



Public Health
England

Protecting and improving the nation's health

Data Analysis Report

Dying with Dementia

National Dementia Intelligence Network
National End of Life Care Intelligence
Network

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: @PHE_uk
Facebook: www.facebook.com/PublicHealthEngland

Prepared by: Tanya Khera-Butler
Project Supervisor: Michael Jackson
For queries relating to this document, please contact: Tanya Khera-Butler

Acknowledgements:

DIN: Marta Szczepaniak, Leslie Salema, Sam Lane and Cam Lugton
NEoLCIN: Columbus Ohaeri, Andy Pring and Shivaun Fleming
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Executive summary

- This data analysis report aims to answer four main questions about people who die with dementia; 1) How have trends of dementia deaths changed over time? 2) Who are the people who die with dementia? 3) Where do people with dementia die? 4) What other conditions do people with dementia die with?
- The age-standardised rate of deaths with any mention of dementia has increased from 106 per 100,000 persons in 2001 to 188 per 100,000 persons in 2014.
- The rate of deaths with a mention of dementia varies by geography, being highest in central England. Rates vary by subtype, where the rate of deaths with a mention of Alzheimer's disease appears highest in the north of England, whereas the rates of deaths with a mention of vascular dementia appear highest in the west of England.
- As expected, there are a higher proportion of women that die with dementia compared to men and a higher proportion of deaths with dementia occur in older age groups; the average age of death for people with a mention of dementia is 86 years.
- Differences were observed by subtype, whereas a higher proportion of women die with Alzheimer's disease and unspecified dementia, a similar proportion of men and women die with vascular dementia.
- A significantly higher proportion of deaths for people aged 65-74 with a mention of dementia occur in the more deprived decile compared to the least deprived decile. This difference is small, but it is significant.
- The place of death for people that die with dementia is significantly different from all deaths. Nearly two-thirds of deaths with a mention of dementia for people aged 65 and over occur in care homes. This is in contrast to a quarter of all deaths for people aged 65 and over. People with dementia are less likely to die at home (8%) compared to all deaths for people aged 65 and over (21%).
- Respiratory disease, circulatory disease and malignant cancers were also a mention for 38%, 36%, and 9% of all deaths with a mention of dementia, respectively.
- People with dementia and an underlying cause of respiratory disease, malignant cancer or circulatory diseases were more likely to die in care homes and less likely to die at home compared to those with no mention of dementia and an underlying cause of one of the above.

Introduction

This report is an analysis of data recorded on death certificates, focusing specifically on people who have died with any recorded mention of dementia. It is written in the context of a number of key strategies for end of life for people with dementia. The Prime Minister's 2020 dementia challenge recommends that people with dementia should be given the opportunity of advanced care planning and should receive access to high quality palliative care from health and social care staff.¹ The dementia 2020 implementation plan reports that people with dementia approaching the end of life, should experience high quality, compassionate and joined-up care.² One of the key strategies to address this was to equip care home staff and carers with the ability to develop their knowledge, skills and behaviours in order to deliver co-ordinated, compassionate and person-centred end of life care for people with dementia. This is supported by the National Dementia strategy, objective 12 discusses improved end-of-life care for people with dementia.³ The National Institute for Health and Care Excellence (NICE) quality statements 5 and 9 recommend an assessment by primary care teams at the end of life and discussions around advanced statements and preferred priorities of care.⁴ Although this study does not report on the quality of care provided prior to death, this report should support discussions around these issues.

The Office for National Statistics (ONS) reports that dementia and Alzheimer's disease (F00, F03, and G30) are the leading cause of death for women accounting for 13.4% of deaths and the second leading cause of death for men, accounting for 7% of deaths.⁵ Work by the Health & Social Care Information Centre has indicated that the median survival time from when patients are first assessed as having 'cognitive impairment or dementia at moderate need' is 3 years and 6 months.⁶

This intelligence briefing, produced for the National Dementia Intelligence Network and the National End of Life Care Intelligence Network, draws on national data to illustrate key facts related to deaths with a recorded mention of dementia. The report covers four main areas including; changes in the number of dementia deaths over time, the demographics of people dying with dementia, the place of death and causes of death for people with dementia. This publication builds on a previous report produced by the National End of Life Care Intelligence Network.⁷

This data analysis report is aimed at health and social care commissioners involved in end of life care services, to provide a current understanding of those who are dying with dementia and, in turn, aid discussions to improve the quality of end-of-life care for people with dementia. Also within this publication release are the intelligence briefing providing policy context to the data findings, a summary infographic, a presentation slideset and a workbook containing data for clinical commissioning groups and local authorities.

Methods

This report is based on deaths of people who were usually resident in England, **aged 20 and over** and died with any record of dementia on their death certificate. Time trend analysis is based on the years 2001 to 2014. The remaining analysis is based on deaths registered over the most recent period 2012 to 2014. The specific conditions were selected using the following ICD-10 codes (International Statistical Classification of Diseases and Related Problems version 10) as shown in Table 1.

Table 1: ICD-10 classification codes of the dementia subtypes

Cause of death	ICD10 codes
Alzheimer's disease	F00, G30 (Any 4 th digit)
Vascular dementia	F01 (Any 4 th digit)
Unspecified dementia	F03 (Any 4 th digit)
Other dementia subtypes	F02, F04, G31 (Any 4 th digit)
Dementia (all subtypes)	F00-F04, G30-G31 (Any 4th digit)

Definitions of the dementia and dementia subtypes

Dementia is an umbrella term classified by a group of symptoms including memory loss, mental agility and difficulties with thinking, judgement, problem solving or language. It is caused by damage to the brain through various aetiologies. This report classifies dementia using the ICD10 codes as shown in Table 1.

Alzheimer's disease is typified by its gradual onset and progression. It occurs when proteins build up in the brain to form plaques and tangles, leading to loss of nerve cell connections which leads to nerve cell damage.

Vascular dementia is caused by reduced blood supply to the brain due to damaged blood vessels, where blood vessels leak or become blocked. This includes stroke related dementia, where blood supply to the brain is cut off by a narrowed blood vessel or a clot, causing brain damage. The risk factors for developing vascular dementia are similar to the risk factors for cardiovascular disease.

Unspecified dementia is classified when the cause of cognitive impairment is not known and symptoms include those found in other subtypes of dementia.

Other dementia subtypes in this report includes the remaining less common subtypes. These includes, conditions such as dementia with Lewy bodies, frontotemporal dementia, Pick disease, and dementia in other disease such as Parkinson's disease.

More information on the dementia subtypes can be found on the Alzheimer's Society website⁸ and the Dementia Revealed Report.⁹

Definitions of main terms

Underlying cause of death, defined as:

- i) the disease or injury that initiated the train of events directly linked to death; or
- ii) the circumstances of the accident or violence that produced the fatal injury.

Contributory cause of death, defined as: part of the causal sequence of events leading to death, or contributing to the death but not part of the causal sequence.

Mention, defined as: a death which has a condition listed as either the underlying cause of death or as a contributory cause of death.

There is one position for the underlying cause of death in the death record, as this is the defined as the primary cause of death. The contributory cause of death is the subsequent 15 positions, so a death record can have a maximum of 15 contributory causes.

For people that have a diagnosis of any dementia subtype but have died from a completely unrelated cause, for example a road accident, dementia will not be coded as either the 'underlying' or 'contributory' cause of death. **Therefore the numbers reported in this report are not a true measure of prevalence, ie. 'who die and have dementia'**. However, the numbers do give an account of the people where dementia is a direct or important factor for their death.⁷

Note that this report uses a wider range of ICD10 codes for dementia compared to the ONS statistical bulletins, which use ICD10 F01, F03 and G30 for dementia.⁵ In addition, our report is restricted to England, whereas ONS bulletins cover both England and Wales. This report will focus on **any mention of dementia**, in contrast to the ONS bulletins which report deaths with an underlying cause of dementia. This in effect includes whether any dementia code was recorded as an underlying cause and/or as a contributory code. Using this method, the report will explore any person who had dementia in their death record, regardless of the ICD10 code position.

This report uses year of registration, not date of occurrence of death. This is consistent with most ONS mortality statistics.

ONS mortality dataset

The data source for this analysis is the ONS: Public Health England Annual Mortality Extract. This dataset encompasses information for the cause of death from civil registration records. This lists the underlying cause of death and other conditions that the patient had at the time of death. Deaths are coded in line with the International Statistical Classification of Diseases and Related Health Problems (ICD).

Statistical Methods

Directly standardised rates are calculated to provide the number of deaths per 100,000 that occurred in that area if it had the same age structure as the standard population and the age-specific rates of the area applied. Directly standardised mortality rates are calculated by dividing the number of deaths by the actual local population in a particular age group multiplied by the standard population for that particular age group and summing across the relevant age groups.¹⁰

Statistical significance was assessed throughout the report by calculating whether the 95% confidence intervals for data points overlap.

ONS coding changes

The ONS codes cause of death using the WHO Internal Classification of Diseases (ICD-10). ONS uses software to automate the translation of the cause of death from text on the death certificate to ICD10 codes, and where this is not possible, it is manually coded.¹¹

For the years 2001 to 2010, ONS was coding deaths with a version of ICD called ICD10 v2001. In January 2011, ONS adopted a new version of the coding software which uses ICD10 v2010. This change included corrections to the software for automated coding, codes for new conditions.¹² On the 1 January 2014, ONS changed the software used to code cause of death to a package called IRIS (ICD-10 v2013). This change was carried out so that a common automated cause of death coding system could be used to code in any language to improve the comparability of mortality statistics across Europe and internationally.¹³ These changes have impacted on the underlying cause of death and should be taken into consideration when interpreting time trends.

This report focuses on all deaths with any mention of dementia in the death record, to capture anyone who had died with dementia regardless of whether it was recorded as an underlying cause or contributory cause. Using any mention of dementia will also improve the interpretation of the trend of deaths over time.¹⁴

Chapter 1: Dementia deaths over time and across geographies

This chapter will explore the numbers of people in England who die that have dementia recorded on their death certificate and how these numbers have changed over time. This includes analysis by major subtypes; such as Alzheimer's disease, vascular dementia and unspecified dementia. The chapter will also explore the geographical variation that exists for different dementia subtypes by Clinical Commissioning Groups and Local Authorities across England.

1.1. Overview of the number of dementia deaths

Between 2001 and 2014 there were 362,798 deaths recorded with an underlying cause of dementia (all subtypes) and 676,186 deaths with a mention of dementia (all subtypes) (Table 2). This represents 5.5% and 10.3% of all deaths (aged 20 and over), respectively. In 2014, there were 73,189 deaths for people aged 20 and over with a mention of dementia, representing 15.8% of deaths. The majority of these deaths were for people aged 65 and over (72,504). This represents 18.4% of all deaths for people aged 65 and over.

Table 2: Deaths recorded with dementia, people aged 20+, England, 2001-2014

Dementia subtype	Underlying cause		Mention	
	Number	%	Number	%
Alzheimer's disease	85,985	24%	126,253	19%
Vascular dementia	37,010	10%	60,253	9%
Unspecified dementia	231,725	64%	485,521	72%
Other dementia subtypes	8,078	2%	14,166	2%
Dementia (All subtypes)	362,798	100%	676,186	100%

Note: The number of deaths with a mention of individual subtypes will not sum the total number of dementia deaths (all subtypes). This is because an individual can be recorded with more than one subtype.

The number of deaths with an underlying cause of dementia (all subtypes) accounted for 3.3% of all deaths in 2001 and 10.7% of all deaths in 2014, a percentage point increase of 7.4%. Suggested reasons for this increase are given in Box 1.

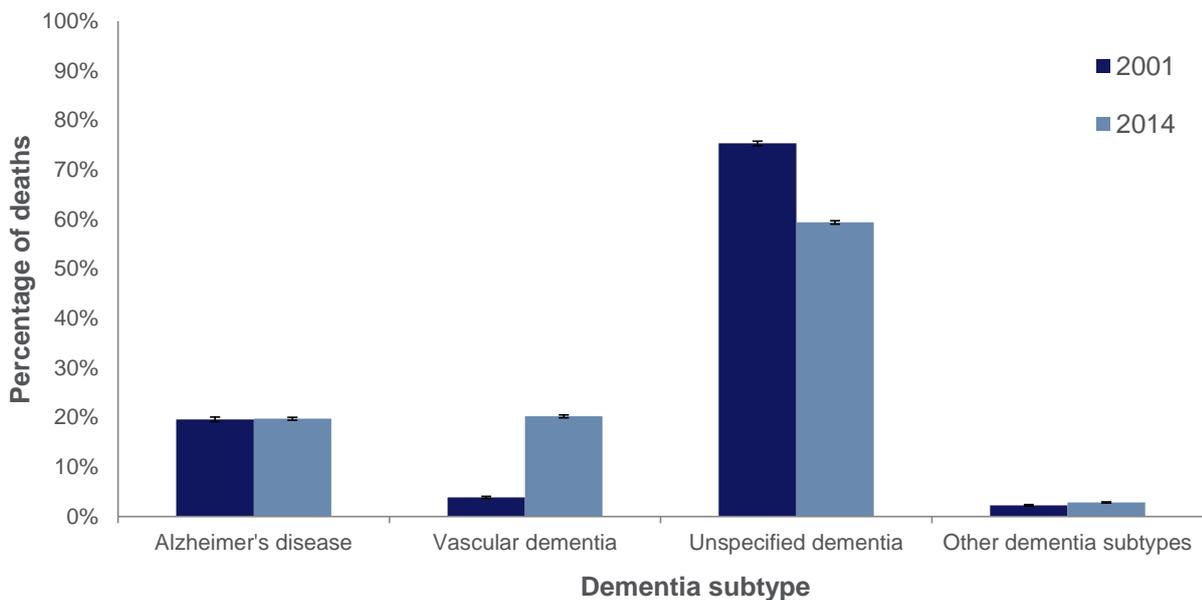
Box 1: Reasons for increased number of deaths with an underlying cause of dementia

- 1) An actual increase in the number of people dying with dementia as people are living longer.¹⁵
- 2) A greater awareness and understanding of dementia, with key policy drivers to increase the dementia diagnosis rate.¹⁶ As a result, clinicians are recording dementia as an underlying cause of death more often.
- 3) Changes in ICD coding frame in 2011 and 2014, for example in January 2011 the structure changed from ICD-10 v2001.2 to ICD-10 v2010. Changes in practice included previously coding vascular dementia deaths as cerebrovascular disease unspecified (I67.9). In addition, previously coding a number of dementia deaths as urinary tract infections, site not specified (N39.0).¹⁷

1.2. Dementia deaths by subtype

Deaths with a mention of unspecified dementia represent the majority of all dementia deaths for both 2001 and 2014 (Figure 1), however, the proportion has decreased with time by 16%. The proportion of deaths with a mention of vascular dementia has increased significantly from 2001 to 2014; deaths with any mention of vascular dementia represents one-fifth of all dementia deaths in 2014. The proportion of all dementia deaths with a mention of Alzheimer’s disease is similar across the two time points. In 2014 deaths with a mention of Alzheimer’s disease also represents a fifth of dementia deaths.

Figure 1: Proportion of deaths with any mention of dementia by subtype, people aged 20+, England, 2001 and 2014

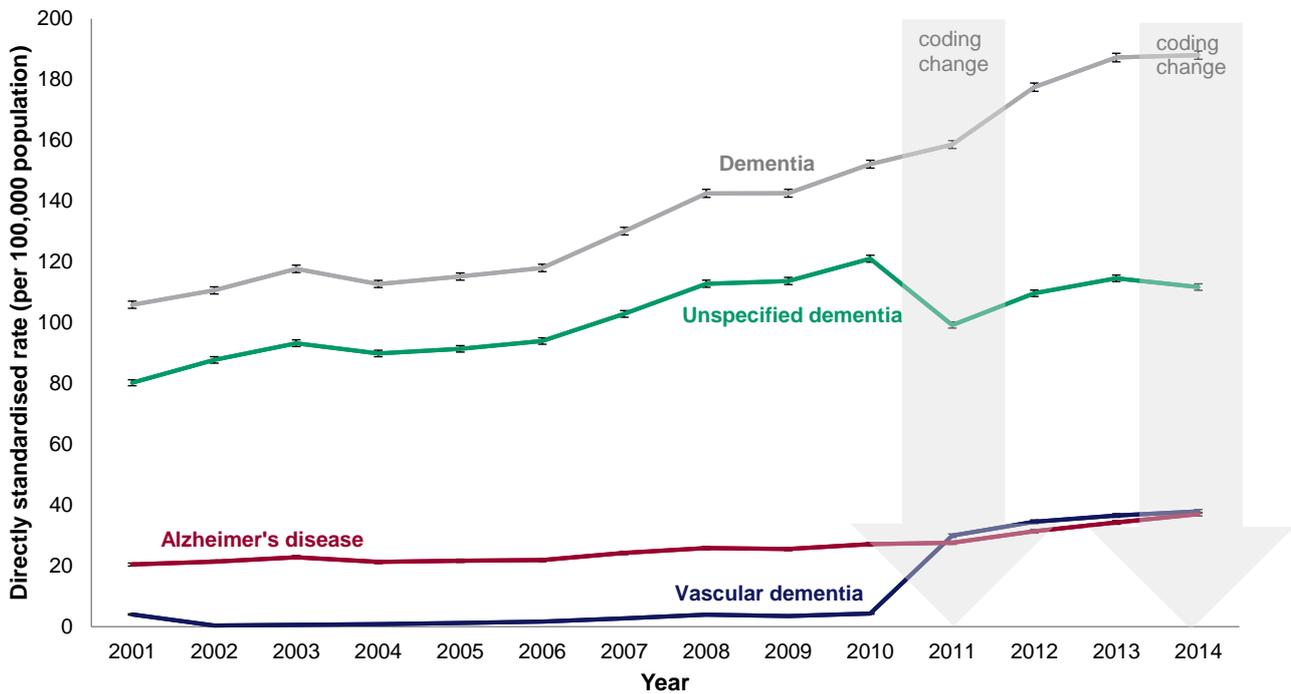


Note: Deaths can be recorded with more than one dementia subtype, there fore the total can be more than 100%.

1.3. Time trends of deaths with a mention of dementia

Dementia (all subtypes) was a mention in 6.6% of all deaths in 2001 and 15.8% of deaths in 2014 for people aged 20 and over. The directly age-standardised mortality rate of deaths with any mention of dementia differs by subtype (Figure 2). Reporting the direct age standardised mortality rate and not the numbers enables us to control for any differences due to having an increasingly older population age structure. The rate of deaths with any mention of dementia has increased from 106 per 100,000 population in 2001 to 188 per 100,000 population in 2014. Reasons for this increase most likely reflect coding practice changes and an increase in dementia awareness (Box 1). The rate of mentions of Alzheimer’s disease has steadily increased from 20 per 100,000 to 37 per 100,000. Whereas deaths with a mention of vascular dementia show a sharp increase in 2011. Between 2011 and 2014, vascular dementia and Alzheimer’s disease have similar age-standardised mortality rates. The rate of deaths with a mention unspecified dementia shows a steady increase, until 2011 where the rate drops (to 99 per 100,000 population), followed by a steady incline to nearly 112 per 100,000 population in 2014.

Figure 2: The directly age standardised mortality rate for deaths with any mention of dementia by subtypes, persons aged 20 and over, England, 2001-2014



1.4. Geographical variation of deaths with a mention of a dementia

The age-standardised rates of deaths with any mention of dementia across England are higher in the North West and lower in the South West and London, as illustrated in figure 3 and Figure 4 CCGs and LAs respectively. The CCG rates for deaths with a mention of dementia range from 108.3 per 100,000 in NHS Harrow to 347.5 per 100,000 in NHS Bradford City. Local authority rates for deaths with a mention of dementia range from 108.3 per 100,000 in Harrow to 263.1 per 100,000 in Halton.

1.5. Geographical variation of deaths with a mention of Alzheimer's disease

The age-standardised rates of deaths with any mention of Alzheimer's disease across England are higher in the North of England and lower in the South West and London, as illustrated in figure 3 and Figure 4, CCGs and LAs respectively. CCG rates for deaths with a mention of Alzheimer's disease were lowest in NHS Central London (12.0 per 100,000) and highest in NHS South Tyneside (76.5 per 100,000). The local authority rates for deaths with a mention of Alzheimer's disease range from 12.1 per 100,000 in Westminster to 76.4 per 100,000 in South Tyneside.

1.6. Geographical variation of deaths with a mention of vascular dementia

The age-standardised rates of deaths with any mention of vascular dementia across England are higher in the West of England, as illustrated in figure 3 and Figure 4, CCGs and LAs respectively. CCG rates for deaths with a mention of vascular dementia range from 11.4 per 100,000 in NHS Barnsley to 71.0 per 100,000 in NHS Fareham and Gosport. Local authority rates for deaths with a mention of vascular dementia range from 11.4 per 100,000 in Barnsley to 73.3 per 100,000 in Reading.

1.7. Geographical variation of deaths with a mention of unspecified dementia

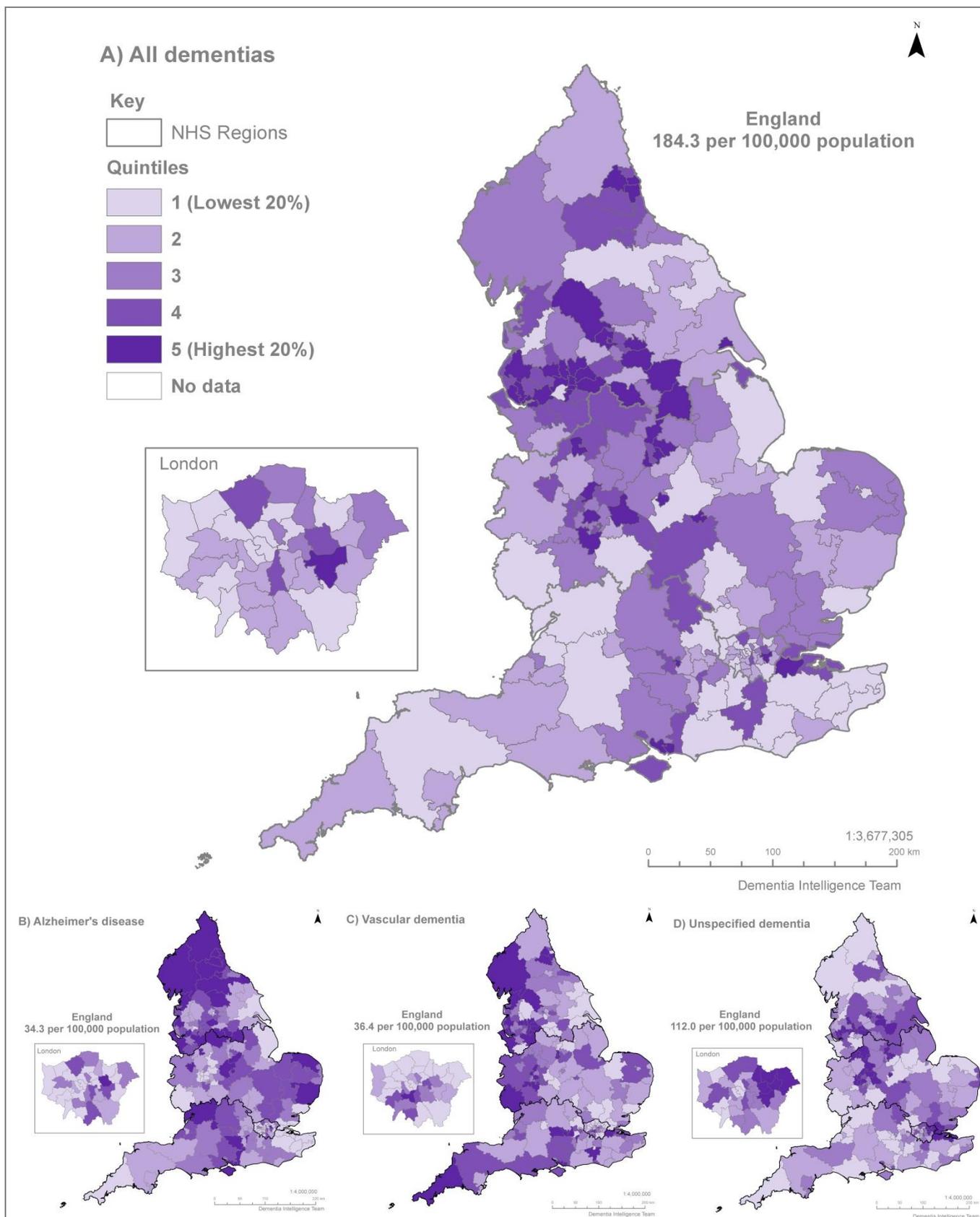
The age standardised rates of deaths with any mention of unspecified dementia across England are higher in Central England and lower in the South West, as illustrated in figure 3 and Figure 4 CCGs and LAs respectively. CCG rates for deaths with a mention of unspecified dementia range from 59.8 per 100,000 in Hambleton, Richmondshire and Whitby CCG to 282.1 per 100,000 in NHS Bradford City. Local authority rates for deaths with a mention of unspecified dementia range from 70.6 per 100,000 in Kensington and Chelsea to 165.0 per 100,000 in Tameside.

Note: Local authority maps do not include data for any counts that were less than 25, as directly standardised rates are not considered robust for small counts. Therefore data for City of London UA and Isle of Scilly UA are not included for all 4 maps and data for Rutland UA is not included in the Vascular dementia map.

Note: Populations are not distributed evenly across geographical areas.

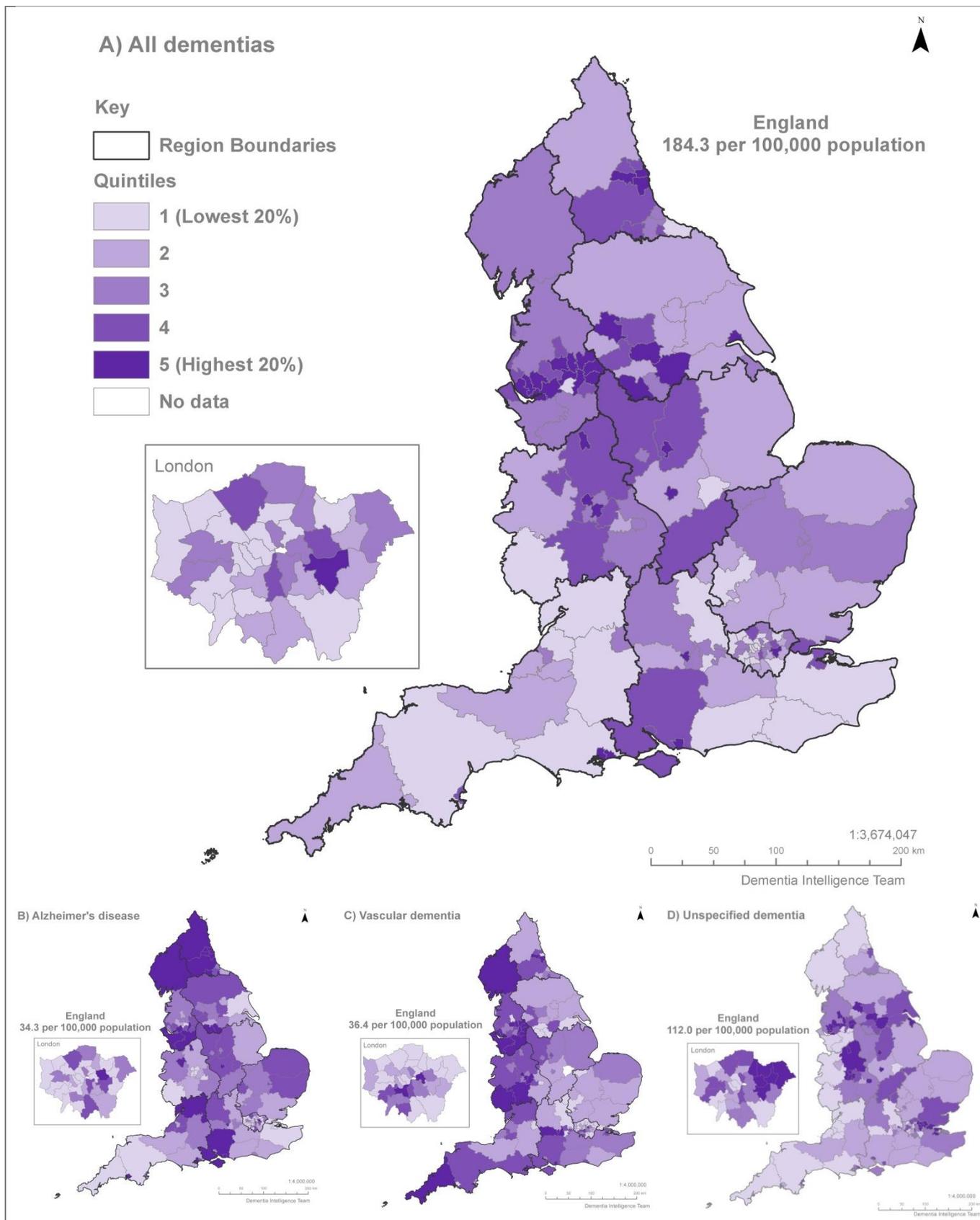
Data for these maps can be downloaded [here](#).

Figure 3: The Directly Age Standardised Mortality Rate of deaths with any mention of A) Dementia (all subtypes), B) Alzheimer’s disease, C) Vascular dementia, D) Unspecified dementia per 100,000 population, people aged 20+, CCGs, England, 2012-2014



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Figure 4: The Directly Age Standardised Mortality Rate of deaths with any mention of A) dementia (all subtypes), B) Alzheimer’s disease, C) Vascular dementia, D) Unspecified dementia per 100,000 population, people aged 20+, Local Authorities, England, 2012-2014



Chapter 2: Who are the people who die with dementia?

This chapter will explore the variations in deaths with a mention of dementia by demographic factors such as age, gender, country of birth and deprivation, with the aim of gaining a better understanding of the population that die with dementia and to assess whether this is different to the demographic picture for all deaths.

2.1. Age and Gender

There were 210,187 deaths with a mention of dementia (all subtypes) in 2012-14 in England, this equates to 15% of all deaths. Of these, 134,870 (64%) are women and 75,317 (36%) are men. It is well understood that there are higher numbers of women that die with dementia compared to men. Figure 5 illustrates that there are higher numbers of women for all of the dementia subtypes compared to men. A higher number of men and women have unspecified dementia as a mention compared to the other dementia subtypes. Compared to all deaths in this period, 19% of all deaths for women aged 20 and over included a recorded mention of dementia, compared to 11% of all deaths for men aged 20 and over.

Figure 6 shows that dementia subtypes account for a varying proportion of deaths for men and women. For example a higher proportion of women die with Alzheimer's disease and unspecified dementia compared to men (Figure 6). In contrast a similar proportion of men and women die with vascular dementia. Nearly all of deaths (99.6%) with a mention of dementia occur in people aged 60 and over and 85% occur in people aged 80 and over.

Over the period from 2001 to 2014, the average age of death recorded for people with a mention of dementia (all subtypes) has increased by 2 years, from 84 years to 86 years. Split by gender, the average age of death has increased from 82 to 84 for men and 85 to 87 for women (Appendix Table 1). In 2014, the average age of people dying with Alzheimer's disease was slightly younger (aged 85) compared to people dying with vascular dementia or unspecified dementia (aged 86) (Appendix Table 2). Overall, the average age of death for both men and women with dementia has increased over time, but the average age of death remains lower for men compared to women.

Figure 5: Number of deaths with any recorded mention of dementia (all subtypes), Alzheimer's disease, vascular dementia, unspecified dementia, England, 2012-2014

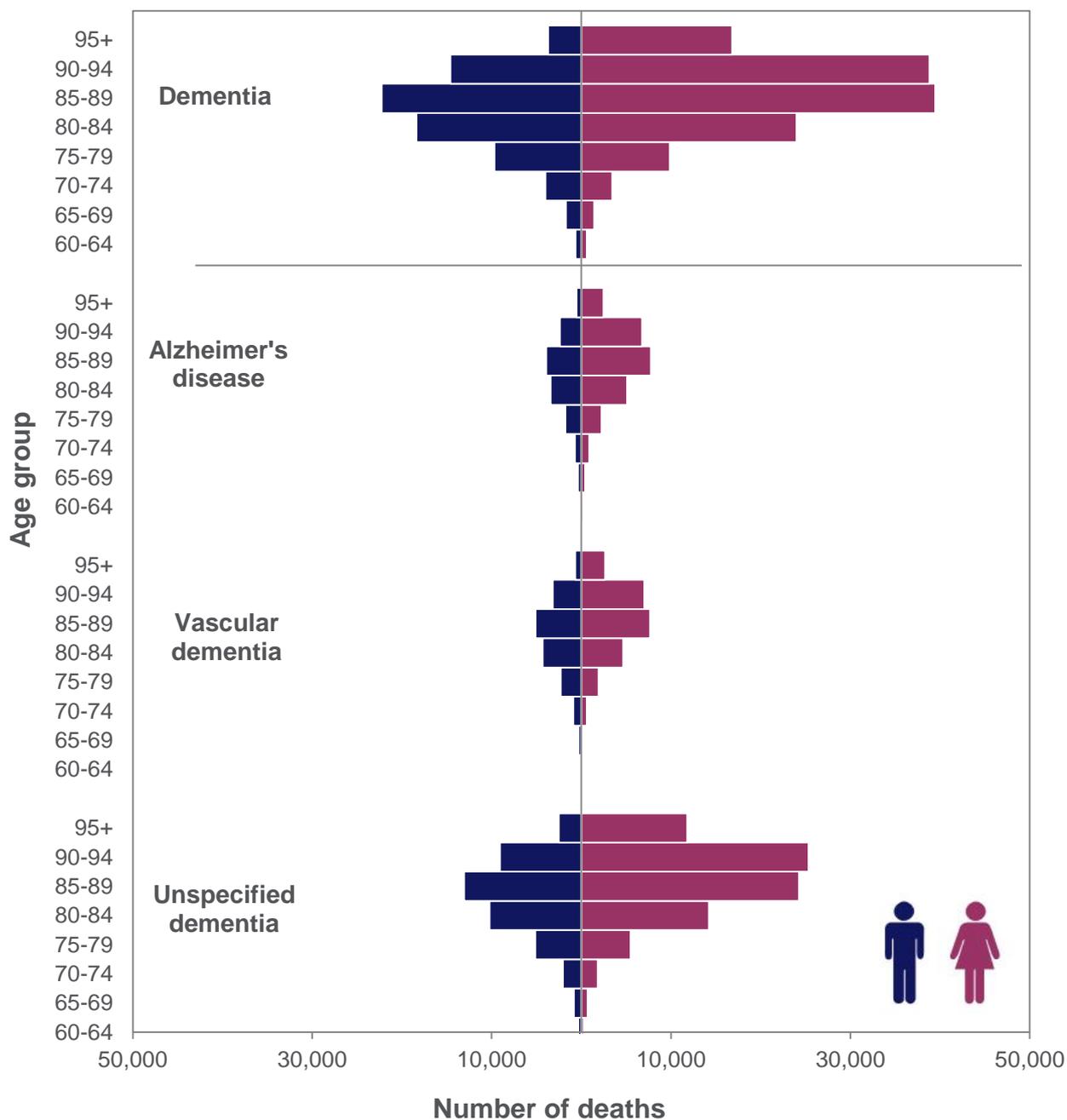
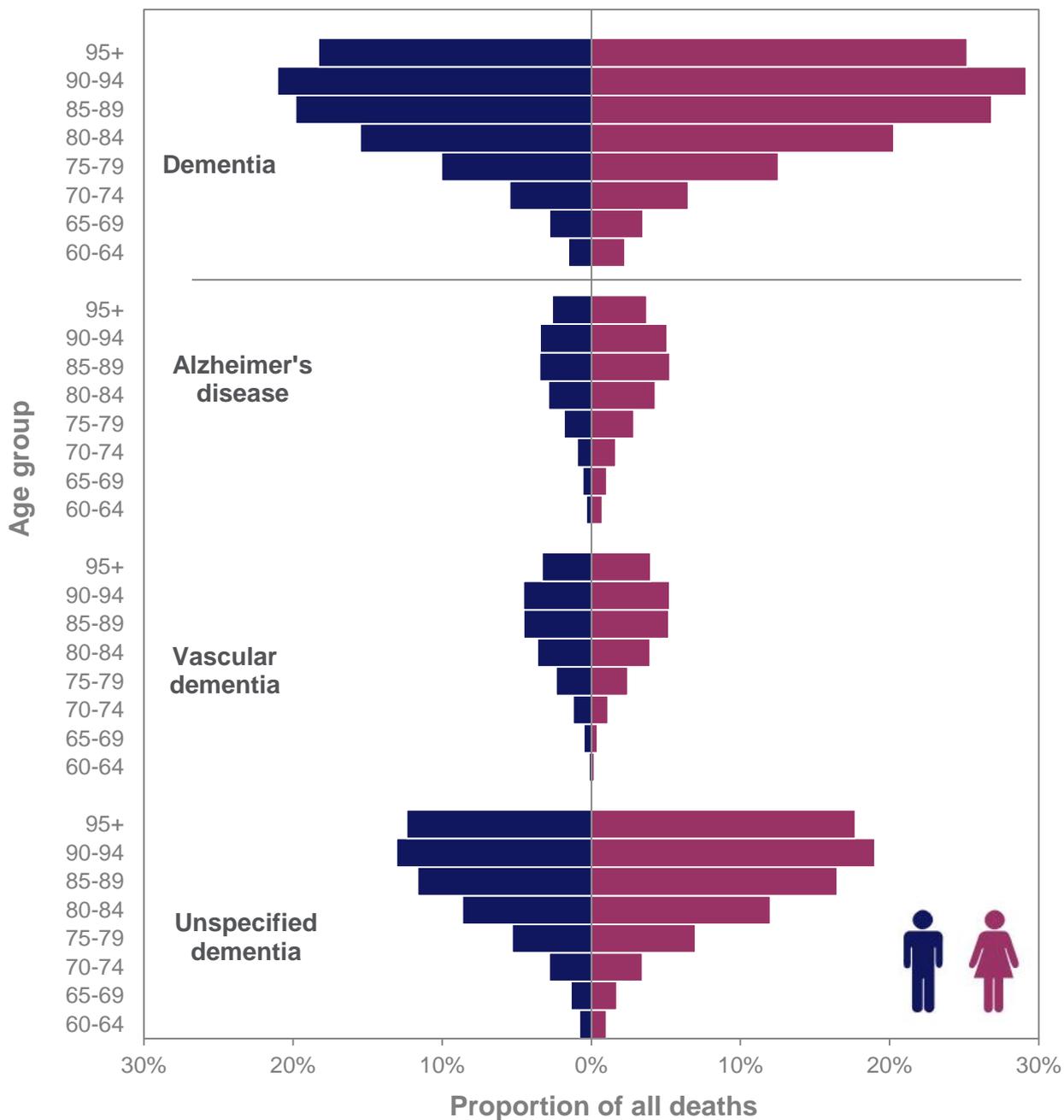


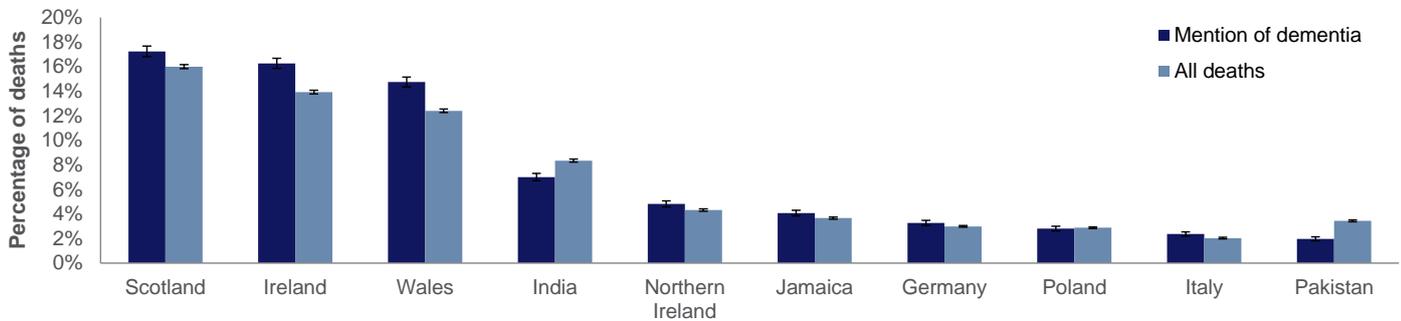
Figure 6: Proportion of all deaths that have any recorded mention of dementia (all subtypes), Alzheimer's disease, vascular dementia, unspecified dementia, England, 2012-2014



2.2. Country of birth

As death records do not include data for the ethnicity of people, this report looks at country of birth as a proxy. The majority of all deaths with dementia occur in people with England as a recorded place of birth (86%). Figure 7 illustrates the countries of birth of those people that have died with dementia, other than those born in England. The main countries of birth include Scotland, Ireland, Wales and India, with countries from the commonwealth and western Europe accounting for between 3% and 5% of deaths. This is a similar picture to that observed for all deaths.

Figure 7: The proportion of deaths with a mention of dementia (all subtypes) and all deaths by country of birth (excluding England), 2012-14



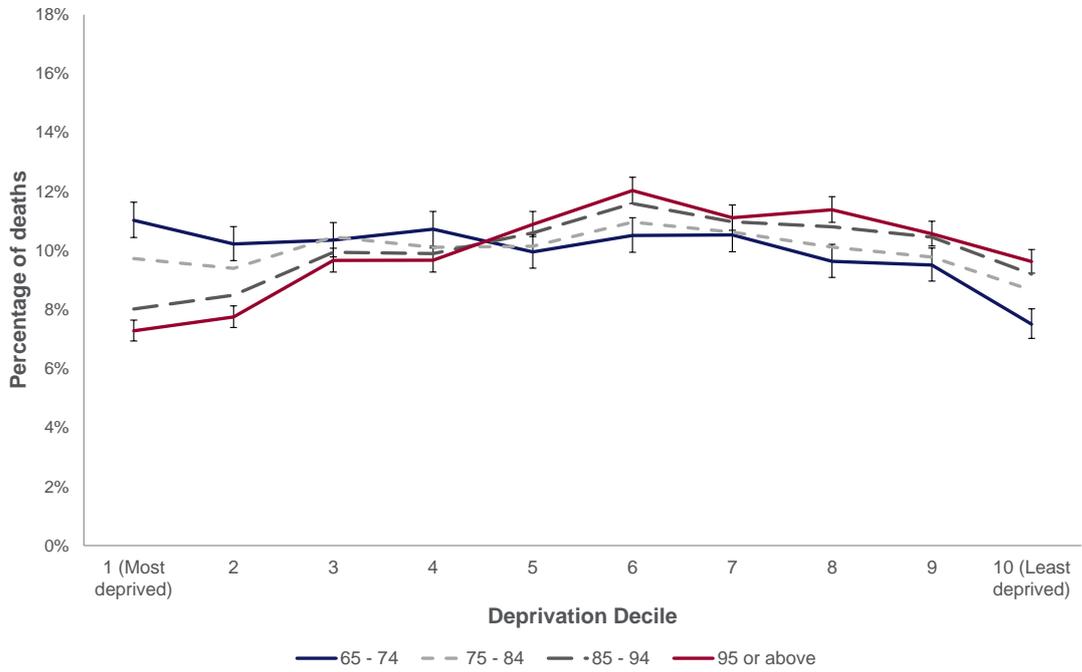
2.3. Deprivation

There is no overall evident relationship between death with dementia and level of deprivation, with between 9% to 11% of deaths in the period in each decile. However, an interesting relationship is observed if age is taken into consideration, where a significantly higher proportion of people aged 65 to 75 who have died with dementia resided in the most deprived decile (11.0%) compared to the least deprived decile (7.5%). Whereas a significantly higher proportion of people aged 95 and over who have died with dementia resided in the least deprived decile (9.6%) compared to the most deprived decile (7.3%) (Figure 8).

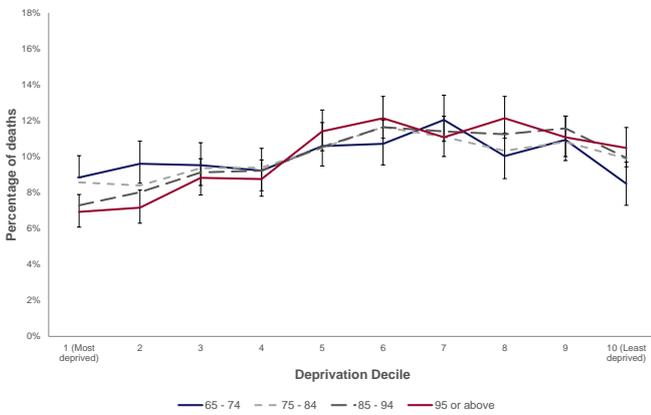
Although the proportion difference is small in both cases, it is a significant difference. This suggests that people that reside in more deprived areas die younger with dementia. In contrast older people with dementia are more likely to reside in the least deprived areas, perhaps due to the increased life expectancy for those in the least deprived areas.¹⁸ For this analysis it is important to take into account that deprivation is calculated from the person's residence, and therefore this may be skewed by the distribution of care homes. However analysis by dementia subtype reveals that this difference is greater for deaths with a mention of vascular dementia, for example a higher proportion people aged 65 to 74 who have died with vascular dementia resided in the most deprived decile (14.6%) compared to the least deprived decile (6.2%).

Figure 8: Percentage of deaths with a mention of dementia by deprivation decile and age group, England, 2012-14

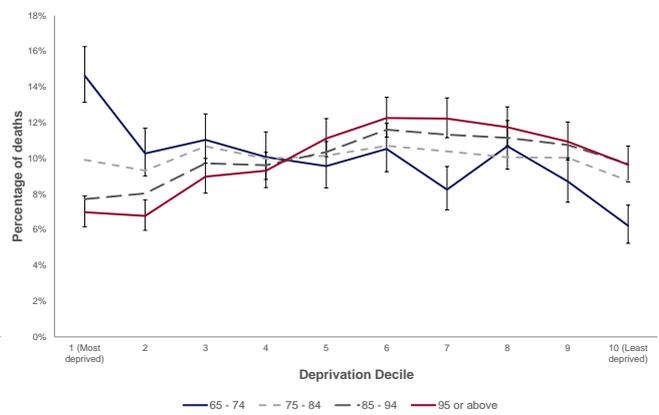
A) Dementia (all subtypes)



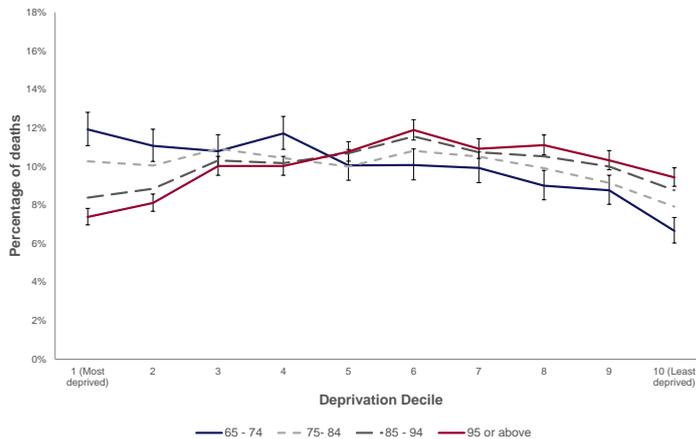
B) Alzheimer's disease



C) Vascular dementia



D) Unspecified dementia



Chapter 3: Where do people with dementia die?

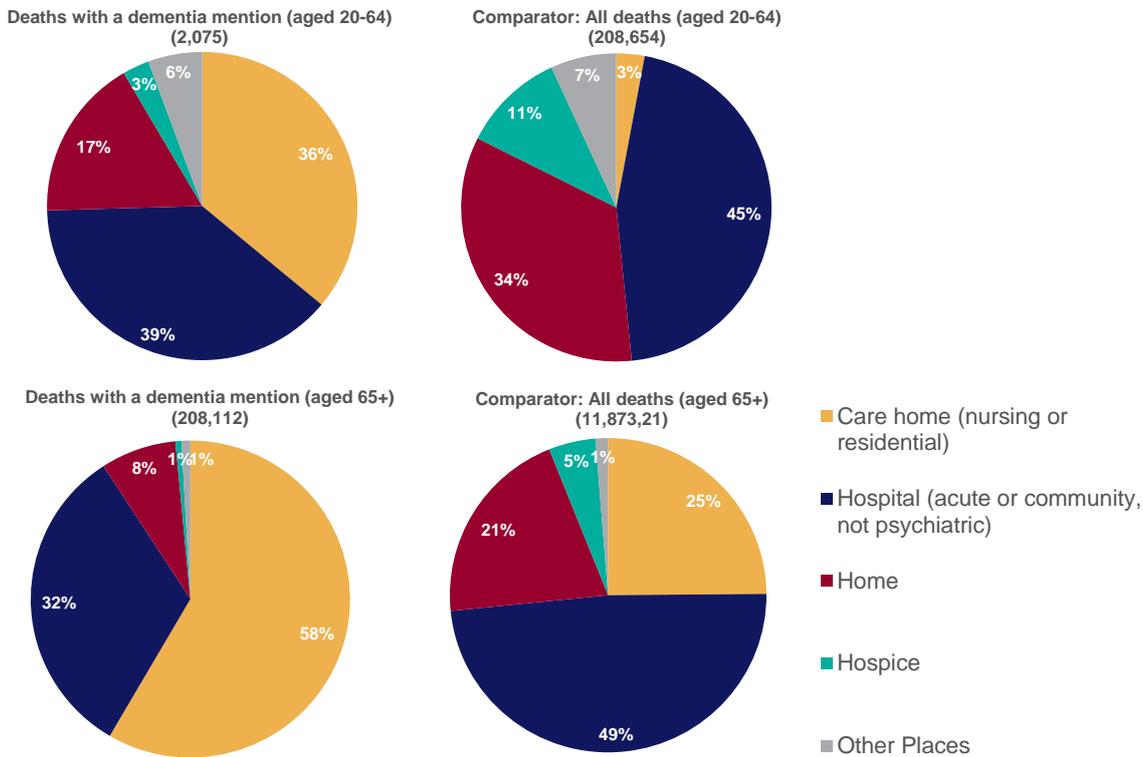
This chapter examines where people with dementia die, whether this is different from the general population and whether these changes are based on subtype, country of birth or deprivation. This has implications for the quality of end-of-life care people with dementia receive.

3.1. Overview of place of death

There are marked differences between the place of death for people with a mention of dementia (all subtypes) compared to all deaths, as shown in Figure 9. A high proportion of deaths of younger individuals (aged 20 to 64) with dementia were recorded in care homes (36%) compared to the general population of the same age (3%). There is a corresponding lower proportion of people with dementia aged 20 to 64 that died at home or in a hospice compared to all deaths. Nearly three-fifths of people aged 65 and over who died with a mention of dementia died in care homes, comparatively only a quarter of all deaths for people aged 65 and over occur in care homes.

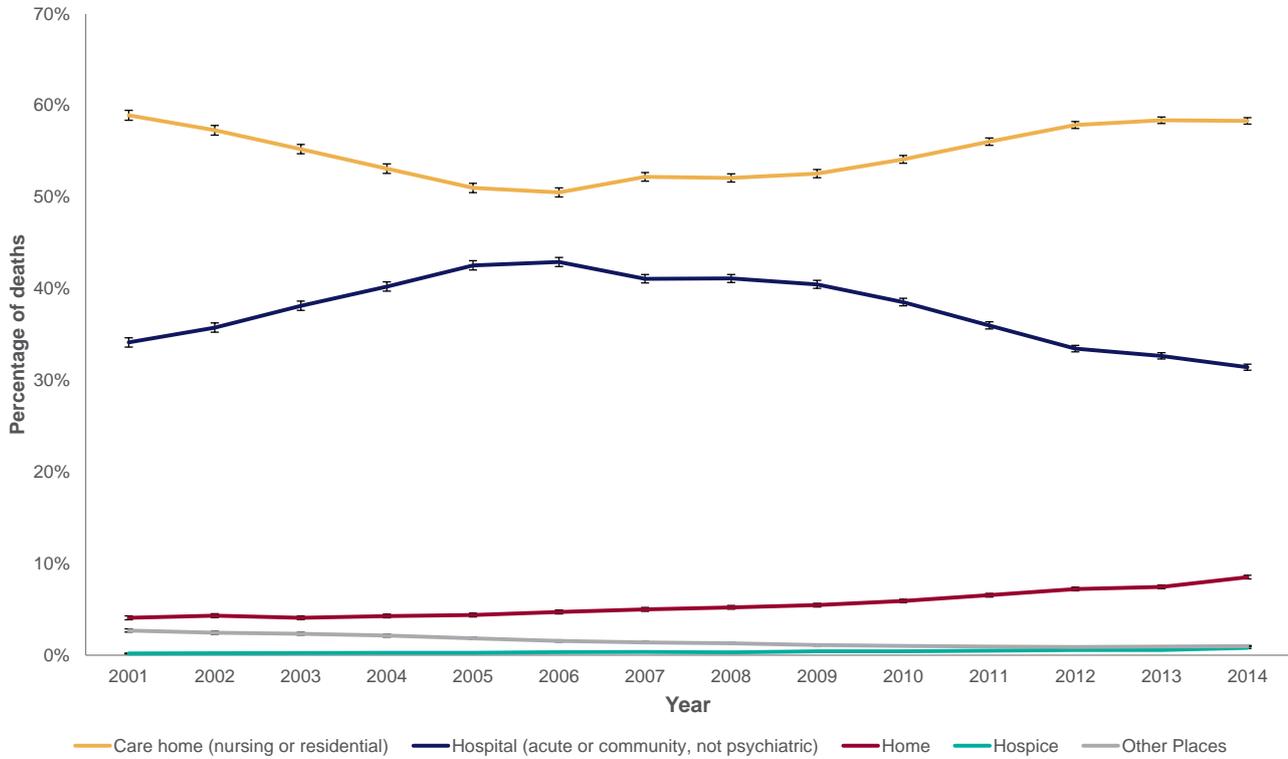
A significantly lower proportion of deaths for people aged 65 and over with a mention of dementia die at home (8%) compared to all deaths for people aged 65 and over (21%). The higher proportion of deaths in care homes for people with dementia compared with all deaths may be due to the higher level of need at the end of life.

Figure 9: The proportion of deaths with a mention of dementia compared to all deaths by place of death, deaths of people aged 20+ and aged 65+, England, 2012-14



The place of death for people with a mention of dementia (all subtypes) has changed over time, from 2007 the proportion of care home deaths has increased to 58% and the proportion of hospital deaths has decreased to 31%, this is a reversal of trends from 2001-2006 (Figure 10). A similar trend has been observed previously, however our analysis now shows that one in three people with dementia died in hospital in 2014 compared to the reported two in five people in 2010.¹⁹ Reasons for the shift from hospitals to care homes included initiatives such as the Community Care Act (2003), where financial incentives were provided to prevent delayed hospital discharges and during this period there were also an increased number of nursing home beds. Although comparatively smaller, deaths at home have significantly increased from 4% in 2001 to 9% in 2014.

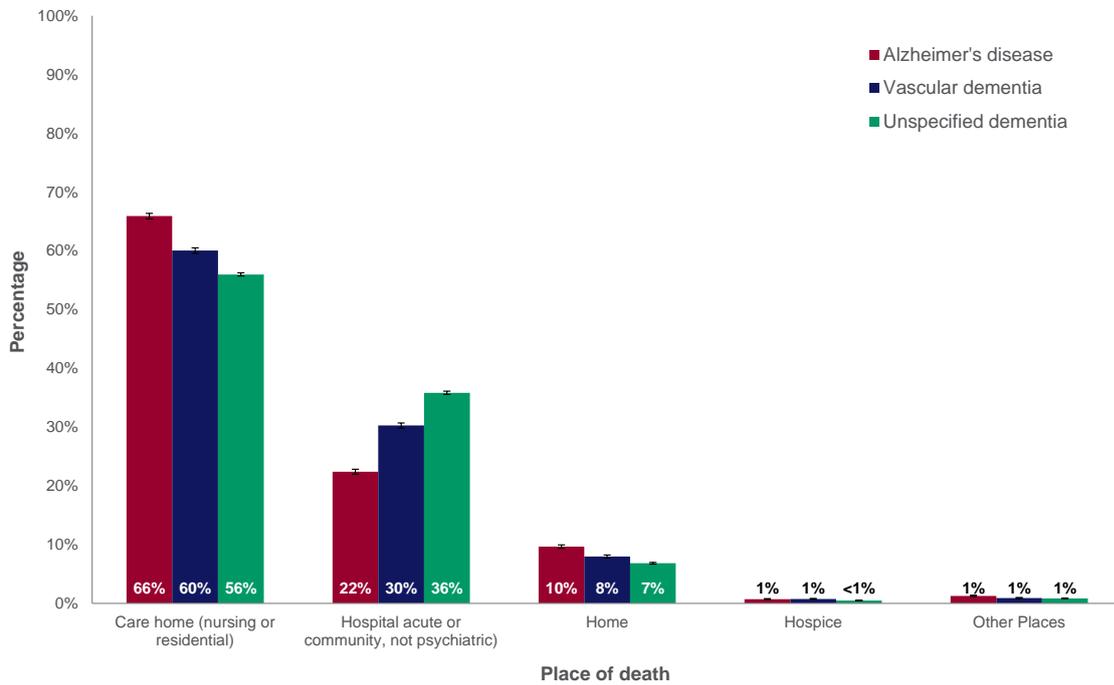
Figure 10: The proportion of deaths with a mention of dementia by place of death, persons aged 20+, England, 2001-2014



3.2. Place of death by dementia subtype

More than half of deaths occur in care homes for all three dementia subtypes. However there is some variation between subtypes, with a significantly higher proportion of deaths with a mention of Alzheimer’s disease in care homes and at home compared to vascular dementia and unspecified dementia (Figure 11). In contrast a significantly higher proportion of deaths with a mention of vascular dementia and unspecified dementia occur in hospital compared to those with a mention of Alzheimer’s disease.

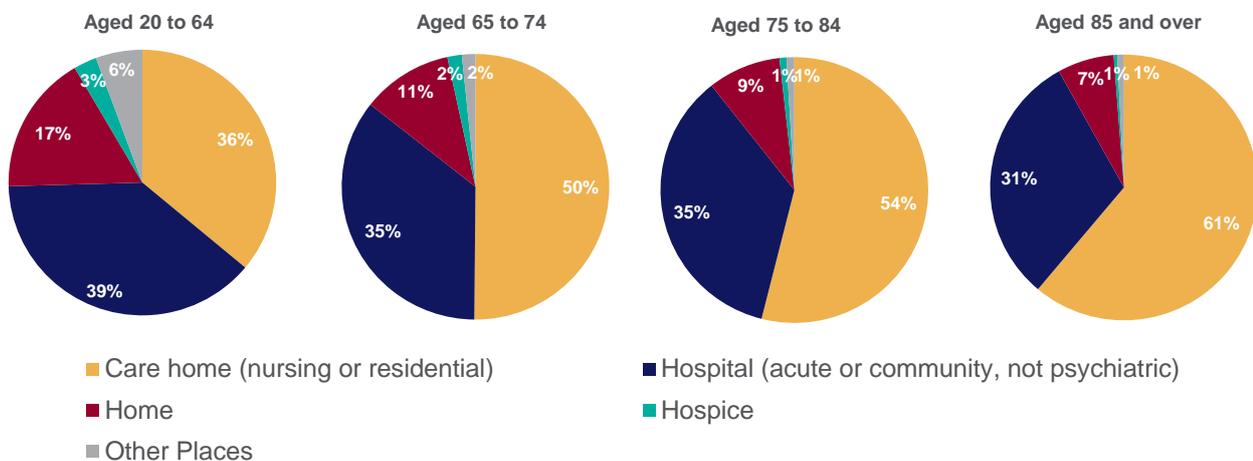
Figure 11: The proportion of deaths with a mention of dementia by subtype and place of death, England, 2012-2014



3.3. Place of death by demographic factors

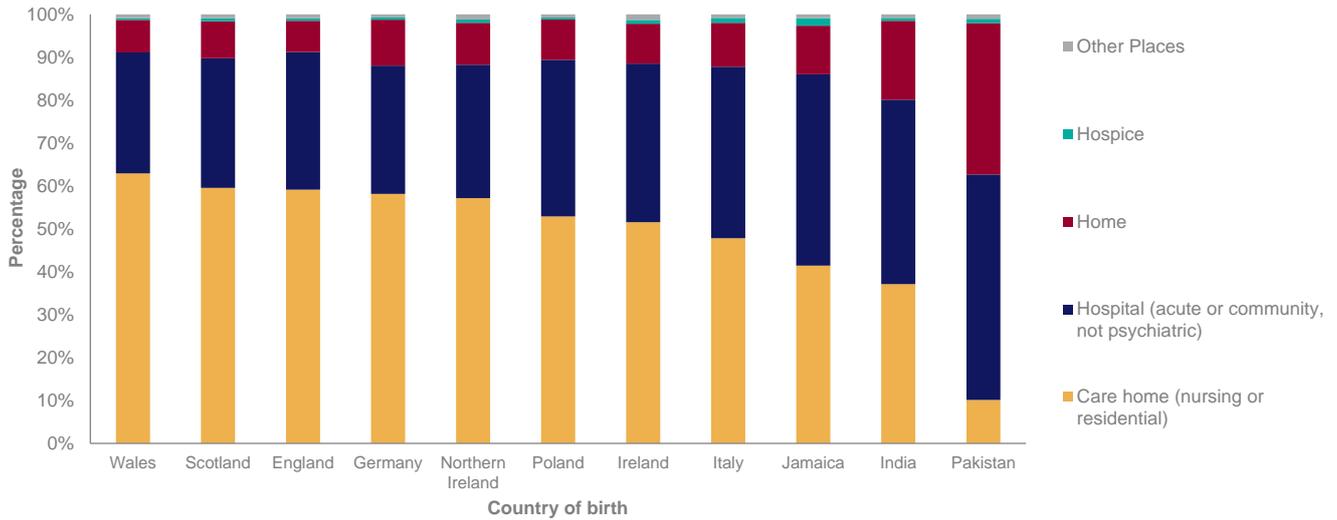
The place of death for people with dementia (all subtypes) changes with age; as people get older they are more likely to die in care homes (Figure 12), whereas the proportion of deaths that occurred in hospitals and at home decreases with age. Differences were also observed between men and women, where women were significantly more likely to die in care homes (62%) compared to men (51%) (Appendix Table 3). Men were more likely to die in hospital (39%) compared to women (29%). This relationship may be related to the higher life expectancy of women compared to men.

Figure 12: The proportion of deaths with a mention of dementia by place of death and age group, England, 2012-14



The country of birth of people with dementia appears to be an influential factor on the place of death, with a higher proportion of deaths in care homes of people born in the UK and Germany, whereas a higher proportion of people born in India and Pakistan have deaths recorded at home (Figure 13).

Figure 13: Proportion of deaths for people with a mention of dementia (all subtypes), by country of birth and place of death, 2012-14



There are small differences between place of death and deprivation. Deaths that happen at home are significantly more likely to occur in the least deprived decile (10.9%) than the most deprived decile (8.4%), although the difference is small. In contrast, deaths that occur in hospital are more likely to occur in the most deprived decile (10.3%) compared to the least deprived decile (8.2%) (Appendix Table 4).

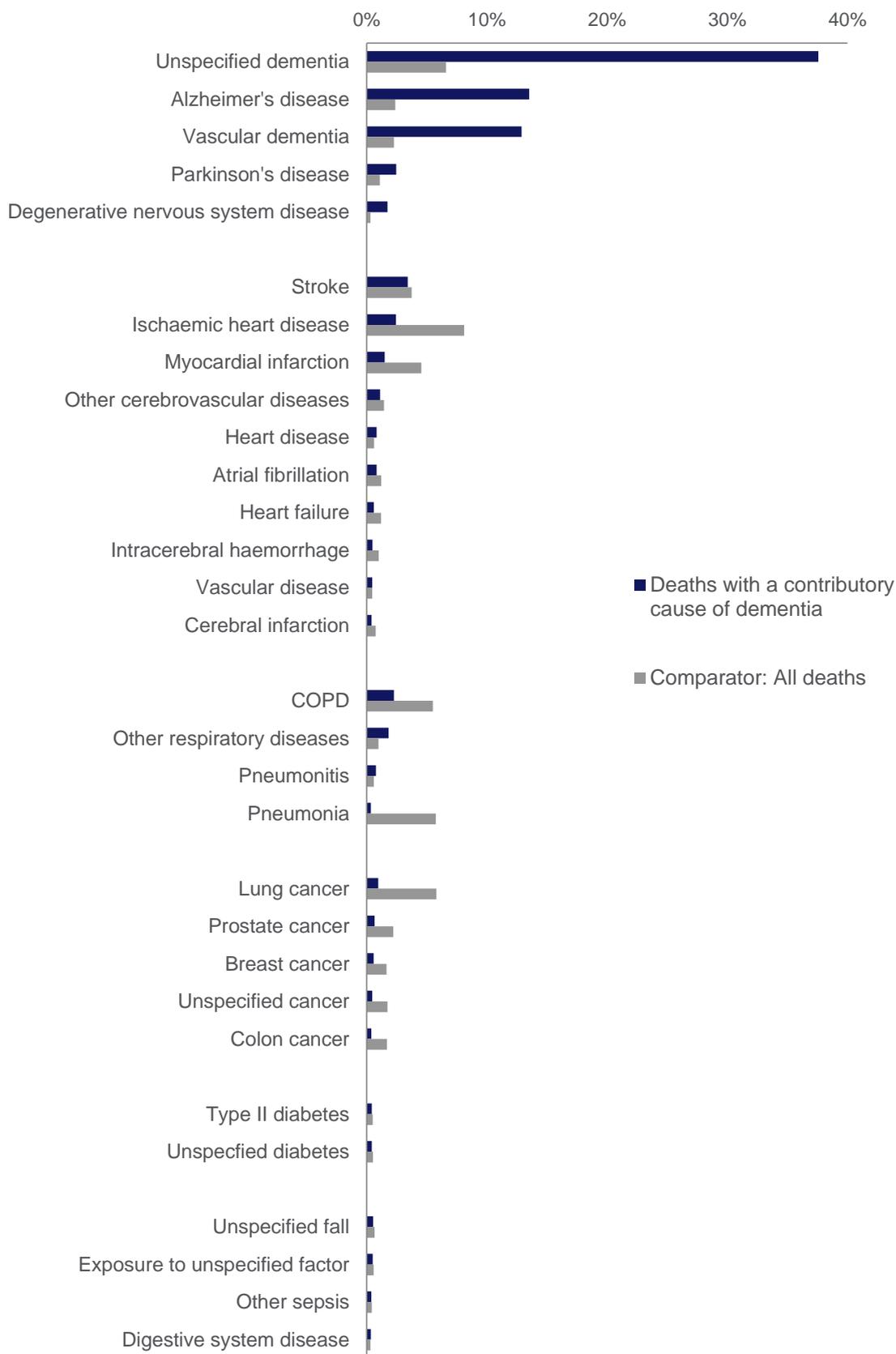
Chapter 4: Causes of death for people with dementia

This chapter looks at what people with dementia die with, specifically looking at the underlying cause of death and the comorbidities within three major mortality groups: respiratory disease, circulatory disease and malignant cancers. This is with the view that people's needs may change depending on their diagnoses. To avoid small numbers in some lower age category breakdowns the following analysis is restricted to people aged 65+.

4.1. Underlying cause of death

The profile of the underlying cause of death for people who died with a contributory cause of dementia (all subtypes) appears to be markedly different from the profile for all deaths (Figure 14). For example for deaths with a contributory cause of dementia, 64% also have an underlying cause of a dementia subtype. Following this the most common underlying cause of death for people with a contributory cause of dementia was stroke, Parkinson's disease and ischaemic heart disease. In comparison, for all deaths for people aged 65 and over, the top underlying causes of death were heart disease, unspecified dementia and lung cancer.

Figure 14: Proportion of deaths by underlying cause of death for those with a contributory cause of dementia and comparator all deaths, (Top 30 causes), people aged 65+, England, 2012-14



4.2. Deaths with a mention of dementia (all subtypes) and three major mortality groups

Respiratory and circulatory diseases in addition to malignant cancers represent the three major mortality groups. From all deaths for people aged 65 and over, 37%, 49% and 30% include a mention of respiratory diseases, circulatory diseases and malignant cancers, respectively.

Between 2012 and 2014, 79,434 people aged 65 and over died with a mention of dementia and a mention of respiratory diseases. This represents 38% of all people aged 65 and over who died with a mention of dementia. The age and gender profile for those dying with dementia and respiratory disease is similar to that observed for dementia overall (Figure 15). A higher proportion of men have a mention of both dementia and respiratory disease (46%) compared to 34% of women. For all deaths of people aged 65 and over with a mention of respiratory disease 18% also had a mention of dementia.

Between 2012 and 2014, 75,089 people aged 65 and over died with a mention of dementia and circulatory diseases. This represents 36% of all people aged 65 and over who died with a mention of dementia. The age and gender profile for people dying with both dementia and circulatory diseases is similar to that observed for dementia overall (Figure 15). A higher proportion of men have a mention of dementia and circulatory disease (38%) compared to 35% of women. For all deaths of people aged 65 and over with a mention of circulatory disease 13% also had a mention of dementia.

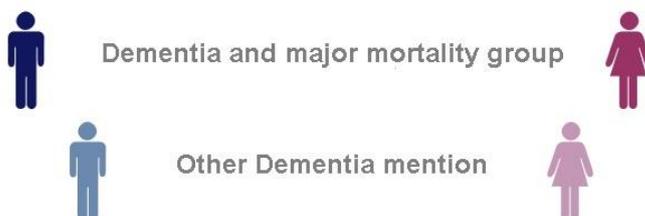
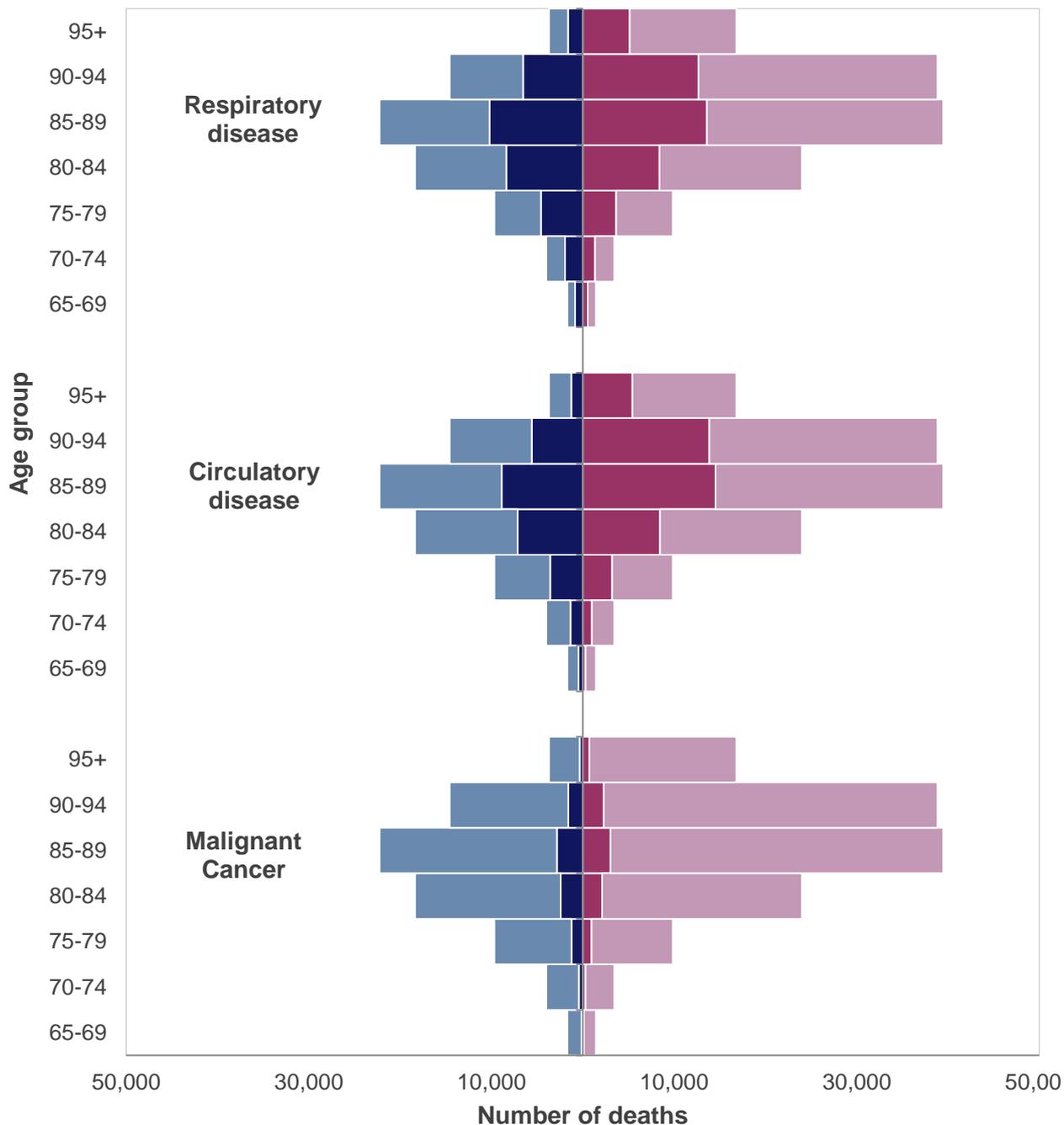
Between 2012 and 2014, 18,532 people aged 65 and over died with a mention of dementia and malignant cancer. This represents 9% of deaths with a mention of dementia. This represents a relatively smaller proportion of deaths with a mention of dementia compared to respiratory disease or circulatory disease, perhaps due to the younger age profile of those who have died with cancer. A higher proportion of men have a mention of dementia and malignant cancer (12%) compared to 7% of women. For all deaths of people aged 65 and over with a mention of malignant cancer 5% also had a mention of dementia.

Box 2: Respiratory diseases occupy codes J00 to J99 in the ICD-10 coding system. Major causes of death within this broad category include influenza (J10–J11), pneumonia (J12–J18) and chronic lower respiratory diseases (J40–J47).

Box 3: Circulatory diseases occupy codes I00 to I99 in the ICD10 coding system, and include some of the most common causes of death, including ischaemic heart diseases (I20–I25) and cerebrovascular diseases (I60–I69).

Box 4: Malignant cancers occupy codes C00 to C97 in the ICD-10 coding system. Major causes of death within this broad category include lung cancer (C33–C34), colorectal cancer (C18–C21), breast cancer (C50) and prostate cancer (C61).

Figure 15: Deaths with a mention of dementia (all subtypes) with and without a mention of three major mortality groups, by age and gender, England, 2012-14



4.3. Place of death by major mortality group and dementia

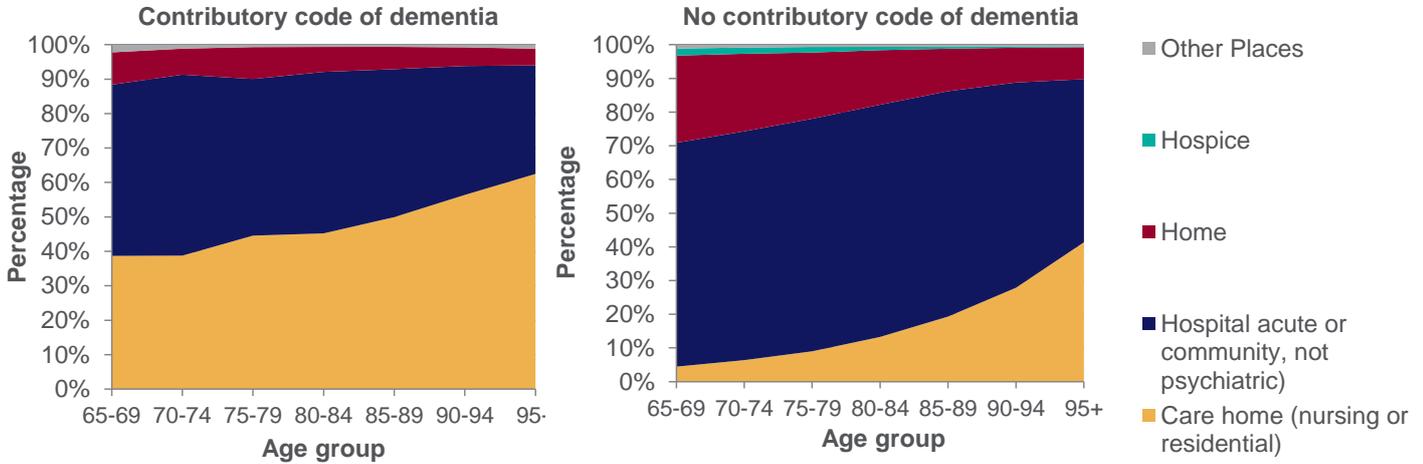
Deaths recorded with an underlying cause of respiratory disease and a contributory cause of dementia are most likely to occur in care homes (50%). This likelihood increases with age, ranging from 39% in people aged 65-69 to 62% in those aged 95 and over (Figure 16). Comparatively, with no contributory cause of dementia, care home deaths range from 4% in those aged 65-69 to 41% in those aged 95 and over. A lower proportion of deaths with an underlying cause of respiratory disease occur in hospitals and at home for people with a contributory cause of dementia, compared to those without a contributory cause of dementia.

The highest proportion of deaths with circulatory disease and dementia die in care homes, ranging from 39% in those aged 65-69 to 59% in those aged 95 and over. In comparison, for people with circulatory disease and no contributory cause of dementia, this ranges from 3% in those aged 65-69 to 42% in those aged 95 and over. People with an underlying cause of circulatory disease and dementia are less likely to die at home (8%), compared to those with circulatory disease and no dementia (26%). For both groups the likelihood of dying at home decreases with age.

More than half of all deaths with an underlying cause of malignant cancer and a contributory cause of dementia occur in care homes (53%). This proportion increases with age. People with cancer are twice as likely to die at home (30%) compared to those with cancer and dementia (15%). This is a higher proportion in all age groups. A higher proportion of deaths with an underlying cause of cancer and no contributory cause of dementia die in hospices compared to people with dementia as a contributory cause.

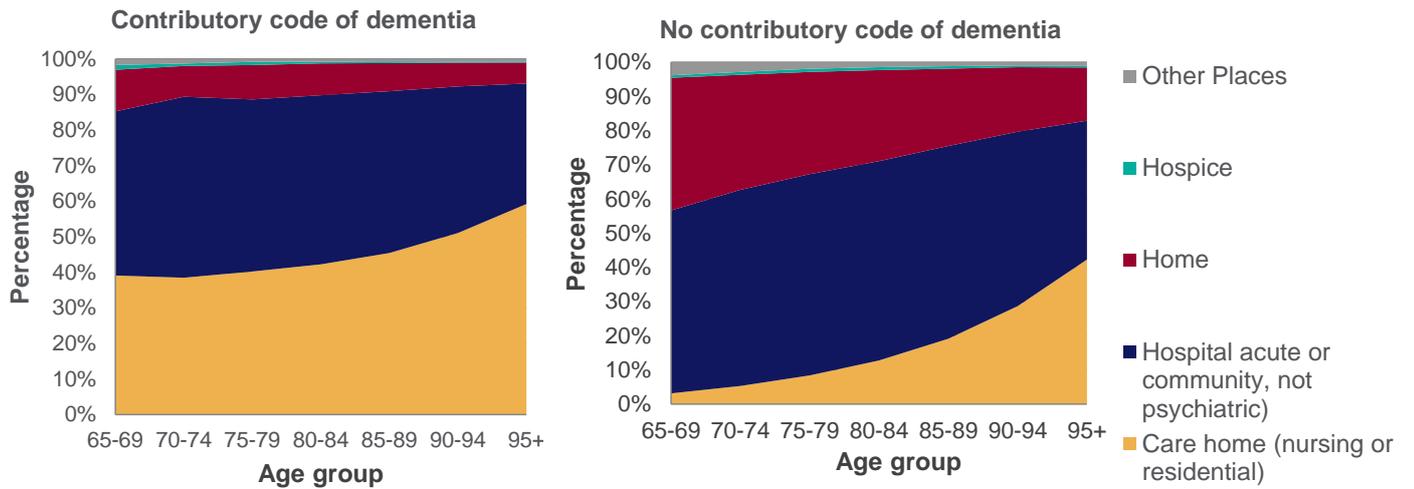
Figure 16: The proportion of deaths with an underlying cause of major mortality groups with or without dementia (all subtypes) as a contributory cause, by place of death and age, England, 2012-14

A) Respiratory disease

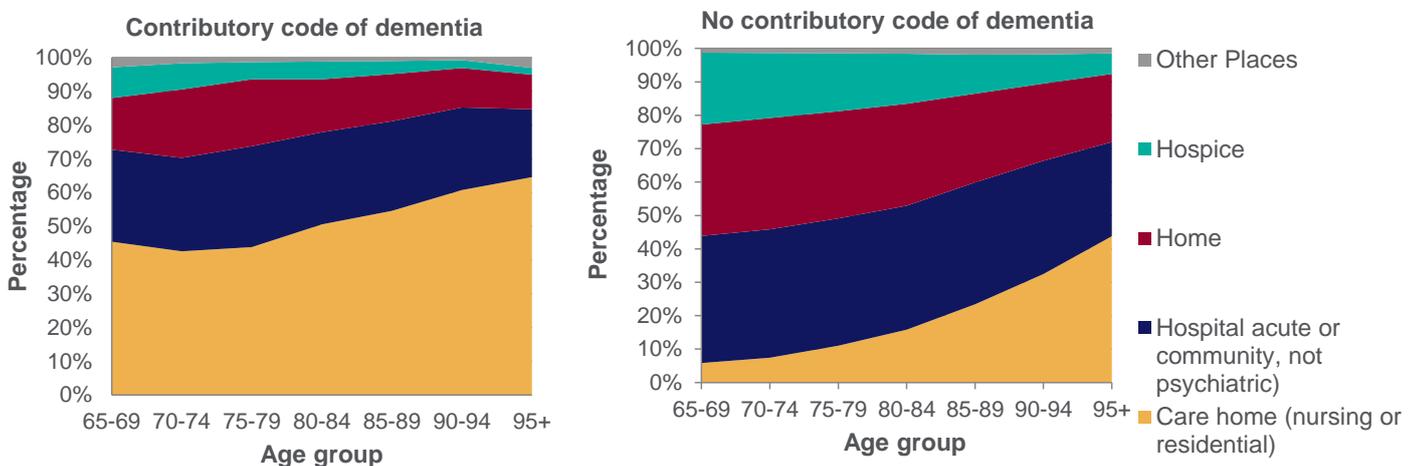


Note: Deaths in hospice with an underlying cause of respiratory disease and a contributory code of dementia have been omitted due to small disclosive numbers.

B) Circulatory disease



C) Malignant cancer



Conclusions

This report provides information on people who have died with a recorded mention of dementia in England. It covers how trends have changed over time, the geographical distribution of deaths with a mention of dementia, demographics of people who have died with dementia, the place of death and the comorbidities recorded on the death certificate.

This analytical report has provided a detailed understanding into deaths with a recorded mention of dementia, with the aim of informing policy and commissioning on end of life for people with dementia. However, it is important to highlight its limitations of the analysis. For example, due to the nature of recording on death certificates, the analysis is restricted to deaths where dementia was recorded a significant contributory factor. Therefore, the figures reported are likely to be an underestimate of all people who have died with dementia.

Further work in this area should focus on the end of life care that people with dementia receive. The linked Hospital Episode Statistics and the ONS mortality dataset will provide an insight into people with dementia reaching the end of life, looking at the nature of admissions and the frequency of emergency admissions in the period leading up to the death. It is also important that work is done to collect and analyse national surveys and audits as this will provide an important understanding on end of life care preferences, in addition to carers' and clinicians' reflections on the end of life journey for someone with dementia. Detail on the policy context and policy implications can be found in the 'Dying with dementia' intelligence briefing within this publication release.

Appendix

Figure 1: Numbers of deaths with an underlying cause of dementia, people aged 20+, England, 2001-14

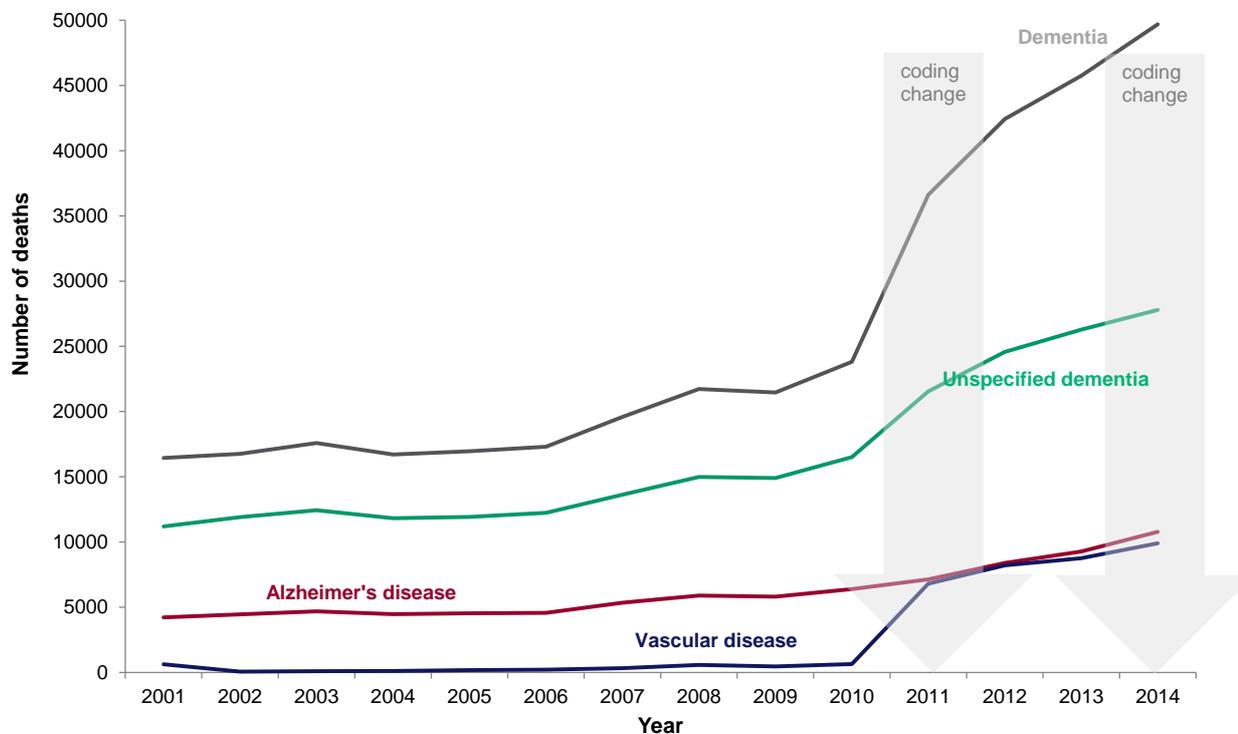


Table 1: Average age of death for people with a mention of dementia by gender, England, 2001-2014

Year	Persons	Men	Women
2001	84	82	85
2002	84	82	85
2003	84	82	85
2004	84	82	85
2005	85	82	86
2006	85	83	86
2007	85	83	86
2008	85	83	86
2009	85	83	86
2010	85	83	87
2011	85	83	87
2012	86	84	87
2013	86	84	87
2014	86	84	87

Table 2: Average age of death for people with a mention of dementia, Alzheimer's disease, vascular dementia or unspecified dementia, England, 2001-2014

Year	Alzheimer's disease	Vascular dementia	Unspecified dementia
2001	83	83	85
2002	83	83	85
2003	83	83	85
2004	83	83	85
2005	83	84	85
2006	83	83	85
2007	84	84	85
2008	84	84	86
2009	84	84	86
2010	84	84	86
2011	84	85	86
2012	85	85	86
2013	85	86	86
2014	85	86	86

Table 3: Number and percentage of deaths with a mention of dementia by place of death and gender, England, 2012-14

Place of death	Men		Women	
	Number	Percentage	Number	Percentage
Care home (nursing or residential)	38,404	51%	83,929	62%
Home	5,958	8%	10,319	8%
Hospice	642	0.9%	696	0.5%
Hospital (acute or community, not psychiatric)	29,614	39%	38,657	29%
Other Places	699	1%	1,269	1%
Total	75,317	100%	134,870	100%

Table 4: Percentage of deaths with a mention of dementia by place of death and deprivation, England, 2012-14

Deprivation decile	Care home (nursing or residential)	Home	Hospice	Hospital (acute or community, not psychiatric)	Other Places	Grand Total
1 (Most deprived)	7.7%	8.4%	9.2%	10.3%	12.4%	8.6%
2	8.2%	8.3%	8.0%	10.0%	6.8%	8.8%
3	9.9%	8.7%	9.6%	10.8%	10.8%	10.1%
4	9.9%	9.8%	9.9%	10.2%	10.7%	10.0%
5	10.5%	10.0%	9.6%	10.5%	11.6%	10.5%
6	11.9%	10.7%	9.1%	10.6%	11.3%	11.4%
7	11.3%	10.9%	11.1%	10.0%	14.7%	10.9%
8	11.0%	11.1%	11.4%	9.8%	7.4%	10.6%
9	10.6%	11.1%	11.8%	9.4%	7.2%	10.2%
10 (Least deprived)	9.1%	10.9%	10.3%	8.2%	7.0%	9.0%

References

- ¹ Prime Minister's challenge on dementia 2020 report
www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020
- ² Prime Minister's Challenge on Dementia 2020 Implementation Plan (March 2016)
www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan
- ³ Living well with dementia: A National Dementia Strategy (2009) Department of Health
www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy
- ⁴ NICE Dementia: support in health and social care <https://www.nice.org.uk/guidance/qs1>
- ⁵ Deaths Registered in England and Wales (Series DR), 2014
www.ons.gov.uk/ons/dcp171778_422395.pdf
- ⁶ Focus on Dementia www.hscic.gov.uk/catalogue/PUB19812
- ⁷ Deaths from Alzheimer's disease, dementia and senility in England (2010)
- ⁸ Alzheimer's Society Dementia Subtypes www.alzheimers.org.uk/typesofdementia/
- ⁹ Dementia Revealed: What Primary Care Needs to Know A Primer for General Practice (2014)
www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf
- ¹⁰ LHO Age Standardised Rates
www.lho.org.uk/LHO_Topics/Data/Methodology_and_Sources/AgeStandardisedRates.aspx
- ¹¹ ONS Mortality Statistics: Metadata (July 2015)
- ¹² Results from the ICD-10 v2010 bridge coding study (Statistical Bulletin), February 2011
- ¹³ Impact of the Implementation of IRIS Software for ICD-10 Cause of Death Coding on Mortality Statistics, England and Wales (Statistical Bulletin 2013), August 2014
- ¹⁴ Griffiths C and Rooney C. Trends in mortality from Alzheimer's disease, Parkinson's disease and dementia, England and Wales 1979-2004. *Health Statistics Quarterly* 30 (2006): 6-14.
- ¹⁵ ONS Statistical Bulletin: Deaths Registered in England and Wales (Series DR), 2013
- ¹⁶ Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015 (2012) Department of Health
www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf
- ¹⁷ ONS Statistical Bulletin Results from the ICD-10 v2010 bridge coding study (2011)
<http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/sunational-health3/results-of-the-icd-10-v2010-bridge-coding-study--england-and-wales--2009/2009/index.html>
- ¹⁸ Inequality in healthy life expectancy at birth by national deciles of area deprivation: England, 2011 to 2013 (ONS, March 2015)
- ¹⁹ Sleeman *et al.* (2014) Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001-2010 *BMC Neurology* 14: 1-9