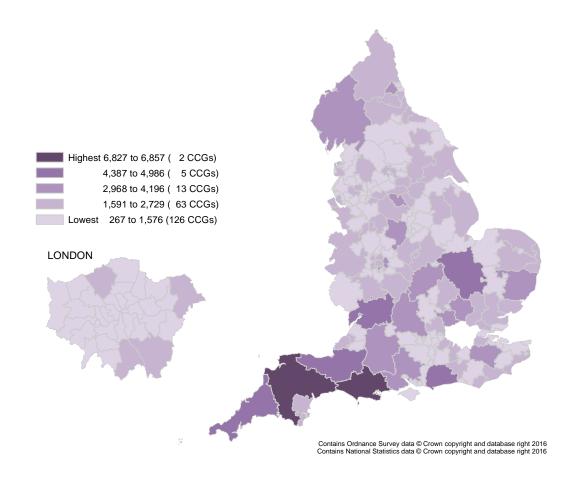
Map 3: Variation in absolute number of people who die aged people aged 75 years or older

The variation between CCGs in the number of deaths aged 75 or older is illustrated in Map 3. In 2015 in England, there were 341,470 deaths aged 75 or older. This was 69% of all deaths.

The fifth of CCGs with the lowest numbers of deaths of people aged 75 or older had 853 or fewer deaths, and the fifth with the highest numbers of deaths had 2,090 or more deaths. (The minimum was 267, the maximum was 6,857).

When the distribution is divided into five equal ranges, 2 groups (7 CCGs) have 4,387 or more deaths of those aged 75 or older. 126 CCGs have 1,576 deaths or fewer.

Map 3: Variation in absolute numbers of deaths aged 75 years or older by CCG, 2015



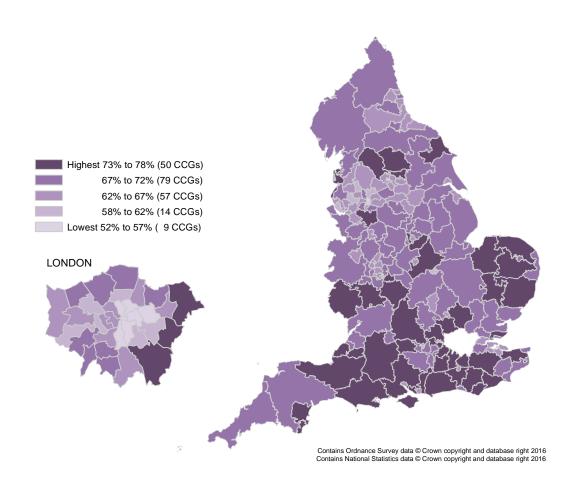
Map 4: Variation in the proportion of people who died aged 75 years or older by CCG

The variation between CCGs in the proportion of deaths aged 75 or older is illustrated in Map 4. In 2015 69% of deaths in England were in people aged 75 or older compared with 67% in 2011.

The fifth of CCGs with the lowest proportion had fewer than 64% and the fifth with the highest had 73% and more of deaths in people aged 75 or older. (The minimum was 52%, the maximum was 78%).

When the distribution of the indicator is divided into equal fifths, as shown in the map, it can be seen that only 23 CCGs have very low proportions in the lowest two fifths of the distribution (up to 62%), many of these CCGs are in London. In contrast, 50 CCGs have values in the highest fifth of the distribution (73% or more).

Map 4: Variation in proportion of deaths aged 75 years or older by CCG, 2015



Current levels of potential need for care for the dying in care homes for people aged 75 or older

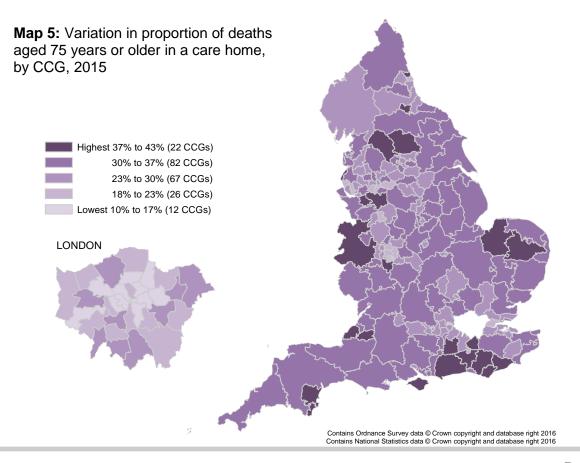
Map 5: Variation in proportion of deaths in people aged 75 or older who died in a care home by CCG

The variation between CCGs in the proportions of people aged 75 or older who died in a care home is illustrated in Map 5. In 2015 in England, nearly one third (30%) of deaths age 75 or older were in a care home compared with 27% in 2011.

The fifth of CCGs with the lowest proportion of deaths in people aged 75 or older had 24% or fewer and the highest fifth had 34% or greater. (The minimum was 10%, the maximum was 43%).

When the distribution of the indicator is divided into fifths, as shown in the map, 12 CCGs have very low proportions (17% or less, the lowest fifth) of people aged 75 or over dying in care homes. In contrast, 22 CCGs had the highest fifth of proportions (37% or more).

These differences reflect not only the underlying demographic of the populations of the CCGs but also variation in levels of care home provision which will be shown below.



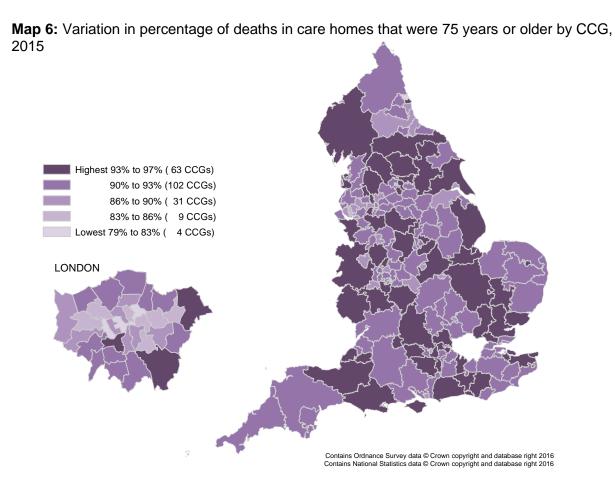
Indicators of care home provision

Map 6: Variation in proportion of people who died in care homes who were aged 75 or older at death by CCG

The variation between CCGs in the proportion of people who died in care homes who were aged 75 or older at the time of death is illustrated in Map 6. In 2015, in England, 92% of people who died in care homes were aged 75 or older.

The proportion of deaths in care home which occurred in people aged 75 or older was universally high, ranging from the minimum at 79% and the maximum was 97%. In the lowest fifth of CCGs 89% or fewer deaths in care homes occurred in people aged 75 or older, and in the highest fifth of CCGs 94% or more deaths in care homes were in people aged 75 years or older.

When the distribution is divided into fifths, as shown in the map, we can see that for the vast majority of CCGs (165 in the top two fifths of distribution) the proportion of people dying in care homes aged 75 years or older was 90% or above. The lowest fifth of distribution comprises four CCGs, all in London. Even for these, four out of five deaths in care homes (79-83%) were 75 years or older.

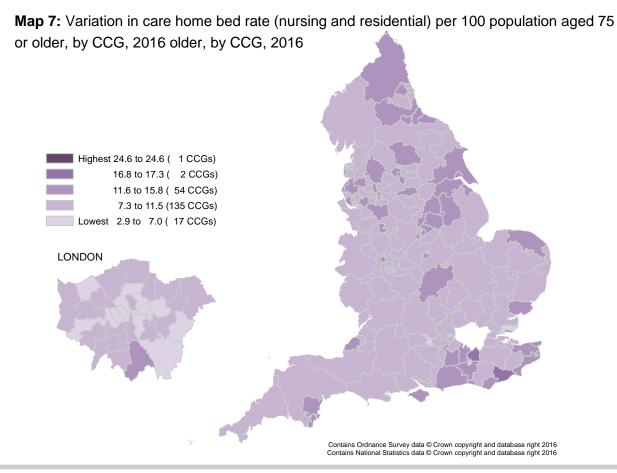


Map 7: Variation in the number of care home beds per 100 head of population aged 75 years or older by CCG – Care home bed rate

The care home bed rate which includes beds in residential and nursing homes gives an indication of capacity to care for older people approaching the end of life. The variation between CCGs in the care home bed rate (number of beds in care homes per 100 population aged 75 or older) is illustrated in Map 7. In England, in 2016 the care home bed rate was 10.4 beds in care homes per 100 population aged 75 or older compared with 11.3 in 2012. This drop reflects both the reduction in care home beds and the increase in numbers of people aged 75 years or older living in England.

There is a wide variation in the care home bed rate per 100 population aged 75 or older. The lowest fifth of CCGs had a care home bed rate of 8.8 or less and the highest fifth had a rate of 12.3 or more. (The minimum was, 2.9, the maximum was 24.6).

When the distribution of care home bed rate is split into five equal portions as shown in the map, only Bradford City CCG is in the highest fifth with a care home bed rate of 24.6. East Surrey and Hastings and Rother CCGs are the only CCGs, in the second highest fifth with a care home bed rate of 17.3 and 16.8 respectively. The majority of CCGs (135) had a care home bed rate of between 7.3 and 11.5.



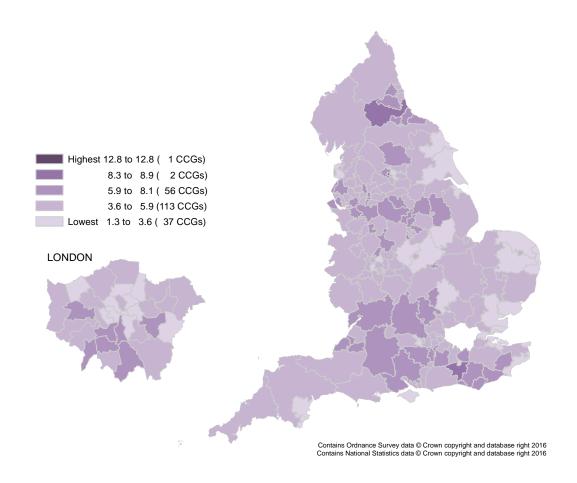
Map 8: Variation in the number of nursing home beds per 100 head of population aged 75 years or older by CCG – Nursing home bed rate

The variation between CCGs in the nursing home bed rate (number of beds in nursing homes per 100 population aged 75 or older) is illustrated in Map 8. In 2016 in England, the average nursing home bed rate was 5.1. It was 5.2 in 2012.

The lowest fifth of CCGs had a nursing home bed rate of 3.7 or less and the highest fifth had a rate of 6.3 or more. (The minimum was 1.3, the maximum was 12.8).

When the distribution of nursing home bed rate is divided into fifths, as shown in the map, only three CCGs (Bradford, Horsham and Mid Sussex, and Durham Dales, Easington and Sedgefield) had rates in the upper two fifths at 12.8, 8.9 and 8.3 nursing home beds per 100 population aged 75 or older respectively. The majority of CCGs (113) had a nursing home bed rate of between 3.6 and 5.9.

Map 8: Variation in care home bed rate for nursing homes per 100 population aged 75 or older by CCG, 2016



Discussion

Half a million people die in England each year, almost 70% are aged 75 years or older. The population of England is ageing and death for many is now preceded by frailty and slow 'dwindling'¹. Care homes are increasingly becoming important providers of end of life care. Indeed, the number of deaths aged 75 years or older in care homes increased from 80,647 in 2011 to 102,946 in 2015 (an increase of 28%).

The pressures on social care services, which includes the provision of care homes has been widely reported². We observed a small decrease (-1%) in number of care home beds in England since 2012. The largest decrease in care home beds was in the residential care home sector. This sector saw a decrease from 249,591 beds in 2012 to 237,182 in 2016 (-5%). Conversely, for the same period there was an increase of 4% in the provision of nursing home beds.

Almost half of care home beds are now in nursing homes. Although the number of beds in nursing homes has increased 4% 2012-2016, the nursing home bed rate was 5 per 100 people aged 75 years or older in both 2012 and 2016. This is because the number of people aged 75 years or older has increased during the same period.

Furthermore, there is large variation in the nursing home bed rate across England. The lowest CCG rate was 1.3 and the highest was 12.8.

We recommend that all CCGs and local authorities should consider their local care home and nursing home rate when commissioning and planning end of life care services for their local elderly population. These data briefings should be considered together with other indicators such as proportion of people dying in hospital. This data is available in the care home domain on our End of Life Care Profiles.

References

- Salisbury C, Johnson L, Purdy S, Valderas, J, Montgomery A (2011)
 Epidemiology and impact of multimorbidity in primary care: a retrospective study. British Journal of General Practice 61 (582) 12-21.
- 2. The state of care in NHS acute hospitals. Care Quality Commission (2016)

Find out more:

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

The NEoLCIN website contains more information and resources related to End of Life Care www.endoflifecare-intelligence.org.uk

The NEoLCIN is a member of the Health Intelligence Network in Public Health England.

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Published: September 2017

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