#### FEATURED ARTICLE



# Incidence, age at diagnosis and survival with dementia across ethnic groups in England: A longitudinal study using electronic health records

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# **Abstract**

**Introduction:** We investigated the incidence of diagnosed dementia and whether age at diagnosis and survival afterward differs among the United Kingdom's three largest ethnic groups.

Methods: We used primary care electronic health records, linked Hospital Episode Statistics and mortality data for adults aged ≥65 years. We compared recorded dementia incidence 1997–2018, age at diagnosis, survival time and age at death after diagnosis in White, South Asian, and Black people.

**Results:** Dementia incidence was higher in Black people (incidence rate ratios [IRR] 1.22, 95% CI 1.15–1.30). South Asian and Black people with dementia had a younger age of death than White participants (mean difference for South Asian participants - 2.97 years, (95% CI -3.41 to -2.53); and Black participants -2.66 years, (95% CI -3.08 to -2.24).

**Discussion:** South Asian and Black peoples' younger age of diagnosis and death means targeted prevention and care strategies for these groups should be prioritized and tailored to facilitate take-up.

#### **KEYWORDS**

dementia, ethnicity, incidence, prevalence, race, survival

# 1 | INTRODUCTION

The number of people living with dementia worldwide is predicted to rise from 57 million to >150 million between 2019 and 2050.<sup>1,2</sup> The number of people with dementia in the United Kingdom (UK) is forecast to increase to over 1 million by 2025 and over 2 million by 2051.<sup>3</sup> UK population-based studies recruiting primarily White British people have found that while the numbers of people with dementia increased, age-specific incidence and prevalence of dementia declined from 1989

to 2011.<sup>4,5</sup> Around 13% of the UK comprises minority ethnic populations; the largest non-White group is South Asian (5.3%) and the second largest group is Black (African or Afro-Caribbean – 3.4%).<sup>6</sup> A previous study of dementia diagnosis from primary care records found that recorded dementia incidence was higher in Black people, and lower in Asian women compared to the White population.<sup>7</sup> However, the Asian group comprised people of either South Asian or East Asian ancestry. The latter group have a lower risk of dementia compared to White people.<sup>8</sup> The authors also did not estimate dementia prevalence or

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investigate outcomes after diagnosis. There are no large studies in community populations of dementia prevalence in UK South Asians (or worldwide in South Asian minority populations). The only population-based UK study of the Black population is from more than 10 years ago and found that dementia was more prevalent than in the White population.<sup>9</sup>

People from minority ethnic groups with dementia seem less likely to receive a dementia diagnosis, <sup>10</sup> possibly due to stigma or healthcare system related barriers. In the United Kingdom, people from minority ethnic groups diagnosed in secondary care, are younger and had more severe dementia at the time of diagnosis. 11 In the United States (US), incidence of dementia was highest in African-Americans and lowest in East Asian Americans.<sup>8</sup> Survival after dementia diagnosis was shortest for White people, followed by African American people and longest in those of East Asian origin. 12 Investigating dementia diagnosis and survival post-diagnosis in different ethnic groups is important for understanding patient journeys, tailoring and planning interventions, giving prognostic information to patients and their families, and understanding whether experiences vary by ethnicity. Recorded dementia diagnosis in electronic health records will miss people who have not been seen or recognized by services but will show differences in recorded diagnoses between ethnic groups and changes over time. Survival time is important to indicate whether people diagnosed at a younger age, are at an earlier stage of illness or develop dementia earlier in life, and whether years of life lost to dementia vary between ethnic groups.

#### We aimed to:

- Investigate trends in incidence of diagnosed dementia in UK electronic health records (primary care Clinical Practice Research Database; (CPRD) linked to Hospital Episode Statistics and mortality statistics in the population overall and the three largest ethnic groups (White, South Asian, and Black) in the UK.
- Estimate the age- and sex-adjusted point prevalence and 95% confidence intervals of dementia, for each year (1997–2018) in the three largest ethnic groups, and whether this has changed over time.
- 3. Compare age at dementia diagnosis, survival time after diagnosis, and age of death in those with dementia across ethnic groups.

#### 2 | METHODS

#### 2.1 | Approvals

We used a fully anonymized dataset from the CPRD which has National Research Ethics Service Committee (NRES) approval for purely observational research using primary care data and established data linkages.

The study was approved by the Independent Scientific Advisory Committee (ISAC) of the Medicines and Healthcare Products Regulatory Agency (MHRA) (protocol 19\_235). We pre-registered this study's protocol prior to analyses (https://osf.io/jp6xu/).

#### RESEARCH IN CONTEXT

- Systematic review: We searched PubMed for studies examining incidence and prevalence of dementia across diverse ethnic groups. We found one study of dementia incidence in a diverse sample in the United Kingdom that used primary care records and two studies from the United States, including one that examined survival after dementia diagnosis across ethnic groups. A similar analysis had not been carried out in a diverse sample in the United Kingdom.
- 2. Interpretation: Dementia incidence and prevalence has risen over time and rates are higher in the Black compared to the White population. People from minority ethnic groups were diagnosed with dementia at a younger age and died at a younger age with dementia. Lower incidence and prevalence of dementia in South Asian people despite a younger age of diagnosis indicates under-recording of dementia in electronic records.
- Future directions: Understanding of reasons for earlier death among people from minority ethnic groups is crucial to reducing ethnic inequalities. Targeted prevention and care strategies for these groups should be prioritized and tailored to facilitate take-up.

# 3 | SAMPLE

# 3.1 Datasets

This study used the CALIBER © resource (https://www.ucl.ac.uk/health-informatics/caliber and https://www.caliberresearch.org/), which links electronic primary care records with hospital and mortality records. Further details are in the supplementary material, which is available online.

#### 3.2 | Sample

As deprivation scores and linked electronic hospital records are country-specific and are only provided for practices in England which have consented to participate in the CPRD patient-level linkage scheme, <sup>13</sup> we restricted analyses to practices from England consenting to the patient-level linkage scheme (around 88% of practices <sup>14</sup>). We focused our analyses on dementia diagnosed after reaching age 65, as dementia is unusual below this age and etiology of younger onset dementia is usually substantially different. <sup>15</sup> The start date for each participant was the latest of their 65<sup>th</sup> birthday, January 1, 1997, date of registration with the GP practice or when the GP practice data met data quality standards. Start date for dementia survival analyses was the date of dementia diagnosis. The end date for each

participant was the earliest of: date of last data collection for the practice; patient transfer out of the practice; death; or the end of study (December 31, 2018). Data linkages and sources of data are shown in the supplementary material.

# 4 | VARIABLES

Full details of all variables are in the supplementary material.

#### 4.1 Dementia

We considered all-cause dementia as our main outcome, defined as any diagnostic code or anti-dementia medication recorded in any of the three data sources.

# 4.2 | Ethnicity

We combined ethnicities into White (all white groups), South Asian (Bangladeshi, Indian, Pakistani), and Black (Black Caribbean, Black African, and Black British). All other ethnic groups including all mixed ethnic groups were combined into a separate group and included in analyses but not reported as we focused on the three main ethnic groups and the fourth group contained large within-group heterogeneity.

# 4.3 | Confounders

Age at study entry and sex as defined in primary care records were used in all adjusted models.

Index of multiple deprivation (IMD)<sup>16</sup> – This is a composite measure based on postcode derived from a number of indicators covering domains of material deprivation: income, employment, education and skills, health, housing, crime, access to services, and living environment. We included IMD quintiles in all models to adjust for deprivation as it is associated with dementia.

# 5 | STATISTICAL ANALYSIS

All analyses were conducted in Stata Version 17.0.

# 5.1 | Incidence of dementia

We summed the number of patients with a first record indicative of dementia diagnosis between 1997 and 2018 and divided this by the total number of person-years at risk to estimate the overall crude incidence of dementia diagnosis per 1000 person years at risk (PYAR). We estimated crude incidence by calendar year for the whole sample. We

then estimated crude incidence by calendar year, split by ethnicity. We estimated incidence rate ratios (IRR) for South Asian and Black ethnic groups (compared to the White group) by fitting univariable and then multivariable Poisson regression models with log person-time as an offset, adjusting for age, sex, and IMD quintile.

#### 5.2 | Prevalence of dementia

We calculated overall dementia point prevalence for each year. The numerator was the number of people aged  $\geq 65$  years diagnosed with dementia prior to  $15^{th}$  April of that year (from any source), as that date is after Quality Outcomes Framework data (key data from primary care, including dementia) from GPs is due. The denominator was all people from each ethnic subgroup aged  $\geq 65$  years contributing data on that date. We calculated overall crude prevalence (and 95% CIs) for the whole sample and White, South Asian, and Black participants per year from 1997 to 2018. We then used the English population structure for  $2018^{17}$  to produce age and sex standardized point prevalence estimates for each ethnic group per year.

# 5.3 | Age at dementia diagnosis

We investigated the age that people were diagnosed with dementia across different ethnic groups by calculating age at first record of dementia diagnosis. We conducted linear regression with ethnicity as exposure, age at dementia diagnosis as the outcome, adjusting for age at baseline, sex, and IMD quintile. We tested for normality of residuals after running the regression model.

# 5.4 | Survival after dementia diagnosis

Among those with diagnosed dementia, we excluded those whose date of death was prior to date of dementia diagnosis as we assumed that diagnosis was made at death; therefore, survival could not be estimated (n = 397), and those whose survival time was more than 20 years as it seemed unlikely they had dementia  $^{18}$  (n = 896). Survival time for those with diagnosed dementia meeting our criteria was calculated as date of death minus date of dementia diagnosis, and for those who were still alive at the end of follow-up, survival time was calculated as the date of the end of their follow-up minus date of dementia diagnosis. We compared survival times in those with dementia across different ethnic groups using descriptive statistics. We then conducted Cox proportional hazards regression in those diagnosed with dementia with time to death as the outcome, and ethnicity as the exposure, adjusting for sex and IMD quintile. We did not adjust for age at dementia diagnosis as we reasoned this was on the causal pathway between ethnicity and survival after dementia diagnosis and it was already taken into account through survival time.

We calculated age at death for those who were diagnosed with dementia and died during the study period. We conducted linear

**TABLE 1** Characteristics of sample

| Characteristic | White N = 481,161 | South Asian<br>N = 6907 | Black<br><i>N</i> = 5403 |  |
|----------------|-------------------|-------------------------|--------------------------|--|
| Mean age (SD)  | 75.5 (7.5)        | 72.3 (6.3)              | 73.1 (6.3)               |  |
| % Female       | 59                | 51                      | 56                       |  |
| % IMD quintile |                   |                         |                          |  |
| 1              | 22.0              | 15.9                    | 6.4                      |  |
| 2              | 23.2              | 20.3                    | 10.2                     |  |
| 3              | 22.0              | 21.9                    | 18.0                     |  |
| 4              | 18.1              | 21.7                    | 28.4                     |  |
| 5 <sup>a</sup> | 14.4              | 20.2                    | 37.0                     |  |
| Missing        | 0.1               | 0.3                     | 0.5                      |  |

<sup>&</sup>lt;sup>a</sup>Most deprived.

regression with age at death as the outcome, and ethnic group as the exposure in a univariable model. We then conducted a multivariable regression model, adjusting for sex and IMD quintile sequentially.

# 5.5 | Missing data

As ethnicity was the exposure of interest, our main analyses were complete cases where data on ethnicity, outcomes, and other covariates were complete. We used multiple imputation with chained equations to impute missing ethnicity and IMD data as previous studies have shown this to be missing at random. We analyzed patterns of missingness and conducted regression analyses to explore associations between missing values of ethnicity and IMD and other variables in the dataset. We found evidence to support the missing at random assumption, finding that all measured health conditions, IMD, age, sex, and dementia were associated with missing ethnicity. We used the multivariate imputation by chained equations algorithm<sup>19</sup> for multiple imputation of missing data in ethnicity and IMD quintile. Multiple imputation was performed in Stata version 17.0 using the "mi impute chained" command. For each incomplete variable, we constructed an imputation model conditional on variables in the main analysis (indicator of dementia, age at cohort entry, sex), other disease indicators recorded at any time (myocardial infarction, stroke, chronic kidney disease, diabetes, hypertension, obesity), lifestyle factors (smoking status, excessive use of alcohol), survival variables (follow-up time, death) and the other incomplete variables. We created 20 imputed datasets. We conducted sensitivity analyses for each of the incidence and survival regression analyses using multiply imputed data combined using Rubin's rules.<sup>20</sup>

#### 6 RESULTS

There were 5,056,123 adults contributing data over the observed period, of whom 662,882 were aged 65 or over. After restricting the cohort to those  $\geq$ 65, there were 481,161 (72.5%) White, 6907 (1.0%) South Asian, and 5403 (0.8%) Black people. A total of 7907 (1.2%) were

of other ethnicities and 161,504 (24.4%) of people had no recorded ethnicity. Mean age(SD) at study entry was 74.2(7.5) for White people, 73.0(6.3) for South Asians, and 73.1(6.3) for Black people. In those  $\geq$ 65, 59% of White people, 51% of South Asian, and 56% of Black people were female. Black people lived in the most deprived areas, followed by South Asian participants and White people in the least deprived (Table 1).

#### 6.1 | Incidence of dementia

There were 662,882 people aged ≥65 who contributed data over 5,164,950 person years of follow-up with 129,417 incident cases of dementia. Overall, annual incidence of dementia was 12.8/1000 PYAR in 1997, increasing to a high of 61.0/1000 PYAR in 2015 and then reducing to 31.1/1000 PYAR in 2018. Patterns of incidence were similar across all ethnic groups over this period (Table 2). Compared with White people, the IRR for dementia in an unadjusted univariable model was lower in South Asian (IRR 0.71, 95% CI 0.66-0.76, P < .0001) and higher in Black people (IRR 1.06, 95% CI 0.99-1.13, P = .071). Adding age to this model, the IRR for South Asian people was 0.82, (95% CI 0.77-0.88) and for Black people: 1.21, (95% CI 1.13-1.29). After adjusting for age and sex, the IRR for South Asian people was 0.84 (95% CI 0.79-0.90) and for Black people was 1.25 (95% CI 1.17-1.34). After adjusting for age at study entry, sex, and IMD quintile the IRR was 0.83 for South Asian people (95% CI 0.78-0.89, P < .0001) and 1.22 for Black people (95% CI 1.15-1.30, *P* < .0001).

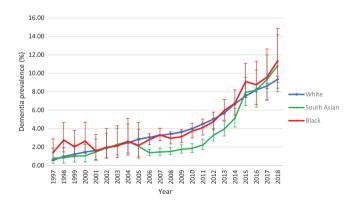
#### 6.2 Prevalence of dementia

The recorded crude point prevalence of dementia increased from 1.22% (95% CI 1.18–1.27) in 1997 to 11.74% (95% CI 10.68–12.86) in 2018. The increase was particularly marked between 2009 and 2016. The pattern of increase in prevalence was found in all ethnic groups with confidence intervals overlapping for all ethnic groups (Figure 1). Age and sex adjusted point prevalence showed increasing prevalence

**TABLE 2** Crude incidence per 1000 person years at risk by ethnic group

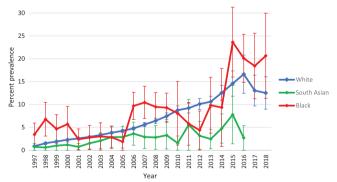
|      | White |      |      | South Asia | South Asian |      | Black | Black |      |  |
|------|-------|------|------|------------|-------------|------|-------|-------|------|--|
| Year | Rate  | LCL  | UCL  | Rate       | LCL         | UCL  | Rate  | LCL   | UCL  |  |
| 1997 | 11.9  | 11.2 | 12.6 | 5.0        | 1.2         | 19.8 | 33.1  | 17.8  | 61.6 |  |
| 1998 | 14.2  | 13.5 | 14.9 | 6.2        | 2.0         | 19.1 | 21.7  | 10.8  | 43.4 |  |
| 1999 | 13.6  | 13.0 | 14.2 | 5.9        | 2.2         | 15.8 | 20.0  | 11.1  | 36.2 |  |
| 2000 | 13.6  | 13.1 | 14.1 | 7.4        | 3.5         | 15.4 | 11.6  | 6.0   | 22.3 |  |
| 2001 | 16.8  | 16.2 | 17.3 | 10.1       | 5.7         | 17.8 | 17.5  | 10.8  | 28.6 |  |
| 2002 | 18.1  | 17.6 | 18.6 | 11.5       | 7.2         | 18.5 | 24.1  | 16.5  | 35.1 |  |
| 2003 | 21.5  | 20.9 | 22.1 | 15.1       | 10.3        | 22.1 | 25.1  | 17.7  | 35.5 |  |
| 2004 | 22.3  | 21.7 | 22.9 | 12.5       | 8.5         | 18.4 | 29.9  | 22.0  | 40.6 |  |
| 2005 | 23.3  | 22.7 | 23.9 | 10.7       | 7.2         | 16.0 | 23.8  | 17.1  | 32.9 |  |
| 2006 | 27.2  | 26.6 | 27.9 | 8.8        | 5.7         | 13.4 | 25.1  | 18.5  | 34.1 |  |
| 2007 | 29.5  | 28.8 | 30.2 | 7.5        | 4.9         | 11.7 | 21.2  | 15.4  | 29.3 |  |
| 2008 | 31.9  | 31.1 | 32.6 | 14.3       | 10.5        | 19.5 | 28.4  | 21.6  | 37.3 |  |
| 2009 | 37.1  | 36.3 | 38.0 | 22.6       | 17.7        | 28.7 | 17.4  | 12.4  | 24.5 |  |
| 2010 | 44.8  | 43.9 | 45.8 | 21.6       | 17.0        | 27.5 | 27.8  | 21.6  | 35.7 |  |
| 2011 | 47.9  | 46.9 | 48.9 | 19.0       | 14.8        | 24.4 | 21.5  | 16.4  | 28.2 |  |
| 2012 | 49.4  | 48.3 | 50.5 | 24.1       | 19.3        | 30.1 | 38.0  | 31.0  | 46.6 |  |
| 2013 | 62.8  | 61.5 | 64.2 | 33.1       | 27.3        | 40.2 | 46.0  | 38.1  | 55.4 |  |
| 2014 | 69.7  | 68.1 | 71.3 | 50.9       | 42.8        | 60.5 | 50.0  | 41.0  | 61.1 |  |
| 2015 | 72.0  | 70.2 | 73.8 | 52.2       | 42.3        | 64.4 | 72.6  | 59.3  | 88.8 |  |
| 2016 | 63.8  | 61.7 | 66.0 | 18.0       | 11.9        | 27.1 | 41.4  | 30.2  | 56.9 |  |
| 2017 | 45.7  | 43.6 | 48.0 | 27.8       | 19.7        | 39.3 | 32.7  | 22.2  | 47.9 |  |
| 2018 | 37.5  | 35.3 | 40.0 | 27.4       | 18.2        | 41.3 | 35.8  | 23.3  | 54.9 |  |

Abbreviations: LCL, lower confidence limit; UCL, upper confidence limit.



**FIGURE 1** Crude dementia prevalence (95% CI) in those aged 65 and over, by ethnic group

across all ethnic groups over time. There was not enough data to calculate age and sex-adjusted prevalence for South Asian people for 2017 and 2018. Estimates of prevalence for Black people from 2015 onward were higher than for White people but confidence intervals were wide for the Black group and overlapped with the White group (Figure 2). We also plotted a graph of dementia prevalence using exponential smoothing and this is in the supplementary material.



**FIGURE 2** Age- and sex-adjusted dementia prevalence (95% CI) in those aged 65 and over, by ethnic group

# 6.3 | Age at dementia diagnosis

Median age at dementia diagnosis was later in White people than in minority ethnic groups: 86.2 (IQR 81.6–90.5) for White people, 82.1 (IQR 77.9–86.5) for South Asian people, and 81.1 (IQR 76.4–86.1) for Black people. After adjusting for age at study entry, sex and IMD quintile, South Asian ethnicity was associated with younger age at diagnosis

than that of White people: -2.7 years (95% CI -3.0 to -2.4, P < .0001) and Black ethnicity was associated with a diagnosis on average 2.9 years younger (95% CI -3.2 to -2.6, P < .0001) than White people. Residuals were normally distributed.

## 6.4 | Survival after dementia diagnosis

During the follow-up period, in those diagnosed with dementia, 81.3% of White people, 57.3% of South Asian people and 59.0% of Black people died. Mean age(SD) at death in those with dementia was 88.9(6.1) in White, 85.5(6.2) in South Asian and 85.6(6.5) in Black people.

In univariable Cox regression analysis, South Asian ethnicity was associated with an increased risk of death in those diagnosed with dementia (HR 1.33, 95% CI 1.24–1.44) but Black ethnicity was not (HR 0.98, 95% CI 0.91–1.05). Adjusting this model for sex and IMD quintile did not alter the estimates (+sex: South Asian HR 1.27(1.18–1.37); Black HR 0.94(0.87–1.00) +sex+IMD: South Asian HR 1.29(1.19–1.39); Black HR 0.96(0.89–1.03)).

In a univariable linear regression model, being from a minority ethnic group was associated with earlier age at death in those with dementia (South Asian Coeff -3.39, 95% CI -3.85 to -2.93; Black participant Coefficient -3.25, 95% CI -3.68 to -2.83). Adding sex to the model with ethnicity reduced the coefficients slightly (South Asian participant Coefficient -3.06, 95% CI -3.50 to -2.61; Coefficient for Black participants -2.87, 95% CI -3.29 to -2.45). In the final model, South Asian and Black ethnicities were associated with an earlier age at death compared to White people after adjusting for sex and IMD quintile (Coefficient for South Asian participants -2.97, 95% CI -3.41 to -2.53; Coefficient for Black participants -2.66, 95% CI -3.08 to -2.24).

# 6.5 Sensitivity analysis – restricting survival sample

To investigate the possibility that different survival times may bias the survival analysis, we repeated our Cox regression, restricting our sample to those who were diagnosed with dementia and died during the follow-up period. In univariable analysis, people from minority ethnic groups had a shorter time to death than the White population (South Asian HR 1.51(1.40–1.6); Black HR 1.12(1.04–1.20). After adjusting for age and sex these changed to: South Asian HR 1.44(1.34–1.55); Black HR 1.08(1.00–1.16). Adding IMD quintile to this model changed the estimates further: South Asian HR 1.45(1.35–1.57); Black HR 1.10(1.03–1.18).

#### 6.6 Sensitivity analysis using MI

Multiply imputed data had percentages of ethnic groups similar to that expected in the general population (see Supplementary Material for ethnicity breakdown in complete case and imputed samples). We repeated our analyses using multiply imputed data for ethnicity and IMD quintile. The IRR for dementia compared to the White population after adjusting for age, sex, and IMD was 0.80 for South Asian people (95% CI 0.75–0.85, P < .0001) and 1.16 for Black people (95% CI 1.08–1.24, P < .0001).

In survival analysis, using multiply imputed data for those diagnosed with dementia, after adjusting for sex and IMD quintile, South Asian ethnicity was associated with higher risk of death in those with dementia (HR 1.26, 95% CI 1.15–1.37, P < .0001) and Black ethnicity was not associated with risk of death (HR 0.97, 95% CI 0.90–1.04, P = .438).

Sensitivity analyses in multiply imputed data for age at death with dementia produced similar results to the complete case analysis after adjusting for sex and IMD quintile: South Asian coefficient -2.95, (95% CI -3.40 to -2.50, P < .0001); Black coefficient -2.78, (95% CI -3.20 to -2.35, P < .0001).

# 7 | DISCUSSION

To our knowledge, this is the first study to investigate incidence and prevalence of dementia as well as age of diagnosis, survival and age of death after diagnosis across ethnic groups, using linked electronic health records. We found more than 20% higher incidence in the Black community compared to the White population but lower incidence in the South Asian population. We found younger age at diagnosis in South Asian and Black people, confirming previous findings, <sup>11</sup> less survival time and younger age of death. Previous studies have estimated incidence using only primary care records.<sup>7</sup>

We have no large population-based surveys of dementia incidence in the South Asian community, so this study represents the best estimate, although previous work indicates that prevalence of dementia is lower in minority ethnic groups when studies are registry based rather than population based. Dementia incidence in this older sample was higher than a cohort study of people aged >50 using primary care records but replicated the findings of higher incidence in the Black population.

The earlier age of dementia diagnosis in people of Black and South Asian in our analyses, even after controlling for material deprivation, may be related to the higher prevalence of some risk factors for dementia such as in older South Asians fewer years of education<sup>22</sup> and in both groups, hypertension, diabetes and obesity.<sup>23</sup>

Black and South Asian people survived for less time after dementia diagnosis and they died at a younger age, which is in line with previous findings of greater dementia severity at diagnosis <sup>11</sup> (but we do not know if this is the cause) and at death <sup>24</sup> in minority ethnic groups with dementia. This also mirrors findings of less timely diagnosis in minority groups in the USA. <sup>25</sup> Our sensitivity analysis considering only those who received a dementia diagnosis and died found that South Asians had a 45% increased risk of death and Black people a 10% increased rate. Given the younger age of diagnosis and increase in dementia prevalence and incidence with age, our finding of similar prevalence suggests an under-capture of minority ethnic diagnoses of dementia, particularly South Asian people with dementia. This may

be related to individuals not presenting or due to healthcare system related barriers.  $^{26}$ 

We have shown an increase in recorded incident and prevalent dementia across all ethnic groups over a 21-year period. Overall crude dementia prevalence was similar across all ethnic groups, but age- and sex-adjusted dementia prevalence was lower in South Asians. There was a large difference in crude versus adjusted prevalence rates, likely due to the fact that over time the age and sex structure of the English population has changed considerably and variations between ethnic groups is considerable. Dementia prevalence by 2018 was higher than population-based surveys from 2011,<sup>4</sup> although recorded dementia rates are lower than true community rates. This could be due to many factors. It could represent a true increase in dementia prevalence over time, as life expectancy in the United Kingdom increased from 77.2 years in 1997 to 81.3 in 2018<sup>27</sup> and dementia prevalence doubles with every 5 years increase in age.

Strengths of the study were a large sample size that is broadly representative of the general population, linkage to multiple sources of health records improving ascertainment of dementia status, long duration of follow-up, and large sample sizes of people from minority ethnic groups. This allowed us to make the best estimations of rates of dementia for people from minority ethnic groups to date. Limitations of the data are the large amount of missing data for ethnicity, but we conducted sensitivity analyses with multiply imputed data, giving similar results to the primary analysis and similar percentages of ethnic groups compared to the census. Additionally, IMD may be on the causal pathway for our outcomes of interest, 28 so our analyses may have been over-adjusted. Analyses omitting IMD from models did not differ greatly from analyses including it, however, indicating a relatively small association with dementia over and above other covariates such as age and sex. Unfortunately, we could not explore the impact of individual-level education as these data were not available but education is included in the IMD composite score. We relied on recorded ethnicity, which may not always be accurate or reflect the ethnic group with which a person self-identifies. Additionally, all ethnic groups contain many diverse groups, but we were not able to disaggregate further due to limited numbers and we could not make any conclusions about mixed or other ethnic groups apart from White, Black, and South Asian. We also had no information on whether people were born in the United Kingdom or immigrated so could not examine possible differences in these groups. Practices that meet data quality standards and consent to data linkage may be better resourced so only including these practices may limit generalizability of our results, although widening inclusion may mean data are less accurate.

Our code lists for dementia were validated and recording of dementia in primary care and hospital episode statistics is generally valid but recorded diagnosis is not the same as a true diagnosis of dementia so some cases may have been missed and others may have had a recorded diagnosis or indicator of dementia but may not have had dementia. IMD is a marker of area level deprivation so may not necessarily represent an individual's circumstances. Some practices stopped contributing data as they switched to different software systems, but

this was likely to be random and not related to exposures or outcomes so unlikely to introduce bias.

Overall, our findings show Black and South Asian patients are diagnosed with dementia at a younger age and die at a younger age with dementia than White patients, losing more years of life. Both require reduction of inequities, tailoring of interventions and optimization of care pathways to reduce disparities.

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#### **CONFLICTS OF INTEREST**

None of the authors have any conflicts of interest to disclose. Author disclosures are available in the supporting information.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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