

Article

# Dementia and all-cause mortality and deaths involving coronavirus (COVID-19), England: 24 January 2020 to 31 December 2022

Risk of death among people aged 65 years and over with and without dementia. Mortality data includes deaths that occurred from 24 January 2020 to 31 December 2022.

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### Correction

#### 25 July 2023 14:10

We have updated the labelling of Figure 6. The previous version did not fully display all the variables in one of the models. We have added additional labelling and relevant notes.

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## 1. Main points

- People aged 65 years and over with a dementia diagnosis had a higher age-standardised mortality rate (ASMR) of all-cause mortality (21,503 and 15,914 deaths per 100,000 person-years for males and females, respectively), compared with those without dementia (4,643 and 3,273, respectively) between 24 January and 31 December 2020; this pattern was the same for deaths involving and not involving coronavirus (COVID-19), and in 2021 and 2022.
- When adjusting for age, the rate of all-cause death for males and females with dementia remained 3.76 and 3.33 times higher, respectively, than for those without dementia in 2020; these patterns were similar in 2021 (3.42 and 3.10) and 2022 (3.32 and 3.01).
- Further adjustments for socio-demographic and socio-economic factors, health-related factors, and care home status reduced the increased risk of all-cause death for people with dementia to 2.38 times (males) and 2.14 times (females) higher than those without dementia in 2020; these patterns were similar in 2021 and 2022.
- The rate of death involving COVID-19 was 2.93 (males) and 2.34 (females) times greater for people with dementia, compared with those without dementia in 2020 after adjusting for age, socio-demographic and socio-economic factors, health-related factors, care home status, and COVID-19 vaccination; this increased risk was similar in 2021 and 2022.
- Between 2020 and 2022, the age-standardised mortality rates for deaths involving COVID-19 decreased for people with and without dementia.
- COVID-19 was the leading cause of death in 2020 and 2021 in people without dementia; while there was a higher proportion of deaths involving COVID-19 in people with dementia, it was not the leading cause of death for this group.

### 2. Mortality rates for people with and without dementia

This analysis is based on people in England aged 65 years and over. The mortality data covers deaths that occurred between 24 January 2020 to 31 December 2022 in the Office for National Statistics (ONS) Public Health Data Asset (PHDA); these data are provisional (see <u>Section 9: Data sources and quality</u> for further information).

Study periods in this release include:

- 2020, covering 24 January (the date of the first coronavirus (COVID-19) case in England) to 31 December 2020
- 2021, covering 1 January to 31 December 2021
- 2022, covering 1 January to 31 December 2022

#### Age-standardised mortality rates (ASMRs)

ASMRs account for population size and age structure in their measure of mortality. In this release, they are reported per 100,000 person-years at risk (more information can be found in <u>Section 8: Glossary</u>).

The ASMRs of all-cause death in the population aged 65 years and over was higher in men and women with a dementia diagnosis (21,503 and 15,914 deaths per 100,000 person-years, respectively), compared with people without dementia (4,643 and 3,273, respectively) in 2020. This was the case across all three study periods and for deaths involving and not involving COVID-19, as shown in Figures 1 and 2. This pattern reflects our <u>Deaths</u> registered in England and Wales: 2021 bulletin, showing that dementia and Alzheimer disease is a leading cause of death.

#### **Deaths involving COVID-19**

For deaths involving COVID-19, ASMRs were higher for people with dementia than without dementia across all three study periods; these decreased over the study period. In 2020, the rate of deaths involving COVID-19 for people with dementia was more than seven times the rate of people without dementia. In 2022, the risk was 4.4 higher for females and 4.7 higher for males with dementia, compared with those without.

#### **Deaths not involving COVID-19**

For deaths not involving COVID-19, mortality rates were higher for people with dementia than those without across all three study periods. ASMRs for deaths not involving COVID-19 increased over the study period, regardless of dementia status. However, for people with dementia, these increases were only statistically significant between 2021 and 2022.

# Figure 1: People with dementia had a rate of death involving COVID-19 more than four times higher than people without dementia

Age-standardised mortality rates for deaths involving COVID-19 among people aged 65 years and over, by sex and dementia status, England: 24 January 2020 to 31 December 2022

#### Download the data

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# Figure 2: People with dementia had a rate of death not involving COVID-19 more than four times higher than people without dementia

Age-standardised mortality rates for deaths not involving COVID-19 among people aged 65 years and over, by sex and dementia status, England: 24 January 2020 to 31 December 2022

Download the data

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#### Ethnicity

Figure 3 indicates that, for deaths involving COVID-19, there was a clear difference when comparing mortality rates across ethnic groups for people with and without dementia.

Among people with dementia, for most ethnic groups, the ASMR of death involving COVID-19 was not significantly different to people in the White British ethnic group. The exceptions included the Black Caribbean group in 2020 and 2022, who had a lower ASMR compared with the White British group in 2020 and 2022. Also included is the Bangladeshi group, who had a higher ASMR compared with the White British group in 2021.

For people without dementia, the ASMR of death involving COVID-19 in 2020 and 2021 was significantly higher for all ethnic groups (except Chinese in 2020 and 2021, and White Other in 2020), compared with the White British ethnic group. In 2022, ethnic minority groups no longer had a significantly higher COVID-19 mortality rate compared with the White British group. This pattern reflects our other analysis, the Ethnic and religious contrasts in deaths involving COVID-19 article.

# Figure 3: Rates of death involving COVID-19 across most ethnic groups were not significantly different for people with dementia

Age-standardised mortality rates for deaths involving COVID-19 among people aged 65 years and over, by ethnic group and dementia status, England: 24 January 2020 to 31 December 2022

Notes:

1. Rates are not calculated where there are fewer than 10 deaths; 2022 data on people with dementia in the Black African and Chinese ethnic groups are therefore not included in this chart. It is ONS practice not to calculate rates where there are fewer than 10 deaths in a cell, as age-standardised rates based on such low numbers are likely to be inaccurate. This chart presents some age-standardised rates which are based on between 10 and 19 deaths, which should be treated with caution.

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Figure 4 shows that, for deaths not involving COVID-19, the pattern across ethnic groups for people with and without dementia is similar. In both populations, most ethnic groups have statistically significantly lower ASMRs than the White British ethnic group in all three study periods. The exceptions to this were the Mixed (for people with and without dementia) and Bangladeshi (people without dementia) ethnic groups in 2020.

# Figure 4: Most ethnic groups had lower rates of deaths not involving COVID-19 than White British, for people with and without dementia

Age-standardised mortality rates for deaths not involving COVID-19 among people aged 65 years and over, by ethnic group and dementia status, England: 24 January 2020 to 31 December 2022

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#### Deprivation

The Index of Multiple Deprivation (IMD) is a measure of relative deprivation at a local level, ranging from one (most deprived) to five (least deprived). For a full definition, see <u>Section 8: Glossary</u>.

For people with and without dementia, there was a positive association between deprivation and ASMRs for both COVID and non-COVID-19 deaths. For example, for deaths involving COVID-19 in 2020, the ASMR for people with dementia in the most deprived areas was 4,906.7. In comparison, the ASMR was 3,398.3 in the least deprived areas. For people without dementia, the rates were 938.0 and 392.9, respectively.

Additional breakdowns of ASMRs by region, National Statistics Socio-economic Class (NS-SEC), and highest level of qualification can be found in <u>Section 7: Dementia and mortality during the coronavirus (COVID-19)</u> pandemic data.

### 3. Place of death

Around half of all care homes in England provide dementia care (see Table 1 in our <u>Care homes and estimating</u> <u>the self-funding population</u>, <u>England</u>: 2021 to 2022 article</u>).

Between 2020 and 2022, over half of all deaths of people aged 65 years and over with dementia occurred in a care home:

- 58.8% in 2020,
- 54.8% in 2021,
- 55.1% in 2022

Over a quarter occurred in a hospital (this could include people who are care home residents as well as non-care home residents with dementia). This differs from deaths of people aged 65 years and over without dementia, where the most common place of death was hospital:

- 46.1% in 2020
- 47.8% in 2021
- 47.4% in 2022

This was followed by home and care home.

Patterns in place of death differed for deaths involving coronavirus (COVID-19). Figure 5 shows that, across the time period, a higher percentage of deaths involving COVID-19 occurred in a hospital regardless of dementia diagnosis. For people with dementia, the percentages were:

- 40.7% in 2020
- 44.8% in 2021
- 48.9% in 2022

For people without dementia, the percentages were:

- 77.2% in 2020
- 79.4% in 2021
- 76.4% in 2022

# Figure 5: Over half of all deaths of people aged 65 years and over with dementia occurred in a care home, whereas the most common place of death for those without dementia was hospital

Percentages of deaths involving COVID-19 and deaths not involving COVID-19 among people aged 65 years and over by place of death and dementia status, England: 24 January 2020 to 31 December 2022

Download the data

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## 4 . Leading cause of death

Leading cause of death groupings are based on categories developed by the World Health Organization (WHO) (see <u>Section 9: Data sources and quality</u>). Dementia and Alzheimer disease was the leading cause of death for people with a dementia diagnosis across all three study periods, accounting for over 50% of female deaths and over 40% of male deaths.

Coronavirus (COVID-19) was the leading cause of death for people without a dementia diagnosis in 2020 and females without a dementia diagnosis in 2021. However, there was a higher proportion of deaths with COVID-19 as the underlying cause in people with dementia (see Table 10 in the dataset found in <u>Section 7: Dementia and mortality during the coronavirus (COVID-19) pandemic data</u>).

## 5. Comorbidities of people with dementia

Differences in the rate of death between people with and without dementia may be partly explained by people with dementia being more likely to have health conditions that are independently associated with a higher risk of death. For example, the age-standardised rate of people with a diagnosis of Parkinson's disease was over six times higher among people with dementia than those without dementia.

For most health conditions, it is also possible that people with dementia have poorer outcomes from the same condition as people without dementia. Therefore, we have adjusted for these health conditions in <u>Section 6:</u> <u>Mortality risk of people with dementia after adjusting for risk factors</u>.

Age-standardised rates of diagnosis of different health conditions in the 20 years prior to the start of the study period is available in Table 8 in our dataset found in <u>Section 7: Dementia and mortality during the coronavirus</u> (COVID-19) pandemic data.

# 6 . Mortality risk of people with dementia after adjusting for risk factors

These results relate to statistical associations and do not imply cause-and-effect relationships.

To adjust for different demographic, socio-economic, and health characteristics we report hazard ratios (HRs) for people with dementia relative to people without dementia (see <u>Section 8: Glossary</u>).

According to Figure 6, risk of death involving coronavirus (COVID-19) and death not involving coronavirus (COVID-19) varied by dementia status, and over time, separately for males and females. Results for all-cause death can be found in Table 7 of the dataset found in <u>Section 7: Dementia and mortality during the coronavirus (COVID-19) pandemic data</u>.

#### Age

When adjusting only for age, the rate of death for all-cause death, death involving and not involving COVID-19, is higher for people with dementia than for those without dementia. For example, the rate of all-cause death for males and females with dementia remained 3.76 and 3.33 times higher, respectively, than for those without dementia in 2020. For death involving COVID-19, the increased risk for people with dementia compared with people without dementia was 4.82 times higher for females and 5.71 times higher for males.

#### Demographic, socio-economic, and health related factors

Additional factors associated with dementia and risk of mortality include:

- ethnic group
- geographical factors
- socio-economic characteristics
- certain pre-existing health conditions
- harmful drinking
- frailty

Adjusting for these factors accounts for some of the excess risk of death in people with dementia.

In this model, the increased risk of all-cause death for people with dementia reduced to 2.38 times (males) and 2.14 times (females) higher than those without dementia in 2020. For death involving COVID-19 in 2020, the risk remained 3.93 times higher for females and 4.29 times higher for males. The pattern for 2021 and 2022 is similar. Adjusting for these additional factors also reduces the increased risk of death not involving COVID-19 for people with dementia, compared with those without.

#### Care home residency

A further factor that can confound the relationship between dementia and risk of death is whether a person lives in a care home. This measure was only available for 2019; therefore, measurement error is likely to be greater in the later periods of this study.

Accounting for care home residency further reduces the estimated risk of death associated with dementia.

An increased risk of death for people living in a care home does not necessarily mean that living in a care home increases the risk of death. Even after accounting for age and frailty, people in poorer health may need to live in a care home. We also know that people who live in care homes have a lower life expectancy than those who do not live in care homes (see our Life expectancy in care homes, England and Wales, 2021 to 2022 article).

# Figure 6: In 2020, after accounting for socio-demographic and socio-economic characteristic, health conditions, frailty and care home residence, people with dementia had a risk of death involving COVID-19 more than two times higher than those without dementia

Hazard ratios for death involving COVID-19, and death not involving COVID-19, for people aged 65 and over with dementia relative to people without dementia, stratified by sex, England: 24 January 2020 to 31 December 2022

#### Notes:

1. The plus (+) symbol refers to all previous adjustments plus the new adjustment in the model.

#### Download the data

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#### **Vaccination status**

Adjusting for COVID-19 vaccination status does not further reduce the increased risk of death involving COVID-19 for people with dementia.

Where the risk remains broadly the same after adjusting for vaccination status, it does not mean the vaccine is not effective. It simply means differences in vaccination coverage between the groups do not explain observed differences in mortality risk. For analyses of vaccine effectiveness, see the government's <u>Guidance for monitoring</u> reports of the effectiveness of COVID-19 vaccination.

# 7. Dementia and mortality during the coronavirus (COVID-19) pandemic data

Dementia and a comparison of all-cause mortality and deaths involving coronavirus (COVID-19), England: 24 January 2020 to 31 December 2022

Dataset | Released 14 April 2023

Age-standardised mortality rates, hazard ratios, and leading cause analysis exploring risk of all-cause mortality, death involving and not involving coronavirus (COVID-19), by dementia diagnosis.

## 8. Glossary

#### Age-standardised mortality rates (ASMRs)

ASMRs allow comparisons between populations that may contain different proportions of people of different ages. These are a better measure of mortality for use in comparison than the number of deaths, as they account for the population size and age structure. As a measure of absolute risk, we calculated ASMRs by dementia status and sex, as deaths per 100,000 person-years at risk, standardised to the <u>2013 European Standard Population</u>. Using 100,000 person-years at risk allows comparing periods of different length of time, such as the 2020 period (24 January to 31 December) with calendar years 2021 and 2022.

#### **Confidence intervals**

Confidence intervals use the standard error to derive a range in which we think the true value is likely to lie. A confidence interval gives an indication of the degree of uncertainty of an estimate and helps to decide how precise a sample estimate is. It specifies a range of values likely to contain the unknown population value. These values are defined by lower and upper limits. See our <u>Uncertainty and how we measure it for our surveys</u> methodology.

#### Cox proportional hazards regression

Cox proportional hazards regression is used to measure the association between a time-to-event outcome (such as death) and a characteristic of interest (in this case, dementia). It can be used to adjust for other characteristics expected to be related to both the characteristic of interest and the outcome.

#### Deaths involving coronavirus (COVID-19)

Deaths involving COVID-19 include those with an underlying cause, or any mention, of International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) codes U07.1 (COVID-19, virus identified), U07.2 (COVID-19, virus not identified), or U09.9 (post-COVID-19 condition). A doctor can certify the involvement of COVID-19 based on symptoms and clinical findings (a positive test result is not required).

#### Hazard ratio

A hazard ratio is a measure of how often a particular event occurs in one group compared with how often it occurs in another group (the reference group), at any particular point in time. A hazard ratio greater than one shows that the rate of the event occurring is higher in the group of interest (people with dementia), compared with a reference group (people without dementia). A hazard ratio of less than one shows that the rate is lower in the group of interest, compared with a reference group.

### 9. Data sources and quality

#### Sources

These analyses use data from the Office for National Statistics' (ONS) Public Health Data Asset (PHDA). The PHDA only covers England and combines:

- 2011 Census records
- death registrations data
- electronic health records, such as <u>Hospital Episode Statistics (HES)</u> and <u>General Practice Extraction</u> <u>Service (GPES) Data for pandemic planning and research (GDPPR)</u>
- NHS England's National Immunisation Management Service (NIMS) data

The inclusion criteria required study participants to be:

- enumerated at the 2011 Census
- aged between 65 and 110 years at the start of each study period (24 January 2020, 1 January 2021, and 1 January 2022)
- linked to the 2011 to 2013 NHS Patient Register (to obtain an NHS number)
- linked to at least one GDPPR record (to identify active NHS patients during the coronavirus (COVID-19) pandemic)
- resident in England according to GDPPR

Dementia diagnoses were identified from GDPPR (primary care) records using SNOMED codes relating to the condition. Dementia diagnoses are replenished for each study period:

- for 2020, people with dementia are defined as those who were diagnosed with dementia by 24 January 2020
- for 2021, people with dementia are defined as those who were diagnosed with dementia by 1 January 2021
- for 2022, people with dementia are defined as those who were diagnosed with dementia by 1 January 2022

We calculated age-standardised mortality rates (ASMRs) by dementia diagnosis and sex, for all-cause deaths, deaths involving COVID-19, and deaths not involving COVID-19. These are expressed as deaths per 100,000 person-years at risk.

We used Cox proportional hazards models to estimate the difference in the risk of death while adjusting for different factors. The models were fitted separately by sex and were adjusted for:

- age
- ethnic group
- geographical factors (region, rural or urban classification)
- socio-economic characteristics (Index of Multiple Deprivation quintile group, highest qualification, National Statistics Socio-Economic Classification, household tenure) comorbidities and harmful drinking (codes in GDPPR indicating acute or chronic excessive alcohol consumption)
- frailty
- care home status, derived from Patient Register 2019

The models for death involving COVID-19 and all-cause deaths were further adjusted for COVID-19 vaccination status (no vaccination, one dose, two doses, or three doses) as a time-varying covariate.

#### Quality

The primary strength of the study is the use of linked population-level data. This combines a rich set of demographic and socio-economic factors from the 2011 Census with electronic health records. This means that we could adjust for a range of factors related to both dementia and mortality.

The PHDA only contains information for individuals who were enumerated at the 2011 Census. It does not include:

- people living in England in 2011 who did not participate in the census (estimated to be approximately 5% of the population)
- respondents who could not be linked to the 2011 to 2013 NHS Patient Registers (5.4% of census respondents)
- people who have immigrated since 2011

Because we used GDPPR to define the population at risk, the study population does not include people who were not registered with a general practitioner (GP) in England in November 2019.

The percentage of people with dementia in the study population was 4.5% at the beginning of 2020, 4.1% at the beginning of 2021, and 4.0% at the beginning of 2022. This is similar to the recorded prevalence of 4.3% for people aged 65 years and over in December 2019, as recorded in the <u>PHE Fingertips Dementia Profile</u>. These percentages were measured by a diagnosis code for dementia in GDPPR at the start of each of the three study periods.

However, this prevalence was lower than the Care and Policy Evaluation Centre's estimates that include undiagnosed cases in their <u>Projections of older people living with dementia (PDF, 385KB)</u> (7.1% amongst people aged over 65 years for England in 2019).

Furthermore, people diagnosed with dementia during each study period (who could have died within that year) are classified as not having dementia. This means that this analysis, and the data for any given year, underestimates risk of mortality for people with dementia.

Analysis is based on people aged 65 years and over because most people with dementia are in older age groups (96.7% of all dementia cases in the population aged 18 to 110 years). According to <u>Alzheimer's Research UK</u>, there is low prevalence of early onset dementia (dementia diagnosed before age 65 years) reported in the UK. Age is correlated with risk of mortality and people with early onset dementia are likely to have different living situations and risk factors, compared with older people with dementia. The inclusion of early onset dementia could, therefore, affect the overall mortality rate for people with dementia and dilute the differences found between those with and without dementia.

We could not control for all factors that may be related to both dementia and COVID-19 mortality, because not all such factors are measured on the census or recorded in electronic health records. As a result, the estimated associations may not fully reflect the causal effects of dementia on the risk of death.

Some of the characteristics included in the model were measured at the 2011 Census and therefore may not represent individuals' circumstances at the time of the coronavirus pandemic. To mitigate this, we updated place of residence based on primary care records. Consequently, area deprivation, rural or urban classification, and region were up to date at the beginning of the pandemic.

The measure of care home residency was only available for 2019. Therefore, measurement error is likely to be greater in the later study periods.

#### Coding of deaths

Our<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. This is 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 of providing policymakers with enough detail to generate appropriate health policies and interventions.

Deaths are cause coded using the WHO's 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 people aged 28 days and over. This accounts for additional information received from medical practitioners or coroners after the death has been registered.

#### Feedback

Comments on this article are welcomed. Feedback can be emailed to us at health.data@ons.gov.uk.

# 10. Related links

Deaths registered in England and Wales: 2021 (refreshed populations)

Bulletin | Released 27 January 2023

Registered deaths by age, sex, selected underlying causes of death, leading causes of death. Death rates and registrations by area, single year of age.

Dementia and Alzheimer's disease deaths including comorbidities, England and Wales

Dataset | 2 December 2020 Deaths registered in 2019 in England and Wales due to dementia and Alzheimer's disease, by sex, age group, ethnicity, region and place of occurrence. Includes analysis of comorbidities.

Dementia Profile Web page | Updated as and when data become available Office for Health Improvement & Disparities Fingertips tool

Coronavirus (COVID-19) latest insights

Interactive tool | Updated as and when data become available The latest data and trends about the coronavirus (COVID-19) pandemic from the Office for National Statistics (ONS) and other sources.

## 11. Cite this article

Office for National Statistics (ONS), released 14 April 2023, ONS website, article, <u>Dementia and all-cause</u> mortality and deaths involving coronavirus (COVID-19), England: 24 January 2020 to 31 December 2022