

Statistical bulletin

Deaths in the care sector, England and Wales: 2019

Registered deaths of care home residents by underlying cause of death and the leading causes of death. Contains characteristics of care home residents and death registrations by area of usual residence. Classified as Experimental Statistics.

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Next release: To be announced

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1. Main points

- In England, there were 131,149 deaths of care home residents (wherever the death occurred); this is a decrease of 2.4% compared with 2018 (134,379 deaths).
- In Wales, there were 6,849 deaths of care home residents (wherever the death occurred); this is a decrease of 8.2% compared with 2018 (7,458 deaths).
- England had a statistically significantly higher age-standardised mortality rate (ASMR) for deaths of care home residents in both males and females (9,516.9 deaths per 100,000 male care home residents and 6,953.0 deaths per 100,000 female care home residents) compared with Wales (7,494.1 and 6,095.7 deaths respectively).
- The North East was the region of England with the highest mortality rates and London was the region with the lowest; this difference was statistically significant.
- Dementia and Alzheimer disease was the leading cause of death in both male and female care home residents in England (30.6% and 37.9% respectively) and Wales (33.8% and 39.0% respectively) in 2019.
- The majority of deaths of care home residents occurred within the care home in England (84.8%) and Wales (79.6%).

This release provides annual 2019 death registration data and should not be compared with the weekly 2020 death occurrence data presented in the <u>Deaths involving COVID-19</u> in the care sector articles. Once we have a full picture of the coronavirus (COVID-19) data for 2020, we can use this release as a baseline comparison.

2. Overview of deaths in the care sector

This is a new release for the Office for National Statistics (ONS) covering deaths registered to care home residents in England and Wales and will be updated on an annual basis. This bulletin contains detailed analysis of all deaths of care home residents that were registered in 2019. These data are based on where the person lived, so deaths of care home residents are counted whether they died in the care home or somewhere else. Some information on deaths of recipients of domiciliary care, living in private homes, is also provided. Please note this release presents England and Wales data separately because of the <u>devolved nature of social care</u>.

The term "care home residents" used in this bulletin refers to all deaths where either (a) the death occurred in a care home or (b) the death occurred elsewhere but the place of residence of the deceased was recorded as a care home. The figures should not be confused with "deaths in care homes" as reported in other releases, which refers only to category (a).

3. Age-standardised mortality rates

This section presents age-standardised mortality rates (ASMRs) for deaths of care home residents. These are a better measure of mortality than the number of deaths, as they account for the population size and age structure. We have calculated the care home population using population projections and <u>2011 Census data</u>; for more information, see <u>Section 12</u>: <u>Measuring the data</u>.

Since 2015, the first year of data currently available for care home resident deaths, mortality rates in England have slowly been increasing for male care home residents. The difference between 2015 (9,111.3 deaths per 100,000 male care home residents) and 2019 (9,516.9 deaths per 100,000 male care home residents) is <u>statistically significant</u>. For female residents, there have been fluctuations in mortality rates over the past five years however none of these changes were significant.

In Wales, there have been fluctuations in mortality rates since 2015 for both male and female care home residents, but none of these changes were significant (Figure 1).

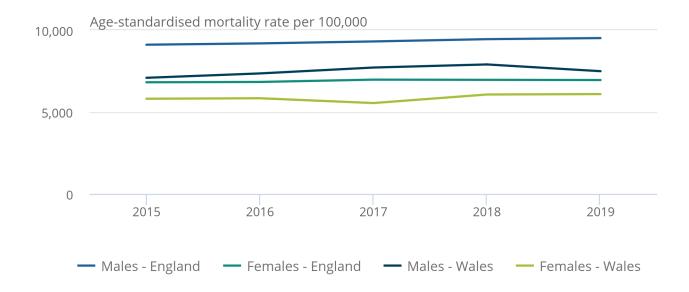
In 2019, England had a statistically significantly higher ASMR for deaths of care home residents in both males and females (9,516.9 deaths per 100,000 male care home residents and 6,953.0 deaths per 100,000 female care home residents) compared with Wales (7,494.1 and 6,095.7 deaths respectively).

Figure 1: Male and female care home residents in England had higher age-standardised mortality rates than those in Wales

Age-standardised mortality rates, England and Wales, deaths registered in 2015 to 2019

Figure 1: Male and female care home residents in England had higher age-standardised mortality rates than those in Wales

Age-standardised mortality rates, England and Wales, deaths registered in 2015 to 2019



Source: Office for National Statistics - Deaths in the care sector, England and Wales

Notes:

- 1. Based on deaths registered in each calendar year.
- 2. Figures exclude deaths of non-residents.
- 3. These rates are for all ages and are standardised to the 2013 European Standard Population.

A lower mortality rate is expected among female care home residents because, on average, <u>women are living longer than men</u>. Furthermore, it is estimated that there are more females in the care home resident population; in our estimates, females account for 66.5% of the care home resident population in England and 67.2% of the care home resident population in Wales.

More research is needed to investigate the reasons of the change in structure of the care home population over time. This is an area we are hoping to investigate further as more data become available.

4. Deaths of care home residents

England

In 2019, the ONS reported there were 6,849 deaths registered in Wales (2,381 male deaths and 4,468 female deaths), an 8.2% decrease in deaths registered compared with 2018 (7,458 deaths).

The Care Quality Commission (CQC) receives statutory death notifications from care home providers in England. In Figure 2, we have plotted Office for National Statistics (ONS) death registrations alongside CQC death notifications to compare. In 2019, there were 126,990 deaths among care home residents notified to the CQC, a 1.4% decrease compared with 2018 (128,821 deaths).

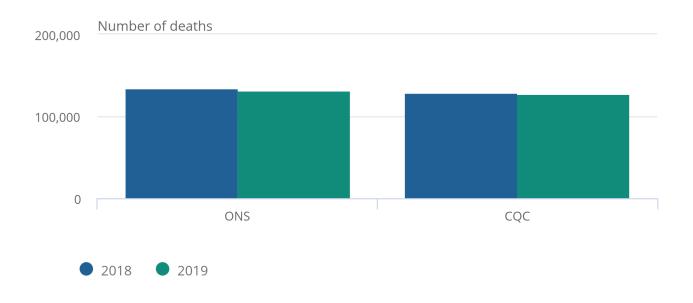
An important difference between the two sources is that the ONS reports death registrations while the CQC notifications rely on death notifications from the care home provider. CQC data are more timely as providers have a statutory responsibility to provide a <u>death notification without delay</u>. The CQC does not hold person-level information that allows a direct comparison between the two sources and so an accurate assessment between the different reporting criteria cannot be determined. More information can be found in <u>Section 12</u>: <u>Measuring the data</u>.

Figure 2: There was a decrease in the number of care home resident deaths between 2018 and 2019

Number of deaths of care home residents, England, 2018 to 2019

Figure 2: There was a decrease in the number of care home resident deaths between 2018 and 2019

Number of deaths of care home residents, England, 2018 to 2019



Source: Office for National Statistics and the Care Quality Commission

Notes:

- 1. All Office for National Statistics (ONS) figures are based on the date the death was registered in each calendar year.
- 2. ONS figures exclude deaths of non-residents.
- 3. Care Quality Commission (CQC) figures are based on death notifications from care homes.
- 4. CQC figures do not report on the local authority of the Isles of Scilly, as the low number of care homes in this local authority would potentially identify specific providers.
- 5. CQC figures do not include the local authority City of London, as for these reporting years there were no care homes located in this local authority.
- 6. The CQC uses ONS postcode directory to assign a local authority to a location. Locations without English local authorities, either those on the border with Wales or newbuilds considered "Unspecified", have had their local authorities reviewed and have been manually changed for them to be included in the data.

Wales

Similar to the pattern observed in England, there was a decrease in the total number of care home resident deaths between 2018 and 2019 in Wales. In 2019, the ONS reported there were 6,849 deaths registered in Wales (2,381 male deaths and 4,468 female deaths), an 8.2% decrease in deaths registered compared with 2018 (7,458 deaths).

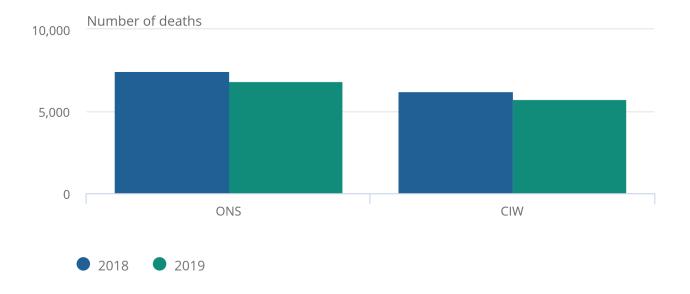
In Wales, care homes are required to notify the Care Inspectorate Wales (CIW) of the location and cause of death of care home residents; see <u>Section 12: Measuring the data</u> for more information. In 2019, CIW were notified of 5,729 deaths of care home residents, a decrease of 8.3% compared with 2018 (Figure 3).

Figure 3: Between 2018 and 2019, there has been a decrease in care home resident deaths

Number of deaths of care home residents, Wales, 2018 to 2019

Figure 3: Between 2018 and 2019, there has been a decrease in care home resident deaths

Number of deaths of care home residents, Wales, 2018 to 2019



Source: Office for National Statistics and Care Inspectorate Wales

Notes:

- 1. All Office for National Statistics (ONS) figures are based on the date the death was registered in each calendar year.
- 2. ONS figures exclude deaths of non-residents.
- 3. Care Inspectorate Wales (CIW) figures are based on death notifications from care homes.

During 2019, care home services were undergoing re-registration with CIW because of new legislation, which introduced a new method of notifying CIW of deaths of care home residents. This may have resulted in some disruptions to notifications being submitted. From 2018, CIW collection and reporting of deaths data changed and therefore no data are available before 2018. More information can be found in <u>Section 12: Measuring the data</u>.

5. Characteristics of deaths of care home residents

This section analyses deaths of care home residents (wherever the death occurred) broken down by the following protected characteristics covered by the Equality Act 2010: sex, age, disability status, ethnicity and religion.

Age

In 2019, there were 131,149 deaths (2.4% lower than in 2018) of care home residents registered in England and 6,849 deaths (8.2% lower than in 2018) of care home residents registered in Wales.

Of total deaths, males accounted for 37.7% (36.5% in 2018) and 34.8% (34.0% in 2018) of all deaths registered in England and Wales respectively. Females accounted for 62.3% (63.5% in 2018) and 65.2% (66.0% in 2018) of all deaths registered in England and Wales respectively.

Since 2015, in England, age-specific mortality rates of both male and female care home residents increased with age, with males having a <u>statistically significant</u> higher age-specific mortality rate than females for ages 65 years and over.

The age group 85 years and over had the highest age-specific mortality rate for both males and females for the past five years. However, while there have been fluctuations, mortality rates were statistically significantly lower in 2019 (57,567.0 deaths per 100,000 male care home resident and 37,071.9 deaths per 100,000 female care home residents) than in 2015 (61,614.9 deaths per 100,000 male care home residents and 40,952.4 deaths per 100,000 female care home residents) for this age group for both males and females.

Male and female mortality rates were higher in the younger age groups (0 to 64 years and 65 to 74 years) in 2019 than in 2015. This difference was statistically significant for males in both age groups and for females in the age group 65 to 74 years. This is likely to have contributed to the overall increase in age-specific mortality rates, but more research is needed into this area.

Figure 4: In England, males aged 65 years and over had statistically significantly higher mortality rates than females

Age-specific mortality rates for deaths of care home residents per 100,000 population, England, 2015 to 2019

Notes:

- 1. Based on deaths registered in each calendar year
- 2. Figures exclude deaths of non-residents.
- 3. These rates are for all ages and are standardised to the 2013 European Standard Population.

Download the data

Similar to England, since 2015 mortality rates for male and female care home residents in Wales increased with age with males having a higher age-specific mortality rate than females for ages 65 years and over. For ages 75 years and over, the difference between male and female mortality rates has been statistically significant across all years since 2015.

Both males and females aged 85 years and over had the highest age-specific mortality for the past five years. However, while there have been fluctuations, mortality rates were lower for this age group for both males and females in 2019 (49,804.7 deaths per 100,000 male care home residents and 35,485.8 per 100,000 female care home residents) than in 2015 (51,057.6 deaths per 100,000 male care home residents and 39,588.7 per 100,000 female care home residents). This difference was statistically significant for females only.

Figure 5: In Wales, females had a higher mortality rate for those aged under 65 years, but males had a higher mortality rate for those aged over 65 years

Age-specific mortality rates for deaths of care home residents per 100,000 population, Wales, 2015 to 2019

Notes:

- 1. Based on deaths registered in each calendar year.
- 2. Figures exclude deaths of non-residents.
- 3. These rates are for all ages and are standardised to the 2013 European Standard Population.

Download the data

The following subsections (Disability, Ethnicity and Religion) focus on characteristics that are not recorded on the death certificate. This information was retrieved through record linkage of death registrations to the 2011 Census, allowing us to ascertain demographic factors of care home residents. In these subsections, the total number of deaths registered will differ to the total numbers of deaths in the rest of the bulletin because we have only included deaths that could be linked to the 2011 Census. We linked 91.5% (126,315 out of 137,998) of the deaths of care home residents that were registered in 2019 to the 2011 Census.

While data from the 2011 Census are now nine years old, they are still the best currently available for large-scale analyses. More detail can be found in our <u>technical appendix</u>, which outlines how we have used census data linkage in our most recent coronavirus (COVID-19) related releases.

Currently, we do not have data sources to provide a breakdown of care home populations for England and Wales for the disability, ethnicity and religion protected characteristics; therefore, we have not been able to provide rates. This is an area we are hoping to investigate as more data become available.

Disability

To define disability in this bulletin, we refer to the self-reported answers to the 2011 Census question, "Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? Include problems related to old age". Answer options included: Yes, limited a lot; yes, limited a little; and no. Those responding that their day-to-day activities were "limited a lot" or "limited a little" were classified as disabled for the purposes of this analysis. More information can be found in Section 12: Measuring the data. Currently, we do not have data sources that will allow us to analyse mortality statistics by learning disabilities or any other specific type of disability.

Table 1 shows the percentage distribution of deaths across disability categories among care home residents. Males who were classified as disabled (those limited a little or limited a lot) accounted for 62.4% (28,106 deaths) and 69.2% (1,506 deaths) of male care home resident deaths registered in England and Wales respectively. This can be compared with females who were classified as disabled who accounted for 71.8% (53,853 deaths) and 77.5% (3,141 deaths) of female care home resident deaths registered in England and Wales respectively (Table 1).

We would expect to see a higher percentage of care home residents classified as disabled than non-disabled since poor health or requiring physical support is a common reason for needing residential care.

Table 1: Male and female care home residents who were classified as disabled accounted for a higher proportion of deaths in England and Wales than non-disabled care home residents

Percentage of deaths of care home residents by sex and disability status, England and Wales, 2019

England		Males	Females
	Limited a lot	30.1	38.0
	Limited a little	32.3	33.8
	No disability	37.6	28.3
	Total	100.0	100.1
Wales		Males	Females
	Limited a lot	41.0	45.0
	Limited a little	28.2	32.5
	Limited a little No disability		

Source: Office for National Statistics - Deaths in the care sector, England and Wales

Notes

- 1. Based on deaths registered in each calendar year.
- 2. Percentage totals do not add up to 100 because of rounding.
- 3. Disability status was defined using the self-reported answers to the 2011 Census question: "Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? Include problems related to old age". Answer options included: Yes, limited a lot; Yes, limited a little; and No.
- 4. The total number of deaths registered in this period differs from total number of deaths mentioned elsewhere in this bulletin because we have only included deaths that could link to the 2011 Census.
- 5. Age-standardised mortality rates (ASMRs) have not been calculated for disability status as we do not have care home resident population data by disability status available for England and Wales for 2019.
- 6. Figures exclude deaths of non-residents.

Ethnicity

Males who identified as having a White ethnic background in the 2011 Census accounted for 97.7% (43,964 deaths) and 99.2% (2,159 deaths) of male care home resident deaths registered in 2019 in England and Wales respectively. Similarly, the majority of female care home residents who identified as having a White ethnic background accounted for 98.5% (73,921 deaths) and 99.7% (4,040 deaths) of total female care home resident deaths registered in England and Wales respectively (Table 2).

The 2011 Census reported that care home residents who identify as having a White ethnic background accounted for 96.8% and 99.1% of care home residents in England and Wales respectively. Therefore, it is to be expected that the great majority of care home resident deaths are to those who identified as having a White ethnic background.

When comparing the ethnic group breakdown in the general population, care home residents had a higher proportion of individuals who identified as having a White ethnic background in the 2011 Census in England and Wales (96.8% and 99.1% respectively) than the general population (85.4% and 95.6% respectively).

Table 2: The majority of care home resident deaths were among those who identified as having a White ethnic background

Percentage of deaths of care home residents by sex and ethnic group, England and Wales, 2019

England		Males	Females
White		97.7	98.5
	English/Welsh/Scottish/Northern Irish/British	94.9	95.5
	Irish	1.7	1.6
	Gypsy or Irish Traveller	0.0	0.0
	Other White	1.0	1.4
Mixed/multiple ethnic groups		0.3	0.3
	White and Black Caribbean	0.2	0.1
	White and Black African	0.0	0.0
	White and Asian	0.1	0.1
	Other mixed	0.1	0.1
Asian/Asian British		1.0	0.7
	Indian	0.5	0.4
	Pakistani	0.1	0.0
	Bangladeshi	0.0	0.0
	Chinese	0.1	0.1
	Other Asian	0.2	0.1
Black/African/Caribbean/Black Britisl	า	0.9	0.5
	African	0.1	0.1
	Caribbean	0.7	0.4
	Other Black	0.0	0.0
Other ethnic group		0.1	0.1
	Arab	0.0	0.0
	Any other ethnic group	0.1	0.1
Total		100.0	100.1
Wales		Males	Females
White		99.2	99.7
	English/Welsh/Scottish/Northern Irish/British	97.2	97.8
	Irish	0.9	0.9
	Gypsy or Irish Traveller	0.0	0.0
	Other White	1.0	0.9
Mixed/multiple ethnic groups		0.3	0.2
	White and Black Caribbean	0.1	0.1
	White and Black African	0.1	0.0
	White and Asian	0.0	0.0
	Other mixed	0.0	0.1
Asian/Asian British		0.2	0.1
	Indian	0.1	0.0

	Pakistani	0.0	0.0
	Bangladeshi	0.0	0.0
	Chinese	0.0	0.0
	Other Asian	0.0	0.0
Black/African/Caribbean/Black British		0.2	0.0
	African	0.0	0.0
	Caribbean	0.1	0.0
	Other Black	0.0	0.0
Other ethnic group		0.0	0.0
	Arab	0.0	0.0
	Any other ethnic group	0.0	0.0
Total		99.9	100.0

Source: Office for National Statistics - Deaths in the care sector, England and Wales

Notes

- 1. Based on deaths registered in each calendar year.
- 2. Percentage totals do not add up to 100 because of rounding.
- 3. The total number of deaths registered in this period will differ to other releases for the same period because we have only included deaths that could link to the 2011 Census.
- 4. Age-standardised mortality rates (ASMRs) have not been calculated for ethnic group as we do not have care home resident population data by ethnic group available for England and Wales for 2019.
- 5. Figures exclude deaths of non-residents.

Religion

In 2019, males who identified with the Christian religion in the 2011 Census accounted for 80.0% (35,992 deaths) and 76.1% (1,656 deaths) of male care home resident deaths registered in England and Wales respectively. Females who identified with the Christian religion accounted for 86.0% (64,547 deaths) and 84.3% (3,416 deaths) of female care home resident deaths registered in England and Wales respectively (Table 3).

In the 2011 Census, 73.9% and 72.3% of care home residents identified with the Christian religion in England and Wales respectively. Therefore, we would expect to see a higher proportion of deaths being in this religious group than others.

When comparing the religious group breakdown in the general population, care home residents had a higher proportion of individuals who identified with the Christian religion in the 2011 Census in England and Wales (73.9% and 72.3% respectively) than the general population (59.4% and 57.6% respectively).

Table 3: The majority of deaths of care home residents were among those who identified as Christian Percentage of deaths of care home residents by sex and religious group, England and Wales, 2019

England		Males	Females
	No religion	11.2	5.3
	Christian	80.0	86.0
	Buddhist	0.1	0.1
	Hindu	0.3	0.2
	Jewish	0.6	0.6
	Muslim	0.3	0.1
	Sikh	0.1	0.1
	Other religion	0.2	0.1
	Religion not stated	7.3	7.5
	Total	100.1	100.0
Wales		Males	Females
Wales	No religion	Males 13.7	Females 6.5
Wales	No religion Christian		
Wales	•	13.7	6.5
Wales	Christian	13.7 76.1	6.5 84.3
Wales	Christian Buddhist	13.7 76.1 0.1	6.5 84.3 0.1
Wales	Christian Buddhist Hindu	13.7 76.1 0.1 0.1	6.5 84.3 0.1 0.0
Wales	Christian Buddhist Hindu Jewish	13.7 76.1 0.1 0.1 0.0	6.5 84.3 0.1 0.0 0.1
Wales	Christian Buddhist Hindu Jewish Muslim	13.7 76.1 0.1 0.1 0.0 0.1	6.5 84.3 0.1 0.0 0.1
Wales	Christian Buddhist Hindu Jewish Muslim Sikh	13.7 76.1 0.1 0.1 0.0 0.1 0.0 0.1	6.5 84.3 0.1 0.0 0.1 0.0 0.0

Source: Office for National Statistics - Deaths in the care sector, England and Wales

Notes

- 1. Based on deaths registered in each calendar year.
- 2. Percentage totals do not add up to 100 because of rounding.
- 3. The total number of deaths registered in this period differ from total number of deaths mentioned elsewhere in this bulletin because we have only included deaths that could link to the 2011 Census.
- 4. Age-standardised mortality rates (ASMRs) have not been calculated for religious group as we do not have care home resident population data by religious group available for England and Wales for 2019.
- 5. Figures exclude deaths of non-residents.

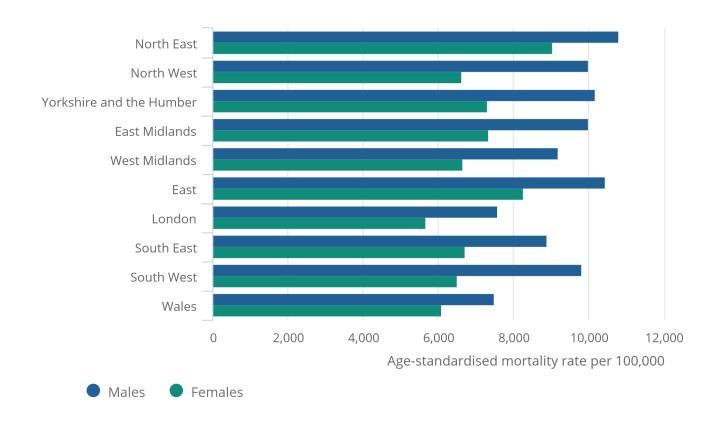
6. Country and regional breakdown of deaths in the care sector

Figure 6: In 2019, care home residents in the North East had the highest age-standardised mortality rates

Age-standardised mortality rates, males and females, English regions and Wales, 2019

Figure 6: In 2019, care home residents in the North East had the highest age-standardised mortality rates

Age-standardised mortality rates, males and females, English regions and Wales, 2019



Source: Office for National Statistics – Deaths in the care sector, England and Wales

Notes:

- 1. Based on area of usual residence as of May 2020.
- 2. Based on deaths registered in each calendar year.
- 3. Figures exclude deaths of non-residents.
- 4. These rates are for all ages and are standardised to the 2013 European Standard Population.

In England, the North East had the highest male and female age-standardised mortality rate (ASMR) with 10,820.0 deaths per 100,000 male care home residents and 9,031.5 deaths per 100,000 female care home residents. This can be compared with London, which had the lowest male and female mortality rate with 7,592.9 deaths per 100,000 male care home residents and 5678.7 deaths per 100,000 female care home residents (Figure 6), and the difference between these two regions was <u>statistically significant</u>. The regional patterns of ASMRs are in line with 2018 data.

Wales had the lowest ASMR for males compared with the regions in England with a mortality rate of 7,494.1 deaths per 100,000 for male care home residents.

Number of deaths broken down by local authority is available in the accompanying dataset.

7. Place of death

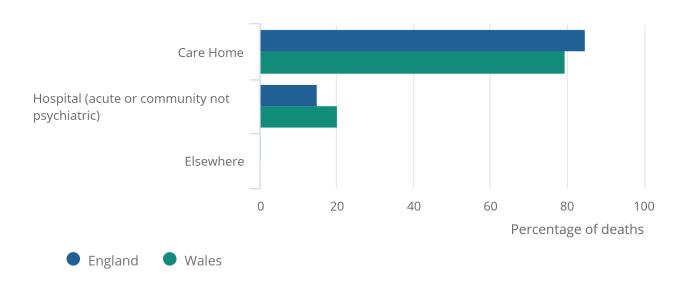
In 2019, the majority of deaths (84.8%) of care home residents in England occurred within care homes (111,179 deaths), compared with 14.9% in hospital and 0.3% occurring elsewhere. A similar pattern is observed in Wales with 79.6% of care home residents deaths occurring within care homes (5,454 deaths), compared with 20.2% in hospital and 0.1% occurring elsewhere (Figure 7). This pattern remains unchanged from 2018 for both countries with 84.4% (113,483 deaths) and 80.9% (6,033 deaths) of deaths registered occurring in care homes in England and Wales respectively.

Figure 7: The majority of care home resident deaths occur in care homes

Percentage of deaths by place of death in 2019, England and Wales

Figure 7: The majority of care home resident deaths occur in care homes

Percentage of deaths by place of death in 2019, England and Wales



Source: Office for National Statistics - Deaths in the care sector, England and Wales

Notes:

- 1. Based on deaths registered in each calendar year.
- 2. Figures exclude deaths of non-residents.

8. Leading cause of death

The Office for National Statistics' (ONS') <u>leading causes of death groupings</u> are based on a list developed by the World Health Organization (WHO). This categorises causes of death using the <u>International Classification of Diseases</u>, <u>10th edition (ICD-10)</u> into groups that are epidemiologically more meaningful than single ICD-10 codes, for the purpose of comparing the most common causes of death in the population. Causes such as cancer and circulatory diseases are split into different subtypes, with the aim to provide policymakers with enough detail to generate appropriate health policies and interventions.

Table 4 shows the top five underlying causes of death registered among care home residents and in England and Wales. A full list of leading causes is available in the <u>accompanying dataset</u>.

Table 4: Dementia and Alzheimer disease was the leading cause of death in male and female care home residents

Percentage of deaths of care home residents for the five leading causes of death in England and Wales, 2019

England

Males		Females	
Dementia and Alzheimer disease	30.6	Dementia and Alzheimer disease	37.9
Cerebrovascular diseases	6.3	Symptoms, signs and ill-defined conditions	7.2
Ischaemic heart diseases	5.7	Cerebrovascular diseases	6.9
Malignant neoplasm of prostate	4.8	Ischaemic heart diseases	4.6
Chronic lower respiratory diseases	4.1	Influenza and pneumonia	4.3
Wales			
Males		Females	
Dementia and Alzheimer disease	33.8	Dementia and Alzheimer disease	39.0
Cerebrovascular diseases	6.6	Cerebrovascular diseases	8.2
Influenza and pneumonia	6.3	Symptoms, signs and ill-defined conditions	6.2
Ischaemic heart diseases	5.6	Influenza and pneumonia	5.4
Chronic lower respiratory diseases	4.5	Ischaemic heart diseases	4.9

Source: Office for National Statistics – Deaths in the care sector, England and Wales

Notes

- 1. Based on deaths registered in each calendar year.
- 2. The symptoms, signs and ill-defined conditions category includes deaths where no more specific diagnosis can be made, including deaths certified as caused only by "old age", "frailty" and similar terms.
- 3. Figures exclude deaths of non-residents.

Dementia and Alzheimer disease was the leading cause of deaths for both male and female care home residents (wherever the death occurred), accounting for 30.6% of male and 37.9% of female care home resident deaths in England and 33.8% of male and 39.0% of female care home resident deaths in Wales.

When comparing with the leading cause of death in the general population, as reported in <u>Deaths registered in England and Wales: 2019</u>, the leading cause of death for females was Dementia and Alzheimer disease, accounting for 16.1% of deaths, whereas the leading causes of deaths in males were ischaemic heart diseases (IHDs) accounting for 13.1% of deaths in England and Wales. Therefore, the prevalence of Dementia and Alzheimer disease is higher in the care home resident population than in the general population.

Looking at leading causes by age group, in England, Dementia and Alzheimer disease was the leading cause of deaths in all male and female care home residents aged 65 years and over. In 2019, for care home residents aged under 65 years, lung cancer was the leading cause of death in males (9.5%), while breast cancer was the leading cause of death in females (8.0%).

In Wales, Dementia and Alzheimer disease was the leading cause of death in all age groups for both males and females. These breakdowns are available in the <u>accompanying dataset</u>.

9. Deaths of recipients of domiciliary care in England

The Care Quality Commission (CQC) collects notifications of deaths of people in receipt of <u>domiciliary care</u>, that is, care provided in a private home by a home care agency registered with the CQC. The needs of people using the services may vary greatly, but packages of care are designed to meet individual circumstances. The person is visited at various times of the day or, in some cases, care is provided over a full 24-hour period. Where care is provided intermittently throughout the day, the person may live independently of any continuous support or care between the visit.

Providers are required to notify the CQC of a death where the person died while a regulated activity was being provided or where their death may have been a result of the regulated activity or how it was provided. More information regarding notifications from providers can be found on the <u>CQC's website</u>.

In 2019, there were 17,448 deaths of domiciliary care recipients in England. This can be compared with 126,990 deaths of care home residents notified to the CQC.

The Care Inspectorate Wales (CIW) do not hold information on deaths in domiciliary care services, as these services are not legally required to notify CIW of deaths. The Office for National Statistics' (ONS') data do not contain information on whether a person was in receipt of domiciliary care, so no direct comparisons are possible.

10. Deaths data

Deaths in the care sector, England and Wales

Dataset | Released 28 October 2020

Registered deaths of care home residents by underlying cause of death and the leading causes of death. Contains characteristics of care home residents and death registrations by area of usual residence.

11. Glossary

Age-standardised mortality rates

Age-standardised mortality rates (ASMRs) are used to allow comparisons between populations that may contain different proportions of people of different ages. The 2013 European Standard Population is used to standardise rates. In this bulletin, we have adjusted the monthly ASMRs to allow for comparisons with annual rates. For more information, see <u>Section 12</u>: <u>Measuring the data</u>.

Care home resident

The term "care home residents" used in this bulletin refers to all deaths where either (a) the death occurred in a care home or (b) the death occurred elsewhere but the place of residence of the deceased was recorded as a care home. The figures should not be confused with "deaths in care homes" as reported in other releases, which refers only to category (a).

12. Measuring the data

This bulletin provides information concerning mortality rates and causes of death in 2019. When interpreting these mortality statistics, please note that:

- death statistics are compiled from information supplied when deaths are certified and registered as part of civil registration, a legal requirement
- this release provides both summary figures and more detail on both individual causes of death and <u>selected</u> <u>leading causes of death</u>, where individual causes are aggregated using a list developed by the World Health Organization (WHO), modified for use in England and Wales
- summary figures published in the release include analysis of causes of death by broad disease groupings
 (a list of these is available in <u>Section 10 of the User guide to mortality statistics</u>)
- figures in this release are presented for England and Wales separately because of the <u>devolved nature of adult social care</u>
- the data in this publication cannot be compared to the 2020 coronavirus (COVID-19) data presented in the
 <u>Deaths involving COVID-19 in the care sector</u> release or the <u>Deaths registered weekly in England and
 <u>Wales</u> release because of differences in the data presented, as outlined in Table 5
 </u>

Table 5: Differences in mortality data presented in Office for National Statistics releases

Deaths in the care sector	Deaths involving COVID-19 in the care sector	Deaths registered weekly in England and Wales
Final data	Provisional data	Provisional data
2019	2020	2020
Death registrations	Death occurrences	Death registrations
Annual data presented	d Weekly data presented	Weekly data presented
Care home resident data (regardless of place of death)	Care home resident data (regardless of place of death)	Deaths in a care home only, does not cover deaths to care residents that occur outside a care home

Source: Office for National Statistics - Deaths in the care sector, England and Wales

Mortality statistics are used for producing population estimates and projections and to quality assure the census estimates. They are also used to carry out further analysis on, for example, life expectancy, health expectancy, causes of death and infant mortality. They also enable the analysis of social and demographic trends.

The information used to produce these statistics is based on details collected when certified deaths are registered with the local registration office.

This bulletin includes breakdowns of certain <u>protected characteristics</u> covered by the <u>Equality Act 2010</u>. These characteristics are not recorded on the death certificate; this information was retrieved through record linkage of death registrations to the 2011 Census, allowing us to ascertain the religious group and other demographic factors of the deceased. More details on the data used can be found in our <u>technical appendix</u>, which outlines how we have used census data linkage in our most recent coronavirus (COVID-19) related releases.

Religion

The 2011 Census question on religion was voluntary, and just over 7% of the population of England and Wales opted not to answer it, equivalent to just over 4 million people in total. As outlined in Table 6, there was a large proportion of people in care homes who did not answer this question.

Table 6: Care home resident religious group breakdown recorded in the 2011 Census (%)

	Table 0. Care no	1116 163	dent rengi
England		Males	Females
	No religion	14.5	6.9
	Christian	67.2	77.1
	Buddhist	0.2	0.1
	Hindu	0.4	0.2
	Jewish	0.9	0.9
	Muslim	8.0	0.2
	Sikh	0.2	0.1
	Other religion	0.2	0.1
	Religion not stated	15.7	14.5
	Total	100.1	100.1
Wales		Males	Females
	No religion	20.4	9.7
	Christian	63.7	76.1
	Buddhist	0.1	0.1
	Hindu	0.1	0.0
	Jewish	0.2	0.2
	Muslim	0.3	0.0
	Sikh	0.1	0.0
	Other religion	0.1	0.1
	Religion not stated	15.2	13.8
	Total	100.2	100.0

Source: Office for National Statistics - 2011 Census

Ethnicity

The breakdown of ethnic group we have used in this bulletin was guided by the number of deaths available for analyses, following the data linkage, and the distribution across ethnic groups. Table 7 displays the breakdown of ethnic groups for care home residents recorded in the 2011 Census.

Table 7: Care home resident ethnic breakdowns recorded in the 2011 Census (%)

England		Males	Females
White		94.9	97.7
	English/Welsh/Scottish/Northern Irish/British	91.9	94.7
	Irish	1.4	1.4
	Gypsy or Irish Traveller	0.1	0.0
	Other White	1.5	1.6
Mixed/multiple ethnic groups		8.0	0.4
	White and Black Caribbean	0.4	0.2
	White and Black African	0.1	0.0
	White and Asian	0.1	0.1
	Other mixed	0.2	0.1
Asian/Asian British		1.6	0.8
	Indian	8.0	0.5
	Pakistani	0.2	0.1
	Bangladeshi	0.1	0.0
	Chinese	0.1	0.1
	Other Asian	0.3	0.2
Black/African/Caribbean/Black British		2.4	0.9
	African	0.5	0.2
	Caribbean	1.6	0.6
	Other Black	0.2	0.1
Other ethnic group		0.3	0.1
	Arab	0.1	0.0
	Any other ethnic group	0.2	0.1
Total		100.0	99.9
Wales		Males	Females
White		98.4	99.5
	English/Welsh/Scottish/Northern Irish/British	97.1	98.0
	Irish	0.5	0.6
	Gypsy or Irish Traveller	0.0	0.0
	Other White	8.0	0.9
Mixed/multiple ethnic groups		0.6	0.2
	White and Black Caribbean	0.3	0.1
	White and Black African	0.1	0.0
	White and Asian	0.1	0.0
	Other mixed	0.1	0.0
Asian/Asian British		0.6	0.2
	Indian	0.2	0.1

	Pakistani	0.2	0.0
	Bangladeshi	0.1	0.0
	Chinese	0.1	0.1
	Other Asian	0.1	0.0
Black/African/Caribbean/Black British		0.4	0.1
	African	0.2	0.1
	Caribbean	0.2	0.0
	Other Black	0.1	0.0
Other ethnic group		0.0	0.1
	Arab	0.0	0.0
	Any other ethnic group	0.0	0.0
Total		100.0	100.1

Source: Office for National Statistics - 2011 Census

Disability

To define disability in this bulletin, we refer to the self-reported answers to the 2011 Census question, "Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? Include problems related to old age". Answer options included: Yes, limited a little; and no. This is slightly different to the current <u>Government Statistical Service (GSS) harmonised "core" definition</u>: this identifies as "disabled" a person who self-reports having a physical or mental health condition or illness that has lasted or is expected to last 12 months or more that reduces their ability to carry-out day-to-day activities.

The GSS definition is designed to reflect the definitions that appear in legal terms in the <u>Disability Discrimination</u> <u>Act 1995</u> and the subsequent <u>Equality Act 2010</u>.

Rates

There is currently not an up-to-date measure for the size of the care home population. In the absence of this, we have used <u>2018-based population projections</u> for communal establishments for England and user-requested <u>2018-based population projections for Wales</u>. These data provide an estimate of all residents in communal establishments; therefore, we have applied a care home resident proportion using the <u>2011 Census data</u> to ascertain an estimated care home population for England and Wales.

Experimental Statistics

These statistics are designated as Experimental Statistics. <u>Experimental Statistics</u> are those that are in the testing phase, are not yet fully developed, and have not been submitted for assessment to the UK Statistics Authority. Experimental Statistics are published to involve customers and stakeholders in their development and as a means of building in quality at an early stage.

1

Collaboration

In the development of this bulletin, we have worked closely with partner departments across government including the Care Quality Commission (CQC) and the Care Inspectorate Wales (CIW). We will continue to work in partnership with the CQC and CIW to provide additional data in the future.

Care Quality Commission (CQC)

The CQC is the independent regulator of health and social care in England. Notifications about deaths in care homes must be sent to the CQC without delay using the <u>CQC Provider Portal</u> or the <u>MS Word form</u> available on CQC's website, and they are typically provided within two to three days of death. The data provided by the CQC are counts of deaths each day of care home residents who died in care homes, by date of notification. More information on the data provided by the CQC can be found in our joint transparency statement.

Notification forms ask service providers about the person who died, including their gender, ethnicity and other protected characteristics. However, these questions are not marked as mandatory and so we may not get all providers answering them, which would render the dataset incomplete. Therefore, Office for National Statistics (ONS) death registration data for characteristics of care home residents have not been compared with 2019 CQC data because of the degree of missingness within the death notification data.

The CQC is improving the information from notifications by providing clarity on the question and giving guidance to providers to notify appropriately. As changes to notifications are implemented, we expect to see improved completeness and availability of death notification data.

Care Inspectorate Wales (CIW)

In Wales, the Welsh Government publishes the number of deaths of registered adult care home residents notified to the Care Inspectorate Wales (CIW).

Data are collected on a daily basis through an online form developed and maintained by CIW. The data are validated against previous returns and any significant changes are queried. Data include all notifications up to midnight each day. The data collection covers residents of adult care homes. CIW are also beginning to capture some other characteristics data on their death notification form such as age, gender and disability status.

The ONS uses a broader definition of care home residents than that used in the CIW data.

Coding of deaths

Deaths are cause coded using the World Health Organization's (WHO) International Classification of Diseases, 10 edition (ICD-10). Deaths are coded to ICD-10 using IRIS software (version 2013). Cause of death reported here represents the final underlying cause of death for ages 28 days and over. This takes account of additional information received from medical practitioners or coroners after the death has been registered.

In 2011, there was an update to the coding framework (detailed in the <u>bridge coding study</u>) used to code cause of death. This meant that deaths from vascular dementia that were previously coded to cerebrovascular disease (I60 to I69) would be coded to vascular dementia (F01). There were further changes to the framework in 2014 (detailed in the <u>dual coding study</u>) where deaths that were coded to chest infection (J98) would now be coded to chest infection (J22), but those with a mention of dementia (F01 or F03) would now be coded to dementia (F01 or F03). Additionally, deaths that were previously coded to aspiration pneumonia (I69) where dementia was mentioned on the death certificate would now be coded to dementia (F01 or F03).

On 1 January 2020, we updated the software used to code causes of death and derive a single underlying cause. This is known as Multicausal and Unicausal Selection Engine (MUSE) (IRIS version 5.5). This will impact data in next year's publication, for deaths registered in 2020. More information is available on the <u>differences caused by the change of software</u>.

Methodology guides

More quality and methodology information on strengths, limitations, appropriate uses, and how the data were created is available in the <u>Mortality statistics in England and Wales QMI</u>.

Our <u>User guide to mortality statistics</u> provides further information on data quality, legislation and procedures relating to mortality and includes a <u>glossary of terms</u>.

The Revisions policy for population statistics (including mortality statistics) is also available.

Feedback

Comments on this release are welcomed. In particular, whether there are any additional data that could be included in future publications. Feedback can be emailed to social.care@ons.gov.uk.

13 . Strengths and limitations

In England and Wales, deaths should be registered within five days of the death occurring, but there are some situations that result in the registration of the death being delayed. For example, when a death needs to be investigated by a coroner.

Figures in this release represent the number of deaths registered in the calendar year: this includes some deaths that occurred in the years prior to this calendar year, while a proportion of deaths occurring in this year will not be registered until subsequent years. We only have a few years' worth of death data to care home residents available; therefore, data used within this bulletin cover death registrations where the death occurred during the period 27 December 2014 to 31 December 2019. Consequently, totals may differ from other publications. More information on this issue can be found in our impact of registration delays release.

Figures in this release represent England and Wales data separately because of the <u>devolved nature of social</u> <u>care</u>; therefore, deaths of those whose usual residence is outside England and Wales, or deaths of residents that happened abroad, are not included in our analyses.

We have used the most up-to-date communal establishment file we have for all years available.

Where possible, we have estimated a care home resident population to present age-standardised mortality rates (ASMRs). Currently, we do not have data sources to provide a breakdown of care home populations for England and Wales for the disability, ethnicity and religion protected characteristics; therefore, we have not been able to provide rates. This is an area we are hoping to investigate as more data become available.

The 2011 Census is nine years old and because of changes in disability status, it is likely that the number of people who are recorded as having an activity-limiting condition is now an underestimate. Those not limited in 2011 may have developed a long-term health condition over the past nine years that limits their activities or any existing health condition may have worsened in severity causing them to become limited. While transitions out of activity limitation are also possible, this is a less likely effect bearing in mind that reported disability tends to increase with age. As such, the proportion of all deaths in care homes made up of disabled people should be considered as conservative estimates.

There is a large degree of comparability in death statistics between countries within the UK. There are some differences, although these are believed to have a negligible impact on the comparability of the statistics. These differences are outlined in the <u>Mortality statistics in England and Wales QMI</u>.

14. Related links

Deaths registered in England and Wales: 2019

Bulletin | Released 1 July 2020

Registered deaths by age, sex, selected underlying causes of death and the leading causes of death.

Contains death rates and death registrations by area of residence and single year of age.

Deaths involving COVID-19 in the care sector, England and Wales

Bulletin | Released 3 July 2020

Provisional figures on deaths involving the coronavirus (COVID-19) within the care sector, in England and Wales.