

Dementia diagnosis rates and the impact of ethnicity, rurality and deprivation

Jemma Hazan, Kathy Y. Liu, Jeremy D. Isaacs & Naaheed Mukadam

To cite this article: Jemma Hazan, Kathy Y. Liu, Jeremy D. Isaacs & Naaheed Mukadam (16 Oct 2024): Dementia diagnosis rates and the impact of ethnicity, rurality and deprivation, *Aging & Mental Health*, DOI: [10.1080/13607863.2024.2374936](https://doi.org/10.1080/13607863.2024.2374936)

To link to this article: <https://doi.org/10.1080/13607863.2024.2374936>



© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



[View supplementary material](#)



Published online: 16 Oct 2024.



[Submit your article to this journal](#)



Article views: 250







[View related articles](#)



[View Crossmark data](#)

Dementia diagnosis rates and the impact of ethnicity, rurality and deprivation

Jemma Hazan^a , Kathy Y. Liu^a , Jeremy D. Isaacs^{b,c,d}  and Naaheed Mukadam^{a,e} 

^aDivision of Psychiatry, University College London, London, UK; ^bSt George's University Hospitals NHS Foundation Trust, London, UK; ^cNHS England, London, UK; ^dNeurosciences and Cell Biology Research Institute, St George's, University of London, London, UK; ^eCamden and Islington NHS Foundation Trust, London, UK

ABSTRACT

Objectives: NHS England publishes monthly national and regional estimated dementia diagnosis rates (DDR) to assess the healthcare system's effectiveness in identifying dementia cases. Previous research indicates that sociodemographic factors, such as ethnic minority status, socioeconomic deprivation, and rurality, influence both healthcare quality and dementia risk. This study aimed to examine the association between these sociodemographic factors and DDR, and to estimate an ethnicity-adjusted DDR using available ethnic group data.

Method: We analysed NHS Digital Primary Care Dementia Data electronic health records for July 2023. We used a linear regression model to determine the association between DDR and ethnicity, deprivation, and rurality factors using local authority region level data. We also adjusted the DDR at the level of sub-integrated care boards based on previously published odds ratios of dementia diagnosis by ethnic group.

Results: Regression modelling revealed that areas with higher proportions of minority ethnic groups and greater rurality had lower DDRs. Conversely, higher levels of deprivation were linked to higher DDRs. After adjusting for different odds ratios for dementia in minority ethnic groups, the national DDR decreased by 1%, with regional diagnosis rates dropping by up to 5.4%.

Conclusion: Higher regional proportional ethnic minority population and greater rurality were associated with a lower DDR which might reflect poorer access to diagnostic services. Higher deprivation levels were associated with a higher DDR which might reflect higher rates of dementia in more deprived populations. We discuss measures to improve the accuracy and utility of the DDR, with a specific focus on ethnicity.

ARTICLE HISTORY

Received 18 January 2024
Accepted 19 June 2024

KEYWORDS


Dementia; diagnosis; ethnicity; deprivation; rurality


Introduction

The UK is estimated to have 850,000 individuals living with dementia (Prince et al., 2014). The global prevalence of dementia is forecasted to almost triple by 2050 (Nichols et al., 2022). In response to the 2015 "Prime Minister's Challenge on dementia," (Department of Health, 2015) which emphasized the need for improved diagnosis rates, the National Health Service (NHS) introduced the Dementia Diagnosis Rate (DDR) as a key quality indicator (Department of Health, 2016). The DDR is calculated as a ratio between the number of people with a recorded dementia diagnosis on primary care registers and the estimated number of people with dementia based on extrapolation of epidemiological data. Following this, NHS England established a national goal for two-thirds of all individuals affected by dementia to receive a diagnosis, and has since published monthly estimates of DDR. This forms part of an ongoing national dementia strategy to increase the number of dementia diagnoses in England (Hazan et al., 2023). Receiving a dementia diagnosis is posited to be beneficial, with survey data revealing that most people affected by dementia see the benefit in getting a diagnosis (Alzheimer's Society, 2023). Some of these benefits include accessing support for patients and carers, access to pharmacological and non-pharmacological management

and research opportunities. However, the DDR varies by region (NHS Digital, 2023a). As factors that affect access to healthcare, such as minority ethnic group proportion (Office for National Statistics (ONS), 2022), deprivation and rurality also vary by region, it is plausible that these could influence the DDR, but this has not been tested quantitatively.

Prior work has established that sociodemographic factors including ethnicity, area-level deprivation and rurality are associated with dementia risk (Cassarino et al., 2016; Chung et al., 2023; Hofbauer & Rodriguez, 2023; Jitlal et al., 2021; Mukadam et al., 2022; Pham et al., 2018; Russ et al., 2012). These associations have been observed in the UK and internationally. Compared to White Americans, higher dementia incidence has been observed in African American, Hispanic and Native American people (Kornblith et al., 2022; Mayeda et al., 2016). A UK study based in east London showed an increased risk of dementia in Black and South Asian groups compared to the White population (Bothongo et al., 2022). However, people from minority ethnic groups are less likely to receive a diagnosis of dementia (Mukadam et al., 2011) and are diagnosed relatively late in their illness (Mukadam et al., 2019). In the UK, minority ethnic groups constitute 18% of the population. After the White Other category, people from Asian ethnic groups make up the second largest percentage of the population (9.3%), followed

CONTACT Jemma Hazan  j.hazan@ucl.ac.uk

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/13607863.2024.2374936>.

© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

by Black (4.0%), Mixed (2.9%) and Other (2.1%) ethnic groups (2021 Census data) (Office for National Statistics (ONS), 2022).

The denominator in the DDR, the estimated number of people with dementia, is derived from the Cognitive Function and Ageing Study II (CFAS II) (Matthews et al., 2013). To provide area-level DDRs, estimated dementia prevalence is adjusted for the age and sex structure of the local population. However, the data are not adjusted for ethnicity, deprivation or rurality. This means that local health systems might be basing policy decisions on inaccurate DDR estimates. Specifically, the current methodology would be predicted to overestimate the DDR in areas with higher levels of ethnic minority population, deprivation and rurality than in the populations studied in CFAS II due to underestimating the denominator. However, this might be outweighed by people from ethnic minority, more deprived and rural populations experiencing poorer access to dementia diagnostic services.

We hypothesised that ethnicity, socioeconomic deprivation and rurality would influence dementia diagnosis rates. We predicted that an increased proportion of minority ethnic groups, controlling for socioeconomic deprivation and rurality, would be associated with a reduction in DDR. We then aimed to adjust the DDR denominator using local area ethnic group, deprivation and rurality data to achieve a more accurate estimate.

Methods

Datasets: Data used in analyses was acquired online from the publicly available NHS England Primary Care Dementia Data for July 2023 (NHS Digital, 2023b) and deprivation data and rurality data that were closest in date to July 2023. Specifics of the data for each analysis are presented below. As this was aggregate data provided by GP practices, processed by NHS England, and published online and publicly available, this study did not require regulatory approval.

We conducted two separate analyses. The first was to examine associations between sociodemographic factors and DDR in a linear regression. The second analysis was to adjust the DDR for differences in population ethnic groups.

Associations between sociodemographic factors and DDR

Variables of interest

Analyses were conducted at the *level of a Local Authority District*. This refers to an entity responsible for administering local government responsibilities. In different regions of England, local government functions are carried out by either single-tier or two-tier local authorities. Single-tier authorities, including the Unitary Authority, metropolitan district, and the London borough, are primarily present in major urban areas. Two-tier authorities, comprising the county and the local authority district, are found in other areas (NHS, 2023; Office for National Statistics (ONS), n.d.).

Dementia diagnosis rates. DDR was included at the local authority level using the Primary Care Dementia Data for July 2023 (NHS Digital, 2023b). The national estimated DDR for England is reported monthly by NHS Digital (NHS Digital, 2023a), and is calculated by dividing the count of individuals aged over 65 years with a documented dementia diagnosis

in each health service region of England (as recorded on dementia registers in GP practices), by the estimated number of individuals aged over 65 years expected to have dementia in the local population, expressed as a percentage. The estimated number of individuals expected to have dementia is calculated using age- and sex-specific prevalence rates, which have been sourced from CFAS II since March 2015 (Matthews et al., 2013).

Ethnicity. Ethnicity was determined through self-report based on the categories specified in the England census (Office for National Statistics (ONS), 2022). These groups included: White (including English, Welsh, Scottish, Northern Irish, British, Irish, Gypsy or Irish Traveller, any other White background); Black (including African, Caribbean and any other Black, African or Caribbean Background); South Asian (including Indian, Pakistani, and Bangladeshi); Other (any other specified ethnicity including mixed ethnicities); and Unknown. We defined a group called 'total minority ethnicity' which comprised of the total count of Black, South Asian and Other categories. We used proportion of minority ethnicity (number from minority ethnicity/total number) or proportion from each ethnic group in our analyses (number from minority ethnic group/total number).

Index of multiple deprivation (IMD). Area-level deprivation was operationalized using the IMD, the official metric for gauging relative deprivation in small areas across England. The IMD ranks each Lower Layer Super Output Area (LSOA), delineated geographical regions encompassing approximately 1500 residents and 650 households. It integrates seven dimensions of deprivation, assigning weights as follows: income (22.5%), employment (22.5%), health and disability (13.5%), education, skills, and training (13.5%), barriers to housing and services (9.3%), living environment (9.3%), and crime (9.3%). Participants were categorized into national IMD deciles based on this ranking with 1= least deprived and 10= most deprived. Additional details can be accessed here (Ministry of Housing & Communities & Local Government, 2019).

Rurality. Rural indices were defined according to the Distribution of Local Authority Districts and Population by The Rural Urban Classification for Local Authorities (RUCLAD) Class, 2011. Local authorities are categorised as rural or urban based on the percentage of their resident population in rural areas or 'rural-related' hub towns. There are six indices which include: Urban with Major Conurbation, Urban with Minor Conurbation, Urban with City and Town, Urban with Significant Rural (rural including hub towns), Largely Rural (rural including hub towns), Mainly Rural (rural including hub towns). These were ranked from 1 to 6, with 1= Urban with Major Conurbation and 6= Mainly Rural. Further details have been previously published (Office for National Statistics (ONS) Department for Environmental Food & Rural Affairs, 2017).

Statistical modelling

All analyses were performed using R Software R version 4.1.2; R Foundation for Statistical Computing.

We first summarised the DDR from local authority district data in terms of mean, standard deviation, 95% confidence intervals, and number of observations according to minority ethnic group and IMD decile ranking and rurality sextile ranking.

Linearity of the data was tested by visual inspection of the relationship between the log odds of the outcome and each predictor variable using partial residual plots. The studentized Breusch-Pagan test indicated no significant evidence of heteroscedasticity in the residuals ($BP = 4.5897$, $df = 3$, $p = 0.2044$). Similarly, the Durbin-Watson test found no significant autocorrelation in the residuals at lag 1 (D-W Statistic = 2.0948, $p = 0.432$). These results suggest that the assumptions of homoscedasticity and independence of residuals were met for a linear regression model. We then performed linear regression analyses to evaluate the association between DDR and different ethnic groups. We included proportion of each minority ethnic group or the proportion of 'total minority ethnicity' group as the exposure and adjusted for socioeconomic deprivation and rurality co-variables sequentially. We performed additional sensitivity analyses to explore the interaction between ethnicity and socioeconomic deprivation.

Adjusting DDR to take ethnicity into account

Variables of interest

Analyses were conducted at the level of an integrated care board (ICB) or sub-integrated care board (Sub-ICB) according to data available from Primary Care Dementia Data. Ethnic group data in the Primary Care Dementia Data was not available at the local authority level. Therefore, these data were analysed at the ICB or sub-ICB level. Integrated Care Boards are statutory NHS organisations responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in a geographical area. Sub-ICBs are a sub-division of an Integrated Care Board's total geographic area. They replaced Clinical Commissioning Groups (CCGs) in July 2022 (NHS Business Service Authority, n.d.). In London, sub-ICBs correspond to local authorities but elsewhere this does not necessarily apply. Data for dementia diagnosis by ethnic group was only available at the ICB or sub-ICB level. Details of data and DDR for all ICB and sub-ICBs is available from Primary Care Dementia Data (NHS Digital, 2023b).

Dementia diagnosis rates. DDR was included at the integrated and sub-integrated care board level using the Primary Care Dementia Data downloaded in July 2023.

Odds ratios. We used findings from Bothongo et al. (2022), which identified increased odds ratios (OR) of dementia relative to the White population for the following ethnic minority groups: Black OR 1.43; South Asian OR 1.17; Mixed and Other OR 1.02.

Ethnicity. We obtained ethnic group data using the Primary Care Dementia Data for July 2023. This collected counts of patients on GP practices' dementia register, which were aggregated into 7 ethnic groups: Asian or Asian British, Black, African, Caribbean or Black British, Mixed or multiple ethnic groups, Not defined - patients whose ethnicity is not recorded, Not stated - patients who were given an opportunity to state their ethnicity but chose not to, Other

ethnic group and White. We defined a group called 'total minority ethnic group' which comprised of the total count of Black, Asian, Mixed and Other categories (NHS Digital, 2023c). We used these categories and were unable to separate out South Asian group from the Asian category.

We chose to classify by ethnicity instead of race as the NHS does not collect data on "race." Furthermore, while race primarily defines biological characteristics, ethnicity is a broader construct encompassing common cultural traits. Ethnicity, as typically recorded in primary care, is often self-defined, rendering it an acceptable measure of individuals' views on their identity (Lu et al., 2022).

Statistical modelling

To determine the effects of ethnicity on DDR we modified the DDR calculation. We used DDR data for the whole of England as well as by ICB or sub-ICB. We used recorded dementia cases in each location as the numerator. For the denominator, we multiplied estimated dementia cases for each area by the proportion of the population in each ethnic group and corresponding odds ratio for dementia.

$$\text{Adjusted DDR} = \frac{\text{recorded dementia cases} > 65 \text{ years}}{\text{by ICB or sub-ICB}} \div \frac{\text{estimated dementia cases} > 65 \text{ years}}{\times \% \text{ ethnicity} \times \text{Odds Ratio}}$$

To calculate diagnoses rates for each ethnic group, we divided recorded numbers of dementia diagnoses in each ethnic group by the estimated cases for that ethnic group.

Missing data

One of the challenges for the data is that many people with a dementia diagnosis do not have their ethnic group recorded in the primary care data. To address this, we allocated reported dementia cases to each ethnic group in proportion to their representation in the underlying population, for example, for England as a whole, we allocated 6.9% of dementia cases with no reported ethnicity to the Asian subgroup in line with the proportion of the population from an Asian background whereas for Leicestershire, we allocated 34.5% of the dementia cases with no reported ethnicity to the Asian subgroup in line with demographics in this region.

Deprivation and rurality

We were unable to perform the same analyses by deprivation and rurality for two reasons. Principally, the research literature to date does not provide comprehensive odds ratios for dementia by socioeconomic deprivation or rurality; therefore, we were unable to adjust the baseline CFAS-II-derived data for these factors. Secondly, GP dementia registers do not record a deprivation or rurality score for each patient; therefore we would not have been able to derive specific DDRs based on levels of deprivation or rurality.

Results

Data was available for 309 local authorities for the linear regression analyses. There was missing data for 0.97% of socioeconomic deprivation values in the IMD data 2019 (Ministry of

Housing & Communities & Local Government, 2019), 1.94% of rurality values in the RUCLAD data 2011 (Office for National Statistics (ONS), Department for Environmental Food & Rural Affairs, 2017) and 0.32% of ethnicity values at the local authority level in the England census data 2021 (Office for National Statistics (ONS), 2022).

Data was available for 106 sub ICBs for the adjusted DDR analysis, of which 95329 (21%) of patients, i.e. individuals on dementia registers, had no recorded ethnicity data in the Primary Care Dementia Data July 2023 (NHS Digital, 2023b).

We summarised the mean DDR for local authority districts, standard deviation, 95% confidence intervals, and number of observations by decile of proportion of minority ethnic group, as well as by decile of socioeconomic deprivation and rurality sextile. These data are shown in the [supplementary material \(Tables S1–S3\)](#).

Linear regression analyses

An unadjusted model of the association between DDR and ethnic group, an adjusted model for socioeconomic deprivation or rurality and a fully adjusted model adjusted for both socioeconomic deprivation and rurality are summarised in [Table 1](#) (minority ethnic group) and [Table 2](#) (Asian, Black, and Mixed and Other Ethnicity group).

DDR and minority ethnic group

In the fully adjusted models, there was a negative association between the proportion of minority ethnic groups in each region and DDR, with a coefficient of -0.15 ($p < 0.001$), indicating that DDR declined by 0.15 percentage points for each percentage increase in the proportion of the population that was from a minority ethnic group. Socioeconomic deprivation was

positively associated with DDR, as indicated by a coefficient of 1.74 ($p < 0.0001$) so each unit increase in socioeconomic deprivation was associated with an increase in DDR of 1.74 percentage points on average. Rurality was negatively associated with DDR, with a coefficient of -1.58 ($p < 0.0001$) so each unit increase in rurality decreased the DDR percentage by 1.58 percentage points on average.

A linear regression model examining the association between rurality and DDR, incorporating an interaction term Minority ethnic group: Socioeconomic deprivation, did not reveal a significant interaction ([Supplementary Table 4](#)).

DDR and other ethnic groups

The association between Asian, Black, and Mixed and Other Ethnicity group and DDR was negative when controlling for rurality and socioeconomic deprivation.

Adjusting DDR for minority ethnic group proportion

For England, after the odds ratios for dementia in each minority ethnic group were accounted for the estimated overall dementia diagnosis rate was 62.97% compared to the published estimate of 63.80%. For England, the DDR for White, South Asian, Black and Other ethnic groups was 56.1%, 22.4%, 28.5% and 20.6%, respectively, when we used only those cases for which ethnicity was reported. When we repeated analyses, allocating dementia cases with no recorded ethnic group to ethnic groups in line with their proportion in the population, the DDR for White, South Asian, Black and Other ethnic groups was 71.9%, 32.4%, 45.8% and 36.1%, respectively.

When ICB and sub-ICB level data were adjusted for the increased rates of dementia in minority ethnic groups, regional DDR was reduced by up to 5.4% where there was the highest

Table 1. Linear regression analyses examining the association between DDR and minority ethnic group, adjusting for socioeconomic deprivation and rurality covariates at the level of a local authority.

Covariate	Regression coefficients (95% CI)							
	Unadjusted model	<i>p</i> -value	Adjusted model (socioeconomic deprivation co-variate)	<i>p</i> -value	Adjusted model (rurality co-variate)	<i>p</i> -value	Fully adjusted model	<i>p</i> -value
Minority ethnic group (per %increase)	0.096 (0.02, 0.18)	0.0181	-0.07 (-0.16, 0.01)	0.1	-0.08 (-0.17, 0.01)	0.07	-0.15 (-0.24, -0.06)	<0.001
Socioeconomic deprivation (per %increase)			2.34 (1.70, 2.99)	<0.0001			1.74 (-2.24, -0.97)	<0.0001
Rurality					-2.22 (-2.82, -1.63)	<0.0001	-1.58 (0.94, 2.31)	<0.0001

Table 2. Linear regression analyses examining the association between DDR and Asian, Black, and Mixed and Other ethnic group, adjusting for socioeconomic deprivation and rurality covariates at the level of a local authority.

Covariate	Regression coefficients (95% CI)							
	Unadjusted model	<i>p</i> -value	Adjusted model (socioeconomic deprivation co-variate)	<i>p</i> -value	Adjusted model (rurality co-variate)	<i>p</i> -value	Fully adjusted model	<i>p</i> -value
Asian group (per %increase)	0.18 (0.04, 0.32)	0.0102	-0.07 (-0.22, 0.08)	0.36	-0.09 (-0.24, 0.06)	0.24	-0.19 (-0.33, -0.03)	0.015
Socioeconomic deprivation			2.19 (1.57, 2.82)	<0.0001			1.59 (0.79, 2.15)	<0.0001
Rurality					-2.11 (-2.69, -1.52)	<0.0001	-1.46 (-2.12, -0.85)	<0.0001
Black group (per %increase)	0.3 (0.03, 0.51)	0.0268	-0.24 (-0.51, 0.02)	0.07	-0.13 (-0.38, 0.11)	0.28	-0.39 (-0.62, -0.10)	0.00285
Socioeconomic deprivation			2.37 (1.73, 3.02)	<0.0001			1.76 (0.92, 2.33)	<0.0001
Rurality					-2.07 (-2.64, -1.51)	<0.0001	-1.4 (-2.04, -0.81)	<0.0001
Mixed and other ethnic group (per %increase)	0.1 (-0.22, 0.42)	0.535	-0.28 (-0.59, 0.03)	0.08	-0.42 (-0.74, -0.11)	0.01	-0.5 (-0.81, -0.19)	0.001
Socioeconomic deprivation			2.22 (1.64, 2.79)	<0.0001			1.48 (0.72, 2.02)	<0.0001
Rurality					-2.23(-2.78, -1.68)	<0.0001	-1.51 (-2.17, -0.92)	<0.0001

proportion of people from minority ethnic groups. The sub-ICB level DDR for ethnic groups ranged from 14.5–89.8% for White, 12.4–76.7% for Asian, 11.5–62.8% for Black and 14.2–88.0% for Mixed/Other ethnic groups. When dementia cases with no recorded ethnicity were re-allocated to different ethnic groups, the DDR ranged from 52.5% to 87.6% for White, 44.9–74.9% for Asian, 36.7–61.3% for Black and 51.5–85.9% for Mixed/Other ethnic groups. Further information is available in the [Supplementary Table 5](https://osf.io/ejprb/?view_only=91ae532a706e4808bee6c35968478bef) available at https://osf.io/ejprb/?view_only=91ae532a706e4808bee6c35968478bef.

Discussion

There are significant associations between ethnic group, socioeconomic deprivation, rurality, and DDR by local authority regions. We have shown that an increased proportion of minority ethnic groups in the population is associated with a lower DDR. There is a wealth of literature which shows that people from minority ethnic groups may be less likely to seek help for memory problems due to concerns about stigma in this population, but also healthcare related barriers (Mukadam, Cooper, Basit, et al. 2011). More rural local authority districts had lower DDR. The reasons for this may include underdeveloped memory services in more rural locations which should be addressed by ensuring equity of resources (Szymczynska et al., 2011). Previous literature has found greater rurality to be associated with increased risk of dementia (Russ et al., 2012). We did not adjust dementia prevalence for rurality, but our findings suggest that the “diagnosis gap” in rural areas might be even larger than suggested here. By contrast, there was a positive association between socioeconomic deprivation and DDR. This may be accounted for by the higher proportional risk effect of dementia in these populations (reflected in a higher numerator) but without adjustment of the denominator to reflect higher expected prevalence. Thus, current DDR estimates in areas with high levels of deprivation might be falsely reassuring. A methodology for adjusting the DDR for area-level deprivation is needed in order the local health and social care systems to plan appropriately. Proposed mechanisms linking socioeconomic deprivation with increased dementia risk include lifestyle factors, environmental exposures and medical co-morbidities (Chung et al., 2023).

We have looked at what happens when the diagnosis rate is adjusted on the basis that ethnic minority populations have higher rates of dementia. The decrease in DDR in proportion to the size of the ethnic minority population suggests that racially marginalised communities face a double hit of increased dementia risk coupled with lower rates of diagnosis. Our work shows that DDR estimates currently in use by NHS England and ICBs systematically underestimate the number of people from ethnic minority backgrounds living with dementia and overestimate the performance of the NHS in diagnosing dementia in non-White populations. This is not a just basis on which to plan and deliver dementia diagnostic and post-diagnostic services. Incomplete ethnicity coding in primary care compounds efforts such as ours to create meaningful local data sets.

The strength of this study is its wide scope. We have managed to test the association between ethnicity and DDR statistically using national data. To the best of our knowledge, this is the first time this has been done. We have taken account of differential dementia risk between ethnic groups which hasn't previously informed DDR estimates. The results presented

suggest that the diagnosis gap for racially minoritised communities is greater than for the White population.

Limitations in our study were related to gaps in the data. A significant minority of people with recorded dementia diagnosis had missing ethnicity data. This had the effect of producing artefactually depressed ethnic group-specific DDRs. Unfortunately, it was not possible to impute missing ethnicity from other data sources. It is possible that missing data biased the results, although we have tried to account for this by estimating missing ethnicity proportions as discussed below.

We have not conducted additional analyses to take into account the missing data for ethnicity, rurality and socioeconomic demographic factors at the local authority level, but the overall percentage of missing data was low.

In terms of the ethnicity data, the South Asian category was not separated out from the Asian group but the majority of this group is likely to be South Asian, based on population structure. Allocating cases to ethnic group based on underlying population structure increased estimated diagnosis rates across all ethnic groups, as would be expected. This approach assumes that ethnicity data is equally likely to be missing across all ethnic groups, thereby increasing the uncertainty in the DDR estimates, which in some cases look implausibly high. There are other ways of addressing missing data; for example, assuming all the missing data is from people of white ethnicity; however, this approach has significant limitations. This highlights the issues with recording of ethnicity in primary care. This improved following incentivisation of ethnicity recording from 2006/7 to 2010/11 but such incentivisation is no longer in place (NHS Digital, n.d.). We had to assume the odds ratios derived from Bothongo et al. (2022) used to adjust the expected prevalence were applicable to the entire ethnic group anywhere in England, which might not be the case. However, region-specific odds ratios for dementia by ethnicity are not currently available.

We were unable to adjust the DDR by socioeconomic deprivation or rurality. The research literature does not currently provide odds ratios by deprivation or rurality to allow for the DDR denominator to be adjusted, while numerator segmentation is not possible due to these factors not being recorded for dementia diagnoses i.e. at patient level, in the published Primary Care Dementia Data.

The linear regression model could not account for non-linear relationships between variables. We acknowledge the interconnectedness of ethnicity and sociodemographic factors. Through sensitivity analyses, we investigated the interaction between ethnicity and deprivation, revealing no significant interaction in our model. Certain ethnic groups exhibit higher likelihoods of lower education levels or elevated rates of specific illnesses (Hayanga et al., 2021). Recognizing that dementia diagnosis among these groups is influenced by multiple risk factors, not solely ethnicity, is crucial. There may be other factors that influence DDR beyond ethnicity, deprivation, and rurality, such as access to healthcare services, public health initiatives, or regional policies.

It is important to recognize that dementia incidence and prevalence in the UK might evolve over time. The figures we employed for prevalence in this article are based on fieldwork performed in 2008–2011 (Matthews et al., 2013). Although a study based on the English Longitudinal Study of Aging indicates a rise in dementia prevalence (Chen et al., 2023), this study relied on imputed data and therefore may not be accurate, with more robust estimates showing stable rates (Ahmadi-Abhari &

Kivimäki, 2024). Hence, we opted to assume static rates, acknowledging the inherent uncertainty in our estimations. However, dementia prevalence might be rising for other reasons, such as increasing rates of medical co-morbidities, for example diabetes and vascular disease. Conversely, dementia prevalence might be continuing to fall, as it did between the CFAS I and II studies, presumably due to reduced population exposure to modifiable risk factors such as low education, smoking and air pollution. The COVID-19 pandemic might also have impacted dementia prevalence through disproportionate mortality in people with dementia (Hazan et al., 2023). Therefore, the CFAS II prevalence data may no longer be representative of the population. For the DDR to remain a useful instrument of public policy, its underpinning epidemiological assumptions need to be updated to reflect secular trends in dementia prevalence. It should also reflect the diversity of the population and the disproportionate burden of dementia carried by racially minoritised, deprived and rural populations.

Improved recording of ethnicity in primary care would provide a more accurate picture of dementia diagnoses in England and facilitate local initiatives targeting currently underserved communities. We only had access to data where these ethnicity categories were used. It is possible that other category definitions, for example race, or more differentiated ethnicity categories, may have presented different findings or been more sensitive to differences. Primary care ethnicity data could also be more specific, for example creating a South Asian category which is distinct and grouped separately from the current “Asian or Asian British” category. In the same way that there has been more onus on capturing dementia subtype diagnoses, there should be a drive to capture other sociodemographic factors at time of diagnosis. Direct national reporting of patient demographics including ethnicity, socioeconomic deprivation and rurality by memory services would be an alternative means of capturing these data and ensuring equity of access.

Although we have used UK data, we envision that most high-income countries have electronic health records, or some other methods of measuring dementia diagnoses and will also have population-based prevalence and incidence data so they can conduct similar analyses. Overall findings suggest that sociodemographic factors play a large role in DDR. This deserves further evaluation coupled with interventions to ensure greater equity in dementia diagnosis.

Disclosure statement

JDI is NHS England National Clinical Director for Dementia and Older People's Mental Health. Until April 2024 he was Clinical Director of NHS England (London) dementia clinical network. He has received conference expenses and consultancy fees (paid to his institution) from Roche, a speaker's fee (paid to his institution) from Biogen and payment from Nestle Health Science for membership of a clinical trial academic steering committee. The other authors have no conflicts of interest to declare.

Ethics statement

This was aggregate data provided by GP practices and processed by NHS England.

Funding

This research was commissioned by NHS England (London). JH is funded by a UCL Academic Clinical Lectureship. KL is funded by the UK

Medical Research Council (MR/S021418/1). NM is funded by the Alzheimer's Society (AS-SF-18b-001).

ORCID

Jemma Hazan  <http://orcid.org/0000-0002-7223-4768>
 Kathy Y. Liu  <http://orcid.org/0000-0002-7482-2758>
 Jeremy D. Isaacs  <http://orcid.org/0000-0002-2745-9597>
 Naaheed Mukadam  <http://orcid.org/0000-0001-8635-9521>

References

- Ahmadi-Abhari, S., & Kivimäki, M. (2024). Do age-standardised dementia incidence rates really increase in England and Wales? *The Lancet. Public Health*, 9(3), e152–e153. [https://doi.org/10.1016/S2468-2667\(24\)00019-7](https://doi.org/10.1016/S2468-2667(24)00019-7)
- Alzheimer's Society. (2023). *Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England*, 1–142. <https://www.alzheimers.org.uk/sites/default/files/2023-10/Raising%20the%20Barriers.pdf>
- Bothongo, P. L., Jitlal, M., Parry, E., Waters, S., Foote, I. F., Watson, C. J., Cuzick, J., Giovannoni, G., Dobson, R., & Noyce, A. J. (2022). Dementia risk in a diverse population: A single-region nested case-control study in the East End of London. *The Lancet Regional Health–Europe*, 15, 100321.
- Cassarino, M., O'Sullivan, V., Kenny, R. A., & Setti, A. (2016). Environment and cognitive aging: A cross-sectional study of place of residence and cognitive performance in the Irish longitudinal study on aging. *Neuropsychology*, 30(5), 543–557. <https://doi.org/10.1037/neu0000253>
- Chen, Y., Bandosz, P., Stoye, G., Liu, Y., Wu, Y., Lobanov-Rostovsky, S., French, E., Kivimäki, M., Livingston, G., Liao, J., & Brunner, E. J. (2023). Dementia incidence trend in England and Wales, 2002–19, and projection for dementia burden to 2040: Analysis of data from the English Longitudinal Study of Ageing. *The Lancet. Public Health*, 8(11), e859–e867. [https://doi.org/10.1016/S2468-2667\(23\)00214-1](https://doi.org/10.1016/S2468-2667(23)00214-1)
- Chung, S.-C., Providencia, R., Sofat, R., Pujades-Rodriguez, M., Torralbo, A., Fatemifar, G., Fitzpatrick, N. K., Taylor, J., Li, K., Dale, C., Rossor, M., Acosta-Mena, D., Whittaker, J., & Denaxas, S. (2023). Incidence, morbidity, mortality and disparities in dementia: A population linked electronic health records study of 4.3 million individuals. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 19(1), 123–135.
- Department of Health. (2015). *Prime Minister's challenge on dementia 2020*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf
- Department of Health. (2016). *Prime Minister's Challenge on Dementia 2020 Implementation Plan*. https://assets.publishing.service.gov.uk/media/5a816d6040f0b62305b8ee55/PM_Dementia-main_acc.pdf
- Hayanga, B., Stafford, M., & Bécares, L. (2021). Ethnic inequalities in health-care use and care quality among people with multiple long-term health conditions living in the United Kingdom: A systematic review and narrative synthesis. *International Journal of Environmental Research and Public Health*, 18(23), 12599. <https://doi.org/10.3390/ijerph182312599>
- Hazan, J., Liu, K. Y., Isaacs, J. D., Burns, A., & Howard, R. (2023). Has COVID-19 affected dementia diagnosis rates in England? *International Journal of Geriatric Psychiatry*, 38(7), e5976. <https://doi.org/10.1002/gps.5976>
- Hofbauer, L., & Rodriguez, F. (2023). The role of social deprivation and depression in dementia risk: Findings from the longitudinal survey of health, ageing and retirement in Europe. *Epidemiology and Psychiatric Sciences*, 32, e10. <https://doi.org/10.1017/S2045796023000033>
- Jitlal, M., Amirthalingam, G. N., Karania, T., Parry, E., Neligan, A., Dobson, R., Noyce, A. J., & Marshall, C. R. (2021). The influence of socioeconomic deprivation on dementia mortality, age at death, and quality of diagnosis: A Nationwide death records study in England and Wales 2001–2017. *Journal of Alzheimer's Disease: JAD*, 81(1), 321–328. <https://doi.org/10.3233/JAD-210089>
- Kornblith, E., Bahorik, A., Boscardin, W. J., Xia, F., Barnes, D. E., & Yaffe, K. (2022). Association of race and ethnicity with incidence of dementia among older adults. *JAMA*, 327(15), 1488–1495. <https://doi.org/10.1001/jama.2022.3550>
- Lu, C., Ahmed, R., Lamri, A., & Anand, S. S. (2022). Use of race, ethnicity, and ancestry data in health research. *PLOS Global Public Health*, 2(9), e0001060.

- Matthews, F. E., Arthur, A., Barnes, L. E., Bond, J., Jagger, C., Robinson, L., & Brayne, C. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the Cognitive Function and Ageing Study I and II. *Lancet (London, England)*, 382(9902), 1405–1412. [https://doi.org/10.1016/S0140-6736\(13\)61570-6](https://doi.org/10.1016/S0140-6736(13)61570-6)
- Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 12(3), 216–224. <https://doi.org/10.1016/j.jalz.2015.12.007>
- Ministry of Housing, Communities & Local Government. (2019, September 26). *National statistics English indices of deprivation 2019*. <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, 23(7), 1070–1077. <https://doi.org/10.1017/S1041610211000214>
- Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, 26(1), 12–20. <https://doi.org/10.1002/gps.2484>
- Mukadam, N., Lewis, G., Mueller, C., Werbeloff, N., Stewart, R., & Livingston, G. (2019). Ethnic differences in cognition and age in people diagnosed with dementia: A study of electronic health records in two large mental healthcare providers. *International Journal of Geriatric Psychiatry*, 34(3), 504–510. <https://doi.org/10.1002/gps.5046>
- Mukadam, N., Marston, L., Lewis, G., Mathur, R., Rait, G., & Livingston, G. (2022). *Incidence, age at diagnosis and survival with dementia across ethnic groups in England: A longitudinal study using electronic health records*. *Alzheimer's & Dementia*.
- NHS. (2023, June 28). *NHS Data Model and Dictionary. Local Authority District*. https://www.datadictionary.nhs.uk/nhs_business_definitions/local_authority_district.html
- NHS Business Service Authority. (n.d). Sub ICB Locations. Retrieved 24 November 2023, from <https://www.nhsbsa.nhs.uk/sicbls-icbs-and-other-providers/organisation-and-prescriber-changes/sub-icb-locations>
- NHS Digital. (n.d). *Quality and Outcomes Framework*. Retrieved 13 December 2023, from <https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data>
- NHS Digital. (2023a). *Series/Collection Primary Care Dementia Data*. <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data>
- NHS Digital. (2023b, August 17). *Primary Care Dementia Data, July 2023*. <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/january-2023>
- NHS Digital. (2023c, November 10). *Primary care dementia data: Supporting information*. <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/primary-care-dementia-data-supporting-information/primary-care-dementia-data-supporting-information>
- Nichols, E., Steinmetz, J. D., Vollset, S. E., Fukutaki, K., Chalek, J., Abd-Allah, F., Abdoli, A., Abualhasan, A., Abu-Gharbieh, E., & Akram, T. T. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: An analysis for the Global Burden of Disease Study 2019. *The Lancet. Public Health*, 7(2), e105–e125. [https://doi.org/10.1016/S2468-2667\(21\)00249-8](https://doi.org/10.1016/S2468-2667(21)00249-8)
- Office for National Statistics (ONS). (n.d). *2001 Census Glossary Terms Beginning H – N* [ONS website]. <https://www.ons.gov.uk/census/2001-censusandearlier/glossary/hn>
- Office for National Statistics (ONS). (2022, November 29). *Ethnic group, England and Wales: Census 2021* [ONS website]. [https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/bulletins/ethnicgroupenglandandwales/census2021#:~:text=%22White%3A%20Other%20White%22%20\(%25%2C%20990%2C000%20in%2020211\)](https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/bulletins/ethnicgroupenglandandwales/census2021#:~:text=%22White%3A%20Other%20White%22%20(%25%2C%20990%2C000%20in%2020211))
- Office for National Statistics (ONS). (2011). *Rural-Urban Classification of Local Authority Districts and Similar Geographic Units in England: A User Guide*. Department for Environmental Food & Rural Affairs. (2017, January). https://assets.publishing.service.gov.uk/media/5a80351ce5274a2e8ab4ecfb/RUCLAD2011_User_Guide_January_2017_.pdf
- Pham, T. M., Petersen, I., Walters, K., Raine, R., Manthorpe, J., Mukadam, N., & Cooper, C. (2018). Trends in dementia diagnosis rates in UK ethnic groups: Analysis of UK primary care data. *Clinical Epidemiology*, 10, 949–960. <https://doi.org/10.2147/CLEP.S152647>
- Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., & King, D. (2014). Dementia UK: update. *Alzheimer's Society*, 1–136. <http://www.alzheimers.org.uk/dementiauk>
- Russ, T. C., Batty, G. D., Hearnshaw, G. F., Fenton, C., & Starr, J. M. (2012). Geographical variation in dementia: Systematic review with meta-analysis. *International Journal of Epidemiology*, 41(4), 1012–1032. <https://doi.org/10.1093/ije/dys103>
- Szymczynska, P., Innes, A., Mason, A., & Stark, C. (2011). A review of diagnostic process and postdiagnostic support for people with dementia in rural areas. *Journal of Primary Care & Community Health*, 2(4), 262–276. <https://doi.org/10.1177/2150131911404705>