



## The role of care homes in end of life care

### Briefing 2 - Place and cause of death for permanent and temporary residents of care homes

## National End of Life Care Intelligence Network (NEoLCIN)

### Introduction

This is the second of two briefings produced by National End of Life Care Intelligence Network to describe the important role that nursing and residential care homes play in the care of many people at the end of life. Collectively they are referred to as care homes. Each year over 100,000 people die in these settings and approximately 29,000 other people normally resident in a care home die elsewhere.

Care homes provide accommodation and personal care for people who may not be able to live independently either permanently or temporarily. Temporary admission to a care home may occur following discharge from hospital during a terminal illness, when someone needs short term support recuperating from an illness or for a trial period to decide whether they want to live permanently in a care home.

This briefing presents information derived from death registration data concentrating on place and cause of death.

This is the second of a pair of briefings on the role of care homes in end of life care provision. Briefing 1 describes care home bed provision and potential end of life care need in people aged 75 years or over in England. These new briefings are part of a

### Key findings:

22% (101,203) of people died in a care home in 2014, up from 16% (76,997) in 2005.

A third (34%) of these people are temporary residents.

In 2014 a further 28,892 permanent care home residents died elsewhere, down from 36,734 in 2005.

The majority of permanent care home residents die in a care home (70% in 2014 up from 58% in 2005).

Nearly two thirds (62%) of people who died in care homes have dementia, Alzheimer's disease or senility as an underlying or contributory cause of death.

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

Information on deaths in care homes was extracted from the Office of National Statistics (ONS) Annual Deaths Extract which is itself compiled from death certification data. Deaths in care homes (both residential and nursing homes) were identified within this dataset using the method of categorising place of death described in our publication [Classification of place of death](#). Analysis focused on deaths of England residents registered in the 10 years 2005 to 2014, excluding neo-natal deaths.

Temporary residence in a care home was inferred if the postcode of residence of someone who died in a care home did not match a care home (as listed in the ONS Communal Establishment database which is used to categorise place of occurrence for all deaths). A further limitation is that the data available to us (ONS mortality/ from death certifications) does not allow us to count the number of people who were temporary residents in a care home at any time during their last year of life (or other suitable time period) and who subsequently died elsewhere (not in a care home).

The presentation of leading underlying causes of death follows the work of [ONS](#) and the [National End of Life Care Intelligence Network](#).

## Results

### Number of deaths

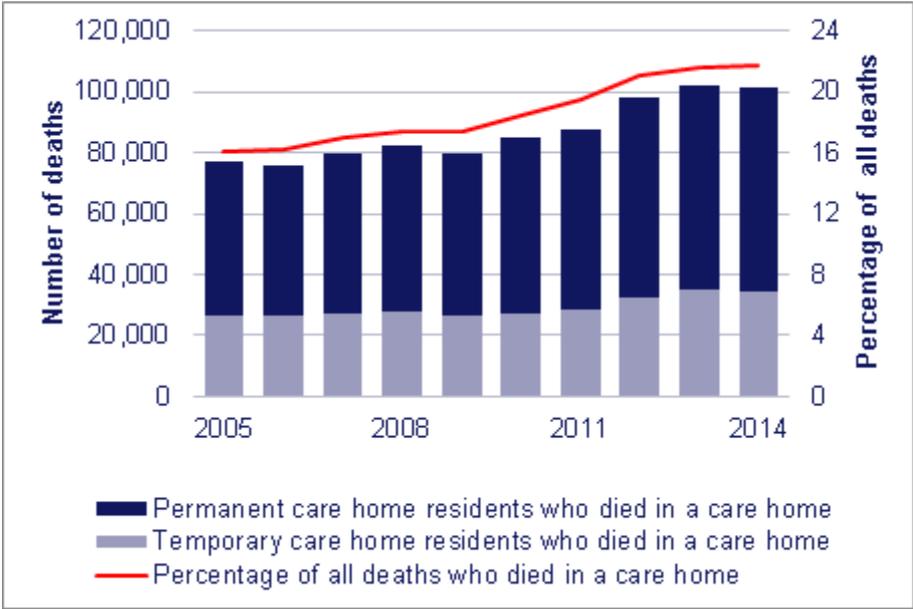
In 2014 in England, care home was the place of death for 22% of people who died (101,203), up from 16% (76,997) in 2005. Table 1 summarises the number of people who died in care homes and together with Figure 1 also shows the rising number of people dying in care homes who were temporary residents. Over these years the percentage of people who died in care homes who were temporary residents remained at 34%.

In addition to care home residents who died in a care home, a further 28,892 permanent care home residents died elsewhere in 2014, down from 36,734 in 2005. Figure 2 shows that the majority of deaths of permanent care home residents occur in a care home (70% in 2014 up from 58% in 2005).

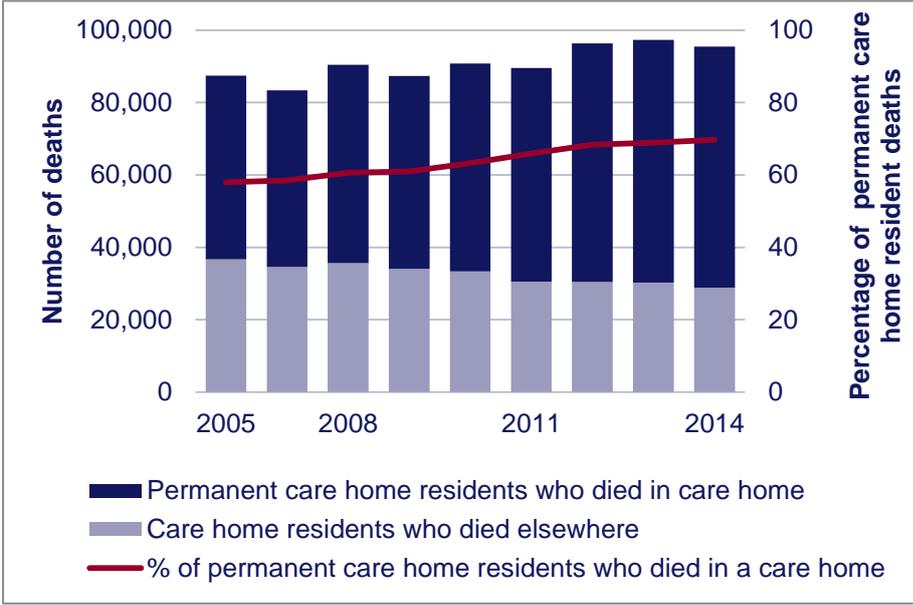
**Table 1** Number of deaths in care home, deaths of temporary care home residents and deaths of care home residents occurring elsewhere, England 2005 and 2014

	2014	2005
Total people who died	467,095	477,567
Number of people who died in a care home, (as a percentage of all people who died)	101,203 (22%)	76,977 (16%)
Number of care home residents who died somewhere other than a care home, (as a percentage of all people who died)	28,892 (6%)	36,734 (8%)
Number of temporary residents who died in care homes (as percentage of all people who died in a care home)	34,638 (34%)	26,272 (34%)
Number of permanent care home residents who died in a care home ( as a percentage of all permanent residents of a care home who died)	66,565 (70%)	50,705 (58%)

**Figure 1:** Number and percentage of deaths in care homes, England 2005-2014



**Figure 2:** Number of deaths of permanent care home residents and where they died, England 2005-2014



**Underlying cause of death**

The distribution of broad underlying causes of death for care home residents are summarised in Table 2.

The most common underlying causes of death in care homes were dementia and diseases of the nervous system (35% of deaths in care homes). Circulatory disease was the most common underlying cause of death group for care home residents who die elsewhere (27% of these deaths).

Cancer as an underlying cause of death was disproportionately common for temporary residents, compared to permanent residents; 61% of deaths from cancer in a care home were temporary residents.

**Table 2:** Distribution of broad underlying cause for death for deaths in care homes and of care home residents who died elsewhere; England 2014

Underlying cause of death (ICD-10 chapter)	All deaths in care homes	Deaths in a care home		Care home residents who died elsewhere
		Permanent residents	Temporary residents	
Mental and behavioural or Nervous system (F & G)	35% (35,926)	41% (27,615)	24% (8,311)	22% (6,224)
Circulatory disease (I)	22% (22,368)	22% (14,964)	21% (7,404)	27% (7,945)
Cancer (C)	18% (18,676)	11% (7,193)	33% (11,483)	12% (3,438)
Respiratory disease (J)	10% (10,325)	11% (7,036)	9% (3,289)	18% (5,195)
Other	14% (13,908)	15% (9,757)	12% (4,151)	21% (6,090)
<b>All causes</b>	<b>100%</b> <b>101,203</b>	<b>100%</b> <b>(66,565)</b>	<b>100%</b> <b>(34,638)</b>	<b>100%</b> <b>(28,892)</b>

A more detailed presentation of leading underlying causes of death is shown in Table 3. Permanent and temporary care home residents have broadly similar leading causes of death, but specific cancers are more common among temporary residents; emphysema/bronchitis, Parkinson's disease, heart failure, acute respiratory diseases and urinary disease are more common among permanent residents.

Care home residents who die elsewhere have similar leading causes of death to permanent residents who die in a care home. However, care home residents who die elsewhere show proportionately fewer deaths attributed to dementia and Alzheimer's disease, and more to urinary disease and accidental falls compared to permanent care home residents dying in a care home.

**Table 3:** The leading underlying causes of death in care homes and among all deaths aged 75 or older, England 2014

Rank  1 is most common	All deaths in a care home,  (101,203 deaths 21.7% of all deaths)	Permanent care home residents who died in a care home  (66,565 deaths 14.3% of all deaths)	Temporary care home residents, who died in a care home  (34,638 deaths 7.4% of all deaths)	Care home residents who died elsewhere  (28,892 deaths 6% of all deaths)	All deaths aged 75 years or older, any place of residence any place of death,  (318,385 deaths 68% of all deaths)
1	Dementia and Alzheimer's 31,585 deaths, 31%	Dementia and Alzheimer's 24,714 deaths, 37%	Dementia and Alzheimer's 6,871 deaths, 20%	Dementia and Alzheimer's 5,195 deaths, 18%	Dementia and Alzheimer's 46,236 deaths, 15%
2	Cerebrovascular diseases 8,968 deaths, 9%	Cerebrovascular diseases 6,272 deaths, 9%	Cerebrovascular diseases 2,696 deaths, 8%	Cerebrovascular diseases 3,055 deaths, 11%	Heart disease 38,536 deaths, 12%
3	Heart disease 6,379 deaths, 6%	Heart disease 4,085 deaths, 6%	Heart disease 2,294 deaths, 7%	Heart disease 2,826 deaths, 10%	Cerebrovascular diseases 25,780 deaths, 8%
4	Flu/pneumonia 4,296 deaths, 4%	Flu/pneumonia 3,137 deaths, 5%	Lung cancer 2,257 deaths, 7%	Flu/pneumonia 2,707 deaths, 9%	Flu/pneumonia 20,248 deaths, 6%
5	Emphysema/ bronchitis 3,609 deaths, 4%	Emphysema/ bronchitis 2,271 deaths, 3%	Emphysema/ bronchitis 1,338 deaths, 4%	Emphysema/ bronchitis 1,728 deaths, 6%	Emphysema/ bronchitis 18,841 deaths, 6%
6	Lung cancer 3,448 deaths, 3%	Parkinson's disease 1,643 deaths, 2%	Bowel cancer 1,305 deaths, 4%	Urinary disease 829 deaths, 3%	Lung cancer 14,150 deaths, 4%
7	Parkinson's disease 2,413 deaths, 2%	Heart failure 1,506 deaths, 2%	Prostate cancer 1,161 deaths, 3%	Lung cancer 679 deaths, 2%	Bowel cancer 7,914 deaths, 2%
8	Heart failure 2,258 deaths, 2%	Lung cancer 1,191 deaths, 2%	Flu/pneumonia 1,159 deaths, 3%	Accidental falls 613 deaths, 2%	Prostate cancer 7,073 deaths, 2%
9	Bowel cancer 2,089 deaths, 2%	Acute respiratory diseases (excluding flu/pneumonia) 1,184 deaths, 2%	Breast cancer 881 deaths, 3%	Cardiac arrhythmias 466 deaths, 2%	Urinary disease 6,807 deaths, 2%
10	Prostate cancer 1,996 deaths, 2%	Urinary disease 1,115 deaths, 2%	Parkinson's disease 770 deaths, 2%	Parkinson's disease 396 deaths, 1%	Lymphoid cancer 6,259 deaths, 2%
11	Other 34,162 deaths, 34%	Other 19,447 deaths, 29%	Other 13,906 deaths, 40%	Other 10,398 deaths, 36%	Other 126,541 deaths, 40%
<b>Total</b>	<b>101,203 deaths, 100%</b>	<b>66,565 deaths, 100%</b>	<b>34,638 deaths, 100%</b>	<b>28,892 deaths, 100%</b>	<b>318,385 deaths, 100%</b>

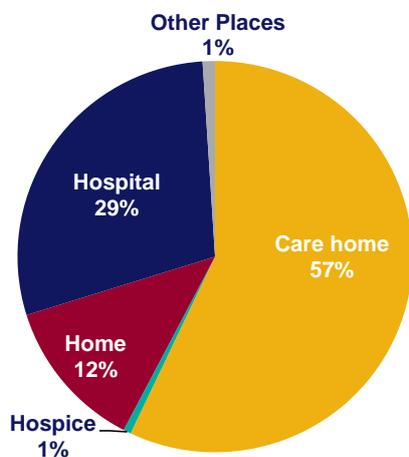
## Estimating the importance of dementia

The count of people who died from dementia based solely on the underlying cause of death is a poor estimator of the number of people who are suffering the effects of dementia at the end of their life; some people with dementia die from other causes.

Death certificates record both underlying and contributory causes of death and by analysing all this data (Box 1) the number of people who died in a care home with dementia can be estimated as high as 62%, approximately double the number of people who died with an underlying cause of these diseases (31%).

Figure 3 shows that the majority (57%) of people who died with dementia, Alzheimer's disease or senility significant enough to be recorded on the death certificate, occurred in a care home. Figure 4 shows that among end of life care settings these people constitute the greatest proportion of people who died for care homes.

**Figure 3:** Distribution of place of death where causes of death include any mention of dementia, Alzheimer's disease or senility, England 2014



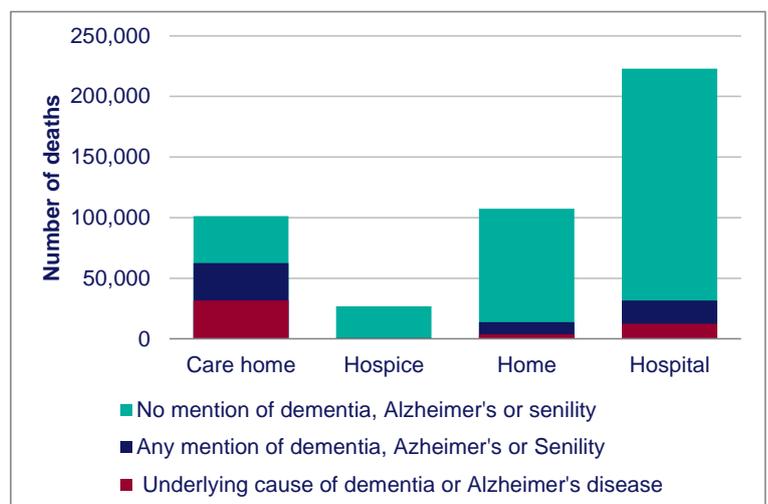
**Box 1:** Alternative methods of estimating dementia prevalence from mortality data; deaths in a care home England 2014

The method used by ONS identifies 31,585 people who died in care homes having an underlying cause of death of 'Dementia and Alzheimer's disease' (31% of all deaths in a care home) selecting underlying cause of death coding (ICD-10) of F01, F03, G30.

PHE in their data briefing '**Dying with dementia**' identifies 42,682 people who died (42% of people who died in a care home) with dementia or Alzheimer's disease by selecting people with underlying or contributory causes of death codes including F01, F02, F03, F04, G30 or G31.

Expanding the previous definition to include people who died with underlying or contributory causes of death of senility (ICD-10 R54) identifies 62,432 people who died in a care home (62% of all people who died in a care home).

**Figure 4:** Number of deaths by place of death and causes of death including dementia, Alzheimer's disease or senility. England 2014



## Age at death

Nationally, between 2005 and 2014, 67% of all people who died were 75 years or older.

Figure 5 shows the age distribution of people who died in a care home and care home residents who died elsewhere.

92% of people who died in care homes were aged 75 years or older.

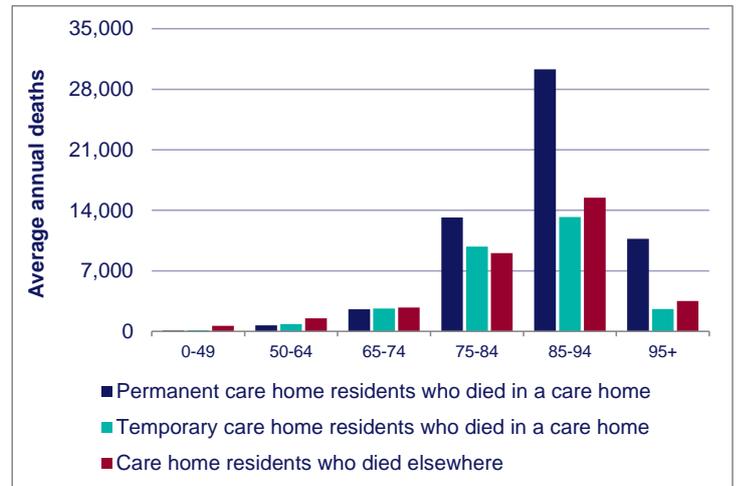
People aged 75 years or older make up 94% of permanent residents who died in a care home and 88% of temporary residents who died in a care home.

Although relatively small in number, just over half (52%) of people aged under 75 years who died in a care home are temporary care home residents.

85% of care home residents who died elsewhere are aged 75 years or older.

66% of all permanent care home residents aged 75 years or over died in care homes, compared to 34% who died elsewhere. In comparison, 41% of permanent care home residents aged under 75 died in care homes, compared to 59% who died elsewhere.

**Figure 5:** Age distribution of deaths in a care, England 2005-2014



## Gender

Between 2005 and 2014, 52% of people who died were female and 48%

male. At 75 years or older 58% of people who died were females and 42% male.

Figure 6 shows the gender and age distribution of people who died in a care home and of care home residents who died elsewhere.

Of the people who died in a care home 68% were female and 32% male.

Females comprised 73% of people who died in a care home who were permanent residents and 57% of those who were temporary residents.

Of the care home residents who died elsewhere 63% were female.

Across all categories the proportion of people who died that were female increased with increasing age. For people who died aged 85 years or older, females accounted for 74% of the people who died in care homes, (78% for permanent residents and 64% of temporary residents) and 72% of care home residents who died elsewhere. Under the age of 75, females accounted for 46% of people who died in care homes (46% for both permanent and temporary residents who died in a care home), and 40% of care home residents who died elsewhere.

**Figure 6:** Gender ratio by age group for deaths in a care home, England, 2005-2014



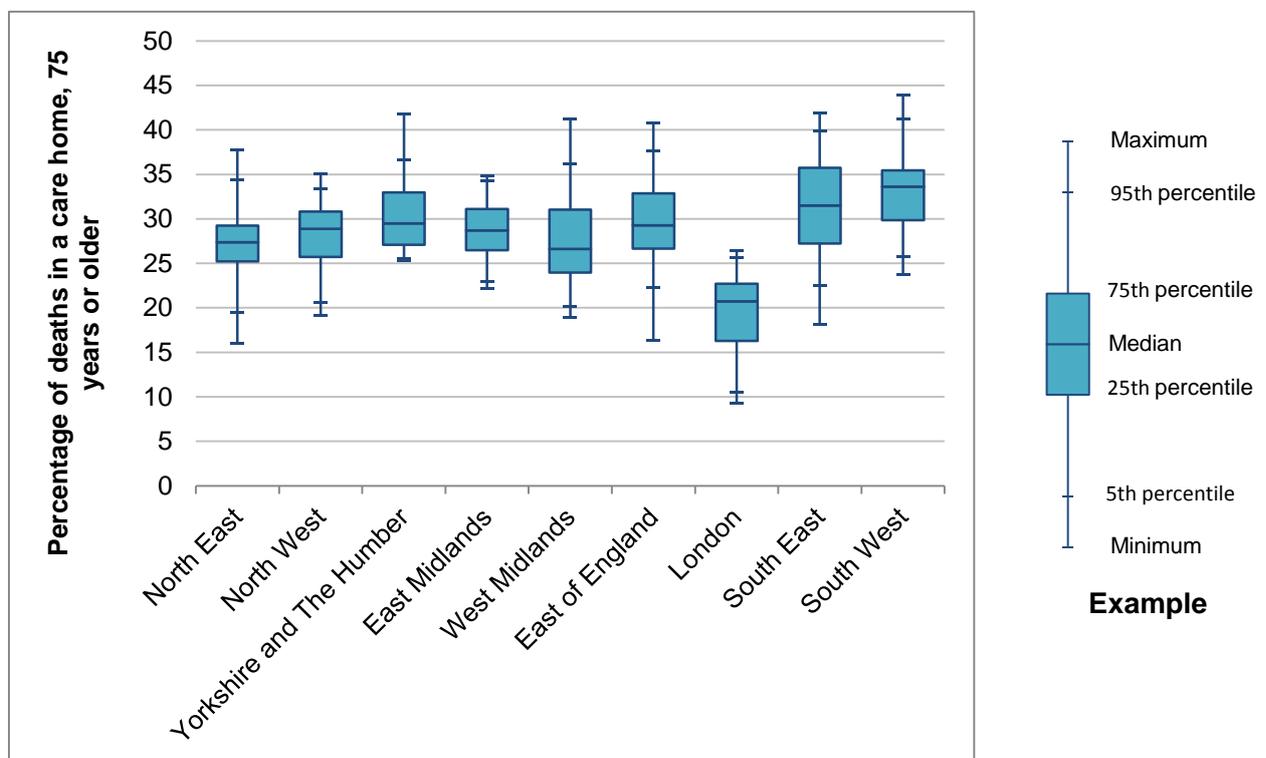
## Geographical variation

There is variation at a local level in the various statistics described in this bulletin. Figures 7, 8 and 9 illustrate this for 324 local authorities grouped together in English regions (formerly known as government office regions). Within the analysis, City of London was grouped with Hackney, and Isles of Scilly with Cornwall. Data for the three years 2012-2014 have been used to average out some of the year to year variation due to small numbers.

### People aged 75 years or older who died in a care home

Nationally 29% of all people who died aged 75 years or older died in a care home. Figure 7 shows there is considerable variation between regions and between the local authorities within regions. The lowest proportions are in local authorities in London (9 of the lowest 10, all 16.3% or lower); while the 10 local authorities with the highest proportions (all over 40%), are spread between the South West, South East, Yorkshire and the Humber, West Midlands and East of England. The greatest range between highest and lowest local authorities is seen in East of England, although the interquartile range (difference between 75<sup>th</sup> and 25<sup>th</sup> percentiles) is greatest in the South East.

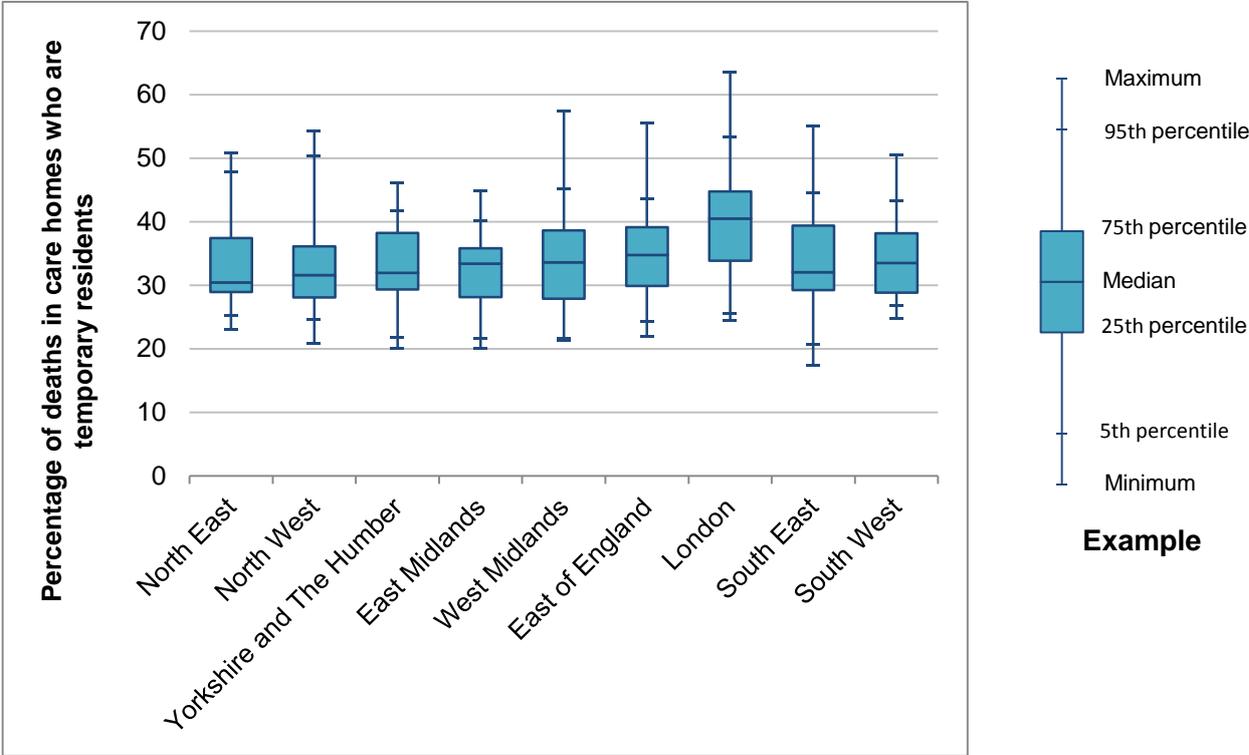
**Figure 7:** The percentage of deaths aged 75 years or older that occur in a care home, distribution for local authorities by region, England, 2012-2014



**People who died as temporary care home residents**

Nationally, 34% of people who died in care homes are in temporary residents. Figure 8 shows there is variation between regions and between the local authorities within regions, ranging from 21.2% or less for the lowest ten to 50.6% for the highest ten. In London, half the local authorities have a percentage greater or equal to 40.5%, while in every other region three quarters or more of local authorities have a percentage lower than 39.4%. London shows the greatest variation between local authorities of all the regions both in terms of absolute range (maximum – minimum) and interquartile range (difference between 75<sup>th</sup> and 25<sup>th</sup> percentiles).

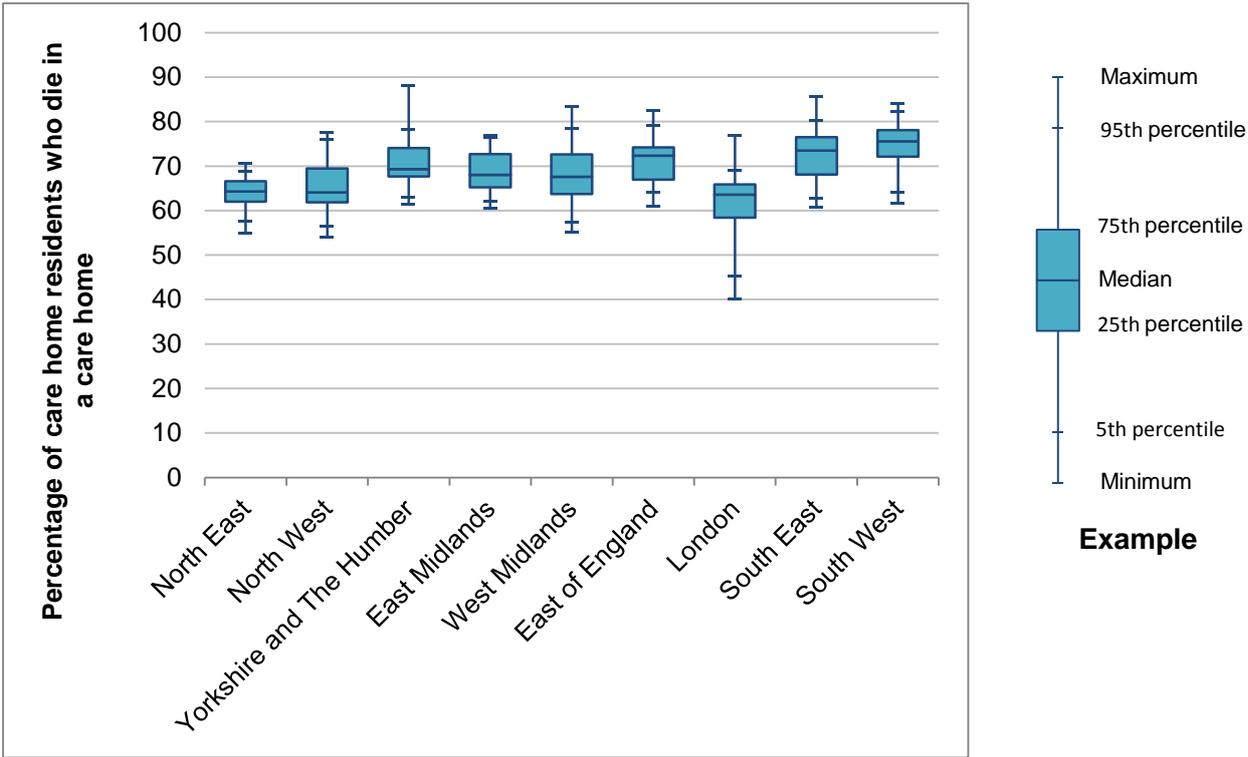
**Figure 8:** The proportion of people who died in care homes who are temporary residents, distribution for local authorities by region, England, 2012-2014



### Care home residents who died in a care home

Figure 9 shows the proportion of permanent care home residents who died in a care home varies between local authorities from a minimum of 40.0% to a maximum of 88.1%. The England average for this period was 69%. Among the lowest 10 local authorities, 6 are in London. The highest proportions are spread more widely, across 5 regions. The local authorities in London show the greatest variation of any region, both in terms of absolute range and interquartile range.

**Figure 9:** The percentage of care home residents who died in a care home, distribution for local authorities by region, England, 2012-2014



### Discussion

Over recent years England has seen care home and private homes as the place of death for an increasing proportion of people who died with a corresponding decreasing proportion of people dying in hospital<sup>1</sup>. This has been encouraged by research indicating that, when asked, many people would prefer not to die in hospital<sup>2, 3, 4, 5, 6</sup>.

This increasing role for care homes comes at a time of huge pressure on the social care market including increasing financial pressure and difficulty recruiting and retaining staff.<sup>7</sup>

People in a care home are some of the most vulnerable in society, many living with multiple co-morbidities. In a nursing home patients needs are likely to be particularly complex. Dementia, Alzheimer's disease or senility is significant enough to be mentioned as an underlying or contributory cause of death for 60% of people who die in a care home. Multiple health care services will visit to provide care and treatment to those in care homes and inevitably decision making in care homes involves managing inherent uncertainties<sup>8,9</sup>. Specialist palliative care services from hospices or hospital are working with care homes in innovative ways both in patient care and staff training.

If the trend in reducing avoidable hospital admissions and consequently reducing the number of deaths in hospital is to be maintained in the context of an increasing number of deaths and an ageing population, there will be an on-going demand for end of life care services within care homes.

## References

1. National End of Life Care Intelligence Network, [Number and proportion of deaths by place of occurrence](#).
2. Sue Ryder, [A time and place](#). (July 2013)
3. Gomes B, Calanzani, N and Higginson IJ (2011). [Local preferences and place of death in regions within England 2010](#). Cecily Saunders International, London. (August 2011)
4. British Social Attitudes Survey. [Discussing and planning for end of life](#). Office of the Chief Analyst, Department of Health
5. NHS England, [Actions for End of Life Care: 2014-16](#).
6. [End of Life Care Strategy: promoting high quality care for adults at the end of their life](#). Department of Health (2008)
7. [State of care](#). Care Quality Commission (2016)
8. Goodman C et al (2015) [End of life care interventions for people with dementia in care homes: addressing uncertainty within a framework for service delivery and evaluation](#). BMC Palliative Care 2015;14:42
9. Dixon J et al (2015) [Equity in the Provision of Palliative Care in the UK: Review of Evidence](#) Personal Social Services Research Unit , London School of Economics and Political Science

## 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](http://www.endoflifecare-intelligence.org.uk)

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

Contact us at: [neolcin@phe.gov.uk](mailto:neolcin@phe.gov.uk)

Published: September 2017

© Crown copyright 2017

Re-use of Crown copyright material (excluding logos) is allowed under the terms of the Open Government Licence, visit <http://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/> for terms and conditions.

PHE supports the UN Sustainable Development Goals

